INTEROPERABILITY SAVES LIVES

HEALTH DATA INTEROPERABILITY WORKING GROUP

A report from the Alberta Virtual Care Coordinating Body

October 2023

Alberta Virtual Care

REPORT CITATION

Affleck, E., Murphy, T., Williamson, T., Price, R., Wolfaardt, U., Price, T., Layton, A., Hamilton, B., Dean, S., Frazer, C., Chapman, A., Shute, R., West., Denman, M., Golonka, R., & Lindeman, C. (2023). Interoperability Saves Lives. (www.albertavirtualcare.org).

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FOREWORD

My entire career has been dedicated to the betterment of healthcare systems for patients. First in the cancer world, and subsequently across the entire health sector. During this journey, it has become crystal clear that data is the lifeblood of all health service, research and innovation, and the foundation of a Learning Health System. For too long, true health data interoperability in Alberta and Canada has remained elusive and out of the reach.

For the past eight months, I have had the privilege of chairing the *Interoperability Working Group* of the *Alberta Virtual Care Coordinating Body* in the creation of this report. Credit for the concepts and ideas expressed in this report rest with the accomplished Working Group members to whom I extend my heartfelt gratitude for their input, ideas, energy, and contribution.

After reading *Interoperability Saves Lives*, the only conclusion one can come to is that maintaining the status quo is NOT an option. Our prior ineffectual approach to health data interoperability is an obstacle to everything from individual patient care to the advancement in our understanding of the complex relationship between health, wellbeing, and the social determinants of health. As this report highlights, digital technology, and content and exchange standards for linking data, exist and are ready to be adopted today. It is the way we relate with each other around data, what we have called in this report *human factor interoperability*, that presents the most significant barrier to meaningful health data use in Alberta and Canada. Understanding this, we must recognize our collective accountability to health data interoperability, and seize the opportunity to mandate it, lest healthcare continue to limp along and endure uncoordinated analytics services; elevated costs, stifled innovation, suboptimal quality of care, and patient harm. Albertans and Canadians deserve better.

The world does not forecast when the 'bell will ring' to mark a significant change; it is only in retrospect that we clearly see the signature moments that have catalyzed meaningful change resulting in improved health outcomes and game-changing innovation. Looking back several years from now I hope we can acknowledge that this report, *Interoperability Saves Lives* signalled one of those moments when the bell rang the loudest.

Sincerely,

Tim Murphy

Chair, Health Data Interoperability Working Group
Member, Alberta Virtual Care Coordinating Body
Vice President, Health - Alberta Innovates

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The Health Data Interoperability Working Group was launched by *Alberta Virtual Care* and is sponsored by Alberta Innovates.

ABOUT THE ALBERTA VIRTUAL CARE COORDINATING BODY

The *Alberta Virtual Care Coordinating Body* (AVCCB) is an advisory, oversight committee created by its sponsoring stakeholders to promote principle-based virtual care public policy, workflow, and technology alignment across the health sector that promotes quality health programs and services. Understanding that virtual care is the remote exchange of data between patients and/or members of their care team using any form of communication or information technology, it follows that interoperability of data across these technologies and between stakeholders is a core requirement of an optimized virtual care ecosystem.

The AVCCB uses the Collective Impact governance model to guide its cooperative efforts to promote evidence-based virtual care service design and function[1] in the belief that citizens, populations, and the health system will be better served by principle-based stakeholder collaboration and co-design. The efforts of the AVCCB and subsidiary Working Groups are accountable to the AVCCB virtual care *Design Principles* which are found in Appendix 1.

AVCCB PROJECTS

Interoperability Saves Lives is the first of a series of reports to be released by the AVCCB. Through broad stakeholder engagement, the AVCCB is engaged in multiple issue-specific projects intended to contribute to the promotion of quality health programs and services. Taken together, the projects are intended to help frame a systematic, comprehensive, and evidential approach to quality-based digital health services.

Forthcoming reports and dissemination products of the AVCCB concern the following topics:

- Private sector / public sector virtual care services
- Digital health equity
- Digital health evaluation
- Interjurisdictional licensure
- Indigenous data sovereignty

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[1] Published by John Kania & Mark Kramer, Collective Impact, 2011, (https://ssir.org/articles/entry/collective_impact#)

MEMBERSHIP OF THE ALBERTA VIRTUAL CARE COORDINATING BODY

- Alberta College of Pharmacy (ACP)
- Alberta Health (AH)
- Alberta Health Services (AHS)
- Alberta Innovates – Health (AI)
- Alberta Medical Association (AMA)
- Alberta Pharmacists Association (RxA)
- College and Association of Registered Nurses of Alberta (CARNA)
- College of Physicians & Surgeons of Alberta (CPSA)
- Health Quality Council of Alberta (HQCA)
- One member with special expertise in health services research & education.
- Two members represent the Alberta Federation of Regulated Health Professions (AFRHP)
- Four patient representative members.
  - At minimum, one of the patient representatives will be Indigenous and have special knowledge of health services as they relate to Indigenous peoples.

INTRODUCTION

All decisions in health care are predicated on the capture, exchange, and analysis of health data. The inability to move health data to where it is needed to support individual care, population and public health, research, management, and health innovation can negatively impact individuals, populations, and the health system. Since health care data is captured in manifold forms by a wide variety of technologies over many locations, the capacity to exchange health data efficiently and safely between these platforms is a core necessity of a high-functioning health care system.

The ability to seamlessly share health data and information between health sector stakeholders, different solutions, and devices, in a form that allows for its meaningful use by all parties is called *health data interoperability*. The capacity to provide virtual care, and indeed many health services, is often dependent on health data interoperability. Although digital technology has empowered the rapid sharing of data across networks in many industries, achieving interoperability in the health sector has been frustratingly elusive, particularly in Canada; currently only one Canadian jurisdiction,[2] Ontario, has regulatory health data interoperability standards.[3]

Recognizing the foundational relationship between health data interoperability and virtual care, the *Alberta Virtual Care Coordinating Body* launched the *Health Data Interoperability Working Group* with a mandate to appraise the potential value that comprehensive health data interoperability offers to the optimization of quality virtual care. This was to be accomplished by:

- Examining the potential value of adopting provincial health data interoperability standards in Alberta.
- If deemed of value, propose:
    - An approach for setting health data interoperability standards.
    - A draft set of health data interoperability principles.
    - Recommendations for an approach to achieving health data interoperability.

Support for the work of the Health Data Interoperability Working Group was provided by Alberta Innovates and the AVCCB secretariat.

> While this report is commissioned for the purposes of promoting excellence in virtual care, it is recognized that the principles articulated herein are relevant to **all care**.

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[2] At the time of publication of this report, other jurisdictions are reviewing opportunities to implement health data interoperability regulations.

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

> *It's a gong-show out there right now, with respect to interoperability. Fear in the community—in the workforce—about if information is getting to where it's supposed to. Results routing, patient communication through portals, our accountability for information that does or even does not come to us (that the patient thinks does). Honestly, it feels like it's just one thing after another. We are playing wack-a-mole with volatile issues. Working around one, and another one pops up. None of the workarounds are particularly satisfactory, but maybe they close the gap a bit. It impossible to build a high functioning system when you are constantly in damage control mode. But its where we are at and where we will be for quite a while.*

Alberta Family Physician, May 2023

STATEMENT ON INDIGENOUS DATA SOVEREIGNTY

Health data ownership and governance is an important consideration and determinant of the approach and capacity to exchange health information for the purposes of quality care. One foundational data governance concern in the Canadian context is Indigenous data sovereignty. In Canada, Indigenous peoples (i.e., First Nations, Inuit, and Metis) are recognized as sovereign in their governance and that extends to their oversight and control of data including that arising from health services. Indigenous data sovereignty refers to the "ability for Indigenous peoples, communities and Nations to participate, steward and control data that is created with or about themselves".[4]

The deployment of health information technology in Canada has not always involved consideration of principles of Indigenous data sovereignty in system design and function. There is a necessity to integrate a framework for the respectful inclusion of Indigenous data sovereignty in the design and deployment of all health information systems. However, as the subject of Indigenous data sovereignty is complex and demands a focused treatment, it was felt by the AVCCB *Health Data Interoperability Working Group* to be beyond the scope of this report. Consequently, the AVCCB is planning a dedicated project to consider Indigenous data sovereignty.

In the interim, although not expressly addressed in this report, we wish to acknowledge that any effort to design and deploy comprehensive health data interoperability in Alberta and Canada as a whole, must take into consideration principles of Indigenous data sovereignty.

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[4] University of Toronto Libraries, Indigenous Data Sovereignty, 2023,
(https://guides.library.utoronto.ca/indigenousstudies/datasovereignty)

HEALTH DATA CHARTER

The *Health Data Charter* is a set of ten principles proposed by the pan-Canadian Health Data Strategy intended to foster a harmonized approach to optimized health data function in Canada.[5] Most of the themes touched upon in this report are framed around the principles of the Charter, including the emphasis on person-centric health data design, the mitigation of data-related harm, the need to harmonize health data governance, policy and evaluation, and the ultimate duty to put persons and populations at the core of all decisions related to health data design and use. The concluding statement of the Charter highlights its intended purpose to "transcend jurisdictional and disciplinary differences" and foster "interoperability both within and across different national systems".

FIGURE 1: HEALTH DATA CHARTER

Health Data Charter

Inspired by the universal human rights to health, to benefit from science, and to non-discrimination, and founded on the five principles of public administration, comprehensiveness, universality, portability, and accessibility (Canada Health Act), the *Health Data Charter* reaffirms Canada's commitment to "improving data collection across health systems to inform future decisions..." (Speech from the Throne, November 23, 2021).

To honour the duty to put persons and populations at the core of all decisions about the disclosure, access and use of health data, the Health Data Charter requires:
- Person-centric health information design to ensure that health data follow the individual for clinical, and analytical access and use;
- Common standards for terminology, health data design, stewardship, interoperability, access and portability;
- The quality, security and privacy of health data to maximize benefits and reduce harm to individuals and populations;
- Timely accessibility of health data to individuals, decision makers, researchers, and the health workforce;
- The use of health data for policies, programs, services, statistics and research for the public good given the importance of open science;
- Data-driven social and technological innovation through partnership, invention, discovery, value creation and international best practice;
- Health data literacy of the public, decision-makers and the health workforce;
- Harmonization of health data, governance, evaluation, and policy;
- Support for First Nations, Inuit and Metis Nation data sovereignty;
- Inclusion of diverse members of the public, patients, communities and other stakeholders in health information system development and oversight.

CONTEXT: The *Health Data Charter* is inspired by, and founded on, human rights whose universal nature transcends jurisdictional and disciplinary differences. Recognizing international standards and data governance norms, the Charter's principled, parsimonious, and prospective nature serves to foster international implementation and interoperability both within and across different national systems.

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[5] 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)

EXECUTIVE 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.[6] 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".[7]* 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.
- 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.

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[6] Healthcare Information Management Systems Society, Interoperability in Healthcare, 2023, (https://www.himss.org/resources/interoperability-healthcare)
[7] Government of Canada, Canada Health Act, 1985, (https://laws-lois.justice.gc.ca/eng/acts/c-6/page-1.html)

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.[8] 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[9], 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[10], and the United States which introduced a program to enforce health data interoperability 19 years ago.[11]

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 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

[8] 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)
[9] Ontario Health, Digital Health Information Exchange Standard, 2022, (https://www.ontariohealth.ca/system-planning/digital-standards/digital-health-information-exchange)
[10] 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)
[11] 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)

categories of factors. The Working Group suggests that human factor interoperability often dictates the level of technical factor interoperability that is achievable.

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*[12] 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.

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[12] Canadian College of Health Information Management, Health Data Charter, 2022, (https://cchim.ca/wp-content/uploads/2022/11/Health-Data-Charter.pdf)

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,[13] 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.

