Data Stewardship Strategic Working Group (DSSWG)

FINAL REPORT

Jan 14, 2022

TABLE OF CONTENTS

Executive Summary

Ontario health data and information assets offer the potential for enormous benefits to improve healthcare delivery, population health, public health, research, as well as the management of Ontario's health system at the provincial, regional, and local level. However, if data is not responsibly managed, there could be possible misuse and harm. To ensure maximum benefits and minimize risks associated with health system data use, data accountability instituted through data stewardship is of the utmost importance. It will enhance understanding and protect the value of digital data residing in Ontario's health ecosystem, enable health research, open data science and analytics across the province, establish "rules of the road" for sharing common health data, and bring awareness of risk management associated with data sharing.

For the purposes of this report, data stewardship is defined as: "data accountability that will ensure the authorized, appropriate, ethical, and responsible use of health data to maximize the potential benefits for the public while minimizing the risk of misuse and harm. Data stewardship aims to build trust and confidence in Ontario's health data by ensuring 'fit for purpose' data quality and 'fit for use' data access in the pursuit of the public good".

Ontario's health ecosystem is provider-oriented and consists of data silos that are based on different standards and technology used at the organizational level. Due to limited ecosystem-wide data governance, decisions based on data silos are not always aligned with ecosystem-wide strategic objectives. No clear accountability exists for provincial digital health data assets. Health data originates from multiple and diverse sources, which quite often use different data standards (i.e. vocabularies, terminologies, and code sets), limiting the ability to have compatible and comparable data. Data exchange among systems is hindered by multiple interfaces that are not always compatible, requiring data mapping. Reliable and consistent data linking is impeded by not having system-wide unique identifiers for the core master data such as client, provider, organization, and location. Due to poor or limited metadata on existing data holdings, disparities in healthcare organizations' workflows and critical business processes, data quality is adversely impacted.

To address those challenges and to enable newer technologies such as artificial intelligence and machine learning, a new paradigm shift is required to treat data as strategic assets. A key success factor in making that shift will be data stewardship which is built on three levels: organizational, provincial data domain, and health sector level. It will require a coordinated effort on all three levels to collaborate along the health data value chain to unlock data value and drive insights.

The Provincial Data Stewardship Framework is intended to provide a framework for managing data as strategic assets supported by a set of foundational principles that all data stewards should adhere to when handling data. It will provide guidance for:

I. Participating in an integrated Ontario health ecosystem that will allow access to reliable and valid health data supporting the needs of all stakeholders and;

II. Responsible and ethical data collection, storage, access, and (re)use.

For more high-level information about data stewardship levels, roles and responsibilities, and principles, please see appendices A, B, and C.

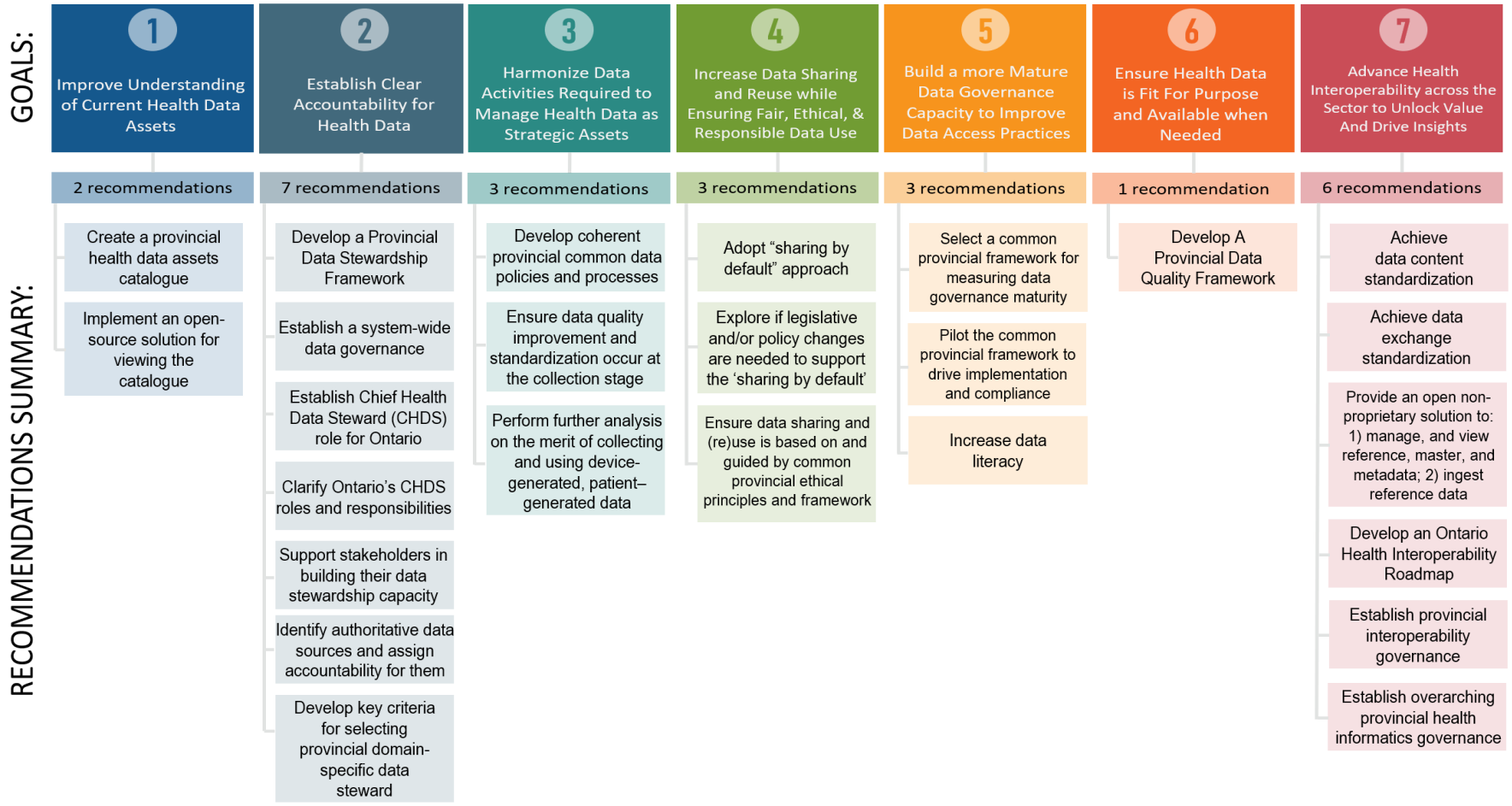
Data Stewardship will help with achieving the following goals:

