Office of the Information and
Privacy Commissioner of Alberta

November 13, 2020

Honourable Tyler Shandro, Q.C.
Minister of Health
423 Legislature Building
10800-97 Avenue
Edmonton, AB T5K 2B6

Re: Bill 46, *Health Statutes Amendment Act, 2020 (No. 2)*

Dear Minister Shandro:

I am responding to the November 5, 2020 introduction of the *Health Statutes Amendment Act, 2020 (No. 2)* (Bill 46 or the bill) that proposes several amendments to the *Health Information Act* (HIA), and in particular to the legal framework of the Alberta Electronic Health Record (Alberta Netcare, EHR or Netcare).

In response to the tabling of the bill, I committed to reviewing the proposed amendments and making my comments public. The *Freedom of Information and Protection of Privacy* Act (FOIP Act) provides me with the ability to comment on the access and privacy implications of proposed legislative schemes and HIA allows me to comment on privacy implications to health information.

My comments on key amendments are set out below. As I was not provided with detailed rationales or context to help understand why amendments are proposed, my review is based on the bill as written.

Alberta Netcare Amendments

Netcare Context

One of HIA's key purposes is to "enable health information to be shared and accessed, where appropriate, to provide health services and to manage the health system". Balance is struck by additional purposes to "prescribe rules for the collection, use and disclosure of health information", and to "establish strong and effective remedies for contraventions" (section 2).

Netcare enables sharing of health information and is defined in HIA as follows:

> "Alberta EHR" means the integrated electronic health information system established to provide shared access by authorized custodians to prescribed health information in a secure environment as may be further defined or described in the regulations (section 56.1(a))

Netcare is not a single system, but rather it is an "integrated" system that supports shared access to health information by participating health service providers known as "authorized custodians". Authorized custodians include physicians, nurses, pharmacists, dentists and optometrists, among other regulated health professions. Tens of thousands of authorized custodians and their affiliates (staff) can access and use health information of every Albertan via Netcare, with limits based on defined roles and access profiles set in Netcare. Once a health service provider[1] is granted access to Netcare (and becomes

[1] "Health services provider" is the term used in HIA. For the purpose of this letter, "health service provider" is used.

an authorized custodian), they have the capability within their role and access profile, to access the health information of every Albertan. This broad and open access places a tremendous reliance on clear and understandable rules for access and use, with appropriate monitoring and oversight to ensure adherence to the rules. These accountability mechanisms help build Albertans' trust in a secure health information system for healthcare delivery.

Obtaining access to Netcare requires that a health service provider sign an Information Manager Agreement (IMA) with Alberta Health. A document called the Information Exchange Protocol (IEP) is incorporated as part of the IMA, and sets out the rules for access to and use of health information made available via Netcare. It also sets out certain privacy protections. The IMA is executed under section 66 of HIA, which allows a custodian to enter into an agreement with a person to provide information management or information technology services. Through an IMA, the participating health service provider is the responsible custodian and Alberta Health is the information manager.

Health service providers hold shared responsibility of Netcare through IMAs and IEPs. In addition, data stewardship is accomplished through a Minister-established multi-disciplinary data stewardship committee that makes recommendations to the Minister with respect to the "rules related to access, use, disclosure and retention of prescribed health information". The committee is known as the Health Information Data Governance Committee (HIDGC).

Netcare supports access to an Albertan's health information without the consent of the individual. The risk of broad access is mitigated by duties set out in HIA that require custodians to maintain safeguards to protect health information. For example, HIA requires that a privacy impact assessment (PIA) be completed and submitted to my office. The PIA is an accountability mechanism that helps offset the risk of increased sharing of Albertans' health information without consent. PIAs outline the controls that are implemented to reasonably mitigate risk.

Bill 46 includes a number of amendments that significantly impact the operation of and responsibility for Netcare. It is important to consider the implementation of Netcare in order to understand the impact of the proposed amendments, and to consider whether such amendments properly balance health information sharing and protection of health information.