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.

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[13] 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)

DEFINITIONS & TAXONOMY

The standardization of key terms related to health data interoperability is required to promote a common approach and understanding.

The following definitions are used in this document:

HEALTH

"A state of complete physical, mental and social well-being and not merely the absence of disease and infirmity".[14]

HEALTH DATA

"Observations, facts, or measurements which relate to the physical or mental health status of individuals, health system performance and socio-economic, community and health system characteristics."[15]

HEALTH DATA INTEROPERABILITY

"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 populations."[16]

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[14] World Health Organization, Constitution, (https://www.who.int/about/governance/constitution)
[15] 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)
[16] Healthcare Information Management Systems Society, Interoperability in Healthcare, 2023, (https://www.himss.org/resources/interoperability-healthcare)

TIERS OF HEALTH DATA INTEROPERABILITY

Foundational Interoperability
"Establishes the inter-connectivity requirements needed for one system or application to securely communicate data to and receive data from another.[17]
Structural Interoperability
"Defines the format, syntax and organization of data exchange including at the data field level for interpretation."[18]
Semantic Interoperability
"Provides for common underlying models and codification of the data including the use of data elements with standardized definitions from publicly available value sets and coding vocabularies, providing shared understanding and meaning to the user."[19]

HEALTH INFORMATION EXCHANGE

"The electronic sharing of healthcare-related information between different healthcare organizations, systems, or stakeholders."[20]

RELATIONSHIP BETWEEN INTEROPERABILITY AND HEALTH INFORMATION EXCHANGE

The difference between Health Information Exchange (HIE) and Interoperability is that HIE merely requires an ability to share information electronically, whereas Interoperability requires an ability to use shared data, and not just exchange information.[21]

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[17] https://www.himss.org/resources/interoperability-healthcare
[18] Healthcare Information Management Systems Society, Interoperability in Healthcare, 2023,
(https://www.himss.org/resources/interoperability-healthcare)
[19] IBID
[20] IBID
[21] David W. Bates and Lipika Samal, Interoperability: What Is It, How Can We Make It Work for Clinicians, and How Should We Measure It in the Future? 2018

HEALTH INFORMATION

"Health data that have been analyzed or interpreted to provide insight or a narrative related to the physical or mental health status of individuals, health system performance, and socio-economic, community and health system characteristics."[22]

For context, *health information* is addressed in the following manner in the *Alberta Health Information Act*:

- *1(1)(k) Provides the top-level definition of "health information", which consists of "diagnostic, treatment and care information" and "registration information."*
- *1(1)(i) Defines the term, "diagnostic, treatment and care information".*
- *(1)(1)(u) Defines the term, "registration information."*
- *"Diagnostic, treatment and care information" refers to a "health service" provided to an individual, so we also need to understand what a "health service" is.*
- *1(1)(m) Defines the term "health service" and refers the reader to the Regulation for a listing of services that are not included in the term "health service". This effectively carves-out services and related information that one might otherwise assume would be included in "health information".*

Health Information Regulation is addressed in the following manner:

- *3 Lists the types of information that are included in the definition of "registration information".*
- *3.1 Lists the services that are excluded from the definition of "health service".[23]*

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[22] 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)

[23] Government of Alberta, Health Information Act, last updated 2022, (https://open.alberta.ca/publications/h05#summary)

DATA CUSTODIAN

"An individual or organization responsible for the secure collection and/or storage of health data and the curation of health data use, disclosure, retention, and disposal. Primarily concerned with security and privacy of health data."[24]

DATA STEWARD

"An entity or senior government role responsible for assuring the quality, integrity and access arrangements of data and metadata in a manner that is consistent with applicable law, institutional policy and individual permissions."[25]

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[24] Pan-Canadian Health Data Strategy Expert Advisory Group, Building Canada's Health Data Foundation, 2021, (https://www.canada.ca/content/dam/phac-aspc/documents/corporate/mandate/about-agency/external-advisory-bodies/list/pan-canadian-health-data-strategy-reports-summaries/expert-advisory-group-report-02-building-canada-health-data-foundation/expert-advisory-group-report-02-building-canada-health-data-foundation.pdf)
[25] Global Alliance for Genomics and Health, 2016, (https://www.ga4gh.org/wpcontent/uploads/GA4GH_Data_Sharing_Lexicon_Mar15.pdf)

KEY IMPERATIVES

The *Health Data Interoperability Working Group* proposes three key imperatives to frame an evidential approach to health data interoperability design and use:

1. Quality Health Programs and Services
2. Health Data-related Harm
3. Technical and Human Factor Interoperability

The design of health data interoperability has dual accountabilities; to promote quality health programs and services and to minimize forms of data-related harm.

QUALITY HEALTH PROGRAMS AND SERVICES

The core purpose and one of the ultimate accountabilities of health care is the provision of quality health programs and services. This is a foundational accountability that must frame the design and use of all health resources, and the common commitment of all health sector stakeholders. *This includes the design of and approach to health data interoperability*.

In this document, the National Academy of Medicine's (formerly Institute of Medicine) definition of quality is used.[26] This framework articulates six distinct domains of quality:

- *Safe* health programs and services
- *Efficient* health programs and services
- *Effective* health programs and services
- *Equitable* health programs and services
- *Timely* health programs and services
- *Person-centred* health programs and services

It follows that the design and use of health data interoperability should promote the delivery of the above domains of quality health programs and services.

DATA RELATED HARM

While health data can be used to promote wellbeing, if used inappropriately it can also lead to harm. Both health data *use* or *non-use*, or a loss of health data *integrity*[27] can result in damage to individuals,

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[26] Agency for Healthcare Research and Quality, Six Domains of Healthcare Quality, 2022, (https://www.ahrq.gov/talkingquality/measures/six-domains.html)
[27] Catherine Cote, What is data integrity and why does it matter? 2021, (https://online.hbs.edu/blog/post/what-is-data-integrity)

populations, or the health system. Although there is not consensus definition for health data integrity, properties include *accuracy, completeness, reliability, relevance, and timeliness*.[28]

We propose three tiers of data-related harm: *individual harm, population harm,* and *health system harm*. Table 1 outlines the types of data-related harm to be avoided in the design of health data interoperability.

TABLE 1: FRAMEWORK

1. Individual Harm

a. Breach of personal health data
b. Damage to physical or emotional health and wellbeing through data misuse, non-use, or lack of integrity
c. Breach of cultural rights to personal health data
d. Breach of legal and ethical rights to personal health data

2. Population Harm

a. Failure to benefit from science and use health data for public good
b. Misuse of data to create misinformation or information that may be used to deceive or promote discrimination and/or inequities

3. Health System Harm

a. Failure to optimize health system function and efficiency due to poor data design, misuse, non-use, or lack of data integrity
b. Damage to health workforce wellbeing from poor data design and/or misuse, non-use, or lack of data integrity
c. Failure to support health innovation through health data misuse, non-use, or lack of data integrity

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[28] IBID

TECHNICAL AND HUMAN FACTOR INTEROPERABILITY

Achieving health data interoperability is a function of the intentional design of a matrix of interdependent factors or determinants. The *Health Data Interoperability Working Group* proposes that the determinants of health data interoperability to be separated into two categories: *human and technical factor interoperability*. Figure 1 illustrates the matrix of determinants of human and technical factor health data interoperability, and Table 2 considers features of each determinant to be considered in the design of health data interoperability.

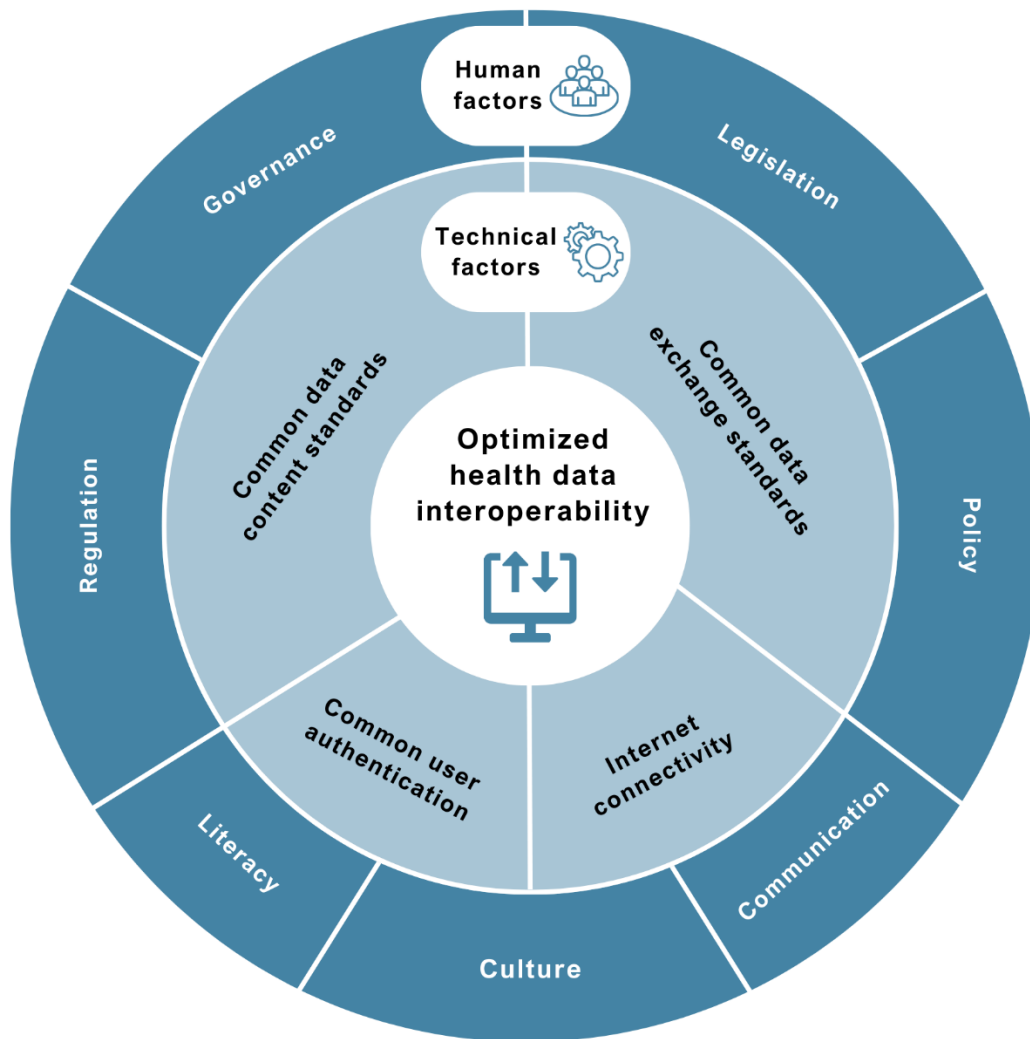**FIGURE 1: DETERMINANTS OF HEALTH DATA INTEROPERABILITY**

Human Factor Interoperability	Consideration
Governance	Is there a harmonized approach to health data interoperability oversight across services, custodians, and jurisdictions, that establishes clear accountability, promotes quality programs and services, and mitigates data-related harm?
Legislation	Does health data legislation uphold a harmonized person-centric approach to health data interoperability that promotes quality programs and services and mitigates data-related harm?
Regulation	Is there a regulatory process for health information technology that mandates health data interoperability, promotes quality health programs and services and mitigates data-related harm?
Policy	Do all stakeholders in the health sector craft and adopt policy that upholds a harmonized person-centric approach to health data interoperability that promotes quality programs and services and mitigates data-related harm?
Literacy	Do the health workforce, the health sector leadership, and the public possess a clear understanding of the current state and value of health data interoperability and its capacity to promote quality programs and services and mitigate data-related harm?
Communication	Is there transparent, broad, and clear communication between all health sector stakeholders, including the public, about accountability for, and nature of, health data interoperability?
Culture	Is there a culture of trust and accountability to interoperability as a determinant of quality health programs and services that supersedes any jurisdictional, regional, custodial, private sector, or organizational agendas?

