

# Ontario Health Data Council Report

## A VISION FOR ONTARIO'S HEALTH DATA ECOSYSTEM

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**Table of Contents**

- Acknowledgements ..... 3
- Executive Summary ..... 4
- 1.0 The Opportunity for Ontario..... 5
- 2.0 The Current Health Data Ecosystem..... 12
- 3.0 The Path Forward for Ontario..... 19
  - 3.1 The Vision for Ontario..... 19
  - 3.2 The Mission ..... 21
  - 3.3 Guiding Principles..... 21
    - 3.3.1 Ethical Principles..... 22
    - 3.3.2 Respect for First Nations, Inuit, and Métis Peoples’ Data Sovereignty ..... 24
- 4.0 Strategic Recommendations ..... 25
  - 4.1 Integrate and use health data to advance health and equity outcomes for people, communities, and populations ..... 26
  - 4.2 Promote health equity through appropriate data collection, analysis, and use .... 29
  - 4.3 Establish system-level trustworthy governance and policies for health data as a public good..... 30
  - 4.4 Respect and support First Nations, Inuit, and Métis Peoples’ Data Sovereignty . 32
  - 4.5 Build data stewardship capacity and enable sharing by default..... 35
- 5.0 Time to Act ..... 37
- 6.0 Appendices ..... 38
  - 6.1 Ontario Health Data Council Membership ..... 38
  - 6.2 References ..... 39

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In July 2021, the *United Nations Declaration on the Rights of Indigenous People Act* became federal law in Canada. The Council acknowledges this Report, and its recommendations, are not based on formal consultations with First Nations, Inuit, and Métis peoples, nor have they consented to the aspects discussed. As this work progresses, the Council recommends Ontario actively engages, consults, and partners with First Nations, Inuit, and Métis peoples using a distinctions-based approach.

## Executive Summary

A sustainable health system requires a learning health data ecosystem that depends on high-quality, timely, and integrated health data. Rapid learning health systems use timely data to continuously improve for better care delivery, health system performance, and strengthen public health measures.

To achieve this modernized health data ecosystem, Ontario must adapt to an increasingly digital world, broaden its understanding of health data to include all factors that shape people's overall health and well-being, and treat data as a public good. The Minister of Health convened the Ontario Health Data Council to provide advice on enhancing the management and use of health data to benefit the people of Ontario.

This Report is an urgent and ambitious call to collectively transform health data's governance and management in Ontario. The Council's vision is for a future state with "data driving better and more equitable health, leading to healthier Ontarians". In support of this, the Council's mission is to "enable ethical, timely, and responsible access to and use of health data for people, communities, and populations in Ontario".

The Council's guiding principles include respecting and protecting the health data of all people, groups, and communities. The Council recognizes and respects the unique and distinct data sovereignty rights of First Nations, Inuit, and Métis peoples.

The Council has identified the following key strategic recommendations to guide the transformation of Ontario's health data ecosystem:

- 1) Integrate and use health data to advance health and equity outcomes for people, communities, and populations
- 2) Promote health equity through appropriate data collection, analysis, and use
- 3) Establish system-level trustworthy governance and policies for health data as a public good
- 4) Respect and support First Nations, Inuit, and Métis Peoples' Data Sovereignty
- 5) Build data stewardship capacity and enable sharing by default.

The Council's Report provides an achievable vision and key strategic recommendations for Ontario, pointing the way to the next phase of our health data ecosystem. We now urge action on implementing the Report's strategic recommendations.

This necessary transformation must begin today.

## 1.0 The Opportunity for Ontario

The future health system needs a strong integrated data foundation that effectively harnesses health data to generate timely actionable insights, enhances care experiences and outcomes, improves system performance, and addresses health inequities. Only then will Ontario's health system truly address Ontarians' needs and expectations and be resilient for future health challenges.

### Expanding the Definition of Health Data

Health is more than the absence of illness. Today, health involves a person's physical, mental, emotional, and social well-being. Health and being healthy are an integral part of each person's life. People need their health data to be available and work for them and those who care for them.

In the past, health data was often considered principally to be personal health information, which generally refers to identifying information about an individual within the context of health care. Personal health information is often generated and collected through many interactions with the health system and its services (e.g., hospitals, home care, community clinics, etc.), contained in a health record, and maintained for the purposes of providing health care.<sup>1</sup>

This definition of health data and personal health information comes from a time before the digital revolution and proliferation of data sources (e.g., smartphones, apps, and wearable devices). Yet "health data" is more than just data about health care. Health data increasingly includes any information that pertains to or affects a person's health such as a person's environment, eating habits, or general lifestyle. A person's daily commute, step count, the availability and cost of goods, location of high-quality food, and a region's pollution levels also contain information that has real and significant impact on a person's health. We also now know how integral the social determinants of health are to shaping a person's overall health and well-being, yet sociodemographic data does not always count as health data.

*Sociodemographic Data:* A person's social or demographic characteristics, such as data about a person's race, ethnicity, gender, sexual orientation, religion, income, or education.

*Social Determinants of Health:* These are social and economic factors that influence and impact the health and well-being of people over the course of their lives, such as early childhood development, employment, housing, social supports, accessibility needs, and food security.<sup>2</sup>

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<sup>1</sup> See the [Personal Health Information Protection Act](#) (2004).

<sup>2</sup> See [What are the social determinants of health?](#) (Canadian Public Health Association, 2022).

A person's health data must be understood as all data points required to collectively provide a longitudinal picture of their physical, mental, and social needs and health behaviours. The pandemic also highlighted how integrated population-level health data informed our understanding of COVID-19 and identified those most at risk, which then directed public health and organizational responses and enabled targeted interventions.

The Council recognizes that the definition of health data must change since it extends beyond people's interaction with the health system and overlaps with the social determinants of health and other socioeconomic factors that shape people's overall well-being. Therefore, the Council uses a broader definition of "health data" and calls on the Ontario government to do the same. Ontario must adapt to these rapid, ongoing changes to leverage health data's full potential.

### The Potential for Health Data in Ontario

Health data plays an important role across a range of care settings and at all health system levels (see Figure 1). Integrated and longitudinal data is needed for primary purposes by patients, families, caregivers, and providers (micro-level) every day to inform care decisions, plans, and experiences, and enable self-management of their own care.

Figure 1 - Uses of Data across the Health System



Beyond direct care, health data is needed for other use purposes within the health system. When combined at a population-level, important knowledge and insights are generated about the unique health and social needs of groups, communities, and populations within Ontario. Administrators and health leaders (meso-level), system planners and policymakers (macro-

level), and researchers and analysts (all levels) can use these insights to deliver more equitable cost-efficient services improving the health and wellness of the people of Ontario.

Ontario is moving towards an integrated population-based, person-centric learning health system, which provides care that is “respectful of and responsive to individual patient preferences, needs, and values” and ensures that “patient values guide all clinical decisions”.<sup>3</sup> The aim is for patients, families, and caregivers to experience tailored, coordinated goals-based care, greater access to providers and services, and smoother transitions across care settings.

To achieve this, providers need to share and have access to real-time integrated clinical, administrative, community, and social data. To transform patient, family, and caregiver care experiences and outcomes and improve the health status and address inequities faced by communities and populations in Ontario, the Council has identified the following high-value system-level uses:

### ***Use Case #1: Integrated and Accountable Care***

An integrated and accountable care approach recognizes that people experience care across many different settings (e.g., doctors’ offices, hospitals, specialists, pharmacies, and community care facilities). Integrated and accountable care occurs when providers across different care settings coordinate to deliver value-based, high-quality, cost-effective services. Providers and organizations must be accountable for their care responsibilities of ensuring cost-effective care, improving the patient and provider experience, and supporting population health outcomes.

Robust data is necessary for timely and efficient planning and delivery in integrated and accountable care systems. Improving information sharing among care teams will enable providers to collect data once and use it for multiple purposes, reducing administrative burden while improving the experiences of each person’s care journey.

### ***Use Case #2: Population Health Management***

“Population health survey data has helped us identify many forms of inequities...yet the lack of standardized and routinely collected socio-demographic data hinders our ability to assess organizational performance and identify improvements for reducing the identified inequities.”

- *We Ask Because We Care* Report, Toronto Health Equity (2013)

Population health management allows healthcare providers to identify defined population segments (e.g., geographic area, socioeconomic bracket, race, gender stratification, age, etc.) and their unique health and social needs by leveraging health and sociodemographic

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<sup>3</sup> See [Crossing the Quality Chasm: A New Health System for the 21st Century](#) (Institute of Medicine, 2001).

data to deliver tailored, proactive outreach programs and services with the goal of improving care experiences and outcomes. Using a data-driven approach, providers can track health and social needs over time to monitor the effectiveness of their services in meeting the needs of defined populations.

Ontario must move towards an integrated population-based, person-centric learning health system where provider decisions are informed by the needs and values of their patients. This would represent a shift from the traditional siloed and reactive model of acute care to community-driven models. This more reactive model depends on high quality, timely care so that needs are appropriately identified, and that targeted programs and services reach those whose lives will be significantly improved.

