

INTEROPERABILITY SAVES LIVES

HEALTH DATA INTEROPERABILITY WORKING GROUP



PLAIN LANGUAGE SUMMARY

To create the conditions for safe care, healthcare teams require accurate health information upon which to establish a care plan. If that health information is inaccurate or unavailable, the likelihood of making errors in care resulting in harm to patients increases. Health teams cannot function safely if they lack access to information or cannot effectively communicate or share information needed for care. As such, it is essential for a patient's care team to be able to access an individual's complete health information at all times. A patient's care team includes the patients themselves, their loved ones, caregivers, and the health care providers caring for them. To achieve this, the various electronic medical record (EMR) systems used in different clinics and hospitals must be able to share health information so that it follows a patient over time and location. The ability of different digital charting systems to seamlessly share patient information is called *interoperability*. Unfortunately, in Alberta and Canada, information often cannot be easily shared putting the safety of patients at risk. The purpose of this report is to examine whether the comprehensive sharing of health information, or interoperability, will improve the safety of patient care and improve health system function.

The *Canada Health Act* is federal legislation that dictates how publicly funded health services in Canada's thirteen provinces and territories - commonly called "medicare" - must function. The Act states that the primary function of Canadian health service is to "*to protect, promote and restore the physical and mental well-being of residents of Canada and to facilitate reasonable access to health services without financial or other barriers*".¹ The promotion and restoration of physical and mental health and wellbeing is achieved by delivering *quality health care*. A literature review on the impact of the comprehensive sharing of health information, or interoperability, on the quality of health care delivered to patients reveals that it can:

- Improve the safety, efficiency, and effectiveness of health services.
- Result in long-term health system cost savings.
- Improve the equity of health services.
- Improve access to timely health services.

Conversely, evidence suggests that a lack of health data interoperability can result in unsafe practices, resulting in harm to *patients, populations, and the health care system*. The forms of harm include:

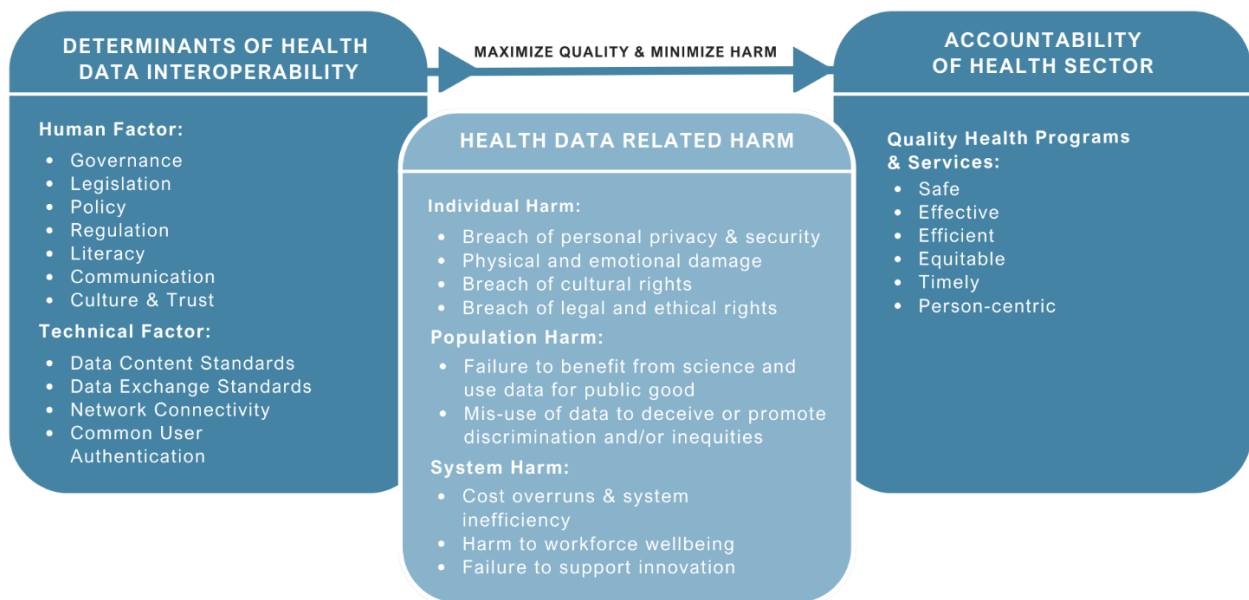
- Damage to people's health.