Technical Factor Interoperability	Consideration
Data Content Standards	Are there common health data content standards that have been set, enforced, and adopted across all jurisdictions that support health data interoperability?
Data Exchange Standards	Are there a common health data exchange standards that have been set, enforced, and adopted across all jurisdictions that support health data interoperability?
Internet Connectivity	Is there universal internet connectivity across all jurisdictions that ensures the capacity for universal health data exchange?
Common User Authentication	Are there common digital identity standards for both providers and patients?

PROJECT METHOD

The *Health Data Interoperability Working Group* followed a structured approach to fulfil its mandate. Based on the Key Imperatives articulated above, the conceptual framework adopted by the 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).

FIGURE 2: RELATIONSHIP BETWEEN DETERMINANTS OF HEALTH DATA INTEROPERABILITY, DATA-RELATED HARM, AND ACCOUNTABILITY TO QUALITY HEALTH PROGRAMS AND SERVICES.
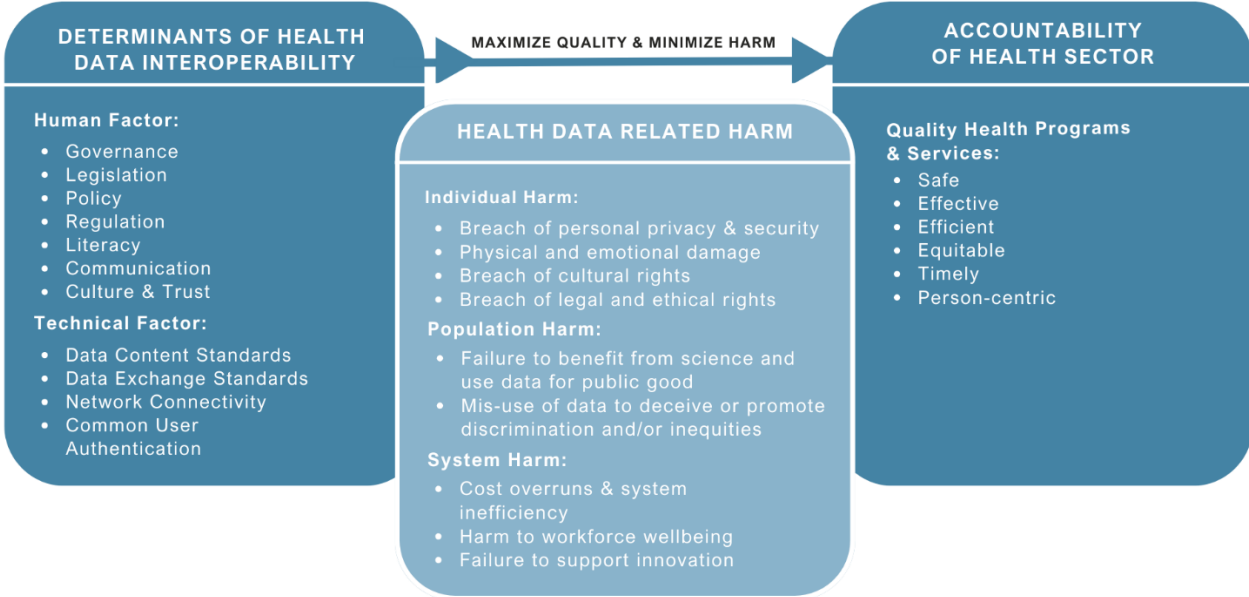
Understanding this, the following approach to the report was taken:

BUSINESS CASE

A cost/benefit analysis of heath data interoperability was conducted using the domains of quality care and indices of harm (articulated under *Key Concepts*).

CURRENT STATE ANALYSIS

A high-level current state analysis of health data interoperability in Alberta was conducted. The current state in Canada, United States, and Denmark were evaluated for comparison. A summary comparison of current state health data interoperability across the four jurisdictions was conducted.

IDENTIFY BARRIERS

Perceived barriers to achieving health data interoperability in Alberta were articulated to assist with framing of potential recommendations.

OPTIMIZED HEALTH DATA INTEROPERABILITY STATE

The description of an optimized health data interoperability ecosystem was achieved through Working Group consensus by articulating the parameters of an ideal health data interoperability ecosystem, presuming no constraints in system design. From this consensus vision, a set of idealized health data interoperability *Design Principles* were developed. These were cross-referenced and refined with global industry best practice.

ESTABLISH RECOMMENDATIONS

Based on an understanding of an idealized state, gap analysis of the current state, business case, and identification of perceived barriers, recommendations were developed for achieving health data interoperability in Alberta.

BUSINESS CASE

To justify an investment in health data interoperability, a business case is needed to consider the resources—often fiscal, human or knowledge—required to support a specific business need and compare them to improved system function. Achieving health data interoperability in Alberta will demand significant investment to address deficits in both human and technical factor interoperability. To date, there has not been significant research dedicated to understanding the cost/benefit of implementing system-wide health data interoperability. Instead, studies have projected cost savings without estimating the resources required to achieve interoperability.[29] Furthermore, the complexity of health services in different countries and within Canada varies so significantly that an accurate and transferrable model of interoperability resource costing is difficult to achieve. Further resource needs are difficult to estimate without fully articulating the scope and timeframe of a project.

As such, although a formal business case is not achievable at this time, it does appear that there are substantial resources available to offset project cost. In February 2023, the Federal government signalled its intent to "work collaboratively with provinces and territories on four shared health priorities to improve integrated health care for Canadians" which included a priority to modernize the health care system with standardized health data and digital tools.[30] Through new investments and leveraging prior health data and digital strategy efforts, provincial and territorial partners have been asked to agree to adopt common standards and policies related to health data.[31] In 2023, federal funding was allocated to Canada Health Infoway (Infoway) to lead a collaborative effort with CIHI and other key stakeholders to advance digital health tools and an interoperability roadmap. Canada Health Infoway proposed an interoperability governance model that aims to create economies of scale by leveraging existing jurisdictional efforts and resources around a common effort to promote health data interoperability.

Evaluating the business need for health data interoperability is easier than estimating resource cost. The business need to be met is whether health data interoperability would result in improved quality of health programs and services. To answer this question, the impact of interoperability on quality health programs and services will be considered by the six domains of quality articulated above (i.e., safety, efficiency, effectiveness, equity, timeliness, and person-centeredness). Although they will be considered individually, it is recognized that the domains of quality are interdependent variables.

It should be noted that experts acknowledge that the measurement of the impact of interoperability on quality health service is limited by a lack of industry consistency in outcome measures and

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[29] Canada Health Infoway, Quantifying the Benefits of Patient Access to their Own Health Information, 2023, (https://www.infoway-inforoute.ca/en/component/edocman/6442-quantifying-the-benefits-of-patient-access-to-their-own-health-information/view-document?Itemid=101)
[30] Health Canada, Working Together to Improve the Health of Canadians, 2023, (https://www.canada.ca/en/health-canada/news/2023/02/working-together-to-improve-health-care-for-canadians.html)
[31] IBID

variation in the approach and quality of studies done.[32] There appears to be consensus that more research is required to clarify the impact of health data interoperability on quality of health care services and programs.[33]

SAFETY

> *The World Health Organization defines safety as the "prevention of errors and adverse effects to patients associated with health care."[34]*

In its landmark 2011 report, *Health IT and Patient Safety: Building Safer Systems for Better Care*, the Institute of Medicine observed that "poorly designed [health] IT can introduce risks that may lead to unsafe conditions, serious injury, or even death."[35] This was born out by an independent inquiry into the care of Greg Price in Alberta in 2012 that found that a lack of health information continuity was a significant contributor to his death.[36] The type of care coordination gaps that occurred in the Price case have been attributed to a lack of health data interoperability.[37] These findings have been upheld by studies that suggest that problems with the integration of health information across different health data platforms can result in "threats to patient safety emerging from the lack of availability of timely information and duplicate data entry."[38]

A 2022 systematic review of studies that examined the relationship between digital medical record interoperability and quality of care, found that electronic health record interoperability positively influenced medication safety, reduced patient safety events, and reduced costs.[39]

Studies have identified a significant increase in unsafe care arising from health care provider burnout that is attributable to health information technology use.[40] although this link is not specifically associated with a lack of health data interoperability. In the context of COVID-19, a 2021 study found that shortfalls in health data interoperability in the United States made it challenging to gain insights to guide safe and appropriate public health interventions.[41] The authors concluded that, "the COVID-

[32] Edmond Li et al., The Impact of Electronic Health Record Interoperability on Safety and Quality of Care in High-Income Countries: Systematic Review, 2022

[33] David W. Bates and Lipika Samal, Interoperability: What Is It, How Can We Make It Work for Clinicians, and How Should We Measure It in the Future? 2018

[34] World Health Organization, Patient Safety, (https://www.who.int/europe/health-topics/patient-safety#tab=tab_1)

[35] https://pubmed.ncbi.nlm.nih.gov/24600741/

[36] Health Quality Council of Alberta, Improving Continuity of Care: Key Opportunities and a Status Report on Recommendations from the 2013 Continuity of Patient Care Study, 2016, (https://hqca.ca/wp-content/uploads/2021/12/Continuity_of_Care_2016_FINAL.pdf)

[37] Lipika Samal et al., Care Coordination Gaps Due to Lack of Interoperability in the United States: A Qualitative Study and Literature Review, 2016

[38] Kathrin M Cresswell et al., Safety Risks Associated with the Lack of Integration and Interfacing of Hospital Health Information Technologies: A Qualitative Study of Hospital Electronic Prescribing Systems in England, 2017

[39] https://pubmed.ncbi.nlm.nih.gov/36107486/

[40] Sasha Han et al., Estimating the Attributable Cost of Physician Burnout in the United States, 2019

[41] Dina N Greene et al., Interoperability: COVID-19 as an Impetus for Change, 2021

19 pandemic has demonstrated that interoperability has major importance for the overall public good."