Increased Role and Responsibility for Alberta Health over Netcare

The proposed section 56.21(1) establishes that Alberta Health would manage and operate Netcare, and appears to give Alberta Health full control and responsibility for information made available via Netcare and its operations. This is a significant departure from how Netcare was established.

Netcare operation currently relies upon a health service provider signing an IMA with Alberta Health. This amendment would shift the role of Alberta Health from an information manager that a health service provider has entered into an agreement with to provide information management or information technology services, to the manager and operator of Netcare.

The following sections outline some of the potential implications this proposed change would have on the governance and operations of Netcare.

Termination of Information Manager Agreement (IMA) and Information Exchange Protocol (IEP)

The proposed sections 56.71(1) and (2) would terminate the Netcare IMA, and the IEP that forms part of an IMA. Termination of the IMA would be necessary in order for Alberta Health to become the manager and operator of Netcare, as opposed to the information manager as defined in section 66 of HIA.

I am not certain of the long-term benefits of this significant transition in responsibility for the management and operation of Netcare. I am also uncertain what consultation occurred with health service providers who signed individual agreements with Alberta Health to be the information manager for Netcare. Termination of this legal agreement would affect thousands of health service providers.

The bill also includes a number of amendments that set out the duties and responsibilities of Alberta Health with respect to Netcare, most of which will require regulatory development. The amendments make it clear that the intent is for new Netcare rules to be established that Alberta Health would be responsible to implement. For example, section 56.21(2) says that Alberta Health would be responsible for taking reasonable steps to maintain safeguards and to determine who gets access to Netcare. The approach as proposed leaves the details of such safeguards and access protocols to the future development of regulations.

I strongly encourage Alberta Health to engage in a detailed consultation with my office and all health service providers affected by these amendments. The consultation should include input on what safeguards are required to reasonably mitigate privacy risk for Albertans' health information.

Reduced Clarity in Recommending Function of the Health Information Data Governance Committee

Sections 56.7(1) and (1.1) would be amended and remove the description of what the multi-disciplinary data stewardship committee, or HIDGC, could recommend to the Minister (for example, rules related to access, use, disclosure and retention).

As noted above, the prior authority for Alberta Health to be the information manager of Netcare was derived, at least in part, through the execution of the IMA signed between Alberta Health and a participating health service provider. There are tens of thousands of health service providers who participate in the shared electronic health record. The HIDGC is extremely important as a governance mechanism through which all participating custodians can make recommendations to the Minister.

Expanded Access by Health Service Providers Outside of Alberta

The proposed amendment to the section 56.1 definition of Alberta EHR would remove "authorized custodians" and "prescribed health information". The effect of this and other proposed amendments within section 56.1 would be to provide Alberta Health with the ability to significantly broaden access to Netcare, including to out-of-province or out-of-country health service providers who provide health services to an Albertan.

Based on Alberta Health's news release on Bill 46 and subsequent public comments, I understand that part of the reason for the proposed amendments is to allow health service providers on the Saskatchewan side of Lloydminster to access Netcare.

Beyond the Lloydminster issue, the bigger concern is that the wording of the amendment is not limited in scope. I do not know Alberta Health's intent. However, the proposed amendment appears to open the door for a health service provider in any part of Canada or beyond to also be granted access to

Netcare to provide a health service to an Albertan. For example, access to Netcare to enable out-of-province or out-of-country virtual healthcare may be contemplated.

Broadening access to Netcare beyond Alberta's borders poses potential jurisdictional challenges for me to effectively investigate or hold accountable any health service provider outside of Alberta. It may also limit the recourse available to Albertans.

Expanding access to Netcare may be necessary to support health service delivery to Albertans, but compensating controls must be implemented to mitigate risk to Albertans' privacy and to provide for effective oversight.

