Digital Health Interoperability Task Force Report

November 2024

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Executive summary

In March 2024, the Canadian Medical Association (CMA), Canada Health Infoway (Infoway), the College of Family Physicians of Canada (CFPC) and the Royal College of Physicians and Surgeons of Canada (Royal College) created the Digital Health Interoperability Task Force (the Task Force). The Task Force had a mandate to encourage the implementation and use of interoperable digital health solutions.

The goals of the Task Force included:

- Improving the quality of patient care and enhancing patient safety through better use of interoperable digital health solutions.

- Advising and supporting efforts to effectively digitally connect physicians to health system resources to reduce administrative work, streamline care delivery and enable the sharing of health data.

- Stimulating innovations and approaches to overcome key barriers and develop practical implementation strategies to enable adoption and ongoing use of interoperable digital health solutions.

While providing an overall analysis of the interoperability issue in the Canadian health care system, this report focuses on the physician perspective and their concerns.

The Task Force believes there is an urgent need to:

Develop a plan to fast-track tangible improvements in interoperability	Aggressively accelerate existing policies and legislation supporting interoperability	Meaningfully include front-line clinicians in deploying health data solutions that involve them
Avoid downloading to clinicians any administrative burden and cost of interoperability initiatives	Have organized medicine play a role in guiding and supporting physicians on interoperability	Commit Canada's research and development funding organizations to investing in continuous innovation in digital health

Introduction

The lack of true interoperability of data in the Canadian health care system has been an issue for as long as electronic medical records and databases of electronic health data have existed – and continues to be.

Recent data from Infoway shows fewer than 40% of Canadians report accessing some of their health information electronically and only 35% of physicians share patient information outside their practice.[1]

All provinces and territories have been challenged in their ability to access data from community providers and particularly from primary care physicians. While access to hospital and repository data is useful, most health care occurs in the community. Yet, almost universally, provinces and territories collect little data from community providers and almost no data from primary care other than billing information.

The inability to assemble all relevant patient information can have a significant impact on quality of care and patient outcomes. Lack of access to patient-specific data is a particular issue when patients are seeing multiple providers or having diagnostic tests in multiple facilities. This undermines the ability for the system to deliver both urgent care and continuity of care in the community.

Without interoperability, critical patient information may not be available when needed, leading to potential medical errors and compromised patient safety. Clinicians experience this every day and while workarounds can minimize these risks, medical errors can and will be made, based on incorrect or incomplete data.

The interoperability gap also creates inefficiencies and frustrations for clinicians and increases their administrative burden. Primary care providers must often spend excessive amounts of time trying to access relevant information to provide care in real time, or to coordinate care more efficiently. The absence of key data elements and lack of standardized data, the challenge of collecting data from multiple sources in a timely way and dated privacy legislation also limit the value of aggregated data for research, performance management, public health, quality improvement and innovation purposes.

Effective, interprofessional, interoperable digital health systems and tools are critical to safe, high-quality patient care in a modern, 21st century health system.

The patient perspective

Patients want their health data to be accessible to themselves and their health care team electronically as and when needed. Too often, patients are still responsible for collecting and maintaining their own health data and having to repeatedly share their stories with those providing care. The absence of interoperable health data can result in gaps in communication leading to less-than-ideal care or even harm. In addition, by making their personal health data available in an interoperable form, patients can improve care for the population as a whole or support research into new advances in care. However, patients want, and should have, a say in how and when these data are shared.
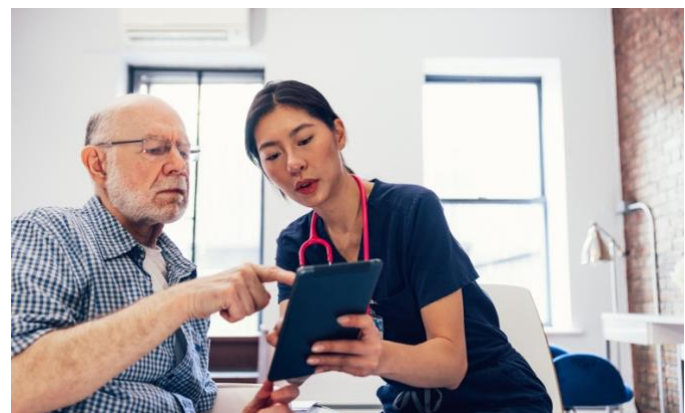
Recent developments

In the last two years, several comprehensive efforts have been undertaken to define and address the interoperability challenge, and progress has been made. Specific initiatives have been undertaken by Infoway, the Canadian Institute for Health Information (CIHI) and the federal government. Provinces and territories are also making significant investments in integrative solutions. However, the lack of more universal interoperability makes the implementation of these solutions challenging, slow and more expensive.

Initiatives in the US and Europe are also helping inform the Canadian experience.

In 2023, Infoway released the *Shared Pan-Canadian Interoperability Roadmap.*[2]

The Roadmap laid out four strategic priorities:

1. Reduce data blocking and ease portability

2. Improve provider access to patient data at the point of care

3. Enable patient access to their health record

4. Improve care coordination and collaboration

The Roadmap was endorsed by the Conference of Deputy Ministers in March 2023 and funding has been provided to Infoway, CIHI and other partners to advance the interoperability agenda.

In March 2023, CIHI initiated work on the Pan-Canadian Health Data Content Framework to define, standardize and model the health data required to enable interoperability in Canada.[3] The purpose of the Pan-Canadian Health Data Content Framework is to lay the foundation for standard health data that can be used within and across various sectors and contexts starting with primary care data.

On June 6, 2024, the federal government introduced Bill C-72, the *Connected Care for Canadians Act*.[4] The aim of the act is to "enable a modern, connected care system, in which health information can be securely accessed by patients and shared between providers, when needed". The legislation and accompanying regulations will also ban data blocking and would require all IT companies providing digital health services in Canada to adopt common standards and allow for protected and secure information exchange across various systems.

Challenges

The Task Force and others identified the following challenges to interoperability:

Clinician administrative burden

- Clinician burnout due in part to administrative burden and perceived additional burden from gathering and sharing health data.
- Reduced capacity for clinicians to see patients due to time spent on data administration.
- Potentially significant out-of-pocket IT and administrative costs to enable interoperability.
- Absence of additional resources such as more funding or change management tools to support clinician involvement in new interoperability initiatives.

