Office of the Information and
Privacy Commissioner of Alberta

Summary Report: College of Physicians & Surgeons of Alberta Survey of Members regarding functioning of and changes to the *Health Information Act*

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CPSA survey analysis and summary of the data

This is a summary report of the data obtained from the Office of the Information and Privacy Commissioner (OIPC) survey of the members of the College of Physicians & Surgeons of Alberta (CPSA). It consists of quantitative data, such as charts where yes/no, scale or multiple choice options were surveyed, and contains processed data of open answers where such charts made sense according to principles of inductive coding (i.e. respondents answered aligned along a limited number of categories of answers and were grouped accordingly). Statistics have been enriched with a short analysis of answers and/or illustrative survey answers where relevant.

Summary of findings and key themes

Current access to health information (Q3,4)

Within the comments associated with these questions, a number of issues are identified in obtaining access to relevant health information. The areas of concern can be summarized as follows.

- No access to certain types of records including consults and social work notes for treating mental health and addiction, prenatal care provided in private clinics, primary care or records of community-based physicians, specialist records that are not recorded in Connect Care, and records that predate Connect Care such as anesthesia records and nursing home records.
- System-related issues such as:
    - inability to access certain systems, such as Connect Care;

  - routing issues from Connect Care;
  - regular Netcare outages; and
  - difficulty finding information needed in Connect Care.

- Data quality associated with Connect Care records such as unstructured reports that make it difficult to assess patient treatment, inability to interpret certain reports such as for prenatal care, failure to upload relevant data to Netcare, lack of detail in reports from Connect Care such as for surgeries, and accuracy.
- Timeliness of receiving information.

There were also comments about the lack of access to health information for research and quality improvement, for out-of-province care, and by the chief medical examiner. There were complaints about:

- information being sent to the wrong location;
- lack of a central source for patient data;
- lack of interoperability between systems; and
- lack of access to private clinic records, including surgical clinics and outpatient clinics.

Changes to HIA to enhance the sharing of health information and the use of technology to support health services delivery (Q8-11)

There was a split on whether changes are needed to HIA to facilitate greater information-sharing. Those who favour changes highlight that more information-sharing is favorable, and to the extent that HIA does not allow this sharing, it should be changed to facilitate the same. Some suggestions included:

- requiring more information to be accessible on Netcare;
- creating one repository for health information such as Connect Care;
- allowing the chief medical examiner access to provincial health information systems;
- allowing greater access to health information for research by making all Albertans eligible for research with the ability to opt out; and
- allowing greater cross-sectoral sharing of health information to better assess social determinants of health.

It was also mentioned that HIA should be amended to ensure that custodians can use technology to support the delivery of health services, such as by:

- ensuring HIA allows them to use technology such as electronic messaging or secure file transfer technology to facilitate more secure communication; and
- ensuring HIA allows the use of AI or other kinds of technology to improve delivery of health care.

Additionally, there were comments on the need to better facilitate the interoperability of systems in Alberta, and the role of patients as gatekeepers where it related to broader sharing of their health information, and consequently amending their rights under HIA.

Functioning and changes needed to EHRs and EMRs in the province (Q5-7,9)

73% commented that they would like to see changes to improve the functioning and access to provincial health information systems. Changes proposed vary but include expanding and/or improving the use of Netcare or Connect Care, harmonizing the two systems, creating EMR interoperability or having a single central province-wide universally-used EHR. Reasons for needing these changes include the ability to 1) have timely and complete access to all relevant records, 2) track patient outcomes to ensure quality of care, and 3) to facilitate other types of research.

Broader access to health information within and outside Alberta (Q9-11)

There was support for allowing practitioners in other provinces to access health information of an Albertan who is receiving care out of province and for expanding access to all health care providers in Alberta. However, it was indicated that such access should be appropriately controlled and limited to authorized and necessary purposes.

Overall effectiveness and functioning of HIA (Q12)

75% felt that the overall functioning of HIA is adequate, but comments indicate that improvements can be made. Some felt that changes are needed to allow greater use of health information for research, quality improvement and use of modern technology including the use of AI. Of those 25% that do not feel that HIA is currently sufficiently protecting patient privacy, snooping in EHR and EMR systems is a concern.

Several responses indicate there should be an increased role for the patient in determining access to their health information, to improve the effectiveness of HIA.

Changes needed if health information is more broadly accessible via digital health information systems (Q13-24)

If health information were more broadly accessible via digital health information systems to health care providers within or outside Alberta, there was general support for a more prominent role for patients to control their own health information, along with other changes including providing patients access to their own health information, allowing them to opt in or out of sharing their health information, reviewing who accessed their health information, consenting to access by care providers, and identifying providers in their circle of care. Other proposed changes include:

- requiring health care providers to agree to abide by appropriate privacy requirements with a clear accountability structure in place to ensure it is followed;
- ensuring that a health care provider can only access the health information of a patient on a need-to-know basis such as when providing them with health care;
- mandatory training requirements and clear safeguarding rules;
- rules that clarify who can access health information and when, including tiered access for sensitive health information, and different levels of access for certain health care providers;

- regular access audits;
- controls regarding the use of health information for quality improvement and surveillance;
- severe penalties for violation including probationary periods for offenders; and
- ensuring there is access to de-identified or anonymous data for research and other health care related purposes.

Adequacy of governance responsibilities under HIA (Q13-24)

It was generally expressed that HIA has an appropriate governance scheme that adequately protects the privacy of Albertans' health information. However, many felt that HIA should be modernized to clarify roles, responsibilities and accountabilities, and to improve privacy protection. Examples include:

- clarifying who is accountable for compliance when there are multiple custodians providing health care in a shared practice and when a health care provider acts in multiple roles, i.e. custodian and affiliate;
- ensuring there are adequate safeguards for custodians when their affiliates violate the Act;
- specifying the safeguards that are necessary to protect health information;
- requiring compliance audits; and
- regulating the use of AI to ensure it is used responsibly.

There were comments that "continuous improvements [to HIA] are necessary" and that the legislation is archaic and can interfere with patient care.

Privacy-enhancing measures (Q13-24)

There was broad support for the following measures to enhance privacy protection under HIA:

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

There was also support for legislating the duty to minimize obstacles to the free flow of health information such as by establishing anti-blocking rules and measures to ensure greater interoperability and imposing duties to facilitate the portability and mobility of health information.

The following comments were made in relation to privacy-enhancing measures.

- The measures need to be functional and not too restrictive.
- Health information needs to be accessible beyond patient care for other purposes, such as for quality improvement or to obtain consent for secondary uses including research.
- If patients can access their audit logs, it "will make everyone more comfortable".

Within the comments were the following recommendations for additional protection.

- HIA should embed enhanced security requirements such as a duty to implement role-based access and ensure systems can authenticate as to purpose of access.
- HIA should require systems that store health information to have masking capability.

Compliance assessment and enforcement (Q25-31)

In relation to PIAs there was majority support for:

- reasonable and not too burdensome PIA requirements;
- a role for vendors in conducting PIAs; and
- making large custodians that are currently exempt from PIA requirements imposed on other custodians subject to this requirement.

There was also support for self-assessment of compliance if the PIA requirement for small custodians would be repealed.

There was majority support for compliance audits to promote compliance and there was strong support for working more closely with the OIPC to facilitate compliance (e.g. for assessing innovative technology in a regulatory sandbox).

Scope of HIA (Q32,33)

There was majority support for expanding custodianship to include health facilities or a similar construct, such as professional corporations, although there were concerns over how this would work and what the implications would be.

There was also support for extending HIA to apps that collect health information where this makes sense.

Technology and innovation (Q35-Q40)

The majority indicated that they are using or are planning to use telehealth solutions and some are using or planning on using AI and/or Smart devices/apps/wearables as part of their practices. However, concerns were expressed about the use of these technologies (either relating to privacy or otherwise), and this is also the reason why some have not yet implemented them despite apparent benefits. It was suggested that to enhance the adoption of innovative technologies, there need to be clear rules and procedures for their implementation and use.

To mitigate the risks associated with these technologies, the majority supports compliance-related assessments related to their use such as PIAs, ethical review, or Algorithmic Impact Assessments[1]. A standalone law to regulate AI in Alberta was also supported along with independent oversight to ensure compliance.

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[1] Such as the Algorithmic Impact Assessment used by Government of Canada.

Per question summary and presentation of the data

Q1 Information about the respondent

There were 202 CPSA members who responded. Of them, 37% were general practitioners. The majority identified as "other". Within this category are a number of specialists.[2]

Q2 Are you the custodian of your patient records?

There is some confusion regarding custodianship. Misconceptions include believing the PCN is the custodian, practitioners are co-custodian with an institutional provider (such as AHS), and some are unsure of their obligations under HIA or their status (8.42% unsure if they are a custodian or not).

> *I work as a Locum Physician. In what way am I responsible for my patient records beyond completing notes?*

The majority of respondents identified that they are the custodian of patient records, 54%. Within the comments associated with this question, there appears to be some confusion about custodianship within a combined practice or PCN.

> *The PCN holds the custodianship of our outpatient records currently but we are transitioning*
>
> *There is also a master custodian at our clinic*

Q3, 4: Are you experiencing any challenges in obtaining access to necessary health information in your current practice? If yes, please describe these challenges, including how they impact your work, and if cross-organizational/location data access is a factor.

60% of respondents have no issue or challenges accessing the health information they need. As one respondent notes:

> *Connect Care and Netcare provide excellent access for patient care.*

Some respondents indicated that there may be a limited appetite for 'more' Connect Care or Netcare.

> *The only issue is the cost to hire staff To get things off Netcare or connect care. But I much prefer this To having community clinics all connected to connect care With all of its horrors.. It further slows down pace, And will further exacerbate Patients inability to access a family doctor. Doctors need to be able to do*

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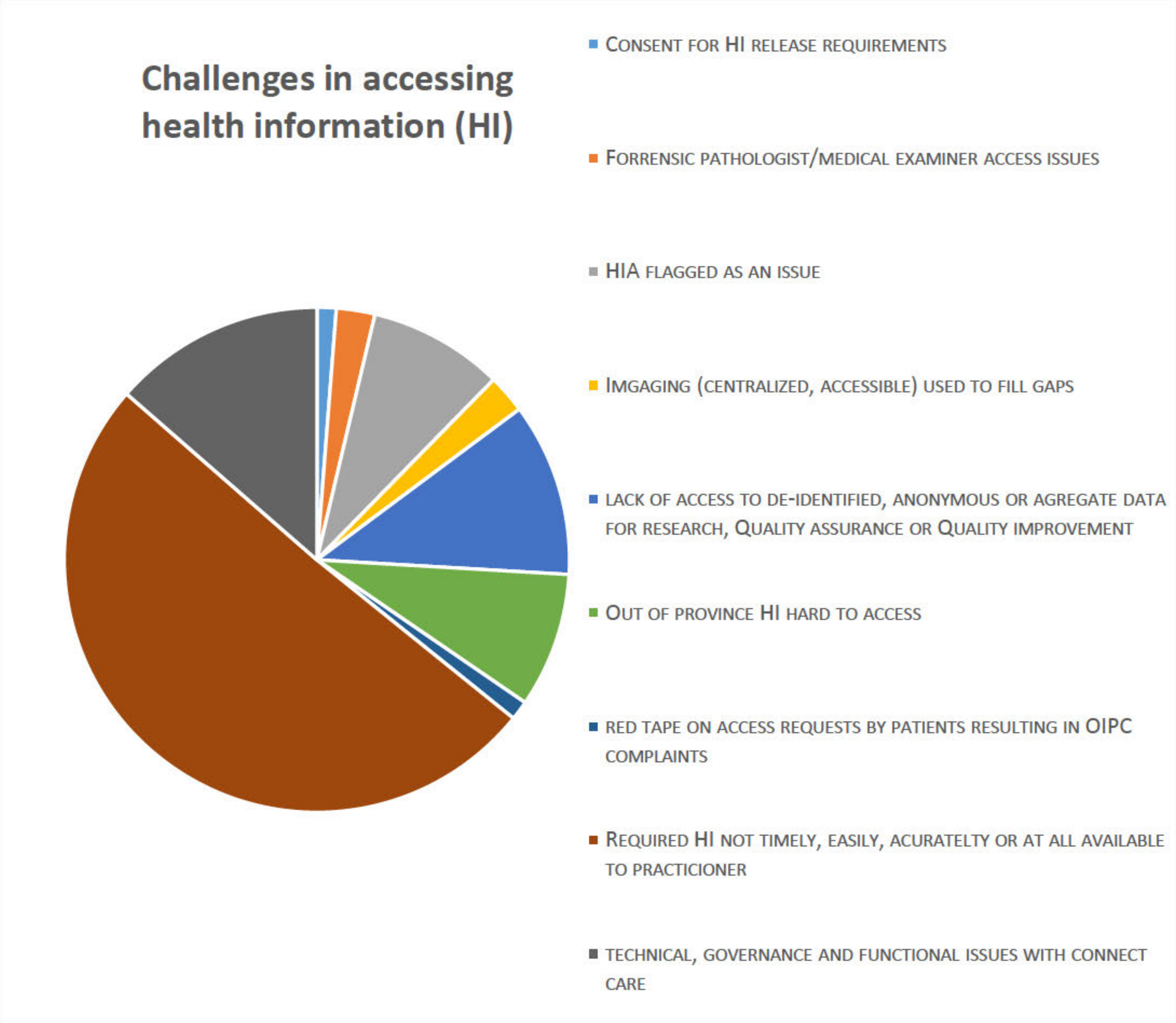
[2] Respondents included one or more specialists in the following areas:
Addiction, Anesthesiology, Cardiology, Critical Care, Dermatology
Diagnostic Imaging, Diagnostic Radiology, Diagnostic Radiology & Nuclear Medicine, emergency care
Family Medicine, Gastroenterology, General Internist, Genetics, GI, maternity/newborn care
Hematology, Infectious Diseases, Internist, Lab, Laboratory Physician, Medicine subspecialist, Neonatology, Nephrology, Nephrology and General Internal Medicine, Neurology, Oncology, otolaryngology, Paediatric Neurology & Neuropathology, pediatrics, Pathology, Pediatric and Adult ER, PM&R, psychiatry, Public health, Public Health and Preventive Medicine, Radiation Oncologist, Radiation Oncology, Radiology Resident physician, Rural Generalist, senior medical advisor, CPSA medical regulator, Sleep Medicine Physician, Specialist gynecologist, specialist physician, sport and exercise medicine, surgeon, Internal medicine with various subspecialties e.g. Infectious Diseases, Respirology, Endocrinology, Infectious Diseases

> *doctors work They should not have to be computer experts, surfing around an enormous computer chart To find a single piece of information.*

Of the 40% who indicated having had challenges in accessing health information for patient care, the reasons provided are split between technical issues (ICT/software related), data access, and data-quality issues (Connect Care access or incompleteness of what used to and is supposed to be in Netcare). Other issues of note are out-of-province access and the inability to use health information for quality improvement/care outcome evaluation.



