HQCA
Health Quality Council of Alberta

HEALTHCARE SYSTEM PATIENT CONCERNS MANAGEMENT REVIEW

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INTRODUCTION

Thousands of Albertans bring forward their concerns every year through a variety of formal and informal channels across every level and sector of the healthcare system. A wide range of concerns are raised including unmet expectations or dissatisfaction with their care, patient safety issues, health system access, scheduling, communication, and interactions with healthcare providers.

Annual number of concern (2020)	
Alberta Health Services	10,888
Covenant Health	1,282
Ministry of Health	461
Office of Alberta Health Advocates	1,353
Regulatory colleges	1,740
Primary care and community care	Not tracked at a system level
Continuing care	Not tracked separately from AHS

In July 2020, the Minister of Health requested the HQCA undertake an independent review of Alberta's patient concerns processes ("the Review"), due to perceived challenges with the current processes.

The Health Quality Council of Alberta's *Patient Concerns Management – a Framework for Alberta* ("the Concerns Framework") describes the link between person-centred care, concerns management, and overall quality and safety management. It provides guiding principles, process steps, and suggestions to facilitate a consistent and effective approach to patient concerns management throughout the province. The four guiding principles are:

- listening to patients and families
- expressing concerns is welcomed and easy
- effectively acknowledge and respond to concerns
- using concerns to improve services

The Concerns Framework provided the lens through which the Review was conducted.

Methodology

Information was collected from numerous sources to inform the findings and analysis of current state, best practices, and resulting gaps in Alberta's patient concerns management systems.

Between, August and December 2020, the Review team engaged with:

- more than 325 healthcare professionals, leaders, and patient concerns management subject matter experts via focus groups and interviews, and 1,748 by surveys. These discussions focused on understanding the current state, identifying what is working well, and where there are opportunities to provide a more person-centred, streamlined, and transparent patient concerns model.
- over 70 patients, family members, and community-based programs and organizations to hear first-hand stories from those with insight or experience navigating Alberta's concern management processes during the past year.
- 1,719 patients and families who responded to an online survey to assess their experience with concerns management based on the guiding principles from the Concerns framework.

In addition, a literature and best practices review was conducted of concerns management processes across Canadian and international healthcare jurisdictions (available upon request at info@hqa.ca), as well as a review of customer services best practices in other industries.

Limitations

The following limitations should be considered regarding the methods used for the survey

- **Convenience sampling**. Open links for the surveys were provided to various organizations. Organizations were instructed to send the web-based link to their membership or individuals who have submitted a concern or who have experience with the concerns management process. This strategy resulted in a sample of respondents which may not represent the entirety of those who have experience with Alberta's concerns management system.

FINDINGS

Three key issues were identified that when addressed will lead to improved overall concerns management in Alberta's healthcare system.

1. Alberta has a complex system of discrete healthcare patient concerns management processes that are confusing and difficult for patients and families to navigate.
2. Patients and families do not consistently experience a patient-centred concerns resolution process when expressing their concerns.
3. There is currently limited ability to track, monitor, and report on individual and system-level patient concerns to inform improvement efforts.

Complex concerns management systems are difficult to navigate

Alberta has a complex system of discrete healthcare patient concerns management processes that are confusing and difficult for patients and families to navigate and in turn does not support multi-jurisdictional investigations or system level learning.

Alberta Health Services and Covenant Health

Alberta Health Services (AHS) and Covenant Health (Covenant) have well-established patient concerns resolution processes for issues about the services that fall within their respective jurisdictions. These processes are defined by the *Patient Concerns Resolution Process Regulation* of the *Regional Health Authorities Act*. This legislation supports the patient as the focus of the process and outlines specific requirements of the process, such as the appointment of a Patient Concerns Officer who is responsible for all aspects of the concerns management process within the organization. This process has been used by AHS and Covenant for over a decade, and represents a standardized and consistent approach to manage formal patient concerns across the two organizations.

However, even within these organizations, concerns that cross multiple departments or service areas may result in disjointed processes and responses. There may be multiple, and sometimes unclear accountabilities for responding to concerns, particularly those that involve contracted service providers, such as continuing care operators. Collaboration in such cases is critical because responding, investigating, and resolving the concern requires communication across different groups, which can be confusing for patients when they expect to only have to deal with a single contact to oversee the entire process. As described by one continuing care operator, "It is not the responsibility of the resident/family to sift through where the complaint should go. It can be frustrating. It's confusing for us – can't imagine how much it is for them."

Concerns addressed to the Ministry of Health

Assigning responsibility for a concern can be confusing when the issue is brought to the attention of the Ministry of Health and the concern is regarding an operational issue for which another

organization has accountability. It is not always clear who owns the concern within government or outside government. Letters can have many concerns within them, or a single concern can be related to multiple issues across several government departments or healthcare organizations. Ministry of Health staff may spend considerable time identifying who is accountable for investigating the concern, which can make it difficult to respond to the person with the concern in a coordinated and timely way. Once the concern is investigated, it is often unclear who is responsible for closing the loop with the individual who raised the concern (e.g., the Ministry of Health branch that supported the response, the elected official who received the concern, or the healthcare organization who investigated and determined the outcome). Inefficient communication channels within government can sometimes result in delays before the responsible organization is made aware of an issue, which in some circumstances may have been easily and quickly resolved.

