

DISCONNECTED CARE

The Impact of the Alberta *Health Information Act* on the Health and Wellbeing of Albertans

SUMMARY REPORT

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*, 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 2023.¹

The *Canada Health Act* (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.² 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.

¹ 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>.

²Government 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>.

- 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.
- 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.*



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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.

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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.

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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.

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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.

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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.

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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.

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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.

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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.

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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.

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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.

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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.

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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.