PATIENT SAFETY FORWARD WITH 4

ENGAGING PATIENTS IN PATIENT SAFETY

A CANADIAN GUIDE

Chapter 2 - Partners at the point of care

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2 Partners at the point of care

"When things go wrong, patients and families need to know what happened. We need to hear the words "I'm sorry" from those involved in the event and, where appropriate, we need to see and hear the organization accept responsibility for their part in the event. When patients and families sense that information is being withheld, we lose trust and we are more anxious, fearful, and angry. We do not expect perfection, but we expect honesty, justice, and shared learning. Disclosing a patient safety incident with honesty, openness, and compassion shows respect for the patient and family. It shows that the organization is worthy of our trust and that the needs of the patient and family are paramount."[1]

Patient safety requires that patients and families partner with providers to prevent patient safety incidents. When these incidents do happen, patients, families, and providers can take actions to protect those involved from further harm, allow them to heal and understand what happened, and to make improvements to the process or system. Rather than blaming or punishing, the goal is to balance and understand care processes and systems that may cause patient safety incidents. How patients, families, and healthcare providers interact at the point of care is central. Everyone involved has a significant opportunity to take individual actions and collaborate to enhance patient safety.

Patient and family experiences and perspectives can help prevent harm and incorporate safety considerations proactively in system design at the point of care. At the core, this chapter answers these questions:

- How can patients and families engage with providers at the point of care to prevent patient safety incidents?
- How are patients and families involved in the response to an incident?

2.1. Partnering in patient safety

Safety at the point of care is everyone's business.[2] This means:

- Patients and families are actively engaged in their own care. They are comfortable asking questions and confident speaking up about their needs, preferences, observations, and ideas about what will improve their care safety and quality. They take responsibility to provide accurate information to their healthcare team, ask questions to understand the information, and help develop and follow the care plan.
- Providers are open to suggestions and comments from patients and families and they openly invite patients to voice concerns and ask questions. If they determine the patient's suggestion enhances safety and can be done, they are quick to adopt it and let the patient know their suggestion is being actioned. If it cannot be adopted, the provider assures the patient their suggestion has been seriously considered, and they describe reasons for not implementing it, leaving the option open to reconsider the idea later.
- Organizations ensure that healthcare teams, including patients and families, have access to reliable resource materials to help them understand how safe care results from patient engagement and partnership behaviours.

Engaging patients can help prevent or reduce patient safety risks by:

- Teaching everyone involved how to identify safety risks and take steps to prevent an incident
- Improving communication between patients and their healthcare providers and among providers on the healthcare team
- Involving families as care team members and encouraging their presence throughout the care journey, according to their wishes

Patients and families are involved in direct care and witness first-hand the precautions to ensure safety. They also have direct experience with how care processes can increase or reduce safety risks or affect the risk severity. They often see solutions and remedies but are commonly not asked for their ideas or to be involved in improvement. Patients and families should be invited and encouraged to provide insights about the way processes influence safety and the care experience (e.g., prescribing and giving medication, transitioning care from one unit to another and to or from home). The information provided by patients and families helps identify safety risks.[3]

Many studies have focused on how patients observe the way that care providers work.[4] Tools have been developed to guide patient observations for activities, such as hand washing,[5,6] medication delivery,[7,8] and patient identification.[9,10]

Patients, families, and providers need support to partner in care through an organizational culture of safety and engagement. Creating a collaborative climate is not easy, but it is important. Patients and families need to feel at ease (psychological safety) to bring up issues or observations that they've made about potential harms. A culture of support and openness can help:

- Minimize fear and anxiety about potential consequences for voicing a concern about safety or reporting a patient safety incident
- Create opportunities for meaningful dialogue about preventing patient safety incidents and identifying solutions that can build safer care systems
- Help foster the expectation that anyone can and should raise awareness about a concern that might adversely affect their care or that of others

To be full partners in care, patients and families need to understand their care plan and be involved in developing it. For example, the It's Safe to Ask campaign improves health literacy, which is a person's ability to find, use, and understand health information. Low health literacy can be a major barrier to patients engaging in their care and can increase patient safety incident risks.[11] The campaign helps patients engage with providers by asking three questions:[12]

1. What is my health problem?
2. What do I need to do?
3. Why do I need to do this?

There are also important challenges engaging patients in identifying risks and patient safety incidents:

- Patients and families do not speak up because they fear it will impact their care or safety or offend providers.
- Patients and families do not know how to bring up these issues with providers in a non-judgemental way.
- Providers are not used to inviting, receiving, and responding to feedback from patients.
- Providers question feedback from people who do not have their medical training and experience.
- Providers feel organizational pressure to increase efficiencies, sometimes at the expense of hearing and understanding patient concerns.

