



Office of the Information and  
Privacy Commissioner of Alberta

# *Health Information Act*

## Engagement Report

February 14, 2025

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# 2024 HIA Engagement Summary

## Acknowledgement

We thank all Albertans who have taken the time privately or in a work-related capacity to provide us with their input on the important topics raised in the various engagement surveys on the *Health Information Act* (HIA). The Office of the Information and Privacy Commissioner (OIPC) is committed to use the information we received in the surveys to guide our comments and recommendations for modernizing the HIA. This includes:

- Addressing challenges to the accessibility of health information for legitimate purposes such as:
  - Providing health care
  - Planning and managing the health care system
  - Conducting research
- Enhancing the use of technology through:
  - The use of deidentified or anonymous information
  - Supporting technology as a component of delivering health care in Alberta

## Overview of activities

HIA governs the collection, use, disclosure and management of health information. It protects the privacy of individuals' health information while ensuring that this information is available for care, research, and management of the healthcare system. The OIPC has engaged extensively with Albertans on this topic, soliciting the views of the public, researchers, and custodians, including members of regulated professional colleges to obtain an understanding of these actors' interaction with HIA in practice.

In light of changes planned by the Government of Alberta, our surveys have given special attention to current and future access to health information by custodians and researchers, changes in processing of health information as a result of the use of innovative technologies, and the privacy protections and rights required for Albertans to ensure ongoing trust in how their health information is handled in Alberta's healthcare system.

## What we heard

This report provides an overview of what we heard from the different groups we engaged with concerning the handling and management of health information in the health sector, challenges experienced by health care providers and researchers in relation to access and use of health information for their specified purposes, and about the changes these groups support to improve health care services and research in the province.

We also heard that there are shared concerns among the groups about the use of innovative technology in the delivery of health care services, including artificial intelligence (AI).

## General public

We surveyed over 2000 Albertans on their views regarding HIA, changes to the ability of healthcare providers to access health information via electronic systems, and the use of innovative technology in healthcare. The common themes we heard from this group are as follows:

1. Concern over health information data breaches is high among Albertans.
2. Even though not very familiar with HIA, there is trust that privacy rights are sufficiently protected.
3. Albertans largely agree that good access by healthcare providers to health information is needed but there is apprehension about access to sensitive health information.
4. Increased access to health information must be balanced by controls, restrictions, and oversight in a reasonable way that enables healthcare while protecting privacy.
5. Opposition to the use of health information to train AI for use in the Alberta health care system, and concern about the impact of AI in general on health outcomes.
6. Consistent views on wanting to be notified if AI is used to make decisions about healthcare and wanting the ability to appeal these decisions.
7. A desire to play a role in reviewing and controlling access by health care providers to their health information that is accessible electronically.
8. Support for granting the Commissioner additional powers to strengthen privacy protection, including issuing administrative monetary penalties (a type of fines).

More detail is contained in the [public survey report](#).

## Healthcare providers

(regulated health care professionals, regulatory colleges, and health care institutions)

We heard from over 200 regulated health care practitioners and from most of their professional colleges<sup>1</sup>. We also heard from health care institutions. Regulated health care practitioners and healthcare institutions are custodians under the HIA. A summary of what we heard from these groups is as follows.

1. Not all records needed to provide care are currently equally accessible.

Some respondents expressed that they experience challenges accessing relevant health records due to the underlying structure of the healthcare system and the legal status of the provider under HIA.

Examples provided include:

- a. the inability to access records that are held by private clinics and healthcare providers who do not have access to Netcare<sup>2</sup> or Connect Care<sup>3</sup>;

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<sup>1</sup> We received a response from 8 out of 11 regulatory colleges.

<sup>2</sup> Alberta Netcare is Alberta's provincial Electronic Health Record system. Each custodian in Alberta maintains its own records of the services provided to patients. In most cases, a copy of information deemed "key health information" is then forwarded to Alberta Netcare for province-wide availability when required.

<sup>3</sup> Connect Care is a clinical information system that enables Alberta Health Services (AHS) to share patient information within AHS facilities. It is used by hospitals and by affiliates of AHS including privileged physicians.

