PATIENT SAFETY FORWARD WITH

ENGAGING PATIENTS IN PATIENT SAFETY

A CANADIAN GUIDE

Patient Engagement Action Team - May 2017

cpsi icsp
Canadian Patient Safety Institute
Institut canadien pour la sécurité des patients

ATLANTIC COLLABORATIVE HEALTH QUALITY & PATIENT SAFETY
COLLABORATIVE DE L'ATLANTIQUE QUALITÉ DES SOINS ET SÉCURITÉ DES PATIENTS

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PATIENTS FOR PATIENT SAFETY CANADA | PATIENTS POUR LA SÉCURITÉ DES PATIENTS DU CANADA

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Introduction: Partnering for safer healthcare

Message from the authors

During the past decade, we have seen evidence that when healthcare providers work closely with patients and their families, we can achieve great things. The healthcare system will be safer, and patients will have better experiences and health outcomes when patients, families, and the public are fully engaged in program and service design and delivery. Patient involvement is also important in monitoring, evaluating, setting policy and priorities, and governance.

This work is not easy and may even be uncomfortable at first. Providers may need to let go of control, change behaviours to listen and understand patients more effectively, brainstorm ideas together, build trust, and incorporate many different perspectives. Patients may need to participate more actively in decisions about their care. Leaders must support all this work by revising practices to embed patient engagement in their procedures, policies, and structures. But finding different and innovative ways to work together, even when it's challenging, benefits everyone.

When patients and healthcare providers partner effectively, the results are powerful. We invite you to join us in advancing this work. We welcome diverse perspectives and beliefs to challenge the status quo. Let's explore ways to shape new behaviours, using everyone's unique perspectives and courage to make healthcare a safe and positive experience.

A deep belief in the power of partnership inspired the Engaging Patients in Patient Safety – a Canadian Guide. Written by patients and providers *for* patients and providers, the information demonstrates our joint commitment to achieving safe and quality healthcare in Canada.

Who is this guide for?

The guide is for anyone involved with patient engagement, including:

- Patients and families interested in how to partner in their own care to ensure safety
- Patient partners interested in how to help improve patient safety
- Providers interested in creating collaborative care relationships with patients and families
- Managers and leaders responsible for patient engagement, patient safety, and/or quality improvement
- Anyone else interested in partnering with patients to develop care programs and systems

While the guide focuses primarily on patient safety, many engagement practices apply to other areas, including quality, research, and education. The guide is designed to support patient engagement in any healthcare sector.

What is the purpose of the guide?

This extensive resource, based on evidence and leading practices, helps patients and families, patient partners, providers, and leaders work together more effectively to improve patient safety. Working collaboratively, we can more proactively identify risks, better support those involved in an incident, and help prevent similar incidents from occurring in the future. Together we can shape safe, high-quality care delivery, co-design safer care systems, and continuously improve to keep patients safe.

What is included in the guide?

Evidence-based guidance

- Practical patient engagement practices
- Consolidated information, resources, and tools
- Supporting evidence and examples from across Canada
- Experiences from patients and families, providers, and leaders
- Outstanding questions about how to strengthen current approaches
- Strategies and policies to meet standards and organizational practice requirements

Chapter summaries

Chapter 1 – Engaging patients as partners

- Why partner on patient safety and quality
- Current state of patient engagement across Canada
- Evidence of patient engagement benefits and impact
- Challenges and enablers to patient engagement
- Embedding and sustaining patient engagement

Chapter 2 – Partners at the point of care

- Partnering in patient safety
- Partnering in incident management

Chapter 3 – Partners at organizational and system levels

- Preparing to partner
- Partnering in patient safety
- Partnering in incident management

Chapter 4 – Evaluating patient engagement

- Introduction to evaluating patient engagement
- Evaluating patient engagement at the point of care
- Evaluating patient engagement at the organizational level
- Evaluating patient engagement integration

How and why was the guide developed?

The National Patient Safety Consortium, a group of more than 50 organizations, established the Integrated Patient Safety Action Plan, a shared action plan for safer healthcare. One of the plan's guiding principles is patient engagement, and one of the shared actions is a comprehensive guide for patient engagement based on evidence and best practices.