Expanded Use of Health Information Available via Netcare

HIA currently permits an authorized custodian's use of health information made available via Netcare for:

- Determining eligibility to receive a health service
- Providing a health service
- Any purpose authorized by an enactment of Alberta or Canada
- Processing payment

The current rules do not allow use of health information made available via Netcare for purposes such as research, education and internal management. Restricted use helps mitigate privacy risk, which, during the outset of Netcare implementation, was an important consideration for health service providers to decide whether to participate as they weighed the benefits of broader access, with privacy considerations. In relation to the points made above about the termination of IMAs and IEPs, it is important to note that when a custodian decided to participate in Netcare, the custodian did so with knowledge of these restricted uses.

Proposed amendments to section 56.5(1) would allow access to health information via Netcare for any section 27 purpose, which significantly expands the permitted uses. These additional purposes include:

- Investigations, practice reviews, discipline proceedings and inspections of a health profession or discipline
- Research
- Education
- Internal management, including planning, resource allocation, policy development, quality improvement, monitoring, audit, evaluation, reporting and human resource management

Specific to Alberta Health and Alberta Health Services, the amendments would also increase the authority for these entities to use health information made available via Netcare for planning and resource allocation, health system management, public health surveillance, and health policy development.

The proposed amendments increase privacy risks in two ways:

1. More health service providers will be given access to Netcare, including users potentially outside of the jurisdiction of HIA and the oversight of my office.

2. There will be significantly broadened purposes for which Netcare information may be accessed and used.

It must be recognized that privacy risks are escalated by proposing to increase the number of users in Netcare and significantly expanding the purposes for how health information available via Netcare may be accessed and used.

I was already concerned that Netcare privacy risks have grown over the past decade as more health information is made available to more health service providers. The privacy risk threshold is growing, and compensating controls may not have kept pace.

There may be a good reason to expand the use of Netcare. In principle, I am not opposed. That said, I am and will remain strongly opposed to any expanded access and use that does not include a robust privacy and security assessment and consultation on increasing risk, with commensurate, updated and enhanced controls that reasonably mitigate such risk. Transparency is critical in this regard.

Expressed Wishes

HIA includes a provision that requires a custodian to consider an Albertan's expressed wishes about how much of their health information should be made available via Netcare.

An Albertan's expressed wishes are currently met where an authorized custodian decides to limit the information made available, by applying a global mask to the individual's health information. This effectively shields the masked health information from being viewed unless the information must be accessed to provide, for example, emergency care. Where the mask is circumvented in an emergency care scenario, a log is kept that supports a subsequent investigation to ensure the decision was appropriately made.

The proposed section 56.4(2) would impose limitations on expressed wishes, in accordance with yet to be drafted regulations. There may be some benefits to setting out in regulation the way in which expressed wishes must be addressed, as this could increase clarity.

There are two areas, however, that concern me related to this amendment:

- It appears that the expressed wishes requirement does not apply to a health service provider located outside of Alberta. This would lead to a lower standard of protection and control of health information for an Albertan who receives a health service from a health service provider outside of Alberta.
- The bill would also repeal section 107(6.1). This section makes it an offence for a person to use masked health information in contravention of section 56.4. The effect of this proposed amendment is untested at this time, and it is therefore possible that contravening section 56.4 may be addressed in a broader section 107 offence provision. However, it is my view that the specificity of section 107(6.1) reflects the seriousness of not respecting an Albertans' expressed wishes that their Netcare record be masked.

The expressed wishes provision is extremely important to the operation of Netcare. Without being able to consent, this is the last measure of control an Albertan has over what health information is made available via Netcare. I request that detailed consultation be held with health service providers and my office on this amendment and the development of related regulations.

Other Amendments

Elimination of the Privacy Impact Assessment Requirement for Alberta Health, Alberta Health Services and the Health Quality Council of Alberta

As proposed, section 64(3) removes the PIA requirement for the collection, use and disclosure of health information shared between Alberta Health, Alberta Health Services and the Health Quality Council of Alberta for any purpose set out in section 27(2), unless implementing a new information system or making changes to an existing information system. Section 27(2) involves public health surveillance, policy development and health system management.