- b. system-related issues such as the inability to access certain systems (Netcare and Connect Care);
  - c. poor data quality within certain systems (Netcare and Connect Care);
  - d. timeliness of receiving information; and
  - e. insufficient access to data needed for research and quality assurance.
2. There are split views on whether changes to the HIA are needed to facilitate more information-sharing and the use of technology to support health services delivery.

Those who favour changes to the HIA highlighted that more information-sharing is favourable, and to the extent that the HIA does not allow this sharing, it should be changed to facilitate the same. Some suggestions included:

- a. making more information accessible via Netcare or creating one repository for health information; and
- b. allowing greater access to information for research and for cross-sectoral initiatives to better assess social determinants of health.

There is support for amending the HIA as necessary to facilitate the use of technology to support services delivery.

3. Broader access to health information to provide care is favoured with adequate controls to protect privacy.

There was broad support for changes to improve the functioning of and access to provincial health information systems, such as by expanding or improving the use of Netcare or Connect Care, harmonizing these systems, or improving their interoperability with other electronic medical record systems (EMRs<sup>4</sup>). The rationale for such changes is to ensure timely and complete access to all relevant health records, track patient outcomes for quality, and facilitate research.

There was also support for allowing practitioners in other provinces to access health information to improve health care for Albertans who seek out-of-province care, subject to appropriate controls that ensure access is limited to those who are authorized, and only as necessary to provide care.

4. Most are of the view that the functioning of HIA is adequate with some improvements. Those dissenting expressed concern that the Act is not sufficiently protecting privacy, citing snooping in health information systems as a concern.

Comments regarding possible improvements to HIA centered around changes needed to enhance quality improvement, facilitate more research, and provide patients with a greater role in determining access to their own health information.

5. Most support expanding access to the provincial EHR (Netcare) both within and outside Alberta so long as there are proper controls including for a patient to control their own health information.

The controls recommended included ensuring that accountability for patient privacy is clear, limiting access only to those who are providing care to the patient, mandatory privacy training and clearer

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<sup>4</sup> EMRs are systems generally used in health care practitioner's offices.

safeguards, more granular access controls and regular audits of the same, and severe penalties for violation.

Recommended patient controls included the ability to control access including through consent, enabling the opt-in or opt-out of such sharing, the ability of the patient to review who has access to their health information, and enabling them to identify those involved in their circle of care.

6. It was generally expressed that HIA has an appropriate governance scheme that adequately protects the privacy of Albertans' health information, although many commented that HIA could be modernized to enhance clarity for accountability.

Examples provided for modernization include the need to clarify accountability in a multi-custodian setting, protection for custodians when their affiliates violate the Act, specifying the safeguards that are necessary to protect health information, requiring compliance audits, and regulating AI to ensure responsible use.

Some commented that continuous improvements to HIA are necessary.

7. There is broad support for privacy-enhancing measures to improve privacy protection for Albertans.

These measures include:

- a. mandatory training of affiliates;
- b. easy digital patient access to health information;
- c. restrictions around sharing sensitive health information;
- d. requiring logging and routine auditing of health information access;
- e. point-of-care access to health information only, except in an emergency situation;
- f. requiring the registering with, or providing of advanced notice to a regulator, when implementing high-risk applications of AI; and
- g. obligations regarding transparency in the use of technology such as AI, automated decision-making, and biometrics.

There is also support for codifying the duty to implement role-based access controls, having effective authentication measures for those with access, and requiring that all systems have masking capability.

Comments about these measures suggest that they should be functional but not too restrictive.

8. There is support for greater interoperability and the removal of obstacles to facilitate the free flow of health information and its portability and mobility. Suggestions offered included:
  - a. using anti-blocking rules or legislation;
  - b. harmonizing requests for data that may reside in different systems or locations; and
  - c. consolidation of various EHR systems and networks.

9. There is a need to clarify how HIA applies in multi-custodian settings.

Issues related to multiple custodians using an EMR, or when a custodian becomes an affiliate of another custodian, were raised as issues by many respondents. Additionally, it was expressed that more

work needs to be done to clarify the custody or control of health information when it comes to shared health records.

