

Written Submission for the  
Study of Bill S-5, *the Connected Care for Canadians  
Act*



Canadian  
Chamber of  
Commerce    Chambre de  
Commerce  
du Canada

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Standing Committee on Social Affairs, Science and Technology  
Senate of Canada  
Ottawa ON K1A 0A4

Via email: [soci@sen.parl.gc.ca](mailto:soci@sen.parl.gc.ca)

**Re: Written Submission in Response to Bill S-5, *the Connected Care for Canadians Act*.**

The Canadian Chamber of Commerce welcomes the opportunity to provide written feedback to the Senate Standing Committee on Social Affairs, Science and Technology as part of their study of Bill S-5, *the Connected Care for Canadians Act*.

For the past three years, the Canadian Chamber has convened an annual health data summit, bringing together federal and provincial government leaders with industry experts and patient group advocates to discuss the importance of pan-Canadian health data interoperability and accelerating its implementation. Our engagement on this issue reflects the tremendous national opportunity of fully leveraging our health data, which is needed not only to improve medical care and patient outcomes, but to strengthen our economic resilience and sovereignty.

Across each summit, one message consistently stood out: **health data saves lives**. Indeed, there are real costs to keeping health information locked away in physical records or electronic medical records systems that are not interoperable. Most importantly, a patient's treatment can be impaired if medical practitioners across treatment settings are unable to quickly access their medical records. Critical time can be lost trying to piece together the patient's story, or diagnoses can be mistaken or missed altogether, resulting in worse health outcomes that could have been avoided.

Beyond the clear benefits to patients, health data interoperability is also a significant economic opportunity. The Canadian Institute for Health Information (CIHI) estimates that fully leveraging Canadians' health data could generate close to \$10 billion per year in financial value. Insights derived from health data can drive improvements in the delivery of care and how we allocate resources in our health systems. It can also be used to evaluate the real-world efficacy of new treatments and will support Canada's standing as a leading jurisdiction for clinical research and investment. We can see how international examples, such as the EU's Health Data Space, which connects health data from across its 27 member states, are boosting confidence and focus in the life sciences ecosystem.

A strong health data foundation is also critical to fully leverage advances in artificial intelligence (AI) models, which will increasingly drive the future of medical innovation, from drug discovery to treatment and diagnostics. AI will also be used to leverage health data to find system-wide efficiencies in our medical systems, which can help improve access to medical care. However, AI models require quality, standardised data to deliver meaningful insights. Shared national standards will therefore be necessary to fully benefit from applications of AI to health care.



Given the significant opportunities arising from better management of our health data, we were pleased to see health data recognized by the Prime Minister as a key priority in *Canada Strong*. We also commend the government for reintroducing the *Connected Care for Canadians Act* in Bill S-5. These developments build on and support the vision laid out in the Pan-Canadian Health Data Strategy and the Interoperability Roadmap.

However, we must also recognize that tangible progress has so far not kept pace. While most other developed nations already offer easy access to medical information to patients and practitioners, as well as access to anonymized data to researchers, Canada continues to lag. Furthermore, provinces and territories have been proceeding with their own interoperability frameworks that, while well-intentioned, are creating a patchwork of unique standards and distancing us from the goal of national interoperability.

The federal government must therefore lead the implementation of shared national interoperability standards. While the federal government should work collaboratively with provinces and territories, it must also be recognized that the status quo is no longer acceptable to Canadians, who expect that they will have a similar level of access to health information as patients in peer countries. Canadians also expect the government to take all reasonable measures to improve access to health care and, as we face unprecedented challenges, strengthen our economic resilience.

We again commend the government for tabling Bill S-5, *the Connected Care for Canadians Act*, which is a critical step towards national health data interoperability. We believe that this bill should be passed without delay to prevent further fragmentation of the Canadian health data landscape. We also submit the recommendations included below to ensure that the legislation achieves its objectives and drives meaningful progress. We would welcome the opportunity to discuss our submission with the Committee.

Sincerely,  
Liam MacDonald

## Contact

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## **Annex – Recommendations**

### **1. Develop transparent and objective criteria for when provincial or territorial requirements are deemed “substantially similar,” aligning with national and internationally recognised technical standards**

Bill S-5 currently states that provisions of the Act or regulations may be applied to provinces and territories when the province or territory does not have requirements that are “substantially similar.” There should be transparent and objective criteria for when provincial or territorial requirements meet the threshold of “substantially similar.” Prohibitions of data blocking while allowing for continued siloed interoperability standards would be insufficient. Criteria should therefore also include technical standards, implementation timelines and reporting expectations to ensure we are moving towards true national interoperability. Standards should be aligned on national and internationally recognised standards such as HL7 FHIR, SNOMED CT, and LOINC.