¹ Government of Canada, Canada Health Act, 1985, (<https://laws-lois.justice.gc.ca/eng/acts/c-6/page-1.html>)

- Breach of legal and ethical rights to personal health information.
- Failure to benefit from science and use health information for public good.
- Failure to optimize health system function and efficiency.
- Health care provider burnout.
- Failure to support health innovation.

These findings suggest that the quality of health service in Alberta is likely to improve, and if patient health information can be properly shared with those who require it, harm to patients and the health system is likely to decrease. Stated more simply, health data interoperability will improve the safety of health care. The conceptual framework adopted by the Interoperability Working Group was to optimize human and technical health data interoperability to minimize data-related harm and maximize the quality of health programs and services.

FIGURE 2: RELATIONSHIP BETWEEN DETERMINANTS OF HEALTH DATA INTEROPERABILITY, DATA-RELATED HARM, AND ACCOUNTABILITY TO QUALITY HEALTH PROGRAMS AND SERVICES.



Further, evidence suggests that comprehensive health data interoperability will be of independent benefit to many organizations and services including government, health authorities, health information technology innovators, health care providers, and most importantly, the public.

Despite this, the capacity to efficiently share health information between digital charting systems is not the norm in Alberta, nor Canada. Although there have been some advances in Alberta in recent years, the interoperability of health information between primary care services (like a family practice office) and other members of a patient’s health care team, is largely absent. A 2020 consultants’ report commissioned by the government of Alberta noted, the province “does not have an integrated

EMR strategy to promote interoperability across the primary care sector” and cited the need for “changes to legislation and policy” to support data integration.²

In Alberta, there is currently no known legislative plan to address this lack of health information integration, and there are currently no enforceable health data interoperability standards or regulations. This stands in contrast to the province of Ontario, which has enacted legislation to define standards and requirements for interoperability³, and nations such as Denmark that initiated a comprehensive approach to health information interoperability 29 years ago and today enjoys a high level of health data integration⁴, and the United States which introduced a program to enforce health information interoperability 19 years ago.⁵

To appreciate why Alberta and Canada lag many nations in the effort to achieve health information interoperability, it is helpful to understand what is required to achieve the capacity to effectively and safely exchange health information between health services and digital charting systems. There are two categories of factors that impact health information interoperability; factors related to technology, and factors arising from how members of the health workforce relate and behave (human factors) around the use and sharing of health information. Technical factors involve the setting of standards so that two different digital charting systems can move health information (like blood pressure measurements, or medication lists) from one chart to another in a form that is consistent and recognizable at both ends. Human factors include the legislation, policy, and culture that society has adopted to define acceptable practices for the use and sharing of health information. Taken together, the state of these technical and human factors determine the level of function of health information interoperability.