10. There is general support for the PIA requirements in HIA.

Most healthcare providers support conducting PIAs but would like to see the burden on them minimized, such as by involving technology vendors in the process or by using a self-assessment instead. Some custodians expressed that for larger institutions, it was important for an organizational PIA to be completed and submitted to the OIPC. Most also indicated support for the use of compliance audits.

11. There is majority support for expanding custodianship to include health facilities or similar constructs, such as professional corporations, with some reservations expressed about how this would work and the potential for negative implications.

12. Adoption and use of new technology, including AI, for the purposes of providing care is favoured, so long as there are guardrails.

The adoption of new technology was reported as relatively high with most practitioners indicating that they either use or plan to use telehealth, AI, or other technological innovations as part of their practice.

Most health care providers expressed concern about the implementation of new technologies and their impact on both patient privacy and care. This was noted as an important factor holding back the adoption of technology. On this front, there was consensus that HIA should be modernized to account for and provide a framework to guide the responsible use of technology including AI and virtual care.

Some custodians felt there should be obligations of transparency and/or consent when using technologies such as AI, automated decision-making, and biometrics, and that the OIPC should be notified before implementing high-risk applications. Some indicated that it should be necessary to conduct PIAs, ethical reviews and algorithmic impact assessments, as applicable, when using these kinds of technology.

Some added that they would like to work more closely with the OIPC including the desire to have a regulatory sandbox to evaluate products for privacy implications and legislative compliance.

There was consensus that Alberta would benefit from a standalone law to regulate the use of AI systems across all sectors.

There was also strong support for the HIA to clarify when the use of health information, and de-identified information and anonymized information are appropriate and for what purposes, and to incorporate standards for the creation of this type of data, and to establish controls for use of the same.

More detail about survey responses is contained in the [College of Physicians & Surgeons of Alberta survey report](#) and the [regulatory Colleges survey report](#).

## Research

(health researchers from academic institutions and non-profit organizations and one custodian)

We invited several provincial research groups to ask their researchers to complete our survey to get perspectives directly from the research community. We wanted to understand the current state of

research in the province involving any use of health information, including that which has been de-identified or anonymized, any challenges they are experiencing as a health researcher, their ambitions for future use of health information, and privacy considerations concerning the use of this information in research.

We received just seven completed surveys (six researchers and one custodian). As such, the information provided in this report is not representative enough of the research community as a whole. Despite this, we have included a summary of what we heard from these respondents for information purposes only.

Of the respondents, some researchers were from academic research institutions, some were from non-profit research organizations. The researchers surveyed stated that they conducted mostly clinical research and secondary research or meta-analysis but some also conducted cancer research, and community health research. We also received a response from a custodian who provided its perspective on sharing health information with researchers for research purposes.

### Researchers

The common themes we heard from researchers are:

1. Overall, researchers want data to be more accessible to improve health outcomes and to improve health services through research and innovation.

The researchers commented on the challenges in obtaining access to health information and derivatives<sup>5</sup> of health information (HI derivatives). They identified that:

- There are significant delays and in some cases they are unable to get access to the data.
- These challenges result in:
  - the inability to assess interventions;
  - cancelled projects;
  - missed timelines to report to a drug agency; and
  - sponsors going to other jurisdictions where data is more accessible.
- This also impacts the ability to launch good projects and innovative ideas.

2. Researchers want data to be accurate and complete.

The researchers commented that some data is not entered into health information systems for years and in some cases data appears to be lost.

3. Researchers supported having HIA amended to ensure clarity, consistency, and uniformity in its interpretation and application in order to reduce different interpretations and inconsistent processes, and better support research. They also want transparency on the processes and

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<sup>5</sup> Such as deidentified or anonymous data.



consistent application of the rules regarding access to health information or HI Derivatives for research. One commented that:

*“Overall, I think the HIA has worked very well for facilitating health research in Alberta. My main concerns are the interpretation of HIA when it slows down the timelines for access or linking data.”*

4. Researchers want modern approaches to data access which allow for improved access while ensuring health information has safeguards to maintain patient privacy.
5. Researchers highlighted challenges with HIA consent requirements. They would like opt-out consent models to determine eligibility (i.e., screen patients for research studies) and then approach them for informed consent. Some commented that individuals should have more control over their health information when it comes to research and offered suggestions on how this could be done.
6. Researchers want definitions for synthetic data and clarification on how to determine levels of de-identification and assessment of risks.
7. Researchers want standards and guidelines to ensure consistency and public trust. The standards should also align with other legislation in Canada and internationally to support multi-jurisdictional research and should be modified as technology evolves.
8. Researchers expressed that the HIA should be amended to clarify whether health information and/or other data, such as de-identified or anonymous data, can be used and disclosed to train AI models.