Patients, families, and providers need support to work together and increase their mutual understanding about how to contribute to patient safety. This doesn't happen on its own. Evidence shows that educating and training patients and providers, ideally together, can have positive results in shifting attitudes towards partnership and teamwork:[13,14, 15]

- Patients need to learn how to deliver constructive feedback to providers so that when a patient signals some potentially dangerous behaviour, the healthcare provider does not feel their competency is being questioned.
- Providers need to learn to listen to patients' concerns and build upon them to improve their practice.

While it's impossible to address all patient safety aspects at once, tackling several priorities at a time can make a tremendous difference to patient safety and can help accelerate improvements. It is also important to focus efforts on organizational factors that influence point-of-care interactions. According to this framework for safer, reliable, and effective care, patients and families, along with culture and a learning system, are at the core.

Priority areas for action are based on the most common patient safety incidents that occur and the actions that are most effective in reducing patient safety incidents. Most are required organizational practices included in the Accreditation Canada's Qmentum Program. Patients and families, patient partners, and the public have a role in all of them. The priority areas include:[16,17]

- Medication safety
- Surgical care safety
- Infection prevention and control
- Patient–provider communication

- Patient identity
- Transitions of care
- Family presence

2.2. Partnering in incident management

When a patient safety incident occurs, the patient and family are the immediate priority. Healthcare providers and the organization take immediate action to reduce further harm, and to provide practical and emotional support to the patient and the family. Next, patients and providers partner to figure out what happened and, most importantly, put safety systems in place so it doesn't happen again. As appropriate, the immediate response continues throughout the incident management process to promote healing, recovery, and learning.

By being engaged in this process, patients and families can help identify and generate opportunities to improve safety and reduce patient safety incidents. A patient and family's experience and insights are included in the incident analysis (e.g., through an interview) to help map out the trouble points in the care process and identify potential solutions that would make care safer. Patient partners can play a role as members of an incident review team or committee.

Reporting

Patients and families should also report patient safety incidents (e.g., wrong medication or dose). Information about patient safety incidents reported directly by patients and families is important and can help identify contributing factors. Patients and families may even know about incidents or risk factors that their health providers don't.[18,19]

Healthcare organizations are implementing ways to help patients to report safety incidents, separate from complaints processing. Medication incidents are reported by patients and providers to the Canadian Medication Incident Reporting and Prevention System (CMIRPS). CMIRPS collects and analyzes medication incident reports from patients, the public, providers, and organizations across the country in a standard form to understand what types of incidents are occurring and to inform system changes that will reduce future incidents.

Every organization, province, and territory has its own legislation with expectations for privacy and information-sharing after a patient safety incident resulting in harm, as well as for the public information reporting. This generally includes the degree that patients and families are provided with information after an incident and how they are included in the review of what led up to it.

Organizations welcome care-related compliments and complaints that are managed through a separate (but related) process from incident management. Every healthcare organization has its own complaints resolution process, which should be clear to everyone. The Canadian Patient Safety Institute and Patients Canada also offer guidance to those who may need it.

Disclosure

Patients and families expect and have a right to know when something harmful or potentially harmful has happened to them. Informing them honestly, fully, and in a timely manner is the right thing to do. Patients and families want to understand what happened and share their own experience, including the impact the safety incident has had on them. They also want to provide their own insights about what went wrong, why, and actions that could have prevented it.

Disclosure describes the structured process whereby the provider openly shares information with the patient and their family after a safety incident. Disclosure leads to a dialogue that can last throughout the incident management process.