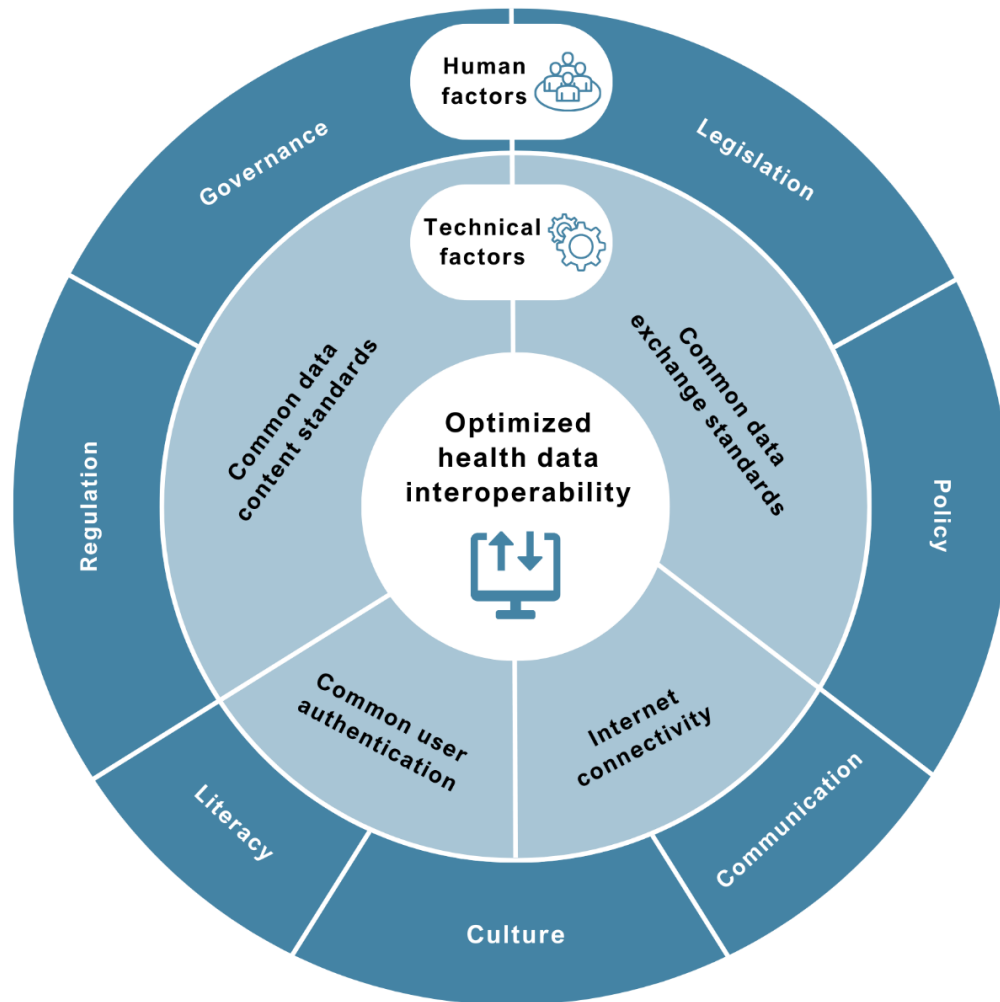
² Ernst & Young , Review of Connect Care, Alberta Netcare and MyHealth Records , 2020, (<https://open.alberta.ca/dataset/1394ebca-9869-40d6-b5af-3c6870557f21/resource/d9558cbb-220e-4b28-a05e-3d9773d4d9ac/download/health-review-of-connect-care-alberta-netcare-myhealth-records-2020-03.pdf>)

³ Ontario Health, Digital Health Information Exchange Standard, 2022, (<https://www.ontariohealth.ca/system-planning/digital-standards/digital-health-information-exchange>)

⁴ Mu-Hsing Kuo, et al., A Comparison of National Health Data Interoperability Approaches in Taiwan, Denmark, and Canada, 2021, (https://dspace.library.uvic.ca/bitstream/handle/1828/6387/Kuo_Mu-Hsing_EH_2011.pdf?sequence=1&isAllowed=y)

⁵ U.S. Government Publishing Office, Executive Order 13335—Incentives for the Use of Health Information Technology and Establishing the Position of the National Health Information Technology Coordinator, 2004, (<https://www.govinfo.gov/content/pkg/WCPD-2004-05-03/pdf/WCPD-2004-05-03-Pg702.pdf>)

FIGURE 1: DETERMINANTS OF HEALTH DATA INTEROPERABILITY



An analysis of the Alberta health care system demonstrates significant deficits in both human and technical factor interoperability. Most notable are:

- There is no clear authority accountable for health information interoperability.
- Current health information legislation impairs health information interoperability.
- There is no legislation that mandates technical interoperability standards.
- There is an absence of health data technology regulation around interoperability.
- There is a poor understanding about the importance of interoperability on the part of the health workforce, leadership, and the public.
- There is incomplete internet connectivity, which impairs health information sharing.
- There is a lack of adherence to the *Canada Health Act* principles of portability and universality as they apply to the sharing of patient information.