1. improve understanding of current health data assets;
2. establish clear accountability for health data;
3. harmonize data activities required to manage health data as strategic assets;
4. increase data sharing and reuse while ensuring fair, ethical, and responsible data use;
5. build a more mature data governance capacity to improve data access practices;
6. ensure health data is fit for purpose and available when needed;
7. advance health interoperability across the sector to unlock value and drive insights.

To achieve these ambitious goals, the working group recommends establishing an implementation team comprised of experts and stakeholders to manage and report on the implementation of the recommendations included in this report. The implementation team should include the DSSWG membership and be supported by task force groups to deal with specific assignments.

Provincial Stewardship Framework Overview

OBJECTIVE To provide a framework for managing data as strategic assets that is supported by a set of foundational principles which all data stewards should adhere to when handling data.



FOUNDATIONAL PRINCIPLES • Valuable • Shared • Trustworthy • Secured & Protected • Accessible • Governed • Usable • Reusable • Standardized & Linkable

1. Improve Understanding of Current Health Data Assets

Recommendations:

- ✓ Create a provincial repository/catalogue of digital health data assets documenting their scope, data quality, structure/format, metadata, data standards, data flow, and uses;
- ✓ Implement a robust open-source solution to view the provincial digital health data assets catalogue to enable greater data discovery and (re)use.

2. Establish Clear Accountability for Health Data

Recommendations:

- ✓ Using an iterative approach, develop a Provincial Data Stewardship Framework that will provide guidance to data stewards on participating in Ontario's health ecosystem. It will be:
    - agile and evolving as the health ecosystem evolves;
    - based on a set of foundational principles applicable to all types of data;
    - comprehensive and will include both clinical and administrative data, which may contain identified or de-identified data, whose sharing provides value to Ontario's health ecosystem;
    - practiced by organizations by default;
    - founded on transparent and effective industry-recognized data management principles and best practices.

- ✓ The first iteration of the Provincial Data Stewardship Framework should include:
    - strategic data stewardship structure;
    - data accountability for provincial digital health data assets used to support care delivery (patient-level clinical data);
    - a set of foundational data stewardship guiding principles applicable to all types of data;
    - high-level requirements with respect to a common framework for measuring data and information governance capabilities;
    - an implementation approach along with a compliance model.

- ✓ Establish system-wide data governance with clear roles and responsibilities of all actors in Ontario's health sector by adopting a data stewardship approach.

- ✓ Establish Chief Health Data Steward (CHDS) role for Ontario's health sector that will be responsible for:
  - overall management and building of data stewardship in Ontario's health sector;
  - leadership and strategic guidance on improving information management capabilities;
  - facilitation of data issues resolution across the sector;
  - collaboration with other Chief Data Stewards outside of the health sector to ensure effective use of data across ministries and other sectors.

