

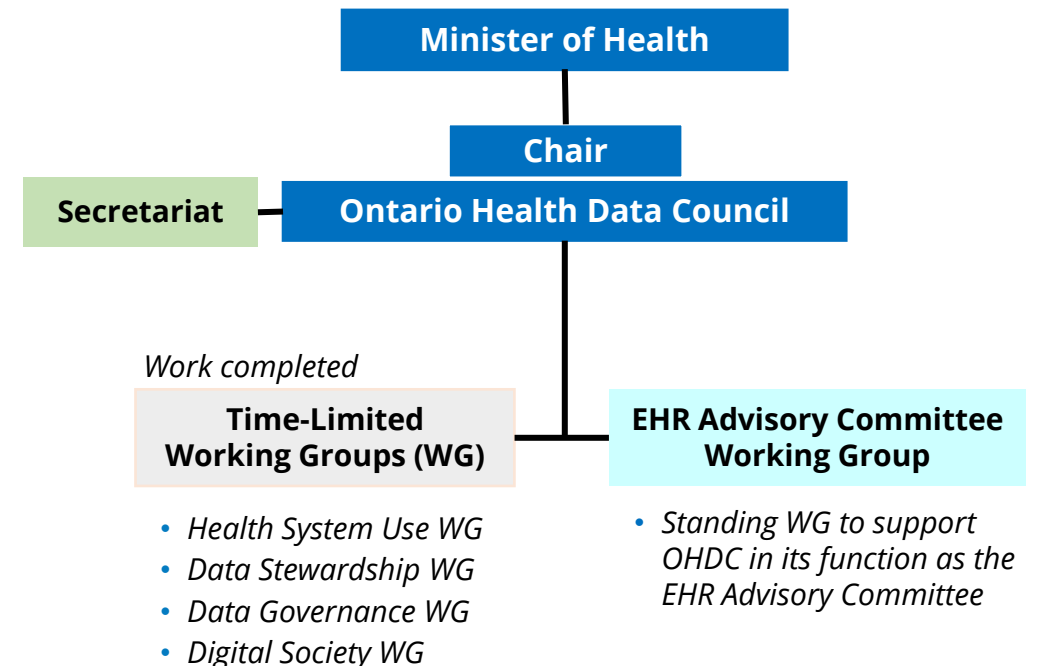
Ontario Health Data Council Report: A Vision for Ontario's Health Data Ecosystem

Ontario Health Data Council

- The Ontario Health Data Council (OHDC) is a short-term advisory body, established by the Minister of Health for a 3-year term in March 2021.

➤ The **strategic management of Ontario's health data** that empowers Ontarians, and supports the evidence-based provision of care, population health, public health research and innovation, and health system policy and planning.

➤ Serve in the capacity of **Electronic Health Record (EHR) Advisory Committee** to fulfill the legislative mandate specified in PHIPA Section 55.11



[Ontario Health Data Council - Public Appointments Secretariat \(gov.on.ca\)](https://www.ontario.ca/gov/ontario-health-data-council-public-appointments-secretariat)

Ontario Health Data Council Membership

Council Members

- **Dr Jane Philpott** (*Queen's University, Chair*)
- **Dr Jennifer Gibson** (*U of Toronto, Vice-Chair*)
- **Andy Best** (*Civic Digital Network*)
- **Ashnoor Rahim** (*KW4 OHT*)
- **Carmen R. Jones** (*Chiefs of Ontario*)
- **Cindy Fedell** (*Northwestern Ontario Hospitals*)
- **Keith Jansa** (*CIO Council*)
- **Natalie Raffoul** (*Brion Raffoul LLP*)
- **Dr Kevin Smith** (*University Health Network*)
- **Dr Kwame McKenzie** (*Wellesley Institute*)
- **Michael Wessinger** (*PointClickCare*)
- **Dr Michelle Greiver** (*NY FHT*)
- **Dr Muhammad Mamdani** (*Unity Health Toronto*)
- **Dr Peter Tanuseputro** (*Ottawa Heart Institute*)
- **Dr Robert Reid** (*Trillium Hospital*)