The Canadian Patient Safety Institute (CPSI), a national organization established by Health Canada to improve patient safety and quality in the Canadian healthcare system, led this work. CPSI, along with the Atlantic Health Quality and Patient Safety Collaborative, and Health Quality Ontario provided leadership and funds to develop the guide. Beginning in 2016, CPSI brought together patients, government, and organizations responsible for improving patient safety and quality at the national or provincial level on an Action Team to help develop the guide.

The Action Team included:

- Accreditation Canada – Health Standards Organization
- Alberta Health Services
- Atlantic Health Quality and Patient Safety Collaborative
- B.C. Patient Safety and Quality Council
- Canadian Foundation for Healthcare Improvement
- Canadian Patient Safety Institute
- Centre of Excellence on Partnership with Patients and the Public
- HealthCare*CAN*
- Health Quality Council of Alberta
- Health Quality Ontario
- IMAGINE Citizens Collaborating for Health
- Manitoba Institute for Patient Safety
- Manitoba Health, Seniors and Active Living
- Ontario Ministry of Health and Long-Term Care
- Ontario Hospital Association
- Patients for Patient Safety Canada
- Saskatchewan Health Quality Council
- University Health Network
- University of Montreal

A consultant team (One World Inc.) supported the Action Team's work by conducting an environmental scan to identify current evidence, leading, and emerging practices, and by drafting the content of the guide. The scan offered examples of patient engagement in patient safety and quality, a targeted review of academic literature, a web scan, and interviews with key informants in the field.

Forty patients and providers from across the country participated in focus groups to help develop the guide's scope and content, including feedback on drafts. Ten patients and providers also participated in a usability pilot to validate the format and provide ideas on how to make the guide easier to use.

The guide will be regularly updated and refined as new evidence emerges and new content is developed. To contribute to the guide (e.g., with resources, leading practices, potential topics) or to be the first to know about the updates, email: patients@cpsi-icsp.ca.

Complementary resources, including the Canadian Patient Engagement Network and the Canadian Foundation for Healthcare Improvement Patient Engagement Hub, are available here.

1. Engaging patients as partners

The vision is "not of staff striving to engage patients in ever more meaningful ways, but of patients and staff having collective ownership of efforts to improve their shared healthcare services; power residing not in any stakeholder group, but within the process of co-production/co-design."[1]

Patients, providers, leaders, researchers, and policy makers now agree that engaging patients and families is essential to safe care. Partnering with patients shows respect, values their insights and experience, and empowers them to take an active role in their care. Many organizations, including hospitals, home and community care, long-term care, and primary care facilities are making great strides towards patient engagement, but they are still learning how to do this work collaboratively. This chapter summarizes the benefits and impact, current state, challenges, and enablers to setting up and embedding patient engagement in an organization.

1.1. Why partner on patient safety and quality?

Canada's healthcare system is faced with growing healthcare costs, increasing rates of chronic disease, and an aging population. While it performs well on some measures, it ranks behind other Western countries on providing patient-centred care (8th out of 11 countries), timeliness of care (11th out of 11), coordinated care (8th out of 11), and safe care (10th out of 11). From 2014–2015, there was at least one harmful incident for every 18 Canadian hospital stays (138,000 out of 2.5 million hospital stays).[2,3]

Patients, providers, leaders, researchers, and policy makers now agree that patients and families are essential to ensuring safe and quality care. They are creating new knowledge and tools to accelerate patient engagement.[7,8,9,10,11,12,13,14]

Patient engagement: an approach to involve patients, families and/or patient partners in:[4]

- Their own healthcare
- The design, delivery, evaluation of health services
- A way that fits their circumstances

Patients' experiential knowledge is recognized and power is shared[5] in ongoing, meaningful, constructive relationships at all system levels:

- Direct care
- Healthcare organization (service design, governance)
- Health system (setting priorities and policies)[6]

Fundamentally, patients expect to be safe while receiving healthcare. Evidence and practice increasingly show that patient engagement is important to prevent patient safety incidents from occurring, respond to incidents, learn from and improve care safety. Because patient safety is an element of quality of care, engaging patients in patient safety is linked to other quality dimensions (e.g., accessible, appropriate, effective, efficient, equitable).