- ✓ Clarify Ontario's Chief Health Data Steward roles and responsibilities specifically with respect to:
  - The authority which may include but is not limited to:
    - provides frameworks and guidance on how to manage data as valuable and strategic assets;
    - mandates data sharing for the public good, including penalties for not sharing;
    - mandates health informatics standards, including penalties for noncompliance;
    - requires certification of interoperability standards, data, and solutions:
      - further analysis is required to examine existing certification frameworks such as the Ontario Health Digital Health Information Exchange program, virtual visit verification and onboarding conformance testing and OntarioMD EMR certification program.
  - Levers which may be used such as:
    - only vendors whose solutions are certified according to the minimum interoperability requirements, including other rules, principles, and protocols for both data exchange and data contribution, will be allowed to participate in Ontario's health ecosystem;
    - engage with vendors through mechanisms such as co-design and innovation to enhance the level of functionality and usability of their solutions to be able to support artificial intelligence/machine learning/natural language processing, which is paramount for automating and standardizing clinical documentation capture.

- ✓ Support agencies and other stakeholders in building their own data stewardship capacity by advocating for proper data accountability through:
  - creation of Chief Data Officer (CDO) and/or Chief Data Steward (CDS) functions. CDO would be responsible for the data assets lifecycle management within an organization, while the CDS would manage the health data value chain across organizations. Those two functions can be embodied in one role;

- development of a standardized set of CDS'/CDO' responsibilities as those are currently ambiguous or nonexistent.

✓ Identify authoritative ('source of the truth') data sources for provincial digital health data assets and assign data accountability for them:

- Accountability will involve two aspects:
  - responsibility for health data assets, including physical assets, data models, metadata, standards, policies, processes, data flow, analytics, and insights;
  - responsibility to collaborate and share data with other data stewards along the health data value chain.

- Data sources to include:
  - Master Data: client, provider, geography, services, and organization
  - Core Clinical Data based on care setting:
    - clinical: acute, primary and specialist;
    - community: home care, long-term care, emergency, mental health and addictions;
    - ancillary Services: lab, diagnostic imaging, drug, and immunization;
    - other health data, which may include patient-generated and device-generated data.

- Further analysis on mapping of data activities to relevant actors for each data source is required.

✓ Develop key criteria for selecting provincial domain-specific data stewards along with:

- clarifying if those roles should be assigned or legislated and;
- identifying potential entity or governance body candidates that are the most suitable to fulfil those roles.

3. Harmonize Data Activities Required to Manage Health Data as Strategic Assets

Recommendations:

✓ Develop **coherent provincial common data policies and processes** that will guide data stewards with the responsible collection, storage, sharing, and (re)use of health data. Those policies and processes will be:

- based on a specific health system use case;
- governed by the same principles;
- harmonized to ensure that a data activity associated with the health data value chain is performed once by a designated actor resulting in greater

consistency, reduction of potential errors and costs associated with those activities.

- ✓ Ensure that data quality improvement and standardization occur at the collection stage while taking into consideration the following:
  - context in which data is collected as it may impact downstream use;
  - newer technologies such as artificial intelligence/machine learning/natural language processing which can decrease the burden on clinicians and enhance shared decision-making;
  - a carefully designed balance between placing the burden on clinicians vs. vendors;
  - incentives and opportunities for retraining clinicians to increase their data literacy;
  - incentives to drive a single sign-on approach, and to integrate data from multiple systems/modules without a need to re-enter the same data multiple times;
  - explore mechanisms including changes to the legislation to institute the "asked once" principle to avoid asking patients the same question multiple times due to inefficient data management practices.

- ✓ Perform further analysis to determine the merit of collecting and using device-generated, patient–generated, and other health data specifically around:
  - purpose and its strategic uses;
  - proprietary aspect associated with device-generated data;
  - sensitivity, authority to store, and retention period.

4. Increase Data Sharing and Reuse While Ensuring Fair, Ethical, and Responsible Data Use

Recommendations:

- ✓ Adopt "sharing by default" approach where data stewards are expected to protect, collaborate, and share data with other data stewards along the health data value chain except if not possible due to legal or other constraints;
- ✓ Explore if legislative and/or policy changes are needed to support the 'sharing by default' recommendation;
- ✓ Ensure data sharing and (re)use is based on and guided by provincial common ethical principles and framework that takes into consideration possible data uses, public value, transparency, fairness, lawfulness, timeliness, engagement with the communities and other dimensions.

5. Build A More Mature Data Governance Capacity to Improve Data Access Practices

Recommendations:

✓ Select a single common framework for measuring data governance maturity that will increase consistency and aid in quantifying existing gaps associated with the following areas: 1) strategy and governance, 2) policies and processes, 3) assets and standards, and 4) people and knowledge. Framework should:

- support advanced integration of care across different care settings and linking of data;
- address interoperability and alignment with the health information network requirements;
- have assessment templates for stakeholders to perform self-assessment as well as an assessment of alignment with a health information network, including:
    - instruction on how to complete assessments along with useful examples;
    - guidance on how to weigh capabilities and avoid subjective measurements;
    - a set of documentation that is required to substantiate assessments;
- identify a minimum set of capabilities that are required of any data steward;
- ensure convergence with accreditation frameworks over time;
- be aligned with the pan-Canadian approach for measuring health data and information governance maturity.

