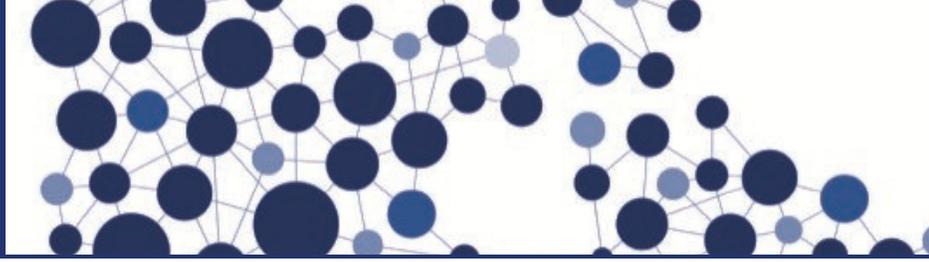


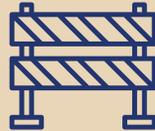
Connecting the Dots



Canada's health systems generate and collect an abundance of data, but efforts to share them across provincial, territorial, and regional borders have been largely unsuccessful. Failure to improve health data sharing could exacerbate existing health inequalities, hinder public health monitoring and interventions, and limit opportunities for new research and innovation. **Connecting the Dots** explores how Canada can modernize its current approach to health data sharing while continuing to protect the privacy of personal health information.



Canada excels at health data sharing for research purposes.



The barriers that prevent more robust health data sharing systems are fundamentally **political and cultural**, rather than technical.

BENEFITS OF HEALTH DATA SHARING



BETTER QUALITY HEALTHCARE

- Improves patient safety
- Increases medication safety
- Creates time savings for health practitioners



ENRICHES PUBLIC HEALTH

- Increases public health collaboration
- Creates more equitable health systems
- Allows for better assessments of public health programs



BETTER HEALTH OUTCOMES

- Allows for faster and more comprehensive access to patient histories, medication records, and lab results



IMPROVES HEALTHCARE DELIVERY

- Reduces duplication of imaging & tests
- Reduces time spent manually re-entering data
- Avoids unnecessary hospital admissions and consultations



ADVANCES RESEARCH & INNOVATION

- Lowers research costs
- Facilitates multidisciplinary research
- Opens new research avenues
- Attracts funding and talent

RISKS OF HEALTH DATA SHARING

Potential breaches of privacy and cybersecurity

Widening of the digital divide

Misuse of patient data

Increased stigmatization and bias

Additional burdens for health professionals



Developing and Implementing Health Data Sharing Systems

Leading systems for health data sharing in international jurisdictions have:



Single points of access for patients, practitioners, and researchers



Data privacy and security features that promote public trust



Federated or decentralized data infrastructure



Institutionally agnostic governance arrangements

A PAN-CANADIAN HEALTH DATA STRATEGY



The cost of implementing data-sharing systems is likely to be offset by even short-term economic benefits.



Will need to address fundamental issues of federalism and jurisdiction



Requires a governance model that does not depend solely on the federal government for leadership



A collective, collaborative approach to health data governance is needed, that involves all stakeholder from across the health system

Research institutes have led the way in collecting and sharing health data with researchers:

Institute for Clinical Evaluative Sciences

An inventory of coded and linkable health data sets covering most publicly funded administrative health services records for the Ontario population eligible for universal health coverage. It supports hundreds of research projects each year.

Manitoba Centre for Health Policy

Houses the Manitoba Population Research Data Repository, a collection of de-identified person-level linkable data from health, education, social services, and the justice system, as well as health insurance, vital statistics, immigration, and population databases.