



DISCONNECTED CARE

The impact of the *Alberta Health Information Act* on the health and well being of Albertans

Alberta Virtual Care Coordinating Body
Interoperability Phase II Working Group

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STATEMENT OF ACCOUNTABILITY


The reports of the Alberta Virtual Care Coordinating Body (AVCCB) are the product of cooperative principle-based collaboration across diverse members of the public and those working in the health field to promote quality health programs and services that will benefit all people receiving care in Alberta and Canada.

Participation of an individual in an AVCCB project, including the publication of a report, does not indicate endorsement of the content of the report by the institution or organization that employs the individual.

Institutional and organizational participation in and endorsement of AVCCB efforts is welcomed and encouraged in support of collective accountability to quality health programs and services.

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FOREWORD

In our increasingly interconnected world, health information lies at the core of effective, efficient, and equitable health care delivery. In Alberta, the existing *Health Information Act* has, for over 20 years, provided the framework for navigating the delicate balance between protecting personal privacy and enabling the use of data to improve care, inform research, and support innovation. Yet, as our health care landscape evolves, it has become increasingly clear that the current legislation must be reassessed—not only to address the complexities of modern care, but also to confront the tangible harm that can arise when we fail to fully leverage health data to inform and improve outcomes.

This report from the Alberta Virtual Care Coordinating Body (AVCCB) offers a timely and thorough examination of the current *Health Information Act*. By evaluating its impact across a range of settings, this report sheds light on how the Act supports—or limits—the flow of health information that is critical for advancing care and meeting the needs and expectations of Albertans. It also highlights the challenges and opportunities inherent in updating our policies to better align with digitized health care delivery and the evolving needs of our communities.

As an academic and advocate for evidence-informed policy, I believe this report represents an opportunity to think boldly about the future of health information in Alberta. It emphasizes the need for policies that not only adapt to the realities of today, but also anticipate and prepare for the challenges of tomorrow. The thoughtful insights presented here invite us to reimagine how health information can be governed to foster quality health programs and services, while minimizing all forms of health data-related harm in service to all Albertans.

I invite policymakers, health care leaders, and every Albertan with a stake in our health system to engage deeply with the findings and recommendations presented here. Let this report be a catalyst for meaningful dialogue and actionable change, ensuring that Alberta's health information policy empowers care teams, advances patient outcomes, and upholds the values of privacy, respect, and equity.

Together, we can build a system that meets the needs of today while preparing for the challenges and opportunities of tomorrow.



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ABOUT THE ALBERTA VIRTUAL CARE COORDINATING BODY

Disconnected Care is a report from the Alberta Virtual Care Coordinating Body (AVCCB) intended to contribute evidential consensus-based insight into potential reform of the *Health Information Act* (HIA).

The AVCCB is an independent advisory committee created by its sponsoring stakeholders to promote principle-based health data governance, public policy, workflow, and technology alignment across the health sector.

Through broad stakeholder engagement, the AVCCB engages in multiple issue-specific projects intended to contribute to the promotion of quality health programs and services. Taken together, these projects are meant to frame a systematic, comprehensive, and evidential approach to health data design and use that fosters the health and wellbeing of Albertans and Canadians.

For more Information please see: <https://www.albertavirtualcare.org/>

INTRODUCTION

The *Health Information Act* (HIA) - Alberta's primary legislation governing health information - is designed to strike a balance between limiting information sharing to protect personal privacy and enabling information sharing for the effective management and delivery of health services. The stated purpose of the HIA is to govern and regulate the “access to and collection, use, and disclosure of health information” by:

- Protecting the privacy and confidentiality of health information;
- Providing Albertans with the right to access their own health information and to request corrections;
- Regulating the information accessible through Alberta's Electronic Health Record (Alberta Netcare); and
- Enabling health information to be accessed and shared to provide health services and manage the health system.¹

The HIA came into force on April 25, 2001, prior to the large-scale emergence of digital health information technology. In subsequent years, with the advent of increasingly powerful digital health information tools, opportunities to enhance both primary and secondary health data use, and shortfalls made evident by the COVID-19 pandemic, the need to adapt public policy to optimize the design and use of health information is manifest. The benefit of integrated health data that can follow patients over time and location while empowering clinical care, population health, research, and health system management has become increasingly clear.

Experts warn of the negative repercussions of data fragmentation in Canada. In 2022, the Competition Bureau of Canada observed that “*disparate privacy and data governance rules across provinces and territories can reduce data sharing among health care providers, impede innovation and lower the adoption of digital health care solutions.*”² This reflects a growing consensus that the fragmentation of health data in Canada can result in widespread harm to individuals, populations, and health system function, and that most forms of health data-related harm are unchecked and overlooked in public policy.³

Accompanying this growing concern is a movement to reevaluate health data public policy, such as health information acts, to assure that they function to best support the dual goals of protecting

¹ Government of Alberta, Health Information Act guidelines and practices manual, Updated April 1, 2021, <https://open.alberta.ca/publications/9780778582922>.

² Government of Canada, Competition Bureau Canada, Updated December 16, 2024, <https://ised-isde.canada.ca/site/competition-bureau-canada/sites/default/files/attachments/2022/04669-DHC-Market-Study-Part-1-Eng.pdf>.

³ Affleck, E. et al., Interoperability Saves Lives, 2023, https://www.albertavirtualcare.org/_files/ugd/3eb345_8a8a4fa4037540698f90a23825b7c328.pdf.

access, privacy and security of health information while fostering quality health programs and services. Several Canadian provinces including Quebec, Ontario, and Newfoundland have recently engaged in health information act reform efforts.

In the spring of 2024, the government of Alberta indicated that the provincial HIA would be opened and amended subject to a consultation process. In response, and in the spirit of transparent, evidential, and principle-based public policy, the AVCCB launched a working group to evaluate the Alberta HIA and contribute by offering policy reform recommendations framed around an accountability to the health and wellbeing of Albertans.

A STATEMENT ABOUT PAN-CANADIAN HEALTH DATA HARMONIZATION

Albertans frequently travel outside the province and sometimes require medical services from adjoining jurisdictions. Yet digitally integrated personal health data does not follow Albertans across jurisdictional boundaries, meaning that critical information may be missing when an individual requires care in another jurisdiction, putting their health at risk. The lack of portability, universality, comprehensiveness and accessibility of health information across Canadian jurisdictions violates the spirit and intention of the *Canada Health Act*.⁴

The Pan-Canadian Health Data Charter, endorsed by the government of Alberta in October 2023, calls for “*person-centric health information design to ensure that health data follows the individual across points of care to support individual, clinical, and analytical access and use while respecting individual privacy with regard to the handling of their information under existing privacy legislation*”.

Although this report is focused on the Alberta HIA, to truly uphold person-centric health data design and honour the health needs of Albertans and other Canadians, there must be efforts to harmonize health data policy - including health information acts – across all Canadian jurisdictions. In this report, the authors have made every effort to honour the fundamental value of person-centric health data design by evaluating the Alberta HIA in a manner that promotes the long-term goal of pan-Canadian health data public policy harmonization.

⁴ Affleck, E. et al., Data Disarray – A Root Cause Analysis of Health Data Dysfunction in Canada, 2024, https://www.albertavirtualcare.org/_files/ugd/3eb345_85ada6635d334c2ba6c102bdd57f20e2.pdf.

EXECUTIVE SUMMARY

A comprehensive evaluation of the impact the Alberta *Health Information Act* (HIA) on the health and wellbeing of Albertans was carried out by comparing current policy performance to the Act's core accountabilities to:

- The *Canada Health Act* (CHA), which defines the anchoring objective of all health care policy in Canada.
- The Pan-Canadian Health Data Charter, which defines the principles of optimized health data design and use in Canada and was endorsed by the government of Alberta in October 2023.⁵

The CHA unambiguously defines the essential and unifying accountability of all health care public policy, including the Alberta HIA, to the provision of quality health programs and services.⁶ This suggests that the stated purpose of the HIA to uphold the safe “access, collection and disclosure of health information”, must be achieved in a manner that *also* fosters the quality of health programs and services, including the provision of safe care to Albertans. Stated more succinctly, the HIA shares dual foundational accountabilities to assure:

- The safe access, collection, and disclosure of health information; and
- The quality and safety of health programs and services.

Implicit in the effort to promote quality health programs and services is the need to minimize harm to patients and populations resulting from poor data access or integrity. For the purposes of this report, harm is defined according to the nine categories of health data-related harm defined by the Alberta Virtual Care Coordinating Body (Figure 1).

The sentinel findings of this report are that:

- The HIA fails to explicitly align its health data regulatory approach with the foundational accountability to foster quality and safety of health programs and services, arguably violating the spirit and intent of the CHA.
- Other than data access and privacy, most categories of health data-related harm are either passively referenced or not addressed at all in the HIA.
- The impact of mainstream digital health data modalities in common use in Alberta, including virtual care, cloud-based information-sharing, advanced analytics such as artificial intelligence, home monitoring, and mobile health modalities are not acknowledged in the HIA.

⁵ Government of Canada, Canada-Alberta Agreement to Work Together to Improve Health Care for Canadians (2023-24 to 2025-26), Updated January 4, 2024, <https://www.canada.ca/en/health-canada/corporate/transparency/health-agreements/shared-health-priorities/working-together-bilateral-agreements/alberta-improve-care.html>.

⁶Government of Canada, Canada Health Act, Updated June 5, 2024, <https://www.canada.ca/en/health-canada/services/health-care-system/canada-health-care-system-medicare/canada-health-act.html>.

- The HIA makes no reference to, nor mandates any form of digital access to personal health information.
- The HIA does not acknowledge any obligations to Indigenous communities and their constitutional right to exercise authority over their health data.
- The HIA employs a custodial framework for health data oversight that can have a negative impact on patient care, research and quality improvement initiatives, management, provider wellbeing, and health system function.
- The HIA permits custodians to choose not to disclose health data without any repercussions for their decision, even if their action hinders patient care, population health, research and innovation that benefits the health and wellbeing of Albertans.
- The HIA inadvertently impairs teamwork by fostering conditions that obstruct the legitimate sharing of health data.
- There is often a lack of consistency in the interpretation of the HIA that can obstruct data flow, increase administrative burden, and frustrate involved parties.
- The HIA can foster a lack of health data interoperability and promotes conditions that can contribute to health workforce burnout.
- A dearth of legislation that prevents physical, mental, cultural or system harm arising from the poor design and use of health information technology suggests a cultural blindness to the core function of health data in Alberta.
- The three Alberta information privacy acts (HIA, PIPA, FOIP) are not harmonized, resulting in the fragmentation of personal health information, hindering teamwork and research, and fostering associated forms of health data-related harm.
- Although the portability, accessibility, universality and comprehensiveness of an Albertan's publicly funded care is mandated through the CHA, the portability, accessibility, universality, and comprehensiveness of their health information is not.
- There is currently no binding process for achieving interjurisdictional health information policy harmonization in Canada, which hinders the capacity of Albertans to receive quality health programs and services in other Canadian jurisdictions.

These findings illustrate that the HIA often fails to support the quality of health programs and services in its approach to regulating health data access and privacy. The HIA can unintentionally have a negative impact on the health and wellbeing of Albertans by inadvertently promoting data fragmentation that can interfere with all facets of health service and lead to system inefficiencies and negative outcomes, including illness and death. This serves as a reminder that all health public policy - including the HIA - must be intentionally designed to honour the core obligation to quality health programs and services, irrespective of its primary purpose.

Based on these findings, the following is recommended:

01 *The custodial model of health data oversight should be evolved into a stewardship model.*

02

The duty to share appropriate health information for primary and secondary purposes should be mandated, in balance with the mitigation of all reasonable privacy and security concerns.

03

An independent oversight body, distinct from the Office of the Information and Privacy Commissioner (OIPC), should be appointed to administer custodian duty to share obligations and requests for review for both primary and secondary data use.

04

A 'duty to share oversight body' must be equipped with the mandate, expertise, and resources to advance the quality of health programs and services for both the primary and secondary use of health data.

05

A 'duty to share oversight body' and the OIPC should be directed to form a joint health data governance committee (Data Stewardship Committee) to optimize the health and wellbeing of Albertans by cooperatively fostering the quality of health programs and services and the mitigation of all forms of health data-related harm.

06

The administration of the duty to share data must be accompanied by transparent public accounting by the Ministry of Health of the 'accepted' and 'refused' data requests for research purposes and the processing time for those requests.

07

The HIA should reframe its current independent custodian data policy processes and foster a collective approach to inter-custodian data management through policy, process and governance harmonization

08

The HIA should implement data custodian authorities, obligations, and standards aimed at fostering data collaboration, including the capacity for a custodian to delegate responsibility for data decision-making to an accredited third party.

09

A clear and comprehensive approach to Indigenous data sovereignty must be incorporated into the Alberta HIA.

10

Data governance knowledge assets and policy efforts of Canada's three distinct Indigenous Peoples should be leveraged to support Alberta's health data policy approach, including but not limited to the HIA.

11

Data-matching provisions in the HIA should be re-evaluated in the context of the importance of the consolidation of an individual's comprehensive health and social services data to benefit team-based quality health services and health data-related harm mitigation.

12

The HIA should be amended to add provisions designed to work in conjunction with Freedom of Information and Protection of Privacy's (FOIP) common or integrated program or service provisions to support the appropriate sharing of health data between data custodians and non-custodians to support care teams.

13

The HIA must modernize its approach to patient access and health data exchange with their care providers by establishing structured digital and portability requirements for patient access, control and communication of their personal health information.

14

The HIA must align its approach to patient access and oversight of health data with complementary public policy and legislation that is similar to former Bill C-72 (the Connected Care for Canadians Act).

15

Due diligence requirements should be comprehensively reviewed to streamline HIA function, with a strong focus on opportunities to eliminate duplicative processes and reduce access-related administrative burdens on health data custodians and the health workforce.

16

The backlog in privacy impact assessments must be addressed through a re-examination of the current process and the development and adoption of a more efficient and effective approach.

17

Similar to the efforts of the EU European Health Data Space, the HIA should support a managed health data ecosystem where data governance, policies, processes, and practices are coordinated and aligned.

18

The HIA should be updated to define a clear ethical framework and process through which data can be used for innovation by both public and private sector entities with clear requirements that create public trust and a social license.

19

In alignment with the principle of duty to share, the HIA should be updated to make the health data held by custodians and health information technology vendors subject to mandatory retention planning requirements and disclosures, with appropriate governance and safeguards accounting for privacy, security, ethics, and proprietary interests in place, for beneficial stewardship purposes and the public good.

20

Modifications to the HIA should be contemplated that support a long-term vision for mandated health data interoperability in Alberta. The nature of these changes will depend on whether the chosen legislative approach to interoperability is within or external to the HIA.

21

Every effort should be made to harmonize the HIA with federal/provincial/territorial best policy practices and consensus data standards arising from the effort to achieve pan-Canadian health data interoperability.

22

The HIA must be intentionally designed to align with pertinent health data legislation that is similar to former Bill C-72 to foster person-centric health data flow.

23

All regulated and non-regulated health care providers that can serve as members of a patient's care team should be subject to harmonized health data policy and privacy legislation to the extent required to enable optimized and appropriate data sharing for teamwork in health care.



24

The provisions of the HIA that are meant to address the same situation as equivalent provisions in other Alberta privacy legislation should be harmonized, and when amendments are made to any one act, these should be reflected across all privacy legislation.

25

The content of the HIA, including any reforms introduced, must be carefully vetted to assure that they are internally harmonious and in support of quality services and data-related harm reduction.

26

The HIA must carry out its express purpose to regulate the collection, use, and disclosure of health information in the context of acknowledging and honouring the core accountability of all Canadian health public policy to foster the quality of health programs and services.

27

The HIA must carry out its express purpose to regulate the collection, use, and disclosure of health information in the context of acknowledging and honouring the mitigation of all nine forms of health data-related harm.

DEFINITIONS & TAXONOMY

The standardization of key terms related to the HIA is required to promote a common approach and understanding.

The following sentinel terms used in this document have been selected for definition:

DATA BLOCKING

“A practice or act that prevents, discourages, or interferes with access to or the use or exchange of electronic health information, including the practices and acts specified in the regulations.”⁷

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.”⁸

DATA MATCHING

“The creation of individually identifying health information by combining individually identifying or non-identifying health information or other information from two or more electronic databases, without the consent of the individuals who are the subjects of the information.”⁹

DATA STEWARDSHIP

The concept of data stewardship is in evolution. For the purposes of this report, we have defined it:

- *“A model of data management whereby the use of data is governed by law, ethics, and other value-based considerations that prioritize the sharing and use of data for public good while ensuring appropriate and necessary privacy protection.”¹⁰*

⁷ <https://www.parl.ca/documentviewer/en/44-1/bill/C-72/first-reading>

⁸ 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>)

⁹ https://kings-printer.alberta.ca/1266.cfm?page=h05.cfm&leg_type=Acts&isbncIn=9780779848423

¹⁰ This is the working definition in use by the pan-Canadian Health Data Stewardship Project

HEALTH

"A state of complete physical, mental, and social well-being and not merely the absence of disease and infirmity".¹¹

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."¹²

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."¹³

HEALTH DATA-RELATED HARM

"Damage suffered by individuals, populations, and/or the health system arising from health data misuse or poor health data access or quality."¹⁴

HEALTH INFORMATION

"Health data that has 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."¹⁵

INDIGENOUS DATA SOVEREIGNTY

"The ability for Indigenous Peoples, communities and Nations to participate, steward, and control data that is created with or about themselves."¹⁶

¹¹ World Health Organization, Constitution, (<https://www.who.int/about/governance/constitution>)

¹² Pan-Canadian Health Data Strategy Expert Advisory Group, Toward a World-class Health Data System, 2022, (<https://www.canada.ca/en/public-health/corporate/mandate/about-agency/external-advisory-bodies/list/pan-canadian-health-data-strategy-reports-summaries/expert-advisory-group-report-03-toward-world-class-health-data-system.html>)

¹³ Health care Information Management Systems Society, Interoperability in Health care, 2023, (<https://www.himss.org/resources/interoperability-health-care>)

¹⁴ Adapted from Interoperability Saves Lives. 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. <https://www.albertavirtualcare.org/reports>

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 <https://guides.library.utoronto.ca/indigenoustudies/datasovereignty>



PERSON-CENTRED DATA ARCHITECTURE

“The design of health data around the individual as owner and basic unit of care to assure that their comprehensive and complete health data follows them over time and location for the entire course of their care journey.”¹⁷

¹⁷ Affleck, E., Tam, S., Bucci, S., Lindeman, C., Hunter, R., Mita, R., McPhail, B., Spithoff, S., Murphy, T., Krempien, J., Kitchen, A., MacQueen, A., Millar, C., Sham, C., Krecsy, S., Fraser, S., Joshi, R., Schamper, A. & Lucyk, A. (2024). Data Disarray.