Ex-Officio Members

- **Patricia Kosseim** (*IPC*)
- **Betty-Lou Kristy** (*MPFAC*)
- **Adil Khalfan** (*OH*)
- **Collen Geiger** (*PHO*)
- **Dr Paul Kurdyak** (*CAMH*)

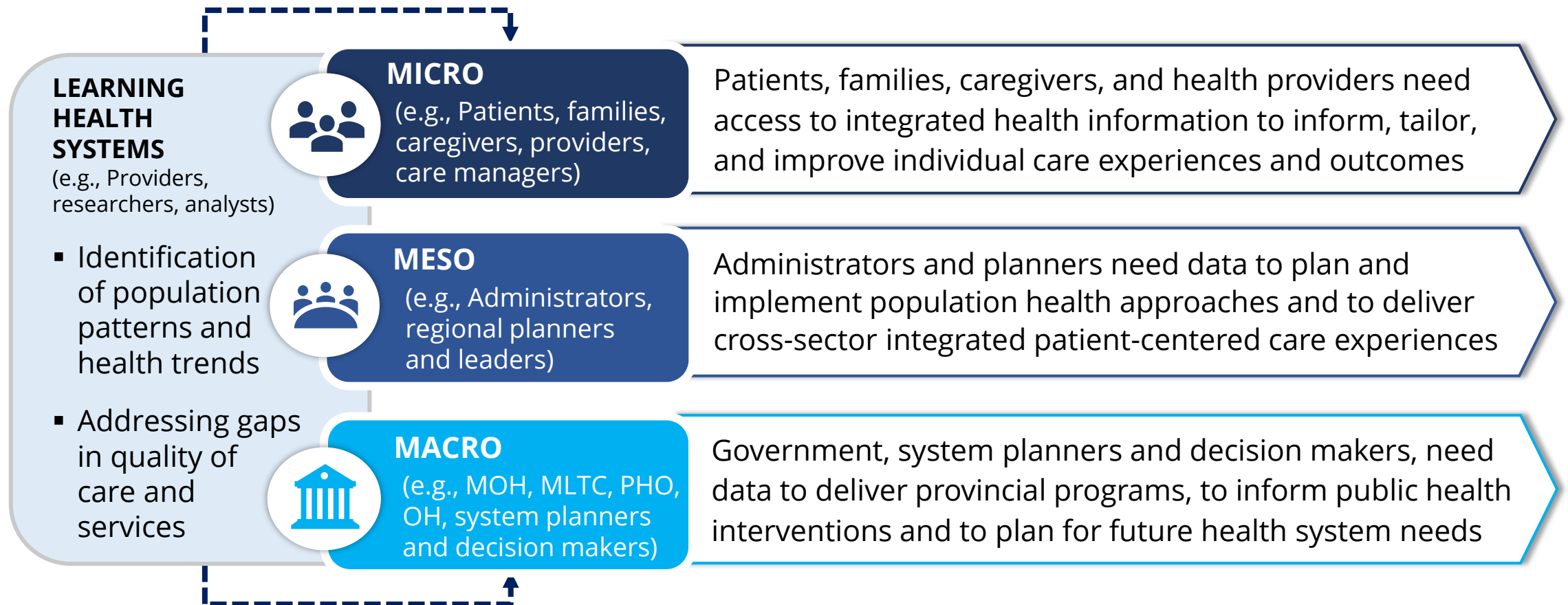
OHDC Report Overview

The Council's report provides a future vision for Ontario's health data, identifies key issues, and urges Ontario to take immediate action implementing key strategic recommendations

- In the report, the Council asserts **the status quo cannot continue** and there is an urgent need for a unified health data strategy in Ontario.
- Informed by its working groups and perspectives from Dialogue on Data, the Council provides clear direction for the path forward to a **harmonized integrated health data approach with system-level leadership**.
- **Failure to act will impact individual and population health outcomes**, increase health costs, widen existing health inequities, and impede health system growth and innovation.

Opportunity : Data is a Critical Driver of Health Outcomes

- Timely integrated health data can positively impact the lives of Ontarians and advance equity goals, leading to healthier people, communities, and populations.



Council: Ontario Needs a Provincial Health Data Strategy



Ontario's health data ecosystem is not meeting the needs of Ontarians

- **Issue:** There is **no clear system-wide data governance** approach leading to a fragmented health data ecosystem with disparate data strategies.
- The value of Ontario's rich health **data assets should be maximized for the benefit of Ontarians** and used to advance equity goals, leading to healthier people, communities, and populations.