Primary care and regulated health professions

Within the primary care system, and for regulated health professionals providing service in the community, there effectively are no formal systems for managing concerns. Concerns that might best be addressed 'close to home' can end up in very formal concern management processes (i.e., a regulatory college) that may not always result in a person-centred resolution for the person raising the concern. This can occur where there is no structure to help mediate a solution to the concern. When there is a lack of clear, consistent patient concerns management processes with documented procedures, clinic staff who have limited experience and skills addressing concerns with patients and families can become frustrated. Because there is no direct connection between concerns raised in a primary or community care setting, and the broader healthcare system, the best these clinics can do for concerns outside of their direct jurisdiction, is refer the patient to AHS or Covenant Patient Relations, or a regulatory college. If the concern relates to another community clinic (i.e., specialist care outside of a hospital setting), the primary care clinic can only try to contact the specialist's office on the patient's behalf to ensure there is follow-up.

Concerns about primary and community-based healthcare are commonly directed to regulatory colleges to be reviewed as professional practice issues, as per the *Health Professions Act* (HPA), even though many of these concerns may not qualify as a professional practice issue. Registering a concern with a regulatory college is a highly structured process (e.g., 'complaint must be submitted in writing and signed by the complainant') and may leave patients and families feeling disconnected from the review process where some patients and families indicated they were not made aware of the outcome of a review. This disconnection is understandable when the purpose of the HPA is not to provide a remedy for a patient who lodges a concern, but to ensure that the profession is governing itself in a manner that protects and serves the public interest. This process is not necessarily designed to be a responsive concerns resolution process. Patients described the need for a patient advocate that is independent from the regulatory colleges to ensure neutrality is maintained, and to provide a valuable resource to guide patients and families through a potentially complicated process. Regulatory colleges provide some assistance to patients and family through the process but feel limited in their ability to offer support as they are expected to remain neutral during the process of investigating the practice of the healthcare professional.

Multi-jurisdictional concerns

Concerns that cross jurisdictional/organizational boundaries are especially problematic as they are examined by separate agencies in a manner that is not coordinated. Frequently, patients and families are left without a clear road map as there is no overarching agency or mechanism to respond to such concerns in a coordinated manner. Concerns can end up on the desks of people who are not able to fully address the issue. This requires referrals to another person or organization who has accountability for the concern, which adds to the confusion for the patient and hinders timely responses, or the concern may be addressed in pieces where each entity looks at their part – leaving patients and family with a concern that may not be fully investigated or resolved. This may result in duplication of effort and is frustrating to both those who lodged the concern, and those who are involved in investigating and determining a response to the concern.

Multiple investigations into the same concern can occur simultaneously, or sequentially, and may result in different resolutions and recommendations. For example, a concern arising from a continuing care home site could involve: the site and organizational leaders of the contracted service provider; AHS home care case managers and continuing care leaders within the AHS Zone and the provincial continuing care team; AHS Patient Relations; Protection for Persons in Care; Ministry of Health Continuing Care Branch, Compliance and Monitoring; and the Office of the Public Guardian and Trustee.

Information sharing between different agencies looking at the same issue is not very well supported or facilitated. This leaves the patient often describing their experience multiple times, which is frustrating and can result in what is termed 'second harm' for the patient when the circumstances are particularly traumatic. Privacy barriers, related to the interpretation of Alberta privacy and health professions legislation, were often cited as the reason for why information could not be shared across health service providers, organizations, and regulatory colleges.

Patients and families

Many patients and families described not knowing who to bring their concern to or where to go. One third of the respondents to the patient survey from the non-AHS/Covenant group indicated they did not make their concern known because they didn't know how. When patients and families inquired about the process outside of the AHS and Covenant patient concerns resolution process, they were often advised to raise the concern first with the manager where the services were received. Although this recommendation makes sense from the perspective of encouraging those closest to the issue to be involved in addressing the concern, the reality is that patients and families may not feel comfortable raising concerns directly to those involved in the care service, especially if the care relationship is ongoing (e.g., in continuing care settings, or in rural areas where there are few options to change providers) or where the concern involved the actions of the manager to whom they were directed to make their concerns known, or if the concern involved multiple care providers. One-third of respondents to the patient survey indicated the reason they did not make a concern known was related to worries about their care.

Patients and families indicated they were not typically made aware at first point of contact or upon admission on how to bring forward concerns and so were left to seek out this information themselves. The exception to this observation was in the continuing care sector where upon admission, residents and families are informed about how they can lodge a concern. In this sector of the healthcare system, there are clear standards for patient concerns policies that include the expectation that information on where and how to express concerns will be shared on admission.

Even healthcare providers who wish to lodge a concern about their own care, and who have a clear understanding of the healthcare system, have difficulty determining where to take a concern if there are many providers involved in their care. For patients, these disconnected and fragmented processes are frustrating and often discourage them from pursuing the opportunity to provide feedback that is intended to help the healthcare system improve.

Person-centred approach to addressing concerns

Patients and families do not consistently experience a person-centred concerns resolution process when expressing their concerns.

A person-centred concerns management process exists when the:

- rights and opinions of patients and families are respected;
- process empowers patients and families to feel safe when submitting a concern;
- patient and family perspectives and experiences are considered in a manner that is respectful; and,
- process responds to issues in a way that are meaningful to the patient and family.