EFFICIENCY

> *Efficiency in the health care context refers to the capacity to provide optimal health programs and services while minimizing the duplication or wasteful use of resources and controlling or minimizing cost.*

Over the past two decades there were many studies that made bold predictions of substantial cost savings associated with the adoption of health information technology, and most suggest financial benefit occurs when interoperability is present.[42] For example, one study from 2005 by the Center for Information Technology Leadership in the United States predicted an annual saving of $78 billion if health information interoperability were fully implemented in the country.[43] According to one of the authors, commenting on this study thirteen years later, these savings were not realized due to poor progress adopting health data interoperability in the United States, not because of the inaccuracy of the prediction.[44] Other countries such as Australia have also predicted large-scale cost saving with health data interoperability.[45] In Canada there have been similar predictions; Canada Health Infoway has projected annual savings of over $2.1 billion if health data interoperability were achieved including value to patients in terms of time and financial savings valued at $500 million, clinician benefits in terms of time savings valued at over $600 million, and health system benefits from avoided waste and increased capacity valued at almost $1 billion.[46] Infoway suggests that optimized health data interoperability will result in the following efficiencies in Canada; the avoidance of over 2 million primary care visits and 500,000 emergency department visits annually, saving over 5 million hours of patient time and over 40 million kilometers of travel, workforce time savings of over 1000 FTEs with an accrued value of almost $700 million annually.[47]

A systematic review from 2022 examining the relationship between digital medical record interoperability and quality of care indicated that electronic health record interoperability reduces system cost.[48] Conversely, a lack of interoperability between health information systems has been

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[42] David W. Bates and Lipika Samal, Interoperability: What Is It, How Can We Make It Work for Clinicians, and How Should We Measure It in the Future? 2018

[43] Jan Walker et al., The Value Of Health Care Information Exchange And Interoperability, 2005

[44] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6153178/#hesr12852-bib-0026

[45] Peter Sprivulis et al., The Economic Benefits of Health Information Exchange Interoperability for Australia, 2007

[46] Canada Health Infoway, Quantifying the Benefits of Digital Health Interoperability, 2023, (https://www.infoway-inforoute.ca/en/component/edocman/6443-quantifying-the-benefits-of-digital-health-interoperability/view-document?Itemid=101)

[47] Canada Health Infoway, Quantifying the Benefits of Patient Access to their Own Health Information, 2023, (https://www.infoway-inforoute.ca/en/component/edocman/6442-quantifying-the-benefits-of-patient-access-to-their-own-health-information/view-document?Itemid=101)

[48] Edmond Li et al., The Impact of Electronic Health Record Interoperability on Safety and Quality of Care in High-Income Countries: Systematic Review, 2022

found to "reduce the quality of care provided to patients and waste resources."[49] A 2022 study of the impact of virtual care services in Canada by the RAND Europe research group found that use of networked videoconferencing and charting technology, which is reliant on data interoperability to function, "could lead to significant benefits for Canadian patients, the Canadian economy, and wider Canadian society", accounting for almost $6 billion in annual savings.[50] The authors state that barriers to achieving this are "a lack of integration, standardisation and interoperability of the technical infrastructure related to telemedicine."[51] The authors also asserted that regulatory barriers and legal discrepancies in the oversight of technologies and the health workforce across jurisdictions are also an obstacle to achieving functionally interoperable virtual health services.[52] They provided the following recommendation:

"Recommendation 1: Ensure technical interoperability of electronic health records.

To ensure an efficient and timely use of electronic patient data, Canada should update the existing fragmented system of electronic health records. To increase the interoperability of health information, experts have called for an establishment of a nationally harmonised patient record system, which could be achieved through mandating and improving a current health record system (e.g., with inputs from practitioners and patients) that would then be used across Canada. The European Commission has adopted a recommendation on a pan-European electronic health record exchange format to unlock the flow of health data across borders and facilitate cross-border interoperability of electronic health records."[53]

EFFECTIVENESS

> *Effectiveness in health care is the ability of an intervention to produce the desired beneficial effect.*

There is some research that supports a positive impact of health data interoperability on the effectiveness of health service. A 2018 study from the United States demonstrated a decrease in mortality associated with improved interhospital health information exchange.[54] Another study from 2019 found a decrease in readmission rates associated with improved inter-service health information exchange.[55] A third example from 2022 by the RAND Europe research group suggests that improved wellbeing of Canadians, equivalent to $ 611 million annually in savings in unnecessary

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[49] Amir Torab-Miandoab et al., Interoperability of Heterogeneous Health Information Systems: A systematic Literature Review, 2023

[50] Marco Hafner et al., The potential socio-economic impact of telemedicine in Canada, 2022

[51] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9242553/

[52] IBID

[53] IBID

[54] Michael Usher et al., Diagnostic Discordance, Health Information Exchange, and Inter-Hospital Transfer Outcomes: a Population Study, 2018

[55] Min Chen et al., Does Health Information Exchange Improve Patient Outcomes? Empirical Evidence from Florida Hospitals, 2019

care, would arise from increased access to primary care through the use of networked virtual care services arising from increased health data interoperability.[56]

Although these and other studies suggest that use of health information technology may have a positive impact on the effectiveness of medical outcomes,[57] there is less compelling evidence in the literature directly linking decreases in morbidity and mortality to enhanced health data interoperability.[58] For example, a 2022 systematic review of the impact of health information exchange on quality care found eleven studies indicating that the strength of evidence is low that health data interoperability reduces unplanned readmissions and mortality.[59] A paucity of conclusive evidence is thought to arise from the fact that this subject has not been adequately studied.[60]

EQUITY

> *Equity in health care is achieved when all individuals can attain their full potential for health and well-being.*

The Canadian government acknowledges that there are health inequities in Canada that are adversely impacting the health outcomes of select individuals and/or populations that are unfair, unjust, and modifiable.[61] Access to and/or capacity to use digital technology is recognized as an increasingly important portal to health service. The inability to engage with digital health technology or its services can adversely impact access to health service. *Digital health equity* is a subset of health equity and an aspirational goal that entails the mitigation of inequities arising from differential ability to engage with digital health services.

Digital health equity is a by-product of *social* and *digital determinants of health*.[62] Digital determinants of health (DDoH) are defined as "conditions in the digital environment that affect a wide range of health, functioning, and quality of life outcomes and risks."[63] Examples of DDoH include access to technology, digital literacy, and infrastructure (e.g., broadband internet). Canada exhibits shortfalls in a variety of DDoH. Almost 10% of Canadians and nearly 40% of those in rural and remote communities do not have access to broadband internet.[64] The Organisation for Economic Co-operation and Development (OECD) found that adult competency scores for digital literacy—such

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[56] Marco Hafner et al., The Potential Socio-economic Impact of Telemedicine in Canada, 2022

[57] Clemens Scott Kruse and Amanda Beane, Health Information Technology Continues to Show Positive Effect on Medical Outcomes: Systematic Review, 2018

[58] William R Hurse et al., Outcomes From Health Information Exchange: Systematic Review and Future Research Needs, 2015

[59] Sarah Dupont et al., Effects of Health Information Exchanges in the Adult Inpatient Setting: A Systematic Review , 2022

[60] https://medinform.jmir.org/2015/4/e39/PDF

[61] Government of Canada, Social Determinants of Health and Health Inequalities, 2023,
(https://www.canada.ca/en/public-health/services/health-promotion/population-health/what-determines-health.html)

[62] Safiya Richardson et al., A Framework for Digital Health Equity, 2022

[63] https://www.nature.com/articles/s41746-022-00663-0

[64] Government of Canada, Canadian Radio-television and Telecommunications Commission, 2023,
(https://crtc.gc.ca/eng/internet/internet.htm)

as numeracy and problem-solving skills in technology-rich environments—are unequally distributed in Canada, especially in areas with higher percentages of indigenous or immigrant populations.[65]

What this suggests is that capacity to achieve equitable health outcomes in Canada is dependent, in part, upon assuring that there is uniform ability for all Canadians to engage with digital health services. As access to internet connectivity and digital health literacy are domains of technical and human factor interoperability, universal person-centric health data interoperability is required to assure comprehensive health equity in Canada.[66] Stated more simply, Canada has clear health service inequities arising from inconsistent health data interoperability. What is less clear is what role differential access to health data interoperability has on acknowledged health outcome inequities in Canada.

TIMELINESS

> *Timeliness of care is the health care system's* capacity to provide care quickly after a need is recognized.

There are many anecdotal references that suggest achieving health data interoperability would result in more timely health service. The evidence to support this is less clear. Once more, this appears to arise from challenges and inconsistencies in efforts to study the impact of a complex entity like health data interoperability on one factor—time to health program and service—in a dynamic ecosystem.

Intuitively, having more efficient access to meaningful health data across digital health platforms should enhance efficiencies and improve timeliness to care. The 2022 *Canadian Interoperability Landscape Study* found that 92% of health care providers believe that "interoperability would enable safer patient care by having more complete, timely and accurate information at their disposal".[67] Yet there are risks inherent with interoperability that high volumes, or redundant data could be shared thereby overwhelming health providers and impacting time to care.[68]

In the Shared pan-Canadian Interoperability Roadmap (2023), Canada Health Infoway suggests that more timely information sharing would result in "fewer emergency visits and shorter hospital stays".[69] This is supported by a study that demonstrated that more timely health information exchange can

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[65] Marco Hafner et al., The Potential Socio-economic Impact of Telemedicine in Canada, 2022

[66] Ewan Affleck, Inequity in Digital Health Planning in Canada, 2022

[67] Canada Health Infoway, Canadian Interoperability Landscape Study, 2022, (https://www.infoway-inforoute.ca/en/component/edocman/6407-canadian-interoperability-landscape-study-executive-summary/view-document?Itemid=101)

[68] Daniel R Murphy et al., Notifications Received by Primary Care Practitioners in Electronic Health Records: A Taxonomy and Time Analysis, 2012

[69] Canada Health Infoway, Connecting you to Modern Health Care: Shared Pan-Canadian Interoperability Roadmap, 2023, (https://www.infoway-inforoute.ca/en/component/edocman/resources/interoperability/6444-connecting-you-to-modern-health-care-shared-pan-canadian-interoperability-roadmap)

improve processes and reduce resource utilization in the acute care setting.[70] Further, there is evidence that health information exchange was associated with improved timeliness of publication of reportable conditions.[71]

PERSON-CENTRICITY

Person-centered care is defined by the Academy of Medicine as care that is respectful of and responsive to individual patient preferences, needs, and values and ensures that patient values guide all clinical decisions.[72]

In Canada most clinical health data conforms to a service or *custodian-centric model*, meaning that the personal health information of any individual is broken up, or distributed in the separate charting systems of the health care providers or services that care for them. This pattern of data use arises from the custodial legislative framework used by all jurisdictions, that confers oversight and accountability for clinical health information to custodians as defined in Health Information Acts. Further the custodial model of health data oversight does not require custodians to seamlessly exchange health information, which results in a fragmented custodial-centric health data environment that very successfully fragments patient information.

Person-centric health data is a framework that expects the interoperable exchange of health information between all the providers and systems involved in the care of a patient over location and time (i.e., the patient's care team). This ensures that relevant health information is accessible to all authorized individuals involved in the person's care when it is needed. As it is unlikely and impractical that Canada or any of the jurisdictions will adopt a single universal charting solution, the only other way to achieve *person-centric health data architecture* is through wholly interoperable health data solutions. To achieve this all human and technical interoperability factors must be aligned in common purpose - a situation which does not currently exist in Alberta or Canada.

The quality domain of person-centricity also defines the obligation to respect the needs and preferences of the patient, which comes into play in concepts of access to and control over personal health information. In 1992, the Supreme Court of Canada ruled that personal health information belongs to the patient, suggesting that Canadians should have complete access to all their health information.[73] While a recent survey of the public found that 4 in 5 Canadians want access to their

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[70] Jordan Everson, Health Information Exchange Associated with Improved Emergency Department Care through Faster Accessing of Patient Information from outside Organizations , 2016
[71] Brian E Dixon et al., Completeness and Timeliness of Notifiable Disease Reporting: A Comparison of Laboratory and Provider Reports, 2017
[72] Institute of Medicine (US) Committee on Quality of Health Care in America, 2001,
(https://www.ncbi.nlm.nih.gov/books/NBK222265/)
[73] SCC -McInerny vs MacDonald

personal health information electronically, a full 31 years after the Supreme Court decision, only 3 in 10 currently have such access[74].

Thus, the concept of person-centricity is deeply linked to the premise of health data interoperability, both as a legal, professional, and architectural concept, and the framework is widely endorsed by many experts, including the Expert Advisory Group of the pan-Canadian Health Data Strategy[75] and the pan-Canadian Interoperability Roadmap.[76]

SUMMARY

In summary, a review of the literature on the impact of health data interoperability on the six domains of quality health programs and services, suggests that interoperability can:

- Improve the safety of health programs and services.
- Improve the efficiency of health programs and services.
- Result in long-term health sector cost savings.
- Improve the effectiveness of health programs and services.
- 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.

