

ENGAGING PATIENTS IN PATIENT SAFETY

A CANADIAN GUIDE

Patient Engagement Action Team – February 2018



The Engaging Patients in Patient Safety – a Canadian Guide (Guide) was developed by the Canadian Patient Safety Institute, the Atlantic Health Quality and Patient Safety Collaborative, Health Quality Ontario and Patients for Patient Safety Canada in collaboration with an expert Action Team representing 16 organizations who are recognized leaders in patient engagement and patient safety. Click [here](#) to read more.

The Guide together with the complementary resources available at www.patientsafetyinstitute.ca/engagingpatients will be regularly updated and refined as new evidence emerges and new content is developed. Visit and bookmark the page above to ensure you are accessing the most up-to-date version.



1400, 10025 102A Ave
Edmonton, AB T5J 2Z2

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For additional information, to contribute, or to provide feedback please contact: patients@cpsi-icsp.ca

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3. Partners at organizational and system levels

“Putting patients in positions of real power and influence and using their wisdom and experience to identify issues and to inform and re-design care... provides the most important force for driving change and has the greatest potential for achieving long-term transformation in the healthcare system.”¹

Safe care is critical for patients and families, providers, and organizations. To realize improvements in care safety, healthcare organizations and providers need to partner with patients in all aspects of patient safety, from prevention to incident response.

Partnering with patients and families for quality and safety in organizations and systems helps:

- Inform changes to processes and policies that shift to safer, more patient-centred care
- Build structures and processes for safer, better quality care

This chapter offers guidance, tools, and practice examples that support patient and family partners to take on roles in safety and quality, helping organizations prevent, respond to, make improvements, and learn from patient safety incidents.

3.1 Preparing for patient engagement

“It brings us back to the deeper meaning of what we should be doing in a health organization. We talk a lot about our patients and we work for the patients, but now we do things with the patients, and that changes the dynamic.”²

People – roles and responsibilities

Many people may come together to partner in quality and safety improvement processes. Patient partners, specialists, and providers each bring a unique role and perspective, but share responsibility for working together in partnership effectively.

Patient partners

Patients are experts in their illness and care experience. Their experiential knowledge and perspectives are critical in improving quality and safety processes.

Successful patient partners are:³

- Respectful of others and their perspectives
- Comfortable speaking in a group and working with others
- Good listeners
- Able to use their personal experiences constructively, seeing beyond their own experience
- Non-judgmental
- Able to work collaboratively with other patients, families, and healthcare providers
- Interested in expanding their knowledge and skills
- Committed to helping bring about meaningful change

Patient partner: an individual who experienced care in the healthcare system (as a patient, family member or caregiver) and who, as part of a patient group (e.g., patient and family advisory council), engages in shaping decisions, policies and practices at all system levels. Other terms used include advisor, leader, champion.

Patient partner participation can range from sharing personal care experiences to providing feedback and testing materials or processes. They may help determine what went wrong and why and contribute the patient perspective to specific improvement initiatives (e.g., reducing falls in seniors’ homes, improving the discharge process to prevent readmission). Patient partners may participate in any healthcare setting (e.g., local health authority, acute care hospital, long-term care institution, residential home).

Some organizations have a permanent structure to help identify priorities that matter to patients and families and to provide a sounding board for providers who are developing new policies, programs or improvement initiatives. In most settings, these are called patient and family advisory councils (PFACs). In residential settings (e.g., seniors’ homes or long-term care facilities), they’re often called residents’ council or family council.

Roles presented in the following table could be filled by an established advisory council. These permanent councils provide early experience to a family partner and lead to their deeper involvement in quality and safety processes in the organization (e.g., incident analysis, quality and safety committee, quality improvement team). In other cases, patient partners may have not been involved with these types of formal patient engagement structures.

Examples of patient partner roles	
Adapted from Partnering to Improve Quality and Safety: A Framework for Working with Patient and Family Advisors ⁴	
Committee/work group to develop educational and communication materials	<ul style="list-style-type: none"> • Help identify information needs or gaps in existing materials and tools • Co-design content and format of materials • Identify language or materials that are confusing or unhelpful, and determine if materials are well-formatted and helpful • Assist with testing and adjusting the materials • Follow up with other patients to gather their opinions
Incident analysis	<ul style="list-style-type: none"> • Share a personal story to ground the team in the lived experience of the patient and family • Identify pieces of the process that are confusing or missing from a patient and family perspective • Participate in information/data. gathering • Discuss and analyze findings • Assist in developing action plans and recommendations
Discharge planning	<ul style="list-style-type: none"> • Help design new materials • Review the materials and process from the end-user’s (patient’s) perspective • Participate in rounds • Assist in piloting new materials
Quality and safety committee	<ul style="list-style-type: none"> • Bring the patient and family perspective into discussions • Collect feedback from other patients about specific issues (e.g., when outside one’s own experience) • Help interpret and analyze patient experience data • Question the assumptions of practitioners that differ from the patient and family experience
Process improvement teams	<ul style="list-style-type: none"> • Serve on improvement teams with patient safety goals (e.g., engaging patients and staff in identifying safety risks, reducing preventable readmissions, medication incidents, falls and infections) • Review materials related to improvement initiatives • Help test and adjust new quality and safety processes

The following table provides additional examples of patient engagement in primary care practices. These examples were collected from a survey of 37 community health centers as well as from people working in the field.⁵ Some of these examples are also used in other settings as they can be adapted from one healthcare setting to another.

