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.

**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

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.
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 P A N - C A N A D I A N  H E A L T H  D A T A S T R A T E G Y

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.