Some of the more significant concerns regarding the inability to access health information were highlighted by these 40%:

- Pre-natal care records are not accessible by a maternity ward if the physician providing pre-natal care is not on Connect Care, this is the same for ER when a primary care physician is not on Connect Care.
- Some pharmacies fail to upload to Netcare which has led to over-vaccination and uncertainty about medication taken or not, e.g. antibiotics.
- Private surgical clinics don't (can't) upload anything [to Netcare] at all, leaving primary care physicians in the dark regarding follow-up care post surgery.

Some respondents indicated that there does not seem to be the ability to share or access records when providing mental health care, highlighting that there seems to be no system, network or process in place to share these even for health care purposes.

Some respondents with access to imaging systems (that were described as highly accessible and interoperable by default (e.g. DICOM and provincial PACS system), commented that most information they need is in these systems, or they use these systems to derive information from the information in these systems to fill in blanks left by other systems.

Of those responses that are categorized as "required health information not timely, easily, accurately or at all available to practitioner", these are almost all related to Netcare, Connect Care, other EHRs (provincial PACS) or lack thereof. Some comments made in relation to these responses are as follows.

1. Practitioners either don't have access and want access for quality or continuity of care.
2. There are problems with other physicians, pharmacies or private surgical clinics not uploading at all, or sufficient/correct information.
3. The information that used to be in Netcare now resides in Connect Care and some do not have access to Connect Care, and to get this information they must go through excessive (manual) hoops to get to required information that they know is in Connect Care (e.g. via Netcare notification).

Some respondents suggested that certain custodians are not meeting their requirements under HIA

> [Custodian] *will not release necessary health information in a timely manner via their processes even when requested by patients to provide information for example to a third party such as a family physician. I work in an* [.] *ambulatory care setting. I have had patients that are waiting 3-6 months to allow me to share my past notes with a new family physician. Cross organizational data access definitely a huge factor.*

Some respondents raised the issue of accessing legacy records that are not in the EHRs or finding them if they are (paper scans).

Many respondents identified concerns about the lack of user friendly access to information in Connect Care, noting that there is information overflow in terms of notes and other information, and it is hard to find relevant information or to determine what is the most up to date or relevant information for the practitioner.

There were also several comments about the inability to access health information for quality improvement purposes.

> *Current privacy legislation significantly impairs quality improvement.* [Custodian] *indicates following up cases on Netcare is a privacy violation. Being able to follow up cases is crucial for quality improvement.*
>
> *As an emergency physician working in an* [custodian] *facility, I provide care to many children and when they get admitted to the hospital, in order to optimize my management, I need to be able to learn from each and every case - did the child need any testing or imaging that I did not perform that may have led to a more accurate and rapid diagnosis? Did the child receive any medications or treatments that I did not provide that I should have provided. It is only through ongoing learning that we can improve what we do but the HIA currently does not permit checking on patients we have seen…*

It was mentioned by some respondents that there seems to be no procedures for disclosing or allowing use of health information for research or quality assurance purposes.

The 40% that have issues accessing health information seem to fulfill complex roles and need multi-disciplinary/multi care-setting information, and an interoperability/governance/technology layer that accommodates this seems to be lacking

> *Obtaining information across departments is difficult. A unified administrative body should be created to allow access. For example, cancer outcomes, pathology and diagnostic imaging should be a single data request rather than 3 separate requests'.*
>
> *Records from non-connect care consultants and records from outside Alberta can be challenging. The biggest challenge is often finding which records are where, and who to request the records from, or getting access to records in a timely fashion. There are times I've delayed investigations, or chosen much more broad investigations (expensive) because I don't have timely access to records from other physicians in the same city.*

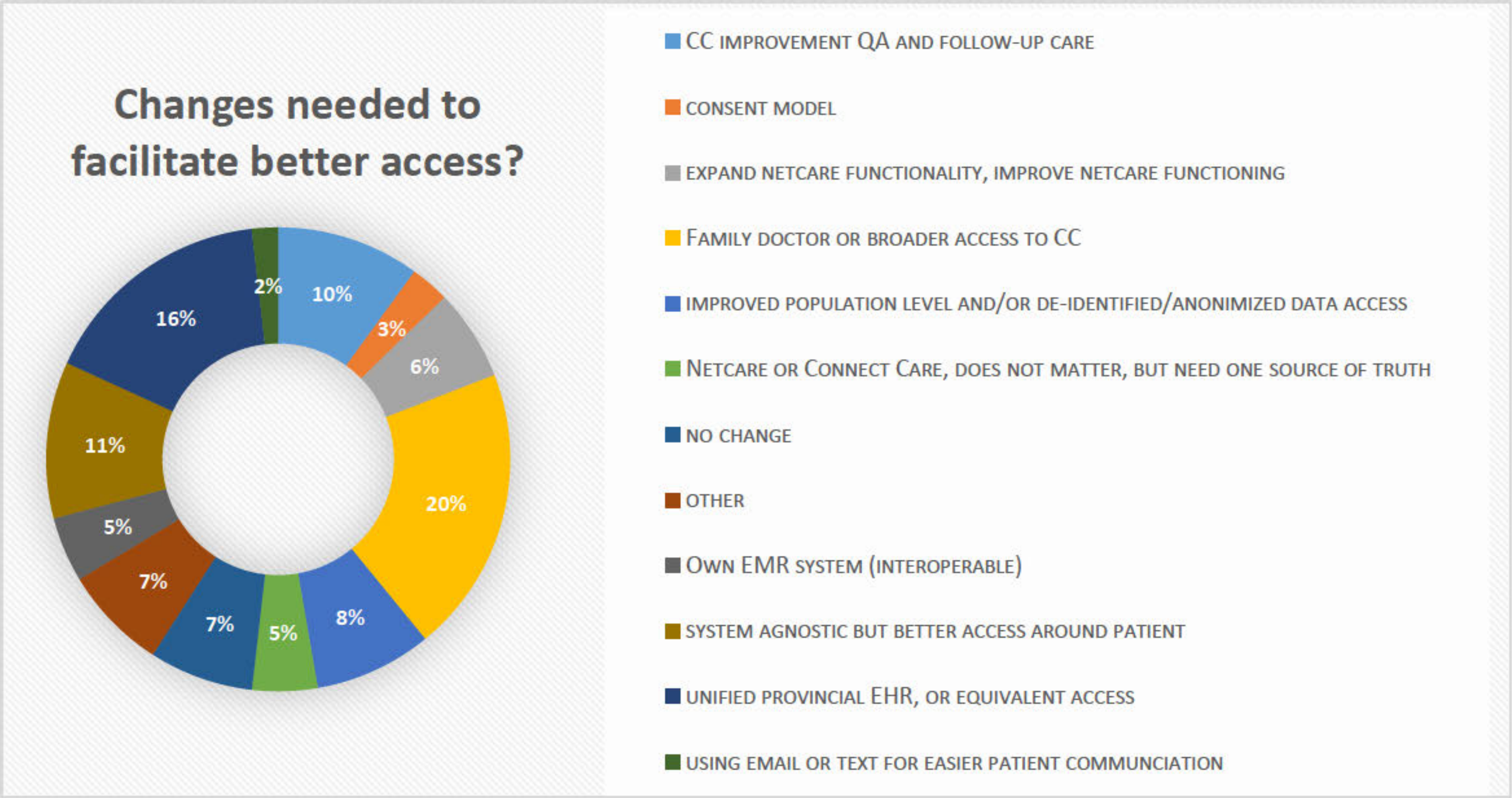
Some respondents highlighted that because PCNs are not custodians they cannot access health information about their patients that they need to provide care.

> *It would be wise to make PCNs custodians since they are responsible for the care of patients in a specific geographic area yet cannot access information about that group of patients.*

Q5-7 Do you think changes to the HIA are necessary for facilitating better sharing of health information among healthcare providers in Alberta?

43% thinks changes to HIA are necessary versus 44% who think this is not needed.

When asked to describe their ideal model and changes needed, most respondents referenced some form of better health information access around the patient and preferably one or few fixed source(s) of truth for patient information. The majority of options vary between a unified provincial EHR, interoperable EHRs and EMRs, or improvements (both functional and in terms of who has access) to Netcare and/or Connect Care or any system that would supersede these (73%).



Of those that think changes to the HIA are needed, the reasons cited are:

- to have timely and complete access to all relevant records;
- to follow-up on patients to inform their own practices (e.g. QA); and
- to conduct other types of research using health information or a derivative of health information.

Q8 What amendments do you think would need to be made to HIA to enable this model?

Most respondents did not recommend specific changes to HIA and most responses where unique one-offs with the exception of recommendations made to:

- regulate AI to responsibly enable care;
- facilitate follow-up care (QA) and broader research;
- regulate access to training/research data, data linking and de-identification/anonymization; and
- expand custodianship to include PCNs and professional corporations.

Some respondents suggested that a change in legislative regime or changes to EHR systems would distract and divert funding, time and energy from the more pressing problems such as improving/properly using current systems, and time spent on care.

Q9: Do you generally support the idea of a shared digital information system that would make most health information accessible to all healthcare providers (and their staff) across the province, even if there is no care relationship between the provider and patient?

71% of respondents supports such a system, highlighting the benefits of harmonized access.

> *I would greatly support ONE electronic medical record (eg, CC) for the whole province. The present status of ~300 e-medical record systems makes patient care difficult, inefficient (still needing to use a clerk requesting to fax a document to me that I need for managing the patient). It also makes research difficult.*

Q10 Do you have any concerns with all healthcare providers in the province (and their staff) having access to the health information of their patients?

Some respondents highlighted that if health information were broadly shared such that it would be accessible by health care providers across the province that there would be a need to monitor access to ensure there is compliance.

The majority of respondents that supported broad sharing included the need for checks and balances for such a system.

> *But except in the case of a designated primary care provider (NP or Family Physician), each new provider should only be allowed to access that patient's records when they are under the care of that particular practitioner. Eg. If one was referred to a specialist, the patient would have to give the new practitioner permission (via a patient PIN number known only to the pt, to access their records). This would prevent the ability for anyone in the Health Care system to just access any patients' records even if that pt wasn't under their care.*
>
> *If I haven't referred my patient to a particular provider, I wouldn't just want any medical offices/ healthcare worker to access the patient's records without reason. Only anonymous mining of the EMR for trends helpful to public health (eg how many diabetics are there in Alberta) might be allowed for purposes of planning health care services*
>
> *A care relationship should exist between a provider and patient, with exceptions allowed for quality improvement and research purposes using de-personalized data and defined privacy protocols.*
>
> *If there was a way to limit the access to those healthcare providers and their staff who have a care relationship that would be ideal. For example, there is no need for an emerg physician/nurse in Medicine Hat to have access to someone's record when they live in Peace River (and have never been to Medicine Hat), until said patient ends up in the Medicine Hat emerg and the care relationship is established.*
>
> *Monitoring of compliance would be needed (to ensure proper usage).*
>
> *with clear guidelines about who can access and when I think it will be beneficial for patient care*

Of those that oppose broad sharing, there are concerns about the impact such a system would have on patient privacy.

> *I believe patients share information based on their relationship with the doctor and sharing their information without their permission can be considered a breach of trust.*

> *Allowing access to multiple people would make it extremely difficult to protect the privacy of the patient and will set the primary custodian up for problems.*
>
> *People should feel safe to provide very sensitive information to their GPs. If this is accessible to all providers, they may not be as forthcoming in providing this information in the future.*
>
> *Patients are not aware* [of how EMR systems work, and how broadly they share] *and regardless of the importance to their care MUST have control over the sharing of information with appropriate informed consent.*

Q11: Do you have any concerns with access by out-of-province healthcare providers to the health information of your patients?

72% of respondents do not have concerns regarding access by out-of-province healthcare providers (who may be involved in the care of their patients due to proximity to the Alberta border) to the health information of their patients.

Many did comment that such a process should be controlled, e.g. only allow access to regulated health professionals with the same safeguards as required by HIA, and authentication of the requestor should take place before access is granted.

> *In areas where AB may become responsible for patient care in certain scenarios (interior BC, Territories, parts of SK), or where patients are specifically sent to AB for care that is unavailable in their home province/territory, it does make sense for the responsible out of province provider to be able to access health information that was generated in Alberta. So long as those physicians undergo relevant AB training, and perhaps have co-licensure in AB and abide by the stipulations in the HIA, it would be overall good to implement. In all honesty, it is ridiculous that all the provinces and territories are so siloed when it comes to health care. It would be nice to see a conjoined health records system covering multiple territories/provinces (or even AB + Territories) since we so often deal with each others' patients.*
>
> *As long as it is monitored and deemed appropriate and necessary for the care of the Alberta patient then it is acceptable.*

Q12 Do you think the HIA is currently effective in protecting the health information privacy rights of Albertans?

75% of respondents feel that HIA is currently effective in protecting the health information privacy rights of Albertans.

> *Some of the language might need updating given the evolution of digital health records, telemedicine/virtual medicine, etc. But overall the principles of the HIA are sound.*
>
> *HIA is currently effective in protecting the health information privacy rights) but it does not reflect the current realities of digital health systems, and the way it is interpreted by* [custodian] *and* [other custodian] *tends to lock information down to much.*

Some advocated for a larger role for patients in deciding what information is shared alongside with functional break-the-glass abilities.