Technological/standards-based

- Lack of foundational technology standards required to support clinical data exchange and transactions, particularly for community providers.
- Lack of broadly mandated data nomenclature and exchange standards for personal health information (PHI)-related data.
- Failure of electronic medical record (EMR) systems to support interoperability. Most existing charting systems are outdated and lack the automation and flexibility required for seamless data exchange.
- Non-integrated portals requiring multiple sign-ins, searches and manual processes.
- Inconsistent, incomplete, inadequate and outdated privacy and data governance policies.
- Incomplete Internet connectivity, especially in rural and remote areas, to support health information sharing.

Policy/legislative

- Absence of a clear authority accountable for health information interoperability.
- Lack of adherence to the Canada Health Act principles of portability and universality as they apply to the sharing of patient information.
- Disconnect between the fiduciary requirement of physicians to be caretakers of the patient record and patient ownership of data in the record.
- Absence of in-force legislation mandating technical interoperability standards.
- Lack of health information legislation to promote health information sharing.
- Inconsistent, incomplete, inadequate and outdated privacy and data governance policies.

Educational

- Inadequate education for physicians to provide leadership regarding digital health tools and how to optimize them.
- Lack of digital health literacy among patients.

Additional challenges

- Failure to consistently involve Indigenous communities when gathering and using data on Indigenous populations, and perpetuation of racist attitudes in health care.
- Cultural resistance among clinicians, vendors and health organizations to sharing data.
- Impaired ability of interprofessional health care teams to share data.
- Absence of incentives for vendors to support interoperability

Discussion

The Task Force is passionate about the potential for interoperability of health data to enhance patient care and acknowledges and supports national efforts currently underway to achieve this goal. But these efforts must be accelerated through greater commitment and collaboration between governments and partners. The Task Force is especially concerned about the lack of mechanisms to ensure the needed participation of front-line clinicians.

A fundamental disconnect remains between the approach taken by organizations and governments to address the interoperability of health data, and the perspective of Canadian clinicians. Unless this is addressed, the Task Force is concerned interoperability initiatives will place additional burdens on clinicians and could lead to a failure of well-intentioned efforts to support connected care.

Patient data gathered during the clinical encounter is captured to document the specifics of the encounter and provide a resource for the physician. The types of data may deviate significantly from the types and formats of patient data required for effective clinical data sharing and clinical workflow applications as well as by health systems for the purposes of public health, quality improvement or other broader goals.

The Task Force believes implementation of new technologies – specifically the use of Artificial Intelligence (AI) and AI-based scribes – could have a significant impact on helping clinicians manage data in a more timely and efficient manner. Automating the processes of data entry, standardization, curation and sharing could significantly reduce the burden on health care providers.

Patient engagement and trust remains central in successfully implementing connected care initiatives. The ability of patients to access their own health data electronically should be a foundational principle for any and all interoperability initiatives in Canada. In an ideal state, patient health information should move with the patient during any journey through the health care system. However, much of the current privacy legislation does not meet the requirements of the digital age and hinders appropriate data portability and sharing.

While physicians aspire to best support patients and provide quality care, an altruistic approach is not sufficient to ensure physicians can participate in interoperability initiatives, especially during the current epidemic of burnout and the crisis related to shortages of primary care and emergency department physicians.

Recommendations

Current efforts underway to implement data standardization, technology interoperability, data stewardship modernization and associated policy are essential elements of interoperability. However, these efforts are not occurring quickly enough, lack mechanisms to enable community-based clinicians to participate effectively and are not backed up with sufficient commitments from government.

A fundamental challenge seen by the Task Force is the disconnect between the overarching need for interoperable patient data to improve the system and patient safety, and the fact that what clinicians collect (in the way of patient data) and the reasons for doing so do not align with this need.

To have community health providers effectively participate in the emerging technically interoperable world, any approach must be practical for the clinicians involved. Interoperability needs to meet workflow and process requirements, business needs, and be clinically meaningful. The Task Force supports technical and policy work that is currently underway to enhance interoperability and notes that Infoway's *Shared Pan-Canadian Interoperability Roadmap* is now in its second year of implementation. But the Task Force believes more commitment and collaboration is required from federal, provincial and territorial (FPT) governments for this work and that progress must be accelerated.

Summary of recommendations

Recommendation 1:

Federal, provincial and territorial (FPT) governments should commit to developing and fast-tracking a comprehensive plan that will deliver tangible improvement in interoperability within five years. The plan should be developed, and its implementation overseen, through the immediate establishment of a collaborative National Health Data Governance Council.

The Council must be empowered by FPT governments to drive accountability, timelines and cross-jurisdictional commitments, ensuring provinces and territories adhere to a unified framework.

Recommendation 2:

The necessary policy and legislation work underway at the federal level to drive comprehensive interoperability of health data in Canada should be aggressively accelerated and supported by provincial and territorial governments. This includes:

a) *Legislation to mandate the data and technology standards required to support clinical data exchange and transactions, such as envisioned in Bill C-72.*

b) *A national framework for modern health data stewardship policies that champion appropriate data sharing, access, secondary use and privacy protection. This must include:*

- *Formalization of Indigenous health data sovereignty policies as determined by Indigenous communities. Secondary uses of Indigenous data, and various forms of data sharing (even of de-identified data), must attend to collective rights around Indigenous health data.*

- *Engagement with the public, clinicians and other partners to co-design the national stewardship framework and promote communication of the policies to engender trust and address privacy concerns.*

- *Requirements that ensure patient ownership and digital access to their health data.*

Recommendation 3:

Provinces and territories need to commit to addressing the key barriers preventing physicians and other health care professionals from participating in health data interoperability initiatives by:

a) *Ensuring that health data solution deployments that impact clinicians are co-designed and include a cross-section of practising clinicians in a meaningful manner.*

b) *Ensuring that the process for every procurement that impacts clinicians includes evaluation of end-user experience, workflow and clinician burden as a critical criterion.*

c) *Co-developing a digitally enabled strategy and roadmap within each jurisdiction aimed at measuring and reducing clinician administrative burden and optimizing clinician workflows.*

d) *Ensuring that the administrative burden and cost of interoperability initiatives are not downloaded to clinicians.*

Recommendation 4:

Organized medicine represented by national and/or provincial/territorial medical associations and other clinically related societies can play an important role in providing guidance and support for physicians on interoperability by:

a) *Continuing to develop best practice guidelines that assist physicians in engaging in the interoperable digital health environment, in the context of improving patient care, patient safety and overall quality improvement.*

b) *Advocating and working collaboratively with government to implement regional strategies to remove the barriers to interoperability identified by the Task Force, including workflow, training, resourcing needs and interprofessional care.*

Recommendation 5:

Canada's research and development funding organizations should commit to investing in continuous innovation in digital health that overcomes critical barriers to interoperability by:

a) *Developing new strategies in activities such as data standardization, curation and report generation from EMRs, including AI, that better support clinician participation and reduce their workload.*

b) *Addressing the inadequacy of current EMRs for health care teams' needs.*

Digital Health Interoperability Task Force Report

Preface

In March 2024, the Canadian Medical Association (CMA), Canada Health Infoway (Infoway), the College of Family Physicians of Canada (CFPC) and the Royal College of Physicians and Surgeons of Canada (Royal College) created the Digital Health Interoperability Task Force (the Task Force). The Task Force had a mandate to encourage the implementation and use of interoperable digital health solutions.

As stated in the terms of reference, the goals of the Task Force included:

- Improving the quality of patient care and enhancing patient safety through better use of interoperable digital heath solutions.

- Advising and supporting efforts to effectively digitally connect physicians to health system resources to reduce administrative work, streamline care delivery and enable the sharing of health data.

- Stimulating innovations and approaches to overcome key barriers and develop practical implementation strategies to enable adoption and ongoing use of interoperable digital health solutions.

The Task Force consisted of physician experts in digital health technology at the national and provincial/territorial level as well as representatives from medical learners and nursing. The Task Force also heard the patient perspective and concerns of the public.

Under the direction of two co-chairs, Task Force members met virtually several times over the spring and summer of 2024 with their deliberations forming the basis for this report and series of recommendations. While providing a general overview of the interoperability issue in the Canadian health care system, this report focuses on the physician/clinician perspective and concerns.

In its deliberations, the Task Force used three definitions of health data interoperability – also known as "Connected Care".

Health data interoperability is the ability of different information systems, devices and applications (systems) to access, exchange, integrate and cooperatively use data in a coordinated manner to optimize the health of individuals and population.

Technical factor interoperability involves the data content standards and technical considerations required to enable secure access and integration of electronic health data and their transmission across disparate health technologies. The four domains of technical factor interoperability are data content standards, data exchange standards, Internet connectivity and common user authentication.

Human factor interoperability involves the system-level relationships that impact the capacity of health sector partners to adopt harmonized health data standards and technology. The seven domains of human factor interoperability are governance, legislation, policy, regulation, literacy, communication and culture.

Task Force members also strongly emphasized that human factor interoperability should be balanced with optimizing the workflow for clinicians and accessibility for patients.

Introduction

The lack of true interoperability of data in the Canadian health care system has been an issue for as long as electronic medical records and databases of electronic health data have existed – and continues to be.

Twenty years ago, the Canadian Medical Association (CMA) launched a magazine called *Future Practice* to help inform physicians about how information technology was changing the practice of medicine. In a column that closed the first edition, Ottawa family physician Dr. Jay Mercer noted that while his practice used an electronic medical record (EMR), he was still very much alone on an electronic island.[5]

> *"We don't have the ability to talk to all of the community pharmacists electronically, so our prescriptions are all on paper," Dr. Mercer wrote. "The specialists we deal with like consult requests to be faxed to them, resulting in the printing of at least one piece of paper in our office and theirs. Laboratory investigation forms must be done by hand … and imaging requisitions must also be printed on paper."*

Much has changed since Dr. Mercer's 2004 column and the use of paper has declined significantly. However, the limited ability of people in the health care system (most significantly, clinicians and patients) to access and share information electronically remains a chronic shortfall.

Just a few years after Dr. Mercer's column appeared, Dave deBronkart (widely known as "e-Patient Dave"), a US citizen with stage IV renal cell carcinoma, gave a keynote address at the Medicine 2.0 conference in Toronto titled "Gimme My Damn Data".[6] In his address, deBronkart catalyzed the frustrations of many patients unable to obtain their own medical records and set the stage for the modern engaged patient movement. The ability for patients to access their own medical records has now become a fundamental rationale for interoperability and a prerequisite for an effective health care system based on digital technology.

> *"If you're a patient you want to have your own data, you don't want to repeat everything you said. Oddly enough, patients already assume that we're sharing data, even though we're not."* — Task Force secretariat

The health care system consists of tens of thousands of independent organizations including hospitals, pharmacies, emergency medical services, physicians, other health professionals and many community organizations. Most health care professionals now use electronic clinical systems to meet the needs of their organization. However, most of the systems were not developed in anticipation of needing to exchange personal health information with other organizations or with patients.

Recent data from Infoway shows fewer than 40% of Canadians report accessing some of their health information electronically and only 35% of physicians share patient information outside their practice.[1] All provinces and territories have been challenged in their ability to access data from community providers and particularly from primary care physicians. While access to the hospital and repository data is useful, most health care occurs in the community. Yet, almost universally, provinces and territories collect little data from community providers and almost no data from primary care other than billing information.

Data contained in electronic health record repositories lacks context for those who do not know the patient. Patients are still required to repeat their story at every new encounter and use a number of patient portals to access information held by different providers or institutions.

The inability to assemble all relevant patient information can have a significant impact on quality of care and patient outcomes. Lack of access to patient-specific data is a particular issue when patients are seeing multiple health care professionals or having diagnostic tests in multiple facilities. This undermines the ability for the system to deliver both urgent care and continuity of care in the community.

Without interoperability, critical patient information may not be available when needed, leading to potential medical errors and compromised patient safety. Physicians and other health professionals experience this every day and while workarounds can minimize these risks, errors can and will be made, based on incorrect or incomplete data.

The interoperability gap also creates inefficiencies and frustrations for clinicians and increases their administrative burden. Primary care providers must often spend excessive amounts of time trying to access relevant information to provide care in real time, or to coordinate care more efficiently. More specifically, lack of digital functionality and transparency (into current appointment status, wait times, service availability, etc.) hinders appropriate health system navigation, and is inefficient and wasteful.