Examples of patient partner roles in primary care practices¹³¹			
Strategy	Description	Advantages	Limitations
Complete patient surveys	One-time surveys given to patients to assess experience of care or components of care delivery	Quick, low cost	Unidirectional, may not capture the right data, limited response
Use the suggestion box	Comment boxes in waiting rooms or exam rooms to collect ideas for practice improvement projects	Ongoing, can help to generate new practice improvement ideas	Typically, low participation, needs upkeep to maintain and collect responses
Be a secret shopper	Patients gather experiential feedback from trial phone calls to clinic or gathering step-by-step feedback on each step of clinic visit	Quick, low cost, can feed into patient experience efforts	Hard to recruit patient volunteers, data may not be representative
Attend a town hall	Large-scale forum to gather community feedback on clinic initiative	Modest cost, if participation is high gains a large pool of feedback, patients can interact/discuss with each other at meeting	One-time feedback, may be challenging to facilitate
Be a partner on a quality improvement (QI) team	Patients are QI or practice improvement team members	Project driven, aligned with clinic QI efforts	Patient is minority among staff, may not feel supported in participating, not necessarily representative feedback
Join providers at conferences/workshops	Patients accompany staff/clinicians to academic or practice-based meetings to share experiences	Provides visibility to patient partners, patients may have unique insights to inform organizational priorities	Limited amount of patient representation, may not have clear follow-up for clinic operational improvements
Become a member of a patient advisory council	Representative group of seven to 15 patients who meet monthly or quarterly to discuss practice improvement	Bi-directional feedback, project driven, can recruit diverse/ representative council, can integrate with QI efforts at the clinic	Time-intensive, higher cost, require staff time, can be hard commitment for patients
Assist in training providers	Patients participate in onboarding and training new clinical staff, particularly in-patient communication	Demonstrates importance of patient perspective to new hires, builds awareness for patient experience of care	Patient partners need support and role clarity within training
Participate in a virtual advisory board/social media opportunity	Use online message boards and social media to collect patient feedback, project-oriented patient working groups that exist for shorter term	Nimble, more action-oriented, may access harder-to-reach patients, such as teens or younger working families	Less tested, some concerns about online security

Patient engagement specialists

Effective partnerships between patient partners, providers, and organizations in safety and improvement initiatives are enabled by patient engagement specialists. Their role is to connect stakeholders, prepare them to work together, provide expertise, knowledge, and tools to do the work, and help them learn from the experience.

Specialists should know the principles of patient and family-centred care, and have engagement methods, tools, and skills to coach patients, families, and providers to work together effectively.

Patient engagement specialists or staff:⁶

- Are friendly and welcoming
- Believe in the importance of the patient perspective
- Understand meaningful engagement
- Are transparent and open
- Listen and communicate well
- Know how to build trusting relationships
- Demonstrate patience and persistence
- Are creative and flexible
- Collaborate
- Provide strategic leadership by linking patient engagement with the program or organization

Depending on the organization’s experience, patient engagement specialists have different titles and may do the work as part of other responsibilities (see the following table). Some organizations have hired patients and families to help carry out patient engagement activities.

Examples of staff responsible for patient engagement	
Dedicated staff position	Support as part of broader staff role
<ul style="list-style-type: none"> • Patient engagement specialist • Patient partnership program coordinator • Patient and family-centred care coordinator • Patient engagement advisor • Patient experience lead • Client and community relations coordinator 	<ul style="list-style-type: none"> • Staff liaison: links patient and family advisory council with the organization • Administrator (in smaller organizations): provides support to a patient council

Patient engagement specialists also connect with patient safety and quality improvement specialists. To succeed, they should have formal and informal linkages (e.g., both are part of the same team, attend meetings) with providers and leaders who support quality and safety improvement processes.

Quality improvement specialists:

- Have complementary methods and tools to help teams work collaboratively to identify patient safety improvement areas, explore, test, and implement solutions to build safer care processes
- Know where to find evidence-based best practices that have been shown to improve safety and quality of care
- Connect with communities of practice that are trying out new approaches and sharing what they have learned

Patient engagement specialists and quality and safety improvement specialists can work together to:

- Recruit and prepare patient partners and staff to participate meaningfully
- Define respective roles in the improvement initiative
- Support team collaboration and ensure that the process and result are influenced by the contributions of patients, families, and providers
- Share initiative results

Providers (clinicians, non-clinicians, clinical leads)

Providers who partner with patients in quality are change agents in the organization. They may be leaders (clinical leads), clinicians, or non-clinicians on a team or supporting the effort.

Clinicians (e.g., physicians, nurses, rehabilitation therapists) offer:

- Medical knowledge and experience
- An understanding of how care processes work within the broader organization's care system
- Information about clinical guidelines and best practices
- Knowledge of the constraints on care delivery (e.g., ethical and professional practice requirements, costs associated with equipment, human resources)
- Access to leaders in the organization to mobilize support for testing new solutions and implementing successful changes

Non-clinicians (e.g., administrative staff, managers, support personnel like housekeeping and porters) offer unique perspectives that are eye-opening and invaluable in redesigning safer care processes. They may participate in quality and safety improvement processes, particularly when changes relate to how information is recorded and shared among:

- Care team providers
- Different departments
- Different healthcare organizations across the continuum of care

Some providers are partnering with patients and families to make improvements and champion patient engagement. They share how patients have brought new knowledge about how the care processes work and feel for them, not just how they are supposed to work. Patients and families may bring new solutions that clinicians haven't considered to make care processes safer and deliver more patient and family-centred care. Through dialogue, everyone can learn about the concerns and develop a mutual understanding.⁷

Providers partnering with patients and families:⁸

- Believe the patient and family perspective matters
- Contribute to creating a trusting space for open and honest discussion
- Are respectful and non-judgmental
- Communicate with all members of the team or committee as equals and use common terms (clarifying medical terms when needed)
- Seek out, value, listen to, and explore everyone's ideas and perspectives
- Are aware of how others perceive their communication style
- Bring a collaborative, problem-solving spirit that invites new ways of working together and understanding issues



Leadership has responsibility to ensure education and training are provided throughout the organization to promote and enhance a culture of client- and family-centred care.

Patient engagement in safety and quality is still not common in every organization. One of the challenges is the readiness of providers to partner which is shaped by their perception of the value of patient engagement. [The Readiness to Partner](#) tool is an example of a resource to assess providers' capacity to partner with patients and to identify actions for improvement.

Planning for partnership

Meaningful patient engagement does not happen on its own; it needs to be carefully planned. Planning is more effective when patient partners are engaged at the beginning of the process, even when it feels a bit messy.