Despite more than 80 per cent of respondents to the patient survey indicating they felt their right to express a concern was respected, when interviewed patients and families described how they had not always felt respected or treated with compassion when expressing their concerns. Specifically, that their unique context is not appreciated (e.g., families may not be included in their efforts to seek resolution to their concerns or their personal beliefs and perspectives may not appreciated). It is very difficult for patients and families to separate their healthcare experiences, from the experiences of making a concern known – both experiences are intertwined. Some noted that when they had a positive experience with the process of how their concern was addressed, they found the resolution of the concern more acceptable. Below is summary of the gaps identified in providing person-centred concerns management.

Patients and families don't feel heard. Providers of healthcare services are not consistently listening to issues raised by patients and families in a respectful, compassionate manner that is culturally responsive.[i] Some described experiencing an arrogant and/or dismissive response when

[i] Being **culturally responsive** means that the provider or concerns management staff is aware of their own assumptions, beliefs, and privilege, and with this self-awareness, the provider or concerns management staff can take a truly person-centred approach to

they brought their concern forward, and that it was a relief when they found someone who believed them. Healthcare leaders and providers also recognized there is a need to improve provider competence to listen to patients. Front-line staff should strive for first-contact resolution, which is proven to be a more effective and timely way to de-escalate and resolve concerns. And staff should be empowered to "let the customer tell their entire story without interruption"[1] and provide the person bringing forward the concern the opportunity to just be heard.

Opportunity to raise concerns. Alberta's Health Charter includes having "the opportunity to raise concerns and receive a timely response to my concerns, without fear of retribution or an impact on my health services and care" as an expectation for when someone interacts with the health system.[2] However, the degree to which Albertans are even aware of the Health Charter and this expectation is unknown. Community-based organizations say some refugees have shared that they had very negative experiences in their home countries when concerns about government services, such as healthcare, were expressed, and as such they are hesitant to bring forward concerns for fear it may affect their future interactions with the healthcare system.

Asking "what matters?" Asking about expectations for resolution should be a standard practice as part of the patient concerns management process, but few patients mentioned this actually occurring. Expectations for resolution can vary greatly, from "I just want acknowledgement or an apology," to "I want heads to roll." Clearly identifying patient and family expectations regarding resolution should be determined at the start of the concerns management process. Patients and families indicated they appreciated a respectful and empathetic conversation about what is possible related to a resolution. When the final answer or resolution was 'that's all we can do,' patients and families felt frustrated and left with unresolved issues. They indicated they may have had reasonable suggestions for ways to resolve the concern, but their opinions were not sought. The current patient concerns resolution process used by AHS and Covenant relies on an intermediary (the Patient Concerns Consultant) as the conduit between the person with the concern and the person investigating the concern. Therefore, there may be no opportunity for the patient to discuss directly with the leader responsible for investigating and responding to the concern a resolution that would be acceptable to them. Fewer than 40 per cent of the AHS/Covenant respondents to the patient survey felt they were welcome to be involved in the management of the concern.

It takes great skill to communicate to patients and families an understanding of the seriousness of their concern and then balance that with a message of the need to uphold principles of Just Culture where everyone – healthcare providers and patients – feel safe to explore the underlying reasons for a concern. Advocacy groups, such as the Office of the Alberta Heath Advocates and the Ontario Ombudsman, advised that training staff who have these conversations with patients and families is important. Staff working in the AHS and Covenant Patient Relations departments indicated this

relationship-building and responding to a healthcare concern. They adjust their approach to engaging with and responding to a patient and family member in a way that respects the patient's or family member's dimensions of identity, which may be different from theirs.

type of training was not required, but many shared that course work on conflict resolution and mediation was helpful to them in their roles.

Assessing and having a conversation with the patient and family about the concern at the start of the process to determine the most appropriate response, was noted by patients and healthcare providers as a mechanism to finding resolutions through the lens of what is most meaningful to patients. For example, support with grief counselling may result in a more meaningful resolution than receiving a vague explanation about what happened.

Support to make concern known. Fewer than 60 per cent of AHS/Covenant respondents to the patient survey indicated there was guidance to express concerns. For those who had challenges making their concerns known, there was little support offered to overcome those barriers. For example, needing help to prepare and submit required documents (e.g., fill out a form, develop a timeline, write a letter, request an appeal, etc.). Although the AHS and Covenant concerns intake process does not require specific documentation to raise a concern, the process for the regulatory colleges does require submission of a written and signed document. Programs such as Scotland's Patient Advice and Support Service (PASS) are noted as leaders in offering support to people who wish to make a concern known. Staff from the PASS program help people clarify their concerns, complete the paperwork required prior to submitting a concern and where necessary, act as case managers as the person navigates through the concerns process.

Those requiring assistance to lodge their concern because of communication challenges (e.g., hearing loss, language barriers) said they were either not aware of or were seldom offered accommodation to assist them (e.g., technologies to support communication for those with hearing loss, or formal translation services for those who do not speak English) to access the concerns process.

Trust. People often don't bring forward their concerns for a variety of reasons. Some don't believe that anything will change as a result of the concern, where others fear they won't be taken seriously. Some patients and families indicated they didn't feel comfortable making a concern known to the same organization/provider that was involved in the concern. Some expressed mistrust of the regulatory college process which seemed to them to protect the interests of the healthcare professional over their interests.