✓ Pilot the provincial common framework to drive an implementation approach and a compliance model using the following scenarios:

- self-assessment at the organizational level - pick two government agencies to perform the self-assessment that will drive:
    I. validation of minimal capabilities that any data steward needs to have to participate in Ontario's health ecosystem;
    II. development of a process for monitoring compliance.

- network alignment assessment at data type level - pick two types of data that will be exchanged in the first release of Ontario's patient summary standards (which are: allergy and intolerance, current medications, problem list, immunization, history of the procedure, and history of illness) and perform alignment assessment with the provincial Digital Health Network that will drive:
    I. validation of minimal capabilities that are deemed critical for the health information network;
    II. development of a process for monitoring compliance;
    III. identification, tracking and reporting on key outcomes and associated metrics to measure data stewardship success.

- ✓ Increase data literacy by collaborating and advocating for the pan-Canadian approach to:
    - standardizing data stewardship capabilities and training through collaboration with universities, colleges, and other bodies that develop the curriculum standards such as CHIMA;
    - developing an open-source data stewardship training on the job that is multifaceted and centralized.

6.Ensure Health Data is Fit for Purpose and Available When Needed

Recommendations:

- ✓ Develop a provincial data quality framework focusing on a set of common principles and practices that are intended to be used to ensure that health data shared across the sector is fit for purpose.

7. Advance Health Interoperability Across the Sector, through data content and data exchange standardization and overarching provincial standards governance, to Unlock Value and Drive

Recommendations:

- ✓ To achieve data content standardization for core data shared provincially (i.e. 'core data for interoperability'), adopt:
    - common metadata and data definitions by developing a provincial data model, business glossary, and data dictionary along with a robust open-source solution to browse those;
    - common and controlled vocabularies, terminology sets, and code sets that are based on structured and recognized terminologies;
    - common core data elements for a particular data set, e.g. Mental health and addictions provincial minimum data set containing aggregated data for performance measurement, patient summary data categories and detailed data elements for inclusion in a patient summary;
    - the provincial data model will:
        - be governed through a well-defined provincial process;
        - provide consistency in data meaning and representation of common clinical concepts exchanged on the provincial level;
        - serve as a foundation for data governance and data stewardship;
        - evolve over time based on strategic direction, e.g. the first iteration to contain data categories referenced in the Ontario Patient Summary interoperability spec. release 1;

- be a reference point for the development of all other implementation data models enabling traceability and data lineage;
- be a communication tool between business and technical people to solicit business requirements;

✓ Provide an open non-proprietary solution on the provincial level to:

- manage and view reference, master, and metadata to advance data discovery and learning;
- ingest reference data, e.g. An application programming interface (API)/tool/web access for ingesting reference data into stakeholder's environment for their own uses/validation. Real-time validation of master and reference data will be required in the future.

✓ Achieve data exchange standardization through the adoption of:

- common metadata-driven data exchange specifications (e.g. FHIR);
- compliance verification supported by the Digital Health Information Exchange (DHIEX) regulation.

✓ Using an iterative approach, develop an Ontario health interoperability roadmap to establish a framework for guiding stakeholders on their journey to interoperability maturity, monitoring and measuring progress towards a more integrated and interoperable health ecosystem. It should address both technical and business aspects of interoperability:

- Business aspects to include:
  - system-wide overarching interoperability governance with clearly defined roles and responsibilities of all actors;
  - supporting policies and processes to enable data exchange and interoperability, especially processes for:
    - interoperability specifications version control;
    - change management (via 'requests for change');
    - standards identifier management (requests for identifiers and terminology standards).
- Technical aspects to include:
  - common infrastructure;
  - consistent mechanism for identification, authentication, audit, and consent management;
  - mechanism for locating/discovering data resources and standards;
  - common testing and certification infrastructure and processes for standards compliance and data conformance;
  - standards for both data content and data exchange;

✓ Ontario health interoperability roadmap should take into consideration:

- current readiness and capability of all stakeholders in the Ontario's health ecosystem:
    - use the bottom-up approach;
    - start with cataloguing all provincial digital assets, products, and standards;
    - identify current data sources' capabilities and limitations;
    - determine short-term vs. long-term goals;
    - identify gaps and timeframe for closing those gaps;
    - document workaround solutions for gaps that cannot be closed due to limitations of legacy systems or other valid reasons.

- partnership and engagement with vendors and other stakeholders to secure their commitment to interoperability - not just to one-off project or standards:
    - Digital Health Information Exchange (DHIEX) regulatory requirements will be the key but will not guarantee interoperability on its own;
    - a collective effort including vendors, healthcare providers, colleges, associations etc., is paramount to help advance how data is collected, accessed, shared, and (re)used.

- alignment with the pan-Canadian interoperability:
    - Infoway: pan-Canadian interoperability governance and services model is being developed;
    - PHAC: Pan-Canadian interoperability framework is being developed in the context of the pan-Canadian Health Data Strategy initiative.

- interdependency and interconnectedness among different roadmaps, e.g. products, standards, and assets, one applying the system-view lens while ensuring they do not contradict each other.
- 'end-to-end' interoperability and data digitization based on open non-proprietary standards.