Ideally, Canada's publicly funded, single payer health systems would enable access to comprehensive data linking patient characteristics, care processes and outcomes. However, the absence of key data elements, the challenge of collecting data from multiple sources in a timely way and dated privacy legislation limit the value of aggregated data for research, performance management, public health, population health, quality improvement and corporate innovation purposes.

Most recently, the COVID-19 pandemic has highlighted the importance of digital health and laid bare shortcomings in delivering it, with lack of interoperability being a key issue.

"Each stakeholder group – patients, policy-makers, health administrators, health professionals, data experts/health informaticians, industry/EHR vendors, health researchers – is necessary but insufficient to address this issue of data and human interoperability by themselves. If collaboration is called for, then the optimal way to go would be through joint vision, shared passion and holding ourselves and each other accountable to meet the goals." — Task Force member

"Too often the debate about how to impact change in the health sector (like implementing comprehensive interoperability) regresses to a longstanding pattern of different groups and powerbrokers pointing the finger at one another, rather than joining forces to solve problems collectively. If we (physicians) can recognize/acknowledge with colleagues and co-workers across the health sector (including big tech/government/other professionals, etc.) a shared and collective accountability to help address the harmful fragmentation of health data, this will help pave the way to a solution." — Task Force member

Recent developments

In the last two years, several comprehensive efforts have been undertaken to define and address the interoperability challenge, and progress has been made. Specific initiatives have been undertaken by Canada Health Infoway, the Canadian Institute for Health Information (CIHI) and the federal government. Provinces and territories also are making significant investments in integrative solutions. However, the lack of more universal interoperability makes it challenging and more expensive to implement these solutions.

Initiatives in the US and Europe are also helping inform the Canadian experience.

In May 2022, an expert advisory group released its third and final report to federal, provincial and territorial (FPT) governments on development of a Pan-Canadian Health Data Strategy.[7] Such a strategy, the group stated, would:

- *create a common policy framework for data sharing;*
- *implement interoperable data standards;*
- *develop common person-centric data architecture;*
- *improve health data literacy; and*
- *produce sound and actionable research and analysis.*

The report stressed the need to foster a person-centric health learning system in Canada rather than the current provider-centric system for collecting and curating health data. Ideally, the report noted, all providers of care for an individual patient would have timely access to health data organized around that individual. Principles underlying this approach are outlined in the Pan-Canadian Health Data Charter endorsed by the FPT governments.[8]

The expert advisory group report also stated that a Pan-Canadian Health Data Strategy would involve ongoing and meaningful involvement of First Nations, Inuit and Métis Peoples to ensure that rights- and distinctions-based expectations and needs are met. This would include supporting Indigenous data sovereignty and ensuring that First Nations, Inuit and Métis Peoples – whether living in urban, rural or remote areas – would have control over data they need for their own evidence-informed approaches to health for their populations.

In March 2023, Infoway's *Shared Pan-Canadian Interoperability Roadmap* was approved by the FPT governments' deputy ministers of health.[2] This document laid out the rationale for interoperability from the perspective of patients, clinicians and the system as a whole. As stated in the executive summary of the Roadmap:

> *"Digital health systems need to interact with each other across all care settings so that Canadians' health information moves with them through the system, ensuring no patients fall through the cracks. For clinicians and care providers, technology must support effective and efficient communications, and improve care delivery and the patient experience. Beyond accessing information for the provision of care, health systems need to be able to access and analyze large data sets to inform health system planning and performance, analytics, research and population health management to protect and optimize a learning health system for the generations to come. Similarly, health data needs to continue to support Canada's reputation of worldclass research (e.g., biotechnology), medical breakthroughs (e.g., genomics) and innovation."*

The Roadmap stated health care leaders across the country had agreed to four key challenges needing to be addressed to achieve interoperability:

1. Systems are not able to easily share electronic health information.
2. Providers have limited ability to make the most informed clinical decisions since health information is siloed across multiple systems and repositories and is often inaccessible to them.
3. Patients have limited ability to access, manage and consensually share their full health record.
4. Care coordination and collaboration is not currently supported by integrated and interoperable tools and systems that support efficient care delivery as patients progress through the system.

The Roadmap then laid out four strategic priorities:

1. Reduce data blocking and ease portability.
2. Improve provider access to patient data at the point of care.
3. Enable patient access to their health record.
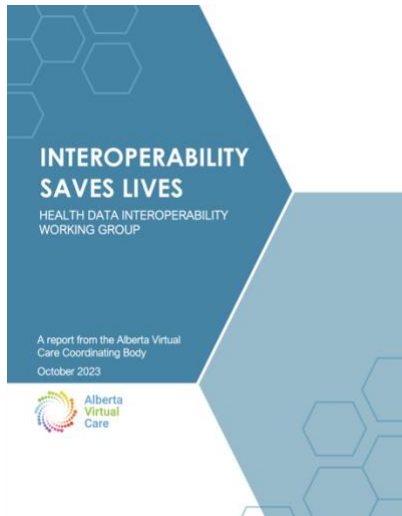4. Improve care coordination and collaboration.

To successfully advance interoperability through the execution of this Roadmap, the Infoway report identified two notable critical success factors:

- Adequate funding, which included noting that "busy clinicians will need to be incentivized to adopt the changes that come with practicing in an interoperable system and be supported by change management strategies and resources."

- Enabling legislation

The Roadmap was endorsed by the Conference of Deputy Ministers in March 2023 and funding has been provided to Infoway, CIHI and other partners to advance the interoperability agenda.

According to Infoway, major activities to deliver the Roadmap and advance interoperability centre around:

1. Developing a data content and data exchange framework, in collaboration with CIHI.
2. Developing specific standards and pilot programs with the provinces/territories related to the four priority initiatives.
3. An aggressive vendor mobilization to implement the first two items.

As part of its work, Infoway is developing an approach, known as Project HALO, for simplifying primary and community care access to digital health services. This program will create a standardized "visual interactive framework" to enable web applications to seamlessly 'plug-and-play' into community EMRs and point-of-care solutions to simplify access to services for community-based providers.[9] At maturity, the program will integrate multiple applications, improve provider workflow and provide a unified view into a patient's record, regardless of location, technology and vendor. Working with Infoway Ontario and BC plan to release working prototypes using the framework by early 2025.