### ***The Connecting Care Act, 2019***

In 2019, the Ontario government laid the groundwork for health system reforms through the creation of Ontario Health Teams (OHTs), which are responsible for delivering comprehensive and coordinated care to a defined population using population health management. OHTs rely on data insights to design care tailored to diverse populations with distinct health service needs.

Meaningful population health management requires a strong equity lens to ensure that the needs of equity-deserving populations are met, that existing health disparities are reduced, and that programs and services are appropriately targeted to meet people's needs.

Thoughtful and intelligent use of data for population health management ensures gaps in data can be identified, monitored, and addressed so that outcomes can be appropriately measured, and the perpetuation or creation of health inequities can be avoided.

### ***Use Case #3: Rapid Learning Health Systems***

In a learning health system, connected data support insights that drive evidence-informed decisions. These data and insights are embedded in health programs, services, surveillance programs, and care delivery. When harnessed effectively, they can produce continual improvements and better and equitable outcomes for all. By learning from their own data, rapid learning health systems can adapt to become more efficient and sustainable while providing better patient and provider experiences. Rapid learning health systems are inherently data-driven and supported by a culture of learning and improvement. By applying analytical power to available data, an ideal rapid learning health system has the potential to reflect, adapt, innovate, and improve on an ongoing basis.

The health data ecosystem should enable the use of real-time and intelligent data for various purposes including patient care delivery, population and public health, informed decision making, precision medicine, health system planning and financing, system transparency and accountability, quality improvement, research and development, analytics, and performance evaluation purposes. An ideal rapid learning health system should have the potential to



adapt, innovate, and improve services through continually harnessing data and analyses to inform ongoing discussion among key stakeholders in addition to population-based interventions to enhance health and prevent disease and injury. It should enable a culture of continuous self-assessment and improvement for the health system.

An example of how health data can be used to improve Ontario's care experiences and outcomes is illustrated in the below Health Data in Action case study:

### **Health Data in Action: Driving Better Care and Empowering Patients**

*Ali is an 80-year-old male who lives alone in rural Ontario. He has multiple chronic illnesses and receives care from several different care providers across a range of care settings including primary care, acute, community, and social services. His main caregiver is his son, who takes Ali to all his health visits and must maintain detailed paper records so that he can update each care provider within Ali's circle of care. At a recent visit, Ali was prescribed new medication. As his health information is not integrated and accessible to his care provider, his care providers were not aware Ali previously developed side effects to a similar medication.*

In an integrated, person-centric data ecosystem where there is seamless real-time data exchange and access to comprehensive integrated health information, population-based and personalized insights are used to inform Ali's care experiences and outcomes:

- *Micro:* Ali, his son, and care providers have access to his digitized health information and can identify trends in his health and can provide timelier, safer, and more informed care. The different providers who care for him can also more easily and efficiently collaborate to deliver an integrated goals-based care plan, which reduces the risk of unintended errors and duplication of services and/or investigations. Ali and his son are now more informed about this health status and needs and can self-manage his care better at home.
- *Meso:* The administrator at the primary care practice notices that other patients like Ali regularly need extra home care services and sets up an outreach service to address this need.
- *Macro:* Based on Ali's health information and others like him, a system planner can use population-level information to identify patients like Ali are more likely to be at risk of falls, and subsequently sets up proactive programs and services that are rolled out across the province.

### **Use Case #4: Public Health**

In Ottawa's Charter for Health Promotion, the Public Health Agency of Canada offers a broader view of health to include the social determinants of health such as safe environments, adequate income, education and shelter, safe nutritious food, peace, equity, and social justice. Public Health can therefore only understand the root causes affecting health by collecting health data beyond injury and illness, so that it can more effectively address health inequities, concentrated disproportionately among Canada's most vulnerable populations, and ensure universal access to the determinants of health.

To protect people from public health risks, the Ontario government has a duty to conduct ongoing, systematic population monitoring. Yet 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. Ontario's fragmented health data ecosystem, including the lack of standardized lab testing data, lacks comprehensive, real-time data to inform public health decisions. Collecting population-based data can tailor prevention, protection, and promotion strategies to people, groups, and communities where they will have the most impact.

### ***Anti-Racism Act, 2017***

Ontario's *Anti-Racism Act, 2017* was created to further the goal of eliminating systemic racism and advancing racial equity in Ontario. Important provisions in the Act require the Minister to create data standards for the collection of personal information that can be used to eliminate systemic racism in Ontario (6(1)). However, Health Information Custodians (HICs) are not included in the scope for various privacy-protective, legal, and practical reasons. For this reason, the Act does not yet apply to public sector organizations who are, by virtue of their providing a program, service, or function, HICs as defined under the *Personal Health Information Protection Act, 2004*.

### ***Use Case #5: Addressing Health Inequities and Promoting Health Equity***

"Inequitable health outcomes produced by COVID-19 in Ontario align with the pre-existing maps of disadvantage, such as economic marginalization, poverty, and racial segregation."

-*Tracking COVID-19 Through Race-Based Data*, The Wellesley Institute & Ontario Health (2021)

Health inequities are health disparities between peoples or groups of people that are unfair or unjust and unnecessary or avoidable. Today, health care is not equitably delivered across Ontario, which leaves people, groups, and communities unrepresented and unprotected. As a result of disparities, health outcomes are also not equitably distributed. Moreover, Ontario residents do not receive equal access to healthy food, physical activity, education, housing, safe environments, and other services that impact health. Among the most affected are First Nations, Inuit, and Métis communities and equity-deserving populations, including people living in lower-income areas or experiencing greater social deprivation.<sup>4</sup>

Health data has the potential to address health inequalities and improve health system quality. Unfair, avoidable, and unjust differences in health and care outcomes can be minimized by using sociodemographic data to understand the needs of people, groups, communities, and populations and facilitate appropriate changes in services and systems. Without integrated health data, then, public sector decision- and policy-making is based on

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<sup>4</sup> See [Key Health Inequalities in Canada: A National Portrait](#) (Public Health Agency of Canada, 2018).

incomplete information, which further exacerbates inequities. Health data can be used to identify, understand, and address these inequities, but only if the data needed is available.

Despite awareness of the social determinants of health, and how they impact people, groups, and communities, there is no system-wide, standardized collection of sociodemographic data across healthcare settings. Without this data, healthcare policymakers and healthcare providers lack the evidence they need to best understand, identify, and address health disparities. The collection, analysis, and use of sociodemographic data to promote health equity is a key function of a high-quality learning health system.

An example of how data can inform public health measures and address health inequities is illustrated in the below Health Data in Action case study:

### **Health Data is Action: Lessons from the COVID-19 Pandemic Response**

In March 2020, the province of Ontario declared a state of emergency in response to the COVID-19 pandemic. Initially, the pandemic response was challenged by the inability to share data. However, faced with the threat of COVID-19, unprecedented collaborative cross-sector efforts to share, use, and disclose population-level health data, as well as legislative changes to enable collection and use of sociodemographic data, helped patients, care providers, funders, and municipalities to understand and navigate the pandemic. Decision-makers could monitor and predict virus infection trends, which informed the public health response, interventions, and health system resourcing.

The pandemic also highlighted how communities suffer real harms when health data is not collected, shared, and used. Faced with a lack of sociodemographic data, health system leaders predicted the pandemic would widen health disparities, disproportionately impacting racialized communities.<sup>5</sup> By Spring 2021, racialized communities had significantly higher rates of COVID-19 infections, hospitalizations, ICU admissions, and deaths. When COVID-19 vaccines became available, initial data highlighted these communities at the greatest risk also had the lowest vaccination rates.<sup>6</sup>

Targeted use of health data directly influenced public health measures including prioritization of certain communities, direct outreaches, targeted campaigns, and pop-up vaccination clinics. The pandemic is a powerful example of health data's potential to inform, direct, evaluate, and adapt responses to community-wide threats to Ontario.<sup>7</sup>

### **Health Data as a Public Good**

“Health information has become one of society’s most valuable public goods. It informs policy, management, care, and research, leading to better more equitable health outcomes for all Canadians.”

- The Canadian Institute for Health Information (CIHI)

<sup>5</sup> See [Letter to Premier Ford](#) (Alliance for Healthier Communities, 2020).

<sup>6</sup> See [“The Vaccine Rollout is Leaving Toronto’s Hardest Hit Postal Codes Behind”](#) (Hune-Brown, 2021).

<sup>7</sup> See [“Socio-demographic data collection and equity in COVID-19 in Toronto”](#) (McKenzie, 2021).