✓ Establish provincial interoperability governance which will govern all dimensions of interoperability and ensure:

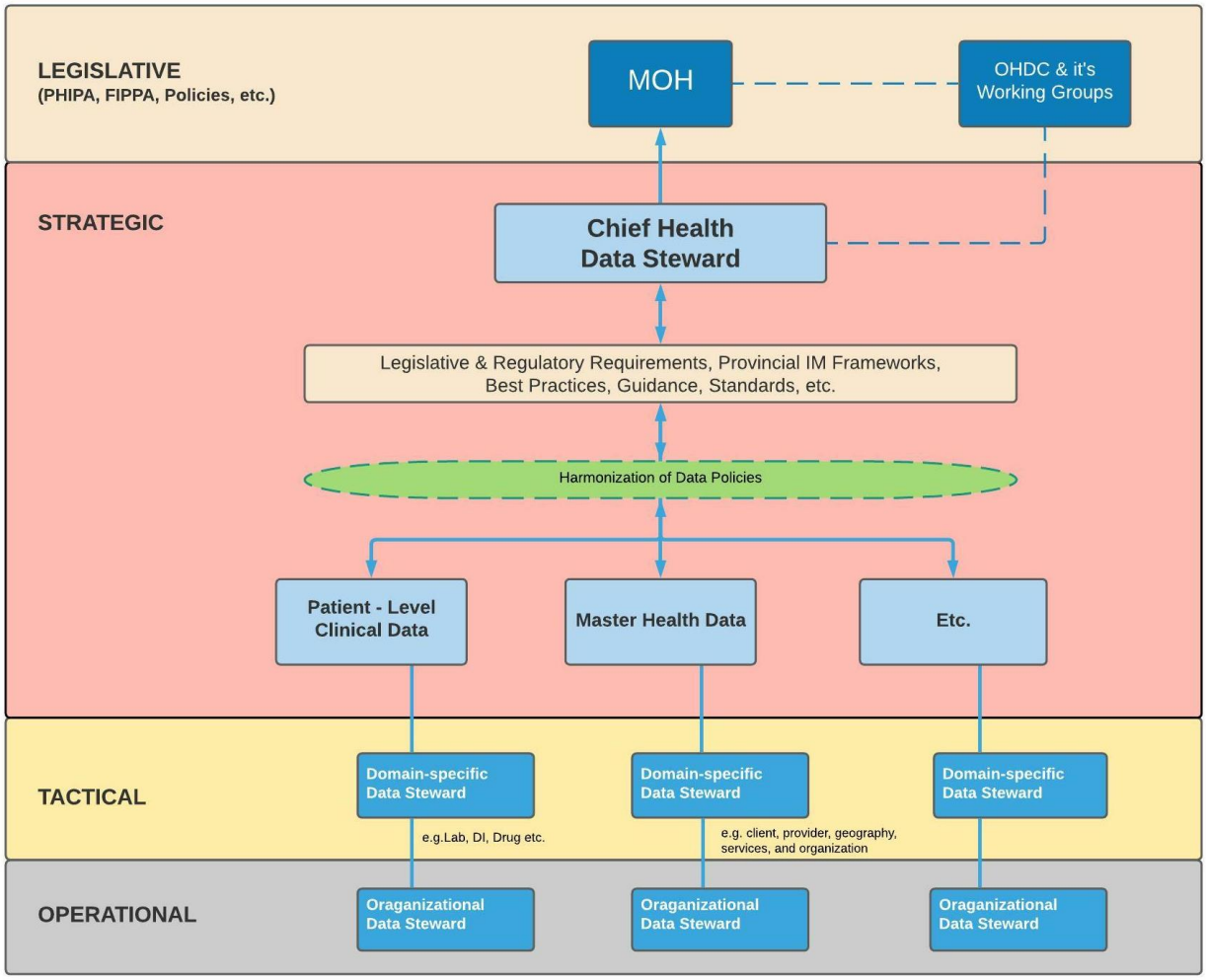
- strategic guidance, planning and priority-setting bringing together interoperability on all three levels:
    - organizational (business processes alignment);
    - provincial (common semantic & syntax for provincial core data) and;
    - pan-Canadian (common semantic & syntax for pan-Canadian core data).

- coordination of efforts across the sector (all actors are marching towards the same vision/aligned priorities), ensuring a common approach to collecting, structuring, formatting, and sharing health data.
- accountability and progress monitoring guided by provincial interoperability roadmap and framework;
- partnership and engagement through formal channels of communication.