> *Patient should be able to decide if this information can be shared and what personal information to be shared.*

> *Patients need to have the right to block access to their information to specific professionals. There also needs to be "break the glass" provisions that allow for this to be overridden in extreme circumstances.*
>
> *Regular access audits. Allow patients to identify providers who automatically have access. Require healthcare providers to state why they need to look if they have not been identified by patients as "usual providers" ex something as simple as "I have established a care relationship with this patient"*

Concerns were raised about the governance and oversight of provincial electronic health information systems.

> *I am not sure (that HIA is currently effective in protecting the health information privacy rights) because I don't know how access to Netcare is "policed" and who is given access to Netcare and what vetting processes are done.*

Of those that do not feel that HIA is currently sufficiently protecting patient privacy, snooping in EHR and EMR systems is a concern.

> *People still access when they aren't supposed   There should be better utilization of access reports rather than limiting appropriate access*
>
> *It is a fallacy that our health information is protected. Anyone with computer knowledge could easily get information if they desired. All this protection with passwords etc is for show*

Q13 In your ideal model of health information sharing in Alberta (from question 7), keeping in mind the fundamental right to privacy and any enhanced risks to privacy in this model, what privacy protection requirements do you think should be included in the HIA?

Various ideas, and points of focus exist among the respondents. Some of the more extensive comments indicate that there is a need for greater access to information to provide care or conduct research that is balanced with safeguards and privacy protections more generally.

> *Each location must have a custodian who is accountable for any access provided to additional staff/providers at that location - personalized username and passwords with secondary identity authentication - create different levels of access (ie. primary care physician would have higher level of access than laboratory technician) - regular auditing of access and enforcement of consequences for inappropriate access*
>
> *Patients should have access to a list of all providers who have accessed their charts, there should be the ability to have global masking of a chart that providers have to break the glass to get into, and similar protections of particular notes (as exists in Connect Care already). The custodial model of responsibility needs to be rethought and likely abandoned moving forward, since the future will have multiple custodians SHARING a single record that spans all facilities at least and potentially much more than this*
>
> *Probably tiered access. Some individuals would have access to certain records but not others. Things like psych and mental health are probably "break the glass" type records in many contexts.*

> *Only the information necessary and full access only for your patients*
>
> *We require controls that oversee QI and surveillance work much as we do with REB approved work (i.e., research).*

Some identify a role for HIA in their ideal model to help with anti-blocking or research more broadly.

> *Improved and streamlined access to ethically approved anonymous data for epidemiology, outcome, and cost work to improve health of Albertans. Too many players with similar roles and overlap and different understanding of the HIA. Easier to block than facilitate and some seems to be self justification of position*
>
> *There should be an allowance to access de-identified data for purposes of research (if approved by a HREB) or quality improvement*

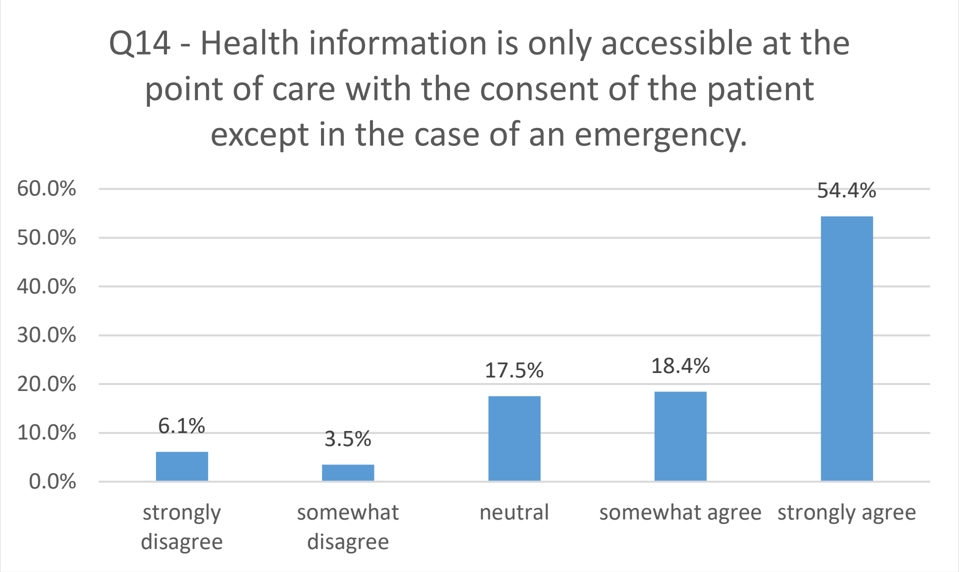
A more prominent role for or empowerment of the patient is a recuring theme.

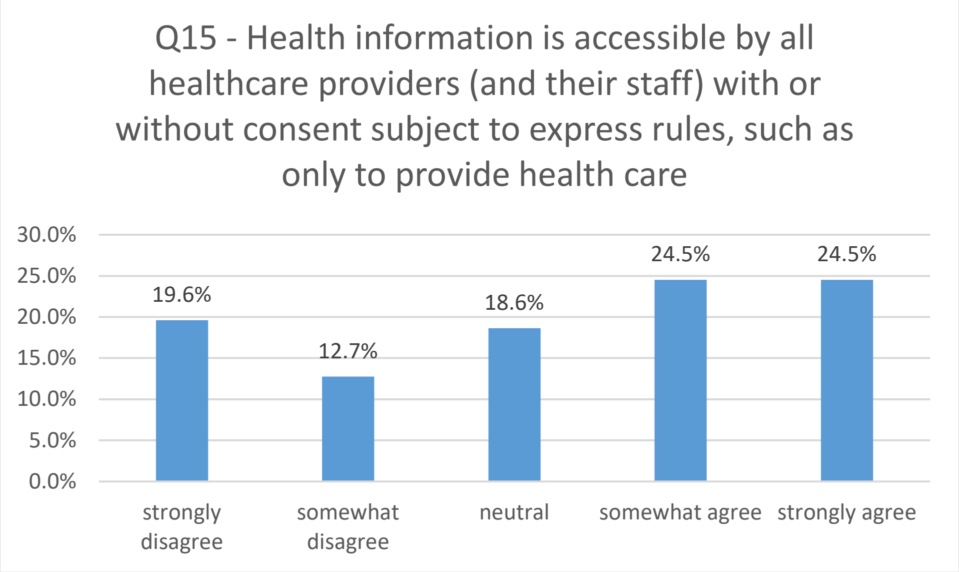
> *Patients need to be able to opt out of their data being shared*
>
> *Patient consent as part of health record access*
>
> *Enhanced mechanisms of surveillance of appropriate usage of health information, empowering patients for tracking of those accessing their own health information*
>
> *No access without patient consent to clinical notes from PCP*
>
> *Patient consent in every file/EMR. One time consent*

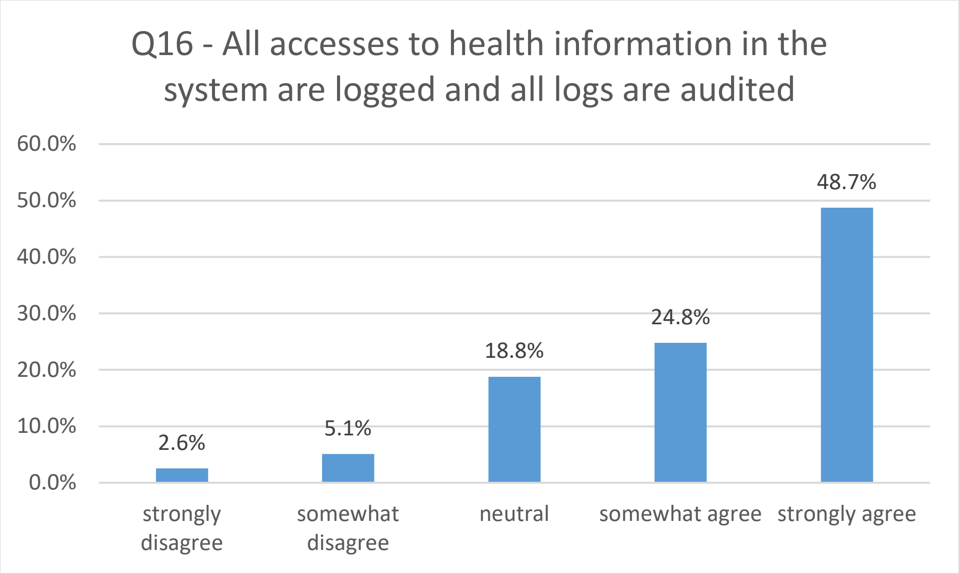
Some advocate for no or limited change to the model or suggest that the model should only be changed after extensive consideration has been given to the need for change and with a clear goal in mind.

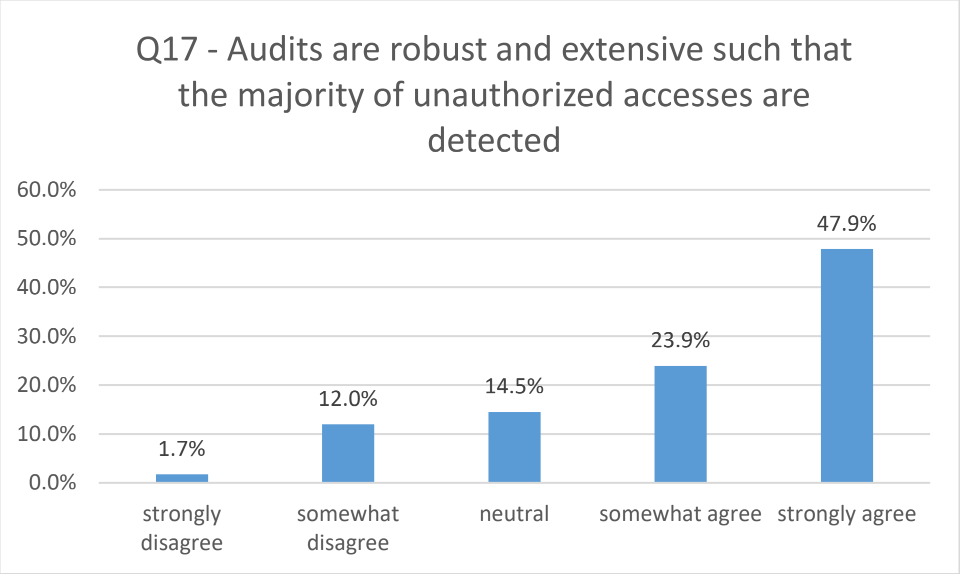
> *I think the HIA does not need to be changed. I think this is change without adequate justification. Or at least, adequately disclosed justification.*
>
> *Similar to now - just account for AI, out of province care.*

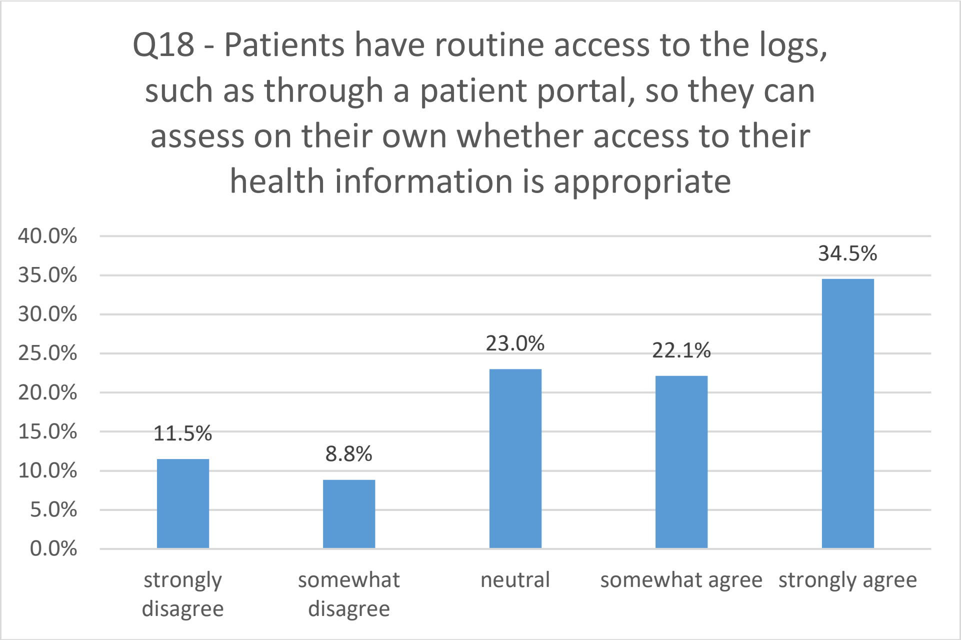
Q14-Q20

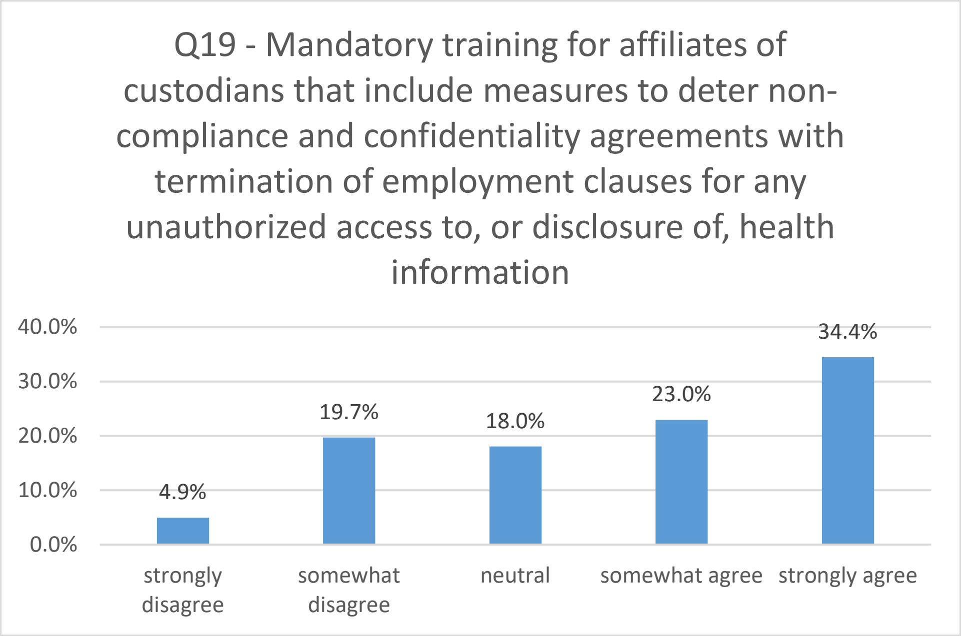

Q14 - Health information is only accessible at the point of care with the consent of the patient except in the case of an emergency.
60.0%
50.0%
40.0%
30.0%
20.0%
10.0%
0.0%
6.1%
3.5%
17.5%
18.4%
54.4%
strongly disagree
somewhat disagree
neutral
somewhat agree
strongly agree

