Towards a Vision for Modern, Connected Care

October 2024

Health Canada Santé Canada

Canada

CONNECTED DIGITAL TOOLS AND HEALTH DATA ARE ESSENTIAL TO MODERNIZE THE HEALTH SYSTEM

- **Lack of connected care** increases risk to patient safety through treatment delays, medication errors, or misdiagnosis, and is adding to the strain of our health system.

- **Harnessing health data will drive connected care and break down health system silos by:**

Empowering Individuals
To improve their health outcomes with access to their complete health record.

Empowering Clinicians
With complete patient information, to support team-based care and the best patient outcomes
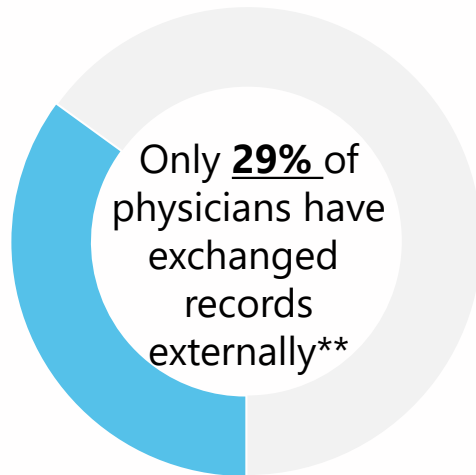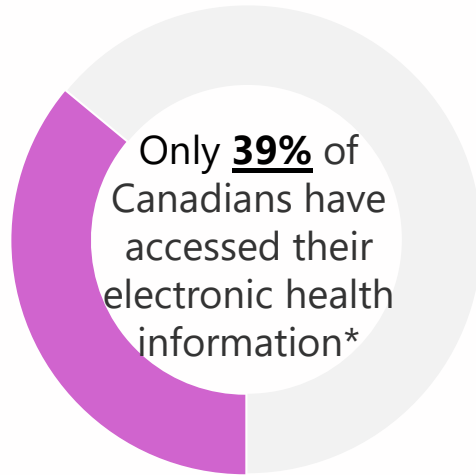
Driving Innovation and Research
To improve the efficiency of care, treatment and diagnostics

Informing and advancing Policy Decisions
To improve health system efficiencies and public health responses

SIGNIFICANT FRAGMENTATION HAMPERS THE ABILITY TO DELIVER HIGH-QUALITY CARE AND IMPACTS HEALTH OUTCOMES

Only **39%** of Canadians have accessed their electronic health information*

Only **29%** of physicians have exchanged records externally**

Current Issues:

- Digital health care solutions cannot connect

- Lack common standards to enable connectivity

- Data locked in proprietary systems

Impacts:

- Increased risk to patient safety with incomplete data to inform health decisions and public health responses

- Individuals lack access to their own health records

- Providers face unnecessary stress and administrative burden

- Falling behind other countries with legislated adoption of standards and prohibited data blocking

*Source: 2023 Canadian Digital Health Survey
**Source: 2024 National Survey of Canadian Physicians

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THE PANDEMIC UNDERSCORED THE IMPORTANCE OF FPT COLLABORATION ON HEALTH DATA

FPT Action Plan on Virtual Care and Digital Health
Focus on enabling equitable access to virtual care and co-developed a Shared Pan-Canadian Interoperability Roadmap

An Expert Advisory Group (EAG) on health data provided advice to FPT governments
- Charting a Path Toward Ambition
- Building Canada's Health Data Foundation
- Toward a World-Class Health System

Collaboration on Health Data Management
FPT Governments collaborated on a pan-Canadian strategy for health data management, outlining a common vision, principles and key elements for collective action.

The Shared Pan-Canadian Interoperability Roadmap **sets a path forward for industry and provinces and territories to enable connected care.**

It is a five-year plan focused on defining common interoperability standards with an initial focus on the building blocks needed to:

- **Prevent data blocking** and enable data sharing within primary care;

- **Enable patient access** to their records;

- **Improve provider access** to patient data at point of care via common patient summary; and

- **Improve care coordination** and collaboration through referral and e-consult.

Shared Pan-Canadian Interoperability Roadmap

May 2023

HISTORIC HEALTH CARE INVESTMENTS IN 2023 INCLUDE FOCUS ON COLLABORATIVELY IMPROVING HEALTH DATA

10-YEAR FEDERAL FUNDING COMMITMENT

Close to $200 billion over 10 years, including $46.2 billion in new funding under the Working Together to Improve Health Care for Canadians plan

$25 billion through tailor-made bilateral agreements with provinces and territories, including a commitment to modernize the health system with standardized data and digital tools

$505 million provided to CIHI, Infoway, and federal partners to advance standardized health data and digital health tools

Indigenous Health Equity Fund of **$2 billion**

Health Canada and PHAC worked with PTs to engage with their Indigenous partners on the development of their Action Plans to reflect Indigenous priorities

CIHI, Infoway and Statistics Canada will continue to work with Indigenous partners in the development of new indicators, interoperability and data standards

Indigenous Services Canada will lead complementary and parallel engagement on broader Indigenous health issues