It was expressed that this clarification should be addressed urgently as many are already using AI for their studies. It was added that Alberta has a lot of valuable health information and researchers who are eager to develop new medical interventions to improve health care. There are also Alberta companies which are looking to offer their services to support innovation and technology.

9. Researchers want the ability to link data from different data sets.

It was expressed that there are challenges in linking data from different data sources. Several researchers suggested the use of a data model.

10. Researchers would like to see more coordination among the different custodians and have a more interoperable environment.

The researchers indicated that they want a coordinated approach by different data custodians to facilitate innovative research. They feel this will drive investment toward the digital infrastructure to support health research. For solutions offered, they highlighted solutions they see working in other jurisdictions, such as a federated model for data access and working in a sandbox to test compliance.

All researchers expressed the need for interoperability across Alberta and Canada. They identified that the current lack of interoperability across Canada makes it incredibly difficult to conduct observational research in Canada, therefore making our country less desirable for clinical trials, which ultimately has

negative impacts on patients. They indicated that having more interoperability would accelerate more innovative research studies.

11. There is general support for a shared accountability model under HIA that involves academic institutions or research organizations, researchers, and custodians.

The researchers did not support direct accountability under HIA. The reasons provided suggest that they are of the view that they are already accountable to their academic institutions or employer and enter into agreements with custodians.

Suggestions were made regarding changes to HIA that would permit data to be shared more readily with trusted entities, such as academic research institutions where these institutions enter into agreements with custodians and assume some accountability.

Some researchers expressed that the Commissioner could work with data custodians to ensure compliance and agreement terms needed, and could audit for compliance and/or conduct joint investigations across jurisdictions.

12. The majority of researchers would like to see an oversight body established in Alberta that would have the ability to make information, including health information, accessible for research and development of innovative health care technology.

- Most felt it should be an independent research data board with funding from the government to establish the framework.
- In order to assess health, technology, ethical and privacy risks, it was suggested that the board would need to have a variety of members with different expertise.
- Ideally, the body would be able to acquire health information from custodians, non-custodians and from health care apps, encompassing various health professions.
- One researcher suggested it should also gather non-health data, such as education, tax, housing, and nutrition information, to support social indicators.
- Another researcher emphasized the importance of collaborating with international organizations on data standardization to enable multinational studies, particularly for rare diseases.
- A concern was raised that while this body could offer benefits, it might also introduce delays, additional bureaucracy, and complexity, potentially discouraging research in Alberta and negatively impacting patients and the health system.
- The majority of researchers wanted the Information and Privacy Commissioner to have oversight of this body to ensure established standards are adhered to.

13. Most researchers advocated for a holistic approach where research was recognized as a benefit to the health system rather than a risk. One noted that in a true learning health system, research should be integrated rather than treated as an external risk.

### Custodian

The one custodian who responded to the survey shared some of the same concerns expressed by researchers and has a similar view on many points. Below is a summary of the response.

1. More resources are needed to support the increasing number of researchers and requests for health information, noting that some requests involve voluminous amounts of health information.
2. HIA should be amended to define de-identified data and address whether custodians can share this information to train AI models. It should also be amended to address the risks when this type of information is used in AI models.
3. HIA should set out a data model that addresses data matching and reuse of data for secondary purposes.
4. There should be better coordination among different data stewards and custodians to benefit research.
5. There is a need for interoperability standards in Alberta and interoperability should be regulated.
6. There should be a shared accountability model.

On this point it was noted that custodians disclose health information to researchers which is linked with the information directly collected by the researchers and “[o]nce the data is combined, it is difficult to differentiate.”

7. Having an independent research oversight body would be beneficial.

On this point the following comment was made.