Here are a few reasons to engage patients and families:

It's the right thing to do

Partnering with patients and families shows respect, values their insights and experience, and empowers them to take an active role in their care. Those working in the healthcare system are morally obligated to engage patients, whether as members of their care team and/or as partners in improving healthcare safety and quality within the healthcare organization or the whole system. "Nothing about me without me," expresses this.

It's the safe thing to do

As respected partners, patients and families can improve their own care quality and safety. The 2014 Report of the Roundtable on Consumer Engagement in Patient Safety[15] described patients as being the extra sets of eyes and ears that should be integrated into the safety processes of all healthcare organizations because:

- They know their symptoms and their responses to treatments better than anyone else.
- They are highly invested in their own well-being and outcomes.

- They are always present in their own care, unless impaired by factors beyond their control. They are the first to know or feel when a symptom changes or they experience treatment impacts, and they can communicate these to their care team.
- Their courage and resilience can inspire and energize their care team.
- They often have insights into the processes of care that providers lack because the providers are focusing on getting the job done.

It enables innovative solutions

Patient engagement has been called the "blockbuster drug of the century."[16] Patients bring new, innovative approaches:[17]

- Patients offer a unique perspective to decisions about their own health and treatment, to care-design processes in their local health organization, or to the bigger policy decisions that shape the healthcare system. They are experts in their own care and are experienced health system users.[18]
- Engaged patients better understand and know more about their care, leading to better health service and resource use.[19]
- Partnering with patients in planning and designing healthcare services is an important way to improve care quality and accountability in the system.[20] Patient partners on incident review teams or committees:
    - Offer a unique perspective:
        - Another "discipline" around the table – specialized in the patient experience
        - An integrated view of systems, where providers only know about their own part of the care journey
        - New insights into incident analysis
    - Involve those who are most impacted by decisions
    - Allow providers to speak exclusively to their own role rather than trying to imagine the patient and family perspective
    - Diversify team problem-solving and identification of solutions

It's an expectation and a standard

Across Canada, governments and healthcare organizations are advancing patient and family-centred care, with patients and families taking on more active, informed, and influential roles.[21,22]

Healthcare organizations work with recognized accreditation bodies to review and strengthen their delivery of safe, high-quality care. New Accreditation Canada standards require patient engagement in governance, leadership, and service delivery. Evidence-based accreditation standards are evolving to require that organizations implement policies and practices to support patient engagement and shift to more patient-centred care.[23] Since 2016, healthcare and social services organizations participating in Accreditation Canada's Qmentum program are evaluated against new client and family-centred care requirements to:

- Partner with patients and families in planning, assessing, and delivering their care.
- Include patient partners on advisory boards and planning groups.
- Monitor and evaluate services and quality with input from patients and families.

Find examples of Accreditation Canada requiremets for patient engagement throughout the guide (identified with the Accreditation Canada logo).

Moreover, the Health Standards Organization is now purposefully engaging patients, families, health service providers, clinicians and policy makers in the co-design and revision of health standards, ensuring that all points of view relating to a new standard or a proposed standard revision are represented.[24]

Some provinces have introduced legislation that requires organizations to engage patients in health system planning. For example, Ontario's *Patients First Act* requires that patient and family advisory councils be put in place for every local health integration network.

1.2. Current state of patient engagement across Canada

In Canada, patient engagement examples reveal courage, collaboration, innovation, and momentum for change in the face of significant obstacles. There is still a long journey ahead until patient engagement is standard practice in every interaction, every setting, and every sector. Since some of the major initiatives in Canada began around 2004, more evidence and changes that result in safer care at all system levels have been published.[25]

Patients and patient groups become trusted partners

For many years, patient groups, often organized around a common disease or health condition, have actively advocated to partner in their own care, in decisions about setting health service and research priorities, and in care-design and delivery.[26] Since 2004, formal and informal patient groups have emerged and continue to emerge across Canada, indicating a strong desire to contribute to safe and quality care.