In March 2023, CIHI initiated work on the Pan-Canadian Health Data Content Framework (pCHDCF) to define, standardize and model the health data required to enable interoperability in Canada, starting with primary care data.[3] The purpose of the Pan-Canadian Health Data Content Framework is to lay the foundation for standardized health data that can be used within and across various sectors and contexts starting with primary care data. The Framework is building on similar work being done in other countries and already underway in some Canadian jurisdictions. Public review of the Framework began in March 2024 with a first draft version released in September and a second review initiated at the beginning of October.

In October 2023, the Alberta Virtual Care Coordinating Body released the report *"Interoperability Saves Lives".* The report stressed the relationship between interoperability and patient safety, noting a lack of interoperability can result in harm to individuals, populations and health care systems, including:

- Damage to physical or emotional health and well-being.

- Breach of legal and ethical rights to personal health data.

- Failure to benefit from science and use health data for public good.

- Failure to optimize health system function and efficiency.

- Damage to health workforce well-being.

- Failure to support health innovation.[10]

The report concluded that health data interoperability should be a priority and should be mandated and regulated both provincially and nationally.

In 2021, Canada and the other G7 nations committed to "…work towards adopting a standardised minimum health dataset for patients' health information, including through the International Patient Summary (IPS) standard." As part of this work, Infoway is advancing the pan-Canadian Patient Summary Specification that defines the terminology that information systems across provinces and territories use to communicate.

A FPT data stewardship working group was formed in August 2023 to address data stewardship in a more coordinated way across jurisdictions. The working group proposed a framework and a new pan-Canadian governance structure that would support an understanding and definition of data stewardship, in which health data is collected once, shared seamlessly with trusted partners and used many times for public good.

In June 2024, the deputy ministers of health endorsed CIHI's continued advancement of this pan-Canadian data stewardship work in collaboration with Infoway, provinces and territories, Indigenous partners and other key groups. CIHI was directed to return in fall 2025 with the refined framework and governance plan for endorsement.

On June 6, 2024, the federal government introduced Bill C-72, the *Connected Care for Canadians Act*.[4] The aim of the act is to "enable a modern, connected care system, in which health information can be securely accessed by patients and shared between providers, when needed". The legislation and accompanying regulations will also ban data blocking and would require all IT companies providing digital health services in Canada to adopt common standards and allow for protected and secure information exchange across various systems.

In the wake of the announcement of the federal legislation, the CMA released a statement noting "Electronic medical records have increased health information exponentially and new national standards are needed to ensure the most meaningful data is clear and accessible to the people who need it most."

Introduction of the legislation follows an agreement by FPT governments to work to modernize the health care system with standardized health data and digital tools as part of the February 2023 "Working Together to Improve Health Care for Canadians" initiative. As outlined by the federal government, these efforts included:

- Collecting and sharing high-quality and comparable de-personalized information to measure progress being made through common indicators to improve health care for Canadians.

- Adopting common interoperability standards guided by the Pan-Canadian Interoperability Roadmap to better connect health care systems and allow Canadians and their health care providers to securely access electronic health information to improve care.

- Promoting alignment between provincial and territorial health data policies and legislative frameworks for consistent approaches to health information management and stewardship that maintains appropriate privacy protections.

- Advancing common principles for the management of health data through a Pan-Canadian Health Data Charter that reaffirms a commitment to a person-centered, ethical approach to health data, public engagement, equity and Indigenous data sovereignty.[11]

In parallel with these efforts, medical associations at both the national and provincial/territorial levels have introduced initiatives to address the administrative burden facing physicians partially because of the lack of interoperability of electronic records. According to the CMA's 2021 National Physician Health Survey, **nearly 60% of physicians have said administrative burden directly contributes to worsening mental health** and 75% said this burden is an impediment to treating patients.

In a 2021 report entitled "Healing the Healers", the Ontario Medical Association noted technology was a leading cause of burnout among physicians[12]. Among the five solutions advocated by the association were: "Making digital health tools a seamless part of physicians' workflow, including by ensuring different systems can speak to each other", and "reducing and streamlining documentation."

A survey conducted for the CMA and Infoway in April and May 2024 with responses from 1,145 physicians and residents showed that while the vast majority (86%) report **clinical care communication between providers occurs electronically**, barriers to true interoperability of patient health data remain significant and impact physician well-being.[13]

86%
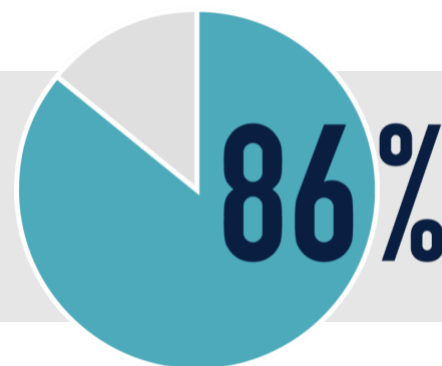
Over a third (35%) of physicians who use an EMR say they spend two hours or more beyond what they should reasonably spend each workday looking for patient information needed to provide care.

Of the numerous barriers reported as preventing access, use or getting full value from digital health technologies, the lack of integration with current systems/having multiple systems that aren't connected was the most commonly identified factor, noted by 73% of respondents.

Artificial Intelligence (AI) is beginning to have a major impact at the front lines to improve clinical care and administrative efficiency. Already, AI scribe tools have become practical, and their use is spreading quickly among clinicians. Direction and oversight are necessary to ensure AI enhances and facilitates interoperability. Currently, AI has the capacity to both enable and undermine interoperability. For example, using AI to convert unstructured data to structured data facilitates data exchange, while the use of generative AI can undermine interoperability by losing data provenance through the separation of data from its original source.

The United States has also worked to tackle the issue of interoperability in health care. The *21st Century Cures Act* is designed to give patients and their health care providers secure access to health information and includes a provision requiring that patients can electronically access all their electronic health information at no cost.[14] The *21st Century Cures Act* legislation also implements other interoperability requirements including prohibiting most information blocking. Through a legislative approach and a Trusted Exchange Framework, the United States has implemented standards and protocols that currently enable millions of records to be securely shared monthly.