[74] Canada Health Infoway, Connecting the Health System: Connected Care. A Healthier Canada, 2022, (https://www.infoway-inforoute.ca/en/component/edocman/6413-connecting-the-health-system-connected-care-a-healthier-canada/view-document)

[75] 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)

[76] Canada Health Infoway, Shared Pan-Canadian Interoperability Roadmap, 2022, (https://www.infoway-inforoute.ca/en/component/edocman/6444-connecting-you-to-modern-health-care-shared-pan-canadian-interoperability-roadmap/view-document?Itemid=103)

CURRENT STATE

HEALTH DATA INTEROPERABILITY IN ALBERTA

A 2017 report on the integration of provincial health care from the Auditor General of Alberta stated, "there is no single comprehensive health record for a patient, and information is severely fragmented".[77] One key provincial health information exchange assets pre-existed the Auditor General report: Alberta Netcare, a central repository of select patient information that can be viewed by authorized health care providers. Since then, there have been meaningful improvements made in health information exchange in Alberta. The Community Information Integration and Central Patient Attachment Registry (CII/CPAR) is a government project to enable physician clinics and their teams to share patient information with Alberta Netcare directly from their electronic medical record (EMR). In October 2018 MyHealth Records, an online patient portal that allows Albertans 14 years of age and older to view select content (e.g., immunization records, medication history, and most lab results) from their own health records was launched. The provincial health authority, AHS, is currently deploying Connect Care, a single charting system across the entirety of its ecosystem. When complete, Connect Care will be a fully integrated and interoperable environment for health data under its custodianship, which accounts for about 30% of provincial health services. The Connect Care initiative also includes both provider and patient portals which enable patient access to their AHS managed personal health information, and Alberta licensed physicians' access to authorized clinical information. These efforts have all contributed meaningfully to the ability to share and view components of patient health information within and across diverse digital platforms.

However, substantive fragmentation of health data persists in Alberta. About 70% of health service is provided by community-based providers who are members of Alberta's 30 regulated health professions – including pharmacists, rehabilitation services, dentists, nurses, primary care physicians, and psychologists – who document health care information on proprietary charting software with limited capacity and an absence of a mandate to interoperate. The CII project is largely focused on integrating *physician-based* health data, and does not include patient information from independent private sector health services (e.g., rehabilitation, mental health, pharmacy), thereby perpetuating the fragmentation of health information across members of a patient's care team,[78] and adversely impacting team-based primary care.[79] The Connect Care deployment has also produced

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[77] Auditor General of Alberta, Better Healthcare for Albertans, 2017, (https://www.oag.ab.ca/wp-content/uploads/2020/05/2017_-_Better_Healthcare_for_Albertans_Report_-_May_2017.pdf)

[78] Alberta College of Pharmacy, Optimizing Virtual Care In Alberta, 2021, (https://abpharmacy.ca/articles/optimizing-virtual-care-alberta)

[79] Government of Alberta, Modernizing Alberta's Primary Health Care System, 2023, (https://www.alberta.ca/modernizing-albertas-primary-health-care-system)

concerns with patient safety arising from a lack of interoperability between the AHS ecosystem and community-based services.[80]

A 2020 consultant's report commissioned by the Government of Alberta stated "Alberta does not have an integrated EMR strategy to promote interoperability across the primary care sector."[81] Further it was noted that "changes to legislation and policy will need to be made to support EMR data sharing."[82] A government led initiative called the *eHealth Ecosystem Modernization Working Group (EMWG)* was struck in 2022 to advise on strategies to address community-based health data fragmentation, with a particular focus on technology solutions. However, there is no evidence of action being taken on the legislative front to address data fragmentation and there are currently no enforceable health data interoperability standards or regulations in the province of Alberta.

The Alberta government makes a significant investment in health innovation. Health Innovation relies on the collection, analysis, and interpretation of large-scale health data to inform insights that can lead to new treatments, interventions, and health system design. Population and public health, as well as health research and informed administration are similarly dependent on systemic data to drive evidence-based insights to serve population wellbeing and health system efficiency.[83] Persistent fragmentation of health information in Alberta arising from a lack of health data interoperability, promotes a poverty of usable data, and the attenuation of health innovation, research, and population and public health.

Alberta lacks a tradition of systematically evaluating provincial digital health technology or interoperability; it is challenging to adjudicate the impact of interoperability, or a lack thereof, if it is not evaluated. This extends to provincial evaluation of the impact of data fragmentation on the quality of health programs and services, which has been largely absent. An overview of the current public policy approach to health data interoperability in Alberta is represented in Tables 3 and 4. Table 3 summarizes current state interoperability in Alberta through the lens of human and technical factors. Table 4 addresses which forms of data-related harm are addressed in legislation and public policy in Alberta.

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[80] 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)
[81] IBID
[82] IBID
[83] Canadian Institute for Health Information, in collaboration with Canada Health Infoway, on behalf of the Conference of Deputy Ministers of Health, Better Information for Improved Health: A Vision for Health System Use of Data in Canada , 2013, (https://publications.gc.ca/collections/collection_2013/icis-cihi/H118-90-2013-eng.pdf)

TABLE 3: STATUS OF HEALTH DATA INTEROPERABILITY FACTORS ALBERTA   YES ☐   NO ☐

Human Factor Interoperability	Consideration	Alberta - Current State
Governance	Is there a harmonized approach to health data interoperability oversight across services, custodians, and jurisdictions, that establishes clear accountability, promotes quality programs and services, and mitigates data-related harm?	There is no provincial strategy to achieve comprehensive health data interoperability
		There is no clear accountability for the oversight of provincial health data interoperability
		There is no harmonization of the approach to health data interoperability across custodians, services, or health stakeholders
Legislation	Does health data legislation uphold a harmonized person-centric approach to health data interoperability that promotes quality programs and services and mitigates data-related harm?	There is robust health data privacy legislation
		The current custodial legislative framework promotes health data fragmentation
		There is no legislative framework mandating health data interoperability
		There is no health data unblocking legislation
		There is a perceived negative imperative for data sharing arising from current privacy legislation
		There is no legislation mandating patient access to their personal health information
Regulation	Is there a regulatory process for health information technology that mandates health data interoperability, promotes quality health programs and services and mitigates data related harm?	There are no processes or resources to regulate health data interoperability
		The design of health information systems and architecture is often carried out by unregulated professionals
		There is limited advocacy for health data interoperability from health professional regulators, nor consideration of the impact of data fragmentation on professional competency and provision of quality care
Policy	Do all stakeholders in the health sector craft and adopt policy that upholds a harmonized person-centric approach to health data interoperability that promotes quality programs and services and mitigates data-related harm?	Health data privacy policy is broadly adopted across health care custodians.
		There is inconsistent interpretation of health information legislation between custodians.
		There is no established process for the harmonization of health data interoperability policy between custodians
		There is often a primary emphasis on health data privacy and security in the policy interpretation of health information legislation

Literacy	Do the health workforce, the health sector leadership, and the public possess a clear understanding of the current state and value of health data interoperability and its capacity to promote quality programs and services and mitigate data-related harm?	There is minimal health data training for health sector professionals
		There is limited health data training for health sector leadership
		There are low levels of public health data literacy and no training
Communication	Is there transparent, broad, and clear communication between all health sector stakeholders, including the public, about accountability for, and nature of, health data interoperability?	There is limited public communication about the current state and importance of health data interoperability to their health and wellbeing
Culture	Is there a culture of trust and accountability to interoperability as a determinant of quality health programs and services that supersedes custodial, regional, private sector, or organizational agendas?	There is a service or custodian-centric culture of care
Technical Factor Interoperability	**Consideration**	**Alberta – Current State**
Content Standards	Are there common health data content standards that have been set, enforced, and adopted across the province to support health data interoperability?	There are no provincial data content standards
Data Exchange Standards	Are there a common health data exchange standards that have been set, enforced, and adopted across the province to support health data interoperability?	There are no provincial data exchange standards
Internet Connectivity	Is there universal internet connectivity across the province to support universal health data exchange?	Broadband connectivity is not universal. Remote and rural populations have noted shortfalls in connectivity.
Common User Authentication	Are there common digital identity standards for both providers and patients?	There is no method for provider and patient user validation across or between systems

TABLE 4: PUBLIC POLICY APPROACH TO FORMS OF HEALTH DATA HARM IN ALBERTA   YES ▮   NO ▮

Individual Harm	Consideration
Breach of personal health data privacy & security	There is robust privacy legislation to prevent harm
	There is robust regulation of technology to prevent harm
	The OIPC is tasked with ensuring compliance with privacy-related health information legislation
Damage to physical or emotional health and wellbeing through data misuse, non-use, or lack of data integrity	Health information legislation is permissive of information sharing, but does not obligate it to assure quality care; sharing of information to assure health and wellbeing is voluntary
	The custodial legislative framework fragments health data negatively impacting quality of care
	There is no regulation of technology to uphold health data interoperability
	There is no data unblocking legislation
	There is no individual or agency tasked with ensuring the health data in Alberta is designed and used to support the health and wellbeing of Albertans
Breach of cultural rights to personal health data	Indigenous data sovereignty is often not considered in health data legislation, or in health information technology strategies.
Breach of legal and ethical rights to personal health data	There is no legislative nor regulatory framework that mandates individual access to their personal health information

Population Harm	Current Alberta Public Policy Approach
Failure to benefit from science and use health data for public good	The custodial model of health data oversight impairs large data pooling needed to fuel population, research, innovation, and health system insights
	An absence of interoperability legislation and regulation promotes data fragmentation and negatively impacts insight from research, population health and innovation
Misuse of data to create misinformation or information that may be used to deceive or promote discrimination and/or inequities	Although there is no legislation specific to health data, there is human rights legislation, access to information legislation, common law, and consumer protection legislation that provides protection.

Current Alberta Public Policy Approach	
Failure to optimize health system function and efficiency due to poor data design, misuse, non-use, or lack of data integrity	System inefficiencies arising from health data fragmentation or lack of interoperability are rarely acknowledged or addressed in legislation or other public policy
Damage to health workforce wellbeing from poor data design and/or misuse, non-use, or lack of data integrity	There is limited acknowledgement on the part of professional regulators about the link between health workforce wellbeing and data fragmentation, nor advocacy to address this problem
	There is an absence of public policy assuring that health professionals are properly trained to understand the core importance of health data interoperability, and its impact on their wellbeing, and capacity to perform competently.
Failure to support health innovation through health data misuse, non-use, or lack of data integrity	The capacity for health information technology innovation to flourish is hampered by the unwieldy custodial / private sector health information construct that fragments health data and emphasizes privacy at the expense of other opportunities.