For more than a decade at the national level, patient groups like Patients for Patient Safety Canada and Canadian Family Advisor Network have worked collaboratively with many leaders, providers, and policy makers to include the patient's perspective in service design and policy making. Their intent is to build a safer, more sustainable healthcare system that is responsive to patient needs. Patients shape tools, resources, guidelines, standards, and learning programs to help other patients, patient partners, providers, and leaders.

At provincial and local levels, patient groups like Patient Voices Network in B.C., and Health Quality Ontario Patient, Family and Public Advisors Council shape provincial and local policies, frameworks, performance measures, and point-of-care interactions.

Informal patient groups and networks are also increasing in number. Patients are connecting, supporting each other, advocating for change, and collaborating with providers, administrators, and policy makers to make positive changes in the healthcare system.

Emerging efforts focus on building connections among different patient groups in a "network of networks," primarily by the Canadian Patient Safety Institute (CPSI). Through meetings and building relationships, CPSI helps reduce duplication, transfer knowledge, and align efforts to achieve a common goal: safer care through patient engagement.

Grassroots efforts became embedded at all system levels

Early efforts in patient engagement for patient safety and quality grew out of the grassroots work of patients, clinicians, and leading healthcare organizations in patient and family-centred care.[27,28,29,30,31]

- The Canadian Foundation for Healthcare Improvement (CFHI) supports organizations to pilot and test projects related to patient engagement. This helped seed a nationwide patient and provider learning community to build evidence for the positive impact of engaging patients.[32]
- CPSI's National Patient Safety Consortium identified patient engagement as a key focus area in the collective effort of key patient safety and quality organizations. CPSI has been modelling patient engagement in patient safety for more than a decade by ensuring that 100% of programs are developed and delivered in partnership with patients. They also develop specific resources for patients and the public, and they support Patients for Patient Safety Canada.
- HealthCareCAN helps train healthcare professionals and organizations through a comprehensive and practical online learning program focused on patient-centred experience and design.
- Accreditation Canada introduced client and family-centred care standards to support organizations increase patient engagement and to advance quality and safety in healthcare organizations across the country.

- The Canadian Institute of Health Research is advancing its own organizational strategy for citizen engagement. Patient engagement is a pillar of its Strategy for Patient-Oriented Research, with provincial and national capacity-building initiatives underway.

At the provincial or territorial levels, jurisdictions launched structures and strategies to progress safe and quality care through patient engagement and patient and family-centred care:

- Saskatchewan's 2009 Patient First review included patient and caregiver opinions in setting priorities for provincial health system reform.[33] These priorities continue to shape progressive change that embeds "Patient First" as a core value and focuses on improving the patient experience. Saskatchewan Health Quality Council's number one priority is to integrate patients and families as partners in all aspects of healthcare.[34]
- British Columbia's Patient Voices Network recruits, trains, and supports patients to partner in change processes that improve care and service design. Health authorities and other stakeholders collaborate to identify opportunities for engagement.
- Health Quality Ontario's Patient Engagement Framework guides a provincial strategy to build capacity for patient engagement across the provincial health system and in its own organization.

Many more health authorities and healthcare organizations are taking steps to integrate patient engagement into their work:

- Kingston General Hospital in Ontario introduced the first organization-wide patient engagement policy. Patient partners are now on all major committees and are involved with hiring decisions, staff orientation, and healthcare provider education.[35]
- Capital Health Authority in Nova Scotia (now the Nova Scotia Health Authority) introduced a policy[36] that embraces patient and citizen engagement as a core value and business process, offering tools and consultation support to build engagement capacity.
- The Centre intégré universitaire de santé et de services sociaux de la Mauricie-et-du-Centre-du-Québec, has developed an integrated strategy based on three principles: (1) shared leadership between a patient and a manager to build the strategy; (2) a clear process for recruiting, training, and coaching patient advisors (PA) so that they can participate in decision-making at the various levels of governance of the establishment; and (3) a feedback process for improving the strategy over time.[37]

Gaps in current practice

Despite progress, a national consultation in 2015 found that more needs to be done to increase patient engagement in organizations and the healthcare system.[38] The report found that providers and administrators in Canada's healthcare system acknowledge that patients—and their perspectives and experiences—should be the guiding factor in clinical care. However, the degree of patient engagement in care varies. Also, while most healthcare organizations collect patient feedback using surveys and most providers share information with patients about their diagnosis and journey of care, many patients said they expect better communication to help them manage their own health, and greater involvement and more collaborative, integrated care that respects their needs.