PROJECT METHOD

A structured process was followed to carry out a comprehensive analysis of the function and impact of the Alberta HIA.

The following steps were undertaken:

1. The HIA was set in the context of a suite of health data public policy that together define how health data design and use occur in Alberta and Canada.¹⁸ By doing so, the scope and the limitations of the HIA were defined to ensure that observations were limited to the legislative parameters of the Act.
2. Input on HIA function and impact was gathered through the following means:
 - Interoperability Phase II Working Group member interviews and survey (individuals and their respective organizational or stakeholder community perspectives).
 - A comprehensive literature search.
 - Analysis of equivalent legislative practices in Canadian jurisdictions.
 - Overview of international best practices.
3. The analysis of HIA function and merit was undertaken by benchmarking the Act against the following core accountabilities:
 - Standards set by the *Canada Health Act* for all health public policy in Canada.
 - Extent to which it upholds the principles of the Pan-Canadian Health Data Charter, which was endorsed by the government of Alberta in October 2023.
4. Thematic Analysis and Discussion
 - Based on the accountabilities of the HIA and its perceived function, themes were identified for discussion.
5. Conclusions and Recommendations
 - Based on this analysis, conclusions were drawn about the function and impact of the HIA, and recommendations made for potential modification and improvement.

¹⁸ Affleck E. et al., Data Disarray: A Root Cause Analysis of Health Data Dysfunction in Canada, 2024, https://www.albertavirtualcare.org/_files/ugd/3eb345_85ada6635d334c2ba6c102bdd57f20e2.pdf.

ALBERTA HEALTH INFORMATION ACT

CONTEXT

The HIA is legislation with a principal focus on issues related to access, collection, and disclosure of health information. The HIA may be perceived by some as single source health information legislation that addresses regulatory standards related to all health data characteristics and functions. This is not accurate. The HIA is principally privacy legislation with a circumscribed scope, and many functions of health data design and use lie outside its purview. It is important to resist ascribing to the HIA functions that are outside its current scope when considering its function in the context of optimized health data design and use in Alberta. This point is reinforced in the Health Information Act Guidelines and Practices Manual, 2011 which says in section 1.3:

“The Health Information Act contains rules about the collection, use and disclosure of health information and aims to make the process transparent to those involved in the health system as well as to the general public. The rules are intended to protect the privacy of individuals and the confidentiality of their health information; ensure that health information is shared appropriately; and ensure that health records are managed and protected properly.”¹⁹

The health data public policy ecosystem in which the Alberta HIA sits is complex and dynamic. Both federal legislation and provincial and territorial public policy from neighbouring jurisdictions impact the design, flow, and use of health information in Alberta. A full appreciation of the nuanced relationship between these nested policy domains and their collective impact on health data function in Alberta is beyond the scope of this report.

While recognizing the complexity of provincial health data public policy, this report endeavors to focus on:

- Attributes of the HIA that are within its defined scope of application; and
- Health data design and function that are intentionally or unintentionally impacted by the Act.

BENCHMARK ACCOUNTABILITIES

A comprehensive and accurate evaluation of the HIA is best achieved by comparing current policy function to a benchmark of excellence defined by core accountabilities of the Act. For this purpose, two benchmark accountabilities have been selected:

¹⁹ Province of Alberta, Health Information Act: Revised Statutes of Alberta 2000 Chapter H-5, Updated June 21, 2024, https://kings-printer.alberta.ca/1266.cfm?page=h05.cfm&leg_type=Acts&isbncIn=9780779848423.

- The *Canada Health Act* (CHA), which defines the anchoring objective of all health care policy in Canada.
- The Pan-Canadian Health Data Charter, which defines the principles of optimized health data design and use in Canada.

CANADA HEALTH ACT

Quality

The CHA states that the “objective of health care policy in Canada” is to ensure “continued access to *quality health care* without financial or other barriers” to maintain and improve “the *health and well-being* of Canadians.”²⁰ In doing so, the CHA unambiguously defines an essential and unifying accountability of all health care public policy, including the Alberta HIA, to the provision of quality health programs and services. This suggests that the stated purpose of the HIA to uphold the safe “access, collection, and disclosure of health information”, must be achieved in a manner that *also* fosters the quality of health programs and services. Stated more succinctly, the HIA shares foundational accountabilities to assure both:

- The safe access, collection, and disclosure of health information; and
- The quality of health programs and services.

For the purposes of this report, quality health programs and services are defined according to the World Health Organization’s seven domains of quality:²¹


- Safe;
- Efficient;
- Effective;
- Equitable;
- Timely;
- Person-centred; and
- Integrated health programs and services.

Harm

Implicit in the effort to promote quality health programs and services is the need to minimize harm to patients and populations. Harm arising from the inappropriate design, quality or use of health data

²⁰ Government of Canada, *Canada Health Act*, Updated December 10, 2024, <https://laws-lois.justice.gc.ca/eng/acts/c-6/page-1.html>.

²¹World Health Organization, *Technical Series on Primary Health Care*, 2018, <https://iris.who.int/bitstream/handle/10665/326461/WHO-HIS-SDS-2018.54-eng.pdf?sequence=1>.



can adversely impact individuals, populations, and/or the health care system.²² This includes harm arising from both the oversharing and under-sharing of health data. For the purposes of this report, harm is defined according to the nine categories of health data-related harm defined by the AVCCB (Figure 1).

The HIA sets rules designed to balance the legitimate use of health information with potential harm arising from the inappropriate sharing or disclosure of health data. Specifically, the HIA aims to reduce two forms of health data-related harm:

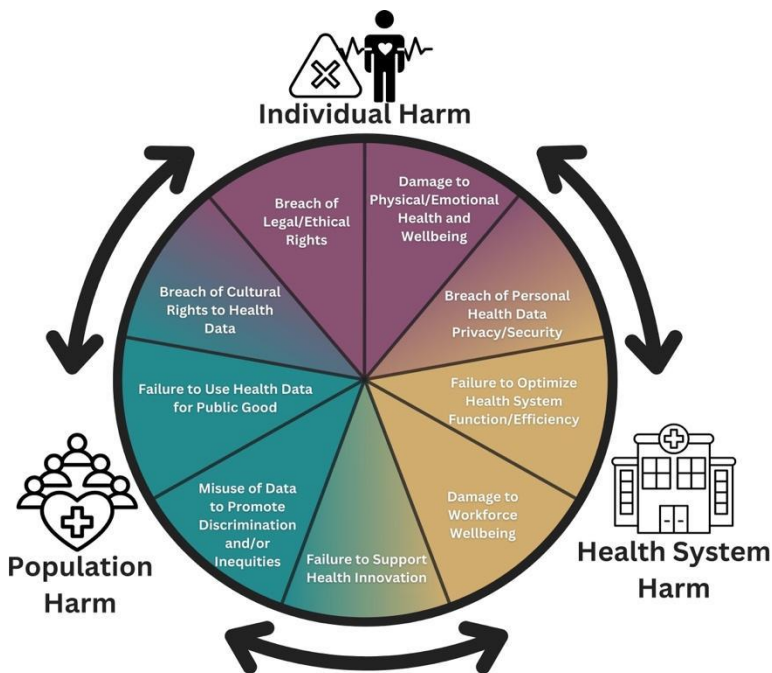
- Privacy concerns arising from the inappropriate disclosure of health data; and
- Breaches of an individual's right to access their personal health information.

These two forms of harm addressed by the HIA do not exist in isolation, but in an interdependent continuum with other forms of health data-related harm (Figure 1).²³ Restrictions on the sharing of information to limit one form of harm may inadvertently exacerbate another form of harm. For example, mitigating a potential breach of personal health information without considering the implications of one's actions on other forms of harm, such as damage to health and wellbeing, cultural harm, or health system dysfunction, creates risks of unintended negative consequences. As such, health data harm mitigation is necessarily an exercise in fostering a balanced approach that concurrently considers all nine forms of harm.

²²Affleck E., et al., Interoperability Saves Lives, 2023, https://www.albertavirtualcare.org/_files/ugd/3eb345_8a8a4fa4037540698f90a23825b7c328.pdf.

²³ IBID

Figure 1: Domains and categories of health data-related harm



Quality & Harm

Understanding the core accountability of health data design and use to the promotion of quality and reduction of harm, it follows that a comprehensive evaluation of public policy aimed at regulating health information is best achieved by assessing its impact on:


- The provision of quality health programs and services, and
- The mitigation of all forms of health data-related harm.

It follows that any failure by the HIA to promote quality health programs and services or mitigate individual, population, or system harm arising from health data design or use could point to shortfalls in the design and function of the legislation.

PAN-CANADIAN HEALTH DATA CHARTER

In October 2023, federal, provincial, and territorial governments committed to work together to improve how health data in Canada is “collected, shared, used, and reported”.²⁴ This commitment

²⁴Government of Canada, Pan-Canadian Health Data Charter, Updated October 12, 2023, <https://www.canada.ca/en/health-canada/corporate/transparency/health-agreements/shared-health-priorities/working-together-bilateral-agreements/pan-canadian-data-charter.html>.



included an agreement to support common health data standards and policies and culminated in the endorsement by most provinces and territories - including Alberta - of the Pan-Canadian Health Data Charter which comprises a set of ten core principles that define optimized health data design and use intended to “guide collective action towards a shared vision for health data in Canada” (Figure 2).²⁵

By endorsing the Pan-Canadian Health Data Charter, the government of Alberta signalled support for common principle-based health data design and use. To achieve this will require the re-evaluation of health data public policy in alignment with the ten core principles of the Charter.

The ten principles of the Charter are carefully crafted to frame a comprehensive and evidential approach to health data design and use that will optimize the quality of health programs and services and minimize health data-related harm in Canada. As such, the Pan-Canadian Health Data Charter can be employed as a framework to guide an evaluation of the function of the Alberta HIA and serve as an aspirational benchmark for an optimized HIA.

²⁵ Government of Canada, Pan-Canadian Health Data Charter, Updated October 12, 2023, <https://www.canada.ca/en/health-canada/corporate/transparency/health-agreements/shared-health-priorities/working-together-bilateral-agreements/pan-canadian-data-charter.html>.

Figure 2: The Pan-Canadian Health Data Charter

Pan-Canadian Health Data Charter

The Charter is based on advice from the Expert Advisory Group of the pan-Canadian Health Data Strategy, which recommended establishing common principles "*inspired by the universal human rights to health, to benefit from science, and to non-discrimination and equity, and founded on the five principles of public administration, comprehensiveness, universality, portability, and accessibility (Canada Health Act).*" This Charter highlights Canada's commitment to respecting Indigenous data sovereignty and Indigenous-led health data governance.

To honour the duty to put people and populations at the core of all decisions about the disclosure, access and use of health information, the Pan-Canadian Health Data Charter requires:

- 1. Person-centric health information design to ensure that health data follows the individual across points of care to support individual, clinical, and analytical access and use while respecting individual privacy with regard to the handling of their information under existing privacy legislation.*
- 2. Inclusion of diverse members of the public, patients, communities and other partners in culturally integrated health information system development and oversight.*
- 3. Commitment to support First Nations, Inuit and Métis data sovereignty and Indigenous-led governance frameworks.*
- 4. Common standards for terminology, health data design, stewardship, interoperability, access, and portability.*
- 5. The quality, security, and privacy of health data to maximize benefits, build trust, and reduce harm to individuals and populations.*
- 6. Timely availability and accessibility of meaningful and comprehensive health data to individuals, decision makers, the health workforce, and researchers to support an individual's health needs, quality health programs and services, population and public health, and research.*
- 7. The ethical use of health data to support decision making, policies, programs, services, statistics, and research for better health outcomes, while respecting the importance of open science and being open-by-design.*
- 8. Data-driven social and technological innovation through partnership, invention, discovery, value creation and international best practice.*
- 9. Literacy regarding health data, health data analysis and digital methods for the public, decision-makers, the health workforce, and researchers.*
- 10. Harmonization of health data governance, oversight, and policy in areas jointly agreed to by FPT governments for pan-Canadian coordination.*

ALBERTA HEALTH INFORMATION ACT

EVALUATION

Based on expert feedback, survey results, and practices in Canadian and international jurisdictions, the following themes and attributes of the HIA were identified for evaluation:

1. Accountability to quality health programs and services
2. Mitigation of health data-related harm
3. Digital health alignment
4. Patient access to/control over personal health information
5. Indigenous data sovereignty
6. The custodial model
7. Health data sharing
8. Secondary use of health data
9. Teamwork in health care
10. Health workforce wellbeing
11. Regulation of health information technology
12. Process considerations
13. Cultural implications
14. Intra-provincial policy alignment
15. Inter-jurisdictional policy alignment

1. ACCOUNTABILITY TO QUALITY HEALTH PROGRAMS AND SERVICES

The CHA is the anchoring federal legislation for all publicly-funded health services in Canada and sets out the primary objective of all Canadian health care public policy. As noted above, the CHA affirms that all Canadian health public policy must foster quality health programs and services.

The HIA is deeply impactful public policy as it helps define aspects of the design and use of health data that shape evidential decisions made by all health programs and services, including clinical care, population health, research, and management. Although the HIA is permissive of the sharing of health data to support care and health sector management if set privacy rules are followed, there is no requirement in the Act to promote access, collection, use, and disclosure of health information in a manner that supports the provision of quality health programs and services. This effectively divorces the imperative to limit the sharing of data from any contemplation of the impact of such limitations on quality health programs and services. Further, while the Act supports the sharing of health data for legitimate purposes, the choice to share data is assigned to individual data custodians and the consequences of not sharing data and the impact on quality care are not considered. The terms quality care, quality health programs or services, or health and wellbeing are not mentioned in the Act. The Health Quality Council of Alberta (HQCA) is referenced, but only in relation to its status as

a data custodian. The HIA does reference conditions for the use of individually identifying health information for quality improvement and assurance efforts; however, the use of data in this context is limited to use by custodians.²⁶

The Pan-Canadian Health Data Charter is explicit in tying health data design and use to “*timely availability and accessibility of meaningful and comprehensive health data to individuals, decision makers, the health workforce, and researchers to support an individual's health needs, quality health programs and services, population and public health, and research*”.²⁷

The failure of the HIA to explicitly align its health data regulatory approach with a foundational accountability to provide quality health services arguably violates the spirit and intent of the CHA. By decoupling the management of health data from its foundational role in the provision of quality health programs and services, the HIA opens the door to the establishment of data access and protection policies and processes that may fail to support the provision of quality health services, inadvertently foster health data-related harm, and adversely impact the health and wellbeing of Albertans.

2. HEALTH DATA-RELATED HARM

The HIA is legislation that is dedicated to minimizing two forms of health data-related harm, damage arising from the inappropriate disclosure or use of health information for primary and secondary purposes, and the failure to ensure the right of access of individuals to their personal health information. All other categories of health data-related harm are either passively addressed or are not referenced in the HIA at all.

An example is the absence of any reference to cultural harm arising from a lack of access and control over community-based health data by Indigenous peoples. Although the HIA is legislation explicitly aimed at ensuring the “right of Albertans to access their own health information”, it fails to consider the nation-to-nation rights of Indigenous communities to access and exercise authority over their collective health information.

The HIA’s approach to most other forms of health data-related harm is passive, suggesting that data can, at the will of individual custodians, be shared for certain health sector purposes. The focus of the Act on rules restricting disclosure that are accompanied by the threat of potential penalties frames data sharing as a risk-inherent activity. What is lost in this singular focus, and not explicitly addressed in the Act, is the potential impact of the *under-sharing* of health data on:

- The health and wellbeing of Albertans;

²⁶ Province of Alberta, Health Information Act: Revised Statutes of Alberta 2000 Chapter H-5, updated June 21, 2024, https://kings-printer.alberta.ca/1266.cfm?page=h05.cfm&leg_type=Acts&isbncln=9780779848423, s. 27(1)(g).

²⁷ Government of Canada, Pan-Canadian Health Data, Charter, updated October 12, 2023, <https://www.canada.ca/en/health-canada/corporate/transparency/health-agreements/shared-health-priorities/working-together-bilateral-agreements/pan-canadian-data-charter.html>.

- The capacity to optimize health system efficiency;
- The capacity to support innovation;
- The capacity to use health data for public good; and
- The health and wellbeing of health sector providers.

The consequence is an imbalance that emphasizes select forms of health data-related harm while minimizing or not addressing others. As all forms of health data-related harm exist in a matrix relationship; modifying one form can impact others. Further, it is important to remember that the root purpose of health information - the reason it is captured, analyzed, and exchanged - is to function as a tool to support health and wellbeing. Yet in legislation, this core function takes a back seat to efforts to limit data use and disclosure, without legislative consideration of the repercussions of this approach.

The Pan-Canadian Health Data Charter emphasizes the necessity of balancing harm mitigation against other properties of data use and control by requiring *“the quality, security, and privacy of health data to maximize benefits, build trust, and reduce harm to individuals and populations.”*²⁸

It may be unfair to expect the HIA to address all forms of health data-related harm, some of which may be out of scope for an act that is expressly focused on issues of access, privacy, and disclosure. However, the challenge for the Alberta health sector is that, beyond the forms of harm addressed by the HIA, the mitigation of other forms of health data-related harm are absent from any alternative legislation. A balanced approach that considers all forms of health data-related harm, be it in one act or complementary legislation, would best serve the people of Alberta.

3. DIGITAL HEALTH ALIGNMENT

Although the HIA came into force decades before the widespread adoption of digital health information technology, it has been amended to include some references to the digital health context. Most directly, Part 5.1, Alberta Electronic Health Record has the express purpose of enabling “the sharing and use, via the Alberta Electronic Health Record (EHR), of prescribed health information among authorized custodians”.²⁹ In this section, the HIA clearly defines which health professionals have access to health information in the EHR, limiting access to custodians defined under the Act. The principal focus of Part 5.1 is on inter-professional EHR information sharing practices for custodians, including patient access to their personal health information.

Reference to any other specific health information technology, or what the broader impact of digitized health data is on the mandate of the Act, is absent from the HIA. This is notable as the capacity to

²⁸Government of Canada, Pan-Canadian Health Data, Charter, updated October 12, 2023, <https://www.canada.ca/en/health-canada/corporate/transparency/health-agreements/shared-health-priorities/working-together-bilateral-agreements/pan-canadian-data-charter.html>.