Health Data Interoperability in Canada

Canada Health Infoway, a federally funded not-for-profit organization responsible for accelerating the development and adoption of digital health solutions across Canada, has a long track record of promoting health data interoperability in Canada. In May 2023, Infoway released the Shared pan-Canadian Interoperability Roadmap[84] to advance pan-Canadian interoperability through Federal/Provincial/Territorial collaboration and strategic partnerships around "common pan-Canadian data, technical and policy standards". This plan is endorsed by the Conference of Deputy Ministers of Health except for the province of Quebec.[85] Bilateral agreements between the federal, provincial, and territorial governments are being established to fund this work among other priorities. However, it is recognized that these agreements and the associated provincial and territorial action plans are intended to be flexible to address local context. As part of this effort, provinces and territories will be asked to agree to adopt common standards and policies related to data appreciating that, "Canadians should be able to access their own health information and benefit from it being shared between health workers across health settings and across jurisdictions."[86]

The Shared Interoperability Roadmap supports and promotes a collaborative and focused pan-Canadian approach for addressing interoperability barriers. Historically, jurisdictions in Canada except for Ontario[87], have not taken a comprehensive standards-based or legislative approach to

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[84] Canada Health Infoway, Shared Pan-Canadian Interoperability Roadmap, 2022, (https://www.infoway-inforoute.ca/en/component/edocman/6444-connecting-you-to-modern-health-care-shared-pan-canadian-interoperability-roadmap/view-document?Itemid=103)
[85] IBID
[86] Government of Canada, Working Together to Improve Health Care For Canadians, 2023, (https://www.canada.ca/en/health-canada/news/2023/02/working-together-to-improve-health-care-for-canadians.html)
[87] Ontario Health, Digital Health Information Exchange Standard, (https://www.ontariohealth.ca/system-planning/digital-standards/digital-health-information-exchange)

health data interoperability. Unlike the United States, Denmark, and other countries where a defined legislative and regulatory approach is pursued, health data interoperability in Canada has largely been approached on an optional, regional, and sectoral basis, and has not been grounded in a vision for, or accountability to, person-centric health data.[88]

Interoperability Successes

Nonetheless there are instances of health information exchange and health data interoperability excellence in Canada, including:

- Diagnostic results and immunizations are almost completely standards-based and being shared digitally with ordering health care providers in Canada.[89]
- The pan-Canadian Patient Summary - based on the Integrating the Healthcare Enterprise (IHE) International Patient Summary (IPS) specification and the HL7 IPS Implementation Guide - is a health record extract comprised of a standardized collection of clinical and contextual information (retrospective, concurrent, prospective) including the minimum necessary and sufficient data to inform a patient's treatment at the point of care.[90] In October 2022, the first iteration of the PS-CA was reviewed and approved for trial implementation by a pan-Canadian collaboration table including representatives from five Canadian jurisdictions. Two jurisdictions are currently in the planning stage of implementation with additional jurisdictions reviewing their plans to consider the PS-CA as part of their digital roadmaps.[91]
- CIHI is leading an effort to set an interoperable *Primary Health Care Common Data Standard* and associated models and architecture in the *pan-Canadian Health Data Content Framework*.[92]
- eHealth Ontario has published EHR interoperability standards. However, they are not binding.[93]
- PrescribeIT, a national e-prescribing service, is an interoperability initiative that enables prescribers to electronically transmit a prescription directly from an electronic medical record to the pharmacy management system of a patient's pharmacy of choice.[94] There is a memorandum of understanding with all 13 provinces and territories to use PrescribeIT and the service is currently live in seven jurisdictions.

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[88] 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)

[89] Canada Health Infoway, Shared Pan-Canadian Interoperability Roadmap, 2022, (https://www.infoway-inforoute.ca/en/component/edocman/6444-connecting-you-to-modern-health-care-shared-pan-canadian-interoperability-roadmap/view-document?Itemid=103)

[90] Allana Cameron, PS-CA Interoperability Specifications, 2022, (https://infoscribe.infoway-inforoute.ca/display/PSCAV1TI/ImplementationGuide)

[91] Canada Health Infoway, Shared Pan-Canadian Interoperability Roadmap, 2022, (https://www.infoway-inforoute.ca/en/component/edocman/6444-connecting-you-to-modern-health-care-shared-pan-canadian-interoperability-roadmap/view-document?Itemid=103)

[92] IBID

[93] eHealth Ontario, Ontario EHR Interoperability Standards, (https://ehealthontario.on.ca/en/it-professionals/standards)

[94] PrescribeIT, (https://www.prescribeit.ca/about-us)

- Although not by definition interoperability, the Northwest Territories enterprise patient chart[95] and Alberta Connect Care[96] are instances where widespread intrinsic health information exchange is achieved through the deployment of single patient-centric charting systems.

Custodial Data fragmentation

These successes suggest not only that interoperability is technically and operationally achievable, but also illustrate the scattered nature of efforts to date that chiefly focus on the needs of a specific service or sector of the health system. Implicit in this is the failure to assure that health data in Canada is designed around and follows the patient or beneficiary of care. As observed by the Expert Advisory Group of the pan-Canadian Health Data Strategy, health data in Canada is largely designed around health services or custodians, in accordance with the custodial legislative approach taken by jurisdictional Health Information Acts.[97] The Expert Advisory Group of the pan-Canadian Health Data Strategy describe that a by-product of the custodial health information framework is the promotion of the fragmentation of health data. Further, Canada possesses no agreed upon standard for health data content and terminology; choice of terminology is optional and tends to be driven by industry need and differs according to the category of clinical application.[98] Electronic data exchange parameters are also not standardized in Canada.[99]

Regulation and Evaluation

The workforce that oversees the design and use of health data is not a regulated profession in Canada. Similarly, unlike other nations such as the United States, a fellowship in health informatics is not a recognized medical speciality in Canada. Both factors contribute to a poverty of knowledge on the part of those involved in designing health data systems. Further, there is limited attention by professional regulators to the impact of health data fragmentation on professional competency and provider burnout.

The Canadian Network for Digital Health Evaluation (CNDHE) was founded in 2022 to fill an acknowledged gap in the impact of digital health interventions on access, quality, and equity of care,

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[95] Paul Webster, Northwest Territories Leads Canada in Electronic Medical Record Coverage, 2017
[96] Alberta Health Services, ConnectCare, (https://www.albertahealthservices.ca/cis/cis.aspx)
[97] Pan-Canadian Health Data Strategy Expert Advisory Group, Building Canada's Health Data Foundation, 2021, (https://www.canada.ca/content/dam/phac-aspc/documents/corporate/mandate/about-agency/external-advisory-bodies/list/pan-canadian-health-data-strategy-reports-summaries/expert-advisory-group-report-02-building-canada-health-data-foundation/expert-advisory-group-report-02-building-canada-health-data-foundation.pdf)
[98] LOINC (Logical Observation Identifiers Names and Codes) for laboratory testing, ICD (International Classification of Diseases) for capturing mortality and morbidity information, CCI (Canadian Classification of Health Interventions) for capturing procedures and interventions, and SNOMED CT (Systematized Nomenclature of Medicine Clinical Terms) for capturing a variety of clinical information from health concerns to the latest immunization administered. Electronic exchange occurring today is largely HL7 v2, with more limited deployment of HL7 v3, CDA and FHIR.
[99] Canada Health Infoway, Shared Pan-Canadian Interoperability Roadmap, 202, (https://www.infoway-inforoute.ca/en/component/edocman/6444-connecting-you-to-modern-health-care-shared-pan-canadian-interoperability-roadmap/view-document?Itemid=103)

and to promote a common strategy for digital health evaluation across Canada.[100] This reflects that until recently there has been a paucity of research evaluating the impact of health data interoperability on the health and wellbeing of Canadians.

Jurisdictional Data Fragmentation

There is widespread divergence of provincial and territorial health data public policy, standards, and technology that impairs the exchange of data across jurisdictional boundaries and threatens the quality of health services for those reliant on cross-jurisdictional care, notably individuals in northern, rural, and remote Canada.[101] There currently is no commitment to, or established process for harmonizing health data public policy in Canada.

The Expert Advisory Group of the pan-Canadian Health Data Strategy was explicit in linking a lack of health data interoperability to "avoidable illness and death, low levels of innovation, perpetuation of health inequities, and ineffective responses to future public health threats."[102] The Expert Advisory Group went on to state that:

> At an extreme, there is a risk of irreparable fragmentation of health data that will harm individuals, communities, and all of Canada due to unaligned and often competing interests that may erode the common values and principles that have defined our health systems to date.[103]

Part of the challenge appears to be perceived confusion about who ultimately has the authority to assure harmonized pan-Canadian health data public policy in Canada. Health care oversight in Canada is constitutionally delegated to the provinces and territories. The *Canada Health Act*, federal legislation that defines the financial support of the federal government for provincial and territorial health services, states:

> That future improvements in health will *require the cooperative partnership* of governments, health professionals, voluntary organizations and individual Canadians[104]…and that continued access to quality health care without financial or *other barriers* will be critical to maintaining and improving the health and well-being of Canadians.[105]

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[100] Centre for Digital Health Evaluation, (https://cdhe.wchwihv.ca/network/)

[101] Pan-Canadian Health Data Strategy Expert Advisory Group, Building Canada's Health Data Foundation, 2021, (https://www.canada.ca/content/dam/phac-aspc/documents/corporate/mandate/about-agency/external-advisory-bodies/list/pan-canadian-health-data-strategy-reports-summaries/expert-advisory-group-report-02-building-canada-health-data-foundation/expert-advisory-group-report-02-building-canada-health-data-foundation.pdf)

[102] 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)

[103] IBID

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

[105] IBID

It follows that if the fragmentation of health data is understood to be a "barrier" to "maintaining and improving the health and well-being of Canadians", as supported by the pan-Canadian Health Data Strategy, then the "cooperative partnership of governments, health professionals, voluntary organizations and individual Canadians" in mitigating data fragmentation is a *requirement of the Canada Health Act*.

INTERNATIONAL HEALTH DATA INTEROPERABILITY COMPARATORS

United States

The United States formalized its commitment to promote national health data interoperability with the establishment of the Office of the National Coordinator for Health Information (ONC) by presidential decree in April 2004.[106] The ONC is mandated to promote health data interoperability through the development of standards, certification criteria, and interoperability frameworks. The Interoperability Standards Advisory (ISA), published by the ONC, is a comprehensive list of standards and implementation specifications that support health data interoperability, and cover multiple domains of health service including clinical services, public health, and research.[107] In 2016 the American government enacted the *21st Century Cures Act*, a broad legislative suite that addresses the promotion of health data interoperability through laws that:

- Prohibit "information blocking", which refers to practices that prevent or hinder the sharing of electronic health information.
- Mandate health information technology vendors to provide patients with access to their personal health information though standardized Application Programming Interfaces (APIs).
- Set criteria for the certification of health information technology products that uphold health data interoperability capability.
- Establish a Trusted Exchange Framework and Common Agreement (TEFCA) to facilitate nationwide principle-based health data interoperability by the ONC.[108]

The American legislative and standards-based approach to health data interoperability is not optional. It demonstrates a clear recognition by the United States that achieving health data interoperability requires robust public policy, defined governance, and clear regulation.

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[106] 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)
[107] Office of the National Coordinator for Health Information Technology, (https://www.healthit.gov/isa/about-isa#:~:text=The%20Interoperability%20Standards%20Advisory%20is,needs%20in%20the%20United%20States)
[108] Michael Lipinski and Mark Knee, 21st Century Cures Act: Interoperability, Information Blocking, and the ONC Health IT Certification Program Proposed Rule, 2019, (https://www.healthit.gov/sites/default/files/facas/2019-03-22_ONC_Cures_Act_NPRM_IB_%20HITAC_IB_Task_Force_508.pdf)

Denmark

Denmark actively promotes health data interoperability through a collaborative effort involving a broad set of stakeholders, including government agencies, healthcare providers, technology vendors, and patient organizations. Health data interoperability was first cited in a national eHealth strategy tabled in 1994, that prioritized the electronic exchange of pertinent health data between health providers.[109] The primary goal of the strategy was to enable the secure and seamless exchange of health information across different Danish healthcare systems and organizations by setting clear data architecture and compliance standards as enshrined in the *Danish Health Act*.[110] By promoting interoperability, Denmark aims to improve care coordination, enhance patient outcomes, and support innovation in healthcare delivery.

The principal features of the Danish approach are:

- *National health data exchange standards* that enable consistent and standardized exchange of health information across different healthcare systems and applications.
- *Common data content standards* which define a person-centric structure and format of health data and ensure that data can be exchanged in a consistent and meaningful manner, regardless of the underlying technology or systems.
- *A robust health data exchange infrastructure* that includes secure networks, protocols, and technical frameworks that enable the secure and efficient exchange of health information between different stakeholders.
- *A governance model and supporting policy suite* including defined roles, responsibilities, and rules for data sharing, privacy protection, and consent management to health data interoperability standards.
- *Collaborative partnerships* between stakeholders, including healthcare providers, technology vendors, and patient organizations aimed at identifying common challenges, share best practices, and develop solutions that promote health data interoperability.
- A *universal patient portal* that allows the public to access personal health information pertaining to their diagnoses, book appointments, renew prescriptions and determine which service providers can view which of their personal data.
- A *unique patient registry* for all residents of Denmark which is used across all data bases.