Patients and families can have reservations about expressing concerns to, or about, a healthcare service where there were limited options for alternate healthcare to be obtained; especially for those who live in rural or remote areas of the province. Patients expressed fear not only of the perception that healthcare services would be withdrawn, but shared examples of this happening. One-third of respondents to the patient survey indicated the reason they did not make a concern known was related to worries about their care. Patients described a power-imbalance in these situations. Continuing care leaders recognized that it is not easy for residents to bring forward concerns due to reduced cognitive ability and fear of repercussion given the power dynamic existing between care providers and residents.

Trusting the patient concerns processes was particularly difficult for those who experienced racism during their care. In these interviews, patients and families indicated how difficult it is to provide "proof" of racism related to their healthcare concern, and so they were often dismissed or told there was "not enough evidence to investigate."

Support during the investigation and resolution process. Patients and families expressed feeling abandoned during the period the concern was investigated, especially if the investigation was protracted. Staff involved in patient concerns management indicated there could be significant delays in obtaining a resolution to the concern (e.g., where a response was required from different parties). Patient Concerns Consultants (PCC) mentioned that it is their practice to tell patients they will be in touch when there is progress to report, but that patients are welcome to contact the PCC at any time for a progress report. Keeping patients informed of the status/progress of their concern is identified as a best practice, such as those described by the Ontario Ombudsman, or the Saskatchewan Health Authority, where they use advocates for patients and families to help with making concerns known, and providing support during the investigation and resolution period. This included advocating for the presence of family members or community supports if the patient agreed.

In both the Ontario and Saskatchewan models, as well as expressed in the patient and family interviews, where an advocate or system navigator was available, the support was appreciated.

Determining when a concern is resolved. Concerns may be considered resolved by the healthcare organization, but the patient and family may continue to have unresolved issues. For many, it was because the response they received lacked empathetic understanding of the patient's perspective, acknowledgement of responsibility, and/or an apology. When responses were empathetic and an apology was heard, patients and families were more likely to assess the resolution of the concern positively. Interviews with leaders from healthcare organizations indicate there is an ongoing program of supporting medical leaders to become competent and supported to disclose information about unintended medical outcomes. Clarifying the implications of, and stressing the importance and appropriateness of, making an apology may help others feel more comfortable providing apologies to patients. Apologies bring comfort to the patient, forgiveness to the provider, and help to restore trust in the relationship.[3]

Some patients and families wanted clearer answers to questions about what happened (e.g., regarding a concern that resulted in harm), and staff indicated they were sometimes unclear what they were allowed to share with patients. Patients perceived this type of vague reporting as an example of healthcare organizations being risk adverse (e.g. trying to avoid litigation). There is an opportunity to explore the true limits of legislation that are perceived to prevent open communication with patients when resolving concerns. Responses to concerns provided by regulatory colleges were reported to be difficult for patients and family to understand (i.e., the language required high levels of literacy, were overly professional, included clinical and quality improvement jargon, and were interpreted by patients as being legal-speak).

Because of the perceived lack of resolution, some were left with unmet healthcare needs. Healthcare leaders stated that complaints management work is frustrating because they often have

limited ability to resolve the issue, especially when the origin relates to government policy and/or funding. For these types of issues, resolution involves educating families about the limits of Alberta's publicly funded healthcare system, and the recognition at the start by providers and patients that the issue may not be satisfactorily resolved. One site director expressed these concerns: ". . . disappointing to me as a Director that I can't do more. Due to limitations in funding, and issues relative to what residents and families perceive as a lack of care, we get caught here." Balancing the healthcare needs of individuals within a publicly funded healthcare system is a challenge, but there are few options for individuals to express concerns about policy issues in a way that can be tracked, collated, and presented to those responsible for making healthcare policy decisions. An observation made was that healthcare policies should not be changed based on an 'n' of one, but should be examined from the lens of many.

Once a concern is closed by the organization, some patients remained unsatisfied with the resolution, but found they had limited options to request another review of the outcome of the decision. Their only recourse was to seek a review by the Alberta Ombudsman, which is limited to only reviewing for procedural fairness. More centralized patient concerns management systems, such as in Australia, have opportunities for a second review of the outcome of a patient concern investigation.

Patient concerns data is under-utilized to inform improvements

There is currently limited ability to track, monitor, and report on individual and system-level patient concerns to inform improvement efforts.

Leading practices for patient concerns management processes suggest that information related to patient and family concerns is required to accomplish multiple objectives:

- Track and monitor the progress of an individual concern through key process steps (e.g., acknowledge, investigate, resolve).
- Keep patients and families informed about the status of their concern.
- Monitor implementation of any recommendations as an outcome of the concerns investigation.
- Provide aggregate data and reporting to inform improvement at the local, organizational, and system levels.
- Provide data to evaluate concerns management processes.

In Alberta, patient and family concerns data is not available for all sectors of care and service delivery, is not integrated where data is collected, and may not be available to leaders in a format that facilitates identifying and prioritizing improvement efforts.

Tracking individual concerns

AHS and Covenant use a common database (Feedback and Concerns Tracking - FACT) to collect data about individual concerns and track progress toward resolution. When the file is closed, the concern is tagged with a category (e.g., environment, delivery of care) which is used for reporting to leaders across the two organizations. Some senior leaders request copies of the responses provided to patients and families, as a means of maintaining awareness of the issues brought forward in their respective areas of responsibilities. Other organizations also track concerns, but the various systems across the province are not integrated, nor do they collect standardized information.

Tracking multi-jurisdictional concerns that involve more than one organization is not possible with the current disparate and non-integrated information systems.