In 2024, the European Union in 2024 agreed to create the European Health Data Space – a set of standards, policies, practices and legislation that simplify the provision of care and encourage interoperability across borders.[15,16] The success of this initiative has depended on four variables: recognizing that national policies must be compatible to prevent barriers to the flow of data, harmonizing technical data standards to simplify data flow across countries, having the trust of the public and providers, and providing incentives to encourage collaboration.

Challenges

Whether characterized as barriers to overcome or opportunities for improvement, there are many issues that must be resolved to realize the benefits of interoperable health data in Canada. The Task Force and others identified the following challenges:

Clinician administrative burden

- Clinician burnout due in part to administrative burden and perceived additional burden from gathering and sharing health data.

- Reduced capacity for clinicians to see patients due to time spent on data administration.

- Potentially significant out-of-pocket IT and administrative costs to enable interoperability.
- Absence of additional resources such as more funding or change management tools to support clinician involvement in new interoperability initiatives.

Technological/standards-based

- Lack of foundational technology standards required to support clinical data exchange and transactions, particularly for community providers.
- Lack of broadly mandated data nomenclature and exchange standards for personal health information (PHI)-related data.
- Failure of EMR systems to support interoperability. Most existing charting systems are outdated and lack the automation and flexibility required for seamless data exchange.
- Non-integrated portals requiring multiple sign-ins, searches and manual processes.
- Inconsistent, incomplete, inadequate and outdated privacy and data governance policies.
- Incomplete Internet connectivity, especially in rural and remote areas, to support health information sharing.

Policy/legislative

- Absence of a clear authority accountable for health information interoperability.
- Lack of adherence to the Canada Health Act principles of portability and universality as they apply to the sharing of patient information.
- Disconnect between the fiduciary requirement of physicians to be caretaker of the patient record and patient ownership of data in the record.
- Absence of in-force legislation mandating technical interoperability standards.
- Lack of health information legislation to promote health information sharing.
- Inconsistent, incomplete, inadequate and outdated privacy and data governance policies.

Educational

- Inadequate physician education to provide leadership in digital health tools and how to optimize them.
- Lack of digital health literacy among patients.

Additional challenges

- Failure to consistently involve Indigenous communities when gathering data on Indigenous populations, and perpetuation of racist attitudes in health care.
- Cultural resistance among clinicians, vendors and health organizations to sharing data.
- Impaired ability of interprofessional health care teams to share data.
- Absence of incentives for vendors to support interoperability.

Discussion

The Task Force is passionate about the potential for interoperability of health data to enhance patient care and acknowledges and supports national efforts currently underway to achieve this goal. But these efforts must be accelerated through greater commitment and collaboration between governments and partners. The Task Force is especially concerned about the lack of mechanisms to ensure the needed participation of front-line clinicians.

A fundamental disconnect remains between the approach taken by organizations and governments to address the interoperability of health data, and the perspective of Canadian clinicians. Unless this is addressed, the Task Force is concerned interoperability initiatives will place additional burdens on clinicians and could lead to a failure of well-intentioned efforts to support connected care.

"There is a disconnect between the data that you want for interoperability and the data that we need clinically."

— Task Force member

"Downloading responsibility for shoring up another part of our health care system will be met with greater attrition from our workforce. Whatever system we pursue will need to have frontline clinician workflow top of mind to improve uptake and rapid transition."

—Task Force member

"You can't define the information a clinician needs because it is so context specific. What I data mine is not what you're ever going to define in your data requirements."

— Task Force member

"People don't go to medical school to become data entry clerks and medical schools … don't train them to be data entry clerks. We do teach them to record information that is important to care but that is not the same as data entry."

—Task Force member

Patient data is gathered during the clinical encounter to document the specifics of the encounter and provide a resource for the physician as well as to meet their fiduciary responsibility as the caretaker of the patient record.

The data is intended primarily to support care provision for the specific patient involved. The types of data may deviate significantly from the types and formats of patient data required for effective clinical data sharing and clinical workflow applications as well as by health systems for the purposes of public health, data sharing, quality improvement or other broader goals.

The Task Force believes implementation of new technologies – specifically the use of Artificial Intelligence (AI) and AI-based scribes – could have a significant impact on helping clinicians manage data in a more timely and efficient manner. Automating the processes of data entry, standardization, curation and sharing can significantly reduce the burden on health care providers. Adopting such automation could help streamline these processes, making participation in data sharing more feasible and less time-consuming. It is now possible that the narrative captured by physicians to document the patient journey can be coded by machines for sharing with other systems in a standardized way.

The ability of patients to access their own health data electronically is a foundational principle for all interoperability initiatives in Canada. This extends to the ability to safely share their data with the patient's circle of care. However, much of the current privacy legislation does not meet the requirements of the digital age and hinders appropriate sharing.

"We know that Canadians need to understand how their data will be used. They need to trust that it will be used for public good. So, we are working with provincial and territorial governments to develop a strategy that will feature communications but also engagement with the public, to make sure that Canadians understand why data sharing is important and how their data will be shared and used, including for secondary use."

—Federal government official

While physicians aspire to best support patients and provide quality care, an altruistic approach is not sufficient to ensure physicians can participate in interoperability initiatives, especially during the current epidemic of burnout and the crisis related to shortages of primary care and emergency department physicians.

"We do have a professional responsibility to advocate on behalf of our patients; however, ultimately the ability to move data across silos falls well outside of our control as individual clinicians."

—Task Force member

Recommendations

Current efforts underway to implement data standardization, technology interoperability, data stewardship modernization and associated policy are essential elements of interoperability. But they are not sufficient to enable community providers to participate effectively. These efforts are also not occurring quickly enough, lack mechanisms to enable community-based clinician to participate effectively, and are not backed up with sufficient commitments from government.

A fundamental challenge seen by the Task Force is the disconnect between the overarching need for interoperable patient data to improve the system and patient safety, *AND* the fact that what clinicians collect (in the way of patient data) and the reasons for doing so do not align with this need.

To have community health providers effectively participate in the emerging technically interoperable world, any approach must be practical for the those involved. Interoperability needs to meet workflow and process requirements, business needs, and be clinically meaningful.

PROVIDING GUIDANCE

The Task Force supports technical and policy work that is currently underway to enhance interoperability and notes that Infoway's *Shared Pan-Canadian Interoperability Roadmap* is now in its second year of implementation. But the Task Force believes more commitment and collaboration is required from FPT governments for this work and that progress must be accelerated. To achieve this goal, the Task Force is recommending establishment of an overarching competency-based National Health Data Governance Council that represents and fosters the collaboration of all jurisdictions.