According to the World Health Organization, health data is a global public good in that it **builds public value** (data informs people, benefits communities, and enhances economies), **addresses knowledge gaps** (data can reduce inequalities and highlight data disparities), and **accelerates progress** towards targets set under the Sustainable Development Goals.<sup>8</sup>

There is increasing global awareness of the importance of health data as a public good. Many countries like the UK, Finland, and Estonia have implemented national data strategies and are using population-level data to better understand the experiences, health, and social needs of their populations and evaluate use of resources and overall system performance. By doing this, they can deliver more tailored connected services, improve care experiences and outcomes, inform policies, advance health equity goals, and design more sustainable efficient health systems.<sup>9</sup>

In Canada, this work is already underway at the federal level. In Fall 2020, the Government of Canada launched the pan-Canadian Health Data Strategy to support the effective creation, exchange, and use of critical health data for the benefit and health of Canadians and public health systems.<sup>10</sup> Reports from the Expert Advisory Group highlight the urgent need for action at federal, provincial, and territorial levels on health data collection, access, and use.<sup>11</sup> To modernize Canada's health system, federal and Ontario political and health system leaders should work closely together on developing and implementing a unified data strategy.

## 2.0 The Current Health Data Ecosystem

Ontario's health system generates enormous amounts of health data: patients, families, and caregivers use health data to plan their health journey; providers use health data to support patient care; public health and policy planners use this data to deliver care; and researchers work with data to discover new insights and develop new treatments.

Although health data is integral to meeting the needs of patients, families, caregivers, and the health system more broadly, Ontarians are not getting the most out of their health system because Ontario lacks a modern health data ecosystem – seamless, timely, equitable, and secure information-sharing between health sector stakeholders, informed by the needs of people, communities, and populations, that simultaneously governs and optimizes health data for everyone. Ontario's outdated health data ecosystem will be costly for Ontario: fragmented patient and provider experiences will mean poorer patient care and outcomes, delayed testing and research will mean slow, ineffective, and potentially harmful public health

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<sup>8</sup> See the Open Data Institute's [Health Data Governance Summit: Health Data as a Global Public Good](#) (2021).

<sup>9</sup> See the United Kingdom's [Data Saves Lives: reshaping health and social care with data](#) (2022), Finland's [Secondary Use of Health and Social Data Act](#) (2019), and Estonia's [e-Health Records](#) (2008).

<sup>10</sup> See the [pan-Canadian Health Data Strategy](#) (2020).

<sup>11</sup> See the pan-Canadian Health Data Strategy [Expert Advisory Group Overview](#) (2020).

and population management, and the failure to create a person-centric, learning health system will overburden and potentially financially paralyze overall health system performance. Ontario's health data ecosystem is unsustainable in its current form.

Ontario's health data ecosystem is also not user-friendly because it is oriented around providers and not people. It is a highly fragmented, poorly integrated, and inconsistently governed analogue and patchwork network of individual HICs who struggle to provide personalized care and share health data for population-based health management and research due to a lack of data literacy – the ability to read, interpret, and communicate data and understand the use of data in decision-making – among patients, families, caregivers, providers, system leaders, system planners, and policy makers as well as health system interoperability barriers. These jurisdictional, technological, and cultural barriers include:

- Unclear data policy, legislation, regulation, and standards
- Concerns about data governance, privacy, and security
- Absent common, timely, and intuitive data infrastructure
- Insufficient data management capacity for new data sources
- Ineffective data literacy, public engagement, and public reporting, and
- Culture of risk aversion and resistance to data sharing.

These issues highlight limitations in the health system's ability to support a data sharing regime that is guided by a clear ecosystem-wide approach that consistently ensures the use of health data benefits everyone. Recognizing these issues, the Public Health Agency of Canada's Pan-Canadian Health Data Strategy champions a more impactful health data foundation for the benefit of all Canadians and the health systems on which they rely. In alignment with this strategy and Ontario's *Digital First for Health Strategy* (2019) and *Building a Digital Ontario* (2021), the Council seeks to advance a health data ecosystem informed by federal expertise but tailored to Ontario.

### **Moving Ontario Forward**

The Ontario government has already taken meaningful steps to modernize the province.<sup>12</sup> Ontario's *Digital First for Health Strategy* (2019) will better streamline digital health systems by offering more virtual care options, expanding access to online appointment bookings, providing greater data access for patients and more connected tools for frontline providers, and enhancing data integration and predictive analytics.

Ontario's Digital and Data strategy, *Building a Digital Ontario* (2021), aims to protect, support, connect, and equip Ontario to succeed in the digital world by simultaneously ensuring privacy and

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<sup>12</sup> See Ontario's [Digital First for Health Strategy](#) (2019) and [Building a Digital Ontario](#) (2021).

security while supporting economic growth. With these strategies, Ontario hopes to become a global leader in health care and digital government.

### **Ontario has Robust and Evolving Privacy Legislation**

The *Personal Health Information Protection Act, 2004 (PHIPA, 2004)* sets out the rules for the collection, use, and disclosure of personal health information (PHI). Ontario's independent regulator, the Information and Privacy Commissioner (IPC), enforces the province's privacy and access to information laws and investigates complaints of alleged non-compliance.

Health data cannot be meaningfully shared across the health system unless it is sufficiently protected. People's privacy expectations and rights are particularly important when it comes to their personal health information (PHI). PHI is imperative for effective health care, yet if used or accessed for inappropriate purposes, people, groups, and communities may be harmed and/or stigmatized (e.g., First Nations, Inuit, and Métis must maintain control over how their data is collected, managed, shared, and used). At the same time, if care providers cannot access real-time, comprehensive PHI, people, groups, and communities will be harmed. When it comes to PHI, people have dual interests: ensuring their data is protected while needing their data to be appropriately shared for timely and personalized care.

In recent years, amendments have expanded PHIPA to simultaneously strengthen the protection of privacy in Ontario's increasingly digitally integrated health data ecosystem and support the sharing of health data. These include:

- Setting rules for operation of the provincial electronic health record (EHR), such as elaborating on patients' consent rights in the system, which must be managed differently in digital systems
- Introducing Ontario Health (OH) as a new entity under the *Connecting Care Act, 2019*; providing it with the authorities as a Prescribed Organization to hold the provincial EHR to increase interoperability, clarify and set standards, and provide providers and patients access to integrated health information
- Developing digital interoperability standards to connect different systems, allowing seamless sharing of health data through the Digital Health Information Exchange (DHIEX)

### **Improving Interoperability**

One example of how Ontario is improving information exchange across the health system in a clear, transparent, and accountable manner is through a new policy initiative called Digital Health Information Exchange (DHIEX). Through the DHIEX policy, Ontario is developing standards to connect systems in different sectors and allow the seamless sharing of health information. The DHIEX policy is enabled by interoperability regulation under the *Personal Health Information Protection Act, 2004* that came into force on January 1, 2021. This regulation, with the Minister's approval, authorizes Ontario Health to establish interoperability specifications and other requirements to uphold the policy's model.

With recent technological advances, it is now possible to collect and connect large amounts of digital data from a variety of sources and process insights more quickly thereby posing an increasing threat to a person's privacy. People's health data must be protected, and any bad actors who deliberately misuse data for inappropriate purposes, including monetizing it for personal gain, must be held accountable and penalized for their actions. Recent amendments to PHIPA have made it an offense to willfully use or attempt to use information that has been de-identified to re-identify an individual. Further amendments to PHIPA have introduced administrative monetary penalties and the Ministry must act swiftly to put the necessary regulations in place for these provisions to take effect as soon as possible. These penalties are intended to encourage compliance and prevent individuals from deriving, directly or indirectly, any economic benefit from non-compliance.

PHIPA is an important tool in Ontario's privacy regime. However, today's data-driven and digitally integrated health data ecosystem presents new opportunities for health, and new challenges as to how data should be collected, used, and disclosed. For example, health data is increasingly used to make inferences about groups of people in Ontario. Traditional privacy mechanisms, such as individual consent or permissible use after de-identification that allow such inferences to be made without regard to their impact on groups, do not provide adequate protection, as there are no specific provisions to protect the (dis-)aggregated data of groups and communities. This gap has led some who have suffered historical misuse to propose their own governance structures and principles to exercise their own rights and protect their community-level data i.e., First Nations (OCAP®),<sup>13</sup> Black Health Equity Working Group (EGAP), and the Jane-Finch community (research principles).<sup>14</sup> Accordingly, Ontario's health privacy legislation and regulations must adapt to the changes happening in Ontario's health data ecosystem to protect their privacy and interests.

### The Public Wants Change

"I'm happy to provide any data that may help someone's future"

- Patient & Caregiver Consultations, *Dialogue on Data*

### **Dialogue on Data Consultation**

The Ministry of Health consulted with more than 25 patient, family, and caregiver groups and more than 15 health sector organizations to inform the modernization of Ontario's health governance and protection framework and better understand the experiences and perspectives of patients, caregivers,

<sup>13</sup> Ownership, Control, Access, and Possession (OCAP®) is a registered trademark of the [First Nations Information Governance Centre](https://fnigc.ca/ocap-training/) (FNIGC). See <https://fnigc.ca/ocap-training/>.