Taken together these factors significantly hamper Alberta's ability to achieve health information interoperability and promote unsafe care.

DISCUSSION

The discussion section of this report takes into consideration the business case, current state, and perceived barriers of health data interoperability, and the proposed principles for health data interoperability design in Alberta. The discussion is framed around a series of ten foundational questions.

01 | Is an investment in the establishment of health data interoperability in Alberta justified?

In this report we established, based on evidence in the literature, that health data interoperability can:

- Improve the safety, efficiency, and effectiveness of health programs and services.
- Result in long-term health sector cost savings.
- Contribute meaningfully to the provision of equitable health programs and services.
- Promote more timely health programs and services.
- Be best achieved through person-centric health data design.

Further, we have demonstrated that health data fragmentation (i.e., an absence of health data interoperability) can promote forms of data-related harm for individuals, populations, and the health care system.

Taken together this suggests that the quality of health programs and services in Alberta will improve, and system costs will decrease with the establishment of comprehensive health data interoperability. This benefit is evident not only on a system-level, but also appears to positively impact individual stakeholders in the Alberta health sector. Table 6 contrasts the potential benefit of comprehensive health data interoperability against the potential harm of maintaining the status quo (fragmented health data) for different health sector stakeholders. It is suggested that only large health sector software vendors may perceive interoperability as a threat.

TABLE 6: POTENTIAL COST / BENEFIT OF COMPREHENSIVE HEALTH DATA INTEROPERABILITY BY HEALTH SECTOR STAKEHOLDER

YES ■ NO ■

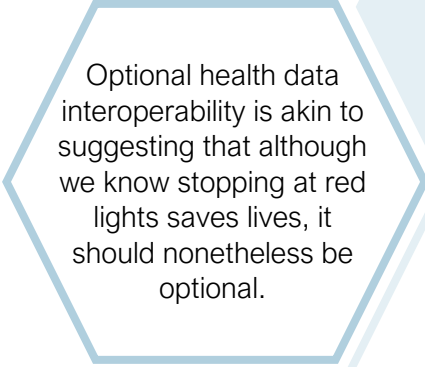
Health Sector Stakeholder	Impact of Comprehensive Health Data Interoperability	Impact of a lack of Comprehensive Health Data Interoperability
Patients/the Public	Improved safety of care	Damage to physical or emotional health and wellbeing through data fragmentation, non-use, or lack of integrity
	Better use of tax dollars through improved health sector efficiency	
	Support for improved equity of care	
	Improved access to personal health records	
Government	Decreased health sector cost	Difficulty optimizing health system function and efficiency due to poor data design, misuse, non-use, or lack of data integrity
	Improved capacity to make data (evidence) informed health sector decisions (learning health system)	Difficulty making data (evidence) informed decisions and using health data for public good
Health Authorities	Decreased health service cost	Difficulty optimizing health system function and efficiency due to poor data design, misuse, non-use, or lack of data integrity
	Improved capacity to make data (evidence) informed management decisions (learning health system)	Difficulty making data (evidence) informed decisions and using health data for public good
Health care providers/ Regulated health professions	Improved capacity to deliver safe, quality care	Ongoing challenges providing quality care because of poor data design, access, or lack of data integrity
	Improved capacity to make evidence-based (data) decisions	Increased health workforce burnout arising from poor data design or lack of data integrity
	Decreased health workforce burnout	Increased workforce attrition
Researchers	Improved capacity to generate insights from health data and drive benefit from science (learning health system).	Difficulty benefiting from science and using health data for public good
Professional Regulators	Improved capacity to measure and assure health provider competence	Increased health workforce burnout arising from poor data design or lack of data integrity
	Promotion of health workforce wellbeing	Challenges delivering upon assurance of quality health programs and services
Population and Public health	Improved capacity to make data (evidence) informed health sector decisions (learning health system)	Failure to benefit from science and use health data for public good
Small Scale Health Data Innovators	Improved capacity for health innovation through data access and integrity	Difficulty supporting health innovation secondary to data fragmentation or lack of data integrity
Large Health Data Software Vendors	Break potential vendor-centric health data monopolies and enhance interoperability and innovation which may be perceived as threat to large vendors.	Perpetuate vendor-centric health data monopolies and data fragmentation, which may be perceived as benefit to large vendors

To summarize, investment in comprehensive health data interoperability is justified both on a system basis, and independently for individual stakeholders across the health sector, including government, health authorities, health information technology innovators, health care providers, and importantly, the public.