Recommendation 1

Federal, provincial and territorial (FPT) governments should commit to developing and fast-tracking a comprehensive plan that will deliver tangible improvement in interoperability within five years. The plan should be developed, and its implementation overseen, through the immediate establishment of a collaborative National Health Data Governance Council.

The Council must be empowered by FPT governments to drive accountability, timelines and cross-jurisdictional commitments, ensuring provinces and territories adhere to a unified framework.

A similar idea was put forth in the Public Health Agency of Canada's 2022 Expert Advisory Group (EAG) report in advocating for implementation of the Pan-Canadian Health Data Charter to be overseen by a national collaborative group.[17]

The goal of the new Council would be to take overall responsibility for, and ensure there is a holistic, executable plan – the Pan-Canadian Health Data Strategy – that aggressively "pulls all the levers" to create a practical interoperability environment across the country.

Success of health data interoperability requires implementing a minimum set of policies, technologies and programs that will impact all governments, health care-related vendors and countless health care providers across the country. To date, no group has taken on the challenge of pulling all the pieces together and driving progress.

Without clear accountability, declared goals, a plan and a sense of urgency, progress at this scale will continue to flounder.

The first action of the Council should be to develop the strategy, and then generate a five-year plan that contains milestones, timelines, accountabilities, budgets and partner commitments.

It will be essential that the Council be carefully chosen, likely including experts in policy, technology and business as well as representatives of interdisciplinary clinicians, patient/caregivers and health care provider organizations.

The Task Force anticipates the Council would be created and empowered through the commitment of FPT governments, with operational support provided by Health Canada, CIHI and Infoway. The Council would be accountable for actioning all recommendations brought forward by this Task Force.

The Task Force also feels that the Council should champion the appropriate development of AI policy to ensure it enhances and facilitates interoperability.

The Task Force notes that, to some extent, the recommendation to create an oversight council mirrors a recommendation from the FPT data stewardship working group for creation of a pan-Canadian data stewardship committee to provide strategic guidance on data collection, linkage, transmission, use, analysis and reporting. Going forward, the Task Force feels that should such a committee be created, that it fall under the direction of the Council.

SECURING COMMITMENT

The Task Force also believes it is important to develop the policy and/or legislation required to support and mandate comprehensive interoperability.

Recommendation 2

The necessary policy and legislation work underway at the federal level to drive comprehensive interoperability of health data in Canada should be aggressively accelerated and supported by provincial and territorial governments. This includes:

a) *Legislation to mandate the data and technology standards required to support clinical data exchange and transactions, such as envisioned in Bill C-72.*

b) *A national framework for modern health data stewardship policies that champion appropriate data sharing, access, secondary use and privacy protection. This must include:*

- *Formalization of Indigenous health data sovereignty policies as determined by Indigenous communities. Secondary uses of Indigenous data, and various forms of data sharing (even of de-identified data), must attend to collective rights around Indigenous health data.*

- *Engagement with the public, clinicians and other partners to co-design the national stewardship framework and promote communication of the policies to engender trust and address privacy concerns.*

- *Requirements that ensure patient ownership and digital access to their health data.*

The Task Force anticipates that implementing these recommendations would:

a) Create and maintain a core set of national data nomenclature and data exchange standards as part of the *Shared Pan-Canadian Interoperability Roadmap*.

b) Create a standardized interoperability framework for community EMRs, including goals for terminology standardization.

c) Require all vendors and stewards of patient health information to use technology that has implemented the above standards.

d) Implement FPT health data governance policies that are consistent across jurisdictions.

The Task Force acknowledges and supports the many initiatives already underway, especially Bill C-72, to develop and introduce policies and legislation to support interoperability. However, this work must be accelerated and done with more collaboration between jurisdictions and with more accountability.

Work on creating and maintaining standards should be the responsibility of CIHI and Infoway, working in collaboration with provincial/territorial governments and vendors.

Public buy-in is essential to achieve true health data interoperability. A public education process will be necessary to improve patient digital health literacy, build trust and inform patients of the value of sharing personal health data to foster system-level improvement.

Obtaining and sharing health data for Indigenous patients remains problematic in many instances because it does not reflect reality and has often been used to misrepresent and harm these populations. While relatively good protections exist for individual health data, they do not exist for Indigenous communities as a whole, especially in urban environments. Collective interpretations and use of data have been, and remain, a source of harm for Indigenous communities.

However, examples of best practices in the collection of Indigenous health data do exist and should be followed. The Task Force recommends that Indigenous oversight of data remains a foundational principle to provide the proper context for these data.

There is now a global movement to address Indigenous data sovereignty. This includes adding CARE (Collective benefit, Authority to control, Responsibility and Ethics) principles to existing mainstream FAIR (Findable, Accessible, Interoperable, Reusable) principles of health data sharing, to promote equitable participation and outcomes from data access, use, reuse and attribution.

ERASING BARRIERS

Eliminating barriers that prevent physicians from participating in health data interoperability initiatives is key to successfully seeing such initiatives integrated into the current health care system. This can only be done successfully by involving them directly in assessing the impact of changes that impact their workflow and ensuring that they do not have to bear the administrative or financial burden of interoperability initiatives.

Recommendation 3

Provinces and territories need to commit to addressing the key barriers preventing physicians and other health care professionals from participating in health data interoperability initiatives by:

a) *Ensuring that health data solution deployments that impact clinicians are co-designed and include a cross-section of practising clinicians in a meaningful manner.*

b) *Ensuring that the process for every procurement that impacts clinicians includes evaluation of end-user experience, workflow and clinician burden as a critical criterion.*

c) *Co-developing a digitally enabled strategy and roadmap within each jurisdiction aimed at measuring and reducing clinician administrative burden and optimizing clinician workflows.*

d) *Ensuring that the administrative burden and cost of interoperability initiatives are not downloaded to clinicians.*

The Task Force feels it is up to provincial and territorial governments to enable this recommendation and address the practical working environment and motivation of physicians. However, the Task Force feels it is critical to involve physicians in procurement, co-design and evaluation, and ensure new solutions fit appropriately into provider workflow.