<sup>14</sup> See the [Ownership, Control, Access, and Possession \(OCAP\)](#) principles for First Nations data (First Nations Information Governance Centre, 2020). See also the [Jane Finch Community Research Partnership](#) (2020) principles and the [Black Health Equity Working Group, Engagement Governance, Access and Protection \(EGAP\)](#) (2021) principles.

and the health sector on health data. These consultations included voices from across Ontario, including urban, rural, and northern, and from groups with specialized interests such as mental health and children and youth. This *Dialogue on Data* informed the Report's recommendations.

In the Ministry of Health's *Dialogue on Data*, patients, families, and caregivers expressed frustration with the practical, financial, and structural barriers in accessing, using, and sharing their health information and how they are forced to repeat their stories and shuttle their health data between different providers and care settings. Providers shared their difficulties with accessing the data they need to make the best possible decisions for their patients. System and community planners emphasized how the lack of accessible, timely, high-quality data prevents them from responding to public health threats. Researchers, analysts, and public health workers conveyed that they cannot generate timely, useful, actionable insights they depend on to address local service and public health needs to inform their practices, services, resourcing, and funding, to improve care experiences and outcomes. Many organizations are already trying to solve today's common data barriers and challenges.

The Council also learned that patients, families, and caregivers consider health an every day lived experience and want their health data to reflect their whole lives, beyond physical health. Many are actively using their health data to self-manage their care and sharing their health data with providers, so that they can make more informed decisions and reduce safety risks like duplication of tests or prescription errors. Patients also want the ability to input key details about their identities (e.g., pronouns, preferred names, language spoken, etc.) that would allow for more personalized care experiences. They would also like the ability to feed patient-generated data, collected by an app or wearable, into the health system to inform their care, provided this information was secure and used to support their goals.

Patients, families, caregivers, and health system stakeholders recognize the value of their health data and want it to be shared with appropriate security and privacy safeguards in place not only to improve their health, but also the health of their families, communities, and public. Patients, families, and caregivers want to know what data is being collected and want transparent and accountable processes so they are informed on how their data will be used, by whom, and for what purposes and benefits. Some were even willing to make trade-offs in privacy so that their health data can be used for broader public good. A top priority was using health data to uncover and address health inequities affecting people in Ontario.

Ontarians want and need access to their health information. Their data needs to work for them so they can be active care partners in their own health journey and share their data for the public good. Patients, families, caregivers, communities, and the health sector – providers, planners, researchers, analysts, public health workers, and innovators – want Ontario's health data ecosystem to evolve, yet still face barriers when trying to access, manage, and use health data, challenges that are particularly harmful on the most equity-deserving members of our communities. As a result, Ontario sees only a fraction of the



potential benefits of health data, which include improving patient health outcomes, enhancing care delivery, and better overall health system performance.

## **Ontario Needs a System-Level Approach to Data Governance and Data Stewardship**

Earning and maintaining trust is foundational to health data exchange. It underlies the collection, sharing, access, and use of health data, and is key to creating, maintaining, and improving the data flows that are necessary for better data use. Trust allows sharing and uses of data for good to grow and expand over time, increasing benefits for everyone.

To cultivate trust within a health system, every organization holding and managing data must have inclusive and transparent governance processes and be held accountable to external oversight. By inclusive, we mean that people and communities are involved and engaged in all governance processes for those data. By transparent, we mean that “clear information describing data flows, data sharing agreements, research objectives, results and their clinical impacts are not only made publicly available but also actively promoted.”<sup>15</sup>

Governance principles need to be grounded in common values and promote the consistent demonstration to Ontario residents that the use of their health data is in accordance with their expectations and results in benefits for them.

### **What is Data Governance?**

Data governance is a critical component of a data ecosystem, and refers to the legislation, 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.

Generally, the capacity to appropriately govern, collect, manage, share, and use data in the health system is uneven and concentrated among the larger organizations. Despite robust local health data governance structures, policies, and practices in place across many institutions, there is no clear data governance approach at a health system-level to ensure common standards, practices, and norms around data collecting and sharing nor are there clearly designated data stewards to enforce this governance structure. These are governance risks that also increase the possibility of gaps in privacy and security approaches, which can result in data being shared or accessed inappropriately.

Gaps in system-level health data governance must be addressed if Ontario hopes to leverage the full value of its health data assets and treat health data as a public good. Data governance approaches must facilitate data sharing, focusing on what data is needed, for

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<sup>15</sup> See “[Our data, our society, our health](#)” (Ford et al., 2019).

what purposes, and how it can be shared. Ontario needs to govern the ethical use of health data, ensuring its uses align with Ontarians' values and promote public interest. At the same time, system-wide data governance must not result in additional layers of bureaucracy.

### **What is Data Stewardship?**

Data stewardship is the data accountability function to ensure the authorized, appropriate, ethical, and responsible use of health data in accordance with Ontario's data governance framework. Data stewardship is the operationalization of data governance.

Ontario's health data ecosystem does not have clear accountability or incentives to share digital health data assets. Decisions to share health data are currently up to the discretion of individual and organizational data holders (known as Health Information Custodians or HICs) who vary in their capacity to collect, manage, and share data, and may not feel confident to share data even when legally permissible.

Lacking common data governance policies, and facing capacity issues, individuals and organizations in the health sector are afraid of accidentally doing something wrong, which has led to an unduly risk-averse "data protectionist" culture in the health system amidst concerns about violating privacy laws (known as privacy chill). They must also navigate burdensome data sharing agreements (DSA), which are time consuming to negotiate and further hamper health data exchange.

The health system must create focused data stewardship capacity to improve its ability to use and manage data. Data stewards act as an intermediary to ensure people's control over their own data and are responsible for the operationalization of data governance frameworks on behalf of data users, while balancing people's rights and using data for public good.

Ontario is data rich but information poor due to large amounts of dormant data within data silos. Before Ontario can realize the potential of health data, it must address its data barriers and data quality issues. Ontario needs a provincial health data strategy to enable a variety of purpose-driven uses of timely, high-quality integrated health data across the health system, which will drive improvements in care delivery and health outcomes, research, system performance and innovation, while strengthening a person's control over their data.

A strong health data ecosystem is the foundation on which a sustainable health system rests. This future health data ecosystem must be founded on the people of Ontario's needs and interests, and enabled by a data literate workforce, system-level data and analytical capacity, and a transparent and accountable culture, which ensures data sharing and promotes data uses for the public good.

### 3.0 The Path Forward for Ontario

Ontario’s health system needs a forward-facing data strategy that enables use of trusted integrated health data to address the health needs and equity concerns of Ontario’s residents, the needs of their communities, and those of the public.

Only a data strategy that addresses the different components of Ontario’s health data ecosystem separately and leverages them collectively can achieve the Council’s vision for Ontario. The Council’s vision, mission, and principles aim to guide collaborative and shared/common approaches to health data management in Ontario to fully leverage Ontario’s health data for the benefit of all.

**VISION : Data driving better and more equitable health, leading to healthier Ontarians**

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

**ETHICAL PRINCIPLES**

**DATA SOVEREIGNTY**

*Values which guide and set expectations for decision-making and actions*

<b>RECOMMENDATIONS</b>				
<i>Use data better and do good with data</i>		<i>Have responsive and inclusive governance</i>		<i>Enable accountability</i>
<p><b>Health</b></p> <p>Integrate and use health data to advance health and equity outcomes for people, communities, and populations</p>	<p><b>Equity</b></p> <p>Promote health equity through appropriate data collection, analysis, and use</p>	<p><b>Governance</b></p> <p>Establish system-level trustworthy governance and policies for health data as a public good</p>	<p><b>Sovereignty</b></p> <p>Respect and Support First Nations, Inuit and Métis Peoples’ Data Sovereignty</p>	<p><b>Stewardship</b></p> <p>Build data stewardship capacity and enable sharing by default</p>

### 3.1 The Vision for Ontario

**VISION: Data driving better and more equitable health, leading to healthier Ontarians**

The Council has set this ambitious and forward-facing vision for Ontario’s future health data ecosystem, one which serves as a North Star for the path ahead.

To realize the anticipated benefits and unlock the value of health data to advance the health and equity goals for everyone, health data should be *governed as a public good*. This means that people’s health data should be considered as a common asset, and by extension, governed and used for defined purposes so that the benefits are maximized. Governing health data as a public good will strengthen and empower Ontarians in their rights to access

and use their own data to benefit themselves as people, as members of groups and communities, and for society at large.

The Council believes that if health data in Ontario is to be governed as a public good and used for beneficial purposes to drive equitable health improvements for everyone, it will be necessary to establish a health data ecosystem which is *trustworthy*, *person-centric*, and *integrated*.