These initiatives are sustained and enabled by a common 'culture of care' that is distinguished by:

- A government coordinated, sustained, and principle-based approach to public health data strategy and investment dating back three decades.

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[109] European Observatory on Health Systems and Policies, Health and Care Data: Approaches to Data Linkage for Evidence-informed Policy, 2023, (https://eurohealthobservatory.who.int/publications/i/health-and-care-data-approaches-to-data-linkage-for-evidence-informed-policy)
[110] International Labour Organization, 2005, (https://www.ilo.org/dyn/natlex/natlex4.detail?p_isn=70825)

- Strong health workforce data skills that ensure professional and meaningful data design, management, and analysis.
- Legislation that ensures a balance between personal data protection and use of data for public good.
- A strong commitment to promote collective good through data science.
- A long tradition of harmonious private and public partnerships.

Moreover, Danes have a high level of trust in the country's leadership; there is an implicit societal contract with the population that states that when you access the health system and receive treatment, you consent to the collection and use of your health data for both the improvement of your personal care, and the welfare of other patients and the Danish population.

The Danish approach to health data interoperability demonstrates a constructive effort to address both human and technical factors through collaborative partnership toward a collective goal of enhancing the quality of health programs and services.

Summary

A comparative analysis of the state of health data interoperability maturity in Alberta, Canada, the United States and Denmark is found in Table 5.

TABLE 5: COMPARISON OF HEALTH DATA INTEROPERABILITY STATUS IN ALBERTA, CANADA, THE UNITED STATES AND DENMARK FOR SELECT HUMAN AND TECHNICAL INTEROPERABILITY FACTORS.

YES ■ SOMEWHAT ■ NO ■

Health Data Interoperability Factor	Alberta	Canada	United States	Denmark
Governance				
Does health data oversight promote a harmonized approach to health data interoperability across jurisdictions, nations and custodians that promotes quality programs and services and mitigates data related harm?	There is no systematic strategic provincial approach to health data interoperability. / There is no clear accountability for the oversight of Alberta health data interoperability. / There is no harmonization of approach to health data interoperability across custodians.	There is a national body that promotes health data interoperability (CHI), but it lacks jurisdictional or national authority. / There is no clear accountability for the oversight of pan-Canadian health data interoperability. / There is advocacy for harmonization of approach to health data interoperability across jurisdictions.	There is an identified oversight group that is accountable for national health data interoperability. / There is clear accountability for the oversight of American health data interoperability.	There is an identified oversight group that is accountable for national health data interoperability. / There is clear accountability for the oversight of Danish health data interoperability.

Legislation

Does health data legislation uphold a harmonized person-centric approach to health data interoperability that promotes quality programs and services and mitigates data related harm?	The current custodial legislative framework promotes health data fragmentation. There is no provincial legislative framework mandating health data interoperability. There is no health data unblocking legislation. There is a perceived negative imperative for data sharing arising from privacy legislation.	The current jurisdictional custodial legislative framework promotes health data fragmentation. There is no federal legislative framework mandating health data interoperability. There is no federal health data unblocking legislation. There is a perceived negative imperative for data sharing arising from privacy legislation.	There is federal legislation obligating health data interoperability including unblocking legislation.	There is national legislation obligating health data interoperability.

Culture

Is there a culture of accountability to interoperability as a determinant of quality health programs and services that supersedes any jurisdictional, regional, custodial, or organizational agendas?	There is a service or custodian-centric culture of health data oversight and accountability as opposed to a patient-centric culture.	There is a service and jurisdiction-centric culture of health data oversight and accountability, as opposed to a patient-centric culture.	There is a dissonance between the national efforts to promote person-centric health data interoperability and state and vendor-based efforts to retain control over health data.	There is a culture of cooperation around health data interoperability between the government, health services, and private sector vendors.

Content Standards

Are there common data language standards that have been set, enforced, and adopted across all health sector platforms?	There are no mandated and enforced provincial health data content standards.	There are no mandated and enforced federal health data content standards	There are mandated and enforced federal health data content standards. Common data content standards have not been universally adopted.	There are mandated and enforced national health data content standards. Common data content standards have been universally adopted.

Data Exchange Standards

Are there a common health data exchange standards that have been set, enforced, and adopted across all health sector players?	There are no mandated and enforced provincial common data exchange standards.	There are no mandated and enforced federal common data exchange standards	There are mandated and enforced federal common data exchange standards Common data exchange standards have not been universally adopted	There are mandated and enforced national common data exchange standards Common data exchange standards have been universally adopted

BARRIERS

To craft an informed approach to health data interoperability in Alberta, potential barriers to interoperability have been identified. Barriers are defined as issues or factors that may obstruct the capacity to implement health data interoperability to support the provision of quality health programs and services. The identification of potential barriers can inform the strategic approach to interoperability design and deployment.

The approach taken by the Health Data Interoperability Working Group was to categorize potential barriers according to the domains of human and technical factor interoperability. Potential or perceived barriers are noted in point form.

Health Data Governance

- There is currently no defined authority or body that oversees health data interoperability in Alberta. Although some perceive that Alberta Health bears this responsibility, this authority has not been asserted, and without enacting legislative change, the government currently lacks the authority to require that custodians comply with any interoperability standards that are set.
- The need to define an entity that is accountable for health data interoperability is not broadly recognized. Without clear accountability to a defined agency or group progress will be impeded.
- Electoral and capital funding cycles can interrupt the strategic progress of issues like health data interoperability that demand long term vision and investment.
- There can be a lack of willingness or mechanisms to work collaboratively across agencies and stakeholder groups toward a common and defined goal such as health data interoperability. There is no shortage of expertise in health data interoperability in Alberta, Canada, or around the world, but seemingly a lack of either interest or ability to leverage this expertise.

Health Data Legislation

- The custodial legislative framework promotes the fragmentation of health data, and in its current form presents an obstacle to health data interoperability.
- There is often a reluctance, or even a broad perception that legislation cannot be changed and is sacrosanct, even when that legislation may be harming individuals, populations, and the health care system.
- Current health data legislation addresses issues of privacy and security, while remaining largely silent on virtually all other forms of data-related harm. The de-emphasis of some forms of data-related harm can skew the perception of the importance of health data interoperability.

Health Data Policy

- There is no mechanism for the harmonization of data policy across health services and stakeholders. Variation in policy interpretation can promote a service or custodian-centered approach to health data use and impair cooperative health data interoperability.

Health Data Regulation

- There is no tradition of regulating health data interoperability, and no existing resources or mechanism for doing so.
- There is a perceived reluctance on the part of large digital health vendors to adopt health data interoperability standards, potentially arising from concern about financial obligations, and impact on proprietary data assets.
- The Colleges that regulate health professions have not been vocal about the importance of health data interoperability as a determinant of professional competency, nor does this appear to be recognized as a pertinent issue by many professions.
- The workforces that are involved in designing health data systems are for the most part non-regulated, meaning that there is no quality-assurance of the skill set required to competently design interoperable health data systems.
- There may be a lack of financial and knowledge resources required to support health data regulation.

Health Data Literacy

- There is a systemic deficit in the understanding of the forms of health data-related harm that arise from health data fragmentation or lack of interoperability.
- There is a global lack of understanding in the health sector about the importance of person-centric health data design as an architectural underpinning of health data interoperability.
- There is a lack of health data literacy among *health care providers* and *leadership*, arising from limited training in health informatics in education programs. This translates into a lack of understanding of the central importance of health data interoperability, and the oversight of health data design by those who may not be qualified.
- There is a lack of academic and applied research in digital health, and specifically a lack of evaluation of health data interoperability which impairs the capacity to inform evidence-based interoperability strategy.
- There is a lack of a standardized approach to health data interoperability evaluation.

Health Data Communication

- There is a virtual absence of communication from the health sector to citizens about the state of health data fragmentation, and the impact of a lack of interoperability on citizen, population, and health system wellbeing.

Health Data Culture

- In Alberta and Canada, there is a *service-centric culture of health data* oversight and use that is reified in legislation by the custodial legal framework. This impairs forward progress on person-centric health data interoperability.
- There is the perpetuation in the Canadian health care sector that health service is "patient-centric", which does not reflect the reality that health data is designed around services and custodians.
- There are perceived threats to autonomy and power with the loss of control of health data by some custodians and technology vendors that may impair advances in interoperability.

Common Data Standards

- There may be a reluctance by some parties, notably large vendors, to accept common data standards.
- Some health sector stakeholders and custodians may have vested interests in health data control that make them reluctant to support common data standards and interoperability.
- There may be a lack of financial resources to support the development and maintenance of common data standards.

Internet Connectivity

- A lack of uniform internet connectivity impairs comprehensive health data interoperability, particularly in rural and remote Alberta.
- There may be a lack of financial resources to deploy universal internet connectivity.

OPTIMIZED HEALTH DATA INTEROPERABILITY STATE

Establishing a common vision or set of principles for the design of an optimized health data interoperability state was accomplished by surveying all Working Group members and consolidating feedback. This was then cross-referenced with best practices, and evidence in the literature. There was a high degree of consensus among Working Group members. Where there was divergence, a consensus was reached through discourse.

The idealized health data interoperability design principles are organized according to report *Key Imperatives*:

- Accountability to quality health programs and services
- Data-related harm mitigation
- Human and technical factor interoperability

PRINCIPLES OF HEALTH DATA INTEROPERABILITY DESIGN

01 | Accountability: Interoperability and Quality Health Programs and Services

    a. The vision for interoperable health data is founded upon the ultimate accountability to quality health outcomes delivered through *safe, timely, effective, efficient, equitable and person-centric* health programs and services.

    b. To achieve accountability for quality health programs and services (1.a.), data interoperability must be designed to promote informed decision-making at all levels of health service, including clinical services, public and population health, research, management, innovation, and oversight.