The Task Force believes strategies could be implemented such as building living labs (where new or existing tools are tested in simulated and routine clinical environments) that include representative panels of primary care providers, and procurement strategies that build in requirements for ongoing improvement based on assessments from routine practice.

As noted earlier in the Task Force report, it is anticipated that EMRs that have implemented the Infoway-led HALO standards framework will be able to display and integrate any standardized third-party application within the EMR. This will allow any compliant application to "plug and play" within an EMR without integration effort, providing a channel to simplify provider workflow.

As new solutions for interoperability are implemented or old solutions replaced, these circumstances can be used as an opportunity to improve and simplify the clinical business processes between organizations in the community. These solutions must be led by clinical requirements rather than as technology initiatives and must integrate into the overall work environment of the providers, rather than being delivered as one-off solutions. As noted above, appropriate supports must be put in place if clinician collaboration is expected.

Clinicians cannot be expected to assume the administrative burden or cost of interoperability initiatives. A number of options are available to ensure interoperability initiatives do not place an additional administrative burden on clinicians such as new funding models and implementation of innovative technologies such as AI.

SUPPORTING CLINICIANS

The Task Force has also identified the importance of providing opportunities for clinicians to champion interoperability initiatives and take a leadership role in their adoption.

National and provincial/territorial medical associations have an important role to play in advocating for interoperability initiatives to be implemented appropriately and best practice guidelines to be made available. These guidelines should clearly illustrate the responsibilities and recommended processes that clinicians should follow related to receiving and sharing personal health information, in alignment with FPT privacy legislation and stewardship policy.

Recommendation 4

Organized medicine represented by national and/or provincial/territorial medical associations and other clinically related societies can play an important role in providing guidance and support for physicians on interoperability by:

a) *Continuing to develop best practice guidelines that assist physicians in engaging in the interoperable digital health environment, in the context of improving patient care, patient safety and overall quality improvement.*

b) *Advocating and working collaboratively with government to implement regional strategies to remove the barriers to interoperability identified by the Task Force, including workflow, training, resourcing needs and interprofessional care.*

The responsibilities of clinicians when sending or receiving personal health information are not entirely clear. This is a result of current privacy legislation, which is often confusing or inadequate, as well as a lack of clarity around physician responsibility in the digital age.

These challenges can be a major cause of administrative burden, may impede patient care and create liability concerns for providers. Clear guidelines are needed to identify best practices and support clinical care.

STIMULATING INNOVATION

Technological innovation is needed in critical areas that currently hinder front-line health care teams from participating in interoperability initiatives.

Recommendation 5

Canada's research and development funding organizations should commit to investing in continuous innovation in digital health that overcomes critical barriers to interoperability by:

a) *Developing new strategies in activities such as data standardization, curation and report generation from EMRs, including AI, that better support clinician participation and reduce their workload.*

b) *Addressing the inadequacy of current EMRs for health care teams' needs.*

Innovations in technology could include (but are not limited to) the following:

Automation: Automating the processes of data entry, extraction, sharing and report generation can significantly reduce the burden on health care providers. Advanced data analytics, AI and machine learning can help streamline these processes, making participation in data sharing more feasible and less time-consuming.

Predictive analytics: Implementing predictive analytics can optimize workflows and ensure that data is used effectively. This can help health care providers anticipate and address potential issues before they arise, improving overall efficiency and patient care.

Cloud-based solutions: Moving data management systems to the cloud can enhance the scalability and manageability of interoperability efforts. Cloud solutions can facilitate the creation of interoperability hubs and sandboxes, where data can be shared securely and efficiently.

AI framework: There is a need to further improve the capacity to use AI in health care and address the regulatory, ethical and security concerns.

The Task Force believes that to be optimally effective, any new strategies must not increase physician workload but should rather reduce their administrative burden.

The Task Force anticipates this work would require support from research and development programs and the involvement of digital health technology vendors. The work should be championed by organizations involved in promoting digital health innovation or research.

Examples include federal departments and agencies as well as organizations funded by the federal government such the Canadian Institutes of Health Research, Canada Foundation for Innovation and programs sponsored by Innovation, Science and Economic Development Canada, including Innovative Solutions Canada, CAN Health Network and the Strategic Innovation Fund.

Conclusion

Better connecting patients with their own health information and allowing health care providers to easily share these data is a critical function of an effective and efficient health care system. Without such connectivity, quality of care suffers, and patients can – and do – die as a result.

Making patient health information available in a digital format has made the connectivity of health data a realistic goal and many countries have made significant advances to achieve it. As this report has shown, Canada has also identified connected care as a goal and is making legislative and policy changes to realize it. But much more is needed with collaboration of all partners including our governments, patients, providers and vendors. Without accountability and a more coordinated approach, interconnectivity solutions are unlikely to be successful.

Today, the Canadian health care system is in crisis with critical shortages of primary care providers and excessive wait times, including for emergency care. The crisis is seriously impacting Canada's physicians. As the most recent CMA/Infoway survey shows, 7% of physicians working in a community setting report being completely burned out and feeling that they may need to seek care or close their practice[1]. The administrative burden of dealing with electronic patient records in their current form is contributing to this situation.

The Task Force is adamant that any solutions to enhance interoperability cannot add to the pressures already facing clinicians. Solutions must fit into existing physician workflows and additional resources – including appropriate remuneration and change management support – must be made available to allow clinicians to participate. Physicians also need technological support so data needed for interoperability can be automatically extracted from patient information they have collected in their EMRs for the provision of patient care.

While focusing on the clinician perspective in this report, the Task Force wants to reiterate the primary importance of delivering on interoperability of health data to improve patient safety and outcomes. Also, delivering on interoperability is a collaborative venture that requires support from all partners and health care providers, and must be aggressively driven by governments.

Work on existing initiatives and new plans must be accelerated with a strong commitment from governments.

The importance of interoperability is not in question: It is about patient safety and better patient care. However, without addressing the barriers to interoperability in true co-design with physicians and other clinicians, we risk revisiting these same challenges 10 years from now. The work of this Task Force is crucial, not only in identifying these obstacles but in ensuring that national and provincial/territorial solutions are resourced, practical, implementable and sustainable for the clinician community.

The Task Force believes the recommendations made in this report address these issues and will help provide the necessary framework to create a truly interconnected health care system for Canada.

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