- To be *trustworthy*, the future data ecosystem needs to have trustworthy rules and approaches to health data governance that allow stakeholders to use this data for the benefit of all while minimizing the risks of harm. This includes all the structures, processes, capabilities, and mechanisms in place that are needed to ensure health data is secure and accessed and used appropriately. Fostering people's trust in the health system will enable more seamless data sharing and new data uses over time.
- In Ontario's *person-centric* data ecosystem, individual-level health information is portable. This means data follows an individual across all care interactions, providers, and settings, and is accessible to them and their providers along their entire health journey. This also means that health data is used to benefit patients, families, and caregivers in Ontario (e.g., care experiences, population health management), drive health system innovation (e.g., research, service improvement, and planning), and advance the community and social issues they care about (e.g., public health, health equity). Uses of population-based data assets at different levels of the health system will collectively improve the quality of health care today in Ontario through enhanced care experiences and outcomes, efficient uses of limited resources, and healthy public policies and promotion of health equity.
- In an *integrated* data ecosystem, Ontario's disparate, fit-for-purpose data systems will reliably capture and consistently analyze standardized health data. When appropriate, they will also securely share for uses such as clinical, administrative, research, system management, and other public benefit purposes. *Integrated* also extends to integration of data and specifically the inclusion of new sources of health data currently not readily shared or used (e.g., home and community, social services, municipal, etc.). This data is important as it provides a comprehensive view of the physical, mental, and social aspects of health and the unique needs of people, communities, and populations in Ontario. These are the factors which inform person-centric and population-based care and drive the provision of integrated accountable care.

Achieving this vision will require an iterative, agile approach, one supported by dialogue, time, and resources, and enabled by the participation and collaboration of people and

organizations across Ontario's health system.

The Council recognizes Ontario's progress made to-date, and that the path forward must be built on current digital and data initiatives, harness existing data assets, and leverage the substantial analytical strengths of Ontario's current health data ecosystem.

### 3.2 The Mission

**MISSION: To enable ethical, timely, and responsible access and use of health data for people, communities, and populations in Ontario**

The Council has proposed the above mission statement to serve as an anchor for the future health data ecosystem, uniting all stakeholders in a common goal to guide the work ahead. This mission underpins the recommendations in this Report, which serve as the foundational pillars for the future health data ecosystem in Ontario.

If Ontario is to realize the full value of health data, it must ensure that health data access and use at individual, community, population, and system levels is:

- *Ethical*: Respects, empowers, and benefits people, groups, and society. This involves the prevention of the harmful use of data and the promotion of equity through data.
- *Timely*: The collection and sharing of data with those who need it, when they need it, while protecting privacy, maximizing benefits, and minimizing risks.
- *Responsible*: Guided by clear rules and governance structures, and by robust accountability and transparency mechanisms.

The Council believes it is a shared responsibility of all stakeholders across Ontario's health data ecosystem to ensure ethical, timely, and responsible health data access and use. Central to this is the need to shift from thinking about how to protect data to enabling timely collection, sharing, use, and disclosure of health data appropriately while maintaining privacy.

### 3.3 Guiding Principles

As Ontario moves towards this vision of an evolved health data ecosystem, the Council recognizes that the values of Ontarians and their desire to live in a diverse, inclusive society must be respected. The future data ecosystem will incorporate more and new sources of health data and enable the use of integrated data for expanded and new purposes.

Foundational to enabling this is the recognition that every data point represents discrete information about a person, some of which are very sensitive and personal to them. The integration of these different pieces of health data provides a more complete picture of that person's health status, goals, and behaviours. However, health data is not just about people;

it also collectively, as statistical and (dis)aggregate data, represents groups of people and communities, and needs to be governed accordingly.

There needs to be thoughtful consideration of the impact to Ontario including the anticipated benefits and unintentional harms that may arise. Ontario must consider how best to pursue the benefits while balancing the responsibility to prevent harms, and to protect the interests, rights, and privacy of people, groups, and communities in this data-rich, digitally integrated future health data ecosystem.

To guide this work, the Council has proposed a set of guiding principles that articulate the foundational values of Ontarians. The development of these principles was anchored on two key considerations:

*1. People have an interest in and right to their health data*

How health data about a person is captured, shared, used, interpreted, and disclosed can impact their well-being and dignity. As the ability to share, use, and analyze data and to generate knowledge increases, there will be a corresponding increase in the ability to derive insights about people, groups, and communities, and potentially to re-identify people. Protecting people's interests, rights, and privacy regarding their health data is paramount. However, it will always be essential to ensure they are adequately informed and/or appropriately consented about the uses of health data.

*2. Groups and communities are at increased risk of misuse of their data*

Many groups and communities have been subjected to historical misuse of their data, which has resulted in mischaracterization, stigmatization, and decisions being made based on data which does not accurately represent them. These very real harms persist today and have led some groups and communities to propose their own data governance principles. They have adopted this approach because current data governance and privacy legislation and regulation in Ontario focuses on protecting the personal health information of people and does not contain specific provisions to protect the (dis)aggregate information of groups and communities. Accordingly, new protections and considerations regarding health data and privacy must be put in place.

The Council recommends that those who access and use health data and/or are involved in the design of health data strategies and policies should be well-versed in these guiding principles and should consistently apply them to the work in which they are engaged.

### **3.3.1 Ethical Principles**

The Council has established a set of five ethical principles to be adopted and used by stakeholders at all levels of the health system. This includes patients and care providers, as

well as (but not limited to) administrators and policymakers who are tasked with planning, evaluating, and designing regulations for health information.

➤ **Data for Good**

*The collection, use, and disclosure of health data should benefit persons, groups, and society at large*

Health data should be collected, used, and disclosed in ways that create a positive impact on people's lives and well-being, and promote and ensure public benefit for everyone.

➤ **Respect for persons, groups, and communities**

*The collection, use, and disclosure of health data should respect persons, groups, and communities by protecting their dignity and integrity, and by promoting their autonomy*

The collection, use, and disclosure of health data should:

- Respect the dignity and integrity of people, groups, and communities. This means users of health data should consider the potential impact a particular use or disclosure of health data may have, including identifying potential harm or stigma that may arise from data representative of people, groups, and communities.
- Support and not interfere with a person's right to autonomy (i.e., their ability to self-determine their life), and to live that life in accordance with their own values. This means users of health data should seek consent for uses of health data where possible, and only proceed without consent as being justified and appropriate.

➤ **Protect against harms**

*The collection, use, and disclosure of personal health data should avoid causing harm to any person, to any group, or to society at large*

The collection, use, and disclosure of health data should be undertaken in a way that avoids adverse effects on a person's well-being, as well as the welfare or prospects of groups, communities, or society at large. This means users of health data should actively consider and plan how to mitigate or avoid causing harm.

➤ **Equity**

*The collection, use, and disclosure of health data should promote health equity in Ontario*

The collection, use, and disclosure of health data should reduce or eliminate pre-existing health inequities and should not result in the emergence of new inequities. This means users of health data should be aware of the risk of introducing new inequities, particularly if existing systems make use of biased data or rely on data that fails to sufficiently reflect the diversity of the population.

➤ **Transparency and Accountability**

*The collection, use, and disclosure of health data in Ontario should be transparent and data users should be held accountable to the needs of people, groups, and communities*

- Transparency – people, groups, and communities should be informed as to how their health data is being collected, managed, used, and disclosed. This allows them to participate in public oversight and governance decisions, be informed of their rights, and contribute to understanding of new insights derived from their data.
- Accountability – data users and system administrators/leaders who are accountable for health data should be responsive to the needs of people, groups, and communities and integrate their feedback to shape and improve policies and programs. Those who collect, use, and disclose health data must be answerable for their actions and decisions, and subject to scrutiny by independent, expert oversight.

Together, transparency and accountability will support public engagement, improve organizational responsiveness, ensuring the continued safe and effective use of health data.

### **3.3.2 Respect for First Nations, Inuit, and Métis Peoples' Data Sovereignty**

The Council advises that Ontario must recognize and respect First Nations, Inuit, and Métis peoples' rights to self-determination, including self-governance. These same rights apply to the governance of First Nations, Inuit, and Métis' health data, and are in accordance with documents guiding Canada's relationship with Indigenous peoples, such as the Truth and Reconciliation Commission's 94 Calls to Action and the *United Nations Declaration on the Rights of Indigenous Peoples* (UNDRIP).<sup>16</sup>

In 2015, the Truth and Reconciliation Commission of Canada (TRC) released 94 Calls to Action, designed to further reconciliation with Indigenous peoples living in Canada. Call to Action #43 calls on provincial governments to adopt UNDRIP as the framework for reconciliation:

*We call upon federal, provincial, territorial, and municipal governments to fully adopt and implement the United Nations Declaration on the Rights of Indigenous Peoples as the framework for reconciliation.*<sup>17</sup>

UNDRIP was adopted by the United Nations General Assembly in 2007 and endorsed by Canada in 2016. On June 16, 2021, Canada's senate passed Bill C-15, *The United Nations Declaration on the Rights of Indigenous Peoples Act, 2021*.<sup>18</sup> UNDRIP identifies "the

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<sup>16</sup> See the [United Nations Declaration on the Rights of Indigenous Peoples \(UNDRIP\)](#) (2007).