*“If such a third party is created, then it could be in position to capture and share other sources of HI, with the consent of the party that originally collected that info. This would include data related to health and well-being, social determinants of health, wearables, data collected by researchers in studies and other sources. Health providers are limited to collected data related to illness and disease. Ideally it could be a trusted independent source / protector of information.”*

The respondent added that this third party would need to comply with the HIA and regulations and that the Information and Privacy Commissioner should have oversight of the body.

Due to the low response rate and the potential to identify the respondents, we have chosen not to make the survey results of this group accessible.

## Consensus

Among all groups surveyed there is a consensus and understanding regarding:

1. The importance of patient privacy and for the right people to be able to access the right health information at the right time.
2. The importance of health information being readily available when and where needed, but well protected and access to it limited otherwise.

Responses regarding any changes to HIA to facilitate greater health information access usually resulted in balanced answers from both public and professional participants (i.e., “no, unless..” or “yes, on the condition that”, ...) stressing the need for an approach that enables both adequate access to accurate health information and adequate privacy protection.

3. The recognition that new technology is opening up opportunities to improve access to and quality of care and access to health information, but also apprehension about the adoption of (healthcare providers), or exposure to (patients) such technology, without the safeguards provided by regulation and oversight.
4. Major changes to the HIA are not needed to modernize the Act.

It is clear from the responses that neither the public nor healthcare providers are eager to see major changes to HIA (i.e. change for the sake of change), and healthcare providers are apprehensive regarding the impact that major regulatory or healthcare system structural changes may have on the time they would need to spend on overhead, such as adjusting processes and systems, instead of providing care. Both the public and healthcare providers largely think, other than for some moderate improvements, that HIA works well as it is, although awareness of its exact contents (rights, obligations) is limited.

Many respondents raised the point that issues of concern such as the current effort needed to access health information across different systems, organizations and jurisdictions are currently not or are only partially hindered by HIA. Larger obstacles are health care system design choices (e.g., differentiation between private and publicly funded care (which is a regulated profession, and which is not, etc.), organizational practices, operational challenges, electronic system limitations, and ‘privacy paralysis’, i.e., unfamiliarity with HIA, or a misconception of what HIA requires. Some suggested that legislation (HIA or otherwise) must be used to help overcome such obstacles, i.e., by anti-blocking and other enabling or directive provisions regarding electronic health record interoperability.

## Next steps

When amendments to HIA are proposed, the Commissioner will issue her comments and recommendations to the Government of Alberta, and to the Legislative Assembly when any proposed

amendments are considered therein. Her comments and recommendations will be informed by the engagement described herein. Additionally, the results will be used to inform our regulatory practices and work processes such as the creation of guidance and to help set priorities for future engagement and education.

# Appendix 1 - Methodology

## Public engagement

### Background

The collection, use and disclosure of health information has evolved rapidly over the past decade due to the introduction of new technologies including the widespread adoption of digital information collection and storage practices. The Government of Alberta is restructuring Alberta's healthcare system with the aim of providing more efficient, better care. This will also impact the way health information is collected, used and disclosed. As a result, the OIPC wanted to hear from Albertans about their views regarding the HIA and use of their health information in the current system and as may be contemplated in a future model that includes broader sharing and access to their health information through digital systems for a variety of purposes (health care, research, development of technology) and whether the privacy rights in the HIA are adequate for these purposes, or if the Act requires bolstering of these rights to ensure health information will continue to be adequately protected in the future model. The public survey was designed to provide us with the views of Albertans on these topics.

### Design

The OIPC identified **key themes** around which the insights and opinions from Albertans were gathered. They are:

- current and future health information rights and collection, use and disclosure practices;
- the role of the OIPC;
- health information breaches;
- the use of Electronic Health Record Systems (EHR) such as Alberta's Netcare;
- patient access to health information; and
- the use of Artificial Intelligence (AI) for care and healthcare research.

**Survey questions** were focused on the experience of respondents with these themes. For example, we asked them:

- if they have concerns about current and future health information access by care providers;
- if they think they have sufficient control over their health information;
- if they are aware of their rights under HIA, and if they think these are sufficient for future changes to the health care system, or in the light of technological changes such as the use of AI; and
- if they have experienced incidents (such as breaches), and how this impacted them.