Partnering involves using methods and tools from different domains (e.g., patient engagement, quality improvement, project planning, communications) to:

- Clarify purpose
- Choose the methods for engagement
- Recruitment and orientation
- Preparation and support

Purpose clarity

Effective engagement begins with purpose clarity. Knowing why you are engaging people and what you hope to achieve is critical for developing clear partnership expectations. To achieve clarity:

- Describe the purpose of the partnership to ensure that everyone involved, now and in the future, has a shared understanding of the goals. At this stage, avoid pre-determining solutions and seek clarity about the problems to address and desired benefits, incorporating all perspectives. For example, are you:
 - Identifying or implementing better ways to track and monitor patient safety incidents?
 - Developing or improving a process to identify safety risks and to reduce the likelihood they will occur?
 - Responding to and understanding what happened after an incident and to identify solutions?
 - Proactively taking steps to improve a policy, care process, or system to make it safer?
 - Changing culture, attitudes, and behaviours to improve safety?
- Articulate your commitment to partner meaningfully to avoid setting false expectations:
 - Make patient partners feel welcomed and that their participation is valued as necessary and useful
 - Invite honest feedback and input about programs and services that patients and families have used or continue to use.
 - Support providers to listen with curiosity and compassion
 - Incorporate patient partner input and ideas into project developments and final decisions about programs and services
- Identify measures early on to help monitor engagement and work progress and outcomes

Choosing engagement methods

Patient engagement may look different, depending on engagement reasons and goals. Involve patient partners early in engagement activity or project planning to help ensure success. The purpose and people will help with selecting the right engagement methods (e.g., survey, focus group, committee member) and level (e.g., inform, consult, collaborate).

Each engagement method has its benefits. Different methods can be used at different stages, depending on the setting, time available, skills, and budget. Using multiple patient engagement methods and creatively adapting them to the context helps ensure perspective diversity.

Patient partners engage in safety and quality in different ways, including one-way input to share their lived experience (e.g., through sharing stories, being interviewed, or completing a survey). In many cases, patient partners are equal partners on teams or committees to co-design care with providers.⁹

Learn about peoples' expectations, interests, and influence in relation to the purpose. Stakeholder engagement tools help map out this information and determine the right level of engagement for the right people.¹⁰

Recruitment and orientation of patient partners

A structured process for recruiting and orienting patients to the patient partner roles includes:

- Inviting the patient partner to complete an application form. The form collects basic demographic and experience data, and asks about their main motivations for becoming a patient partner
- Conducting an in-person or telephone interview to assess fit for the patient partner interests, their availability, and organizational requirements
- Completing organizational requirements (e.g., signing a confidentiality agreement or a police record check)
- Matching the new patient partner with an experienced partner for mentoring or coaching
- Orienting the new patient partner. Some topics that might be covered include the patient partner role, the organization's approach to improving safety and quality, and the history of the team or committee.
- Providing training on specific skills that will help them succeed (e.g., storytelling)

Strengthen recruitment efforts by engaging patient partners who can:

- Provide input into the role description
- Help identify where to find potential participants and the best methods
- Make presentations at patient and family groups to explain the opportunity and encourage people to get involved
- Reach out in their own networks.
- Answer questions for people who may be interested but want to hear first-hand from someone who has been involved

Aim for diversity and inclusion¹¹

- For patient engagement to be effective in shaping healthcare service design and delivery, those involved need to reflect the diverse lived experience of the people the organization serves and the broader community.
- Providers need to deliver culturally appropriate healthcare and be sensitive to social, language, and cultural differences and preferences. Social and cultural background affects a patient's care experience in many ways, including ways that can impact patient safety.
- To increase diversity, consider the following characteristics:
 - Age, sex/gender, income variety, education, differing neighbourhoods, and/or disability
 - Languages, ethno-racial communities, and cultures
 - Lifespan perspectives (e.g., elderly vs. young family)
 - Family structures and roles (e.g., single, married, caregiver, friend).
 - Different experiences with health issues and healthcare
- Consider barriers that different groups may have to participating:
 - Avoid recruiting only those with certain capacity, skills, and experience (e.g., being articulate, well educated, able to represent others from their group)¹²
 - Use different outreach and engagement methods to include those who are not typically involved or are more vulnerable or marginalized.

To learn more about why diversity matters, kinds of diversity, removing barriers to participation, tips and tools for reaching out, and case examples, see Health Quality Ontario's [Recruiting for Diversity](#).

Providers, leaders, sponsored groups (e.g., cancer survivor support group, online forum for new mothers), organizational web pages, newsletters, and social media posts can all help with outreach.

The [Alberta Health Services Patient Engagement Toolkit](#) includes a self-assessment tool to help potential patient partners think through their strengths, attitudes, and other practical interview considerations (e.g., who should be involved, how to set up the interview, sample questions). Be sensitive to when individuals may not be ready for patient partner roles (e.g., individuals who have experienced harm and may be at risk for being re-traumatized).

Building capacity for partnership can shape an organization's culture. To do this, include patient engagement, patient and family-centred care, and their link to quality and patient safety in orientation programs.¹³ Experience shows that it is essential to train everyone involved to partner effectively.

The University of Montreal trains patient partners and providers to collaborate on quality improvement initiatives. The training is co-led by a patient and provider and focuses on building the competencies needed for effective patient partnership and collaboration, such as:¹⁴

- Understanding roles and responsibilities
- Developing shared goals
- Organizing effective meetings
- Communicating effectively
- Leading collaboratively
- Evaluating the partnership together

Preparation and support for patient engagement in patient safety

Selecting patient partners for patient safety initiatives begins with clearly describing the required skills and experience.¹⁵ This is done by the people leading the initiative, team, committee, or those designated to bring patient partners on board. Whenever possible, look for patient partners with program, service, or care-process experience. Provide them with clear expectations, participation benefits, available supports, and a primary contact.

Established patient and family advisory councils are usually the first place to look for patient partners, but they might not include members with the required skills and experience. You may need to look elsewhere, which also helps overcome the tendency to work with the same experienced patient partners on multiple projects. Patient partners may burn out and diversity is always beneficial.

Preparing patient partners

To ensuring a good fit between patient partners and an engagement opportunity:

- Clarify the background, experience, and/or skills needed to participate
- Specify the type and extent of participation (e.g., tasks, expected contribution, duration, location, other stakeholders involved)
- Develop a recruitment strategy and provide training and orientation. Consider:
 - Do people need to have personally experienced a health condition, specific care process, program, or unit?

- Could the participation cause harm? (e.g., Will the incident analysis trigger difficult memories or emotions?)
- Do people need specific experience, skills, or training to participate meaningfully? (e.g., knowing how to reflect on their own experience and think about what it means for improving care processes or systems).
- What diversity will accurately reflect the people affected by the care process, program, or service?