<sup>17</sup> See the [Truth and Reconciliation Commission](#) (2015).

<sup>18</sup> See [Bill C-15, the United Nations Declaration on the Rights of Indigenous Peoples Act](#) (2021).



minimum standards for the survival, dignity, and well-being of the indigenous peoples of the world.”

To respect and support First Nations, Inuit, and Métis’ data sovereignty, and in accordance with UNDRIP, the Government of Ontario must:

- Engage with First Nations, Inuit, and Métis peoples, through their own representative institutions, to determine their needs and preferences in how their respective data will be governed.
  - *States shall consult and cooperate in good faith with the indigenous peoples concerned through their own representative institutions in order to obtain their free, prior, and informed consent before adopting and implementing legislative or administrative measures that may affect them. UNDRIP, Article 19*
- Respect the rights of First Nations, Inuit, and Métis peoples to separately and uniquely develop their own data governance models and strategies for how their health data will be governed in Ontario.
  - *Indigenous peoples have the right to determine and develop priorities and strategies for exercising their right to development. In particular, indigenous peoples have the right to be actively involved in developing and determining health, housing and other economic and social programmes affecting them and, as far as possible, to administer such programmes through their own institutions. UNDRIP, Article 23*

All engagements should be undertaken using a distinctions-based approach in recognition of the diversity between and within First Nations, Inuit, and Métis peoples living in Ontario, who have a wide diversity of history, cultural heritages, languages, needs, preferences, and values.

The Council advises that the five ethical principles and the principle of Respect for First Nations, Inuit, and Métis peoples’ Data Sovereignty must be taken as the fundamental guiding values of Ontario’s health data strategy. The Council’s recommendations should be read in alignment with these values and should seek to uphold them in all contexts.

#### **4.0 Strategic Recommendations**

The Council urges Ontario to seize the opportunity presented to create a world-class, effective, trusted health data ecosystem in which health data is governed as a public good, for the benefit of people, communities, and populations to advance health and equity goals.

To guide Ontario in the work ahead, the Council has identified five strategic recommendations, which are key to supporting Ontario's direction and realizing the health data ecosystem that the people of Ontario need and deserve.

## Strategic Recommendations

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- 4.1 Integrate and use health data to advance health and equity outcomes for people, communities, and populations
- 4.2 Promote health equity through appropriate data collection, analysis, and use
- 4.3 Establish system-level trustworthy governance and policies for health data as a public good
- 4.4 Respect and support First Nations, Inuit, and Métis Peoples' Data Sovereignty
- 4.5 Build data stewardship capacity and enable sharing by default

The vision of a trustworthy, person-centric, and integrated health data ecosystem will not be realized overnight. This will be a multi-year journey for Ontario and will require the active participation of the health system and all its stakeholders. Only with the support and goodwill of all can this succeed: everyone must work together to harness health data for good, govern data for the benefit of all, prevent harms, and avoid reinforcing any existing or creating any new health inequities.

### 4.1 Integrate and use health data to advance health and equity outcomes for people, communities, and populations

Health data must be harnessed and used effectively to better inform Ontario's understanding of health and improve its quality of care. When using health data, every decision and action should be guided by the intent to create meaningful benefit and value for everyone, as patients, family members and caregivers; as members of communities and populations; and as healthcare providers, administrators, and decision makers.

### Supporting Recommendations

- *Enable purpose-driven uses of health data to drive better outcomes for all.*

Ontario must immediately take a common use, case-based approach to addressing the purpose-driven data needs at all levels of the health system. These uses should be prioritized for consideration and abide by the Council's Data for Good ethical principle

ensuring data is “...collected, used, and disclosed in ways that create a positive impact on people’s lives and well-being, and promote and ensure public benefit for everyone.”

A unified approach will focus the attention, efforts, and resources of stakeholders towards enabling these prioritized use cases and move Ontario closer to attaining the Council’s vision. Creating system-wide data pathways and informing the core data elements to be collected, shared, and used across the health system will ensure that people, communities, and populations from whom the data originates will be able to see how their data is being used to make better decisions, fund, resource, and plan more effectively and to advance health and equity outcomes.

All purpose-driven uses of data must be anchored in the goals and expectations of Ontarians. Strong governance is needed when interpreting and using knowledge and insights generated, particularly where it pertains to communities and populations who experience or are at risk of health inequities today. This requires ongoing engagements with Ontario residents, particularly as expanded or new uses of health data emerge, supported by a culture of learning and improvement.

The Council advises that population health management, integrated and accountable care, public health, learning health systems, and promoting health equity be considered as initial priority, purpose-driven data use cases.

- *Provide timely health information exchange and access to comprehensive integrated health information.*

Ontario must enable real-time exchange of standardized high-quality individual and collective (e.g., community, population) level health data and facilitate roles-based access to integrated health data sources for use in the health system. These data are a key enabler of the prioritized purpose-driven use cases, provided the data is appropriately enabled for use. When using health data for good, data must be collected once and used many times for legislatively enabled, appropriate uses.

If Ontario is to move the needle on advancing health and equity goals, data from other sources (e.g., interdisciplinary health professionals, community, and social care), as well as other types of data (e.g., sociodemographic, social determinants of health, patient experience and outcomes measures, housing, and educational data) will need to be systematically collected, shared, and used.

These considerations need to be addressed by policies and legislation, which will remove existing structural, operational, and cultural barriers to enabling timely exchange, integration, and use of clinical, administrative, and social health data.

- *Foster an inclusive data-enabled culture, which enables active participation of all stakeholders.*

As Ontario moves forward, resources must be invested to prepare all stakeholders and to engage them in open dialogue continuously along this journey. Ontarians need to be actively engaged and informed on the future vision, why it is needed, what is expected of them, and how they and others will benefit.

Everyone should be afforded the ability, capacity, and opportunity to participate. They must be empowered and enabled to participate and use their health data. This starts with building and strengthening data literacy and capabilities across all stakeholders, with approaches tailored to their specific needs, interests, and roles. For example, providing data resources for the public, patients and providers, and more targeted interventions for system leaders, and decision makers.

Creating that common language and shared understanding is central to the shift from a data-protectionist culture to one which is inclusive and focused on enablement of data for the public good. Then people, groups, communities, providers, and other health system stakeholders can truly engage, participate, and help to shape the future health data ecosystem that Ontario needs.

### **Recommended Implementation Actions**

- Empower people to be partners in their care and help them achieve improved health outcomes through increased access to their own health data.
- Implement policies and technologies that enable patients and caregivers to read, review, contribute to, and manage their health information.
- Incentivize the use, standardization, and integration of patient-reported experience and outcome measures in the health system.
- Account for the full scope of all types of data in Ontario's health system, including clinical and administrative data, both identified and de-identified.
- Identify, leverage, and support ongoing initiatives that can best support the data-driven objectives of Ontario's health sector and offer good opportunities for implementation, with a focus on health system, population health, integrated care, public health, and equity.

## 4.2 Promote health equity through appropriate data collection, analysis, and use

As the volume, velocity, and variety of data grows, and used for more purposes, so too will the understanding and sensitivity to the possible risks of the use of big data, in addition to its benefits. In undertaking this journey to a trustworthy, person-centric, and integrated health data ecosystem, it will be vital to continuously engage with communities and stakeholder groups on data governance and ensure that data is used for good.

### Supporting Recommendations:

- *Ensure that health data in the ecosystem adequately represents equity-deserving groups.*

Ontario has a duty to serve the entire population equitably and therefore needs to be able to measure equity of access to and outcomes of health care across its diverse population. For this, data in the ecosystem must include all equity seeking groups and be of sufficient quantity and quality that analyses can be undertaken. Furthermore, the data elements collected should be representative of these groups and communities and contain accurate and consistent categories which are meaningful to them.

- *Systematically collect and use health data to promote equity.*

In addition to collecting health data in a way which ensures equity seeking groups are appropriately included, there is a need for specific forms of data to be collected which equip the ecosystem to promote equity. Widespread, consistent, and standardized collection of sociodemographic data, including measures of culture, ethnicity, and racial identity, produces a data ecosystem which allows decision-makers to accurately identify and act on health inequities.

These data have a variety of secondary uses, including public health, population health, analytics, and research. Experts and equity-seeking communities request that sociodemographic data should be systematically collected and used in line with clear and enforceable rules and standards to ensure data quality and trust in the data ecosystem. Transparency in the collection, sharing, and use of data not only helps to increase trust in data systems, but also improves the quality and appropriateness of insights drawn from the analysis.

- *Develop accountability mechanisms to promote trustworthy practices for collection, use, and disclosure of health data.*

Some racialized and equity-deserving groups are concerned that data may be misused. Accountability mechanisms that increase the control that communities have over their data are needed. This increases trust in the data ecosystem, which in turn, improves the quality and comprehensiveness of data available. In line with and informed by tools such as the Black Health Equity Working Group's EGAP framework, community governance tables could provide guidance and oversight for how sociodemographic data is collected and used in Ontario. These tables could promote trust through accountability and transparency. To be most effective, community governance tables should be composed of members of racialized and equity-deserving communities in Ontario.