While partnering with patients is a recognized strategy to improve safety and quality of care, more work needs to be done to:

- Create a culture that supports partnership and collaboration.
- Provide supporting structures and policies, information, and tools.
- Ensure the purpose of the patient participation fits the needs, preferences, and capacity of those engaged.

1.3. Evidence of patient engagement benefits and impact

Because patient engagement in healthcare is still a relatively new approach, few high-quality studies have been conducted.[39,40,41] Emerging evidence shows real-world improvements in health outcomes and healthcare delivery from partnering with patients. Most evidence is from pilot projects, formal case studies, and anecdotal evidence from patients and

providers. Imagine Citizens Collaborating for Health (Alberta)[42] considers a broad definition of evidence that includes five sources. Understanding healthcare challenges and identifying solutions requires looking at research alongside other evidence.

The research in patient engagement is still catching up with current practice, including the most innovative approaches.[43,44] Even without research evidence, a growing number of Canadians expect that healthcare decision-making reflects patient priorities and is based on collaborative partnership at all levels.[45,46]

It simply makes good sense to partner with patients to better understand their experience and needs. This deeper understanding informs those who design and provide care to focus efforts on improving patients' well-being and quality of life.

Five sources of evidence

How partnering with patients is making an impact

Examples of how patient engagement makes a difference in safety and other quality areas are included in the following table.[47,48] Some outcomes (e.g., efficiency) are linked to other quality areas and are described as "integrated" indicators in the Health Quality Ontario's Indicator Technical Specifications – Quality Improvement Plans 2015/16.

Select quality areas	Example of improvements
Safety	• Improved hand hygiene rates and reduced infection rates • Better medication self-management[49] • Reduced patient safety incidents, such as medication errors or patient falls • Increased identification of potential safety issues by patients and families that prevent safety events from occurring[50,51]
Patient and family-centred care	• Reduced anxiety and stress with the presence of family/supports • Improved patient/provider communication • Better understanding of health, options, and the care plan • Improved patient satisfaction and care experience[52]
Coordination of care	• Better transition from hospital to home, discharge planning • Improved interprofessional teamwork
Equity	• Improved cultural awareness and consideration when providing services
Health outcomes[53]	• Improved patient emotional health • Better symptom resolution, functioning, pain control • Improved physiologic measures, (e.g., blood pressure, blood sugar levels) • Decreased death rate for people with chronic obstructive pulmonary disorder[54]
Effectiveness and appropriateness	• Improved care and service delivery after co-design with patients, (e.g., staff wearing identification badges, purposeful hourly rounding at the bedside) • Reduced rates of preventable readmissions to hospital[55] • Reduced lengths of stay in hospital[56]
Efficiency	• Lower costs per patient stay in hospital • Better staff recruitment and retention and staffing mix • Lower medical and legal costs from law suits against the provider/organization

Impact on patient safety

Studies show that patients and families can provide unique safety information and be valuable partners in safety surveillance.[57,58,59,60] For example:

- In 2008, a study of 998 recently hospitalized patients in Massachusetts found that patients identified about twice as many of the harmful patient safety incidents that took place during their hospital visit as the providers who reviewed the medical records.
- A recent study of more than 746 parents/caregivers of hospitalized children found that they reported similar rates of errors and harmful patient safety incidents as providers. They also reported five times more errors and three times more harmful incidents than those recorded in formal hospital incident reports. Overall detection rates of errors increased by 16%, and harmful patient safety incidents increased by 10%.

Evidence proves that involving patients can help improve infection control (e.g., their own hand hygiene, the hand hygiene of their providers).[61] The Women's College Hospital successfully engages patients as observers in hand hygiene.