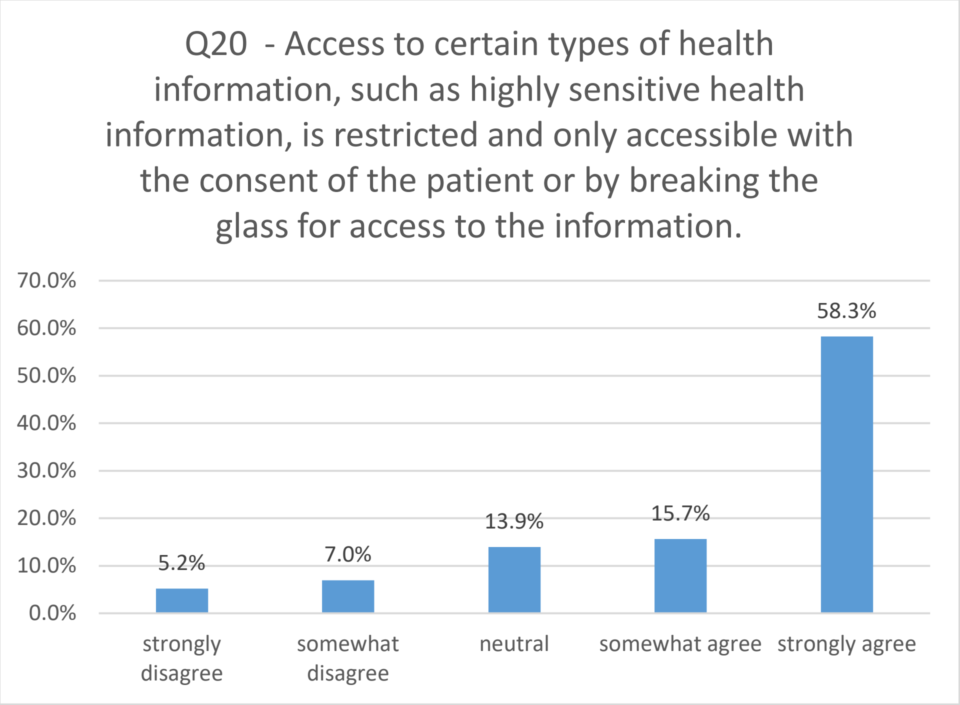

Q15 - Health information is accessible by all healthcare providers (and their staff) with or without consent subject to express rules, such as only to provide health care
30.0%
25.0%
20.0%
15.0%
10.0%
5.0%
0.0%
19.6%
12.7%
18.6%
24.5%
24.5%
strongly disagree
somewhat disagree
neutral
somewhat agree
strongly agree


Q16 - All accesses to health information in the system are logged and all logs are audited
60.0%
50.0%
40.0%
30.0%
20.0%
10.0%
0.0%
2.6%
5.1%
18.8%
24.8%
48.7%
strongly disagree
somewhat disagree
neutral
somewhat agree
strongly agree


Q17 - Audits are robust and extensive such that the majority of unauthorized accesses are detected
60.0%
50.0%
40.0%
30.0%
20.0%
10.0%
0.0%
1.7%
12.0%
14.5%
23.9%
47.9%
strongly disagree
somewhat disagree
neutral
somewhat agree
strongly agree


Q18 - Patients have routine access to the logs, such as through a patient portal, so they can assess on their own whether access to their health information is appropriate
40.0%
35.0%
30.0%
25.0%
20.0%
15.0%
10.0%
5.0%
0.0%
11.5%
8.8%
23.0%
22.1%
34.5%
strongly disagree
somewhat disagree
neutral
somewhat agree
strongly agree


Q19 - Mandatory training for affiliates of custodians that include measures to deter non-compliance and confidentiality agreements with termination of employment clauses for any unauthorized access to, or disclosure of, health information
40.0%
30.0%
20.0%
10.0%
0.0%
4.9%
19.7%
18.0%
23.0%
34.4%
strongly disagree
somewhat disagree
neutral
somewhat agree
strongly agree



<u>See charts on page above.</u>

Most measures proposed in Q14-Q20 enjoy strong support (c.a. 50%-75% the participants agreed or strongly agreed with the proposed measures). The strongest consensus is about the need to restrict access to sensitive health information (Q20), the most disparity in views are on the broad accessibility proposed under Q15.

Q21, Q22 Do you think HIA's governance of health information obligations as they currently exist are adequate to ensure compliance by custodians?

71% of respondents said that the governance model in HIA is adequate, whereas 14% did not agree. 15% answered 'other'.

> *I would like to see some tweaking but I think that it strikes a fairly reasonable balance.*

Reasons provided in response to this question identified concerns about the functioning of the custodial model and the need to clarify the relationship between custodians and affiliates when acting in multiple roles.

> *In general yes but the issue is with who is an affiliate and what roles are they allowed to play. Most individuals play multiple roles. I am a physician, employed and paid by AHS and by UofC. In both roles I am a clinician, researcher and administrator. It does not make sense that at times I am an affiliate and at others I am not. If I am an affiliate bound by these regulations that should be at all times and access should be permitted in accordance with that role but to say that when I want to conduct surveillance work on behalf of a federal or provincial entity I am not an affiliate does not make sense. Moreover I have to hire staff through UofC and not through AHS*

and they thus are also not considered affiliates with creates further barriers to doing the work AHS is paying me to do to improve the care of children and the health of our population.

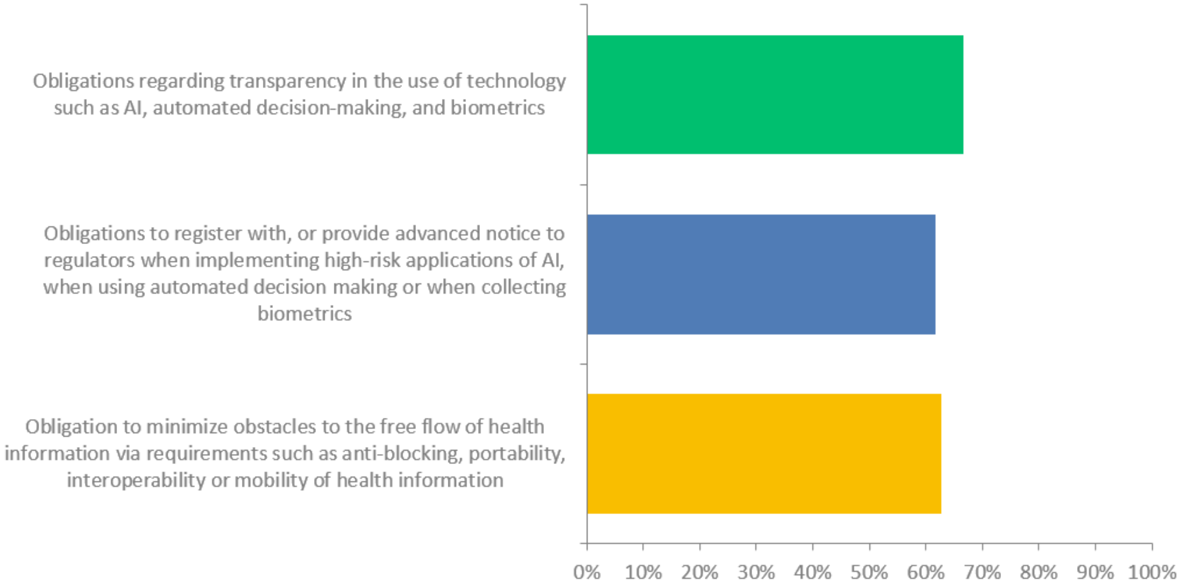
Many physicians work in environments where they do not manage the clinic and therefore are limited in fulfilling the role of custodian.

Unclear in the case of shared custodianship in group practices between MDs and managers

There were also concerns expressed about the impact of innovative technology and related practices.

However, I think that we should consider AI, cloud storage, and remote care more explicitly.

Q23 In your ideal model of health information sharing in Alberta (described in question 7), keeping in mind the fundamental right to privacy and any enhanced risks to privacy in this model, what enhanced governance measures do you think should be included in the HIA?



There was majority support, between 60% and 70% for enhanced governance measures for the use of technology in the provision of health care including artificial intelligence. There was also strong support, more than 60%, to require the minimization of obstacles to the free flow of health information including through legislating anti-blocking, portability, interoperability or mobility of health information.

Q24 If health information is accessible through a shared digital information system by all healthcare providers (and their staff) in the province, regardless of any care relationship between a patient and provider, what enhanced governance measures do you think are necessary to ensure the privacy rights of individuals will be upheld and ensure this information remains secure (availability, confidentiality and integrity)?

Many respondents indicated that enhanced governance measures would be needed if health information is accessible via a shared health information system that balances this accessibility against greater controls needed to ensure compliance, such as through more auditing and enhanced oversight.

> *Electronic and regulatory compliance monitoring.*
>
> *Logging of all access, rigorous audits, Government has no role in this other than the passing the legislation.*
>
> *Then there must be regular audits, but this will become incredibly cost prohibitive.*
>
> *Robust auditing*
>
> *There should be proof of the reason to access a person's health records and strong deterrents to prevent access by practitioners NOT actively involved in care*

Others flagged the need to have appropriate access controls.

> *release info at level of access needed for each staff person's role in patient care*

Some were opposed to such a system altogether or see problems with the same.

> *This should never be done or allowed in the first place*
>
> *i don't believe this should be done – PERIOD*
>
> *I have concerns regarding some of the accuracy of the information that gets perpetuated and the difficulty in correcting it (ie medications and their use, past medical history)*

Others flagged the need for more education or the need for de-identification and similar measures.

> *None. We need to trust that health providers are acting with integrity. Training to health care providers is the most important part*
>
> *measure so data not identifiable to particular patients*
>
> *clarity on why the information is being accessed is key. BUT please ensure ethically approved, appropriately anonymized data is accessible for health care research and care delivery*

Q25 PIAs for administrative practices and information systems (EMRs)

Comments from respondents varied and were divided among supporters: those who support the PIA provisons as is but advocate for support; some who prefer a more limited, streamlined assesment; some who are unsure about the requirement; and some that oppose PIAs. There was more support for completing PIAs for information systems, but less so for administrative practices, with some indicating that they see no real benefit for the latter.

> [PIAs are] *problematic for small custodians*
>
> *this must not be too detailed ie should be thematic. we do not need separate PIA for everything*
>
> *ARECCI Ethics screening tool can be used/modified to determine if a Privacy Impact Assessment is required*
>
> [information system PIAs are] *Not needed, the EMR vendor should ensure PIA obligations*