I cannot stress more emphatically my concerns with this amendment. The duty to complete a PIA offsets risks to broad sharing of Albertans' health information without consent. This is the construct of HIA. HIA enables broad sharing of an Albertans' health information without consent, and offsets accrued risk through stringent duties and strong controls such as required PIAs. PIA requirements are an important accountability mechanism that I believe to be the most effective proactive privacy protective measure in HIA.

Frankly, it is shocking and disappointing to see an amendment that proposes to remove this PIA requirement that supports and documents the assessment of privacy risk and ensures that reasonable controls are in place.

Completion of a PIA is a duty with which all custodians must comply. There is no acceptable reason why Alberta Health, Alberta Health Services and the Health Quality Council of Alberta should get a pass on assessing privacy risk through a PIA. This is particularly so for Alberta Health, given the amendment for Alberta Health to assume management and responsibility of Netcare.

This proposed amendment is further confounding at a time when PIAs are becoming a baseline standard around the world, such as in the European Union's *General Data Protection Regulation*, and when other measures, such as algorithmic transparency and ethical assessments of big data initiatives, are being considered. This amendment takes a big step back when other jurisdictions around the world are stepping forward.

Removing this PIA requirement is simply unacceptable.

New Authority to Indirectly Collect Health Information

The proposed new section 22(2)(h) would authorize indirect collection where disclosure is authorized by an enactment. Indirect collection is collection of health information from someone other than the individual who is the subject of the information.

I am unsure of the purpose or intent of this proposed amendment. However, it will be important to monitor and assess privacy risk related to possible amendments in other laws that could then allow for broader indirect collection by a custodian.

Removal of the Imminence Test for Disclosure to Avert Risk of Harm

The proposed amendment to section 35(1)(m)(ii) would remove the words "imminent danger" and substitutes "significant risk of harm", which would revise the threshold for disclosing health information without consent to avert or minimize harm.

I support this amendment. The amendment would provide health service providers with greater latitude to exercise their professional training, expertise and judgment to disclose health information to prevent harm.

I am aware of many situations that have arisen over the years where a custodian held health information about an individual that could have been disclosed to prevent harm, but felt the law did not authorize the disclosure because they could not demonstrate imminence. In some cases, health information was not disclosed that may have reduced risk to an individual.

Improved Accountability for Researchers

Section 54(3.1) proposes to increase accountability by requiring a researcher to comply with the research agreement they have signed with a custodian, and with the conditions set out by a Research Ethics Board (REB), and to collect, use and disclose health information only in accordance with the agreement and the research protocol. Proposed section 54(4) clarifies that if the researcher is in contravention then the research agreement is cancelled, and the researcher is no longer authorized to use the health information and must destroy or return it.

I support these proposed amendments, both of which increase accountability by requiring a researcher to comply with a research agreement and the conditions set out by an REB.

Expanded Authority for Commissioner to Not Hold an Inquiry Where Circumstances Warrant

The proposed amendment to section 78 would allow me to refuse to conduct an inquiry where circumstances warrant.

I support this amendment, which now aligns with the FOIP Act.

Increased Fines for Contraventions

The proposed amendments to section 107 would increase the fines for an individual to up to $200,000 and for an organization to up to $1,000,000, and changes the limitation period, which will commence when an alleged offence first came to the attention of the Commissioner.

I support the amendment to increase fines, but note that it is the court that levies fines upon conviction of an individual or organization. There have been 15 convictions for knowingly gaining or attempting to gain access to health information in contravention of HIA. The two highest fines issued in 2007 and 2011 were $10,000 and $15,000, respectively. Since then, the average fine has been around $3,500 (and may be associated with other penalties, such as a victim fine surcharge or probation including no access to health information for a specified period of time). No organization has been convicted in Alberta so there is no precedent in that regard.