²⁹ Province of Alberta, Health Information Act: Revised Statutes of Alberta 2000 Chapter H-5, updated June 21, 2024, https://kings-printer.alberta.ca/1266.cfm?page=h05.cfm&leg_type=Acts&isbncln=9780779848423.

capture, analyze, and share health data has changed dramatically since the HIA was first introduced in 2001. For example, the impact of mainstream digital health data modalities that are in common use in Alberta, such as virtual care, cloud-based information-sharing, advanced analytics such as artificial intelligence, home monitoring, and mobile health modalities, are not acknowledged in the HIA.

It could be argued that the HIA does not need to evolve with advances in information technology as principles of privacy are relatively fixed irrespective of technology platform. However, this view would ignore the novel applications of technology that require nuanced policy approaches to mitigate risks appropriately while enabling the benefits of the technological advancements. Moreover, while the capacity for personal health information to follow an individual over time and location is now entirely technically achievable, the HIA remains fixed on a pre-digital model of health information oversight that promotes the fragmentation of patient information between custodians. As the fragmentation of personal health information is now understood to result in health data-related harm and hinder quality health programs and services, indisputably, the HIA needs to be updated for a digital-age context.

4. PATIENT ACCESS TO / CONTROL OVER PERSONAL HEALTH INFORMATION

The HIA addresses an individual's right to access their personal health information in compliance with the 1992 Supreme Court of Canada decision in *McInerney v. Macdonald*, which states that while a custodian owns the physical patient file, the “expectation [arises] that the patient's interest in and control of the information will continue.”³⁰ This is supported by the Pan-Canadian Health Data Charter which requires “timely availability and accessibility of meaningful and comprehensive health data to individuals”.³¹ The HIA states that a patient has a right of access to “any record containing health information about the individual that is in the custody or under the control of a custodian”.³² However, ready access to personal health information is not necessarily made easy or convenient, at least certainly not by today's standards. For an individual to obtain their health information, the HIA requires that they must make a request to the custodian in control of the record.³³ In response, a custodian may contact an applicant to seek further information or request a fee, or in certain extraordinary circumstances refuse access.³⁴

The HIA makes no reference to or mandates any form of digital access to personal health information. Even the right of access to a person's record within the Alberta EHR is not necessarily digital access, as the right is limited to receiving a “copy” of what is in the EHR, which could be paper printouts.

³⁰ Supreme Court of Canada, Supreme Court Judgements: *McInerney v. Macdonald*, 1992, https://decisions.scc-csc.ca/scc-csc/scc-csc/en/item/884/index.do?site_preference=normal&pedisable=false&.

³¹ Government of Canada, Pan-Canadian Health Data Charter, updated October 12, 2023, <https://www.canada.ca/en/health-canada/corporate/transparency/health-agreements/shared-health-priorities/working-together-bilateral-agreements/pan-canadian-data-charter.html>.

³² Province of Alberta, Health Information Act: Revised Statutes of Alberta 2000 Chapter H-5, updated June 21, 2024, https://kings-printer.alberta.ca/1266.cfm?page=h05.cfm&leg_type=Acts&isbncln=9780779848423 part 2, s. 7(1).

³³ *IBID* part 2, s 8(1).

³⁴ *IBID* part 2, s 9(1).

Further the HIA is silent on mechanisms for, or the ability of the public to exercise control over the design and use of their personal health information, beyond various forms of consent for its use. Currently, personal information design and use, whether by deliberate planning, or lack thereof, has shared oversight by governments through legislation, custodians through operationalization, and the OIPC through regulation, but lacks any governance body representing the right of patient personal health information oversight.

5. INDIGENOUS DATA SOVEREIGNTY

Indigenous data sovereignty is defined as “the ability for Indigenous Peoples, communities, and nations to participate, steward, and control data that is created with or about themselves.”³⁵ The Pan-Canadian Health Data Charter requires a “*commitment to support First Nations, Inuit, and Métis data sovereignty and Indigenous-led governance frameworks*”.³⁶

Yet, as noted above, the HIA does not acknowledge any obligations to Indigenous communities and their right to exercise authority over their health data. The HIA is principally focused on individual rights and privileges and does not reference the ability of groups or communities to have access to, or control over, the design and use of their collective information. Given the focus of the HIA on health information control, access, and disclosure, it would seem to be within the scope of the legislation to address community-based data rights.

Although there are ongoing efforts by national and regional First Nations, Inuit, and Métis organizations to promote the adoption of public policy in support of their sovereign rights to manage data from and about their communities, currently Indigenous data sovereignty is not addressed in most provincial or federal health legislation. An exception is Yukon Territory’s *Health Information Privacy and Management Act* which explicitly designates Yukon First Nations entities as a type of data custodian with independent rights and obligations under the Act.³⁷ British Columbia is fostering the capacity of First Nations and the Métis Nation to assume full governance of their health data.^{38 39} Some national health organizations, such as the Canadian Institute for Health Information (CIHI) and

³⁵ University of Toronto Libraries, Indigenous Data Sovereignty, updated October 23, 2024, <https://guides.library.utoronto.ca/indigenoustudies/datasovereignty>.

³⁶ Government of Canada, Pan-Canadian Health Data Charter, Updated October 12, 2023, <https://www.canada.ca/en/health-canada/corporate/transparency/health-agreements/shared-health-priorities/working-together-bilateral-agreements/pan-canadian-data-charter.html>.

³⁷ Unofficial Consolidation of the Statutes of Yukon, Health Information Privacy and Management Act, 2013, <https://laws.yukon.ca/cms/images/LEGISLATION/PRINCIPAL/2013/2013-0016/2013-0016.pdf>.

³⁸ First Nations Health Authority Province of British Columbia, the British Columbia Ministry of Health, & Indigenous Services Canada, 2021, Tripartite Data Quality and Sharing Agreement, <https://www.fnha.ca/Documents/TDQSA-2021-Annual-Report-On-Progress.pdf>.

³⁹ Métis Nation British Columbia, Office of the Provincial Health Officer Letter of Understanding, December 7, 2023, <https://www.mnbc.ca/OPHLOU2023>.

the Canadian Institute for Health Research (CIHR), have adopted institutional Indigenous data sovereignty policies.^{40 41}

6. THE CUSTODIAL MODEL

The HIA employs a custodial framework for health data oversight, a model shared by most Canadian jurisdictions. The HIA defines the regulatory standards to which designated health data custodians are accountable and furnishes a list of provincial health data custodians that include both organizations, such as the government and provincial health authority, and select health professions. 11 of 29 regulated health professions in Alberta are identified as custodians under the HIA (see Table 1). The remaining 18 provincial regulated health professions are considered non-custodians, and subject to separate generic privacy legislation, the *Personal Information Protection Act* (PIPA).

Table 1: Alberta’s health professionals by custodian status⁴²

Custodians - Governed by HIA	Non-Custodians - Governed by PIPA
<ul style="list-style-type: none"> • Chiropractors • Optometrists • Pharmacists & Pharmacy Technicians • Dentists • Registered Nurses • Denturists • Midwives • Opticians • Physicians • Podiatric Physicians • Dental Hygienists 	<ul style="list-style-type: none"> • Acupuncturists • Dental Technologists • Laboratory and X-ray Technologists • Dietitians • Medical Diagnostic and Therapeutic Technologists • Hearing Aid Practitioners • Occupational Therapists • Licensed Practical Nurses • Paramedics • Physiotherapists • Social Workers • Respiratory Therapists • Speech-Language Pathologists and Audiologists • Medical Laboratory Technologists • Naturopathic Doctors • Dental Assistants • Psychologists • Psychiatric Nurses

The HIA sets rigorous health information collection, use, and disclosure standards for custodians and requires them to complete a privacy impact assessment for any new information technology they employ to manage an individual's personal health information. Custodians are given the privilege of

⁴⁰ Government of Canada, Setting New Directions to Support Indigenous Research and Research Training in Canada, updated November 22, 2023, <https://www.canada.ca/en/research-coordinating-committee/priorities/indigenous-research/strategic-plan-2019-2022.html>.

⁴¹ Canadian Institute for Health Information, A Path Forward: Toward Respectful Governance of First Nations, Inuit, and Métis Data Housed at CIHI, updated August 2020, <https://www.cihi.ca/sites/default/files/document/path-toward-respectful-governance-fnim-2020-report-en.pdf>.

⁴² Affleck, E. et al., Data Disarray: A Root Cause Analysis of Health Data Dysfunction in Canada, 2024, https://www.albertavirtualcare.org/_files/ugd/3eb345_85ada6635d334c2ba6c102bdd57f20e2.pdf.

access to personal health information found on the provincial EHR, unlike non-custodian health professionals.

The Pan-Canadian Health Data Charter calls for “*common standards for terminology, health data design, stewardship, interoperability, access, and portability.*”⁴³ Yet, the HIA is silent on the topic of health data interoperability and custodians are free to procure technologies independent of any established or enforced data content or exchange standards. This fosters a health system marked by disconnected custodian health information technology platforms that effectively fragment digital patient information by health service. This ‘custodian-centred’ health data fragmentation can have a negative impact on patient care, research and quality improvement initiatives, management, provider wellbeing, and health system efficiency among other concerns.⁴⁴ Further, this approach contravenes the Pan-Canadian Health Data Charter which calls for “*person-centric health information design to ensure that health data follows the individual across points of care to support individual, clinical, and analytical access and use.*”⁴⁵ The Expert Advisory Group of the pan-Canadian Health Data Strategy observed in 2022 that “the fragmentation of health information that arises from analogue custodial health information policy compromises both the capacity to provide comprehensive clinical care and to integrate health information for population-based health management and research.”⁴⁶

In instances when a custodian health professional is working for an institutional custodian, such as a health authority or the government, custodian responsibilities default to the institution and the health professional becomes an affiliate of the institutional custodian. Non-custodian health professionals and non-regulated providers can also be affiliates when working for a custodian. The HIA defines affiliates as:

- An individual employed by the custodian;
- A person who performs a service for the custodian as an appointee, volunteer or student or under a contract or agency relationship with the custodian;
- A health services provider who is exercising the right to admit and treat patients at a hospital as defined in the *Hospitals Act*;
- An information manager as defined in section 66(1); and
- A person who is designated under the regulations to be an affiliate.

⁴³Government of Canada, Pan-Canadian Health Data Charter, updated October 12, 2023, <https://www.canada.ca/en/health-canada/corporate/transparency/health-agreements/shared-health-priorities/working-together-bilateral-agreements/pan-canadian-data-charter.html>.

⁴⁴ Affleck, E. et al., 2023, Interoperability Saves Lives, https://www.albertavirtualcare.org/files/ugd/3eb345_8a8a4fa4037540698f90a23825b7c328.pdf.

⁴⁵ Government of Canada, Pan-Canadian Health Data Charter, Updated October 12, 2023, <https://www.canada.ca/en/health-canada/corporate/transparency/health-agreements/shared-health-priorities/working-together-bilateral-agreements/pan-canadian-data-charter.html>.

⁴⁶ Government of Canada, Pan-Canadian Health Data Strategy: Building Canada’s Health Data Foundation Expert Advisory Group Report 2, November 2021, <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-02-building-canada-health-data-foundation.html>

An affiliate of an institutional custodian is entitled to data privileges, including access to Alberta Netcare and Alberta Health Services (AHS) Connect Care, when working in the custodian's institutional environment. This results in location-based variation of access to clinical information resources whereby the very same non-custodian health provider can have access to Netcare when working as an affiliate for an institutional custodian but will be restricted from Netcare when they return to work at their private clinic.

Further, if a health care professional is incorporated – whether a designated custodian or not - they are deemed to be a private enterprise and therefore subject to PIPA. If they charge private fees for health services, they also fall under PIPA in the context of these services. However, if a health professional performs work on behalf of a non-profit or on a volunteer basis without any fee, they are exempt from accountability to any privacy legislation.

7. SHARING HEALTH DATA

The HIA permits custodians to share personally identifying health data “where appropriate” to “provide health services and to manage the health system”.⁴⁷ The HIA articulates a clear set of conditions when sharing personally identifying data is deemed appropriate, which include:

- Providing health services.
- Determining or verifying the eligibility of an individual to receive a health service.
- Conducting investigations, discipline proceedings, practice visits or inspections relating to the members of a health profession or health discipline.
- Conducting research or performing data matching or other services to facilitate another person's research.
- Sharing data to protect public health and safety.
- Providing for health services provider education.
- For internal management purposes, including planning, resource allocation, policy development, quality improvement, monitoring, audit, evaluation, reporting, obtaining or processing payment for health services, and human resource management.⁴⁸

Although sharing personally identifiable health data is conditionally permissible, the exchange of such information is not mandated in the HIA. The decision to share personally identifying health data rests exclusively with individual custodians. If a custodian chooses not to share health data, there are no consequences for them, even if this decision results in harm to an individual or population. Further, the HIA does not provide any recourse for failure to implement programs, processes, and systems that facilitate better data sharing to optimize health services and minimize harm. This approach runs counter to the approach of the Pan-Canadian Health Data Charter which advocates for “*timely*

⁴⁷ Province of Alberta, Health Information Act: Revised Statutes of Alberta 2000 Chapter H-5, updated June 21, 2024, https://kings-printer.alberta.ca/1266.cfm?page=h05.cfm&leg_type=Acts&isbncln=9780779848423, s. 2(b).

⁴⁸ IBID, s. 27(1).

*availability and accessibility of meaningful and comprehensive health data to individuals, decision makers, the health workforce, and researchers to support an individual's health needs, quality health programs and services, population and public health, and research”.*⁴⁹

A custodian may disclose “non-identifying health information for any purpose”.⁵⁰ However, the HIA does not define conditions when the disclosure of non-identifying health data is mandatory, nor asserts any repercussions for non-disclosure of non-identifying health information that result in health data-related harm.

This stands in sharp contrast to the consequences of inappropriate sharing of personally identifying information, for which a custodian can be subject to legal recourse, discipline, and fines. Section 107(6), which outlines the penalties for custodians related to inappropriate data sharing and use, states:

“A person who contravenes this section is guilty of an offence and is liable
(a) in the case of an individual, to a fine of not more than \$200,000, and
(b) in the case of any other person, to a fine of not more than \$1,000,000.”

According to the Alberta OIPC website, there have been “15 convictions for unauthorized access to health information under HIA since 2001. Of those, 13 convictions have occurred since April 2014.”⁵¹ The number of poor health outcomes that have arisen in the same timeframe from a lack of data sharing or fragmentation of health data is unknown, as this is not measured in Alberta or anywhere else in Canada.

The only death in Canada ascribed by an independent adjudicator to a lack of proper data sharing is that of Greg Price in 2012.⁵² Yet the problem is not felt to be insignificant; the Expert Advisory Group of the pan-Canadian Health Data Strategy stated in 2022 that health data fragmentation “*risks continued escalation of health care costs, underperformance of health services and poor health outcomes including avoidable illness and death, low levels of innovation, perpetuation of health inequities, and ineffective responses to future public health*

The stiff penalty for ‘oversharing’ health data dictated by the HIA seems misaligned with the absence of consequences for the ‘under-sharing’ of health data that can adversely impact the health system function, research, population health, and individual health and wellbeing.

⁴⁹ Government of Canada, Pan-Canadian Health Data Charter, updated October 12, 2023, <https://www.canada.ca/en/health-canada/corporate/transparency/health-agreements/shared-health-priorities/working-together-bilateral-agreements/pan-canadian-data-charter.html>.

⁵⁰ Province of Alberta, Health Information Act: Revised Statutes of Alberta 2000 Chapter H-5, updated June 21, 2024, https://kings-printer.alberta.ca/1266.cfm?page=h05.cfm&leg_type=Acts&isbncln=9780779848423, s. 32(1).

⁵¹ Office of the Information and Privacy Commissioner of Alberta, Multiple Penalties Issued to Individual Convicted of Health Information Breaches, updated September 10, 2020, <https://oipc.ab.ca/hia-conviction-15/>.

⁵² Health Quality Council of Alberta, Continuity of Patient Care Study, December 19, 2023, https://hqca.ca/wp-content/uploads/2021/12/Dec19_ContinuityofPatientCareStudy-2013.pdf.

*threats.*⁵³ The group concluded, “*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 that have defined our health system to date.*”⁵⁴

Seen through this lens, the stiff penalty for ‘oversharing’ health data dictated by the HIA – up to a one million dollar fine – seems misaligned with the absence of consequences for the ‘under-sharing’ of health data that can adversely impact the health system function, research, population health, and individual health and wellbeing.

8. SECONDARY USE OF HEALTH DATA

The secondary use of health data is broadly understood to mean the use of an individual’s personal health information for purposes other than their direct care. Secondary use involves the aggregation of population-level health data for purposes including research, quality and safety measurement, public health, provider certification or accreditation, management, and innovation.⁵⁵ The Pan-Canadian Health Data Charter supports the secondary use of health data by advocating for “*the ethical use of health data to support decision making, policies, programs, services, statistics, and research for better health outcomes, while respecting the importance of open science and being open-by-design*”.⁵⁶

The Alberta HIA functions as a gatekeeper for both primary and secondary health data use. Part 5, Division 3 of the Act defines the required conditions to be met to access health data for the purposes of research. To carry out health research, the basic steps required to obtain data are:

- The submission of a research protocol to a Review Ethics Board (REB).
- Subject to approval by the REB, a submission in writing to a custodian requesting disclosure of health information to be used in the research.

The Act states that a custodian who has received a written request from a researcher “*may, but is not required to, disclose the health information or perform data matching or other services to facilitate the research*”. Like the disclosure of health information for direct care, the onus rests on an individual custodian to decide whether they will share information for the purposes of research. Custodians who

⁵³ Pan-Canadian Health Data Strategy: Toward a World-Class Health Data System: Expert Advisory Group – Final Report, May 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>

⁵⁴ IBID

⁵⁵ Charles Safran et al., Toward a National Framework for the Secondary Use of Health Data: An American Medical Informatics Association White Paper, Jan/Feb 2007, <https://pmc.ncbi.nlm.nih.gov/articles/PMC2329823/pdf/1-S106750270600212X.main.pdf>.

⁵⁶ Government of Canada, Pan-Canadian Health Data Charter, updated October 12, 2023, <https://www.canada.ca/en/health-canada/corporate/transparency/health-agreements/shared-health-priorities/working-together-bilateral-agreements/pan-canadian-data-charter.html>.

choose not to disclose health data are in no way accountable for this decision, even if their action impedes research that is clearly understood to benefit the health and wellbeing of Albertans.

Custodians that elect to disclose health information for research must establish an agreement with the researcher that sets conditions, including:

- The imposition on the researcher of “conditions suggested by the research ethics board”.
- Compliance with regulations under the HIA.
- Limitations on the use of the disclosed information.
- The de-identification of personal health information being published.
- Access of the custodian to the researcher’s premises to inspect and confirm compliance with the terms of the agreement.