Data and reporting to inform improvement at the local, organizational and system levels

Leading practices suggest that concerns management information systems should allow for a standardized approach to data entry and analysis that includes:

- routine quantitative analyses at the aggregate level to identify "hot spots" at the organizational level
- quantitative analyses are followed up with qualitative analyses to identify contextual causes of and human factors associated with concerns
- all concerns, regardless of the sources, are charted for analysis
- concerns are coded for severity using a standardized approach
- standardized training and guidelines for coding have been established

Leading practices for reporting also suggest that:

- annual reports include actions taken or how concerns were handled, as well as a summary of concerns made
- internal reports include recommendations for resolving concerns and improving quality of care
- reports that describe changes made as a result of learnings from patient concerns reviews are shared with the public
- annual concerns reports are systematically reviewed internally to improve service delivery

One of the more important gaps noted by patients and families was the lack of evidence or transparency regarding changes or improvements made based on their feedback. As reflected in the patient/family survey, only 24 per cent of patient from AHS and Covenant, and 39 per cent of all other respondents, indicated they were aware of changes or improvements that had been made as a result of expressing a concern. This was distressing to patient and families, as a prime motivation for bringing forward their concern was to make things better for others. Patients and families felt that the healthcare system as a whole does not embrace learning and improvement from concerns.

Patients and families felt their concern was something to be "shooed away" and many did not understand why the person who they were speaking with didn't immediately want to help them, and "fix things that are broken."

Some organizational leaders indicated it is difficult to identify and prioritize local improvements based on the information contained in reports they receive, as they reflect numbers and broad categories of concerns (e.g., environment, delivery of care). As one leader said, "If I have patient concerns related to the environment in my area, does this mean the bathroom was dirty, or the room was too cold? Was it one particular day, or does this happen all the time?" In addition, concerns data at the local level may not provide sufficient volume to see trends over time. Leaders readily acknowledged the potential to use patient concerns data to improve care and services, but there were few examples given of how this would be accomplished.

The Continuing Care Health Service Standards require continuing care sites to have policies and procedures for responding to concerns about the healthcare they provide. Although this standard does not require tracking patient concerns for purposes of quality improvement, many continuing care providers do have systems in place to track concerns. One continuing care leader suggested that a way to encourage improvement might be to include this expectation in the Quality Improvement Reporting standard in the Continuing Care Health Service Standards.

These local continuing care databases are not linked to the AHS and Covenant FACT database, so integration of the data for purposes of quality improvement at the system level is not supported. It is difficult to get a 'full picture' of the type and frequency of patient concerns when the data resides in multiple systems.

Taking action on feedback about concerns that fall within the leader's scope of authority is easier than responding to concerns that have a shared accountability to address, or are completely outside the leader's jurisdiction. For example, systemic access to care and services issues are decided by healthcare policy set by the larger organization or by government. Concerns that span the entire care continuum require a system-wide response that is beyond a local leader's authority. Patients, families and healthcare system leaders expressed that for some concerns, there is "nothing that can be done." Some noted that the healthcare system is not set up to monitor common concerns across the continuum of care. One continuing care leader suggested that it would be helpful if an external agency existed that had the role of reviewing complaints across agencies, providers, and areas of the health system to identify if there are issues that are interlinked with a root cause, related to policy, funding, or process. This agency could recommend solutions or "maybe implement systemic solutions to address root causes."

Concerns that are investigated by agencies such the Mental Health Patient Advocate, Protection for Persons in Care, or the Compliance and Monitoring Branch of the Ministry of Health result in recommendations to specific healthcare delivery organizations. These agencies indicated that there are limits to monitoring the sustainability of the changes they recommend. Trending of issues brought to the attention of these agencies, happens informally and on an ad hoc basis and rely on personal relationships to confirm and address emerging issues.

In the primary and community-based sector of the healthcare continuum, patient concerns are not typically tracked or recorded in a local or clinic database, and not at all in a centralized database. There are also no formal mechanisms in place to ensure that learnings are shared for quality improvement purposes with other clinics or providers. Particularly if a patient and family concern is multi-jurisdictional – spanning a combination of healthcare providers and delivery organizations, such as a family doctor, specialist, diagnostics, and a hospital – there is no mechanism to connect the concern in a central database. This results in a wealth of missing data that could be used to inform improvement at the system level. Primary care and other regulated healthcare professionals that work in community settings, acknowledge the value of learning from concerns, and are receptive to expanding upon existing ad hoc approaches to improve on their current processes, where they exist.

Where investigations of concerns are reviewed by regulatory colleges, the focus of the review is on the practice of the individual healthcare professional. Observations on ways the healthcare system could be improved to prevent similar incidents may be revealed during college investigations, but there is no formal mechanism for regulatory colleges to share such information with the broader healthcare system or with each other. It was identified that proposed amendments to the *Health Professions Act* may not go far enough to support better information sharing to enable system improvement. Processes and structures need to be created to give colleges the ability to formally report and share any insights that arise from investigations, which would provide an opportunity to inform system-related issues that could potentially prevent similar situations from reoccurring. The ability for organizations, including regulatory colleges, to share aggregate anonymous concerns data would support and encourage system-level learning and improvement.

Centralized concern management systems, such as those found in Australia and New Zealand, are able to coordinate reviews of patient concerns and include regulatory colleges as appropriate to investigate the practice of individual healthcare professionals and support aggregate reporting about concerns and make recommendations based on the system level learning. Their centralized information systems also support patients and families and healthcare professionals to track the progress of the concern through the steps toward resolution.