✓ Establish an overarching provincial health informatics governance to:

- define and execute coordinated governance processes required for achieving consensus-based agreements on standards guided by high-level principles:
  - adopt, adapt, develop, or inform about standards;
  - align with national and international standards.
- provide strategic direction for the use of standards in Ontario.
- make key decisions in the standards decision-making process, such as approving or amending standards.
- develop a consistent and common approach for:
  - identifying needs for standardization and standards which should be driven from both the top-down and the bottom-up:
    - allow and enable data content standardization to be driven at local levels;
    - priorities for standards are determined by legislated and market forces.
  - evaluating standards candidates using common and transparent processes, agreed-upon criteria, and evaluation method.
  - endorsing and mandating standards which will help with:
    - resolving an issue of data being captured and shared using multiple standards, different and sometimes incompatible versions of the same standards, different terminology sets etc.;
    - standards rationalization and alignment over time (interoperability specs and administrative standards will reference the same clinical data structure/content);
    - reducing new data collections and increasing data (re)use.

Appendix A – Data Stewardship Model



Appendix B – Data Steward Roles and Responsibilities

Data Stewardship

System Level	Role	Responsibility	Health Informatics (HI) Standards	Data Policies	Partnership Engagement	Collaboration	Artifacts
Health Sector	Chief Health Data Steward	> Overall management and building of data stewardship in Ontario > Leadership and strategic guidance on improving information management capabilities & enabling data reuse > Facilitation of data issues resolution across the sector	> Strategic direction on adopting international/national/ provincial standards and practices > Mandates HI standards *(HI standards development and conformance verification performed by designated agencies)*	> Approves data policies per health system use case > Approves cross-cutting policies (e.g. IP, de-identification, vendor management etc.) co-developed with key stakeholders	> Ensures transparent and open engagement with public, patients, and communities, including First Nations, at strategic level	> Collaborates with other sectors' chief data stewards (CDS), jurisdictional health CDS & Government of Canada CDS on enterprise-level information management strategic direction	> Data Strategy > Interoperability Roadmap > Data Stewardship Framework > Data Quality Framework > Data Governance Capability Framework > Ethical Data Use Framework
Provincial	Provincial Data Domain Steward	> Management of data stewardship in a particular data domain > Leadership and guidance on improving information management capabilities > Data domain-level issues resolution and escalation of issues > Provincial data governance participation > Data sharing benefits vs. risks assessment and management	> Participates in provincial HI standards development representing data domain business requirements > Facilitates HI standards implementation	> Co-designs provincial policies with organizational data stewards (e.g. collection, storage, processing, access, use/reuse, archive/purge) per health system use case > Ensures adherence to policies	> Leads transparent engagement at provincial level ensuring all actors affected by a specific health data use case are represented	> Collaborates with other data domain data stewards on provincial initiatives/collaboratives ensuring cross-domain alignment > Shares knowledge and insights with relevant provincial/national/international interest groups/communities of practice	> Domain-specific roadmap, frameworks, policies, and standards that are aligned with provincial direction and objectives > Domain-specific data model derived from provincial data model > Domain-specific data flow model
Organizational	Chief Data Officer/Steward	> Manages the data as valuable assets through its entire lifecycle > Ensures appropriate level of data quality > Ensures core metadata capture and maintenance > Specifies rules for data access and security > Data sharing benefits vs. risks assessment and management > Includes broader data consumers' needs when performing data planning > Participates in data domain data governance	> Implements provincial HI standards > Develops new standards where they do not exist using provincial/national/international guidelines and shares with others > Participates in relevant HI SDO's community of practice to influence and align with	> Develops internal data policies > For data that are shared at regional/provincial/national level, aligns internal data policies with those ones	> Performs transparent community engagement at project level ensuring all members are represented	> Collaborates with other data domain or organizational data stewards for specific initiatives/projects/collaboratives > Shares knowledge and insights with relevant provincial/national/international interest groups/communities of practice	> Organizational strategy, roadmap, data management policies and procedures that are aligned with provincial and/or domain-specific direction and objectives

Appendix C – Data Stewardship Foundational Principles

VALUABLE

- Health data is a **valued and shared asset**.
- Health data is collected and used based on the needs and value proposition of the **health ecosystem** underpinned by the **patient-centric architecture** with the aim of improving individuals' well-being.
- Data requirements **reflect the needs of all stakeholders** involved throughout the entire health data value chain (HDVC).

SHARED

- Health data is **shared by default** for the **public good** based on the **ethical** framework & best principles in accordance with the **applicable legislation.**
- Data is **collected once** and **shared** with those who **need** it and are **authorized** to access it.

TRUSTWORTHY

- Data quality **fits intended purpose.**
- **Data quality** is **consistently** measured and supported by defined improvement processes.
- Data is described with **sufficient metadata** including **data provenance** and **metadata** explaining **changes** that have occurred to the data.

SECURED & PROTECTED

- Data about patients is **protected** at the point of collection, storage, integration, movement, and use.
- Patients are **empowered** with appropriate control over their data according to the declaration of personal health data rights in Canada.
- Processing, including use and disclosure, of data about patients is **controlled, monitored, and audited**.
- Data consumers are **authenticated/authorized** according to provincial policies and protocols.
- Data **de-identification/re-identification** is performed in accordance with the applicable legislation, standards, and best practices.

