Analysis

The *Connected Care for Canadians Act*: an important step toward interoperability of health data

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■ Cite as: *CMAJ* 2024 December 9;196:E1385-8. doi: 10.1503/cmaj.241123

See related article at www.cmaj.ca/lookup/doi/10.1503/cmaj.241351.

In June 2024, the Government of Canada introduced Bill C-72[1] (Box 1) requiring that health information technology (IT) be interoperable.[2] This is a key step toward patients easily accessing all their health data and ensuring all their health providers (with permission to do so) have access to the same information. This bill is needed because, without regulation, health care institutions and electronic medical record (EMR) vendors have not taken the steps necessary to ensure health information can be shared easily and securely.

Canada Health Infoway, an independent federally funded organization promoting the adoption of digital health tools, defines interoperability by explicitly recognizing the connection between seamless data exchange and improved health care: “The quintessential characteristic of an interoperable health system is person-centric care, in which standardized data can follow the patient across all care settings and geographies to enable more informed care provision, leading to better health outcomes.”[3] We discuss the benefits of interoperability, describe how this legislation should improve Canada’s fragmented health information ecosystem, and discuss challenges related to provider behaviour, timelines for implementation, data governance, and minimizing the influence of the commercial determinants of health.

Key points

- The federal government introduced Bill C-72 in June 2024 to promote health data interoperability and prevent blocking of access to data.
- Interoperability of electronic medical records can be expected to reduce medical errors, decrease duplication of health services, improve patient care, decrease health care costs, and accelerate medical research and innovation; it should be achieved in a timely manner.
- Regulation is needed to achieve data interoperability, and the legislation’s approach of enforcing data portability standards by fining vendors of health information technology that are noncompliant may be an effective strategy.
- Preventing data blocking by institutions and clinicians, establishing appropriate data governance, minimizing the influence of the commercial determinants of health, and preventing financialization of health data are important issues to be addressed.

We focus on the implications of this bill for clinical care, specifically, the interoperability of EMRs. Our focus on EMRs is owing

Box 1: Summary of the proposed *Connected Care for Canadians Act* (Bill C-72)[1]

- One of the goals of the bill is to ensure that Canadians and their health providers can securely access their complete health information.
- To achieve this goal, the bill prohibits data blocking by vendors of health information technology (IT) and requires all health IT to be interoperable.
  - Health IT is defined as all “hardware, software, integrated technologies, intellectual property and upgrades that are designed for creating, maintaining, accessing, using or exchanging electronic health information or that support such activities.”[1] The bill applies to all technology used to manage health data; in this article we focus on electronic medical records and their implications for clinical care.
  - Data blocking is “a practice or act that prevents, discourages or interferes with access to or the use or exchange of electronic health information.”[1]
  - Health IT is interoperable if it “allows the user to easily, completely and securely access and use all electronic health information and exchange all electronic health information with other health information technologies.”[1]
- To achieve interoperability, the proposed legislation authorizes the creation of regulations specifying what standards health IT vendors must meet, the process of verifying compliance, and the financial penalties if violations are found.

to their importance in clinical care. We recognize that interoperability of health data will also benefit public health, research, quality improvement, and health care administration.

Why is interoperability of EMRs needed?

Electronic medical records are digital systems used by health providers to document care, and in Canada they are not currently interoperable. Although 9 in 10 health care providers in Canada believe that securely sharing electronic health information would improve patient safety and quality of care, only 4 in 10 are able to do so.[4] Similarly, only 4 in 10 patients have accessed their health information electronically, whereas 8 in 10 patients would like to.[4] Although patients can request printed copies of their health data, this process is slow, is a burden on patients and providers, and does not integrate into other digital health systems. Having EMRs that cannot communicate decreases quality of care and increases health care costs.[5] Canada Health Infoway estimates that improved interoperability would save as much as $2.4 billion annually.[6]

There are also legal and ethical reasons to implement interoperable health IT systems. The principle of patient autonomy means that patients ought to be able to view and correct their own health data. These rights exist in legislation and case law,[7,8] but the practical difficulty in accessing and amending medical records limits patients' ability to exercise them.