Checklist: preparing patient partners for work on committees, workgroups, and teams¹⁶	
Information to share	Topics to cover
Terms of reference	<ul style="list-style-type: none"> • Purpose • Goals and objectives • Duration (if not an ongoing committee, work group, or team) • Frequency of meetings • Confidentiality
Decision-making	<ul style="list-style-type: none"> • Process for setting the agenda • How decisions are made (e.g., rules, voting, consensus)
Membership	<ul style="list-style-type: none"> • List of members and their background • Roles and responsibilities (e.g., who chairs the meeting)
Background	<ul style="list-style-type: none"> • Accomplishments to date • Barriers • Record/minutes of recent meeting(s)
Progress	<ul style="list-style-type: none"> • Upcoming agenda items • Success measures • Any priority shifts • Strategic objectives
Background information	<ul style="list-style-type: none"> • Current research • Relevant policies and protocols

Handbooks help orient patient partners to their role, with tips on:

- How to prepare to participate in meetings
- Using their voice effectively to make change
- The difference between debate and dialogue
- Understanding the dimensions of patient experience

Depending on the patient partner’s role, clarify when [sharing a personal story](#) is appropriate and helpful and when they need to move beyond it to focus on and provide input into the improvement work’s goal. Participating on a quality and safety improvement team or committee is unique from other patient partner roles and requires additional preparation and support for patient partners. (See the following table.)

Preparing for the partner role on a quality and safety improvement team or committee¹⁷
<ul style="list-style-type: none"> • Explain jargon or acronyms commonly used by the team or committee and encourage patient partners to speak-up when they do not understand • Prepare patient partners for the clinical manner in which providers may discuss patients or disease progression. It may seem harsh or insensitive. • Check-in early and often to find out how patient partners are reacting to what they are hearing • Provide general training on quality improvement methods and explain the organization’s specific approach. Mention current quality and safety issues and priorities in the organization. Having some background will help the patient partner become an active member of the team. <p>Consider also:</p>

Preparing for the partner role on a quality and safety improvement team or committee¹⁷
<ul style="list-style-type: none"> • Having patient partners participate in the same training that staff receive • Creating basic training tailored to patient partners and their role • Identifying a mentor or coach who can help prepare and support the patient partner. This could be another provider on the team or committee, a quality improvement specialist or coach, or an experienced patient partner.

Preparing providers and leaders

As patient engagement on teams or committees becomes more common, providers and leaders also need to prepare for their role. The following table offers guidance for leaders and others supporting providers in the partnership.

Preparing providers to work with patient partners¹⁸	
Consideration	Description
Link patient partner involvement to specific goals and objectives	<ul style="list-style-type: none"> • Identify how patient partners have contributed to the objectives of the committee, work group, or team • Show that patient partners are valued as integral members
Provide opportunities for staff members to ask questions, express concerns, and give feedback	<ul style="list-style-type: none"> • Concerns might be about: <ul style="list-style-type: none"> ○ Health information privacy and confidentiality ○ Fit and culture ○ Impact on existing work processes • Keep communication channels open to: <ul style="list-style-type: none"> ○ Catch any concerns early in the process ○ Build a culture of transparency and acceptance
Provide a mechanism for ongoing feedback	<ul style="list-style-type: none"> • Periodically check in with staff members to: <ul style="list-style-type: none"> ○ Evaluate how the partnership is working ○ Address any barriers as necessary (typically done by committee chair)

Providers should engage with patient partners as equal members of the safety and improvement team or committee. Providers might consider them “honoured guests” and give them special treatment. Instead, patient partners should receive the same professional treatment and expectations as any other team or committee member. Remembering that a patient partner is a full member of the team leads to a more successful partnership.

Team or committee members should be reminded that this is a unique and, for some, a new experience:

- Patient partners may need to time to feel comfortable. All members should understand each other’s perspectives and experiences (e.g., harm event or other bad experience) to partner effectively.
- Providers might need more information about the benefits of including the patient and family perspective and how the process worked for other teams or organizations. Share information in advance about the patient partner’s background, their training and experience, and about the team or committee members.
- Being explicit about ground rules may help reduce defensiveness and allow members to truly listen to understand one another’s experiences. These can be established ahead of time or as part of the group’s process.

For team or committee chairs or clinical leads, create supportive, positive, constructive working relationships through:

- Briefing the patient partner before and after meetings to share information, answer questions, and

- check in on any hesitations or concerns
- Keeping patient partners informed
- Inviting input from everyone, ensuring that partners have a structured opportunity to share their perspectives and ideas

Ensure information privacy and confidentiality, which is a common concern for providers, through:

- Providing patient partners with the same training on these issues as other members of the team or committee
- Creating guidelines for information-sharing and confidentiality
- Taking steps to de-identify sensitive information when appropriate
- Real-time reminders (e.g., at the end of each email)

Other best practices for supporting partnerships on teams or committees include:

- Including two to three patient partners
- Identifying a primary contact to help prepare and stay informed
- Providing different ways to participate (e.g., virtual, in-person, in writing)
- Paying attention to logistics and practical support (e.g., meeting times, location, expenses)
- Offering a mentor for new patient partners and working with them to identify training and support needs, including emotional support
- Bringing patient and family stories of their care journey into discussions about safety and quality.¹⁹ When meetings open with a patient experience, it helps to:
 - Ground discussion in this critical truth—that care safety and quality has a very personal and very direct impact on patients and families
 - Motivate members to find solutions and make changes
 - Unearth the contributing factors for the problem and the specific points in care where solutions are needed to improve safety and quality²⁰

3.2 Partnering in patient safety

“‘First do no harm.’ This principle remains central to the provision of high-quality healthcare. The mission to make care safer unites professionals and patients alike, and safety is a key component of any quality initiative.”²¹

Patient partners are linked to the following two safety and quality processes:²²

- Patient safety management: The actions that help to proactively anticipate patient safety incidents and prevent them from occurring. These include managing patient safety risks, co-designing and testing safety solutions, and quality improvement processes. Patient safety incident reporting, quality and safety committees, monitoring and reporting on safety and quality outcomes and quality improvement initiatives all work together as part of a learning system.
- Incident management: The actions that follow patient safety incidents (e.g., near misses), including immediate response, disclosure, incident analysis, implementing actions to reduce risk of recurrence, and sharing learning.