Concerns about safety

There is an evolving body of evidence that patient concerns data can be an early warning system for patient safety concerns in the healthcare system. Researchers in the UK have been working on ways to mine data from patient concerns data to find early indications of safety issues. They propose that databases for capturing patient concerns data provide a mechanism to help monitor the safety and quality of the healthcare across large systems using natural language algorithms (a form of artificial intelligence).

Leaders from AHS indicated that significant safety issues are sometimes revealed through their internal clinical safety processes (e.g., reported through the patient safety reporting and learning system) before they arise as a patient concern. In South Australia, when an investigation into a concern finds evidence of a safety issue, the concern file is closed, and the issue is directed to the safety investigation team for follow up. This allows a systematic review of the safety concern, and

sharing of learning about the specific safety concern that might not occur if the concern remained in the patient concerns resolution stream.

Use data to evaluate patient concerns management processes

Leading practices identified the following related to evaluating concerns management processes:

- A series of key performance indicators are developed in collaboration with patients and families.
- Key performance indicators are used to determine the effectiveness of the patient complaints process and management system, are measured annually, and the results are made publicly available.

Patients and families support regular evaluation of concerns management processes by a third party, including the collection of patient and family experience information.

In addition, leaders from healthcare organizations mentioned the need for regular evaluations. It was noted that there had been infrequent assessment of the AHS and Covenant patient concerns resolution process over the years. They identified that they did not have information from patients and families and others about what was working well and what wasn't. It was also mentioned that regular evaluation and learning from multiple perspectives such as patients and families, a provider with a complaint against them, an employee tasked with reviewing the concern, a Patient Concerns Consultant, and senior leaders would be helpful.

RECOMMENDATION

Upon consideration of the three key issues, a centralized model for Alberta's patient healthcare concerns management system is recommended. This model best addresses the key issues by providing streamlined access, enhance person-centred approaches, and includes a provincial information system to identify opportunities to improve the system and the authority to monitor for implementation of healthcare improvement based on recommendations.

A significant gap that would also be addressed in the recommended centralized model is the management of patient concerns that arise in primary and community-based healthcare (e.g. specialists, dentists, pharmacists, etc.). Currently these concerns are mostly directed to the regulatory colleges for review. *The Health Professions Act* is not designed as a patient concerns resolution process (as the AHS and Covenant regulations describe), but rather is a mechanism for ensuring safety of the public through review of healthcare professional practice. The proposed centralized model would provide a patient concerns resolution process for patients who have concerns about healthcare services in primary and community care.

Centralized models were observed as well-established approaches in other jurisdictions (e.g., New Zealand, Australia, and the UK), and although no formal evaluation of these systems was found, the structure of these centralized concerns management systems seemed best suited to address the challenges identified in Alberta's current system. The scoping review of the literature found no ideal system for addressing concerns currently in place, but the review did provide clear identification of best practices that have been incorporated into the proposed patient concerns model for Alberta.

The following describes the components of the model. The HQCA strongly recommends that implementing all components of the model would be required to maximize improvements in how patient concerns are addressed across Alberta's healthcare system. However, given the lack of evidence from other jurisdictions regarding the success and effectiveness of this type of centralized system, it will be critical that a formal formative evaluation process be established at the planning stage for the recommended model to embed a "systematic assessment of the design, implementation, and results of the model for the purposes of continuous learning and decision-making"[4].

Following the description of the recommended centralized patient healthcare concerns management model are a series of implementation options for consideration.

Centralized model for patient healthcare concerns management

Establish an independent organization responsible for overseeing an effective concerns management system which leverages existing expertise and resources wherever possible.

The centralized concerns organization will provide:

- a single, easy-to-access point of entry for patients and families to raise formal healthcare concerns;
- a person-centred concerns resolution process; and,
- the ability to track, monitor, and report on individual and system-level patient concerns to inform improvement efforts.

The following best practice guiding principles must be considered in order to address the gaps identified, and to achieve a high performing person-centred concerns management system for all Albertans. Where current patient concerns resolution processes are intended to remain (e.g., AHS and Covenant), the following best practices could be used to guide improvements to those existing processes.

Guiding principles for Alberta's concerns management system

Accessible

- Information about the process is proactively shared with patients and families.
- Instructions for submitting a concern are clear and easy to follow, and assistance to navigate the process is offered/provided when needed.
- Concerns are accepted through multiple mechanisms (e.g., online, email, telephone, in person) and assistance or accommodation is provided to persons with disabilities (e.g., vision, mobility, cognitive impairment, etc.) or where language is a barrier.

Person-centred

- The rights and opinions of patients and families are respected.
- Process empowers patients and families to feel safe when submitting a concern.
- Patient and family perspectives and experiences are considered in a manner that is respectful, compassionate and culturally responsive.
- Process responds to issues in a way that is meaningful to the patient and family and considers the patient's expectations for resolution.

Transparent

- The organization is open about the process for managing concerns i.e., potential outcomes and rationale, timelines, and who to contact for more information.
- There are clear and objective mechanisms for handling the concern while ensuring confidentiality.

- Patients and families are provided with clear explanations for any decisions made throughout the process.
- Investigation of concerns follows principles of Just Culture where staff feel safe participating in concerns investigations.