02 | Should health data interoperability be optional?

Health data interoperability in Alberta, and Canada as a whole, is currently optional; there is no regulatory mandate that enforces compliance to technical or human factor interoperability standards. On a jurisdictional level, health data custodians, and health information technology vendors can choose whether to adopt or promote standards of health data interoperability. On a national basis, although Infoway's [Shared pan-Canadian Health Data Interoperability Roadmap](#) has been endorsed by the Conference of the Deputy Ministers of Health (excepting Quebec), this endorsement is voluntary and in no way compels jurisdictions to participate in project activities. This approach runs counter to the province of Ontario, and countries like the United States and Denmark where health data interoperability is legislatively mandated and enforced.

Given the evidence that fragmentation of health data is harming individuals, populations, and the health care system, then is it acceptable that interoperability remain voluntary? We suggest it is *not acceptable*, and a voluntary approach contravenes regulatory, professional, and governmental obligations to ensure quality health programs and services. In short, health data interoperability should be mandated and enforced through regulation.



Optional health data interoperability is akin to suggesting that although we know stopping at red lights saves lives, it should nonetheless be optional.

03 | Who oversees health data design in Alberta?

In Alberta, health data custodians have legal authority to securely manage the health data they gather in the course of service provision, as dictated by the *Health Information Act*. As such, there is no single provincial authority overseeing health data design, but this authority is legislatively conferred upon a wide group of individual custodians. This means that government currently has no capacity to enforce health data interoperability short of enacting legislative change or issuing a Ministerial Order. This is further complicated by the fact that health information technology vendors that hold health data are not considered custodians but fall under the regulation of the *Personal Information Protection Act* (PIPA). Given that Alberta lacks provincial legislation mandating compliance with health data interoperability standards, individual custodians and health information technology vendors are free to manage the health data under their control without any regard to interoperability. Consequently, in the current custodial or *service-centric* health data oversight model, there is no single agency in Alberta with authority over health data design, meaning that any approach to health

data interoperability in Alberta is *legislatively fragmented* and distributed across multiple health services and health technology vendors who have no obligation to promote interoperability.

04 | Who is accountable for assuring that health data interoperability is achieved?

Many assume that the government of Alberta is uniquely accountable for assuring the creation of provincial health data interoperability. However, the government of Alberta is hampered by the current legislative framework that confers accountability over health data to custodians. All provinces and territories in Canada have a similar obstacle. Short of legislative change, accountability for achieving health data interoperability is currently distributed among all Alberta health data custodians, including the government. Further, non-custodial health sector stakeholders and agencies including health regulators, administrators, researchers, professions, and educators who are mandated to uphold quality health programs and services, share a professional accountability to promote health data interoperability. Lastly health information technology vendors arguably share a moral or ethical accountability to promote health data interoperability. As such, in the current Alberta legislative framework, there is a complex and fragmented intersectoral accountability to comprehensive health data interoperability.

05 | Who should be involved in establishing health data interoperability?

Understanding the complex health data oversight and accountability model in Alberta, without legislative change or a Ministerial Order, that efforts to work toward health data interoperability in Alberta will require broad intersectoral cooperation. Given the pressing imperative to deliver upon health data interoperability as a determinant of quality health programs and services, the work to establish interoperability must begin immediately, and cannot await legislative change. As such, broad intersectoral cooperation around a set of evidence-based standards is likely the best approach to moving the interoperability agenda forward.

The meaningful inclusion of beneficiaries of care at all levels of this effort must be obligated, namely the public and Indigenous representation, to which the health sector is ultimately accountable. This effort should harness the substantive health data interoperability human and knowledge resources Canada has to offer, including pan-Canadian Health Organizations, universities, professional associations, regulators, and researchers. Lastly to achieve truly person-centric health data interoperability, and leverage economies of scale, pan-Canadian partnerships are encouraged, as directed by the *Canada Health Act* and the principles of portability and universality.