ACCESSIBLE

- Data is available when needed based on consumers' data needs.
- Data access is designed to **optimize data flows and to minimize security risks.**
- Data access is supported **by verifiable data sharing protocols** and utilizes **consensus-based open provincial health informatics standards**.
- **Data about members** within the health ecosystem is **accessible** by members themselves, including an explanation **of how their data is used** by others.

GOVERNED

- All **authoritative** sources and their proxies ("managed duplications") are identified.
- **Accountability** for data is well-defined via **data stewardship** and monitored via the **applicable data governance maturity model.**
- Data is **managed** through defined **data governance models** according to recognized **best practices and standards a**t each stage of the **health data value chain.**
- Data governance model demonstrates **participatory transparency** by consulting and engaging with members of the health ecosystem.

USABLE

- Based on consumers' needs, data is provided in **open data formats** adhering to industry recognized standards and best practices to ensure data **portability** and suitable data **consumption.**

REUSABLE

- Data is **reused for multiple purposes** whenever benefits outweigh risks.
- **Artifacts** developed to **process data** for different purposes are made available for **reuse** by the health ecosystem.
- Data adheres to the **FAIR principles** for easy discovery and reuse.
- **Data retention** specifications support current and future uses of health data.

STANDARDIZED & LINKABLE

- Data and metadata conform to provincial **reference data models,** derived from **industry recognized international or national data models.** They support **cross-sector exchange of common data categories** to ensure **comparability, compatibility,** and consumption by **multiple data consumers.**
- Data is exchanged according **to consensus-based open provincial health informatics (HI) standards**. Where provincial HI standards do not exist they are developed **locally, leveraging national or international** standards to **influence and align with** international standards.
- Data is **standardized at the source** according to provincial health informatics standards whenever feasible.
- Data is **linked** according to industry recognized **standards and best practices** whenever possible to add value.

Appendix D – 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*
Interoperability	The ability of different health information systems, devices, and applications to access, exchange, integrate and cooperatively use data in a coordinated manner, within and across organizational and regional boundaries to provide timely and seamless supportability of information and to optimize the health of individuals and populations globally *Source: HIMMS*
Integrated Data	Disparate health care information connected to create an integrated digital health record – one that provides a lifetime record of an individual's health history. *Source: Digital Health Playbook*
Data Literacy	The ability to read, write, and communicate data in context. This includes an understanding of data sources and constructs, analytical methods and techniques applied, and the ability to describe the use case, the application, and the resulting value. Source: Gartner 2015
Health Information Network	An organization or a group of organizations with a single governance structure that provides broader capabilities such as business and clinical process management, health information services and information exchange and interoperability. *Source: Gartner, 2015*
Metadata	Describes the data itself (e.g. databases, data elements, data models), the concept the data represents (e.g. business processes, application systems, software code, technology infrastructure), and the connections (relationships) between the data and concepts. *Source: DAMA book*
Data Flow	The transfer of data between systems, applications, or data sets. As data flows, it is secured, integrated, stored, recorded, catalogued, shared, reported on, analyzed, and delivered to the stakeholders. Along the way, the data may be verified, enhanced, linked, certified, aggregated, anonymized, and used for analytics until archived or purged. *Source: DAMA book*
Health Data Value Chain	A cycle of inter-connected stages where different actors add value and contribute to data reuse. It consists of the following stages: collect, store, process, share, access, use, and reuse.

Appendix E – DSSWG Membership

The Working Group was struck in August 2021, and tasked with the design challenge "How might we improve health data quality and streamline data access to achieve an integrated health data ecosystem that is responsive to the data needs of its stakeholders?"

Membership Chart

Organization	Name	Title	Role
CIO Strategy Council	Keith Jansa	Executive Director	Chair
Canadian Mental Health and Addiction	David Rotenberg	Director, Data Strategy and Business Intelligence	Contributor
OntarioMD	Ben Macerola	Solution Architect	Contributor
North York General Hospital	Corey Clarke	Manager, Health Records and Enterprise Data Quality	Contributor
Ontario Health	Julie Klein-Geltink	Director of Enterprise Data & Analytic Services	Contributor
Ontario Health	Dwayne Pickering	Manager, Architect	Contributor
Ontario Health	Sue Schneider	Director eHealth Standards	Contributor
Canadian Institute for Health Information	Claudiu Grecu	Manager, Data Architecture	Contributor
Ontario Brain Institute	Tom Mikkelsen	President & Scientific Director	Contributor
Northwestern Ontario Hospitals	Cindy Fedell	Regional Chief Information Officer	Contributor
ICES	Charles Victor	Senior Director, Strategic Partnerships and Digital Services	Contributor
Public Health Agency Canada	Eric Sutherland	Executive Director, pan-Canadian Health Data Strategy	Reviewer

REFERENCES

Main Text

Finnish Ministry of Economic Affairs and Employment. *(2021). Finland's AI course to contribute to digital skills of Europeans across the continent (Press Release). Available online at* https://valtioneuvosto.fi/en/- /1410877/finland-s-ai-course-to-contribute-to-digital-skills-of-europeans-across-the-continent

International, DAMA (2017) DAMA-DMBOK: Data Management Body of Knowledge. Technics Publications LLC.