The **data collection method** for this engagement was a larger-scale survey of Albertans, conducted by a third party on behalf of the OIPC.

The **data analysis** of the survey was partially outsourced and partially done in-house. The type of survey done yielded quantitative results (yes/no, categorical or point-scale answers), but also included open questions. The open questions were analyzed according to the [principles of inductive coding](#).

The validity of the survey relies on the mapping of various themes and questions, in regard to what the OIPC is seeking to learn from Albertans. To enhance **internal validity**, some layered questions (questions that drilled down on previous answers) had counterparts that functioned as ‘check’ questions. Screening of answers by software and survey staff ensured no blank or bogus answers were included in the sample. However, many of the questions were simple questions of opinion and did not measure any causality or correlation. **External validity** is determined by the representativeness of the population within the sample, in relation to the target population. The survey took into account a representative distribution among urban/rural, indigenous/non-indigenous, various income and education levels, etc. to ensure an accurate profile of Alberta’s society. The one limitation on external validity is that due to time constraints, the OIPC was not able to conduct a small sample offline version of the survey with vulnerable populations lacking internet access.

**Reliability** of the survey is determined by its size vis-à-vis the population surveyed, given a sample size of N=2000+ on a population of roughly 5 million, the margin of error of this survey is roughly 2%, which is relatively low.

## Health care providers, colleges, institutions and researchers

### Background

Health care providers, researchers, health care institutions, and regulatory colleges are important participants in Alberta’s health care system and are the primary users of health information in the province. The OIPC set out to survey each of these groups to understand current challenges, necessary changes, and opinions on change in relation to the accessibility of health information for legitimate purposes and any amendments to HIA needed to improve accessibility. We also sought views on the use of innovative technology, such as AI, and canvassed about whether greater controls, including enhanced privacy rights, are needed for the use of this technology. Perspectives were sought on the current model and the contemplated futuristic model as described above.

### Design

For each of the groups we engaged with, we identified **key topics** on the crossover of HIA and their specific practice. They are:

- health care providers’ current experience with accessing health information required to provide care to Albertans;
- health care providers’ thoughts about improving access to health information and changes needed to HIA;
- researchers’ current experience and desired improvements when accessing health information for research purposes;

- large institutions' current functioning under HIA and their observations regarding necessary reforms to the healthcare system;
- the impact of innovative technology, such as AI, on all the identified stakeholder groups; and
- the preferred measures needed to regulate changes resulting from technology and health care system changes and how to balance protection, accountability, transparency and other privacy rights, with the need to enhance access to health information.

**Survey questions** were created for each group, and these were used to break up key topics into specific issues.

The **data collection method** for this engagement was surveys containing closed, categorical and open questions. For the most part, we engaged with stakeholders ourselves, but we also received help from the College of Physicians & Surgeons of Alberta (CPSA) to reach its members, and Alberta Innovates to connect us to researchers. **Data analysis** was done by compounding values and counts for the closed and categorical answers. For the analysis of open-text answers, we leveraged data coding using a combination of deductive codes (drawn from the research questions) and inductive codes (generated by the data itself). We used coding to open-text answers to identify the presence of trends, or groupings of data, if any were present.

The primary aim of the surveys was to get an overall impression from stakeholders' opinions on the identified key themes. Given time and resource constraints, it was not feasible to achieve high **reliability** and external **validity** for each subgroup; instead, we opted for using representative sampling, e.g. by engaging regulatory colleges to get an impression of what their members experience, and expert opinions of a select number of researchers.

To enhance internal validity, some layered questions (questions that drilled down on previous answers) had counterparts that functioned as 'check' questions. Screening of answers by staff ensured no blank or bogus answers were included in the sample. However, many of the questions were simple questions of opinion, and did not measure any causality or correlation. External validity is determined by the representativeness of the population within the sample, in relation to the target population. The large institutions survey and regulatory colleges surveys were small in sample size by necessity and covered important entities in a qualitative way. The researcher survey had a small sample size (N<10) due to time constraints. The CPSA helped the OIPC conduct a survey of its regulated members (N=202).