The administrative obligations to manage the sharing of health research data can be significant and serve as a disincentive for custodian participation in health research. This is particularly true for non-

As health data privacy legislation in Alberta (HIA, PIPA, FOIP) is not standardized, the capacity to link administrative data sets from non-health ministries subject to different legislation with custodian health data is a cumbersome task that can impede public health, research, and health system management.

institutional custodians like individual health professionals who often lack both the knowledge and resources to fulfill the administrative requirements. Further, the variable interpretation of the provisions of the HIA by independent custodians, regulators, or even successive privacy commissioners, can contribute to impedes in the capacity to share data for secondary use. This becomes a critical obstacle in primary care research, management, and innovation as the Alberta primary care ‘system’ consists of a distributed assortment of individual custodians using disparate technology platforms that comprise data islands with limited capacity to administer the aggregation of their data. Further,

most primary care providers lack incentives – financial and otherwise – to participate in research efforts that demand the knowledge and capacity to properly interpret the HIA. At the risk of falling afoul of privacy regulations, it may be much easier for many to elect not to share the data under their oversight.

Understanding that health data comprises observations, facts, or measurements which relate not only to the physical or mental health status of individuals, but to health system performance and socio-economic, community, and health system characteristics,⁵⁷ it becomes evident that the scope of data relevant to health researchers extends beyond that held by traditional custodians. Data from disparate sources like ministries of justice and education, and community-based health non-governmental organizations (NGOs) can provide rich insights to inform health and social services planning. Yet, as health data privacy legislation in Alberta (HIA, PIPA, FOIP) is not standardized, the capacity to link administrative data sets from non-health ministries subject to different legislation with

⁵⁷ Government of Canada, Pan-Canadian Health Data Strategy: Toward a World-Class Health Data System Expert Advisory Group – Final Report, May 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>

custodian health data is a cumbersome task that can impede public health, research, and health system management. The same is true for research that requires data from care teams composed of both non-custodian community-based services and custodian health providers.

The advent of advanced analytics is driving the need for larger pools of more readily available health data. Although advances in artificial intelligence (AI) hold great promise for an overburdened and under-resourced health sector, research is required to fully appreciate the cost/benefit of these technologies. The capacity for data legislation and regulation to keep pace with technological advances is becoming increasingly challenging, particularly as the unique promise and risk of AI is not acknowledged in the HIA. Valuable research in the domains of AI and machine learning (ML) can be stymied by regulatory standards written before these advances were imagined. Nor is the secondary use of data for the purposes of health innovation expressly addressed in the HIA. Alberta invests heavily and is renowned as a leader in digital health innovation, yet provincial data legislation does not contemplate how best to leverage provincial health information resources to support this investment.

Although Alberta invests heavily in digital health innovation, provincial data legislation does not contemplate how best to leverage provincial health information resources to support this investment.

9. TEAM-BASED WORK IN HEALTH CARE

The Alberta government's Modernizing Alberta's Primary Care System (MAPS) final report, published in 2023, highlights the foundational importance of "team-based primary care" to the health and wellbeing of Albertans.⁵⁸ Of the 11 recommendations made in the report, three refer to team-based primary care. The report also emphasizes the importance of "improved integration and data sharing capabilities across EMRs and other systems" as a core enabler of optimized primary care.⁵⁹ This suggests that team-based care is dependent on the comprehensive and reliable sharing of patient information across a care team; if information exchange fails, then team function is interrupted and quality of care can suffer.

While the MAPS report acknowledges that "legislative, policy, infrastructure and process-related barriers are among the factors that are contributing to challenges with information sharing and interoperability"⁶⁰, it fails to identify what specific public policy might pose such an obstacle.

The HIA impairs teamwork by fostering conditions that obstruct the legitimate sharing of health data. This occurs in several ways:

⁵⁸ Alberta Government, Modernizing Alberta's Primary Health Care System (MAPS): Strategic Advisory Panel Final Report, March 31, 2023, <https://open.alberta.ca/dataset/2b933143-39f4-45e4-aeb3-523f5bd3a7b8/resource/9f4d5ad7-cdb6-418a-b0d9-a04bb1dc467f/download/hlth-maps-strategic-advisory-panel-final-report.pdf>.

⁵⁹ IBID.

⁶⁰ IBID.

- The HIA requires that information technology procured by custodians is secure and assures data privacy, but in no way expects that this technology can interoperate with the information technology of other custodians. Unless custodians or a third-party elect to invest in bridging technology that enables cooperative information sharing, this results in custodian-centred information silos that impair the capacity for members of a patient's care team to share information easily and reliably.
- The HIA divides Alberta's 29 regulated health professionals into two distinct regulatory categories: custodians and non-custodians, subject to different health information obligations and privileges. Further, only custodians have access to the provincial EHR, meaning that some members of a patient's care team are legislatively deprived of access to essential patient information from this platform, which impairs team function. In addition, the legislative accountability of non-custodian health providers changes depending on work location; they can variably be accountable for compliance with the HIA, PIPA, or FOIP depending on their work setting. The differing acts confer different obligations and privileges that can confuse and sometimes impair team-based information sharing.
- Community-based unregulated health providers are not governed by the HIA yet can furnish essential health services and function as core members of an individual's health care team. This also applies to community-based organizations that aim to address social determinants of health with services, such as housing and food distribution, that are integral to the health and wellness of individuals. Once more, segmenting legislative health information accountability by subsets of caregivers and health-related services hinders legitimate team-based health data exchange.
- The HIA affixes legal authority for the management of health data to individual health service custodians, not to the patient.⁶¹ This effectively distributes the management of a subset of each individual's health information across a series of health service providers that the patient has seen for care. The patient - beyond rights of access to their information - is not given the capacity to oversee how their health information is managed or consolidated. They have no recourse but to accept that their information will often be fragmented across service-based custodians and must work to manage their information within this unwieldy construct. The responsibility to manage a patient's health information, and the decision whether this personal health information should be shared with other members of a patient's care team rests with individual custodians. If a custodian chooses not to share this information, there are no consequences for them. Although patients can intervene and request that their personal health information be shared, this is often a cumbersome exercise. This custodian-centric accountability is a hindrance to teamwork.

⁶¹ Province of Alberta, Health Information Act: Revised Statutes of Alberta 2000 Chapter H-5, updated June 21, 2024, https://kings-printer.alberta.ca/1266.cfm?page=h05.cfm&leg_type=Acts&isbncln=9780779848423.

- The Alberta HIA is not harmonized with health information legislation in other jurisdictions. For patients supported by cross-jurisdictional care, the impact of legislative and health data oversight variation contributes to shortfalls in inter-jurisdictional health data interoperability that can impair the capacity for efficient and effective communication between members of a patient's distributed care team. This is a significant problem for some border communities in the province and for residents of the Northwest Territories receiving care in Alberta.
- As privacy legislation that focuses on issues of access, control, and disclosure, the HIA promotes a relative emphasis on risk arising from oversharing health data that may contribute to a culture of care that is disincentivized to embrace comprehensive team-based information sharing.
- The assignment of different categories of a patient's care team to different legislative accountabilities (custodians (HIA)/non-custodian regulated professions (HIA / PIPA / FOIP)/non-custodian non-regulated providers (HIA / PIPA / FOIP)) presents an obstacle for health information technology vendors trying to deploy bridging technology that allows information exchange across a patient's care team. Technology must be able to recognize the status of the recipient of health information as a custodian, affiliate, or non-custodian, which can vary with their location, and adopt the information flow in compliance with the privileges of the specific provider. This can be a complex technical endeavor and can disincentivize technology innovation in this space and compromise team-based information sharing.
- Organizations and services that support the optimization of social determinants of health and operate outside the traditional health sector sphere, such as food banks and housing shelters, serve as integral members of a comprehensive health care team. These organizations are core members of what is envisioned in the government of Alberta's MAPS report as an Integrated Health Neighborhood (IHN).⁶² Non-profits that support social determinants of health in Alberta are not subject to PIPA or any other privacy legislation. They may be subject to legislation if acting on behalf of an organization that is subject to privacy legislation, or if they manage personal health information through a commercial activity. However, the application of the legislation in these circumstances is only partial and can create an imbalance in governance and oversight. The legislative incongruity between non-profits and traditional health services can impair essential team-based sharing of health information, adversely impact the health and wellbeing of Albertans, and promote health data related harm.

⁶² Alberta Government, Modernizing Alberta's Primary Health Care System (MAPS), Strategic Advisory Panel Final Report, updated October 18, 2023, <https://open.alberta.ca/publications/maps-strategic-advisory-panel-final-report>.

10. PROVIDER WELLBEING

Much attention – both in Alberta and nationwide - is currently directed toward what has been called the health human resource crisis.^{63 64 65} Harm to workforce mental health and wellbeing, known colloquially as burnout, is identified as a significant contributing factor to the crisis through health human resource attrition.⁶⁶ Data fragmentation or a lack of interoperability is thought to contribute significantly to physician burnout; it has been suggested that “solving the data interoperability problem in health care is a critical step toward easing the burnout epidemic”.⁶⁷ The relationship between health workforce wellbeing and health data design and use is captured in the health data-related harm framework which identifies burnout as one of the nine categories of harm.⁶⁸

The HIA employs a custodial model of health data oversight that unintentionally promotes the fragmentation of patient health information by promoting custodian-specific health information technology platforms.⁶⁹ The Act in no way compensates for this by fostering data interoperability between custodians; the imperative to share health data to ensure the portability, accessibility, and comprehensiveness of an individual’s health information is not addressed.

Access policies and processes for health information technologies are set within the parameters defined by the HIA and interpreted, often variably, by individual custodians. This means that health care providers needing access to systems and data held by different custodians often must follow rules and data governance processes unique to each custodian. The absence of a standardized approach to data access protocols across clinical data platforms can be a source of frustration for health care providers. The consequence is a lack of health data interoperability and the promotion of conditions that can contribute to health workforce burnout. The potential link between the health and wellbeing of Alberta’s health workforce and the impact of the HIA on health data interoperability should be evaluated and considered in any modifications to the Act.

⁶³ Government of Canada, Summary Report of the Health Human Resources Symposium, updated November 1, 2022, <https://www.canada.ca/en/health-canada/services/health-care-system/health-human-resources/summary-report-symposium.html>.

⁶⁴ Royal College of Physicians and Surgeons of Canada, What are we doing about Canada’s health human resources crisis?, November 14, 2023, <https://news.royalcollege.ca/en/newsroom/posts/what-are-we-doing-about-canada-s-health-human-resource-crisis-.html>.

⁶⁵ Jennifer Lee, Health workforce planning should be priority with system in flux, says Alberta doctors, nurses, March 28, 2024, <https://www.cbc.ca/news/canada/calgary/health-workforce-planning-priority-alberta-doctors-nurses-1.7158272>.

⁶⁶ Government of Canada, Summary Report of the Health Human Resources Symposium, updated November 1, 2022, <https://www.canada.ca/en/health-canada/services/health-care-system/health-human-resources/summary-report-symposium.html>.

⁶⁷ Carolyn Ward, Physician Burnout is a Data Problem, June 20, 2023, <https://www.particlehealth.com/blog/physician-burnout-is-a-data-problem>.

⁶⁸ Blanka Wawrzyniak, The interplay between data-related harm and the secondary use of health data, June 13, 2024, <https://medium.com/odi-research/the-interplay-between-data-related-harm-and-the-secondary-use-of-health-data-09ffd59f7cf0>.

⁶⁹ Government of Canada, Pan-Canadian Health Data Strategy: Building Canada’s Health Data Foundation Expert Advisory Group – Report 2, November 2021, <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-02-building-canada-health-data-foundation.html>

11. REGULATION OF HEALTH INFORMATION TECHNOLOGY

Although the HIA does not directly regulate health information technology, it does impact health information technology design and function by establishing clear conditions for the access, control, and disclosure of data used by information technology platforms. A privacy impact assessment (PIA) must be conducted and vetted through the OIPC for each new instance of an information technology deployed in the province.⁷⁰

Health information technology platforms can be owned and operated by both private sector corporations, public sector custodians, or a hybrid of the two through licensing or contractual agreements. The information accountability of technology owners and operators differs according to their status as a custodian or non-custodian.

Health information technology in Alberta and Canada is largely unregulated, except with respect to the health data that the technology captures and manages.

The federal *Food and Drugs Act* (FDA) governs the safe and effective use of certain medical devices, which are defined as “instruments used to treat, reduce, diagnose, or prevent a disease or abnormal physical condition.”⁷¹ Despite their use to “treat, reduce, diagnose, or prevent disease”, health information technology is excluded from consideration by the FDA. Similarly, there is no provincial legislation in Alberta that regulates the safe design and use of health information technology. As a result, health information technology in Alberta and Canada is largely unregulated, except with respect to the health data that it captures and manages.

Former Bill C-72 was prospective legislation tabled in the federal parliament on June 6th, 2024, aimed at mandating the interoperability of health information technology in Canada. If it had succeeded in passing through parliament, it would have been the first federal legislation that binds the sharing of health information to the promotion of quality health programs and services. Quebec’s recent Bill 3 similarly aligns the design and use of health data with an accountability to quality health programs and services.⁷²

12. PROCESS CONSIDERATIONS

The HIA sets out clear processes by which the collection, use, and disclosure of health information by custodians is to be regulated. Process issues that hinder the compliance with these standards can impede the function of the Act. These process issues fall into two broad categories:

⁷⁰ Province of Alberta, Health Information Act: Revised Statutes of Alberta 2000 Chapter H-5, updated June 21, 2024, https://kings-printer.alberta.ca/1266.cfm?page=h05.cfm&leg_type=Acts&isbncln=9780779848423, s. 64.

⁷¹ Government of Canada, Justice Laws Website, updated December 10, 2024, <https://laws-lois.justice.gc.ca/eng/acts/F-27/>.

⁷² National Assembly of Quebec, Bill 3 (2023, Chapter 5): An Act respecting health and social services information and amending various legislative provisions, updated April 4, 2023, https://www.publicationsduquebec.gouv.qc.ca/fileadmin/Fichiers_client/lois_et_reglements/LoisAnnuelles/en/2023/2023C5A.PDF.

- A lack of consistency of legislative interpretation, and
- Capacity limitations.

A recurring frustration expressed by respondents across a spectrum of health sector domains in an unpublished survey conducted by Alberta Innovates is a lack of consistency in the interpretation of the Act resulting in obstruction to data flow, increased administrative burden, and vexation. This issue appears to arise from independent and inconsistent interpretation of the HIA by individual institutional and health professional custodians, which can impede the transfer of health data between them. The survey observed that this appears to touch all branches of health service, and it was suggested that health data hurdles and red tape, along with overhead and administrative burden, have driven physicians to stop engaging in research.

This may be caused by differing levels of risk tolerance and exacerbated by a lack of public policy literacy on the part of independent health profession custodians. It may also arise from a lack of health system literacy on the part of the legal counsel of large institutional custodians who may not understand the impact of their decisions concerning the relative risk of disclosure versus non-disclosure on the quality of health programs and services. Moreover, it could be that such individuals do not consider it to be within their purview or authority to look beyond the data protection focus of the HIA in applying its provisions. Regardless of the reason, Alberta lacks a provincial authority that has the capacity to navigate such variation and compel policy harmonization to support efficient, effective, and safe data use.

In Alberta, almost all PIAs are required to be reviewed by the OIPC. Unfortunately, given demand, there has frequently been delay in processing PIAs of up to 12 months,⁷³ meaning that information technologies cannot be deployed in a timely manner or may be in use long before they are assessed, in violation of the Act. This can have a significant impact on the deployment of new technology, and the adoption and promotion of health information innovation. Alberta is only one of two provinces that direct PIAs in a broad range of circumstances (e.g. implementation of new health information systems, changes to existing systems, and data matching initiatives) through a mandatory review by their respective privacy commissioners.⁷⁴ ⁷⁵ On October 1st, 2024, the OIPC instituted a new approach to evaluate PIAs in order to optimize system function and “to support our legislative mandate and to improve timelines”.⁷⁶

⁷³ Office of the Information and Privacy Commissioner of Alberta, Privacy Impact Assessments: Frequently-Asked Questions, 2025, <https://oipc.ab.ca/resource/privacy-impact-assessments-frequently-asked-questions/>

⁷⁴ Province of Alberta, Health Information Act: Revised Statutes of Alberta 2000 Chapter H-5. updated June 21, 2024, https://kings-printer.alberta.ca/1266.cfm?page=h05.cfm&leg_type=Acts&isbncln=9780779848423.

⁷⁵ Prince Edward Island, Prince Edward Island Health Information Act, updated September 9, 2024, https://www.princeedwardisland.ca/sites/default/files/legislation/h-01-41-health_information_act.pdf.

⁷⁶ Office of the Information and Privacy Commissioner of Alberta, Privacy Impact Assessment Process Changes Now in Effect, as of October 1, 2024, 2025, <https://oipc.ab.ca/resource/changes-to-privacy-impact-assessment-process-now-in-effect-as-of-october-1-2024/>

Every custodian must perform a PIA for a technology that is new to their service, even if another custodian has already performed a PIA for the same technology. There are no means to rely upon or “receive credit” for due diligence conducted under prior PIAs to inform future effort or expedite the process, which can add to administrative burden, resource consumption, and delays. Also, different privacy officers conducting independent PIAs may come to different conclusions about what is required from a privacy compliance perspective for the same technology, as the standard of taking “reasonable steps in accordance with the regulations to maintain administrative, technical, and physical safeguards” is open to interpretation.⁷⁷ Variation in the interpretation of privacy compliance may hinder the capacity to appropriately share health data between platforms.

13. CULTURE OF HEALTH DATA

The mandate of the HIA is concerned principally with health data privacy and personal access. There is an absence of legislation in Alberta that regulates how health data is to be used to promote quality health programs and services. This is counterintuitive given that the fundamental purpose of health data is to promote health and wellbeing. One would think that the protection of privacy and rights of individual access is something one would assure while focusing on this core purpose of health data, yet this is not what currently occurs in public policy.

The relative over-emphasis on health data privacy and under-emphasis of the mitigation of other forms of health data-related harm is not unique to Alberta but found in similar legislation in other provinces and territories in Canada. The dearth of legislation that prevents physical, mental, social, cultural, or system harm arising from the poor design and use of health information and technology suggests a widespread blindness to the core function of health data. This may reflect a culture of health data where sharing is synonymous with risk, punishment, and the promotion of self-protection at the expense of greater health good.⁷⁸

14. INTRA-PROVINCIAL POLICY ALIGNMENT

The HIA is one of three provincial data privacy acts, the other two being PIPA and FOIP. Although the HIA is the only legislation specifically designed to address health information, all three privacy acts impact the design and use of health data in the province.