*"Now is the time for action:
Ontario's health system needs a forward-facing data strategy
that enables use of trusted integrated health data."*

Advancing a Data-Driven Vision for Healthier Ontarians



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



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

GUIDING PRINCIPLES: *Values guiding and setting expectations for decision making and actions*

**Ethical
Principles**



**Indigenous
Data Sovereignty**

**STRATEGIC
RECOMMENDATIONS**

Guiding Principles

The benefits of using data must be balanced with the responsibility to prevent harms, and to protect the interests, rights, and privacy of people, groups, and communities.

Ethical Principles

- Data for good
- Respect for persons, groups and communities
- Protection against harms
- Equity
- Transparency and accountability

Indigenous Data Sovereignty

- 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.
- 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.

These principles should be adopted and used by all stakeholders within the health system

Strategic Recommendations to Achieve this Vision

**Use Data
Better And
Do Good
With Data**



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

**Establish
Responsive
And Inclusive
Governance**



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

**Enable
Accountability**



4.5 Build data stewardship capacity and enable sharing by default

Ontario Has An Obligation To Use Data Better And Do Good With Data



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

To achieve this - Ontario needs to:

- Enable purpose-driven uses of data to drive better outcomes for Ontarians
- Provide timely health information exchange and access to comprehensive integrated health information
- Foster an inclusive data-enabled culture, which enables active participation of all stakeholders



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

To achieve this - Ontario needs to:

- Ensure health data adequately represents equity-seeking groups
- Systematically collect and use health data to promote equity
- Develop accountability mechanisms to promote trustworthy practices for the collection, use, and disclosure of health data

Ontario Needs Responsive And Inclusive Governance



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

To achieve this - Ontario needs to:

- Establish inclusive governance structures, responsive to the needs of Ontarians, that advance data use for public good and are respectful of data sovereignty
- Enable responsible data sharing, access, and use while protecting individual privacy and securing health data



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

To achieve this - Ontario needs to:

- Establish distinction-based partnerships with First Nations, Inuit, and Métis peoples to ensure data sovereignty is respected
- Affirm First Nations, Inuit, and Métis peoples' right to self-govern their data
- Empower and support First Nations, Inuit, and Métis peoples to develop their own data governance and stewardship capacities

Ontario Must Enable Accountability for Data



4.5 Build data stewardship capacity and enable sharing by default

To achieve this - Ontario needs to:

- Establish a common and collaborative, principles-based data stewardship framework
- Adopt a common data model that standardizes data content and enables model-driven data exchange to advance interoperability
- Ensure health data is 'fit for purpose' to increase confidence in Ontario's health data

OHDC Priorities : From Strategy to Implementation

OHDC Recommendations	OHDC Priorities
<p>RESPONSIVE & INCLUSIVE GOVERNANCE</p> <ul style="list-style-type: none"> ▪ Governance: Establish system-level trustworthy governance and policies for health data as a public good ▪ Sovereignty: Respect and support First Nations, Inuit, and Métis Peoples' Data Sovereignty 	<ul style="list-style-type: none"> ▪ Advising on development of a system-level health data governance framework and model for Ontario ▪ Sponsorship of consultations to identify policy barriers and inform health data legislation modernization ▪ Advising on distinctions-based engagement approaches to partnering with First Nations, Inuit and Métis Peoples
<p>ENABLE ACCOUNTABILITY</p> <ul style="list-style-type: none"> ▪ Stewardship: Build data stewardship capacity and enable sharing by default 	<ul style="list-style-type: none"> ▪ Advising on development of a provincial health data stewardship model and implementation plan
<p>USING DATA FOR BETTER & FOR GOOD</p> <ul style="list-style-type: none"> ▪ Health: Integrate and use health data to advance health and equity outcomes for individuals, communities, and populations ▪ Equity: Promote health equity through appropriate data collection, analysis, and use 	<ul style="list-style-type: none"> ▪ Co-developing a civic engagement strategy with patient advisors to establish civic models and literacy resources to advance data transparency and public participation ▪ Advising on Ministry sociodemographic data initiatives