#### **Recommended Implementation Actions:**

- Acknowledge and address health inequities that can stem from the use of health data and use health data to address pre-existing inequities.
- Identify the ways in which data, including aggregate data, can be used in biased or harmful ways, and implement rules to guard against the misuse of health data.
- Incorporate the perspectives of racialized and equity-deserving communities and community governance in the definitions and standards for the collection of sociodemographic and other highly sensitive data.
- Ensure everyone can access their own comprehensive patient data, including those who need their information in other formats (i.e., non-digital, or in other languages).
- Improve data literacy and expand Ontario's existing digital infrastructure, including access to high-quality, fast, and affordable internet across the province.

### **4.3 Establish system-level trustworthy governance and policies for health data as a public good**

Ontario must develop responsive, transparent, and inclusive system-level data governance. Good data governance is foundational to the creation, implementation, and sustainment of an integrated health data ecosystem. Earning and sustaining the trust of Ontarians is essential to building confidence in this ecosystem. Good governance in every organization holding data earns internal trustworthiness, and in turn, promotes external trust. Health data must be governed to advance health and equity goals as determined and articulated through ongoing consultations with Ontario's people and communities.

#### **Supporting Recommendations**

- *Establish inclusive governance structures, responsive to the needs of Ontarians, that advance data use for public good and are respectful of data sovereignty.*

Good governance needs to be anchored in the Council's guiding principles and responsive to the needs and expectations of the people of Ontario, with particular

attention to the people, groups, and communities who are at risk of, or experience health inequities and/or are at risk of data misuse.

Ontario needs to establish safe, respectful, and culturally appropriate permanent data governance structures with community governance tables, in partnership with Ontario's diverse communities. These will provide opportunities for people, groups, communities, and organizations to learn more about data, and participate, discuss, and establish common understanding, and engage in shared decisions making regarding the use of health data. The shared perspectives, needs, and requirements need to be incorporated into health data policies, processes, practices, and accountabilities and will inform the design of mechanisms to determine success in advancing health and equity goals.

Ontario must engage and include people and communities who have been or are at risk of being stigmatized and harmed by misuse of their data. Meaningful and respectful relationships, partnerships, and alliances will be established with First Nations, Inuit, and Métis peoples, informed through a distinctions-based approach, and common understandings of data governance principles implemented. For more information, please refer to the next recommendation on Respect and support First Nations, Inuit, and Métis' Peoples' Data Sovereignty.

- *Enable responsible data sharing, access, and use while protecting individual privacy and securing health data.*

To be trustworthy, Ontario's health data ecosystem must have the appropriate infrastructure, standards, and policies in place to ensure timely, secure, and privacy-protected access to and sharing of health data. Guided by the strategic direction of the Council, Ontario should develop and adopt a common health data governance framework to manage and oversee health data, which is accountable to external and independent oversight. A framework should be developed which strengthens people's ability to access, use, and benefit from their own health data. Ontario needs to develop well-established roles and responsibilities relating to system-level data governance and stewardship to enhance data sharing, access, and use, strengthen accountability of data users, and increase transparency about the collection, use, and disclosure of health data. The Information and Privacy Commissioner of Ontario would ensure compliance with Ontario's privacy and access laws.

As digital and data literacy and capacity around health data is strengthened in Ontario, and as new technologies and uses for health data arise, the requirements for health data may change and adapt. Ontario's health data governance strategy must remain agile and

responsive to these changing circumstances. It must identify and scale best practices in data and adapt to the needs of Ontarians and the health system.

### **Recommended Implementation Actions:**

- Develop shared, responsive governance for the creation, implementation, and sustainment of a trustworthy, integrated, and accountable health data ecosystem using an iterative approach that engages all health system stakeholders.
- Foster a transparent approach to the governance of health data, including increased public reporting and transparency about the collection, use, and disclosure of health data.
- Set standard, permanent, and meaningful advisory roles for the public in health data governance structures, including but not limited to community governance tables.
- Review policy opportunities to identify where barriers could be removed and new enablers installed, including removal of legislative or bureaucratic obstacles to health data access.
- Strengthen data and digital literacy and capacity across the health system and Ontario at large by empowering, engaging, and educating the public about health data.

## **4.4 Respect and support First Nations, Inuit, and Métis Peoples' Data Sovereignty**

Indigenous peoples in Canada, including First Nations, Inuit, and Métis peoples, have inherent rights to self-determination, including self-governance, that have not always been respected. Furthermore, they have been harmed by appropriation, misrepresentation, and exploitation of their data for uses which have not been in their best interests. As a result, trust has been lost. This trust can only be rebuilt through open dialogue and relationships founded on mutual respect and understanding.

The Council's guiding principles state that Ontario has an obligation to recognize and respect First Nations, Inuit, and Métis peoples' rights to self-determination including self-governance, and their respective rights to health data sovereignty. To avoid engaging in harmful and appropriative uses of health data, and to respect First Nations, Inuit, and Métis peoples' rights to self-determination, all who collect, use, or disclose First Nations, Inuit, or Métis' health data, including governments, organizations, and people, must do so in line with the rights, needs, preferences, and desires of the people whose data they are using.

The Council acknowledges the importance of supporting First Nations, Inuit, and Métis peoples' rights to health data sovereignty, and in the spirit of friendship, respect, and reconciliation, advises that Ontario implement the following recommendations:

### **Supporting Recommendations**



- *Establish distinctions-based partnerships with First Nations, Inuit, and Métis peoples to ensure data sovereignty is respected.*

The province of Ontario should commit to respectful and ongoing engagement with First Nations, Inuit, and Métis peoples living in Ontario on their data and digital needs, preferences, values, and their data and digital strategies, in accordance with the rights described in the *United Nations Declaration on the Rights of Indigenous Peoples* (UNDRIP).

Establishing distinctions-based partnerships recognizes that First Nations, Inuit, and Métis peoples are not one unified group, but rather represent many different and unique peoples with distinct cultural heritages, languages, values, needs, and rights. First Nations, Inuit, and Métis peoples have different needs, preferences, and strategies regarding the governance of their health data. Engagement should be undertaken via their representative organizations with the aim of determining how their respective data shall be governed in Ontario. Respecting these differences means collecting, using, and disclosing data in line with the distinct needs of each community and disaggregating data according to differing identities, so that it can be used to generate meaningful insights about each community, in accordance with that community's rights to self-determination including self-governance.

- *Affirm First Nations, Inuit, and Métis peoples' right to self-govern their data.*

The province of Ontario should affirm and support First Nations, Inuit, and Métis peoples' rights to data sovereignty, by supporting First Nations, Inuit, and Métis peoples' distinct governance models for the self-governance of First Nations, Inuit, and Métis health data.

This may include supporting the development of policies, procedures, and governance structures for how First Nations, Inuit, and Métis health data is collected, stored, used, and disclosed in Ontario. These models should be in accordance with whatever principles, policies, and procedures each group recommends, such as the First Nations principles of OCAP®, or the Inuit principles of Qaujimajatuqangit.

In accordance with the rights set out in UNDRIP, this should be undertaken with an emphasis on obtaining the free, prior, and ongoing informed consent of First Nations, Inuit, and Métis peoples, for the collection, use, and disclosure of their respective health data.

- *Empower and support First Nations, Inuit, and Métis peoples to develop their own data governance and stewardship capacities.*

The province of Ontario should commit to supporting First Nations, Inuit, and Métis peoples in the design, development, and implementation of their own data governance and stewardship capacities. The form of this support should be aligned with their needs and preferences as determined through distinctions-based engagements with their representative organizations.

First Nations, Inuit, and Métis peoples should be empowered to use their own health data for a range of purposes including research to maximize the benefits to their own communities, and to mitigate the impact of ongoing harms and health inequities. This may include, but not be limited to, policies and procedures put in place to ensure transparent and accountable governance and stewardship of their health data, including the collection, sharing, use, analysis, and interpretation of this data. Furthermore, analyses, research, and insights should be returned to the people and communities affected in a timely manner, thereby ensuring they have access to and directly benefit from the collection, use, and disclosure of their health data, and enabling them to actively respond to insights with speed and precision.

The Council believes adopting these recommendations is the best way for the province of Ontario to demonstrate respect for the health data sovereignty of First Nations, Inuit, and Métis peoples. It also ensures their health data is protected appropriately, empowers, and enables those people affected, and prevents data being used in anti-racist and non-paternalistic ways.