The three Alberta information privacy acts are not harmonized. The result is a complex suite of regulatory standards that can vary by organization, provider, and location. This legislative approach to data in Alberta effectively segments the privacy approach to an individual’s personal health information by institution, provider, and location. Such policy inconsistency hinders the appropriate

⁷⁷ Province of Alberta, Health Information Act: Revised Statutes of Alberta 2000 Chapter H-5, updated June 21, 2024, https://kings-printer.alberta.ca/1266.cfm?page=h05.cfm&leg_type=Acts&isbncln=9780779848423, s. 60.

⁷⁸ Blanka Wawrzyniak, The interplay between data-related harm and the secondary use of health data, June 13, 2024, <https://medium.com/odi-research/the-interplay-between-data-related-harm-and-the-secondary-use-of-health-data-09ffd59f7cf0>.

sharing of data, promotes the fragmentation of personal health information, hinders teamwork and research, and fosters associated forms of health data-related harm.

Table 2 outlines the accountabilities of different individuals and organizations in the Alberta health sector to various data privacy legislation.

Table 2: Health data privacy legislative accountability of different segments of the health sector (generalized)

Segment of Health Workforce	Governed by HIA	Governed by PIPA	Governed by FOIP
Custodians - 11 Regulated Health Professions - Select Institutions - Health Authorities - Select Government Ministries	The majority of the time	Sometimes (when employed/contracted by Regulatory Colleges under the HPA)	Sometimes (when employed/contracted by government and public sector health institutions)
Non-Custodian Regulated Health Professions	Sometimes (when an affiliate of custodian)	The majority of the time	Sometimes (when employed/contracted by government and public sector health institutions)
Unregulated Health Care Providers	Sometimes (when an affiliate of custodian)	The majority of the time	Sometimes (when employed/contracted by government and public sector health institutions)
Non-Governmental Health Care Organizations	Sometimes (when an affiliate of custodian)	The majority of the time	Sometimes (when employed/contracted by government and public sector health institutions)
Health Education Institutions (public sector)	Sometimes (if operating a health clinic)	No	The majority of the time
Non-Profit Organizations	Sometimes (when an affiliate of custodian)	Sometimes (for any personally identified information not managed in the context of a commercial activity)	Sometimes (when employed/contracted by government and public sector health institutions)

15. INTER-JURISDICTIONAL POLICY ALIGNMENT

The mandate of the HIA is the oversight of health data in Alberta, which aligns with the accountability of the Alberta health care system to the health and wellbeing of Albertans. Albertans regularly travel to other Canadian jurisdictions, where - as dictated by the CHA – they are entitled to publicly-funded

health services through reciprocal intergovernmental agreements. Unfortunately, although the portability, accessibility, universality, and comprehensiveness of an Albertan’s publicly-funded care is mandated through the CHA, the portability, accessibility, universality, and comprehensiveness of their health information is not. This is a concern because the quality of decisions in health care is dependent upon the access to and the integrity of health information. If information is missing or inaccessible this can promote forms of harm, including unsafe care.

Accepting the foundational importance of informational integrity to the delivery of quality care, to uphold accountability to the CHA and ensure “continued access to *quality health care* without financial or other barriers” to maintain and improve “the *health and well-being* of Canadians”⁷⁹, Alberta must assure that comprehensive personal health information follows its residents across jurisdictional boundaries. The pan-Canadian Health Data Strategy upholds the importance of inter-jurisdictional data alignment by calling for the “harmonization of health data governance, oversight, and policy in areas jointly agreed to by federal/provincial/territorial governments for pan-Canadian coordination”.⁸⁰ To accomplish this will not be a simple task, but require the cooperative harmonization of health data public policy across jurisdictions, an aspirational goal articulated in the federal/provincial/territorial Bilateral Agreements.⁸¹

To uphold accountability to the Canada Health Act to ensure “continued access to *quality health care* without financial or other barriers” to maintain and improve “the *health and well-being* of Canadians”, Alberta must assure that comprehensive personal health information follows its residents across jurisdictional boundaries.

There are thirteen different provincial/territorial approaches to health information public policy in Canada, plus federal private sector privacy legislation⁸² that applies to businesses that handle health data in provinces that do not have equivalent provincial private sector legislation. Therefore, together there are fourteen different legislative constructs that address the access, use, and disclosure of health information, almost all of which utilize some variation of the custodial model. This jurisdictional health data policy variation is not mandated in federal law, but has simply evolved without strategic intent, evidently without considering the implications for health system function or the health and wellbeing of Canadians. There is currently no binding process for achieving interjurisdictional health information policy harmonization in Canada.

⁷⁹ Government of Canada, Justice Laws Website, updated December 10, 2024, <https://laws-lois.justice.gc.ca/eng/acts/c-6/page-1.html>.

⁸⁰ Government of Canada, Pan-Canadian Health Data Charter, updated October 12, 2023, <https://www.canada.ca/en/health-canada/corporate/transparency/health-agreements/shared-health-priorities/working-together-bilateral-agreements/pan-canadian-data-charter.html>.

⁸¹ Government of Canada, working together to improve health care in Canada: Working Together bilateral agreements, updated March 28, 2024, <https://www.canada.ca/en/health-canada/corporate/transparency/health-agreements/shared-health-priorities/working-together-bilateral-agreements.html>.

⁸² Office of the Privacy Commissioner of Canada, The Personal Information Protection and Electronic Documents Act (PIPEDA), <https://www.priv.gc.ca/en/privacy-topics/privacy-laws-in-canada/the-personal-information-protection-and-electronic-documents-act-pipeda/>.

ALBERTA HEALTH INFORMATION ACT

THEMATIC ANALYSIS & DISCUSSION

Based on the above analysis of the function and impact of the HIA, and considering the need to optimize its dual accountabilities to health data-related harm mitigation and quality health programs and services, the following themes have been identified for discussion:

1. Reimagining the Custodial Model
2. Collective Data Governance
3. Delegated Data Responsibilities
4. Indigenous Data Sovereignty
5. Teamwork in Health Care
6. Rights of the Patient
7. Process Efficiencies
8. The Health Data Ecosystem
9. Innovation
10. Technical Interoperability
11. Policy Harmonization
12. Overarching Accountabilities

Comparative analysis with the approaches of other Canadian jurisdictions will inform the discussion.

Recommendations for modifications to the HIA are interpolated in the discussion.

1. REIMAGINING THE CUSTODIAL MODEL

Health Data Stewardship

The evaluation of the HIA raises concerns about the capacity of the current custodial model to optimize health data design and use and serve the interests of Albertans and the health care system. Principle shortfalls identified are that the custodial model:

- Places a strict emphasis on the individual data custodian's role in data protection.
- Inadvertently fragments individual personal health information by promoting custodian-specific health information technology procurement and data management.
- Unintentionally undermines the ability of patients to have access to and control over their entire health record.
- Promotes variable interpretation and application of health data public policy.
- Impedes teamwork in health care.

A key decision arising from a reappraisal of the HIA is whether a continued focus on the custodial model is merited, or if a fundamental shift to a new model of health data oversight is required. This decision hinges on what model of data oversight is best suited to promote quality health programs and services and mitigate all forms of health data-related harm.

Internationally, there is growing interest in moving toward a stewardship model of health data oversight.^{83 84} To understand what a “stewardship model” means, it is important to clarify the distinction between traditional forms of ‘data stewardship’. Historically, from a micro perspective this term has been used in the context of health information management and analytics, which is a technical and operationally-focused activity. However, from a macro perspective, data stewardship has referred to the use of data as a societal asset that requires prudent oversight and management so that its full benefit can be realized for the public good. The failure to make this important distinction can impair the ability of parties to achieve common understanding of underlying problems and solutions to address them. The result can be misalignment of stakeholders' understanding about the purpose, intent, and value behind data governance initiatives and programs designed to improve data stewardship. Therefore, for the purposes of this report, we will define the former as “operational data stewardship” and the latter as “strategic data stewardship”.

Operational data stewardship is usually concerned with the responsible management and oversight of data through its operational lifecycle, ensuring it is properly handled, maintained, protected, and used in compliance with ethical, legal, and organizational standards. In this context, a data steward within an organization is often tasked with ensuring the quality, integrity, security, and accessibility of data while meeting privacy and regulatory requirements.

Strategic data stewardship involves looking at data from a collective and societal perspective as a precious resource that needs to be stewarded properly now and for future generations, similar to how it is important to steward land or other natural resources for the benefit of society. This model upholds data as a valuable asset and resource to be overseen and governed to ensure it contributes to health-system, scientific, social, and economic advancement while mitigating harm.

The mitigation of harm is also considered through a macro lens, examining ethical concerns such as privacy, consent, and fairness, including principles of social responsibility aimed at preventing misuse of data that could reinforce biases or inequalities. Equally, this approach to data-related harm also encompasses damage arising from the insufficient sharing and suboptimal use of data and its impact on quality health programs and services.

⁸³ Organisation for Economic Co-operation and Development, Data Stewardship, Access, Sharing and Control: A Going Digital III Module Synthesis Report, Revised Draft, January 19, 2023, [https://one.oecd.org/document/DSTI/CDEP\(2022\)6/FINAL/en/pdf](https://one.oecd.org/document/DSTI/CDEP(2022)6/FINAL/en/pdf)

⁸⁴ Sarah Rosenbaum, Data Governance and Stewardship: Designing Data Stewardship Entities and Advancing Data Access, October 2010, <https://pmc.ncbi.nlm.nih.gov/articles/PMC2965885/>

Finally, like the stewardship of shared lands, strategic data stewardship also promotes transparency and collaboration and encourages open data initiatives where data is shared responsibly among stakeholders, including governments, health care organizations, and the public, while maintaining privacy and security. Moreover, just as environmental stewardship considers the long-term sustainability of natural resources, strategic data stewardship emphasizes sustainable data use, which includes ensuring that practices today do not undermine the future availability or reliability of data, such as through misuse that erodes public trust.

Although both operational and strategic data stewardship are important to optimize health data interoperability and sharing, in the reimagination of the custodial model, it is strategic data stewardship that historically has been largely absent from the overall health data management approach. As such, adopting a strategic stewardship model will necessitate a thorough re-evaluation of the HIA, including its overall objectives, tone, underlying assumptions, and require the introduction of new concepts and means to facilitate better data interoperability and sharing.

To reframe its approach to health data oversight, the government of Quebec recently passed Bill 3, *An Act respecting health and social services information and amending various legislative provisions* (“Bill 3”)⁸⁵. Bill 3 offers a precedent for a shift to a strategic stewardship model. If one compares the language used to explain the overall purposes of the Alberta HIA to that employed in Bill 3, there is a marked difference in tone. Section 5.2 of the Alberta Health Information Act Guidelines and Practices Manual, which summarizes the obligations of data custodians, says:

“Under the Health Information Act, the collection, use and disclosure of health information must, in all cases, be carried out in the most limited manner and with the highest degree of anonymity that is possible in the circumstances.”

It goes on to say that another fundamental purpose of the Act is:

“...the establishment of strong and effective mechanisms to protect the privacy and confidentiality of an individual’s health information.”

In contrast, Quebec’s Bill 3 states:

“This Act establishes a legal framework specific to health and social services information that is applicable to every health and social services body that holds such information. The purpose of the Act is to ensure the protection of the information while enabling optimization of the use made of it, excluding its sale or any other form of alienation, as well as its timely communication. It thus aims to improve the quality of the services offered to the population

⁸⁵ National Assembly of Quebec, Bill 3(2023, Chapter 5): An Act respecting health and social services information and amending various legislative provisions, updated April 4, 2023, https://www.publicationsduquebec.gouv.qc.ca/fileadmin/Fichiers_client/lois_et_reglements/LoisAnnuelles/en/2023/2023C5A.PDF.

*by simplifying the circulation of such information so that it follows the persons concerned by it in their care journey, and by enabling management of the health and social services system that is based on knowledge of the needs of persons and of the utilization of services.*⁸⁶

Bill 3 sets the ambition to optimize the quality of health programs and services through excellence in health information design and use while ensuring the protection of data privacy and security. The Bill explicitly states improved quality of health services are to be achieved by ensuring that data follows a patient's care journey and encompasses both health and social services information. In this way, Bill 3 aligns with the person-centred approach upheld by the Pan-Canadian Health Data Charter and declares a broad and inclusive approach to team-based health data use. Bill 3 is not only aspirational in its introductory explanatory notes but backs up the vision with key concepts and provisions that create a true strategic stewardship model of health information governance, compared to the traditional custodial data protection focus of the HIA.

► **Recommendation 01** | *The custodial model of health data oversight should be evolved into a stewardship model.*

Duty to Share

A stewardship model of health information governance also necessitates giving effect to the concept of a “duty to share”. As articulated in the report *Data Disarray*,⁸⁷ although health information legislation is permissive of health information sharing, this is often insufficient to overcome disincentives arising from robust privacy requirements. As was discussed above, what can result is a propensity for data custodians to err on the side of data protection, without considering the consequences of a failure to share health data. This bias towards data protection can foster manifold forms of data-related harm, including suboptimal health outcomes.

Understanding the full scope of harm arising from insufficient data sharing, it is logical to ask whether a legislated “duty to share” is merited. Such an approach could achieve a nuanced balance between the oversharing and under-sharing of health data within the context of the reduction of all forms of health data-related harm and the promotion of quality health programs and services. A full analysis of the case for a legislated duty to share is found in Appendix A.

Quebec's Bill 3 has provisions that foster a duty to share for both primary and secondary data use. Health and social service providers have an explicit right to seek access to data “to provide health services or social services to the person concerned” or for “teaching, training, or reflective practice” and the body holding such data must provide it (see ss. 38 and 69).

Under Section 47 of the Act - which addresses research access to health data - it states:

⁸⁶ IBID

⁸⁷ Affleck, E. et al., *Data Disarray: A Root Cause Analysis of Health Data Dysfunction in Canada*, November 2024, https://www.albertavirtualcare.org/_files/ugd/3eb345_85ada6635d334c2ba6c102bdd57f20e2.pdf.

“The person exercising the highest authority within the body to which the researcher is attached may authorize the researcher to be informed of the existence of and to have access to the information, if the person considers that the following criteria are met... An unfavourable decision must give reasons and be notified in writing to the researcher who submitted the request.”

As such, a researcher seeking access to certain data for their research project - once they have met the requirements set out in Section 47 - is entitled to receive such information and, should the data custodian refuse, must provide written reasons for the refusal.⁸⁸

Further, a data requestor has a right to seek a review of the custodian's decision by the Quebec privacy commissioner under Section 132 of the Act, which says:

“A person whose request for access or rectification has been refused, in whole or in part, by the person in charge of the protection of information may apply to the Commission for a review of the decision.”⁸⁹

It should be noted that although the Alberta HIA does not incorporate a duty to share, it does include liability protection for data custodians who make decisions about data sharing in good faith, and are later subject to complaints, claims, or allegations of inappropriate data sharing. Section 105 of the HIA says:

“No action lies, and no proceeding may be brought against the Crown, a custodian or any person acting for or under the direction of a custodian for damages resulting from anything done or not done by that person in good faith while carrying out duties or exercising powers under this Act.”⁹⁰

Incorporating duty to share principles in health information legislation could make a profound difference in the culture and practice of data use without requiring the wholesale overhaul of legislation. The obligation to share data can be added to the traditional data custodian role to support the evolution to a stewardship construct. In this model, data custodians would no longer have unfettered discretion to refuse to share information without a valid justification. The intent would be to foster a sense of responsibility and accountability for data sharing in harmony with privacy and security requirements and nourish a culture where data sharing is seen as beneficial and positive.

⁸⁸ National Assembly of Quebec, Bill 3 (2023, Chapter 5): An Act respecting health and social services information and amending various legislative provisions, updated April 4, 2023, https://www.publicationsduquebec.gouv.qc.ca/fileadmin/Fichiers_client/lois_et_reglements/LoisAnnuelles/en/2023/2023C_5A.PDF.

⁸⁹ IBID

⁹⁰ Province of Alberta, Health Information Act: Revised Statutes of Alberta 2000 Chapter H-5, updated June 21, 2024, https://kings-printer.alberta.ca/1266.cfm?page=h05.cfm&leg_type=Acts&isbncIn=9780779848423.

- ▶ **Recommendation 2** | *The duty to share appropriate health information for primary and secondary purposes should be mandated, in balance with the mitigation of all reasonable privacy and security concerns.*

Quebec's Bill 3 designates the province's privacy commissioner as the agent accountable for administering the duty to share and adjudicating a request for review of denied access requests. Understanding the scope of responsibilities of the Alberta OIPC, the current backlog of privacy-related deliverables, and the value of setting a data governance approach that strikes a balance between data protection and sharing, finding an alternative body to administer the duty to share as a counterpoint to the responsibilities of the OIPC seems strategically prudent. Ideally, an oversight body whose main mandate and expertise is to advance quality of health programs and services should be considered.

With increased use of advanced data analytics and data-driven decision support systems, there will be a growing need for dedicated expertise to oversee the safe and effective use of modalities, such as AI by the health sector. Rather than creating a new agency, consideration could be given to evolving an existing organization whose mandate and expertise already includes advancing health service quality to carry out this function. The Health Quality Council of Alberta (HQCA) and similar health quality oversight bodies in other jurisdictions could serve to facilitate the harmonization of this function across the country. Additionally, should federal or equivalent provincial health data interoperability legislation, such as the former Bill C-72, come into force, the same body could be relied upon to monitor and enforce data standards and anti-data blocking rules.

- ▶ **Recommendation 3** | *An independent oversight body, distinct from the Office of the Information and Privacy Commissioner (OIPC), should be appointed to administer custodian duty to share obligations and requests for review for both primary and secondary data use.*
- ▶ **Recommendation 4** | *A 'duty to share oversight body' must be equipped with the mandate, expertise, and resources to advance the quality of health programs and services for both the primary and secondary use of health data.*
- ▶ **Recommendation 5** | *A 'duty to share oversight body' and the OIPC should be directed to form a joint health data governance committee (Data Stewardship Committee) to optimize the health and wellbeing of Albertans by cooperatively fostering the quality of health programs and services and the mitigation of all forms of health data-related harm.*

Quebec's Bill 3 has a provision (Section 92) aimed at optimizing the use of health data, which states:

"Based on the reports obtained under sections 53 and 61, the Minister must, each year, publish on his or her department's website a report on the requests for authorization

submitted by researchers under Division II of Chapter IV, which must, in particular, state the number of requests accepted or refused and the processing time for those requests.”⁹¹

The evident intent of this provision is to establish transparency and accountability in the management of health data and incentivize custodians to work collaboratively around their use of health data to benefit science and public good. This nature of public accountability is best practice and should be considered in the Alberta context.