Patient engagement in patient safety and incident management needs to move beyond pilot projects to a more strategic approach²³ and be structured into an organization’s quality and project management processes.²⁴

Patient engagement in patient safety

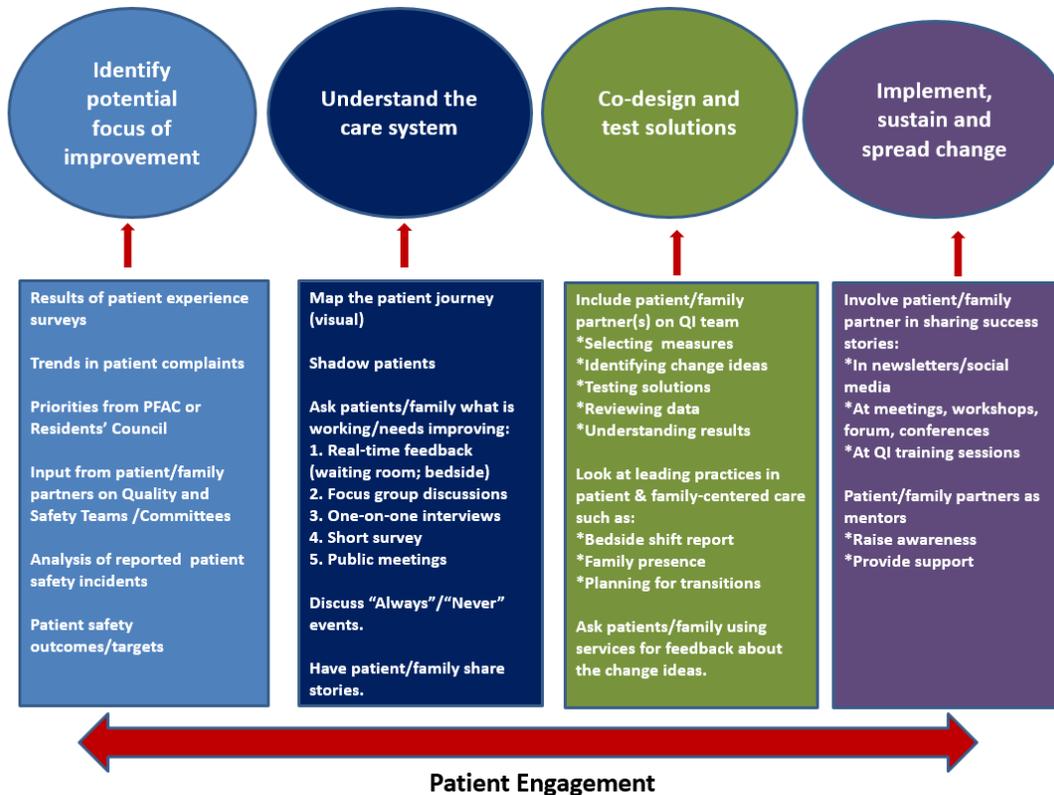
Patient engagement in preventing harm and maintaining care safety:²⁵

- Provides insights and ideas for quality improvement efforts
- Challenges assumptions
- Improves communication between patients and providers
- Motivates providers to make changes by seeing them from the patients’ perspectives
- Ensures that patients are full participants in decisions that affect them
- Empowers patients to become active partners in their own health care
- Results in meaningful changes to healthcare services

Patient partners²⁶ help prioritize, develop, and review organization-wide [quality and safety plans](#) by:

- Participating on the quality and safety committee responsible for developing the plans and reports to the board
- Providing input into plan development through the patient and family advisory council or another patient group
- Reviewing the plan’s progress reports and providing guidance on reaching the targets or new priorities
- Participating in focus groups or town hall meetings to provide feedback on the plans
- Getting involved in planning and implementing the quality improvement and change activities described in the plan

The following figure (adapted from Alberta Health Services and Health Quality Ontario) summarizes the steps in the quality improvement process with ideas for patient engagement.



Identify potential focus for improvement

Areas for patient safety improvement can be identified by examining existing patient or family input, including:

- Patient complaints data
- Patient experience surveys
- Incident reports that include reports from patients
- Incident analysis findings
- Quality and safety improvement plans

If required, engaging patient partners helps gather more information about designing effective tools and processes, outreach, collecting information, and compiling results through:

- Real-time feedback at the point of care (e.g., waiting room, bedside rounds, at discharge)
- Focus groups or town hall meetings
- One-on-one interviews
- On-line patient forums
- Meetings with the patient and family advisory council (or local equivalent)
- Strategic planning meetings where patients, families, and providers provide feedback to better deepen understand challenges and improvement opportunities

Organizational [self-assessment tools](#), completed by both providers and patients, can help evaluate patient engagement in direct care, and key influence on patient safety.²⁷ Remember to consider diversity in all efforts.

Patient partners who help identify potential improvement focus areas may not be the same people engaged in other steps. This is a good opportunity for those interested in participating in other steps of the improvement process (e.g., understanding the system of care or being involved in co-designing and testing solutions).

Understanding the care system

Early in the improvement process, develop a good understanding of what works and what doesn't in the full care journey²⁸. Ways to engage patients include:

- Helping create a visual map of the patient journey
- Providing real-time feedback about the experience of care (e.g., in the waiting room, at the bedside)
- Participating in focus group discussions, one-on-one interviews, or public meetings.
- Completing a survey (e.g., paper, on-line)
- Sharing patient and family stories with the improvement team or committee

Patient partners together with the improvement team set goals and measures that are meaningful to patients and will impact care outcomes. The [Picker Institute](#) in Europe identified these dimensions of quality that are important to patients and families and that can impact the safety of their care:²⁹

- Relationships and communication:
 - Involvement in decisions/respect for preferences
 - Clear information and support for self-care
 - Emotional support, empathy, respect
- The healthcare service/system:

- Fast access to reliable healthcare service
- Effective treatment by trusted professionals
- Attention to physical and environmental needs
- Involvement of and support for family/caregivers
- Continuity of care and smooth transitions

Co-designing and testing ideas and solutions

Engage patient partners and others who can provide useful input into possible change ideas, including:³⁰

- Brainstorming change ideas to provide a useful perspective on what change matters most. Often patient suggestions are the ‘low-hanging fruit’.
- Asking patients who have had difficult experiences in the system or who have experienced harm about what could be done to avoid the problems in the future.

Respect patients’ perspectives and communicate if suggestions are not within the scope of the project or are not feasible. Solutions should consider leading practices in patient and family-centred care that improve safety and quality of care (e.g., bedside shift reports, family presence policies, and patient engagement in planning for transitions).

When testing changes, ask patients and families currently using services for feedback about the change ideas. After they are implemented, seek out feedback on how the changes are making a difference to the experience of care.

There are synergies between patient engagement and quality improvement approaches. Patient engagement and quality improvement specialists can work together to bring the experiences of patients and family into improvement processes and increase the potential for success.