In a 2021 essay, Blease and colleagues[9] argued that preventing patients' access to their health information is not only a restriction of autonomy but amounts to epistemic injustice, which can take 2 forms.[9] Testimonial injustice occurs when a person is prevented from "giving information/knowledge to others," whereas hermeneutical injustice is when a person is prevented from "making sense of one's experiences."[9] If patients cannot access their own health information, they are effectively blocked from contributing to their record (testimonial injustice) and making sense of their providers' impression of their health (hermeneutic injustice).

Health research would also benefit from improved interoperability because accessing data for secondary uses would be simpler and more secure. Artificial intelligence research may particularly benefit because a lack of reliable data is a bottleneck in developing these technologies.[10]

What are the positive features of the *Connected Care for Canadians Act?*

Data portability standards as an effective approach to decentralized interoperability

The news release[2] accompanying Bill C-72 suggested that the government hopes that the regulations authorized under the bill will roughly follow the approach outlined in the Pan-Canadian Interoperability Roadmap.[3] Therefore, a single EMR across Canada, as some have called for,[11] will not be instituted. A single EMR is suboptimal because many EMR platforms are now in use across Canada (in Ontario alone, at least 10 different EMR vendor systems are being used in 2024[12]), and the effort and costs associated with migrating all providers to a single EMR vendor would be prohibitive. Further, if interoperability unlocks a competitive EMR market, this could have a positive impact on innovation. Finally, a single EMR would not create an interoperable health system because important health information resides on platforms other than EMRs, ranging from wearables to public health databases.

The most promising path to interoperability of health data is the use of portability standards, as recommended in the Pan-Canadian Interoperability Roadmap.[11] To understand how data standards allow for communication in a decentralized system, consider the World Wide Web,[13] which is defined by a suite of protocols or instructions for how Web browsers and servers can access, display, and send information. Each browser is a different piece of software, but they all can share information by conforming to the protocols. The Web's protocols include functionality for demonstrating who a user is (authentication) and whether they have access to the requested resource (authorization). Online banking demonstrates that these protocols can achieve a high level of security and trust. For health data, protocols for sharing information securely must be established and universally enforced.

Canada is not alone in struggling with interoperability. The international nonprofit Health Level 7 (HL7) has been coordinating an effort to define a foundational standard for health data exchange called the Fast Healthcare Interoperability Resources (FHIR).[14] Owing to its international scope, this standard needs to be adapted to a Canadian context, and Canada Health Infoway and the Canadian Institute for Health Information (CIHI) are collaborating to do so. The Canadian Institute for Health Information was scheduled to complete the Pan-Canadian Health Data Content Framework in the fall of 2024, which will define the minimum data fields necessary for interoperable care.[15] Canada Health Infoway is developing the CA Core+ standard, which translates the Pan-Canadian Health Data Content Framework requirements to the FHIR format.[16] That the regulations associated with Bill C-72 may require conformance to such a standard is encouraging.

Financial penalties for health IT vendors as a promising enforcement mechanism

Providers have little ability to switch EMRs even if the software fails to meet regulatory requirements. The bill targets noncompliant IT vendors by authorizing the creation of "a system of administrative monetary penalties applicable to every health information technology vendor."[1] This strategy has the potential to change vendor behaviour if the fines are large enough.

What are the challenges to achieving interoperability?

Health care institutions and data blocking

The proposed bill targets only health IT vendors, but health care institutions such as hospitals and individual health providers sometimes also participate in data blocking. Some organizations justify this with expressions of concern that allowing patients to access their records will sometimes create confusion and increase the length of visits.[9] However, in an American study of a multisite implementation of providing patients digital access to their notes, the proportion of primary care clinicians who felt the change would make visits considerably longer decreased from about 50% before the implementation to less than 5% after.[17] Regardless of whether the health information might worry patients, it should be a patient's choice whether to risk additional anxiety. Providing patients with access to health data should be done carefully, and patient education and digital health interfaces will be necessary, but these institutional concerns do not justify data blocking.