► **Recommendation 6** | *The administration of the duty to share data must be accompanied by transparent public accounting by the Ministry of Health of the ‘accepted’ and ‘refused’ data requests for research purposes and the processing time for those requests.*

2. COLLECTIVE DATA GOVERNANCE

Another feature of the HIA that should be contemplated is the impact of the distinctly independent nature of data custodian decision-making. Custodian obligations in the HIA are individualized, requiring each custodian to exercise duties from their own perspective, and subject to legal requirements related to the specific data under their oversight.

The fragmentation of the patient health record arising from a custodian-centric approach to data governance has been well-documented.^{92 93} Legislated independent custodian data oversight reinforces and perpetuates this fragmentation. While this aligns with the traditional analogue approach to information capture and management in a paper-based system, in a digital world information can be more efficiently exchanged between custodians through common data systems or shared digital repositories. Although the HIA reflects this trend through the support of Netcare, there are strict limitations that prevent full access to the Alberta EHR by some members of a patient’s care team.

Beyond Netcare, there is very little in the HIA that speaks to how data custodians can or should collaborate with one another to facilitate data sharing other than provisions that permit custodians to disclose information to one another. The HIA is silent on any requirement or even expectations that custodians foster data policy and process harmonization. Further, the Act does not contemplate that groups of custodians may wish to create common data systems and repositories amongst themselves. The lack of a collaborative data sharing framework in the HIA does not prevent this from

⁹¹ National Assembly of Quebec, Bill 3 (2023, Chapter 5): An Act respecting health and social services information and amending various legislative provisions, updated April 4, 2023, https://www.publicationsduquebec.gouv.qc.ca/fileadmin/Fichiers_client/lois_et_reglements/LoisAnnuelles/en/2023/2023C5A.PDF.

⁹² Affleck E. et al., Interoperability Saves Lives, October 2023, https://www.albertavirtualcare.org/files/ugd/3eb345_8a8a4fa4037540698f90a23825b7c328.pdf.

⁹³ Government of Canada, Pan-Canadian Health Data Strategy: Building Canada’s Health Data Foundation Expert Advisory Group – Report 2, November 2021, <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-02-building-canada-health-data-foundation.html>

occurring, but the absence of provisions for joint data governance and stewardship is an impediment, resulting in reluctance for widespread person-centric data collaboration.

- ▶ **Recommendation 7** | *The HIA should reframe its current independent custodian data policy processes and foster a collective approach to inter-custodian data management through policy, process, and governance harmonization.*

3. DELEGATED DATA RESPONSIBILITIES

One key feature that collective governance and decision-making can benefit from is the ability for a custodian to delegate responsibility for decision making around data sharing to another party. Quebec's Bill 3 endeavours to address this by enabling the ability for a custodian to delegate decision-making to another. Section 101 of the Act states:

“A body may enter into an agreement with another body under which all or part of its obligations under this Act are to be assumed by the other body. A copy of the agreement must be sent to the Minister and to the Commission d'accès à l'information.

Moreover, in the case of a body referred to in subparagraph 4 of the first paragraph of section 4, the person in charge of the protection of information within the body with which it has entered into an agreement acts in that capacity for both bodies, unless they agree otherwise.”⁹⁴

The delegation of decision-making is also reflected in the process that the Act contemplates for administering access to data for research. Bill 3 creates a research access model which includes “attaching” a researcher to a particular hospital which serves as a coordinating body for a collective of data custodians participating in a research project (see ss. 44 and 46).⁹⁵ For researchers not attached to a hospital, the Act creates “research access centres” through which a custodian may request access to data (see s. 55).⁹⁶ In either case, once a coordinating body approves an access request, such bodies holding the data must disclose it to the researcher (see ss. 70 and 71).⁹⁷

The delegation of responsibility for data decision-making addresses many important shortfalls in an independent approach to custodian data decision-making. Firstly, it promotes the standardization of modes of data disclosure by centralizing the decisions of multiple custodians in one common coordinating body. Secondly, it can decrease the administrative burden of individual custodians to manage data disclosure issues. Thirdly, it can consolidate data public policy literacy, that is often

⁹⁴ National Assembly of Quebec, Bill 3 (2023, Chapter 5): An Act respecting health and social services information and amending various legislative provisions, updated April 4, 2023, https://www.publicationsduquebec.gouv.qc.ca/fileadmin/Fichiers_client/lois_et_reglements/LoisAnnuelles/en/2023/2023C_5A.PDF.

⁹⁵ IBID

⁹⁶ IBID

⁹⁷ IBID

missing at the level of smaller independent custodians in one central coordinating body. Lastly, this approach can help leverage a single PIA to inform the approach to privacy and security risk mitigation in relation to the same data or technology project involving multiple custodians.

Introducing rules that foster data collaboration between different data custodians, like those found in Bill 3, will help surmount obstacles created by the *ad hoc* nature of data sharing and inconsistent custodian HIA interpretation that currently occur. Such rules should support more efficient data sharing and collaboration, including data trusts, health information sharing networks, or other types of data collectives.

- ▶ **Recommendation 8** | *The HIA should implement data custodian authorities, obligations, and standards aimed at fostering data collaboration, including the capacity for a custodian to delegate responsibility for data decision-making to an accredited third party.*

4. INDIGENOUS DATA SOVEREIGNTY

The First Nations Data Governance Strategy (“First Nations Data Strategy”),⁹⁸ the Pan-Canadian Health Data Charter⁹⁹ and various other national and regional reports,^{100 101} have pointed to the need to support the right of Indigenous data sovereignty, enabling Indigenous Peoples, communities, and Nations to participate, steward, and control data that is created with or about their citizens, cultures, territories, and communities. Although not dedicated to health data alone, the First Nations OCAP® principles¹⁰², the Manitoba Métis principles of OCAS¹⁰³, and the Inuit principles of Qaujimajatuqangit¹⁰⁴ have been identified as key policy efforts aimed at promoting Indigenous data sovereignty. The First Nations Data Strategy outlines a data governance and operational model, including the creation of a network of regional First Nations data centers that are linked across the country.¹⁰⁵

⁹⁸ First Nations Information Governance Centre, First Nations Data Governance Strategy, 2024, <https://fnigc.ca/what-we-do/first-nations-data-governance-strategy/>.

⁹⁹ Government of Canada, Pan-Canadian Health Data Charter, updated October 12, 2023, <https://www.canada.ca/en/health-canada/corporate/transparency/health-agreements/shared-health-priorities/working-together-bilateral-agreements/pan-canadian-data-charter.html>.

¹⁰⁰ Affleck, E. et al., Interoperability Saves Lives, October 2023, https://www.albertavirtualcare.org/files/ugd/3eb345_8a8a4fa4037540698f90a23825b7c328.pdf.

¹⁰¹ Government of Canada, Pan-Canadian Health Data Strategy: Toward a world-class health data system Expert Advisory Group – Final Report, May 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>

¹⁰² First Nations Information Governance Centre, The First Nations Principles of Ownership, Control, Access, and Possession (OCAP), <https://fnigc.ca/ocap-training/>.

¹⁰³ Canadian Institute for Health Information, A Path Forward: Toward Respectful Governance of First Nations, Inuit and Métis Data Housed at CIHI, updated August 2020, <https://www.cihi.ca/sites/default/files/document/path-toward-respectful-governance-fnim-2020-report-en.pdf>.

¹⁰⁴ IBID

¹⁰⁵ First Nations Information Governance Centre, First Nations Data Governance Strategy, 2024, <https://fnigc.ca/what-we-do/first-nations-data-governance-strategy/>.

Currently, Indigenous data sovereignty is not acknowledged in the HIA. Any efforts to address Indigenous data sovereignty in the Act should consider building upon and aligning with these frameworks. It is essential that legislation enables the flow of First Nations, Inuit, and Métis data, including comprehensive health records, to Indigenous data centers or their equivalents.

One means to foster this would be to acknowledge First Nations (and Métis and Inuit, should they be created) data centres in the HIA, defining them as custodians for purposes of the Act. The legislation could specify several roles for these centres, including the power to request Indigenous data from custodians, set data standards for collection, use, and disclosure, and provide support for Indigenous data governance reviews on specific health data projects.

Additionally, consideration should be given to adding a requirement under the HIA to incorporate Indigenous data sovereignty principles (such as OCAP[®], OCAS, Qaujimagatuqangit) into privacy impact assessment requirements to ensure that such principles become standard considerations when conducting privacy and governance reviews of data and technology projects. This would help infuse Indigenous data principles into the day-to-day practice of health data management and governance in Alberta.

- ▶ **Recommendation 9** | *A clear and comprehensive approach to Indigenous data sovereignty must be incorporated into the Alberta HIA.*
- ▶ **Recommendation 10** | *Data governance knowledge assets and policy efforts of Canada's three distinct Indigenous Peoples should be leveraged to support Alberta's health data policy approach, including but not limited to the HIA.*

5. TEAMWORK IN HEALTH CARE

Much of privacy law is dependent on the concept of “reasonable expectation of privacy” of individuals. In the early 2000s, when EHRs were first introduced, there was much concern about the inherent risk associated with consolidation of patient electronic health information into large digital repositories. The emphasis of the current HIA on data protection can be understood in part as a byproduct of this era, reflecting a fear and uncertainty about the risk to privacy and security spawned by the adoption of electronic medical records.

Arguably, the perception of the risk/benefit of digital health information has since evolved; the general expectation is now that a patient's complete health record should be available to members of their care team. Models of care have also evolved in the last two decades; the trend is toward greater collaboration and teamwork among providers. Whereas historically, subsets of data, such as mental health information, were considered highly sensitive and held separately from a patient's principal chart, more recently there is a growing consensus that mental health information is needed by all members of a patient's care team to support their health and wellbeing. Further, efforts to de-stigmatize mental health conditions have prompted models where all members of a patient's care

team are afforded a more comprehensive view of a patient's overall health status, care needs, and information. More broadly, health and wellbeing are now fully understood to be a byproduct of both traditional health services and social determinants of health. A health care team is no longer limited to regulated health professions, but can involve a broad constituency of providers, including community-based unregulated service providers and lay caregivers.

There have also been significant attempts to bring together integrated acute and primary care teams, which necessitates the ability to see the patient's entire record across the continuum of care. Moreover, there is growing evidence that suboptimal information sharing can contribute to adverse outcomes for patients as documented in *Interoperability Saves Lives*.¹⁰⁶ The introduction of former Bill C-72, the *Connected Care for Canadians Act*, was a direct response to address obstacles in information sharing by introducing anti-data blocking provisions and compliance to data content and exchange standards.¹⁰⁷

Despite a shift in attitude about the cost and benefit of sharing health information, the HIA retains provisions founded on the premise that the risk to patient privacy arising from the consolidation of their data across different providers or systems outweighs the benefit of sharing. For example, the Act has a substantial section dealing with data matching and places strict parameters around such activity, including conducting a PIA and submitting it to the OIPC for review and comment before such activity begins. Historically, the concern about data matching was the risk that personal health information brought together from different sources and collected for different purposes would be used for a new purpose inconsistent with the original intent. However, the purpose of data to deliver clinical services does not change, regardless of the source of the information, suggesting that data matching in a clinical context does not present an inherent privacy risk. Rather, establishing barriers for data matching for clinical purposes appears to contravene today's general trend towards greater access to more comprehensive health records to support quality care. Further, by promoting data fragmentation, such barriers likely attenuate the capacity of health care providers to provide quality care and amplify forms of health data-related harm.

This is not to suggest that all forms of data matching or data linking should not be monitored, but that a more nuanced approach that balances the cost and benefit should be adopted. For example, matching of data across sectoral domains such as health and law enforcement likely merit thoughtful regulation, lest data be used for unforeseen or unsanctioned purposes, and inadvertent breaches result. In British Columbia, these types of situations are described as common or integrated programs or activities within the province's FOIP Act.¹⁰⁸ Alberta's FOIP Act also has a similar provision in section 40(1)(i). These are the circumstances that require more scrutiny, and the privacy impact

¹⁰⁶ Affleck, E. et al., *Interoperability Saves Lives*. October 2023,

https://www.albertavirtualcare.org/files/ugd/3eb345_8a8a4fa4037540698f90a23825b7c328.pdf.

¹⁰⁷ Parliament of Canada, House of Commons of Canada: Bill C-72 (First Reading): An Act respecting the interoperability of health information technology and to prohibit data blocking by health information technology vendors, June 6, 2024, <https://www.parl.ca/documentviewer/en/44-1/bill/C-72/first-reading>.

¹⁰⁸ Government of British Columbia, Freedom of Information and Protection of Privacy Act (RSBC 1996) Chapter 165, updated December 24, 2024, https://www.bclaws.gov.bc.ca/civix/document/id/complete/statreg/96165_00.

assessments for such integrated programs must be vetted by the province’s privacy commissioner. Under New Brunswick’s *Personal Health Information Privacy and Access Act*, there is an exemption from conducting a PIA where data matching will not affect the privacy of the individual, as s. 57(3) of the Act says:

“A custodian is not required to conduct a privacy impact assessment if data matching is being done for an authorized purpose and will not result in a use of personal health information that will affect the privacy of the individual to whom the information relates.”¹⁰⁹

Understanding that the underlying assumptions on which some provisions in the HIA may no longer be valid, the Act must be reviewed to accommodate for changes in health care delivery, evolving expectations of patients and the public, and a more evolved understanding of the accountability of the Act to quality health programs and services and harm mitigation.

► **Recommendation 11** | *Data-matching provisions in the HIA should be re-evaluated in the context of the importance of the consolidation of an individual’s comprehensive health and social services data to benefit team-based quality health services and health data-related harm mitigation.*

Although the sharing of data between health and non-traditional health-related community-based services united in the provision of integrated service delivery to an individual or population can be integral to health and wellbeing, such data integration is complicated by variable legislative accountability and may merit closer examination to avoid privacy-related harm. Ideally the HIA should be structured to work in conjunction with FOIP to enable both data custodians and non-custodians to share data with each other in support of integrated care teams. Examples of health information privacy legislation which specifically support integrated service delivery include Saskatchewan’s *Health Information Protection Act*, which prescribes such scenarios,¹¹⁰ and Yukon Territory’s *Health Information Privacy and Management Act* where it states in section 58(ff):

“A custodian may disclose an individual’s personal health information without the individual’s consent...(ff) to a partner in the provision of an integrated service, in respect of which the custodian is also a partner, for the purpose of providing the integrated service to the individual.”¹¹¹

► **Recommendation 12** | *The HIA should be amended to add provisions designed to work in conjunction with Freedom of Information and Protection of Privacy’s (FOIP) common or integrated program or service provisions to support the appropriate sharing of health data between data custodians and non-custodians to support care teams.*

¹⁰⁹ Government of New Brunswick, *Personal Health Information Privacy and Access Act*, updated January 1, 2024, <https://laws.gnb.ca/en/document/cs/P-7.05>.

¹¹⁰ Government of Saskatchewan, *Health Information Protection Act*, H-0.021, updated August 13, 2024, <https://publications.saskatchewan.ca/#/products/4523>.

¹¹¹ Government of Yukon, *Health Information Privacy and Management Act: Section 58ff*, 2013, <https://laws.yukon.ca/cms/images/LEGISLATION/PRINCIPAL/2013/2013-0016/2013-0016.pdf>.

6. RIGHTS OF THE PATIENT

There are several reasons why comprehensive patient access to their health information is justified, including the legal right of patients to their personal health information without undue delays or obstacles. How access ought to be provided is less clear.

Most Canadians still do not have digital access to their health information.¹¹² Although patient portals represent a step in the right direction, they tend to be designed to provide patient access to the subset of their health information that a given custodian holds. Comprehensive patient access to their entire medical record is highly unusual. Patient access to personal health information is custodian-centric not patient-centric.

The future of personalized medicine and patient empowerment lies in customized digital health solutions that analyze a patient's data, such as AI algorithms, that furnish insights to enable individuals to steward their own health journeys. Regardless of the technology, health information legislation should strive to foster a data ecosystem that supports patient-centric data oversight.

To this end, the HIA should follow the lead of other jurisdictions in creating individual rights to data portability, such as Quebec's Bill 3 (s. 66)¹¹³ and the European Union's General Data Protection Regulation (GDPR) (Article 20),¹¹⁴ which requires data custodians (or equivalents) to provide an individual access to their information in a structured, commonly used, and machine-readable format. The GDPR goes further and gives individuals the right to direct that their data be transferred from one custodian to another (where technically feasible).

- ▶ **Recommendation 13** | *The HIA must modernize its approach to patient access and health data exchange with their care providers by establishing structured digital and portability requirements for patient access, control and communication of their personal health information.*
- ▶ **Recommendation 14** | *The HIA must align its approach to patient access and oversight of health data with complementary public policy and legislation that is similar to former Bill C-72 (the Connected Care for Canadians Act).*

¹¹² Canada Health Infoway, Connecting the Health System: Connected Care. A Healthier Canada, November 15, 2022, <https://www.infoway-inforoute.ca/en/component/edocman/6413-connecting-the-health-system-connected-care-a-healthier-canada/view-document?Itemid=103>.

¹¹³ National Assembly of Quebec, Bill 3 (2023, Chapter 5): An Act respecting health and social services information and amending various legislative provisions, updated April 4, 2023, https://www.publicationsduquebec.gouv.qc.ca/fileadmin/Fichiers_client/lois_et_reglements/LoisAnnuelles/en/2023/2023C5A.PDF.

¹¹⁴ Intersoft Consulting, General Data Protection Regulation (GDPR) Article 20, <https://gdpr-info.eu>.

7. PROCESS EFFICIENCIES

The HIA, like all legislation, is subject to interpretation and operationalization. In feedback received through a survey process of Alberta stakeholders, a common theme that emerged is that process inefficiencies arising from the operationalization of the HIA play a significant role in creating barriers to effective health information sharing and use. Specifically, the issues of variable interpretation of legislation and the processing of privacy impact assessments were highlighted.

Variable Interpretation

There is a concern that differential interpretation of the HIA by legal and privacy professionals employed by different custodians can lead to variable policy positions over time and across different contexts/organizations. The lack of custodian policy harmonization in turn can hinder appropriate data flow to support clinical care and secondary data use, as due diligence requirements are multiplied in terms of volume and complexity. As noted above (section on Collective Governance), Quebec's Bill 3 appears to have been designed to address this problem by prescribing and making available various relationship frameworks amongst custodians that reduce the number of decision-making points, which inherently minimizes the impact of differing views of how compliance requirements ought to be met.

Privacy Impact Assessments

As previously noted, under current HIA requirements, it appears that a very substantial number of PIAs must be reviewed by Alberta's Office of the Alberta OIPC. The volume of PIAs has outstripped the capacity of the OIPC to process them in a timely fashion, resulting in significant delays.¹¹⁵

Alberta is one of only two Canadian provinces that require that all new health information technology deployments, as well as changes to existing ones, have a PIA that is reviewed by the OIPC. The other jurisdiction is Prince Edward Island.