Responsive

- Concerns are handled in a timely way i.e., acknowledged, processed, investigated (if applicable), and resolved within reasonable timeframes.
- Patients and families are proactively kept informed of the status of their concern in the method they prefer (e.g., phone, email, letter, etc.).

Equitable

- Patients and families are treated with impartiality, fairness, and cultural responsiveness.
- Patient and families receive an unbiased and thorough review.
- There is an opportunity for second review if the concern is unresolved to the complainant's satisfaction, or to appeal an outcome should the patient and family feel the process was unfair.

Continuous learning and improvement

- Principles of Just Culture guide the organization's response to concerns where staff feel safe to discuss learning and improvements to prevent similar concerns in the future.
- A summary of the concern is shared with those who can make operational or policy decisions that improve the quality of services delivered.
- There are mechanisms for monitoring progress on the implementation of outcomes/findings from a concern process.
- Feedback on how the concern has been successful in improving service is provided to the complainant.
- Monitor trends in concerns management across the healthcare system and lead discussions about improvements required.

Accountable

- Responsibility is assigned for the implementation of actions and decisions that result from the concerns investigation.

Quality assurance (of the patient concerns management system)

- Evaluation is conducted on a regular basis to inform continuous improvement of the concerns management system's policies, processes, and mechanisms.

Options for implementation

If the centralized concerns management recommendation is not implemented as described above, there are still opportunities to improve the current state of patient concerns management in Alberta, although not all issues identified would be addressed.

The current patient concerns management processes could be enhanced by assigning responsibility to complete, in collaboration with patient and family advisors, the following activities:

1. Develop a **competency framework** that identifies the competencies required to respond to patient concerns when raised in clinical settings (informal concerns) and to address patient concerns raised formally. This framework would build on the current capacity in the system in AHS and Covenant and incorporate gaps and improvement opportunities identified through the patient and family interviews conducted for this Review.
2. **Develop and promote resources** to support increased competence of healthcare providers to respond to patients and families in the moment when concerns are raised in the care environment.
3. Increase understanding of **person-centred care** in the provision of healthcare services across the healthcare system as a means of reducing the number of concerns raised.
4. Promote the adoption of principles of **Just Culture** and Just Individual Assessment (fair review of individual's actions) for all healthcare entity or regulatory college involved in investigation of patient concerns. These principles aim to ensure that staff are not unduly blamed for outcomes that may stem from system-level contributing factors.
5. Study alternate mechanisms to obtain feedback from patients and families who are **hesitant to express concerns**, including people from **underrepresented groups**. Explore the implementation of platforms such as Safespace (platform designed by Indigenous healthcare leaders to seek feedback about healthcare experiences in a culturally appropriate manner) or Care Opinion (moderated public webpage for expressing healthcare concerns – originating in UK).
6. Require those who currently respond to patient concerns to make public how patient concerns have **influenced changes in healthcare services**.
7. In partnership with groups that currently receive patient concerns (e.g., AHS and Covenant Patient Concerns; regulatory colleges; Protection for Persons in Care; Office of the Alberta Health Advocates) develop a strategy to obtain **regular feedback** about the concerns management processes and develop improvement plans to address this feedback.
8. **Seek mechanisms for regulatory colleges to share information with healthcare entities**, such as AHS and Covenant on concerns about healthcare professionals who work in those organizations as a means of seeking ways to address system-level concerns. The UK has an emerging concerns committee that could be a model for these conversations.

9. Correct the legislative barriers that impede the efficient resolution of concerns that are reviewed under the **Protection for Persons in Care** legislation, such as increasing the number of people who can make final decisions on investigations to improve the timeframe in which these investigations are completed.
10. Investigate the requirements of a **provincial information system** to track patient concerns. Explore the possibility of expanding the current AHS Covenant FACT database to track concerns from all sectors of the healthcare system.
11. Assign responsibility for managing formal healthcare concerns that arise from the **primary and community-based services including**: intake and recording of concerns in an information system; investigating the concern and involving the regulatory colleges if the concerns involves professional misconduct; supporting patients and families throughout the concerns management process; monitoring for implementation of recommendations arising from concerns; reporting on concerns raised from this sector of the healthcare system.
12. Assign responsibility for leading and coordinating investigations into concerns that **cross jurisdictional boundaries** (e.g., concerns that involve AHS and/or Covenant and a primary or community-based health service).

Implementation of these activities would improve the current state, but would not address the following gaps that a centralized approach could address:

1. Access to concerns management processes would remain confusing for patients and families with multiple, fragmented processes and no central intake system.
2. There would be no system for providing a second review of the resolution for concerns investigated by AHS or Covenant.
3. There would be no agency with the authority to monitor the implementation of recommendations from concerns investigations.
4. There would be missed opportunities for system-level learning from analysis of aggregate data that a centralized information system designed to track patient concerns data across the healthcare system would provide.
5. There would be no overall agency responsible for supporting improvements in patient concerns management processes.

PHASE 2: FURTHER ENGAGEMENT AND CONSENSUS CONFERENCE

The Minister of Health accepted in principle the key findings from the February 2021 report that made recommendations to enhance current concerns management processes. The Minister directed health system partners to review their current processes in light of the eight principles and 12 activities and improve them accordingly.

The Minister also asked the HQCA to bring health system partners together at a consensus conference to inform development of a shared recommendation endorsed by participants.