Combining quality improvement tools and science with the art of purposeful, meaningful patient engagement is optimal. Sometimes engagement methods or tools can be built into the quality improvement process to fill gaps (e.g., using video to increase understanding of vulnerable people, such as elders, palliative patients, and those with multiple chronic conditions who are not well represented in focus groups and advisory councils.³¹

Experience-based co-design (EBCD) connects providers, patients, and families to collaborate, identify, and implement improvement projects. This is preceded by a careful process to capture and understand the experiences of patients and front-line providers.^{32,33} Specific EBCD tools include:

- Interviews: individual interviews with patients, families, and staff to capture care experiences
- Touchpoints and emotion map: emotionally significant moments during patient care journeys depicted visually using an “emotion map”
- Video: clips from patient and family interviews that depict collective experiences for a specific care process and highlight emerging themes
- Feedback events: individual group or joint events held with staff, patients, and families to deepen understanding of care experiences and identify improvement areas
- Co-design events: meetings with patients, families, and staff to develop solutions to the problems identified during the feedback events
- Surveys: EBCD participants surveyed after events to monitor engagement quality and processes and capture insights that may not have emerged during group activities.

Implementing, sustaining, and spreading change

Change management approaches that reach both the rational brain and the emotional brain³⁴ can help increase the likelihood that providers and patients will change behaviours. Patient partners help implement, sustain, and spread successful changes within the healthcare organization and more broadly. To do so, involve patient partners in sharing success stories of improvements in safety (e.g., through newsletters, social media, by co-presenting at meetings, workshops, conferences, and at QI training sessions). Patient partners can:

- Make an emotional connection through stories and examples
- Help providers overcome barriers to adopting changes
- Serve as mentors
- Help raise awareness about the changes
- Motivate and support all involved
- Guide other patient partners who are new to improvement processes

3.3 Partnering in incident management

This section focuses on the opportunities for patient engagement in patient safety incident reporting, incident analysis, and quality improvement processes.

Reporting

There is emerging evidence³¹ that patients can recognize patient safety risks and incidents, some of which are not otherwise identified by existing monitoring systems. They are also willing and able to report this information reliably. It enables healthcare organizations to detect systemic problems in care³⁵ and identify priorities for safety and quality improvements.



A patient safety incident management system is developed, reviewed, and updated with input from clients, families, and team members, and includes processes to report, analyze, recommend actions, and monitor improvement.

Patients and families are partnering to identify safety risks and concerns in different ways, such as:

- [Saskatchewan's Stop-the-Line](#), where patients and providers can alert of a safety risk or incident in real-time
- The Canadian Institute for Healthcare Improvement's [National System for Reporting Medication Incidents](#)
- Complaints reporting systems unique to each healthcare organizations

Patient safety incident reporting is still an emerging area for patient engagement.³⁶ Most incident reporting systems are not set up to include or are not accessible to patients so they can report (e.g., a hard-to-access technical database). Some incident reporting systems are set up specifically for patients. One hospital in the U.S. asked patients to give feedback about the same patient safety incidents as providers reported. The additional information from patients helped identify preventive solutions to build safer care.³⁷

Patient partners can work with providers to design and test new methods that engage patients and family in incident reporting. Schneider recently tested a new system-level approach that allows patients and families to report observed safety risks and concerns, patient safety incidents, and near misses online or over a toll-free phone number to a real person.³⁸ Patient partners helped design the system by providing feedback on the incident reporting forms through focus groups and individual interviews, and testing the final form.

Incident analysis

“The first thing said and something I will never forget is that the purpose of [the incident analysis] was not to see how the person may have failed the system but how did the system failed the person. That philosophy stuck with me and it was so inspiring and encouraging. The beauty of the [analysis] is that it is very structured and it’s said over and over again that we are not looking at the individual *person*, we are *looking at what failed in the system*.”³⁹

- “In the last 12 months, Seattle Children’s Hospital has shifted its expectation from asking ‘Should we involve a parent in this Serious Safety Event?’ to ‘Why wouldn’t we involve a parent in this Serious Safety Event?’ This has presented a major culture shift at Seattle Children’s with providers, leaders, and families. ... We did get initially, and sometimes still, some push back about involving [patient family advisors] at the table. The feedback we get is that it’s just one [patient family advisor]... but sometimes it’s just one doctor or one nurse. Having a [patient family

advisor] at the table is just like having any other discipline at the table... it is a [patient or family member] who is well-informed, supported and educated about how to be at that table.”⁴⁰

Incident analysis is part of responding to a patient safety incident that resulted or could have resulted in harm. Other terms used for harmful patient safety incidents include “critical incident” and “adverse event.” Incident analysis^{41,42,43} is a structured, objective process that aims to determine:

- What happened?
- How and why it happened?
- What can be done to reduce the likelihood of recurrence and make care safer?
- What was learned?

The process:

- Is guided by thorough information gathered about the incident and best practices for the care processes related to the incident
- Focuses on understanding what went wrong in the system (system failure) rather than on placing blame on an individual involved in the incident
- Helps with understanding the whole care system that contributed to the incident, and the human factors (e.g., peoples’ behaviours, abilities, limitations, and their relationship to the physical organization and cultural work environment). Understanding human factors helps improve technology design, processes, and work systems to be safer, efficient, and effective.
- Results in recommended actions to strengthen safety of systems and care processes, which may result in specific safety improvement initiatives

Because harmful incidents may have serious consequences for the patient and family, the review process can be emotional. Take care to provide practical and emotional support to patients, families, and healthcare providers as well as those reviewing the case and recommending a plan to prevent future harm.

How are patients and family engaged in incident analysis?

After a patient safety incident occurs, gather initial information to determine the actions that should be taken to understand what happened and to develop recommendations to prevent a future similar incident.

For an incident where a patient has experienced serious harm, conduct a formal incident analysis process that involves a review team. The specific method used to analyze the incident, and patient and family involvement varies among healthcare organizations.

The patient and family directly affected by the incident should receive information through the disclosure process, an incident analysis interview, and through updates about follow-up actions. They may also choose to be more involved in organizational change for their own healing journey.