### **2. Accelerate the implementation of national interoperability by applying requirements to provinces and territories by Order in Council when necessary**

While the federal government should seek to work collaboratively with provinces and territories, national health data interoperability cannot be delayed any longer. Where provinces and territories do not have requirements that support national interoperability, the federal government must not hesitate to apply requirements by Order in Council, as provided for in Bill S-5.

Enforcement mechanisms should also be paired with transition supports, including sandbox environments for device-system interoperability testing and national maturity assessments that can guide phased implementation. A two-to-three-year implementation timeline would be ambitious, while allowing vendors sufficient time to transform appropriately and effectively.

### **3. Amend the definition of “health information technology vendor” and define “health information custodian” to ensure that obligations are not created for activities intended to be outside the scope of the Bill’s application.**

Bill S-5, as currently drafted, could create obligations for activities outside the legislation’s intended scope. It is necessary to distinguish between health information technology vendors and health information custodians because the latter often do not have control over primary health information systems and therefore should not inherit obligations designed for vendors. We propose amending the definition of “health information technology vendor” and adding a definition for “health information custodian” as follows:

***Health information technology vendor*** means an individual, corporation, joint venture, partnership or unincorporated organization or association that licenses or sells information technology to **health information custodians** or supplies it as a service **to a health information custodian for use in the assessment, care, treatment, management or diagnosis of patients.**

***Health information custodian*** means an individual, corporation, joint venture, partnership or unincorporated organization or association that has custody or control of personal



health information as a result of or in connection with performing their duties in providing health care services pursuant to relevant legislation, regulation or professional guidelines.

**4. Ensure there are appropriate guardrails around the access of deidentified and anonymized health data for secondary uses to protect intellectual property.**

Bill S-5 currently applies to both identified and deidentified data. The EU Health Data Space regulations require parties seeking access to data to receive authorisation from a Health Data Access Body, which can deny or limit access if there are concerns that such access may jeopardise IP rights, which are essential to encouraging data-driven health innovation. Similar protections should be included in Canadian regulations.

**5. Clarify that medical device manufacturers whose products support clinical care or workflow, but do not function as systems of record, are not subject to obligations intended for health information custodians or record-management platforms.**

The Bill treats medical device manufacturers as though they are health information custodians or are responsible for the recordkeeping systems of healthcare institutions, despite their role as adjunct clinical technologies rather than repositories of patient records.

**6. Explicitly affirm that healthcare institutions retain primary responsibility for patient information stewardship, and that vendors acting at their direction are not deemed data owners or custodians of personal health information.**

The Bill does not clearly recognize that healthcare institutions are the legal and appropriate custodians of patient health information and owners of the health information records that are created. The healthcare institutions are responsible for governance, access, and disclosure decisions with respect to patient health information. The Bill implies that medical device manufacturers have obligations with respect to the processing of patient health information that go beyond the scope of current provincial privacy laws.

**7. Clarify that obligations related to patient access of their personal information apply only to entities that directly provide patients with health care services or access to their health records.**

While the Bill focuses on improving patient access to health information, medical device manufacturers do not provide patient-facing access to records and are not points of access for patients seeking their own personal information. Healthcare institutions as custodians have responsibility for access under provincial privacy laws.

**8. Allow appropriate cost recovery for data provided by health information technology vendors**

Interoperability regulations should not prevent vendors from charging reasonable fees that consider the cost of delivering data. Allowing for cost recovery relating to the provision of data will protect the economic viability of platforms that host and secure electronic health information.



## About the Canadian Chamber of Commerce

We are Canada's largest and most activated business network — representing 400 chambers of commerce and boards of trade and more than 200,000 businesses of all sizes, from all sectors of the economy and from every part of the country — to create the conditions for our collective success. We use deep local connections to create a powerful national vantage point no other network can equal. And, from working with government on economy-friendly policy to providing services that inform commerce and enable trade, we give each of our members more of what they need to succeed: insight into markets, competitors and trends, influence over the decisions and policies that drive business success and impact on business and economic performance.