Although some provinces, such as British Columbia, have a similar requirement that PIAs are reviewed by that province's privacy commissioner, the number of PIAs required is limited by less inclusive criteria that exempt many technology projects (described in more detail above in Teamwork in Health Care section).¹¹⁶ Other provinces and territories require the completion of PIAs, but these are not reviewed by the jurisdictional privacy commissioner's office. Yet other jurisdictions, including

¹¹⁵ Office of the Information and Privacy Commissioner of Alberta, Privacy Impact Assessments: Frequently-Asked Questions, 2025, <https://oipc.ab.ca/resource/privacy-impact-assessments-frequently-asked-questions/>

¹¹⁶ Government of British Columbia, Freedom of Information and Protection of Privacy Act (RSBC 1996) Chapter 165, updated December 24, 2024, https://www.bclaws.gov.bc.ca/civix/document/id/complete/statreg/96165_00.

Manitoba, Saskatchewan, Nova Scotia, and Yukon Territory, do not have any explicit requirement for custodians to conduct PIAs.^{117 118 119 120}

Quebec's Bill 3 has a provision that a PIA is not required if a custodian is adopting or deploying a technology that has already been assessed and certified by a prior PIA (see ss. 92 and 106).¹²¹

Given the current PIA review model in Alberta and associated processing delays, unless the OIPC is given a budgetary and resource boost, what is intended to be best practice from a data protection perspective will remain a bottleneck for technology projects and digital health innovation. Further, it could be argued that it may not be appropriate for the OIPC to be intimately involved in operational processes, as the office also functions to adjudicate any allegations that a process does not comply with the HIA, potentially creating a situation where impartiality could be questioned.

In summary, the requirements of the HIA can be subject to differential interpretation and processes that can hinder effective and appropriate information use. The absence of a mechanism for collective policy planning can lead to undue burden on individual parties and a health ecosystem where data is fragmented and not shared optimally, resulting in the impairment of patient wellbeing and health system function.

- ▶ **Recommendation 15** | *Due diligence requirements should be comprehensively reviewed to streamline HIA function, with a strong focus on opportunities to eliminate duplicative processes and reduce access-related administrative burdens on health data custodians and the health workforce.*
- ▶ **Recommendation 16** | *The backlog in privacy impact assessments must be addressed through a re-examination of the current process and the development and adoption of a more efficient and effective approach.*

¹¹⁷ Government of Manitoba, The Personal Health Information Act (PHIA), updated December 31, 2024, <https://www.gov.mb.ca/health/phia/index.html>.

¹¹⁸ Government of Saskatchewan, Health Information Protection Act, H-0.021, 2024, <https://publications.saskatchewan.ca/#/products/4523>.

¹¹⁹ Nova Scotia Legislature, Personal Health Information Act, December 10, 2010, https://nslegislature.ca/legc/bills/61st_2nd/3rd_read/b089.htm.

¹²⁰ Government of Yukon, Health Information Privacy and Management Act, 2013, <https://laws.yukon.ca/cms/images/LEGISLATION/PRINCIPAL/2013/2013-0016/2013-0016.pdf>.

¹²¹ National Assembly of Quebec, Bill 3 (2023, Chapter 5): An act respecting health and social services information and amending various legislative provisions, updated April 4, 2023, https://www.publicationsduquebec.gouv.qc.ca/fileadmin/Fichiers_client/lois_et_reglements/LoisAnnuelles/en/2023/2023C5A.PDF.

8. THE HEALTH DATA ECOSYSTEM

As described in the report *Data Disarray*, the health data ecosystem in Alberta and by extension, across the country, is largely unmanaged from a strategic perspective.¹²² The management of data access that exists today is primarily the result of whatever processes have been set up by individual data custodians, which are inherently designed to fulfill their respective HIA privacy and data protection requirements. They are not designed for the needs of patients or other data users who currently must negotiate their way through various, often inconsistent processes if they require data from multiple sources. This often means having to repeat the unique due diligence requirements of each custodian, including access agreements, privacy, and security training, and user identification and authentication.

To streamline and enhance the data user access experience requires coordination among data custodians to create joint due diligence processes that serve their collective needs. The European Union's European Health Data Space (EHDS) initiative - which came into effect in April 2024 - is an example of a broad and ambitious effort to create a managed health data ecosystem across EU member countries.¹²³ The EHDS consists of new and better processes for data access, a joint data governance model, and standardized privacy and data protection practices, all aimed at achieving the European Union's general data protection regulation (GDPR)¹²⁴ compliance while enabling streamlined processes for access to data for clinical services, research, and innovation.

Effective and efficient data access and sharing within a complex ecosystem of a myriad of data custodians does not happen organically, even with relatively well-defined privacy and access rules, such as the GDPR; Alberta and other Canadian provinces and territories are no different. It requires the active coordination of all data ecosystem stakeholders to tangibly improve data access processes.

The HIA needs to reflect the imperative for a more managed health data ecosystem to achieve improvements in data interoperability and flow. The European Health Data Space model has been developed by working within the GDPR framework. For HIA reform, there is an opportunity to go one step further and design the Act to facilitate a data ecosystem that is purpose-built to effectively and efficiently steward data to achieve robust privacy and data protection, while reducing other data-related harms and fostering quality health programs and services.

► **Recommendation 17** | *Similar to the efforts of the EU European Health Data Space, the HIA should support a managed health data ecosystem where data governance, policies, processes, and practices are coordinated and aligned.*

¹²² Affleck, E. et al., *Data Disarray: A Root Cause Analysis of Health Data Dysfunction in Canada*, November 2023, https://www.albertavirtualcare.org/files/ugd/3eb345_85ada6635d334c2ba6c102bdd57f20e2.pdf.

¹²³ The European Health Data Space (EHDS), What is the European Health Data Space EHDS?, April 24, 2024, <https://www.european-health-data-space.com/>.

¹²⁴ General Data Protection Regulation, Complete Guide to GDPR Compliance, 2025, <https://gdpr.eu/>.

9. INNOVATION

Section 32(1) of the HIA says: “a custodian may disclose non-identifying health information for any purpose,” which on its face should support the ability to use de-identified health data for innovation, but the reality appears to tell a different story. Respondents to an unpublished survey conducted by our group suggested that the standard for “non-identifying health information” is often so high that it can prevent data from being used for innovation.

This is an example of where relative risk of forms of harm must be considered. While there is often a theoretical risk that in certain situations it may be possible to re-identify the data, taking a position that there must be zero chance of re-identification in any circumstance results in data that is completely aggregated and anonymized to the point that it becomes unusable, or access is simply denied because the threshold cannot be met. However, the inability to access the data may foster harm by impeding innovation and the capacity for improving patient care, which are not factored into the equation of determining whether data is considered “non-identifying”.

Moreover, without proper strategic data stewardship, the debate ends up focusing on the somewhat academic exercise of defining “non-identifying information”, which becomes futile after a certain point, especially considering that there are practical steps to eliminate the risk of re-identification. For example, if the de-identified data is required to be in a secure environment in which no unsanctioned data can be brought in to attempt to re-identify it.

The other limiting factor when it comes to enabling data for innovation is overcoming pre-conceived ideas and political sensitivities around the notion of “selling” health data to or by private industry. There are ways in which data can be de-identified, undergo appropriate governance and ethics reviews, and have strict legal terms and conditions applied to its utilization, such as through a robust data licensing agreement, before data is released or made accessible for innovation projects. In this way, data is not “sold” in the traditional sense such that the receiving party can do whatever they wish with it, but instead they are only given a limited license to use the data within the defined parameters of a particular project and under strict privacy and security protocols.

Similar to the European Health Data Space initiative, efforts should be made to create a clear and consistent ethical framework to govern data for innovation to create confidence that when data is administered in accordance with the framework, the public can be assured that the data will be used for social good with privacy and security risks appropriately mitigated. This would create the right social license for the data to be used in this manner, even when private and commercial entities conduct the activity.

► **Recommendation 18** | *The HIA should be updated to define a clear ethical framework and process through which data can be used for innovation by both public and private sector entities with clear requirements that create public trust and a social license.*

In Data Disarray, it was pointed out that a health information technology vendor has no authority to retain data for the benefit of the patient if the custodian chooses to stop using the IT vendor's solution.¹²⁵ Seen from the narrow perspective of privacy and data protection and applying the principle of limiting retention, it appears to make sense for health information technology vendors to delete data of custodians who are no longer using their services. However, when looking at this practice from a health system perspective, the loss of that type of data represents potential missed opportunities for collective quality improvement, population health, research, innovation, and the fostering of a vibrant health technology industry. This is particularly true in the age of AI, where having broader and more representative samples of health data lead to better, more robust AI models and algorithms with less bias.

The challenge is that our current custodian-centric paradigm of data governance with its reliance on individual data oversight prevents us from seeing the forest for the trees. There is no reason why the data within health technology vendor systems cannot be properly protected while optimizing its use, if proper stewardship and governance is applied to health technology vendor systems independent of the data custodian relationship. It merely takes a shift in mindset to assure that appropriate data protection can be achieved if a wholistic approach is taken that coordinates the roles and responsibilities of the different actors in the data eco-system, so that data custodians and health technology vendors can both play a part in managing collective data to benefit all Canadians. After all, the data holdings held within health technology vendor systems are created largely in the process of the delivery of public-funded health services by data custodians. Should such data assets not be stewarded for the public good?

A collective approach with a view toward greater societal benefit is more compelling when one considers that the boundaries that are drawn between the different legal entities which represent the different data custodians is fundamentally arbitrary from a data design and use perspective. For example, as a health system, should our ability to make use of data that is held by a collection of individual medical clinics be different than our ability to make use of that data held by a single entity that amalgamates all those same clinics? As we have seen, the legal boundaries that are drawn between different health entities change over time for various corporate governance reasons. When Alberta Health Services (AHS) was created in 2009, it brought together many hospitals and health care facilities under a single legal entity, which facilitated the consolidation of health data under a single data custodian under the HIA. With the recent decision to separate AHS into four distinct agencies, should the previously consolidated data holdings now be automatically fragmented and our collective ability to utilize those same data holdings change simply because there are now four entities instead of one? If the answer is no, then we need an approach to collective data stewardship and governance through the lens of collective data good, not according to independent custodian legal entities that vary over time, location, and status.

¹²⁵ Affleck E., et al., Data Disarray: A Root Cause Analysis of Health Data Dysfunction in Canada, November 2023, https://www.albertavirtualcare.org/_files/ugd/3eb345_85ada6635d334c2ba6c102bdd57f20e2.pdf.

Freed from the limitations of the traditional custodial model, it is possible to create new forms of collective data governance and oversight that can optimize its use for purposes such as innovation. Imagine a legal framework where data held by information technology vendors, primary care clinics, and other custodians are not exclusively controlled by the individual custodians, but also subject to certain “public trust” or “public interest” conditions where such data is mandated to be made available for research, innovation, and public health with the right controls, governance, and safeguards in place. This would help unlock the value that currently resides in the collective data that is stored in the many separate systems controlled by many data custodians across the Canadian health sector.

- ▶ **Recommendation 19** | *In alignment with the principle of duty to share, the HIA should be updated to make the health data held by custodians as well as health information technology vendors subject to mandatory retention planning requirements and disclosures, with appropriate governance and safeguards accounting for privacy, security, ethics, and proprietary interests in place, for beneficial stewardship purposes and the public good.*

10. TECHNICAL INTEROPERABILITY

The capacity to share data electronically is dependent upon health information technology interoperability. Health information technology is currently unregulated in Canada; only the data managed by information technology platforms is subject to regulatory oversight that is primarily limited to a focus on protection.¹²⁶

The introduction of the former federal Bill C-72 represented a significant first step toward mandating technical data interoperability by requiring vendor compliance to data content and exchange standards, and anti-data blocking provisions, a concept borrowed from the United States *21st Century Cures Act*.¹²⁷ Data blocking is defined as “a practice or act that prevents, discourages, or interferes with access to or the use or exchange of electronic health information, including the practices and acts specified in the regulations.”¹²⁸ Under Section 6 of former Bill C-72, health information technology vendors would have been prohibited from engaging in data blocking.

Quebec’s Bill 3 offers examples of what equivalent provisions may look like. Under Section 106 of the Act, it advances data interoperability by stating that in certain circumstances a body completing a PIA for a health information technology initiative:

¹²⁶ Affleck, E. et al., *Data Disarray: A Root Cause Analysis of Health Data Dysfunction in Canada*, November 2023, https://www.albertavirtualcare.org/files/ugd/3eb345_85ada6635d334c2ba6c102bdd57f20e2.pdf.

¹²⁷ Authenticated U.S. Government Information, Public Law 115-255, December 13, 2016, <https://www.congress.gov/114/plaws/publ255/PLAW-114publ255.pdf>.

¹²⁸ Parliament of Canada, House of Commons of Canada, Bill C-72 (First Reading) An Act respecting the interoperability of health information technology and to prohibit data blocking by health information technology vendors, June 6, 2024, <https://www.parl.ca/documentviewer/en/44-1/bill/C-72/first-reading>.

“...must ensure that such a project allows computerized information collected from the person concerned to be communicated to the person in a structured, commonly used technological format.”¹²⁹

In this way, Bill 3 is building into the privacy impact assessment process a mechanism to ensure data interoperability and portability, at least as far as individual ability to access and transfer their data to care providers.

Section 92 of Bill 3 is another provision that fosters health data interoperability by giving the government the ability to require the exclusive use of certified technologies, which may include interoperability requirements:

“92. The Minister may, by regulation, determine the cases and circumstances in which only a certified technological product or service may be acquired or used by a body. The Minister may also determine, by regulation, (1) the certification procedure for a technological product or service, including the documents to be provided by the supplier; and (2) the criteria for obtaining certification, in particular with respect to the protection of personal information, the security provided by the product or service, its functionalities and its interoperability with other devices, systems and information assets used by bodies.”¹³⁰

Health data interoperability must be legislated in Alberta. The best means to achieve this, however, is not necessarily within the strict parameters of the HIA. Options include integrating interoperability provisions into the HIA, awaiting federal legislation similar to former Bill C-72, or developing an equivalent and distinct Alberta health data interoperability act. Irrespective of the path chosen, at minimum, modifications to the HIA should be contemplated that support Alberta’s long-term vision for legislated health data interoperability.

► **Recommendation 20** | *Modifications to the HIA should be contemplated that support a long-term vision for mandated health data interoperability in Alberta. The nature of these changes will depend on whether the chosen legislative approach to interoperability is within or external to the HIA.*

11. POLICY HARMONIZATION

To support the health and wellbeing of residents of Alberta, their comprehensive health information must follow them over time and location. This includes between appropriate custodian and non-

¹²⁹ National Assembly of Quebec, Bill 3 (2023, Chapter 5): An Act respecting health and social services information and amending various legislative provisions, updated April 4, 2023, https://www.publicationsduquebec.gouv.qc.ca/fileadmin/Fichiers_client/lois_et_reglements/LoisAnnuelles/en/2023/2023C5A.PDF.

¹³⁰ IBID

custodian health services within the province and across jurisdictional boundaries in other provinces and territories where a resident is receiving care. A failure to achieve this contravenes the spirit and intent of the conditions of the *Canada Health Act* which dictates that insured health services must be portable, comprehensive, accessible, and universal.

Person-centered data architecture is the term used to describe the design of health data around the individual as the basic unit of care. Person-centered data architecture assures that an individual's comprehensive and complete health information follows them for the entire course of their health journey. Further, person-centered data architecture ties the design of health data technology, public policy, and workflow to the legal right of individuals to their health information. As individuals frequently travel between both custodian and non-custodian health services and across jurisdictions for care, optimizing the capacity for their health data to follow them over time and location demands the harmonization of custodian, non-custodian, and jurisdictional health data governance, public policy, technology, and workflow.

To achieve this in Alberta will require the harmonization of the three distinct privacy acts which function independently and are applied variably to health service providers depending on their status and location. Similarly, there has been no mechanism for the harmonization of health data legislation across provinces and territories, and although recent federal/provincial/territorial agreements point in the direction of health data policy cooperation, such efforts are not binding.¹³¹

This problem is exacerbated by the fact that health care institutions are currently under significant stress to meet basic health service needs and often lack resources or expertise to dedicate to health information policy harmonization and alignment. Further, perhaps due to poor health data literacy, such efforts may not be considered critical, and the work can often go undone. This speaks to the importance of having strategic data stewardship that considers overall collective data needs and takes action to facilitate policy harmonization when the impetus among the community of data custodians and jurisdictions is not strong enough to trigger action on their own.

To promote broad health data policy alignment, Canada Health Infoway tabled the Shared Pan-Canadian Interoperability Roadmap¹³², which calls for policy harmonization, including health information privacy legislation, across provincial and territorial boundaries in support of pan-Canadian health data interoperability. Similarly, a pan-Canadian Health Data Stewardship initiative under the direction of CIHI is intended to foster broad data policy alignment. Unfortunately, both initiatives are voluntary and have seen variable engagement from jurisdictions.

¹³¹ Government of Canada, working together to improve health care in Canada: Working Together bilateral agreements, updated March 28, 2024, <https://www.canada.ca/en/health-canada/corporate/transparency/health-agreements/shared-health-priorities/working-together-bilateral-agreements.html>.

¹³² Canada Health Infoway, Connecting you to Modern Health Care: Shared Pan-Canadian Interoperability Roadmap, May 29, 2023, <https://www.infoway-inforoute.ca/en/component/edocman/resources/interoperability/6444-connecting-you-to-modern-health-care-shared-pan-canadian-interoperability-roadmap?Itemid=103>.

Although the focus of this report is on the Alberta HIA, recommendations have been developed with the express intent that they can be applied more broadly across other provinces and territories. Intentional efforts to harmonize pan-Canadian health data policy based on a model law approach will pay long-term dividends for all Canadian governments by promoting the portability, accessibility, universality, and comprehensiveness of health data and rendering the health care system more efficient and effective. Most importantly, recognizing the harm that arises from health data fragmentation, this should benefit the health and wellbeing of all Canadians.

Although the focus of this report is on the Alberta HIA, recommendations have been developed with the express intent that they can be applied more broadly across other provinces and territories.

In the context of the Alberta HIA, this suggests that any legislative reform should endeavour to consider how to learn from and leverage best practice from other Canadian jurisdictions to seek long-term legislative common ground. To this end, national data standards, the practices in other provinces and territories cited in this report, and unifying policy like the former federal Bill C-72 should be considered when framing HIA reform.