I am, however, pleased with the proposed change to the limitation period.

I would also like to discuss with Alberta Health and other stakeholders the role that administrative monetary penalties could play for certain infractions under HIA as a more meaningful enforcement measure. This type of enforcement mechanism would significantly reduce red tape by cutting the resources required to prepare court submissions, provide more timely investigations and not add to court backlogs.

Summary

Many of the proposed HIA amendments present a significant change in direction. In particular, I am concerned with expanded access to Netcare and use of health information available via Netcare without compensating controls to address risks to Albertans' privacy. Expanded access to Netcare to out-of-province health service providers may pose significant jurisdictional challenges and obstacles to effective oversight by my office.

I also cannot stress strongly enough how concerning it is for Alberta Health, Alberta Health Services and the Health Quality Council of Alberta to receive a pass on PIA requirements, a pass no other custodian in Alberta receives. This amendment will significantly reduce transparency and accountability for certain information sharing initiatives. Given Alberta Health's role in facilitating implementation of HIA and the significant amount of health information about every Albertan the ministry holds, it is disappointing that removing the PIA requirement for certain activities is even considered. This is particularly true today with the ever-increasing ways in which data can be collected, used, matched, manipulated or disclosed, and the opaqueness with which these activities can occur.

OIPC Proposed Amendments

In addition to the comments above, please see the additional suggestions for HIA improvements, attached as Appendix A.

Thank you for your consideration of these comments.

Sincerely,

[Original signed by Jill Clayton]

Jill Clayton
Information and Privacy Commissioner

Appendix A: Suggested HIA Improvements

	Issue	Policy Consideration
1.	Research repositories are created to collect health information for future research.	Amend HIA to clarify under what circumstances repositories for future research can be created and managed.
2.	Patients are asked to consent to future research that has yet to be approved by a research ethics board (REB).	Amend HIA to clarify the circumstances where it may be appropriate for a patient to consent to future research where the REB has not yet reviewed the study or the study may not have been created.
3.	It is not clear whether section 34(2) consent requirements apply to consent for research.	Amend HIA to clarify that HIA s. 34(2) also applies to research related consents.
4.	It is not clear as to how HIA applies to an Information Manager (section 66).	Amend HIA to clarify the obligations and duties of an information manager under HIA, when the information manager is not acting as an affiliate or custodian.
5.	The Alberta EHR provisions do not align well with the *Alberta Electronic Health Record Regulation*.	Amend HIA and the EHR Regulation to clarify logging requirements that apply to the AB EHR vs. an electronic health record information system.
6.	HIA does not recognize the concept of a shared electronic medical record (Part 5.1).	Amend HIA to recognize shared control in EMRs where use occurs involving multiple custodians, and require that a governance structure be established that outlines how HIA duties will be addressed.
7.	HIA does not include an offence for an attempt to re-identify health information.	Make it an offence to attempt to re-identify non-identifiable health information disclosed for the purpose of quality improvement or research.
8.	Vendors play a significant role in providing electronic medical record systems to custodians, but do not have clear responsibilities or duties under HIA.	Consider an amendment to HIA that directly makes vendors responsible for privacy and security assessment of an electronic health record information system, including submission of a PIA in relation to a system that is being implemented by Alberta custodians.
9.	More meaningful enforcement measures with the aim to reduce court burdens.	Consider the role administrative monetary penalties could play for certain infractions under HIA as a more meaningful enforcement measure. This type of enforcement mechanism would significantly reduce red tape by cutting the resources required to prepare court submissions, provide more timely investigations and not add to the courts backlog.
10.	There have been practical challenges posed by HIA mandatory breach reporting and notification provisions.	Consider aligning HIA requirements with the *Personal Information Protection Act*, including the threshold for reporting and timing of notification, and Commissioner's powers. Consider amendments to clarify certain aspects of HIA mandatory breach reporting and notification provisions to address practical operational issues for both custodians and the Commissioner that have arisen since coming into force.