A JOINT ACTION PLAN ON HEALTH DATA AND DIGITAL HEALTH

Collecting and sharing high-quality and comparable de-identified information to improve health care for Canadians

Adopting common interoperability standards to better connect Canada's health care system

Implement aligned provincial and territorial policies to support health data sharing for the public good and strong privacy and security protection
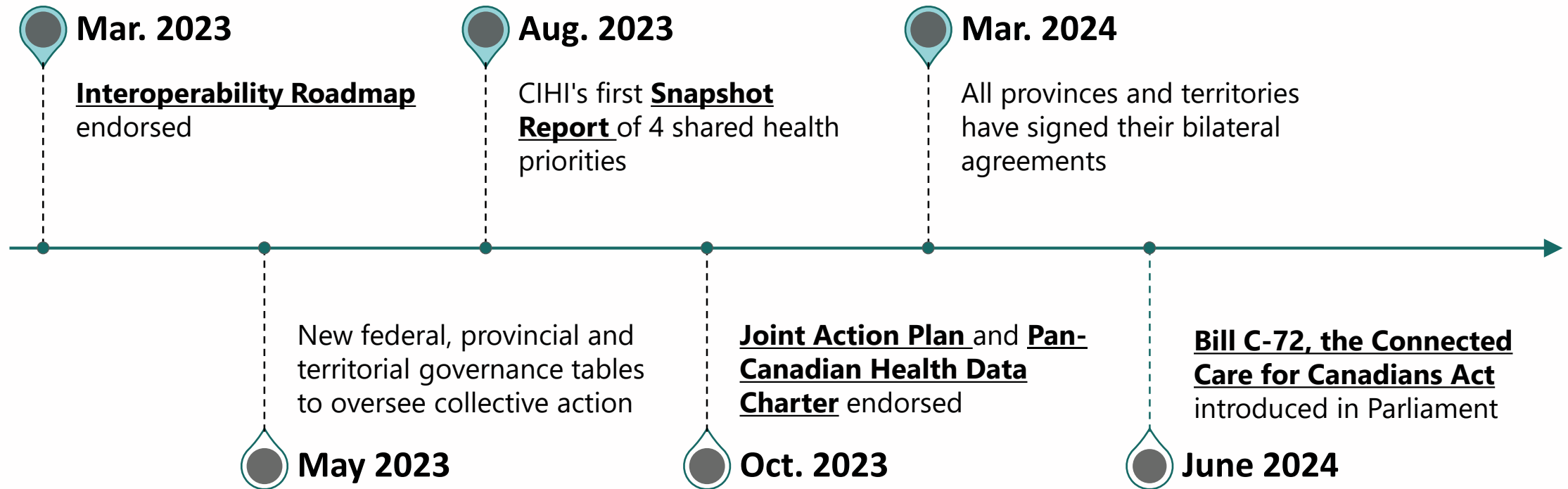
Advancing shared person-centered principles outlined in a Health Data Charter for the management of health data

Collecting and sharing public health data to support Canada's preparedness and response to public health events

SIGNIFICANT MOMENTUM TOWARDS CROSS-COUNTRY COLLABORATION TO IMPROVE HEALTH CARE

Mar. 2023

Interoperability Roadmap endorsed

Aug. 2023

CIHI's first **Snapshot Report** of 4 shared health priorities

Mar. 2024

All provinces and territories have signed their bilateral agreements

New federal, provincial and territorial governance tables to oversee collective action

May 2023

Joint Action Plan and **Pan-Canadian Health Data Charter** endorsed

Oct. 2023

Bill C-72, the Connected Care for Canadians Act introduced in Parliament

June 2024

PRIORITY ACTIONS OVER THE NEXT FEW YEARS...

Interoperability

- Infoway and CIHI release **interoperability standards** for seamless and secure flow of health data and work with Provinces and Territories, vendors and clinicians to adopt standardized digital tools and data
- **Federal legislative approach (Bill C-72)** to accelerate standards adoption / prevent data blocking
- Infoway continues to develop enabling tools for data exchange (e.g., **Trusted Exchange Framework**)

Policy Alignment

- CIHI and partners work to develop and build consensus on a **framework for health data stewardship**
- Provinces and territories share best practices to **expand promising virtual care models** across Canada
- Jurisdictions collaborate on guiding principles and actions for **ethical and responsible use of AI** for health

Apply Principles of Health Data Charter

- Define essential elements for **cybersecurity** programs suitable for health data systems and AI
- Support participation of First Nations, Inuit and Metis in governance & promote **Indigenous data sovereignty**
- Advance strategy to **build trust and literacy** in health data and digital health

Improve public health data

- Launch a new framework for Federal/Provincial/Territorial/Indigenous public health data sharing
- Improve **interoperability of immunization data** through standards, governance and enabling technology

Report on Results

- Jurisdictions continue to collect and share data (including disaggregated data) with CIHI to **report on progress**;
- Expand and release **new common indicators** on Canada's shared health priorities, including for public health

BILL C-72, *CONNECTED CARE FOR CANADIANS ACT*

- Bill C-72 would support the goals of connected care in Canada by:
  - **Establishing and maintaining requirements for interoperability** and health data standards that health information (IT) vendors must follow; and
  - **Prohibiting data blocking** by health IT vendors and determine reasonable and appropriate exceptions to prohibitions against data blocking.