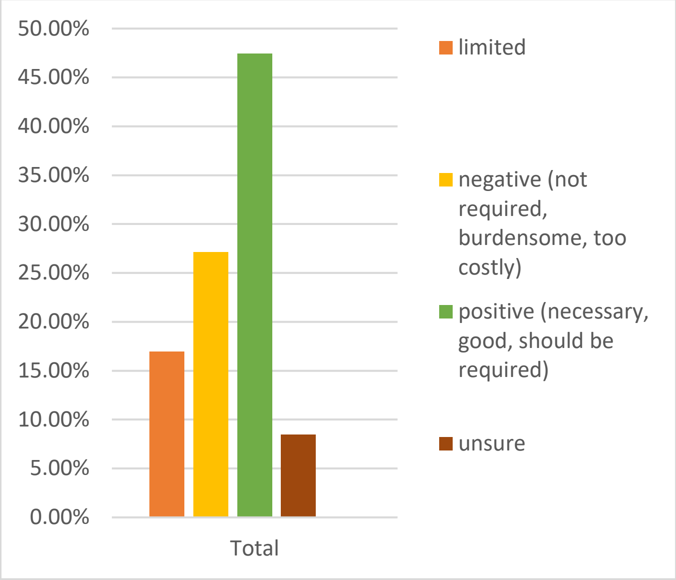


Figure 2 - PIA requirement for adm. practices

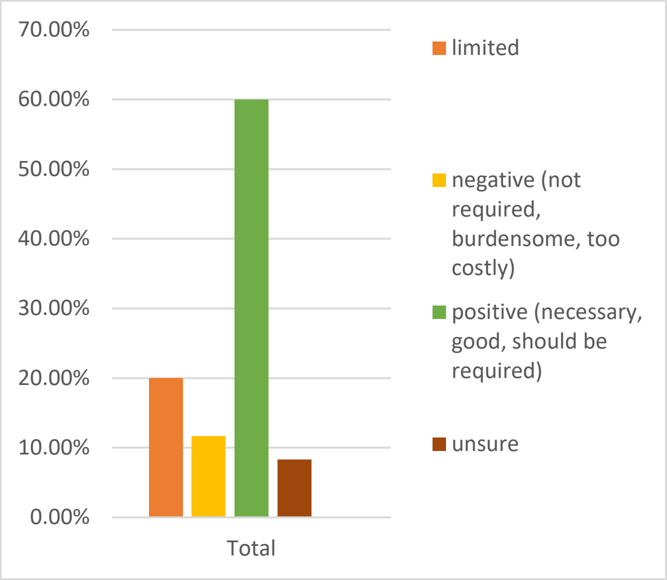
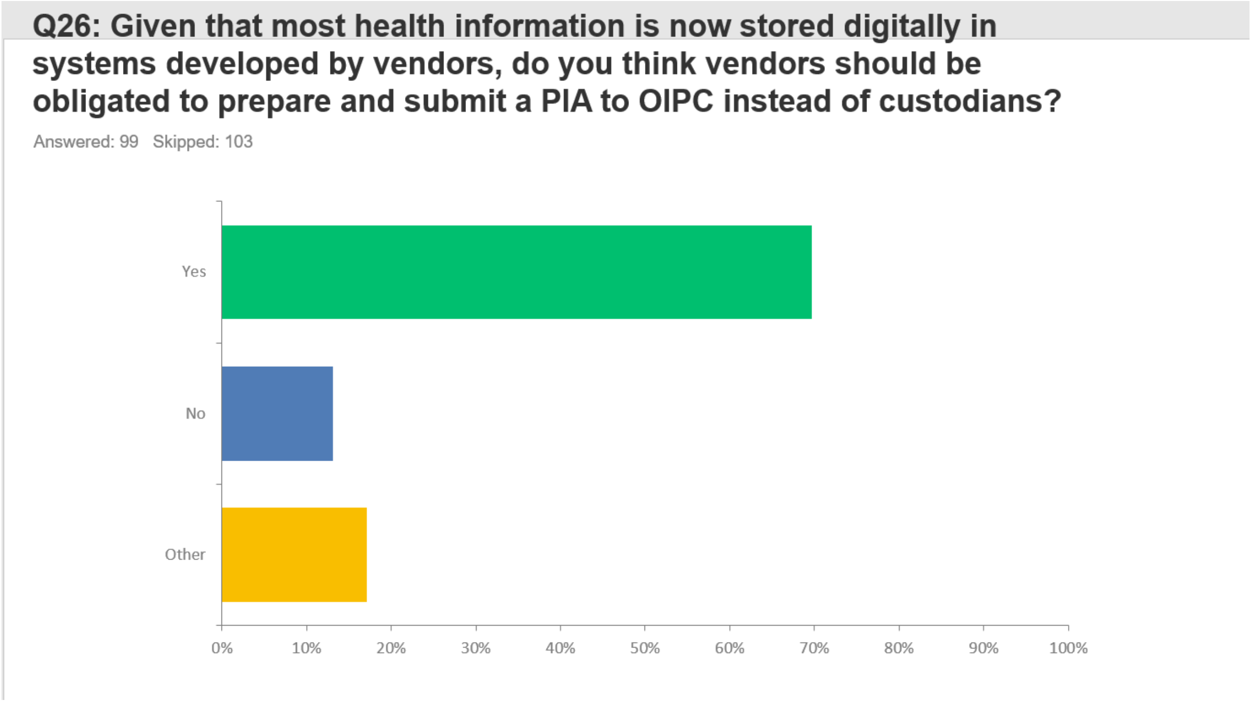


Figure 1- PIA requirement for information systems

Q26 Considering that health information is some of the most sensitive information, what are your views on the duty to complete a PIA in the following circumstances relating to the collection, use and disclosure of individually identifying health information that may affect patient privacy:



Q26: Given that most health information is now stored digitally in systems developed by vendors, do you think vendors should be obligated to prepare and submit a PIA to OIPC instead of custodians?

Answered: 99 Skipped: 103

Below are some of the comments that were provided by respondents to this question.

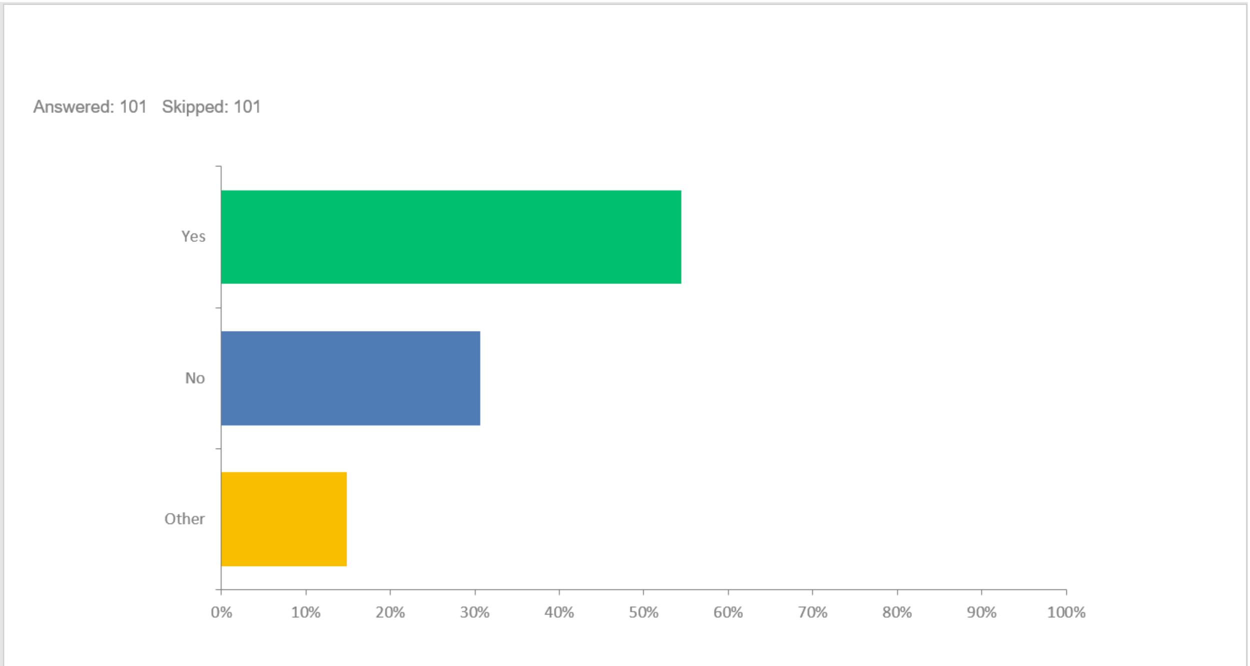
Most respondents indicated that they would like to see a total or partial shift of the PIA burden to vendors. Nuances include that this should be a joint process, with the caveat that the vendor should do the ‘heavy lifting’ on anything related to technology and technology related safeguards.

> *This should be a joint process*
>
> *Each level should provide a PIA*
>
> *I think they both need to do this.*
>
> *A vendor can more easily have a standard 40+ page PIA than every individual small clinic. It puts further administrative burden on clinics/doctors and should be handled by another party such as EMR vendors who could do it more easily en mass.*
>
> *Yes for main implementation of an EMR but subsequent changes such as adding connect care access become too expensive and big burden. It should just be an email to update or similar*
>
> *Because there is absolutely no way that custodians can have the expertise in privacy/technology to be able to ensure that their vendors are completely compliant.*
>
> *They should be responsible for the technical aspects of data security as a healthcare provide has no expertise in this complex realm.*
>
> *And the cost borne by the Vendor. Ultimately, the safety of my notes are in the hands of the EMR vendors. If their servers are breaches, I am at risk of my patient's data being leaked*

There should be a centralized process for the preparation and submission of PIAs.... Vendor + representatives from OIPC should be doing most of the work and helping health care custodians through most of the process.

The individual practice has limited sway over much of the important security steps, particularly when the system is not run locally (e.g. Connect Care and many other EMRs are hosted remotely, and no patient information is stored on the computer). You will get more impact on security by Focusing on education about appropriate use and auditing

Q27 If PIA requirements for smaller custodians were modified or repealed, would you support the duty to self-assess compliance with the HIA on an annual basis using a tool and guidance prepared by the OIPC for this purpose?



Respondents are generally in favour of self-assessment over having to complete PIAs, but some stressed the need for such an assessment to be streamlined, not overly lengthy, and not too heavy on legal language. Some doubt the efficacy of self assessment for various reasons.

It would very much depend on the tool and its validity

Depends on how long the assessment would take and whether it would truly enhance patient privacy. Custodians (and physicians in particular) are getting very tired of filling out boxes just for the sake of filling out boxes.

But it needs to be something simple and not with complex legal language.

I don't know if I fully understand, but annual is a lot. I suspect office managers will copy forward from the previous year. Would this turn into security theatre?

This requirement could be made part of professional license renewal, as already exists for the CPSA. This could be part of Quality Improvement Project to be completed every 5 years.

As long as it's way simpler than a pia. PIAs are ridiculously long, complicated and hard to understand for a physician in private practice.

I would be concerned that this is not robust enough and patient information could be at risk.

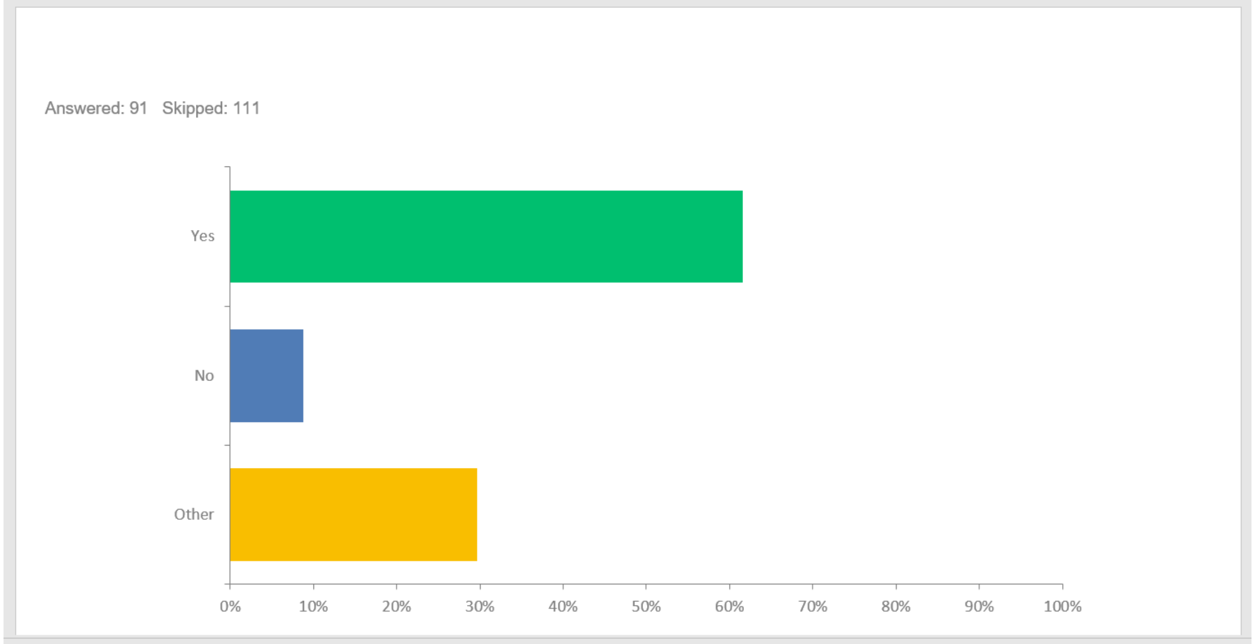
This is possible but sounds burdensome. Are physicians going to be supported in the administration and cost of implementing this tool?

I don't think this would be especially helpful as those who take a lax view of this are least likely to do the self-assessment despite being most likely to commit violations. I think something streamlined that provides little to no burden on smaller custodians unless an issue arises would be more appropriate.

Not self assess. too loose. has to be applied by a regulator and enforced.

Generally no, again this adds extra burden on the care providers. I do agree with allowing self assessment for compliance but the annual tool would need to be simple and quick (under 15 mins of time committement). Since I feel like any tool developed would be much more lengthy than this then an annual check would most likely be cumbersome.

Q28 Do you think the PIA requirement for large custodians (e.g., Alberta Health Services) should remain as is*, be expanded, or reduced?



This question was poorly worded and should have read expand, reduce or remain as is. This flaw was recognized in the responses provided by respondents. Those that did respond generally favoured holding large custodians to account in one way or the other.

the PIA requirement should be expanded to require large provincial systems to submit a PIA. They have the resources to have a dedicated "PIA Officer"

Provincial health agencies need to complete PIAs because as the entities with the largest number of employees, that is where the largest chance of breaches are.

Remain as is--although will need to be modified to reflect Recovery Alberta, Primary Care, Continuing Care and Acute Care inclusions

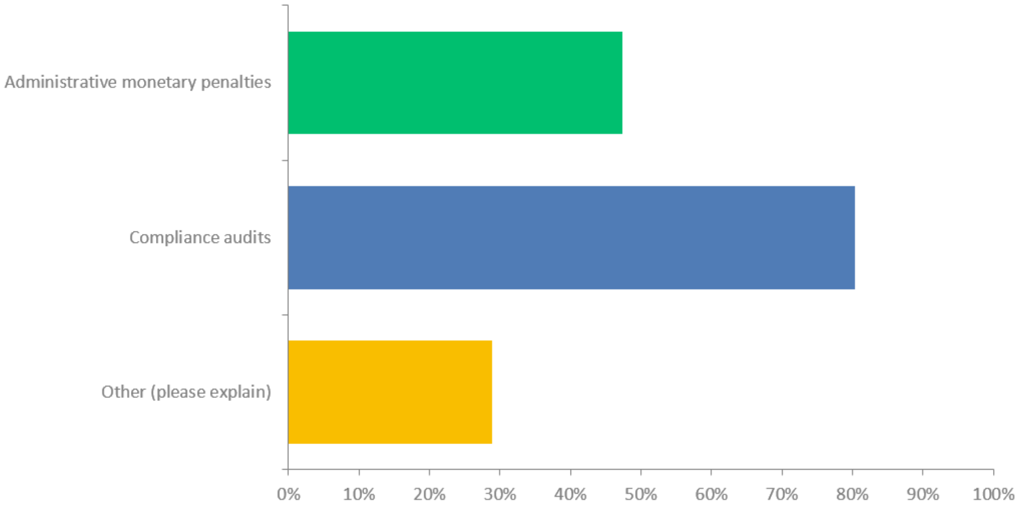
Required, AHS should be required to meet the same privacy requirements as other providers and services.

Just because you are big does not exempt you from the need to be professional, to follow the highest standards.

A more robust description of what AHS will be doing with all of this information is required for transparency and accountability.   Full disclosure of the sharing or selling of aggregate data should be made to Albertans. Patients should have the ability of "locking" their personal health data and preventing the government from accessing it, even if in batch format.

expanded. my prior example re connect care pcp designation shows why they won't try to fix anything. they apparently don't have to

Q29 In your ideal model of health information sharing in Alberta (as described in question 7), what enforcement measures do you think are necessary to promote compliance and deter non-compliance?