The *21st Century Cures Act*, an American federal law intended to accelerate medical innovation, included provisions penalizing health providers and IT vendors for participating in data blocking.[18] Similar regulations should be put in place in Canada, and institutional capacity within the health system must be built to coordinate information sharing. In an environment where clinicians are already struggling to keep up with administrative workloads, these policies will need to minimize further strain on the health system. Although work will be required from clinicians in the short term to adapt to an interoperable system, in the long term these changes should reduce administrative burdens.

Developing patient and community-based data governance

The legislation states that data access and sharing must be secure. The FHIR specification provides tools to control access but does not indicate which users can grant access to others. The current model of health care organizations or clinicians acting as custodians of health data needs to be updated to centre patients in a new data governance model. Patients should control access to their health information, although this should include the ability to delegate this authority to other trusted parties beyond their clinicians. In the context of population health, patients from marginalized communities could delegate civil society data governance organizations to manage data access.[19] The health information stewardship council proposed by CIHI's Pan-Canadian Health Data Strategy could be a promising model.[20] These new governance structures would also help defend against the increasing financialization of health care data and must be introduced urgently if this bill is passed.[21]

The potential for commercial determinants of health to derail the regulatory process

Finally, the influence of the commercial determinants of health, which the World Health Organization defines as the "conditions, actions and omissions by commercial actors that affect health," must be considered.[22] For example, dominant EMR vendors have an economic incentive to make exchange of health information difficult to prevent providers from switching to another EMR platform. Vendors of EMRs are an important partner and must be consulted in the development of policies and regulations related to interoperability. However, market forces alone have not resulted in interoperable health IT systems, and it is critical that the government and civil society ensure that commercial interests are not prioritized over the health of Canadians.

Conclusion

The *Connected Care for Canadians Act* must be implemented urgently. The federal government committed to improving health data exchange with the creation of Canada Health Infoway in 2001.[23] It invested an initial $500 million to create common pan-Canadian standards, but in 2024, those standards still do not exist. The data standards in the Pan-Canadian Interoperability Roadmap are due to be completed in 2027.[3] It will likely take several more years for vendors to implement these standards. This timeline is too slow. More resources should be dedicated to Canada Health Infoway and CIHI to finish the standards and have them implemented more rapidly. Many countries have already gone through this process, and Canada should learn from their efforts, including using their data standards and open-source software where appropriate. Provincial, territorial, and federal governments should cooperate to allow speedy implementation of this legislation as Canada can ill afford to wait another decade before interoperability is achieved. The new act is an important step toward fixing Canada's dysfunctional health information ecosystem. However, much work and investment will be required for it to make a difference.

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Competing interests: At the start of manuscript drafting, David El Sabawy was a family medicine resident with the University of Saskatchewan, and this project was part of an elective learning opportunity with Andrew Pinto. Andrew Pinto has received grants from the Canadian Institutes of Health Research (CIHR) and Canada Biomedical Research Fund related to data science and artificial intelligence applications in health care and public health. Dr. Pinto serves on the Institute Advisory Board for the CIHR Institute for Population and Public Health. Dr. Pinto is currently the director of the University of Toronto Practice- and Community-Based Learning and Research Network (UPLEARN), is the lead for clinical research in the Primary Care Ontario Practice-based Learning and Research Network (POPLAR), and helps lead the Canadian Primary Care Trials Network. Dr. Pinto has previously served as an unpaid advisor to Mutuo Health Solutions.

No other competing interests were declared.

This article has been peer reviewed.

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Contributors: Andrew Pinto conceived of the work. David El Sabawy contributed to the first draft. All authors contributed to revising the manuscript for important intellectual content, gave final approval of the version to be published, and agreed to be accountable for all aspects of the work.

Funding: Andrew Pinto is supported as a clinician scientist by the Department of Family and Community Medicine, Faculty of Medicine at the University of Toronto and at St. Michael's Hospital. Andrew Pinto is additionally supported by the Li Ka Shing Knowledge Institute, St. Michael's Hospital, and a Canadian Institutes of Health Research Applied Public Health Chair in Upstream Prevention. The opinions, results, and conclusions reported in this article are those of the authors and are independent from any funding sources.

Acknowledgements: The authors thank Sheryl Spithoff for comments on previous versions of this manuscript and Roxana Rabet for assistance with editing.

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