Disclosure is a Required Organizational Practice which includes:
- ✓ *Documenting the disclosure of patient safety incidents*
- ✓ *Reviewing and updating the disclosure process, if necessary, once per accreditation cycle, with input from patients, families, and team members*
- ✓ *Training on disclosure provided for those responsible*
- ✓ *Communicating throughout the disclosure process with patients and families*

Studies have shown that only 25 to 30% of physicians will disclose a patient safety incident to their patient, and often only after a patient has pressed them for details.[20] There are many barriers that might prevent a healthcare provider from disclosing a patient safety incident, including:[21]

- Lack of knowledge about how and when to disclose
- Concern about causing further distress to the patient or family
- Fear of consequences (e.g., shame and embarrassment, being sued or losing their reputation, loss of or increased cost of liability insurance coverage)
- An organizational or professional culture that advises against or indirectly discourages open disclosure

All healthcare team members, especially physicians (as required by their professional organizations), must disclose a incident. Healthcare organizations should ensure their policies support open, honest disclosure.[22] Some policy statements on disclosure include a commitment to apologize. In the case of a patient safety incident, the apology is about saying, “We are sorry.” The legislation protects the apology given to a patient following a patient safety incident because it cannot be used in a court of law. The expectation is that the apology is accompanied by full disclosure and meets the patient’s and family’s needs for it to be sincere and effective.

Patient partners from Patients for Patient Safety Canada have shaped the *Canadian Disclosure Guidelines*[23] and the *Patient Safety and Incident Management Toolkit*.[24] The *Canadian Disclosure Guidelines* were developed in 2011 to promote a clear and consistent approach to disclosure at the individual level and in healthcare organizations across the country. These guidelines emphasize interprofessional teamwork and a culture that supports learning from patient safety incidents.

Incident analysis

The review process (or incident analysis) to understand what happened and what actions are needed to prevent future similar incidents is an important step in incident management. It is critical for organizations to appropriately respond to and learn from patient safety incidents to make patient safety improvements in care systems.

Patient safety incidents are analyzed to help prevent recurrence and make improvements, with input from clients and families.

Because harmful incidents can have serious consequences for the affected patient and family, the review process can be emotional. Practical and emotional support should be provided to patients, families, and healthcare providers involved in the incident, as well as those active in reviewing the cause and recommending a plan to prevent future harm.

Patients and families are important in incident analysis:

- The patient who experienced harm and their family can shed light on what went wrong by sharing their experience and, if they choose, advocating for changes in the organization.
- An experienced patient partner can offer the patient’s perspective as a member of an incident analysis review team.

Research and practice are revealing powerful reasons for seeking patient and family input, even from patients directly involved in the safety incident, such as the following:

- Patient and family input pushes providers to think about alternative perspectives.
- Patient insights into the circumstances of the incident can shed greater light and lead to a deeper analysis of the underlying cause(s).

- A patient's practical knowledge can provide insights into possible improvements and solutions to prevent further incidents (e.g., "The family advisor came up with the most interesting part of the action plan.").

Leading and emerging practices suggest two ways that patients and families should be involved:

1. In the incident, patients and families are:
    - Informed about what happened and what will be done through the disclosure process
    - Interviewed to inform the incident analysis
    - Kept updated about recommended actions
    - Asked to participate further
2. In incident analysis and management, patient partners:
    - Receive training and information about the incident analysis process
    - Participate on teams that carry out structured incident analysis
    - Participate on a quality and safety committee that oversees monitoring and improvement at the organizational level, including follow-up from incident reviews

2.3. Summary – What you can do

Patients and families

For your safety and the safety of others:

- Get informed, educate yourself, and ask questions.
- Actively participate in your own care and treatment.
- Share information, concerns, and suggestions.
- Work closely with your care providers, especially during care transitions.
- Learn how to reduce infection risks while at home and in the community.

If you or your family member has experienced unanticipated harm:

- Speak up and ask questions about what happened, why, and what will be done about it.
- Seek out the proper way to report the incident.
- Expect an apology and to be informed about next steps.
- Ask for practical or emotional support to cope with the incident.
- Find out where else you can find support if you feel you are not getting the answers you need (e.g., patient complaints or ombudsman office).
- Share ideas, concerns, and suggestions to improve the incident management process.