The majority of respondents, 80%, support compliance audits as a measure to promote compliance and deter non compliance with another 50% supporting the use of administrative monetary penalites. As for the "other" measures, ideas varied.

> *Additional limitations oversight after breaches have occurred with potential to lose access completely*
>
> *Disclosure to the college*
>
> *Perhaps repeat offenses (snooping) can be more harshly fined, but otherwise remain the same.*

Some respondents advocated for stronger enforcement by organisations.

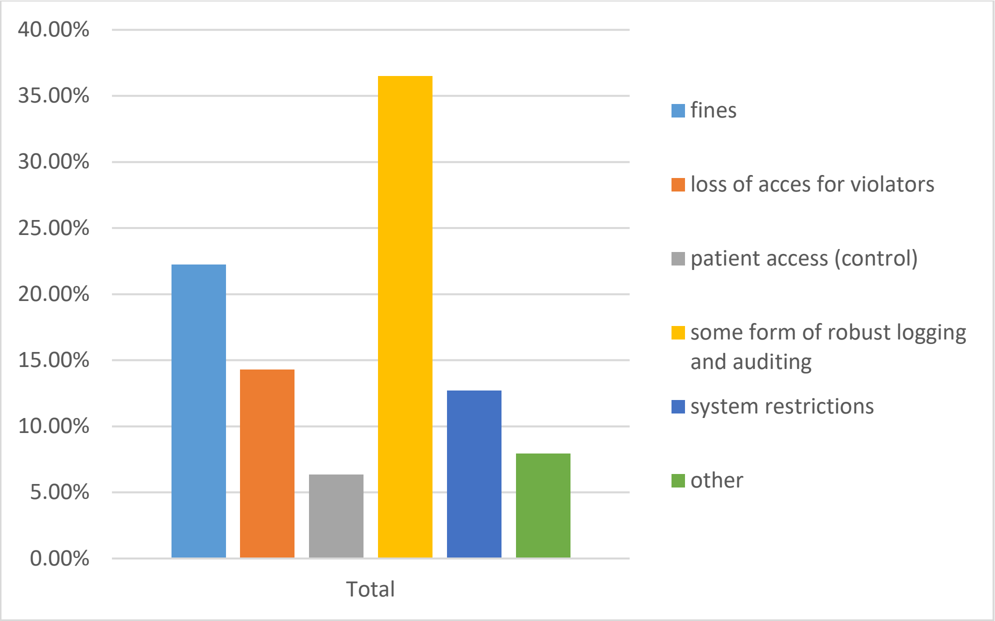
> *Immediately fire the snoopers. And make it very clear to every new hire, That audits are conducted and if they are caught snooping, they are getting this huge fine and they are being fired. Period.*
>
> *Important to have a range of discipline options*

Others expressed that the focus should be on training and education and not 'hard' enforcement.

> *These audits need to be non-punitive but more educational and also be used ot inform how the system should be improved to enable certain access that should be permitted but might not be but also if repeat ofenses occur for actions that should not be permitted those should lead to consequences.*

Q30 If health information is accessible through a shared digital information system by all healthcare providers (and their staff) in the province regardless of any care relationship between a patient and provider, what enforcement measures do you think should be included in the HIA to promote compliance and deter non-compliance?

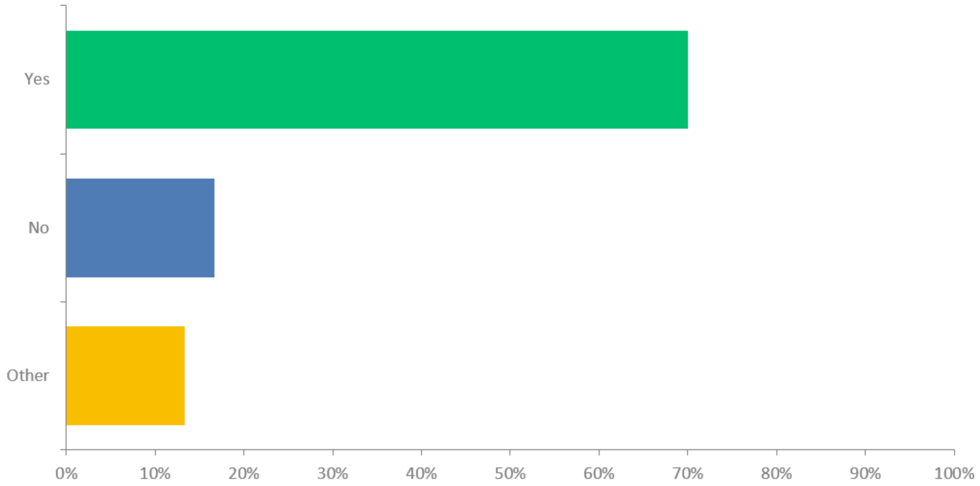
The responses provided suggest support for more robust logging and auditing with fines being second, loss of access for violaters and system restrictions were next, followed by more patient control.



Comments from those that responded “other” include the following.

> *The custodian must be protected from being sued since they no longer have control of their information. Monatary fines and/or jail time depending on the severity of the abuse.*
>
> *Digital Audits, and sending audits to providers. If there is an episode of non-compliance there should be education provided to the provider on why it was non-compliant, and offer steps/instructions to said provider on avoiding such episodes in future.*
>
> *As far as I am concerned, The family physicians chart Is off-limits. There is no way a family physician record should be shared in anyway with anybody else throughout the province. That is a sacred relationship where many very sensitive topics are brought up And documented If this is the direction the provinces going, I believe alot of harm is going to come of it For very very little added benefit. For all the reasons I have already described But if this gets pushed through anyway, Despite the warnings, Then again, every single person that is trained on that computer Must be told upfront that if you were caught snooping You immediately get fired With no severance pay, And you have a huge fine coming your way. And then most importantly, Stick with the promise. Zero tolerance.*

Q31 Do you support working more closely with the OIPC, such as through the use of regulatory sandboxes, as a measure to facilitate compliance?



Most respondents, 70%, indicated support for the use of a regulatory sandbox[3].

> *sandboxes for selected and volunteer users if new technology*
>
> *I think this is a good idea. I am aware that innovation is currently being stifled is some areas for Connect Care as its "not in the PIA" and since updating the PIA is so cumbersome. In the past, Alberta has lead heatlh care innovation, but in my opinion we are lagging behind in some areas and part of this is due to the way the HIA is being interpretaed. Working together with the OIPC in this fashion could definetly foster innovation, while ensuring that security, privacy, confidentiality are maintained.*
>
> *If allows for innovation in a safe way to explore how normal usage may help or hinder privacy*
>
> *Allows innovation without fear of penalty for inadvertent lapses*
>
> *If this does not exist, there are many technologies or improvements that will be impossible to implement in Alberta because no data or best practices will exist to prove their compliance.*
>
> *I think we need health care innovation to be protected, even if only temporarily*

Of those that were not in support or have a different opinion, they expressed a need to reduce regulatory burdens or did not understand their role in relation to a sandbox.

> *Reducing regulatory burdens and improving efficiency should be prioritized*
>
> *Uncertain of how this would involve me as a smaller custodian of charts*

---

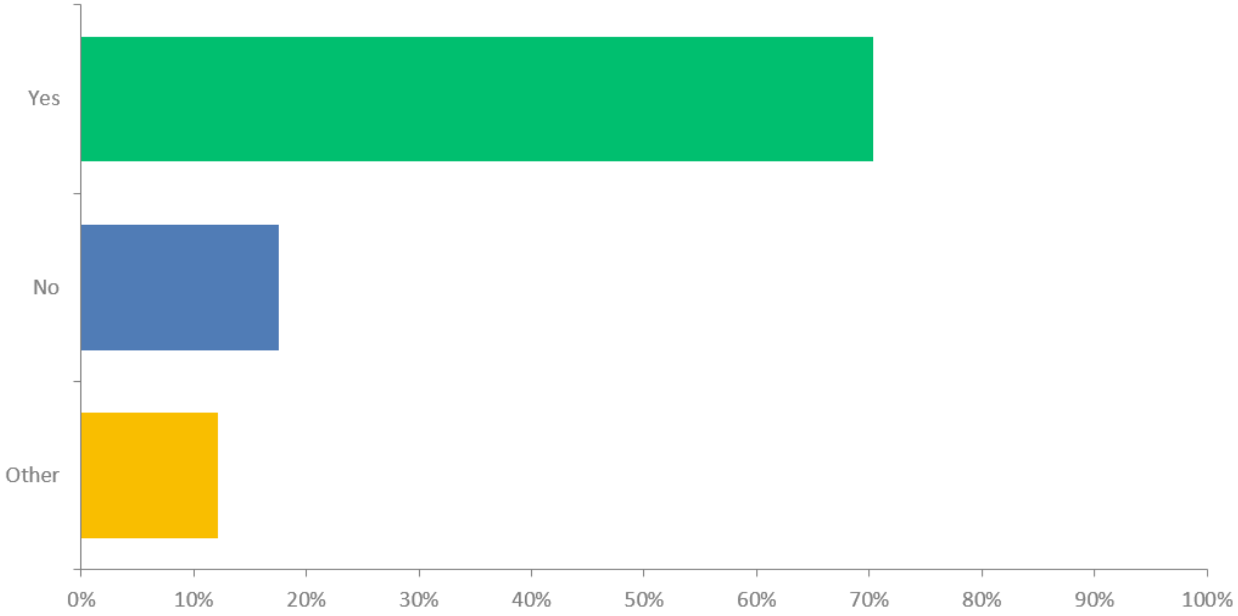
[3] A regulatory sandbox is a controlled environment that allows organisations to test new technology, products and services while enjoying some leeway while working through compliance requirements under oversight by a regulator.

> *Not sure what this means*

One respondent flagged that the OIPC may not have the capacity to conduct such a program.

> *OIPC does not have capacity.*

Q32 Do you think the scope of the HIA should include health facilities, or something similar, as a custodian?



The majority of respondents, 70%, support including health facilities, or something similar, as a custodian. The comments of supporters vary.

> *We currently have a significant shortage of primary care providers in the province. The solution to this is team based care. As a consequence, organizations providing care should be held responsible for the use of health information gathered on behalf of the practitioners present, who may or may not have longitudinal relationships with these patients, and are not appropriate to act themselves as the custodian.*
>
> *This would potentially make team-based care more realistic.*
>
> *note there has to be one custodial administrator for any physician 'group'*
>
> *Depends what the underlying reason for that facility's need for the information is. For example, AHS is a custodian. They should have access to health care utilization data etc. They are a not-for-profit with presumably a fiduciary responsibility to the patients as well. If the operator of a health facility is a for profit company, I do not think that patient information should be available to them for business related purposes. For example, while I am ok having AHS have access to my information (given that it is only accessed for medical purposes, or deidentified in order to improve the system), I am not ok with* [private sector organization] *having access in order to maximize their profits.*

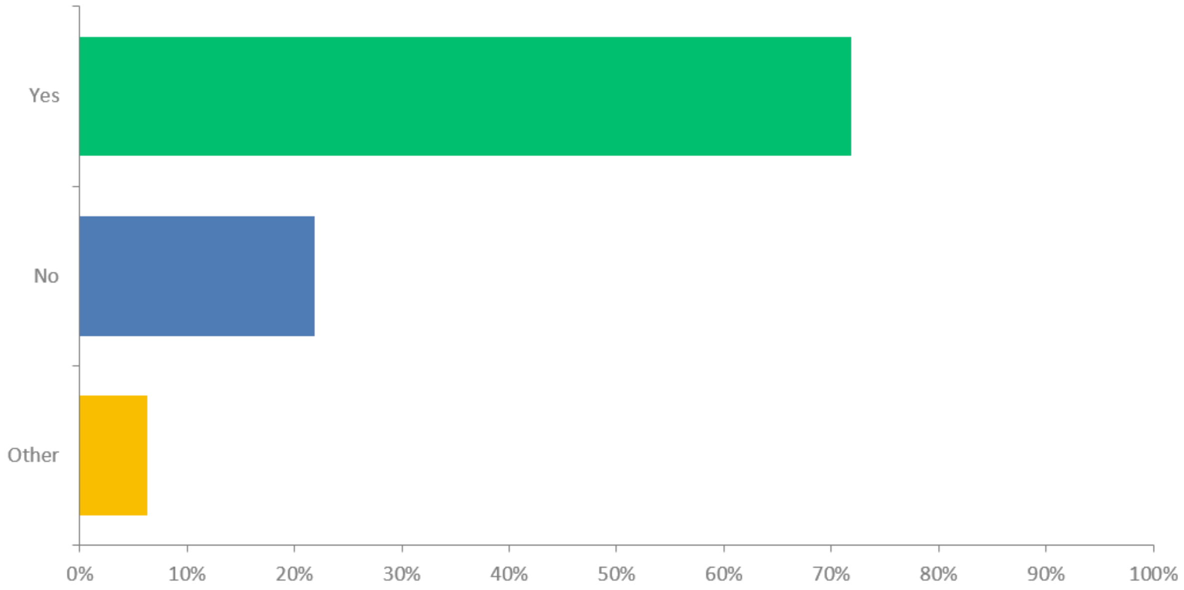
20% of the respondents oppose expanding the meaning of custodian in such away.

> *It creates more complications*
>
> *Each person should be responsible for their own actions. It is not a facility's fault if a secretary does something bad.*

Those that are unsure had various reasons.

> *I am unsure--will this just add another layer of liability to individual practitioners who have no individual involvement in a privacy breach? for example, if one support staff of a primary care network breaches privacy, does this open all professional members of the PCN to become liable?*
>
> *I think it would be better to move away from the concept that one custodian has "ownership" over some subset of health information that they can share with another. In the context of digital health records, large portions of the health record are not really "owned" by one custodian but rather shared by all and contributed to by all. For example if two custodians are both using the same instance of Connect Care, it is very challenging to tease this apart because the system is not designed at the database level with this in mind. One can ONLY enable sharing between custodians by accepting that some types of information are not owned by either custodian but are rather shared between them, with a mutual understanding that each party has the right to share the other's shared information. Even the data from a clinical visit that can be clearly defined as having arisen under a custodians jurisdiction will usually be "contaminated" by some information that is in the shared information class. As stated elsewhere the concept of custodial ownership that arose out of having bricks and mortar facilities that owned a paper record does not really apply properly in the context of digital health records.*

Q33 Do you think the scope of the HIA should apply to the collection, use and disclosure of health information by apps and devices?