- The proposed federal framework would act as a **backstop** when there is an absence of similar laws in provinces and territories.
  - Regulations would outline criteria and process to determine whether a province or territory has substantially similar legislation in place.

- It would complement existing privacy laws and **only enable, not compel, the secure access, use and exchange of health information** across health IT systems in Canada.

- Bill C-72 would **accelerate the aims of the Pan-Canadian Interoperability Roadmap**.
  - Regulations would specify requirements and standards to be adopted by health IT vendors to enable secure access, exchange and use of electronic health information.

SHIFTING CULTURE: RESPONSIBLE HEALTH DATA STEWARDSHIP

- The current custodian approach to data sharing overlooks the impact of under-sharing, stifles innovation, and impedes system improvement.

- Shifting to an approach of data *stewardship* will support the alignment of policies, governance structures and tools for sharing data responsibly and ethically; key priority in the Action Plan.

- An FPT working group outlined the elements needed for a more structured approach to data stewardship.

Health Data Charter
Establishes the guiding principles for data stewardship.

Data Strategy
Identifying shared data requirements for health system priorities.

Data Governance
Establish clear accountabilities, authorities, legislation, policies, and agreements for trusted data management in the public good.

Data Collection & Use
Quality, timely, and fit-for-purpose data for primary and secondary uses.

Data Management
Collect, store, and share data in a fair, safe, and equitable way through:
- Data Standards
- Data Quality
- Data Architecture
- Data Modeling
- Data Lineage
- Data Glossary
- Master Data Management
- Data Protection
- Metadata
- Data Operations
- Interoperability
- Data Access & Sharing
- Analytics Infra.

Indigenous Data Sovereignty
Ensure support for, and alignment with, First Nations, Inuit, and Métis data principles and governance structures.

Data Capacity & Literacy
Increase health system skills and competencies needed to understand and use data.

Public Trust & Engagement
Provide meaningful civic engagement to ensure data stewardship reflects public values, needs, and expectations.

- The Canadian Institute of Health Information (CIHI) is leading the development of a **pan-Canadian Health Data Stewardship Framework** in consultation with PTs, Indigenous partners, stakeholders and Canada Health Infoway.

CONNECTING CARE THROUGH HEALTH DATA AND DIGITAL TOOLS WILL DRIVE MEASURABLE RESULTS

Enable access to safer, better, and more equitable care, and improve health outcomes for Canadians by:

- Empowering individuals to securely access their health data, while protecting privacy

- Supporting mobility by making health data accessible regardless of location or solution used

- Improving access to connected solutions, especially in rural and remote areas

- Reduce burden on health care professionals and improve care coordination

- Streamlining interoperability requirements and harmonize with international standards helping to increase industry innovation and competition across the country

- Enhancing quality, inclusivity, and comprehensiveness of data for decision making

ANNEX A: THE PAN-CANADIAN HEALTH DATA CHARTER

Based on advice from an Expert Advisory Group on Health Data, which recommended establishing common principles "inspired by the universal human rights to health, to benefit from science, and to non-discrimination and equity, and founded on the five principles of public administration, comprehensiveness, universality, portability, and accessibility (Canada Health Act)."

To honour the duty to put people and populations at the core of all decisions about the disclosure, access and use of health information, the Pan-Canadian Health Data Charter requires:

1. **Person-centric health information** design to ensure that health data follows the individual across points of care to support individual, clinical, and analytical access and use while respecting individual privacy with regard to the handling of their information under existing privacy legislation.
2. **Inclusion of diverse members of the public**, patients, communities and other partners in culturally integrated health information system development and oversight.
3. **Commitment to support First Nations, Inuit and Métis data sovereignty** and Indigenous-led governance frameworks.
4. **Common standards** for terminology, health data design, stewardship, interoperability, access, and portability.
5. **The quality, security and privacy of health data** to maximize benefits, build trust, and reduce harm to individuals and populations.
6. **Timely availability and accessibility of meaningful and comprehensive health data** to individuals, decision makers, the health workforce, and researchers to support an individual's health needs, quality health programs and services, population and public health, and research.
7. **The ethical use of health data** to support decision making, policies, programs, services, statistics, and research for better health outcomes , while respecting the importance of open science and being open-by-design.
8. **Data-driven social and technological innovation t**hrough partnership, invention, discovery, value creation and international best practice.
9. **Literacy** regarding health data[2], health data analysis and digital methods for the public, decision-makers, the health workforce, and researchers.
10. **Harmonization of health data governance**, oversight, and policy in areas jointly agreed to by FPT governments for pan-Canadian coordination.

[2]"the degree to which an individual has the capacity to obtain, communicate, process and understand basic health information and services to make appropriate health decisions", US Centre for Disease Control, Healthy People 2010 and Healthy People 2020.