- ▶ **Recommendation 21** | *Every effort should be made to harmonize the HIA with federal/provincial/territorial best policy practices and consensus data standards arising from the effort to achieve pan-Canadian health data interoperability.*
- ▶ **Recommendation 22** | *The HIA must be intentionally designed to align with pertinent health data legislation that is similar to former Bill C-72 to foster person-centric health data flow.*

On a more granular level, appropriate intra-jurisdictional health data flow will benefit from policy harmonization across all members of a health care team. Recall that only 11 of 29 regulated health professionals in Alberta are considered custodians. Although the HIA permits disclosure of health information between custodians and non-custodians (see ss. 35(1)(a) and (b)), the method of sharing is cumbersome and inconsistent due to bifurcated access rights amongst the members of a patient's care team. This includes access to Alberta's EHR (Alberta Netcare) that is restricted to "authorized custodians" (see s. 56.1(b)). This puts patient care at risk as significant clinical information sharing is reliant on Alberta NetCare and not all members of a care team have access to necessary information.

By comparison, Ontario's *Personal Health Information Protection Act* (PHIPA) captures all regulated health professionals as data custodians (see s. 3 and definition of "health care practitioner") and the designation as a "health information custodian" is also a basis for determining access to Ontario's EHR.¹³³

- ▶ **Recommendation 23** | *All regulated and non-regulated health care providers that can serve as members of a patient's care team should be subject to harmonized health data policy and*

¹³³ Government of Ontario, *Personal Health Information Protection Act*, updated December 3, 2024, <https://www.ontario.ca/laws/statute/04p03>.

privacy legislation to the extent required to enable optimized and appropriate data sharing for teamwork in health care.

- ▶ **Recommendation 24** | *The provisions of the HIA that are meant to address the same situation as equivalent provisions in other Alberta privacy legislation should be harmonized, and when amendments are made to any one act, these should be reflected across all privacy legislation.*

Lastly, the HIA must be internally harmonious to function optimally. Should the HIA be reformed in line with suggestions in this report, this will necessitate weaving together concepts such as duty to share, collective data governance, and delegation of decision-making amongst custodians. Moreover, it should also include examining how existing provisions of the HIA interact with each other and whether they are aligned and consistent. For example, while section 32(1), which ostensibly enables simple means for a custodian to “disclose non-identifying health information for any purpose”, sections 49 and 50 contemplate a relatively elaborate process of ethics board reviews for research projects that may require consent of patients for the use of their data. It raises the question whether the ethics boards are properly equipped to reconcile their recommendations, which are historically more based on medical ethics considerations as opposed to legislative compliance, for the proper handling of health data with the specific rights and obligations of custodians under the HIA. For example, research studies generally only use de-identified data for analysis; therefore, do any further stipulations placed by an ethics board on the use of the data negate a custodian’s apparent right under section 32(1) to disclose non-identifying health information for any purpose?

- ▶ **Recommendation 25** | *The content of the HIA, including any reforms introduced, must be carefully vetted to assure that they are internally harmonious and in support of quality services and data-related harm reduction.*

12. OVERARCHING ACCOUNTABILITIES

Understanding the core accountability of all Canadian health data public policy to promote quality health programs and services and minimize health data-related harm, the following overarching recommendations are proposed:

- ▶ **Recommendation 26** | *The HIA must carry out its express purpose to regulate the collection, use, and disclosure of health information in the context of acknowledging and honouring the core accountability of all Canadian health public policy to foster the quality of health programs and services.*
- ▶ **Recommendation 27** | *The HIA must carry out its express purpose to regulate the collection, use, and disclosure of health information in the context of acknowledging and honouring the mitigation of all nine forms of health data-related harm.*

RECOMMENDATIONS

01 *The custodial model of health data oversight should be evolved into a stewardship model.*

02 *The duty to share appropriate health information for primary and secondary purposes should be mandated, in balance with the mitigation of all reasonable privacy and security concerns.*

03 *An independent oversight body, distinct from the Office of the Information and Privacy Commissioner (OIPC), should be appointed to administer custodian duty to share obligations and requests for review for both primary and secondary data use.*

04 *A 'duty to share oversight body' must be equipped with the mandate, expertise, and resources to advance the quality of health programs and services for both the primary and secondary use of health data.*

05 *A 'duty to share oversight body' and the OIPC should be directed to form a joint health data governance committee (Data Stewardship Committee) to optimize the health and wellbeing of Albertans by cooperatively fostering the quality of health programs and services and the mitigation of all forms of health data-related harm.*

06 *The administration of the duty to share data must be accompanied by transparent public accounting by the Ministry of Health of the 'accepted' and 'refused' data requests for research purposes and the processing time for those requests.*

07 *The HIA should reframe its current independent custodian data policy processes and foster a collective approach to inter-custodian data management through policy, process, and governance harmonization*

08 *The HIA should implement data custodian authorities, obligations, and standards aimed at fostering data collaboration, including the capacity for a custodian to delegate responsibility for data decision-making to an accredited third party.*

09 *A clear and comprehensive approach to Indigenous data sovereignty must be incorporated into the Alberta HIA.*

10 *Data governance knowledge assets and policy efforts of Canada's three distinct Indigenous Peoples should be leveraged to support Alberta's health data policy approach, including but not limited to the HIA.*

11 *Data-matching provisions in the HIA should be re-evaluated in the context of the importance of the consolidation of an individual's comprehensive health and social services data to benefit team-based quality health services and health data-related harm mitigation.*

12 *The HIA should be amended to add provisions designed to work in conjunction with Freedom of Information and Protection of Privacy's (FOIP common or integrated program or service provisions to support the appropriate sharing of health data between data custodians and non-custodians to support care teams.*

13 *The HIA must modernize its approach to patient access and health data exchange with their care providers by establishing structured digital and portability requirements for patient access, control and communication of their personal health information.*

14 *The HIA must align its approach to patient access and oversight of health data with complementary public policy and legislation that is similar to former Bill C-72 (the Connected Care for Canadians Act).*

15 *Due diligence requirements should be comprehensively reviewed to streamline HIA function, with a strong focus on opportunities to eliminate duplicative processes and reduce access-related administrative burdens on health data custodians and the health workforce.*

16 *The backlog in privacy impact assessments must be addressed through a re-examination of the current process and the development and adoption of a more efficient and effective approach.*

17

Similar to the efforts of the EU European Health Data Space, the HIA should support a managed health data ecosystem where data governance, policies, processes, and practices are coordinated and aligned.

18

The HIA should be updated to define a clear ethical framework and process through which data can be used for innovation by both public and private sector entities with clear requirements that create public trust and a social license.

19

In alignment with the principle of duty to share, the HIA should be updated to make the health data held by custodians and health information technology vendors subject to mandatory retention planning requirements and disclosures, with appropriate governance and safeguards accounting for privacy, security, ethics, and proprietary interests in place, for beneficial stewardship purposes and the public good.

20

Modifications to the HIA should be contemplated that support a long-term vision for mandated health data interoperability in Alberta. The nature of these changes will depend on whether the chosen legislative approach to interoperability is within or external to the HIA.

21

Every effort should be made to harmonize the HIA with federal/provincial/territorial best policy practices and consensus data standards arising from the effort to achieve pan-Canadian health data interoperability.

22

The HIA must be intentionally designed to align with pertinent health data legislation that is similar to former Bill C-72 to foster person-centric health data flow.

23

All regulated and non-regulated health care providers that can serve as members of a patient's care team should be subject to harmonized health data policy and privacy legislation to the extent required to enable optimized and appropriate data sharing for teamwork in health care.



24

The provisions of the HIA that are meant to address the same situation as equivalent provisions in other Alberta privacy legislation should be harmonized, and when amendments are made to any one act, these should be reflected across all privacy legislation.

25

The content of the HIA, including any reforms introduced, must be carefully vetted to assure that they are internally harmonious and in support of quality services and data-related harm reduction.

26

The HIA must carry out its express purpose to regulate the collection, use, and disclosure of health information in the context of acknowledging and honouring the core accountability of all Canadian health public policy to foster the quality of health programs and services.

27

The HIA must carry out its express purpose to regulate the collection, use, and disclosure of health information in the context of acknowledging and honouring the mitigation of all nine forms of health data-related harm.

CONCLUSION


The subtitle of this report “*the impact of the Alberta Health Information Act on the health and wellbeing of Albertans*”, clearly references the indisputable accountability of all health public policy in Canada to the promotion of quality of health programs and services, as affirmed in the CHA. This report illustrates that the HIA often fails to support the quality of health programs and services in its approach to regulating health data access and privacy. The HIA can adversely impact the health and wellbeing of Albertans by inadvertently promoting data fragmentation that can interfere with all facets of health service and lead to system inefficiencies and negative outcomes, including illness and death. This serves as a reminder that all health public policy - including the HIA - must be intentionally designed to honour the core obligation to quality health programs and services, irrespective of its primary purpose.

While one focus of this report has been to consider modifications to the HIA that enhance the capacity to use health data to foster quality health programs and services, it is important to emphasize that the recommendations are not meant to diminish the importance of privacy, data protection, and the maintenance of public trust. This is particularly true in the context of increasing health institution cyberattack risk. Rather, the proposed improvements are meant to *augment* the capacity and responsibility of custodians and stewards to support appropriate data sharing without compromising privacy and data protection. The concept of a duty to share is advanced on the premise that the privacy and data protection rights of individuals remain intact; the duty to share is triggered in conjunction with proper safeguards to protect those rights.

In essence, the findings and recommendations made in this report coalesce around the central idea that more attention to strategic data stewardship will result in improvements to data interoperability and sharing while maintaining robust privacy and data protection. These are not mutually exclusive objectives. In fact, a lack of good data governance can result in both inadequate data sharing and inadequate security controls. If parties act cooperatively to create streamlined data access and sharing while maintaining privacy and security, optimal data utilization and protection can be achieved.

Further, privacy breaches and poor data protection as potential forms of harm should not be considered exclusive of other forms of harm. The segregation of forms of health-data related harm is antithetical to good data governance and likely to potentiate an imbalanced and potentially injurious approach to data design and use. While the HIA may not be the appropriate legislation to address the mitigation of all forms of health data-related harm, it must be carefully aligned with complementary legislation that focuses on forms of harm not covered in the Act.

To achieve these goals will require a shift in the mindset from the HIA’s focus on individual custodians, to data governance that embraces a collective responsibility to steward health data in alignment with the CHA’s promise of pan-Canadian quality health programs and services.



The approach to health data governance and stewardship can no longer be reliant on an individual data custodian acting independently with the hope and expectation that behaviours and processes will naturally and organically align based on good intentions. Collective accountability needs to frame the approach to legislation that sets the conditions and tools required to collaborate effectively, including the ability to hold each other accountable.

Person-centric, portable, universal, comprehensive, and accessible health data can be achieved to the collective benefit of all through a principled reimagination of health data public policy. With statutorily mandated collective information oversight, the potential of data-driven health care and learning health systems can be achieved. This is essential to foster the improvements needed to mitigate all forms of health data-related harm and rebuild trust in the ability of the Canadian health care system to deliver the quality programs and services that are needed today and in the future.

APPENDIX A - THE CASE FOR A DUTY TO SHARE

Background

Is it time to legislate a “duty to share” when it comes to health data? There has been recent recognition that the traditional approach to privacy legislation as it applies to the health sector in Canada is not conducive to health information sharing to the extent required to optimize care and mitigate preventable harms, including deaths. It is now accepted that the traditional custodian model of data legislation only emphasizes the responsibilities of the data custodian to protect the data against privacy and security risks.¹³⁴ This results in data custodians perceiving their primary role as protectors of information, applying their permissions to share health data very cautiously and ultimately leading to a tendency for risk avoidance and non-disclosure.

The problem is that there is limited consideration of the harm arising from lack of data sharing, as data custodians have no such obligations in the legislation. Given this, it has been proposed by various expert reports^{135 136 137 138} that a shift towards a “data stewardship” model of governance is required, which emphasizes the importance of being “good stewards” of data to achieve a balance between privacy and access.

Analysis

The question is: how does one legislate being a good steward of health data? A helpful analogy to consider is that under freedom of information (FOI) legislation, there is often a duty to assist the records requestor to help identify, locate, and provide the record(s) that the requestor is seeking. The obligation obviously has reasonable limits, but the premise is that because the records held by public bodies are regarded as public records and there is a public interest in making them available to ensure transparency and accountability of public institutions, then there is a positive obligation on public bodies to support the disclosure of those records.

One can argue that a similar principle ought to apply to health data that is created by publicly-funded dollars, i.e. that the data held by health institutions must be managed and stewarded for the public

¹³⁴ Affleck, E. et al., Data Disarray: A Root Cause Analysis of Health Data Dysfunction in Canada, November 2023, https://www.albertavirtualcare.org/files/ugd/3eb345_85ada6635d334c2ba6c102bdd57f20e2.pdf.

¹³⁵ Government of Canada, Pan-Canadian Health Data Strategy: Toward a World-Class Health Data System Expert Advisory Group – Final Report, May 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>

¹³⁶ Government of Canada, Pan-Canadian Health Data Strategy: Building Canada’s Health Data Foundation Expert Advisory Group - Report 2, November 2021, <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-02-building-canada-health-data-foundation.html>

¹³⁷ Affleck, E. et al., Interoperability Saves Lives, October 2023, https://www.albertavirtualcare.org/files/ugd/3eb345_8a8a4fa4037540698f90a23825b7c328.pdf.

¹³⁸ Affleck, E. et. al, Data Disarray: A Root Cause Analysis of Health Data Dysfunction in Canada, November 2023, https://www.albertavirtualcare.org/files/ugd/3eb345_85ada6635d334c2ba6c102bdd57f20e2.pdf.

good. An essential component of good stewardship is proactively looking for ways to manage the data in a way that serves the best interests of patients and the health care system.

As we have now seen with multiple reports¹³⁹ in the last two years, including Connecting the Dots¹⁴⁰ and Interoperability Saves Lives¹⁴¹, health data is not being shared optimally, thereby causing patient and health system harm.

Clearly, data custodians cannot and should not suddenly give up their privacy protection obligations and share health data without taking appropriate steps to mitigate privacy and security risks. However, being subject to a duty to share would mean that data custodians would now have the dual mandate to ensure that health data is principally used and shared to support quality health programs and services while also ensuring that appropriate privacy and security safeguards are in place. Simply ‘sitting’ on the data when there are known opportunities to leverage it for the betterment of patient care should become unacceptable behaviour, both legally and ethically.

In the law of negligence, a duty of care is created when it is reasonably foreseeable that one’s acts or omissions are likely to cause harm to someone else. In the foundational case of *Donoghue v. Stevenson*¹⁴², the plaintiff had become ill after drinking a bottle of ginger beer that contained a decomposing snail. The House of Lords held that the manufacturer of the ginger beer owed a duty of care to her, which was breached when it failed to have adequate product safety measures in place, and it was reasonably foreseeable that failure to ensure the product’s safety would lead to harm to consumers. There was also sufficient proximity in the relationship between the consumer and product manufacturer to justify the creation of the duty of care.

Arguably, with advances in technology and the known ability to improve outcomes and save lives through better, more comprehensive data, whether through direct clinical decision-making or indirectly through secondary data use, we are at the point where failure to adequately share health data in certain circumstances can foreseeably cause harm to individuals or, at the very least, foreseeably deprive patients of the best available care. Data custodians and stewards must understand that their decisions to either share or withhold data, and whether they are creating the right conditions for better data interoperability and security with streamlined access, have very real consequences for patient safety, health, and well-being. This accountability should be taken as seriously as other types of patient health and safety responsibilities, such as infection control.

In the United States, this problem has been tackled through what are called “anti-data blocking” provisions under the *21st Century Cures Act*. The legislation has had a significant impact and success

¹³⁹ Government of Canada, The Pan-Canadian Health Data Strategy: Expert Advisory Group Reports and summaries, updated May 3, 2022, https://cca-reports.ca/wp-content/uploads/2023/10/Connecting-the-Dots_ENdigital_FINAL.pdf.

¹⁴⁰ Council of Canadian Academies, Connecting the Dots: The Expert Panel on Health Data Sharing, October 19, 2023, <https://cca-reports.ca/reports/health-data-sharing-in-canada/>.

¹⁴¹ Affleck, E. et al., Interoperability Saves Lives, October 2023, https://www.albertavirtualcare.org/files/ugd/3eb345_8a8a4fa4037540698f90a23825b7c328.pdf.

¹⁴² British and Irish Legal Information Institute, *Donoghue v Stevenson* [1932] AC 562, May 26, 1923, *Donoghue v Stevenson* [1932] AC 562 <http://www.bailii.org/uk/cases/UKHL/1932/100.html>

in enabling patient data access, portability, and flow between health sector parties. Complaints about “data blocking” or practices that are “likely to interfere with the access, exchange, or use of electronic health information”¹⁴³ by health sector actors can be filed with a governance and oversight body called the Office of the National Coordinator for Health Information Technology.

Creating a duty to share within health information legislation is, in principle and substance, very similar to having an anti-data blocking regime in place. Implicit in rules against practices that interfere with data sharing is a legal obligation to use reasonable efforts or at least cooperate with legitimate requests to share data.

The difference is that a “duty to share” is more of a foundational principle and “anti-data blocking” policy operationalizes that principle. It is important for health sector stakeholders to first agree that the principle of duty to share needs to feature more prominently in health information legislation in Canada. The practical implementation of the principle can be developed in due course. As mentioned in the report above, Quebec’s Bill 3 contains many duty to share concepts, as well as the former federal Bill C-72, which had introduced anti-data blocking legislation into Canada for the first time.

Being vested with a duty to share would give custodians legitimate reason to look for solutions to enable appropriate data sharing and to invest resources into it, similar to the way public bodies must hire FOI staff to respond to FOI requests. Custodians would also be provided with a mechanism to defend their actions to share information in good faith, even if those actions upon closer scrutiny may have technically violated a privacy rule. It should be noted that many health information and privacy acts already provide protection against liability for custodians who make decisions in good faith that are later determined to have been in violation of the legislation.

The duty to share is consistent with an individual’s right of access to their own information. It can be seen as upholding the right of access to information for the treatment of the individual to whom it pertains.

Reasonable limits can be put in place around the duty to share to ensure that it is not overly onerous or unreasonable; precedents can be seen within FOI legislation in Canada and the anti-data blocking legislation in the US. These can include harm to patient privacy, availability of the data, and resource limitations.

In the simplest terms, the importance of creating the duty to share is that decisions to not share data would no longer be arbitrary or at the sole discretion of an individual custodian but based on an evidential framework that upholds accountability to quality health programs and services. Such a legislative mandate can spur a shift in culture and create programs to foster better data sharing amongst health care institutions and organizations.

¹⁴³ Assistant Secretary for Technology, Information Blocking, updated October 23, 2024, <https://www.healthit.gov/topic/information-blocking>.