The majority of respondents, 70%, support expanding HIA to regulate the collection, use and disclosure of health information by apps and devices. Included in the responses received from the proponents of this expansion are the following.

> *Health info should be protected in all mediums*
>
> *It is also part of medical records collection*
>
> *However, HIA should not restrict use of new technologies in an unreasonable manner as it seems to today. Especially with AI, current interpretations of the HIA seem to be that its use should be discouraged.*

The following comments were provided by those that do not support this expansion.

> *PIPA allows and respects patient autonomy in releasing information. HIA overrules such individual autonomy so should not apply*
>
> *Depends on the types of app or device. If the purpose of the device/app is the provide personal medical advice and diagnose patients with conditions, then it should be subject to HIA. If the purpose of the device/app is to monitor biometric information for the individual's own information e.g. Apple Watch monitoring one's heart rhythm, I think PIPA is sufficient.*

Q34 Please share any other information you think will be useful in formulating comments and recommendations for amendments to the HIA.

In response to this question, respondents provided the following comments some of which focus on the need for harmonization among privacy laws locally and nationally and on and reducing barriers to accessing and using health information for various purposes.

Harmonization

Streamline, simplify, and consolidate various acts and be practical. please not paralyze the system with rules that have multiple interpretations and many overseers but few with authority to interpret. Overdoing it with complex ill understood regulations is bad for privacy patient health and health care system

Harmonization across the country would be helpful, as would a national records system so we could share records better nationally. I have fewer issues accessing local records as I do accessing records from someone who is seeing me from only a few kilometers away, if those kilometers happen to cross into Sask or BC.

Netcare and Connect Care

The fact that Netcare and Connect Care are currently managed differently under the HIA creates endless problems for those tasked with working with both. Please try and unify the rules between them.

Netcare and Connect Care overlap too much. Switch to just one and then make sure it works well. No apps. Keep things streamlined. The fewer people who have access, the better. The less complicated a program is, the fewer IT people needed and the safer it is. No amount of signing papers will make bad people become good.

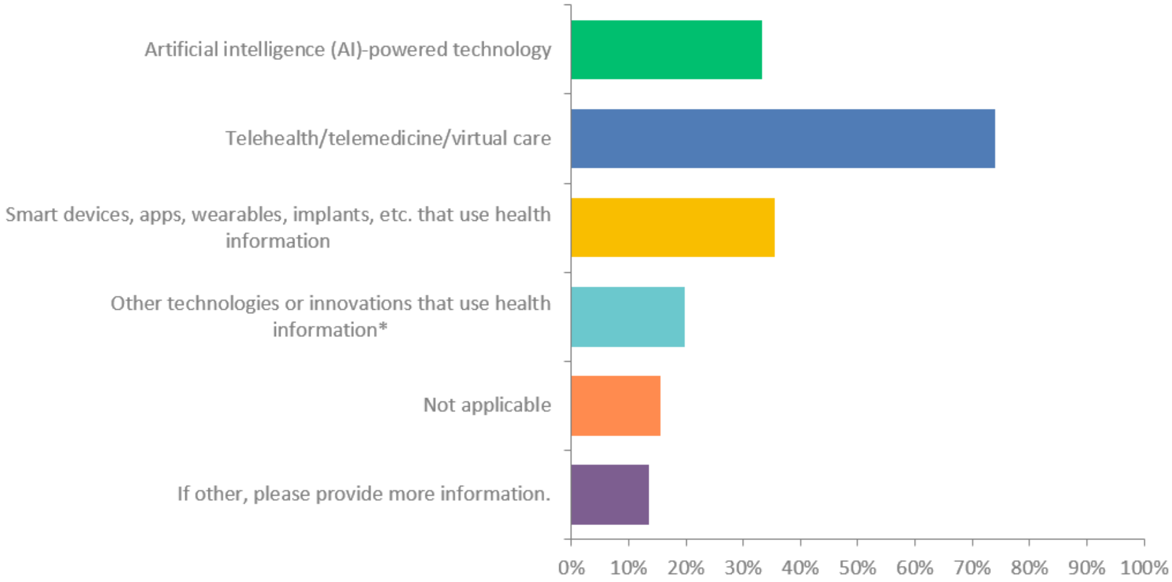
It is ridiculous that physicians cannot view their own patient information on NetCare or ConnectCare. This is petty and punitive.

Other

Bottom line, I think the HIA is adequate the way it is, But if changes are that important, I would focus on the snooping issue, Patient's ability to control accuracy in their chart (Which means giving them easy access to all documentation, not just selected few) and who is in their chart, and putting more responsibility on government to be the custodians of all of these patient records until they provide adequate Med school spots etc to keep up with population growth and ageing doctor numbers (nearing retirement/decreasing patient load)

This is a massive area of patient care and responsibility. All levels of administration must be accountable and monitored. Sharing of all health information may be unwieldy and inefficient in the emergency care of patients. It may not be necessary to widely share PCP clinical notes.

Q35 Are you currently using, or planning to use, prescribe or test any of the following technologies as part of the provision of health care?



The majority of respondents, between 70 and 80%, indicated that they are using or plan to use telehealth, telemedicine or virtual care as part of delivery care to their patients. Approximately 40% of respondents indicated that they are using or plan to use AI or smart devices or apps as part of health care delivery. Comments from respondents about the uses of technology include the following.

> *planning to integrate an AI scribe into my practice. I am not planning on using automated decision making.*
>
> *Patient messaging, reminders, etc*
>
> *I am not planning to use any of the above*
>
> *Considering AI but waiting to see what is available and how this can integrate safely*

Q36 If you are not using these kinds of technology, we would appreciate understanding your general reasoning.

Of those respondents who indicated that they are not using the kinds of technology set out Q35, their responses included lack of certainty about compliance obligations if they were to use this technology, scepticism regarding its usefulness or positive impact on care outcomes, or they expressed reservations about using certain kinds of technology because of the unknown risks.

> *I absolutely do not see current value in "AI" though this may change in the future. The risks of disclosure are simply too high.*
>
> *AI is not secure yet...I would love to see it integrated into connect care but I am reluctant to use something that I don't view as 'safe' yet.*

I haven't started yet because I am not clear on what my responsibilities are regarding patient privacy

I do not know that AI is reliable enough to implement. I am also concerned about privacy issues related to using AI in clinical practice.

I think there is considerable potential with the use of AI and similar technologies (and from a research standpoint am exploring the use of these tools). I think the challenge is ensuring that private companies are using data responsibly, as my opinion is that individuals outside of healthcare tend to have less of an appreciation of the importance of following rules around appropriate use of data,

at this moment, these technologies are not proven

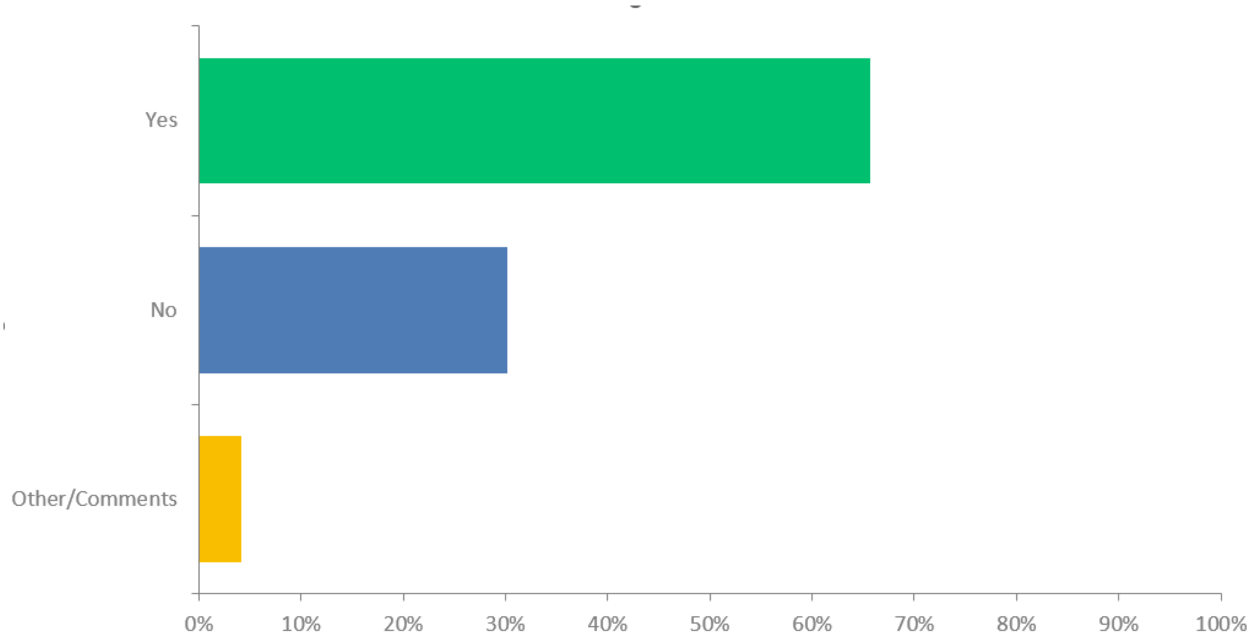
Expensive more and more, invasive more and more, time consuming more and more, requiring more and more barriers to protect information and changing/ expiring faster and faster and then you have to pay again and again.

I am a traditional physician and I believe in traditional hands on medicine. Many of these apps and devices are flawed and a poor substitute for a physician-patient relationship. Virtual care and much of that related technology etc is a substandard healthcare delivery model...

AI is way too premature to roll out into family medicine, And even once it gets more robust, It is still too dangerous in a family medicine realm (Because again, it depends on the accuracy of the input Into the algorithm, which gets more dicey in highly complex general fields like family medicine). It works great for reading CT scans etc. There is no way I would see a family Doctor who depends on an AI algorithm to come to a diagnosis and treatment course, So why would I subject my patients to that risk?

Very dangerous for a trust- based system to be using AI or apps. Patients have divulged many abusive situations and worries about cancer etc in confidence to a nurse or doctor in a quiet room. Never happens with an app and certainly not if they don't know if you are real or an AI robot.

Q37: Do you have concerns about patient privacy in the use of these technologies?



The majority of respondents, between 60% and 70%, indicated that they have concerns about patient privacy with the use of these kinds of technology. Of those with concerns, key was access by third parties, the risk of third-party misuse, and lack of control over patient information. Comments from these respondents include the following.

> *AI in particular, but also vendors of cheap devices who do not prioritize patient privacy are undoubtedly subsidizing their costs through the use of this valuable patient health information.*
>
> *You wonder if data is being collected in the background. I also worry about loss of control of the data on my patients.*
>
> *This is why I haven't started yet. I worry that I will be held responsible for a breach not under my control.*
>
> *AI in particular. Where is the information going. Is patient data being added to the training corpus? I have no idea.*
>
> *what non-healthcare organizations have access to the data. where are the physical servers located. who has physical or digital access to those servers. Do those servers meet data security requirements for health care data storage.*
>
> *I am concerned that data from wearables could be used by third parties to discriminate against patients - eg. An insurer who increases premiums because I patient is not active according to their wearable device.*

> *There is the potential for private industry to exploit individual patient information for profit. An example would include an insurance company purchasing information from a smart device company to monitor their clients/claimants.*
>
> *patients upload sensitive health data on their Apple watches and to various apps nowadays and I'm not sure they understand (I certainly don't) who can access that data within the companies hosting the apps*
>
> *lack of transparency by third party vendors*
>
> *Many of these are cloud offerings where the data flow is either not clear, or only known by the developers. It would be nice if there were a "PIPA" or "HIA" compliant badge that could be offered so I can be confident that the vendors are honest.*

Concerns were also expressed about the security of this technology.

> *Huge concerns, cyber attacks, identity thefts, chasing patterns of behaviours to manipulate people politically etc. It’s already happening!*
>
> *I have a concern with patients using the new technologies, in particular when they don't know who can access their data, and how their data can be mis/used.*
>
> *Everything other than paper charts is hackable*
>
> *Anyone can hack into an app. No one can ever hack into a quiet room with a family meeting with a social worker and nurse and doctor who actually care about the patient and their relatives.*
>
> *AI can easily make mistakes, and provides a lot of complexity that can be easily hacked. Major privacy issues can arise. The technology is not yet robust privacy wise.*

Some respondents shared the view that there is value to these technologies if implementation is approached right. Of these respondents, they flagged the need for guidance, standards, laws, and other supports to properly implement the technologies.