Etchegaray et al.⁴⁴ found that patients and families are somewhat aware about what contributed to their incidents. Out of 72 people interviewed, all could identify at least one factor that contributed to the incident and, on average, people identified three to four factors. The most frequently mentioned factors were:

- Provider qualifications/knowledge (79 per cent)
- Safety policies/procedures (74 per cent)
- Communication (64 per cent)

Patients and families identified these factors from their own personal observations (32 per cent), personal reasoning (11 per cent), personal research (seven per cent), record review (either their own medical records or reports they received in their own investigation) (six per cent), and being told by a physician (five per cent). They were also able to provide suggested actions to address each of the contributing factors. Most people in the study were not involved in the incident analysis process, so vital information may have been missed. The study concluded that healthcare organizations should interview patients and families about the event that harmed them to help ensure a full understanding of the causes of the event.

In Alberta, patients and families are involved in two steps of patient safety incident reviews:⁴⁵

- Interviewed at the information-gathering stage to gain their understanding of the incident's cause, what could have prevented it, and any actions they think the organization should take to improve the safety of the system
- Invited to review draft recommendations for feedback and refinement

Patient partners can be involved in helping the organization learn and improve after patient safety incidents by:

- Bringing the patient voice to an organizational safety and quality committee responsible for policies and processes to monitor and improve safety and quality
- Participating on quality improvement teams that design and test improvements to improve safety of care processes

Involving patient partners in incident analysis is a specialized and emerging practice.⁴⁶ It requires training for the patient partner and the team or committee. Patient partners bring a unique and valuable perspective, especially in identifying areas where things went wrong and opportunities to improve.⁴⁷

Incident analysis teams typically have four to six members, including providers with expertise in the related care process and people from different levels of the organization. Do not include people who were directly involved in the incident, but interview them for information—both patients and their families, and providers.

Organizations should gain experience engaging patient partners in other ways before bringing them into a complex, sensitive process, such as incident analysis. Demonstrating positive results from other patient engagements will help create a supportive culture with the trust needed to bring a patient partner to the incident review table.

Select the patient partner and prepare, train, and support them to participate on the incident review team. As with any member of the review team, the patient partner should sign a confidentiality agreement and keep sensitive information private. Overcome challenges with sending confidential information over e-mail by communicating verbally with the patient partner before meetings and providing them with written information to review on-site before and during meetings.

Developing a strong analysis team

Incident analysis involves very confidential, sensitive, and often legally protected information. It is an emotionally charged situation, where feelings of shame, embarrassment, and fear can risk harming the participants. For these reasons, building trust is imperative. Strategies include:

- Providing opportunities for providers and the patient partner to talk to each other about their hopes and concerns about participating on the team

- Being clear that the organization has a just culture and that incident review is focused on understanding “how the system failed the person, not how the person failed the system.” A just culture balances two factors: understanding system failure, and the responsibility and accountability of providers delivering care.
- Approaching patient engagement in analysis incrementally:
 - Decide how you will measure success of the partnership in incident analysis
 - Begin with one experienced patient partner who is well trained, well informed, and well supported to participate
 - Start with a simpler incident review
 - Test out the process
 - Review together and assess success. What worked well and what could be improved?
 - Build on success slowly, training a small number of experienced patient partners to participate to build relationships and ensure consistency
 - Support experienced patient partners to mentor newer patient partners
 - Create opportunities for patient partners to come together to support each other and share learnings

Concerns of staff/providers about involving a parent in incident analysis⁴⁸	
Concerns from providers	Response from patient partners
<p>What if the patient or family member (e.g., child) is still receiving care in the area being discussed? Won't that destroy the trust they have in the organization or service?</p> <p>What if it hits too close to home for the patient partner? We don't want to make things harder for them.</p> <p>What if they feel scared it could happen to them or their family member?</p>	<ul style="list-style-type: none"> • “Makes me feel more secure and trusting because it takes a lot to admit fault.” • “Builds more trust because things you would think the hospital doesn't notice... you see that they do notice them.” • “A lot of patients and families don't realize how much respect the provider has for them.” • “I trust them more, ten-fold.” • “I now feel less intimidated when I come in for her care.” • “It didn't change my trust because what came to the forefront was the dedication of everyone in the room to face the hard issues... to find out why this happened and not just try to grasp something simple or easy to fix and hold it up as the cause.”

Experienced patient partners and providers will more likely have the skills needed to participate in a patient safety incident analysis because they:

- Are confident speaking up in groups that include figures of authority (e.g., leader, director of a clinical area)
- Have insight into their own emotional triggers and the emotional responses of others (e.g., discussing the details of an incident of harm can be distressing to all involved)
- Are comfortable with technical discussions

While it is useful for the patient partner to have had some personal experience with the procedures/diagnoses for the incident, don't involve someone “too close to home.” Have an open conversation with the potential patient partner about the risks and benefits to arrive at the best decision.

Orient patient partners to a patient safety incident analysis team:

- Ensure experienced patient partners are well-briefed and well-prepared before the first review meeting
- Share the following information in advance:
 - The method for the incident analysis

- Common and likely patient safety and medical terms
- Analysis scope, including any concepts or best practices that may help understand what led to the incident and what actions could be taken to prevent a future similar incident
- Areas where the patient or family perspective is most needed
- Potentially contentious discussions areas and conflicting opinions
- Debrief the patient partner after participation to provide emotional support, appreciate their work, and learn how to improve the process
- Debrief the incident review team with a follow-up survey to the team leader or through a follow-up discussion with the team leader or full team (see the following table for possible questions)

Kalbach et al. recommend the following debrief questions after incident analysis⁴⁹	
Patient family advisor	Incident analysis team (lead or full team)
<ul style="list-style-type: none"> ● What was it like for you to be involved? ● How did you feel about your contribution? ● Do you have questions or are you confused about anything you heard? ● Were details discussed that were difficult for you to hear/process? (emotional impact of involvement) 	<ul style="list-style-type: none"> ● How did the patient partner’s participation impact the outcome? ● Are there ways we can better prepare patient partners for involvement? ● Are there ways we can better prepare staff/providers for involving a patient partner?

Learning from patient engagement at organizational level

Partnership requires regular check-ins to assess what is working well and what needs to be improved. Sometimes obvious tension points need to be addressed to prevent them from getting in the way of the improvement work. As a safety or quality plan or project wraps up, set aside time to evaluate the experience of working together. Do this through dialogue, exit interviews, or structured feedback surveys. Use lessons learned from the evaluation to strengthen partnerships in the future.