Other academic articles are cautious about stating the positive impacts of engaging patients in patient safety.[62,63] For example, not all patients are interested in being actively involved in identifying patient safety incidents. In some cases, patients and providers do not agree on what should be considered a patient safety incident. Data on patient experience does not include enough patients over a long enough period to provide good quality, generalizable results.

Impact on staff

There is some evidence that patient engagement can increase healthcare provider satisfaction and engagement, improving recruitment and reducing staff turnover, sick time, and overtime.[64] This contributes significantly to delivering safe and quality care.

Impact on patient partners

In many cases, a personal experience with harm motivates patients to get involved and volunteer for safer care. Sharing personal stories and partnering for change can be part of the healing process[65]. This intimate experience allows patients to contribute valuable insights into preventing and responding to harm.

Evidence on promising practices for engaging patients in direct care

The Partnerships for Patients initiative found that the more that patients were engaged in their care, the greater the potential to prevent their readmission to hospital.[66] The hospitals that had achieved four or five metrics were more successful in keeping patients out of hospital following discharge.

A 2017 evidence review analyzed the impacts of practices that engage patients in direct care.[67] The following practices can lead to better outcomes in safety, quality, and patient experience:

- Shared decision making with patients
- Family presence and involvement in care
- Advanced care planning
- Compassionate care delivery
- Provider training to improve their ability to partner and to improve empathy and communication skills

A 2012 academic journal article presents the evaluation results from research studies (e.g., trials, systematic reviews) on patient engagement approaches, including the evidence that support the most promising approaches.[68]

Evidence on engaging patients in health research

Some evidence shows that patient involvement in health research can result in research that is more focused on patient

needs and help bring the research results into practice. However, evaluating patient engagement in research is still in its early stages and the best methods of engagement are not yet well understood.[69]

Building stronger evidence for patient engagement

To build a stronger evidence base, systematic patient engagement monitoring and evaluation is crucial. Equally crucial is sharing and spreading existing learning, knowledge, research, and practices. A stronger evidence base will help build better and more relevant programs, policies, and strategies to help accelerate patient safety and quality efforts.

1.4. Challenges and enablers to patient engagement

"Patients and families face challenges, the most critical being the need to convince more healthcare organizations and service providers to engage patients and families in every aspect of patient safety initiatives. These include health professional education, meetings, consultations, advisory committees, patient safety councils, research and knowledge transfer initiatives, disclosure guidelines and policies and patient safety policies. What is currently in place in these areas is not working, and transformation requires everyone's commitment."[70]

Patient engagement challenges

Some common challenges related to patient engagement in general are also common to patient engagement in patient safety. They include:[71,72,73]

- Shifting the culture of receiving and delivering care
- The practicalities of engaging patients in their own care and during planning

Shifting culture

Changing from a provider-centred mindset and care system involves rethinking the current policies, structures, and processes that get in the way of patient engagement. It means shifting the culture from individual services delivered by professionals or experts to integrated, collaborative care.

Healthcare providers and leaders may be concerned that:

- Patient perspectives might differ from their own and lead to unwanted change
- Patients might not have the required knowledge to participate meaningfully
- Patients might lose confidence in the healthcare organization (e.g., while learning about and discussing challenges with care processes, safety risks, or patient safety incidents that have resulted in harm)
- Patients may not respect privacy and information confidentiality
- Decision-making authority and roles could lead to confusion and unmet expectations

The governing body has responsibility to provide oversight of the organization's efforts to build meaningful partnerships with clients and families.

Patients may also have fears or demonstrate resistance because:

- Providers are the experts and patients should defer to their advice and direction
- Responsibility and accountability will be shifted onto the patient
- Patients might not have the confidence, knowledge, and ability to be partners
- Patient engagement will be token and their input will not be used to make decisions

Putting patient engagement into practice

Making patient engagement a priority in practice and in the hearts and minds of patients, providers, and health leaders is challenging for many reasons, including:

- Competing priorities
- High demands on providers at the point of care
- Limited healthcare resourcesF
- Pressures to increase efficiency
- Inadequate healthcare provider time, resources, and expertise to support patient engagement
- Lack of diversity in the patients engaged (i.e., not representative of the populations served)
- Patients and providers may lack knowledge, skills, and experience in patient engagement
- Scheduling meetings and working within the limits of a patient's volunteer time
- Adapting to changes in a patient's health status when dealing with chronic conditions
- Identifying opportunities for meaningful patient engagement
- Sustaining patient and provider interest in the work over time
- Bureaucracy and technicalities (e.g., sharing information that is protected by privacy regulations)

The unique nature of patient engagement in patient safety

There are specific challenges to engaging patients in their safety which may not be the same the point of care and organization and system levels.[74] When patients are asked to help identify potential safety risks, they may be reluctant to discuss their safety concerns with providers due to:

- Fear that speaking up could impact relationships
- A belief that they may not be qualified enough to contribute
- Finding some patient safety activities difficult to do
- Concern that engaging in patient safety will trigger reactions that may harm them again or harm others

Providers may also resist engaging their patients in safety matters due to:[48]

- The amount of effort, time, and resources required to engage in the patient safety activity
- Fear of repercussions if they share incidents with patients, team members, and the organization
- Fear of re-traumatization in the case of providers who were involved in a patient safety incident

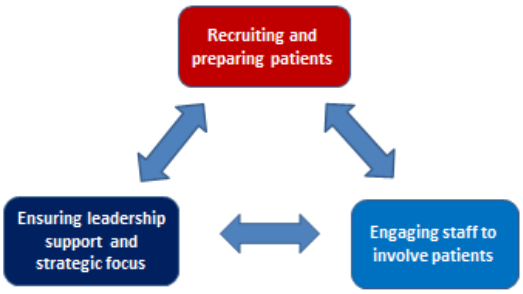
Finally, organizational patient safety performance targets and incentives may not always be consistent with patient engagement.

Some organizations consider a patient to be anyone who's had health services or will need them in the future. They focus on preparing patients to be partners and building patient safety awareness before illness and all through the care journey.

Patient engagement enablers

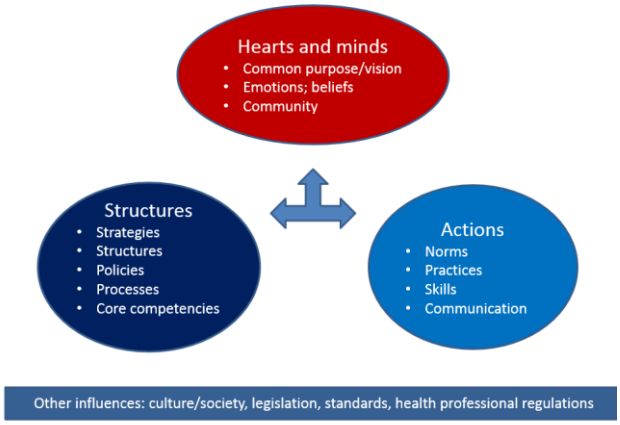
Based on a research and practice review, researchers found three tightly linked factors that reinforce each other to enable patient engagement:[75]

1. Recruiting and preparing patients as partners and team members and in other roles.
2. Engaging healthcare providers to involve patients as partners in teams, councils, boards, and other bodies.
3. Ensuring leaders support patient engagement and patient and family-centred care across the organization and at the point of direct care.



A way to support to patients, providers, and leaders to influence patient engagement includes focusing on:[76]

1. Shifting hearts and minds through a common purpose and vision. Partnership and collaboration is the organizational culture and patient engagement is a visible and lived value tied to a commitment to patient and family-centred care. [77] People need to think, feel, and believe it.
2. Supporting action through norms, practices, and communication. Reinforce partnership, engagement, and opportunities to build skills in patients and providers.
3. Putting supportive structures in place (e.g., policies, processes, and expected core competencies). Embed patient engagement throughout the organization and at the point of care.