Mons, B. (2020). Invest 5% of research funds in ensuring data are reusable. Nature, 578(7796), 491-491. *Available online at* https://www.nature.com/articles/d41586-020-00505-7

Public Health Agency of Canada. (2021). *Pan-Canadian Health Data Strategy: Expert Advisory Group Report 1, Charting a Path Toward Ambition. Available online at* https://www.canada.ca/content/dam/phac-aspc/documents/corporate/mandate/about-agency/external-advisory-bodies/list/pan-canadian-health-data-strategy-reports-summaries/expert-advisory-group-report-01-charting-path-toward-ambition/pCHDS-first-EAG-report-en.pdf

Public Health Agency of Canada. (2021). *Pan-Canadian Health Strategy: Expert Advisory Group Report 2, Building Canada's Health Data Foundation. Available online at* https://www.canada.ca/content/dam/phac-aspc/documents/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/expert-advisory-group-report-02-building-canada-health-data-foundation.pdf

Federal Government Data Strategy. (2018). *Report to the Clerk of the PRIVY council: A Data Strategy Roadmap for the Federal Public Service. Available online at* https://www.canada.ca/en/privy-council/corporate/ clerk/ publications/ data-strategy.html

Annexes

Aiken, P., & Billings, J. (2013). Monetizing data management: finding the value in your organization's most important asset. Technics Publications. ISBN-13: 978-1935504665

EU Health Data Space and eHealth: Digital Health and Care information (Accessed 2021.12.01). *Available online at* https://ec.europa.eu/health/ehealth/dataspace_en

EOSC Secretariat, FAIR Terminology: A Terminology [Computer Software]. *Available online at* https://terms4fairskills.github.io/

Global Alliance for Genomics & Health. (2014). Framework for Responsible Sharing of Genomic and health Related Data. *Available online at* https://www.ga4gh.org/genomic-data-toolkit/regulatory-ethics-toolkit/framework-for-responsible-sharing-of-genomic-and-health-related-data/#fp

GovLab. (2020). (Re-)Defining the Roles and Responsibilities of Data Stewards for an Age of Data Collaboration. Available online at https://thegovlab.org/static/files/publications/wanted-data-stewards.pdf

Helo Parikka, Jaana Sinipuro, Hannu Hämäläinen, Markus Kalliola, Juhani Luoma-Kyyny, Saara Malkamäki,Kirsi Suomalainen.(2019). *Innovating and*

promoting the secondary use of social and health data. A Finnish Model for the Secure and Effective Use of Data. (Report No: 153). Sitra Studies Finland. *Available online at* https://media.sitra.fi/2019/05/07121654/a-finnish-model-for-the-secure-and-effective-use-of-data.pdf

Jetten, M., Grootveld, M., Mordant, A., Jansen, M., Bloemers, M., Miedema, M., & Gelder, C. W. G. V. (2021). Professionalising data stewardship in the Netherlands. Competences, training and education. Dutch roadmap towards national implementation of FAIR data stewardship. https://doi.org/10.5281/zenodo.4320505

Johan Hansen, Petra Wilson, Eline Verhoeven, Madelon Kroneman, Mary Kirwan, Robert Verheij, Evert-Ben van Veen. (2019) *Assessment of the EU Member States' Rules on health Data in the Light of GDPR* (Report No: SC2019 70 02) Consumers, Health, Agriculture and Food Executive Agency. *Available online at* https://ec.europa.eu/health/sites/default/files/ehealth/docs/ms_rules_health-data_en.pdf

Kanaan, S., & Carr, J. (2009) Health Data Stewardship: What, Why, Who, How-AN NCVHS Primer. *National Committee on Vital and Health Statistics. Available online at* http://bok.ahima.org/PdfView?oid=94786

NHS Digital. Guides of Data Security and Information Governance (Accessed on 2021.12.01) *Available online at* https://digital.nhs.uk/data-and-information/looking-after-information/data-security-and-information-governance

NHS Data Security and Information Governance guidance and resources (Accessed 2021.12.01). *Available online at* https://digital.nhs.uk/data-and-information/looking-after-information/data-security-and-information-governance

Research Data Alliance, Professionalizing Data Stewardship Group. *Available Online at* https://rd-alliance.org/groups/professionalising-data-stewardship-ig

Stats NZ information services. *Data Stewardship Framework, Data Stewardship Toolkit, Value Proposition Assessment Tool. Available online at* https://data.govt.nz/toolkit/data-stewardship/

Wildgaard, L., Vlachos, E., Nondal, L., Larsen, A. V., & Svendsen, M. (2020). National Coordination of Data Steward Education in Denmark: Final report to the National Forum for Research Data Management (DM Forum). https://doi.org/10.5281/zenodo.3609515