Questions to assess the patient partner engagement in improvement⁵⁰
<ul style="list-style-type: none"> ● How at ease did you feel by joining the team? <ul style="list-style-type: none"> ○ What was your experience of welcome by the team (respect, language, fairness, and understanding)? ○ Have you felt like a full member of the team? ○ Were you comfortable communicating your ideas and perspectives? ○ To what extent did you feel that your ideas and perspectives were considered by other team members? ● What most helped your participation in the team? <ul style="list-style-type: none"> ○ Did you receive support from anyone to help you participate (e.g., staff person, coach, experience patient partner)? How did they help? ○ What other support would have been helpful? ● What do you most appreciate about your contribution? ● To what extent did the objectives of the initiative address the needs of patients and family? What do you think are the greatest impacts that the work may have on patients and family? ● In your opinion, what did you bring to the team/to the improvement process? ● How did you personally benefit from participating? What skills did you gain? ● How did your participation benefit the organization? ● What is your overall satisfaction with your involvement on the team? ● What are the greatest challenges/obstacles to involving patient partners in these quality improvement processes?

3.4 Summary – what you can do

Patient partners

- Find out how to participate in quality and patient safety work. If no opportunities exist or match your interests, provide this feedback.
- Reflect and be honest about your motivations for becoming a patient and family partner (e.g., to help prevent harm and improve experiences or to resolve a contentious issue).
- Learn how to become an effective patient partner and ask how the organization will support you in your role (e.g., expense reimbursement, training, resources, emotional support).
- Get clarity about your role, expectations, and the purpose of the work.
- Ask about or suggest ways to bring in more patient perspectives if you are not sure the topic is felt or experienced more broadly (e.g., surveys or interviews with other patients and families).
- Clarify unfamiliar language and terms used by quality team or committee members.
- Ask about the organization's quality and safety frameworks and become familiar with the basic concepts, tools, training, and mentorship opportunities.
- Find out when and how you will hear about project outcomes and next steps.
- Provide input into risk and patient safety priorities based on your experience.
- Understand the patient engagement processes and help identify gaps and solutions.
- Help develop goals and indicators that matter to patients and families.
- Ask how to get involved in incident analysis and incident management.
- Find out the procedure and resources available to patients and families after harm. Bring forward questions, concerns, and improvement ideas to the incident management process.

Providers, patient engagement specialists

- Understand how patient engagement in patient safety is organized and resourced in your organization.
- Reflect and be honest about your own beliefs, attitudes, and behaviours that help or hinder authentic patient engagement.
- Continue to develop your patient engagement competencies and skills; invite feedback on your performance from patient partners.
- Learn about, champion, and help advance good patient engagement practices.
- Build coalitions, solicit feedback, and get support from others about engagement processes.
- Support patient partners and team or committee members:
 - Transfer knowledge between newer patient partners and experienced ones
 - Always try to include at least two patient partners
 - Facilitate a good fit between patient partners and the work.
 - Ensure everyone has relevant information to effectively participate
 - Involve patient partners as early as possible and establish lines of communications
 - Introduce patient partners as key members and experts in the patient experience
 - Create rules of engagement early on to set shared principles and mutual expectations
 - Create a safe space for all—especially patient partners—to speak up. Explicitly invite every new patient partner to speak up and take time to address their points.
 - Check in with everyone regularly to see how engagement is going and what to improve
- Know and follow your organization's policies and procedures for patient safety incident management (e.g., reporting, disclosure, incident analysis, learning, improvement).
- Ensure all involved, including yourself, have access to practical and emotional support after an incident.

Leaders

- Support patient engagement in your organization:
 - Embed expectations for working with patients and families as partners wherever possible (e.g., mission, vision, policies, performance measures)
 - Provide an organizational framework, training, and support for patient engagement
 - Position patient engagement structures and functions to effectively influence and contribute to patient safety, organizational goals, and priorities
 - Communicate about patient engagement internally and externally. Make sure the people who use your services can access this information
- Nurture, support, and sustain patient engagement in patient safety:
 - Integrate patient engagement with patient safety across the organization, clarifying how teams, departments, and programs influence one another
 - Ensure time and resources for patient engagement are appropriately allocated
 - Provide opportunities for staff, patients, and families to learn how to create safe care
 - Ensure a collaborative process for developing safety and quality improvement plans
 - Test and embed promising patient engagement practices in your organization
- Incident management:
 - Value the role that patient partners play in responding to patient safety incidents

3.5 Practice examples

Patient engagement in incident analysis – Seattle Children’s Hospital

Seattle Children’s Hospital uses root cause analysis (RCA) as the method to understand what happened after a serious patient safety incident and to develop recommendations for action. A multidisciplinary team includes anywhere from five to 20 people, depending on the type of incident, but not the individuals who were part of the event (e.g., the physician, nurse, other care providers). Roles of those supporting the review team are described in the following table.

It has been a challenge involving patient family advisors in reviewing serious incidents, and the organization continues to learn from and build upon their experience. Extensive work has been done to create a dialogue between patients, families, and staff involved in incident review to understand the barriers to involving patients and families, and to build trust and mutual understanding. This has shifted the way that root cause analysis is done in the hospital.

Currently, the organization has a policy that an experienced patient family advisor (PFA) is involved as a member of every RCA.

- To date, five PFAs have been trained to take on this role to provide consistency and to learn how to refine and strengthen their engagement in the process.
- A recent survey found that 60 per cent of PFAs in the organization were interested in participating.

Seattle Children’s Hospital review of serious patient safety incidents	
Roles	Responsibilities
Facilitator(s) of the RCA Staff of quality and safety team/ department	<ul style="list-style-type: none"> • Conduct interviews with each person involved in the incident (patient, family, healthcare providers) before the review team comes together • May observe care processes, research on best practices, document-related policies and procedures • Lay out the timeline, the context, and each person’s description of what happened and why • Prepare structured tools to help the team (e.g., a care process map, a cause and effect diagram).
Health leader	<ul style="list-style-type: none"> • Make sure the RCA team is supported • Understand the challenges surrounding the incident • Remove barriers that could block the process or the action items
Process owner: director of the clinical area or whoever has oversight of where the incident occurred	<ul style="list-style-type: none"> • Help coordinate the investigation • Present the information at the review team meetings • Assist in completing the action items
Team members: provider and experienced patient partner	<p>Those who can speak to similar events or experience in the care processes:</p> <ul style="list-style-type: none"> • Review the case • Help determine the causes • May be responsible for owning action items.
Patient engagement specialist	<ul style="list-style-type: none"> • Help to recruit and select the experienced PFA to participate on the team • Work with the quality and safety team to train and prepare the PFA • Provide support before, during, and after the review

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