The intent was to gather feedback about key findings in the HQCA report that, if addressed, could lead to improved overall concerns management in Alberta's healthcare system; and the independent centralized model proposed in the HQCA report.

Approach

In preparation for the Patient Concerns Consensus Conference (Conference), the HQCA re-engaged with a subset of individuals who provided information in the original review. This feedback, obtained from patients and families, community-based support organizations, and healthcare organizations / providers (providers), led to four alternative options.

Two items were consistent across all four options:

- The complaints process as prescribed in the *Health Professions Act* for regulatory colleges would not change. Only the mechanism that would trigger the college process would differ depending on the option.
- Indigenous concerns would be managed through a distinct, Indigenous-led patient concerns resolution process (PCRP). This process would include culturally responsive approaches to hearing concerns (intake) and the authority to investigate concerns by those with the skills to identify cultural bias and systemic racism. This distinct process would also have the mandate to identify and hold organizations accountable for the implementation of changes to the healthcare system to address systemic racism.

The four options were subsequently presented to the Conference participants. The following is a summary of the Conference findings.

Intake

Overall, many participants at the Conference favoured and agreed upon the value of a central intake concept, while raising significant cautions about implementation within the current, complex concerns management system.

Investigation and resolution

In general, patients and families support a structure where investigation and resolution is conducted by an independent centralized body, while providers prefer a structure where the accountability for investigations and resolution is retained by the organization.

Monitoring and reporting

There is agreement and support for a centralized database to support measuring, monitoring, and reporting on patient concerns management across the healthcare system, and participants seemed open to working collaboratively through the limitations and challenges of implementing a centralized database.

Structure

Consensus was not reached on the best structure to support improvements in the patient concerns management system. Patients and families and providers disagreed; they have different perspectives on accountability mechanisms, who should be trusted to own the investigation process, and what constitutes resolution.

Patients and families and community-based support organizations, including feedback from First Nations and Métis health leaders, generally expressed a preference for a structure that would:

- Be simpler to access (e.g., a central intake function; local intake to a trusted source for Indigenous patients and families).
- Allow for increased transparency and person-centredness of patient concerns investigation/resolution.
- Support and promote system-level learning.

Providers expressed a preference for a structure that would provide:

- Control over the investigation process by organizations/individuals with knowledge of the sector and local context.
- Opportunity for learning about ways to improve the system by conducting the investigation (e.g., healthcare leaders being involved in investigation/resolution of the concern).
- A coordinated approach to the investigation and resolution of concerns that cross jurisdictional boundaries.

Capacity building

The need to increase the knowledge and skills of providers/staff to respond to patient concerns (both informally in the care setting and in formal patient concerns management processes) was noted in the original report and confirmed in the pre-conference engagement activities.

Indigenous perspective

At the Minister of Health's direction, Alberta Health collaborated with the HQCA and led two conferences in November 2021 with First Nations health directors and Métis health leaders to begin to understand their experiences with the current patient concerns management processes.

Themes identified from the conferences focused primarily on the AHS patient concerns processes and included:

1. Few First Nations or Métis are aware of or trust the current AHS patient concerns process.
2. There is no feedback mechanism [to those who make concerns known] or accountability [to make a change] when it comes to patient concerns.
3. First Nations and Métis go to trusted individuals [in their own community] for services because the healthcare services available in hospitals and clinics are neither welcoming nor trusted.
4. Language, culture, and communication barriers matter [to Indigenous patients and families who experience the healthcare system as complex, unwelcoming, and racist].

First Nations health directors and Métis health leaders recommend the establishment of independent concerns review mechanisms, led respectively by First Nations and the Métis Settlements and Métis Nation of Alberta.

APPENDIX A: TERMS

Patient-centred vs. person-centred: Although there is no one accepted definition of patient-centred care, the term generally indicates the importance of recognizing patients as unique individuals and treating them with respect and dignity. An evolution of this concept broadens the lens of 'the patient' to include the context around them (e.g., beliefs and preferences, family, influences of social determinants of health, etc.) as impacting on the acceptability of the healthcare that is prescribed to them. Person-centred care is the term used to describe this broader lens of the patient and his/her context and further considers how the relationship with healthcare providers impacts their experience and the outcome of healthcare services they receive. The premise of person-centred care is that when patients and families and healthcare providers work together to determine the best course of action for the patient (taking into account the patient's unique context), the outcome of care is better for the patient and reflects more efficient use of healthcare services[5].

Both terms are used in this report. Patient-centred is used to reflect terminology used in previous HQCA concerns frameworks (e.g., *HQCA Patient Concerns Management – a Framework for Alberta*) and in the findings from the scoping review of the literature describing the best practices of patient concerns management processes. In the analysis and recommendation sections of the report, the term person-centred is used to reference this broader concept of addressing patient concerns from a lens that includes the context of the person with the concern, and includes reference to the relationship from whom they received healthcare services.

Concern vs. complaint: During the data collection for this Review, many people — patients, family members, providers, patient concerns management staff, and healthcare staff — indicated that the term complaint is not a preferred term for the following reasons:

- It can have a negative connotation/definition and assume that all feedback is negative.
- It can set up an adversarial relationship between the person raising the concern and the person responding to the concern.
- It can be contrary to the cooperative nature of people who provide feedback to help make the system better.
- It has the potential to make the person giving feedback feel they are seen as a 'complainer.'

Throughout this report, concern refers to the feedback provided by patients and family members about their healthcare experiences.

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