INTEROPERABILITY SAVES LIVES

HEALTH DATA INTEROPERABILITY WORKING GROUP

Alberta
Virtual
Care

REPORT SUMMARY

All health services require the exchange of health data, or information (meaning contextualized data) to function. The "*ability of different information systems, devices and applications to access, exchange, integrate and cooperatively use data in a coordinated manner to optimize the health of individuals and populations"* is called health data interoperability.[1] The capacity to provide virtual care, and most health services, is often dependent on health data interoperability. The purpose of this report is to appraise the potential value that comprehensive health data interoperability offers to the optimization of quality health programs and services, including virtual care.

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".[2]* Further, the Act states that this accountability requires the mitigation of "*financial or other barriers*", to provide "*continued access to quality care*". The examination of the impact of health data interoperability on quality care can help establish if a lack of interoperability is a barrier, as defined in the *Canada Health Act*, to achieving quality health programs and services such as virtual care.

The National Academy of Medicine (formerly the Institute of Medicine) defines quality of care according to six distinct domains; care that is safe, effective, efficient, equitable, timely, and person-centred. A literature survey of the impact of health data interoperability on these six domains of quality conducted by the Working Group found that 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 access to health programs and services.
- Be best achieved through person-centric health data design.

Conversely, a lack of health data interoperability can result in unsafe practices, resulting in harm to individuals, populations, and health care systems. The forms of harm we identified include:

- Damage to physical or emotional health and wellbeing.

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[1] Healthcare Information Management Systems Society, Interoperability in Healthcare, 2023, (https://www.himss.org/resources/interoperability-healthcare)
[2] 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 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 wellbeing.
- Failure to support health innovation.

Thus, the quality of health programs and services in Alberta are likely to improve and data-related harm including system cost to decrease with the establishment of comprehensive health data interoperability. By evaluating these factors across the health sector, the Working Group concluded that with comprehensive health data interoperability, there will be broad benefit for individual health sector stakeholders including government, health authorities, health information technology innovators, health care providers, and importantly the public. Stated simply: health data interoperability will improve the safety of health care.

Despite this, comprehensive health data interoperability has been frustratingly elusive in Alberta and Canada as a whole. Advances in Alberta, reside mostly on the technical front, including enhancements to Alberta Netcare, the establishment of the Community Information Integration and Central Patient Attachment Registry project, the introduction of the MyHealth records patient portal, and the custodian based Connect Care initiative of Alberta Health Services (AHS). Yet interoperability of health data across community-based health services (e.g., primary care services), and different members of a patient's distributed care team has not materialized. As a 2020 Ernst & Young 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 recommended the need for "changes to legislation and policy" to support data integration.[3] To date, there is currently no known legislative plan to address this data fragmentation, and there are currently no enforceable health data interoperability standards or regulations in Alberta. This stands in contrast to the province of Ontario's DHIEX, a regulatory framework to define standards and requirements for use in interoperability[4], and nations such as Denmark which initiated a comprehensive public policy approach to health data interoperability 29 years ago and today enjoys a high level of health data integration[5], and the United States which introduced a program to enforce health data interoperability 19 years ago.[6]

Optimized health data interoperability is the by-product of a matrix of interdependent factors that this report groups into two broad categories: *technical and human factor interoperability*. Technical

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[3] 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)

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

[5] 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)

[6] 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)

factors constitute issues related to technology and data configuration, data content standards, data exchange standards, internet connectivity and common user authentication. Human factors constitute issues related to how human beings behave and function around health data and technology, governance, legislation, regulation, policy, literacy, communication, and culture. An optimized health data interoperability environment demands a significant level of maturity in both categories of factors. The Working Group suggests that human factor interoperability often dictates the level of technical factor interoperability that is achievable.

FIGURE 2: RELATIONSHIP BETWEEN DETERMINANTS OF HEALTH DATA INTEROPERABILITY, DATA-RELATED HARM, AND ACCOUNTABILITY TO QUALITY HEALTH PROGRAMS AND SERVICES.
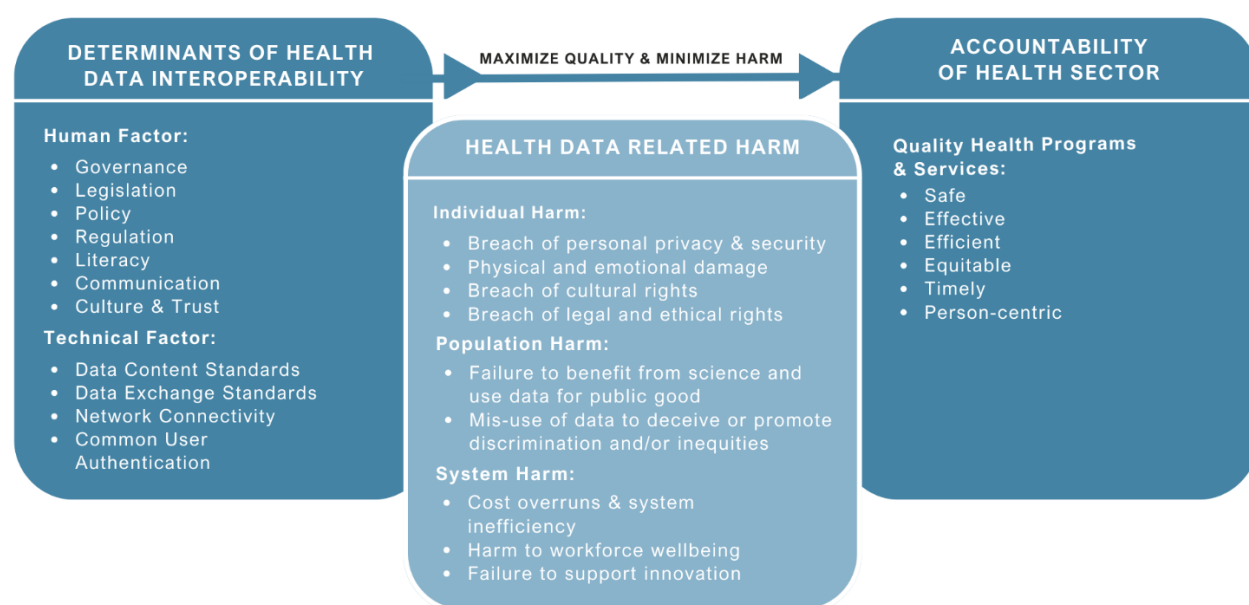
An analysis of the Alberta health care sector demonstrates significant deficits in both human and technical factor interoperability. Most notable are:

- Fragmented health data accountability and oversight
- Antiquated health data legislation and absent interoperability legislation
- Limited or absent health data technology regulation
- A lack of health sector literacy about the foundational importance of interoperability
- A culture of custodian-centricity and intersectoral distrust
- A lack of data content and exchange standards
- Incomplete internet connectivity
- An absence of system-wide patient and user validation
- A lack of adherence to the *Canada Health Act* principles of portability and universality as they apply to the barrier of data fragmentation

Taken together these factors significantly hamper provincial progress in health data interoperability.

Based on our analysis we concluded the following:

- Comprehensive health data interoperability will elevate the safety of patients and health professionals and reduce harm that has persisted in the face of safety improvement efforts that do not address interoperability. In doing so it will enhance health programs and services (including virtual care) resulting in improved health and wellbeing of Albertans and Canadians.
- Health data interoperability should be a priority and should be *mandated and regulated* both in Alberta and Canada.
- Investment in comprehensive health data interoperability is justified in Alberta, both on a system basis, and independently for individual stakeholders across the health sector including government, the health authority, health information technology innovators, health care providers, and the public.
- The most challenging barriers to achieving comprehensive health data interoperability in Canada are primarily human, not technical interoperability factors.
- Intersectoral cooperation around a set of evidence-based human and technical factor interoperability design standards is the best approach to a health data interoperability strategy.
- The meaningful inclusion of public and Indigenous representation at all levels of this strategy, including oversight, must be obligate.
- This strategy should harness the substantive health data interoperability human and knowledge resources Canada has to offer.
- Pan-Canadian partnerships are encouraged, as directed by the *Canada Health Act* and the principles of *portability and universality*.

Based on these conclusions, the following is recommended:

01	Health data interoperability in Alberta should be mandated through legislation.
02	Health data interoperability in Alberta should be regulated for quality improvement and assurance.
03	The oversight of health data interoperability design and management in Alberta should promote trust through broad intersectoral representation (akin to the *Alberta Virtual Care Coordinating Body* membership), including meaningful public and Indigenous representation.
04	Health data interoperability oversight should be public-facing, accountable and fully transparent.

05 Health data interoperability legislation should at minimum address the following:
a) mandatory health data content standards
b) mandatory health data exchange standards
c) health data unblocking legislation
d) mandatory patient access to personal health information though standardized Application Programming Interfaces (APIs)
e) a regulatory process for ensuring compliance with mandatory health data interoperability standards

06 All health data system design and management, including that pertaining to health data interoperability, must maximize the delivery of quality health programs and services, and minimize health data-related harm.

07 Alberta should endorse and adopt the *Health Data Charter[7]* as a guiding framework for all provincial health data design and management, including health data interoperability.

08 The design and management of health data interoperability should be accountable to evidential health data interoperability principles such as those proposed in this report, not to the agenda of any given organization or interest group, nor subject to the limitations imposed by electoral or capital funding cycles.

09 All forms of data-related harm, not just harm arising from breaches of privacy, should be acknowledged, and considered in health data interoperability legislation, public policy, and regulation.

10 The negative impact of the custodial legislative framework on health data interoperability and its contribution to the promotion of individual, population and health system harm should be acknowledged and addressed.

11 A stewardship model of health data oversight, as proposed in the pan-Canadian Health Data Strategy,[8] should replace the custodial model of health data legislation.

12 Alberta, in conjunction with the Canadian Institute for Health Information (CIHI), and other jurisdictions and partners should develop metrics for measuring and evaluating indices of health data-related harm and benefit.

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[7] Canadian College of Health Information Management, Health Data Charter, 2022, (https://cchim.ca/wp-content/uploads/2022/11/Health-Data-Charter.pdf)
[8] Pan-Canadian Health Data Strategy Expert Advisory Group, Toward a World-class Health Data System, 2022, (https://www.canada.ca/en/public-health/corporate/mandate/about-agency/external-advisory-bodies/list/pan-canadian-health-data-strategy-reports-summaries/expert-advisory-group-report-03-toward-world-class-health-data-system.html)

13   Alberta efforts to modernize provincial health data interoperability should align with national efforts including, but not limited to the CIHI efforts to promote national health data content standards, and Canada Health Infoway efforts to promote health data exchange standards.

14   The effort of Alberta to create comprehensive health data interoperability should uphold person-centric health data design and cross jurisdictional quality care, population health and research.

15   The training of health professionals should include content on health data literacy and the value proposition of health data interoperability.

16   All Albertans should have access to comprehensive internet connectivity.

17   Iterative evaluation should inform all efforts to achieve comprehensive health data interoperability in Alberta.

18   Procurement processes for health information technology must adhere to legislated standards of health data interoperability.

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