> *yes but try to be vigilant to risks and use when benefit is worthwhile   due to complexities unclear who can help advise re compliance for implementation   most advice seem to be that not worth effort as it would contravene some act and someone would "pop up" with a new role/title and disapprove its use*
>
> *Has been adapted in many setting without proper rollout and education. Even for virtual care, rollout broadly in the chaos of COVID, although there is a standard it was not properly trained in practice. Are all ensuring the patient is in an appropriate place to speak even? More complex technologies even greater potential risk. Needs better planning, rollout and protections in place.*
>
> *Would need guidelines/protocols around use of AI*
>
> *New technology is an inevitable transition in modern healthcare. But as they are new and outside existing systems of course I worry. There needs to be a standard so we can trust these technologies will meet the needs of our patients. For instance I use an EMR in one clinic environment which facilitates charting via AI if enabled. I do not enable this feature because*

> *endorsement by the CPSA is murky with respect to privacy. If there was clear guidance regarding this technology for Alberta from the CPSA or the ministry then I would expect the product developers would be incentivized to meet that standard so I could actually use it.*
>
> *We need a clear way of working on these technologies in a safe environment. Lack of laws surrounding how to manage this is causing a lag in our ability to apply this technology and improve efficiency and patient care*
>
> *Yes, but these (challenges) are not insurmountable. We should be providing the best care, and that means using technologies as they arise, not 20 years after they come out.*

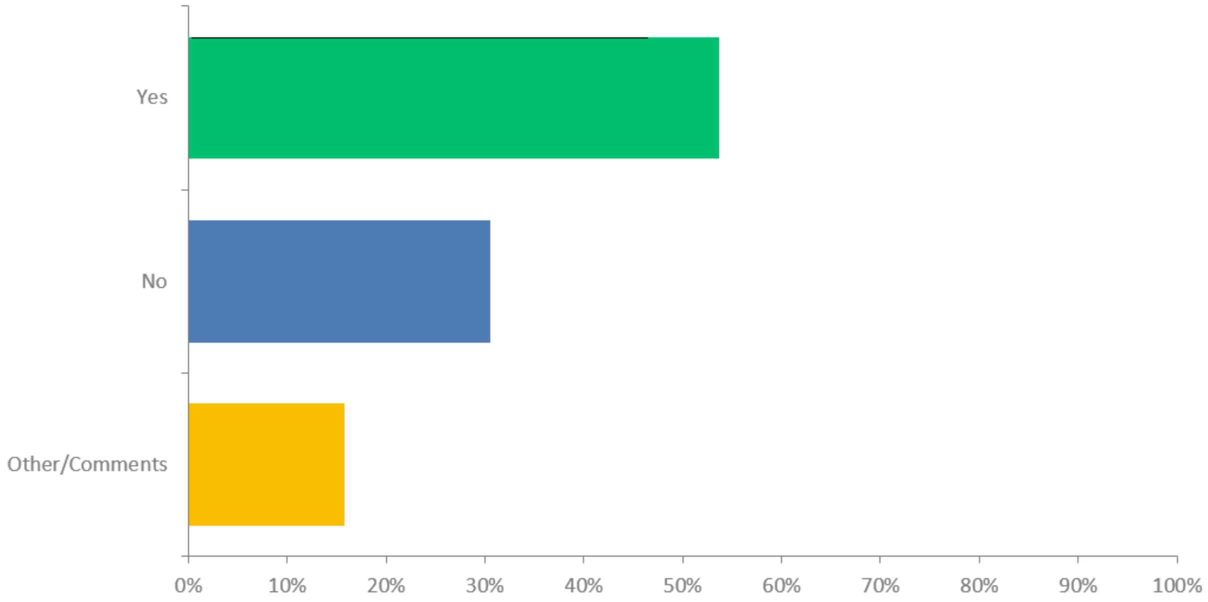
Some flagged new challenges with technology (e.g. verifying the patient).

> *One challenge is regarding telehealth (ensuring patient can speak freely and ensuring the patient is actually the patient).*
>
> *Impossible to control external factors when using technology such as public place of contact, hacking, AI generated likeness of patient etc*

Others shared concerns about the impact on quality of care and privacy.

> *Many physicians do not seem to recognize the privacy concerns and are lax about just trying and using these without going through a risk assessment first such as a PIA*
>
> *I would hope that any tech we use would adhere to privacy and confidentiality. This I am waiting to see how these new technologies are used in real life before I start using them*

Q38 do you think custodians should be required to conduct a PIA and/or use other types of proactive tools, such as algorithmic impact assessments* or be subject to ethical review prior to using these kinds of technology?



The majority of respondents, approximately 60%, agree that risk mitigation tools, such as PIAs or AIAs should be used, to assess the privacy risks and ethical factors when considering the use of these kinds of technologies. The comments by these respondents include the following.

> *Important to prevent patient harm and protect patient privacy so physicians need to do some type of risk assessment before using any such technology*
>
> *HREB and evaluation testing should definitely be a requirement*
>
> *PIA or AIA makes sense to make custodians aware of the risks and ensure these technologies comply with the HIA. However, the PIA/AIA or other tool should not be unnecessarily onerous on the custodian.*

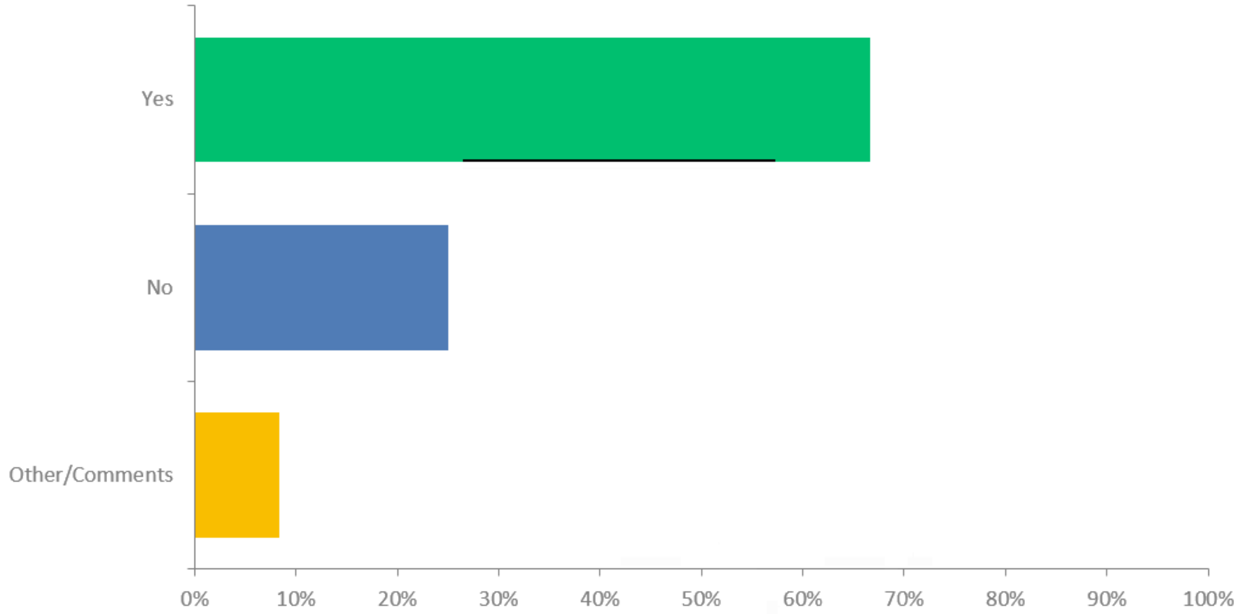
Comments by those that oppose the use of risk mitigation tools to assess the risks in using these technologies include the following.

> *These are tools. The interpretation of their output falls squarely within the domain of medical expert. The responsibility of the decision taken is the responsibility of the provider. If they don't understand the limitations of the tools they are using, they need more training in those tools and shouldn't be using them. No decision should be completely automated in health care.*
>
> *The application vendor should be mandated to do this.*
>
> *Need to reduce barriers to innovation.*
>
> *This seems situation dependent. A popular use of AI currently is AI scribe. Beyond ensuring that nothing is recording and maintaining responsibility for what is written, there is not much more to be done, so a PIA seems excessive.*

Of those in the “other” category, some of these respondents indicated that they would rather see other types of controls, or a managed, outsourced process for AI vetting

> *Patients should be able to choose whether these technologies are a part of their care*
>
> *Instead of requiring all custodians to use an AIA or similar, I would suggest AHS work to develop a suite of AI tools available to all areas of the healthcare system that are integrated and pre-vetted. AIA could be required for tools that are not pre-vetted.*

Q39: Currently, technology related to healthcare (e.g., apps, use of AI, etc.) is not regulated in Canada. Do you think Alberta would benefit from a standalone law to regulate the use of AI systems across all sectors to ensure there is consistent and effective regulation to mitigate harm and ensure oversight for infractions?



The majority of respondents, between 60% and 70%, agree that there should be a standalone law in Alberta to regulate the use of AI across all sectors. However, opinions are varied on how effective such a law would be.

> *Because, DUH!!! Of course this should be regulated, even more so in health care! We already have a problem with misinformation, decision making based on flawed information and flawed data. Healthcare (whether it's apps, use of AI, research etc.) should not be a Wild West situation!*
>
> *Helpful to have consistency and standardization rather than the ad hoc process that exists now, where physicians can easily think they can just start using products without any type of risk assessment or PIA (our physicians want to use an AI scribe and keep saying things like "why do we need a PIA first? my friend's clinic didn't do one" which leaves me very concerned about the apparent ignorance of some physicians regarding risks and privacy*
>
> *Probably a noble cause, but will be very difficult to apply.*
>
> *Any government would be too slow to react to those things effectively…*

Some respondents commented that AI should be regulated on a national level.

> *This should be national governance, not provincial*
>
> *national strategy needed*

> *Should be a national law*
>
> *But this would be better done at a national scale.*
>
> *should be federal jurisdiction*
>
> *Allow Federal Government to develop these laws to complex and evolving topic in line with international partners*

Some suggested that modification of existing laws to address the use of AI is preferred.

> *Possibly. I would say that it would be helpful if it was embedded in existing regulations for healthcare as the content is so personal.*
>
> *Just modify current laws*

Some suggested that Alberta should follow suit with what is occurring internationally, i.e., following the EU AI Act.

> *I suppose because we can't stop AI and other technologies, We have to waste our time and money on this. But yes, agree to go ahead and follow what Europe is doing Rather than wasting millions of dollars reinventing a wheel We need that money for infrastructure and workforce to care for the patients that can actually get access , and hopefully eventually improve access*

Others expressed that now is not the right time to regulate AI.

> *No. Other than ensuring that it is HIPAA (or equivalent) compliant. Again, we have regulatory agencies that do this already. Increasing the bureaucratic load of the system will not help anyone.*
>
> *Not yet. I think this field is evolving too quickly. I think the basic principles of chart management apply regardless (eg you are responsible, the info is available to the patient, it stays in Canada, etc.) I like AHS's approach of putting a ban on it for now. It should be allowed in research. It will be one a thing in the coming years but it is still very fluid.*

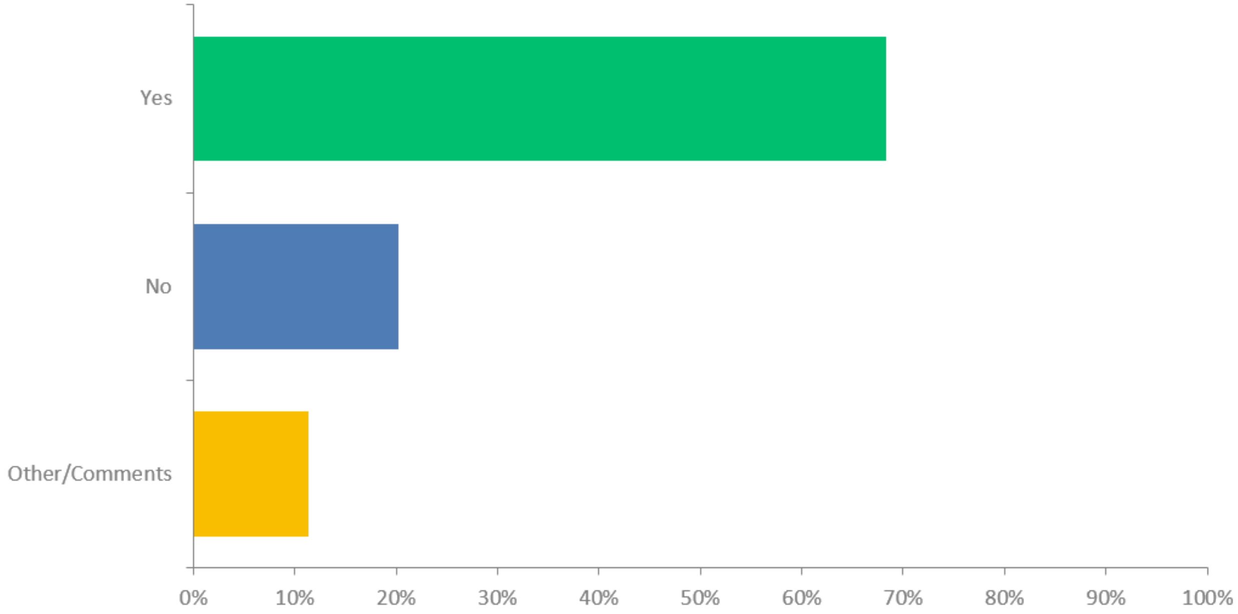
Some see AI regulation as a barrier to innovation and care.

> *Patients will be harmed by delayed implementation of AI*
>
> *Need to reduce barriers to innovation.*

Some are sceptical of AI altogether.

> *Only if you outlaw it. Again, no patient has ever said they were more happy using an app or talking to an AI robot about their health. Again, you will push this through for companies that will profit off of Albertans but it is a shame for actual health care.*

Q40: If you answered yes to the previous question, do you think it would be beneficial to have an individual designated to assess these systems who is independent of government (e.g., the Information & Privacy Commissioner)?



68% of respondents agree that there should be someone designated to assess AI systems with many commenting that this work should not involve government.

> *Yes. This should not be a political thing that could potentially change with every election. Ideological influence (both "right" and "left" ends of the spectrum) should be left out of the conversation.*
>
> *… An independent third party organization staffed with non-partisan professionals should be leading this area.*
>
> *Should not be government controlled as then could be ideologically influenced*
>
> *Need to not be subject to political interference*
>
> *Except not in Alberta where such appointees tend to be government agents.*

Among those that provided comments, concerns were expressed regarding the independence of the OIPC or whomever else would provide oversight.

> *Realistically in Alberta today are we going to get someone who is independent of Government in this position?*
>
> *I am uncertain how independent* [the Information and Privacy Commissioner] *actually is.*

Some respondents indicated that they were unsure if the OIPC is the right body to do this work.

But not the OIPC - since there are more things to consider with AI than just privacy. And OIPC is already overburdened.

Based on the historical role of the OIPC if such a process is developed the OIPC would really have to change the way they work, become much more well versed in how the health system works, be willing to actually meet with the health care delivery experts and consult meaningfully and offer advice. To date, none of these have been the experience of those needing to interact with the OIPC and in the current state I would not want this function delegated to the OIPC. I think that a multidisciplinary advisory council such as the previous Integrated Clinical Working Group that used to be sponsored by AH would be a better type of structure for this, that has a mix of clinical, academic and business interests in mind.