02 | Mitigation: Interoperability and Data-Related Harm

    c. Health data interoperability must be designed to minimize all forms of health data-related harm including:
        i. Individual harm
            a. Threats to physical and mental wellbeing
            b. Threats to personal privacy and security
            c. Threats to cultural wellness

> d. Threats to legal, ethical, and constitutional rights
>
> ii. Population-based harm
>> a. Threats to the use of health data for public good
>> b. Promotion of inequities or discrimination through inappropriate use of pooled health data
>
> iii. Health system harm
>> a. Threats to health sector cost and sustainability
>> b. Threats to health workforce wellbeing
>> c. Threats to health innovation

03 | Human Factor Interoperability

d. Governance

i. Health data interoperability standards are set and maintained by a competency-based multidisciplinary group of representative health sector stakeholders that include meaningful public and Indigenous representation.

ii. Accountability of the oversight group is to an agreed upon vision for interoperability, not to any specific organization or stakeholder group.

iii. The public has meaningful inclusion in the oversight of health data interoperability.

iv. There is an evergreen process to assure health data interoperability standards are up to date.

v. In support of person-centric health data, quality health programs and services, and to leverage economies of scale, inter-jurisdictional (Federal, Provincial, Territorial / First Nations, Inuit, Metis) harmonization of health data interoperability standards is sought.

vi. First Nations, Inuit, and Metis data sovereignty is considered in all health data interoperability design specifications.

e. Legislation and Policy

i. Health data interoperability is legislated, mandated and enforced through regulation. Specifically, consideration is given to:
>> a. Legislated common data content standards.
>> b. Legislated common data exchange standards.
>> c. Legislated data unblocking.
>> d. Legislated citizen access to their personal health information.

ii. Health data interoperability legislation fosters digital health innovation.

iii. The approach to health data interoperability upholds citizen access to personal health information and is framed around the patient and the patient's care team.

iv. Citizens can view who has accessed their personal health information and understand how it is used.

f. Regulation
  i. An independent health data regulatory agency monitors/evaluates health data interoperability for the purposes of quality control and continuous quality improvement.
  ii. Universal standards for roles-based access to health information achieve a nuanced balance between data sharing and protection.
  iii. Professional health regulators recognize the foundational need for interoperability as a determinant of member competency.
  iv. Access to health data for clinical purposes occurs on a need-to-know basis by members of the patient's care team.
  v. The oversight and design of health data, including interoperability is carried out by regulated professionals licensed to do so.

g. Literacy
  i. Health care providers and leadership are data literate, including core knowledge of data interoperability, assured through evidence-based training, accreditation, and regulation.
  ii. Public health-data literacy is fostered, including a sound understanding of the fundamental right of individuals to their personal health information, and the collective accountability of the health sector to the mitigation of individual, population and system data-related harm.
  iii. A universal and standard health data lexicon supports health data interoperability.
  iv. An academic tradition of applied digital health evaluation - a *learning health system* - informs health data interoperability.

h. Communication
  i. There is open and transparent communication about the value and potential harm of health data interoperability with all stakeholders.

i. Culture
  i. Private health data technology vendors and the public sector health providers work in partnership to achieve interoperable health data for public good.
  ii. Partnership between custodians, vendors, levels of government and jurisdictions around interoperability is embraced.
  iii. Accountability to evidence-based interoperability across health sector stakeholders informs system design.

j.   Syntactic interoperability is required with a long-term goal of semantic interoperability.

k.   Universal data content and exchange standards are selected and enforced.

l.   Technology procurement standards support health data interoperability.

m. There are simple and standardized procedural and technical processes to monitor and revoke health data access.

n.   There are technical mechanisms for pooled de-identified health information and data to be available for population-based analysis for public good.

o.   There are universal provider and patient registries to support health data interoperability.

p.   There is universal internet connectivity.

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
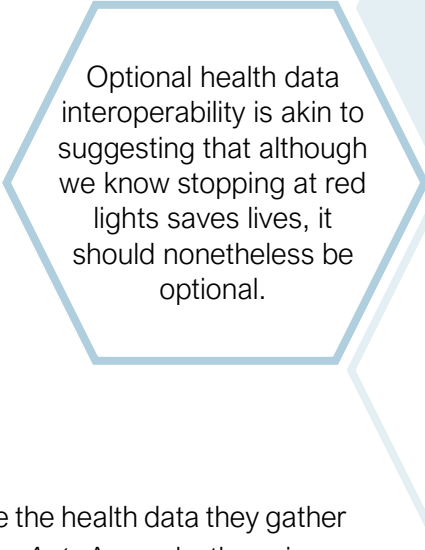
YES ▉ NO ▉

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 Better use of tax dollars through improved health sector efficiency Support for improved equity of care Improved access to personal health records	Damage to physical or emotional health and wellbeing through data fragmentation, non-use, or lack of integrity Breach of legal and ethical rights to personal health data Poor use of tax dollars
Government	Decreased health sector cost Improved capacity to make data (evidence) informed health sector decisions (learning health system)	Difficulty optimizing health system function and efficiency due to poor data design, misuse, non-use, or lack of data integrity Difficulty making data (evidence) informed decisions and using health data for public good
Health Authorities	Decreased health service cost Improved capacity to make data (evidence) informed management decisions (learning health system)	Difficulty optimizing health system function and efficiency due to poor data design, misuse, non-use, or lack of data integrity 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 Improved capacity to make evidence-based (data) decisions Decreased health workforce burnout	Ongoing challenges providing quality care because of poor data design, access, or lack of data integrity Increased health workforce burnout arising from poor data design or lack of data integrity 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 Promotion of health workforce wellbeing	Increased health workforce burnout arising from poor data design or lack of data integrity 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 in 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 heath 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*".[111] 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.

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[111] 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.

RECOMMENDATIONS

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:
- f) mandatory health data content standards
- g) mandatory health data exchange standards
- h) health data unblocking legislation
- i) mandatory patient access to personal health information though standardized Application Programming Interfaces (APIs)
- j) 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*[112] 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.

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[112] Canadian College of Health Information Management, Health Data Charter, 2022, (https://cchim.ca/wp-content/uploads/2022/11/Health-Data-Charter.pdf)

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,[113] should replace the custodial model of health data legislation.
12	Alberta, in conjunction with CIHI, and other jurisdictions and partners should develop metrics for measuring and evaluating indices of health data-related harm and benefit.
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 include 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.

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[113] IBID

CONCLUSION

Comprehensive health data interoperability will enhance health programs and services, including virtual care, resulting in the improved health and wellbeing of Albertans and Canadians. 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, meaning that there is no justification for not pursuing interoperability as a strategic priority. In short, health data interoperability is imperative, and should be *mandated and regulated*, both in Alberta and Canada.

The source barriers to achieving comprehensive health data interoperability are *human* not technical. In simple terms, this means that the lack of ability of health sector stakeholders to agree on harmonized health data governance, legislation, public policy, and regulation is obstructing the capacity to achieve comprehensive health data interoperability, and damaging Albertans and Canadians. Intersectoral cooperation around a set of evidence-based human and technical factor interoperability design standards is the best approach to overcome this impasse. The meaningful inclusion of public and Indigenous representation at all levels of this strategy, including oversight, must be obligate.

In this effort, Alberta health sector stakeholders should harness the substantive health data interoperability human and knowledge resources both Alberta and Canada have to offer. Provincial, interjurisdictional, and pan-Canadian partnerships are not only encouraged because of accountability to the *Canada Health Act* and the principles of *portability and universality*, but because achieving comprehensive health data interoperability by its very nature will be easier to realize if we all *choose to interoperate* rather than build barriers to cooperation. This should not be a difficult choice; either we interoperate in support of our collective accountability to the delivery of quality health programs and services, or we perpetuate data-related harm arising from the fragmentation of health data around our own services and jurisdictions. The choice for our province seems clear; let us lead by working cooperatively to build comprehensive health data interoperability that will benefit all Albertans, the health workforce, and serve as a model for partners across Canada.
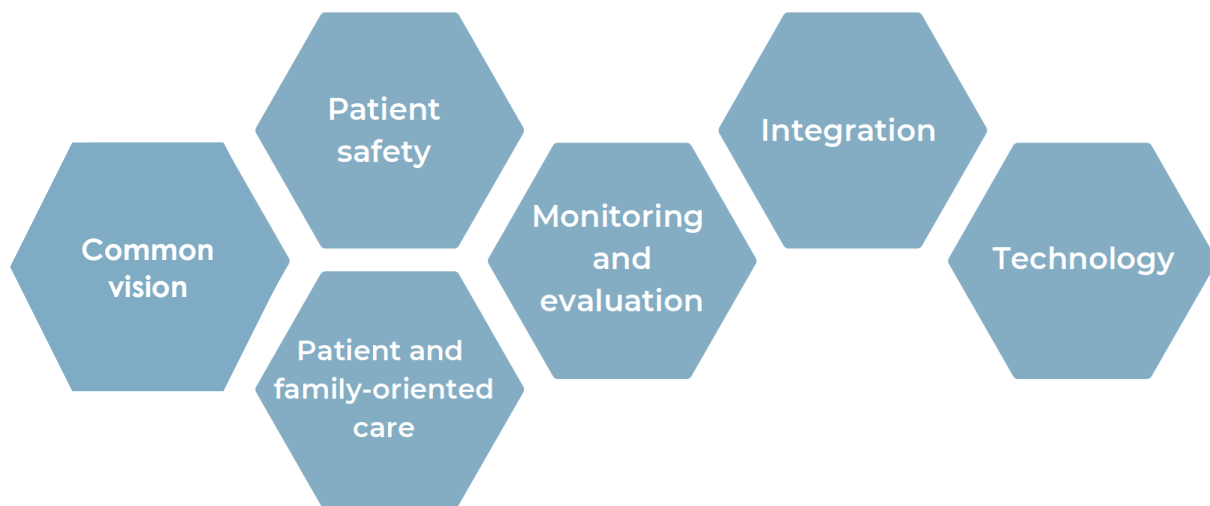
APPENDIX 1 – DESIGN PRINCIPLES

ALBERTA VIRTUAL CARE DESIGN PRINCIPLES

Virtual care Design Principles were developed based on the agreed characteristics of an idealized virtual care system. They dictate clear parameters for virtual care that, taken together, present a collective vision for an optimized virtual care system. The Design Principles can serve as a unifying blueprint for enterprise system design and oversight.

The Design Principles are aspirational, and demand a standard for virtual care accountability, function, and performance that is currently not achieved by general in-person health service. The consensus was that the current state health system shortfalls should not limit aspirational principles needed to promote excellence in virtual care.

The virtual care Design Principles were organized into six sections that focus on:

Common vision / Patient safety / Patient and family-oriented care / Monitoring and evaluation / Integration / Technology

01 | There is a common vision for Alberta virtual health care

   a. The vision for virtual care is founded upon the ultimate responsibility to provide quality care; meaning safe, timely, effective, efficient, equitable, and person-centric virtual care.

   b. A collaborative Coordinating Body of representative stakeholders should advise on virtual care system design and high-level direction.

c. Virtual care design principles should align with and inform the overarching provincial eHealth strategy.

d. Healthcare standards, policy and legislation, and the virtual care vision should be transparent, in alignment and mutually supportive.

e. Virtual care design principles should be supported by a nimble strategic approach that is responsive to the complex, dynamic health, and technology industries.

02 | Virtual care service will be safe

a. The competency of providers to deliver safe virtual patient care should be assured through training, licensure, and regulation.

b. The capacity of virtual care technology to deliver safe patient care should be assured through standards and monitoring.

c. Health information for virtual patient care should be comprehensive and accessible to providers as permitted by privacy legislation and standards.

d. Personal health information used in virtual care should be private and secure.

03 | Virtual care will be patient and family-oriented

a. Patients and families should be recognized and included core members of virtual healthcare teams.

b. Patients should have meaningful representation at all oversight levels of provincial virtual care.

c. Health information flow and retention should be designed to follow the patient through their entire health journey.

d. Patients, as information owners, should have access to their complete and composite health information.

e. Patients and their family should have training and knowledge resources to promote virtual care literacy.

f. Equitable access to virtual care services and resources should be a long-term goal.

g. Virtual care must function to uphold principles of Indigenous data sovereignty.

04 | Virtual health care will be integrated at all levels of health service provision

a. Virtual healthcare service should enhance continuity by integrating with, complimenting, and optimizing in-person health services, not replacing them.

b. Virtual care should support bidirectional communication between any two or more members of a patient's circle of care.

c. Virtual care user support and training should be standardized and integrated across services.

d. Virtual care technology should be interoperable and functionally integrated.

e. Virtual care technology and information workflow should support and promote team-based care.

f. All members of a circle of care should be trained to provide collaborative virtual care over distance and time.

g. Interjurisdictional virtual care for Albertans should be accountable to these Design Principles.

05 | Virtual care will support ongoing monitoring and evaluation

a. Data and experience gathered through the provision and management of virtual care should be used for the purposes of continuous quality improvement.

b. The evaluation and oversight of virtual care services should be transparent to appropriate stakeholders, including patients, and subject to regular reporting requirements.

06 | Virtual care technology will foster quality health service

a. Virtual care system Design Principles should drive technology requirements.

b. Virtual care Design Principles should be vendor agnostic.

c. Virtual care technology should be designed to decrease workflow complexity and promote ease of use for providers and patients.

d. Virtual care technology procurement should be transparent and follow set standards that uphold quality care, fairness, and promote innovation.