### **Recommended Implementation Actions:**

- Commit to respectful and ongoing engagement with First Nations, Inuit, and Métis peoples living in Ontario on their data and digital needs, preferences, values, and on their data and digital strategies, in accordance with the rights described in UNDRIP.
- Affirm First Nations, Inuit, and Métis peoples' right to govern their health data in accordance with their own values, needs, and preferences and in accordance with their rights to self-determination and self-governance, as described in UNDRIP.
- All engagements, collections, uses and disclosures of data must be in accordance with a distinctions-based approach that recognizes the diversity of First Nations, Inuit, and Métis peoples, including their distinct cultural heritages, languages, and rights.
- Identify, in partnership with First Nations, Inuit, and Métis peoples in Ontario, appropriate standards for Indigenous-identifying data, controls on how and when it should be collected, for what use purposes, and under what circumstances and conditions it can be disclosed.
- Ensure First Nations, Inuit, and Métis peoples in Ontario have access to and can benefit from the collection, use, and disclosure of their health data, and that any collections,

uses, and disclosures of First Nations, Inuit, or Métis-identifying health data are actively communicated to the communities affected.

- First Nations, Inuit, and Métis peoples must not be systematically disadvantaged by the governance rules implemented in Ontario regarding their health data, and any potential disadvantaging effects should be actively identified and mitigated.

#### **4.5 Build data stewardship capacity and enable sharing by default**

Ontario's health data ecosystem should transition from a data custodian model and embrace a data stewardship model to enable "sharing by default" for defined uses that benefit the public good. Sharing by default does not mean data should be shared in an unqualified way. It must be guided by a clear policy framework and legal authorities that ensure the privacy and security of health data while maximizing the benefits of its use.

Data stewardship will help identify opportunities for cross-sector collaboration focusing on public good and equity and enable responsible access to the right data for generations of actionable insights, while protecting the rights of people and communities. Data stewards will be responsible for adopting common standards throughout the entire data life cycle, which will help structure and organize data to enhance data discovery, access, and usability.

#### **Supporting Recommendations**

- *Establish a data stewardship approach to promote data sharing by default while ensuring data protection.*

Ontario must implement a data stewardship approach with clearly specified roles and responsibilities for managing and sharing health data assets across sectors in a responsible and ethical way. Data stewards will be accountable for identifying the ways in which data can be used in biased or harmful ways and implementing rules to guard against the misuse of health data. This data stewardship approach will be founded on effective industry-recognized principles and best practices for the full scope of all types of health data, including clinical and administrative data, both identified and de-identified.

To ensure readiness of organizations to adopt sharing by default, Ontario should adopt a common framework to measure data and information governance capabilities of organizations. Healthcare organizations will remain accountable and responsible for the management of their health data.

- *Ensure health data is 'fit for purpose' to make data reusable for various current and evolving uses of data.*

To enable various uses of data, the data needs to be accurate, reliable, integrated, timely, and accessible. Ontario must implement a provincial data quality framework focusing on a set of common principles, dimensions, and practices for assessing fitness of health data. Furthermore, it will require establishing clear roles and responsibilities for assuring fitness of health data throughout the entire health data value chain.

- *Adopt a common data model that standardizes data content and enables model-driven data exchange to advance interoperability.*

To ensure that data retains consistent meaning and representation while it is exchanged between systems and platforms, Ontario must adopt a common data model, including metadata and data definitions, by developing a provincial data model, business glossary, and data dictionary. Such a model needs to be supported by common and controlled industry-accepted vocabulary and terminologies. Besides data content standardization, advancing interoperability will require the adoption of model-driven data exchange specifications, such as the Fast Health Interoperability Resources (FHIR), compliance verification supported by the Digital Health Information Exchange (DHIEX), and establishing provincial interoperability governance, including health informatics standard governance.

### **Recommended Implementation Actions:**

- Assign clear accountabilities for provincial health data assets through a clear data stewardship structure.
- Establish appropriate authorities and accountabilities needed for the management and oversight for data stewardship, including providing frameworks and guidance on improving data management capabilities; mandating health informatics standards; requiring certification of interoperability standards, data, and technology solutions; and assigning penalties for noncompliance to mandatory interoperability standards and other requirements.
- Develop a compliance model to ensure transparent and trustworthy stewardship of all health data assets.
- Adopt common metadata and data definitions by developing a provincial data model, business glossary, and data dictionary to ensure data retains meaning as it flows across sectors.
- Develop an Ontario health interoperability roadmap to guide stakeholders on their journey to interoperability maturity, monitoring, and measure progress towards a more integrated and interoperable health data ecosystem that addresses both technical and business

aspects of interoperability.

## **5.0 Time to Act**

Across Ontario, there is a pressing need for timely, high-quality, and integrated health data. Patients, families, caregivers, and their providers need health data to inform, shape, and empower their care, experiences, and outcomes.

The Council urges Ontario to act quickly to move on all recommendations and cautions against taking no action. Inaction is a decision to sustain and validate the status quo, permitting Ontario's current health system trajectory. Inaction reinforces the fragmented approach to data today, leaving Ontario without the ability to effectively govern and enable uses of health data assets for good.

Without action and adoption of a system-level approach, supported by shared data policies and frameworks, further harms to Ontarians will occur. Critical projects and opportunities to improve patient experiences, outcomes, and overall system performance will quickly become liabilities as they fail to deliver, with additional costs and liabilities accrued to the province. In addition, failure to act now, particularly when faced with the rapid cycles of technology and innovation, will ultimately result in higher costs to the province and its people. Ontario needs to manage these risks and steward provincial responsibility through strong health data governance.

The Council believes Ontario's health data ecosystem has considerable strengths. It is data-rich and there are system-level investments in data and digital capabilities to benefit patients and providers. Most importantly, Ontario is full of empowered people and communities who want to be informed and be active partners in their own care. The Council also realizes that the journey towards a health data ecosystem that works for and benefits everyone is not without challenges. It will require sustained commitment, investment of time, effort, and resources, and the ongoing collaboration of stakeholders, with the needs and expectations of Ontarians kept always at the centre.

Now is the time for action. Ontario must commit to a data strategy that the people of Ontario need and deserve, one which ethically governs health data as a public good to benefit all.

## 6.0 Appendices

### 6.1 Ontario Health Data Council Membership

- **Dr. Jane Philpott (Chair)**, Special Advisor to Minister of Health and President of the Treasury Board on the COVID-19 Ontario Health Data Platform; Dean of the Faculty of Health Sciences and Director of the School of Medicine, Queen's University; CEO, Southeastern Ontario Academic Medical Organization
- **Dr. Jennifer Gibson (Vice-Chair)**, Sun Life Financial Chair in Bioethics and Director, University of Toronto Joint Centre for Bioethics; Associate Professor, Dalla Lana School of Public Health, University of Toronto
- **Andy Best**, CEO, Civic Digital Network
- **Cindy Fedell**, Regional Chief Information Officer, Northwestern Ontario Hospitals
- **Dr. Michelle Greiver**, Family Physician, North York Family Health Team; Gordon F. Cheesbrough Chair in Family and Community Medicine- Research, North York General Hospital; Director, University of Toronto Practice-Based Research Network; Associate Professor, Department of Family and Community Medicine, University of Toronto
- **Keith Jansa**, Executive Director, CIO Strategy Council
- **Carmen Jones**, Director of Research and Data Management, Chiefs of Ontario
- **Dr. Muhammad Mamdani**, Vice President, Data Science and Advanced Analytics, Unity Health Toronto; Director, Temerty Centre for Artificial Intelligence Research and Education in Medicine (T-CAIREM), University of Toronto
- **Dr. Kwame McKenzie**, CEO, Wellesley Institute; Professor, Department of Psychiatry, University of Toronto; Director, Health Equity, Centre for Addiction and Mental Health
- **Natalie Raffoul**, Managing Partner, Brion Raffoul IP Group
- **Ashnoor Rahim**, Executive Director, KW4 Ontario Health Team
- **Dr. Robert Reid**, Hazel McCallion Research Chair in Learning Health Systems, Chief Scientist at the Institute for Better Health (IBH) and Senior Vice President of Science, Trillium Health Partners
- **Dr. Kevin Smith**, President and CEO, University Health Network
- **Dr. Peter Tanuseputro**, Scientist, Ottawa Hospital Research Institute and Bruyere Research Institute; Assistant Professor, Division of Palliative Care, University of Ottawa
- **Mike Wessinger**, Founder and CEO, PointClickCare

#### Ex-Officio Members

- **Dr. Sacha Bhatia**, Executive Lead, Population Health and Value Based Health Systems, Ontario Health
- **Colleen Geiger**, President and Chief Executive Officer (A), Public Health Ontario
- **Patricia Kosseim**, Information and Privacy Commissioner of Ontario
- **Betty-Lou Kristy**, Chair, Minister's Patient and Family Advisory Council, Ministry of Health
- **Dr. Paul Kurdyak**, Director, Health Outcomes and Performance Evaluation, Institute for Mental Health Policy Research, Senior Advisor, Centre for Addiction and Mental Health (CAMH) and Vice President, Mental Health & Addictions-Clinical, Ontario Health

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