Providers

To advance patient safety in partnership with patients:

- Ensure patients and families are engaged in their care and feel comfortable voicing concerns and asking questions.
- Educate patients and families about patient safety, especially those dealing with chronic illnesses, and ensure they are engaged.
- Participate in and encourage open sharing and team learning about patient safety risks.
- Listen closely to patients and families, as they are all unique.
- Make sure information is accurate and understood by patients and families.
- Adapt your communication to fit the needs of patients and families.
- Establish collaborative work habits with colleagues and patients and families, especially around leading practices (e.g., bedside shift report, transitions of care).
- Continue to improve your communications skills.

If you are involved in a patient safety incident:

- Follow the organization's procedures, practices, and guidance for reporting, disclosure, and incident management.
- Find out who can support you and seek out practical and emotional support.
- Use the advice and resources offered through your professional organizations and regulatory colleges.

Leaders

- Ensure your organization's policies, processes and resources for patient safety and incident management are used.
- Ask everyone involved in a patient safety incident about their experience and how to prevent it.
- Share patient safety and incident management information across the organization and incorporate improvement ideas into policies, procedures, and training.
- Ensure timely, honest, and transparent communications with patients, families, and providers.
- Visibly value and support patient engagement in patient safety.
- Strive towards a safe and fair culture that is centred on patients and families.

2.4. Practice examples

Patient engagement to prevent harm (Safety alert/Stop the line) – Saskatchewan

Safety Alert/Stop the Line invites patients and expects staff and physicians to be safety inspectors, to identify and fix potentially harmful mistakes in the moment, or to "stop the line" and call for additional help to restore safety. Saskatchewan is implementing this initiative to strengthen the safety culture and make healthcare environments safer for patients, staff, and providers. The initiative includes processes, policies, and behavioral expectations. Research shows that organizations that experience close to zero safety incidents (called high reliability organizations) demonstrate Safety Alert/Stop-the-Line's effectiveness. The goal is to implement Safety Alert/Stop the Line process in all provincial health care environments by March 31, 2019.

The approach is based on everyone taking responsibility for making healthcare settings **SAFER**:

Stop if you see something that is unsafe.
Assess the situation. Ask for support from others, supervisors, or leaders.
Fix the unsafe situation if you can. If you can't, then…
Escalate your concern. Call in help from a team member or leader.
Report unsafe situations, environments, and practices, including both instances of no harm and incidents that have resulted in harm to patients or staff. We can't improve what we don't know about.

Saskatoon Health Region is testing the value a 24/7 call centre to report safety incidents. Similar to 911, this one phone line is used to report all safety incidents and is for everyone's use (patients, families, staff and physician).

For more information about a co-design project that involves patients and staff in identifying safety alerts, including patient and provider stories, watch this Saskatoon Health Region video.

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[2] Shift to Safety. http://www.patientsafetyinstitute.ca/en/About/Programs/shift-to-safety/Pages/public.aspx.

[3] Ibid., Khan et al., 2017.

[4] Le-Abuyen, S., et al. "Patient-as-Observer Approach: An alternative method for hand hygiene auditing in ambulatory care setting." *American Journal of Infection Control* 42 (2014): 439–42.

[5] Public Health Ontario offers this resource to train patients to observe hand washing. https://www.publichealthontario.ca/fr/eRepository/Hand%20Hygiene%20Compliance%20Observation%20and%20Analysis.ppt.

[6] The Canadian Patient Safety Institute offers observation tools for hand hygiene. http://www.patientsafetyinstitute.ca/en/toolsResources/pages/hand-hygiene-observation-tools.aspx.

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[15] Health Quality Ontario's Team Building Resource Guide for Ontario Primary Health Care Teams offers practical advice. Available at http://www.hqontario.ca/Portals/0/documents/qi/pc-team-building-guide-intro-en.pdf.

[16] Canadian Patient Safety Institute. Four Priorities of Patient Safety. http://www.patientsafetyinstitute.ca/en/topic/Pages/default.aspx#MedicationSafety.

[17] Canadian Foundation for Healthcare Improvement. The Power of Partnerships: Patients and Staff Co-designing Bedside Care. Webinar presentation. http://www.cfhi-fcass.ca/sf-docs/default-source/on-call/oncall-sept28-2016-e.pdf?sfvrsn=2

[18] Ibid., Khan, et al., 2017.

[19] Manitoba Institute for Patient Safety. The Facts about Critical Incident Reporting and Disclosure. https://www.gov.mb.ca/health/patientsafety/docs/pamphlet.pdf

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