06 | Are there technical barriers to achieving health data interoperability in Alberta?

Although there are substantive technical issues to resolve to achieve health data interoperability, the technical obstacles appear to be principally a matter of lack of execution rather than an absence of solutions. Many other industries, such as the banking sector in Canada, have demonstrated that technical interoperability is entirely achievable. Similarly, other countries have demonstrated success in achieving technical health data interoperability. The principal challenge Alberta and Canada face are in the domain of human factor interoperability, including a lack of clear data governance, antiquated or absent public policy and regulation, and a culture of jurisdiction and custodian-centered health data. The challenges with technical factor interoperability seem largely to arise from fragmented human factor interoperability.

07 | Why is there not a clear roadmap for achieving comprehensive health data interoperability in Alberta?

Alberta is not alone in Canada in lacking a comprehensive roadmap or stated strategic approach for achieving comprehensive health data interoperability. Given that there is compelling evidence that health data interoperability will improve the safety and quality of health services for Albertans, afford individual benefit to health sector stakeholders, and decrease data-related harm, it is difficult to justify why this is not a strategic imperative. The reason for this failure most likely rests with a lack of clarity about health data accountability and oversight, a lack of understanding about the foundational importance of interoperability in health leadership, and a culture of service-centricity and intersectoral distrust.

08 | What is the accountability of the Alberta health sector to health data interoperability?

The *Canada Health Act* states that the primary objective of Canadian health care policy is "*to protect, promote and restore the physical and mental well-being of residents of Canada and to facilitate reasonable access to health services without financial or other barriers*".⁶ Further the Act states that this accountability requires the mitigation of "financial or other barriers", to provide "continued access to quality care". It follows that the accountability of the Albertan health sector is to mitigate barriers to quality care and promote and restore the physical and mental well-being of residents of the province. As health data fragmentation, or a lack of health data interoperability, has been identified as a barrier to quality care, the Alberta health sector, including health professionals, health educators, regulators, and government have a collective, legal, and professional accountability to deliver upon comprehensive health data interoperability.

⁶ Government of Canada, Canada Health Act, 1985, (<https://laws-lois.justice.gc.ca/eng/acts/c-6/page-1.html>)

09 | Does a lack of health data interoperability benefit anyone?

A lack of health data interoperability does not appear to benefit any health sector stakeholder including the public, Indigenous groups, health professionals, regulators, health innovators and the government. This is a powerful observation as it can serve to unite all stakeholders in a common and mutually beneficial effort to achieve interoperability.

This includes many health technology vendors who recognize that industry cooperation around interoperability can open opportunities to innovate and develop cutting-edge products that leverage data, analytics, and AI. One possible exception are large health information technology vendors that could choose to protect or promote corporate data monopolies afforded by health data fragmentation and resist efforts to advance systemic health data interoperability.

10 | Is there any justification for not investing in health data interoperability in Alberta?

If one considers the benefit society, the rising cost of health service, the collective obligation to promote quality health programs and services by government and health sector providers, financial and health accountability to the public and Indigenous peoples, the integrity of the health workforce, and the mitigation of data related harm, there is no justification for not investing in comprehensive health data interoperability in Alberta, or Canada as a whole.

CORE RECOMMENDATIONS

- 01** Health data interoperability in Alberta should be mandated through legislation.
- 02** The oversight of health data interoperability design and management in Alberta must include meaningful public and Indigenous representation.
- 03** Health data interoperability oversight should be public-facing, accountable, and fully transparent.
- 04** The design and management of health data interoperability should not be hampered by the agenda of any given organization or interest group, nor subject to the limitations imposed by electoral or capital funding cycles.
- 05** Alberta should endorse and adopt the Health Data Charter as a guiding framework for all provincial health data design and management, including health data interoperability.
- 06** The adoption of health data interoperability in Alberta should align with national efforts.
- 07** All Albertans should have comprehensive internet connectivity to ensure equitable virtual health care access.

For the complete report, please see: www.albertavirtualcare.org