There are specific, interconnected factors that enable patient engagement in patient safety, influenced by a culture of safety. To enable patient engagement, organizations should:[78]

- Collect, analyze, and actively share relevant safety information
- Create an atmosphere where people are confident and feel safe to report safety concerns without fear of blame. They need to trust that concerns will be acted upon
- Consider preventable patient safety incidents as opportunities for learning and make changes as a result
- Balance policies and practices to address system failures and clarify responsibilities
- Believe people can adapt effectively to changing expectations

Culture and leadership as patient engagement critical enablers

"A culture that is caring and supports partnerships, continuous system improvements, teamwork and accountability will naturally lead to an unrelenting desire to pursue the perspectives of patients and families in everything the organization does."[79]

Culture and values

Culture is commonly described as "the way we do things around here," and is rooted in people's attitudes, beliefs, and actions. Organizations that have been successfully engaging patients for a long time have cultures that engage patients in all major activities and decisions. They also place patient engagement front and centre when designing and delivering safe care.

Preventing and responding to patient safety incidents requires systemic actions to improve the many connected factors that impact a safety culture.[80,81] Organizations should combine improvement efforts in safety and quality with patient engagement to include every aspect of care and every strategy.[82,83]

A safety culture applies to everyone involved in care processes and systems, including patients, providers, and leaders (i.e., everyone has a role and a responsibility). To be successful in nurturing this culture, organizations should strive towards:[84]

- Leadership and board commitment, and visibility
- Effective and open teamwork and communication at all levels
- Team members, including patients and families who openly report problems and incidents, and measure, monitor, and learn from safety incidents
- Organizational learning
- Organizational resources for patient safety

- Values that prioritize safety over production (e.g., efficiency, cost)
- Education, training, and resources so everyone knows how culture supports patient safety and their role within it

Making a cultural change requires:[85,86]

- A long time-frame to make the change
- Setting clear, realistic goals, and measuring progress
- Supporting partnership and collaboration
- Helping people understand the purpose and the benefits of engagement
- Linking patient, family, and provider experiences
- Encouraging learning by doing and learning together

Leadership and governance

Leaders are critical to patient engagement. Leading healthcare organizations prove that senior leaders can shift culture and practice by setting the tone, creating a supportive environment, and providing resources to engage patients and families. A strong mission, vision, values, and strategy will not move to action without visible and practical leadership commitment.

Effective patient engagement and patient-centred care leaders:[87,88]

- Are visible champions (e.g., share patients' care experiences; report on patient partnerships and engagement impacts to the board, staff, and patients; and communicate the organization's commitment to patient engagement)
- Link patient engagement efforts to other organizational strategies (e.g., improve care processes and outcomes, advance safety and quality)
- Engage patients and staff in developing shared engagement goals to improve safety[89]
- Are role models for partnering with patients and family members (e.g., seek out and act on patient advice, invite patients to participate at meetings, work with patient partners to identify priorities and develop strategies)
- Provide the necessary infrastructure, people resources, and budget for patient engagement
- Ensure systems are in place to:
  - Bring the patient experience into organizational planning, priority-setting, and improvement initiatives
  - Support patients to identify and report safety risks, and report complaints and patient safety incidents
  - Monitor and evaluate the results of engagement, including partnerships and collaboration
  - Cultivate a learning environment that connects patients with providers for collaborative learning
- Involve and support clinicians and hospital staff in patient engagement initiatives
- Integrate patient engagement into human resource policies and practices (e.g., Engagement Policy from Capital Health, now the Nova Scotia Health Authority)

The leadership has responsibility to support teams in their efforts to partner with clients and families in all aspects of their care.

For patient and family-centred care strategies to be properly developed and implemented, healthcare organizations should strive towards:[90]

- A vision, mission, values, and principles that collectively point to the reasons why patient engagement is necessary
- Ensuring that everyone understands the concept, including the organization's board, senior leaders, providers, patients, and families
- Clearly explaining and showing that patient engagement is critical to achieving patient and family-centred care in care processes, decision making, and service design

Many provinces and leading healthcare organizations have developed a vision, mission, values, and principles to advance patient and family-centred care and patient engagement. For example, Alberta Health Services (AHS)[91] values tie compassion and respect together with patient safety, accountability, and excellence; the Patients First strategy and the Patient Safety Framework for Albertans puts patient engagement front and centre for patient safety.

1.5. Embedding and sustaining patient engagement

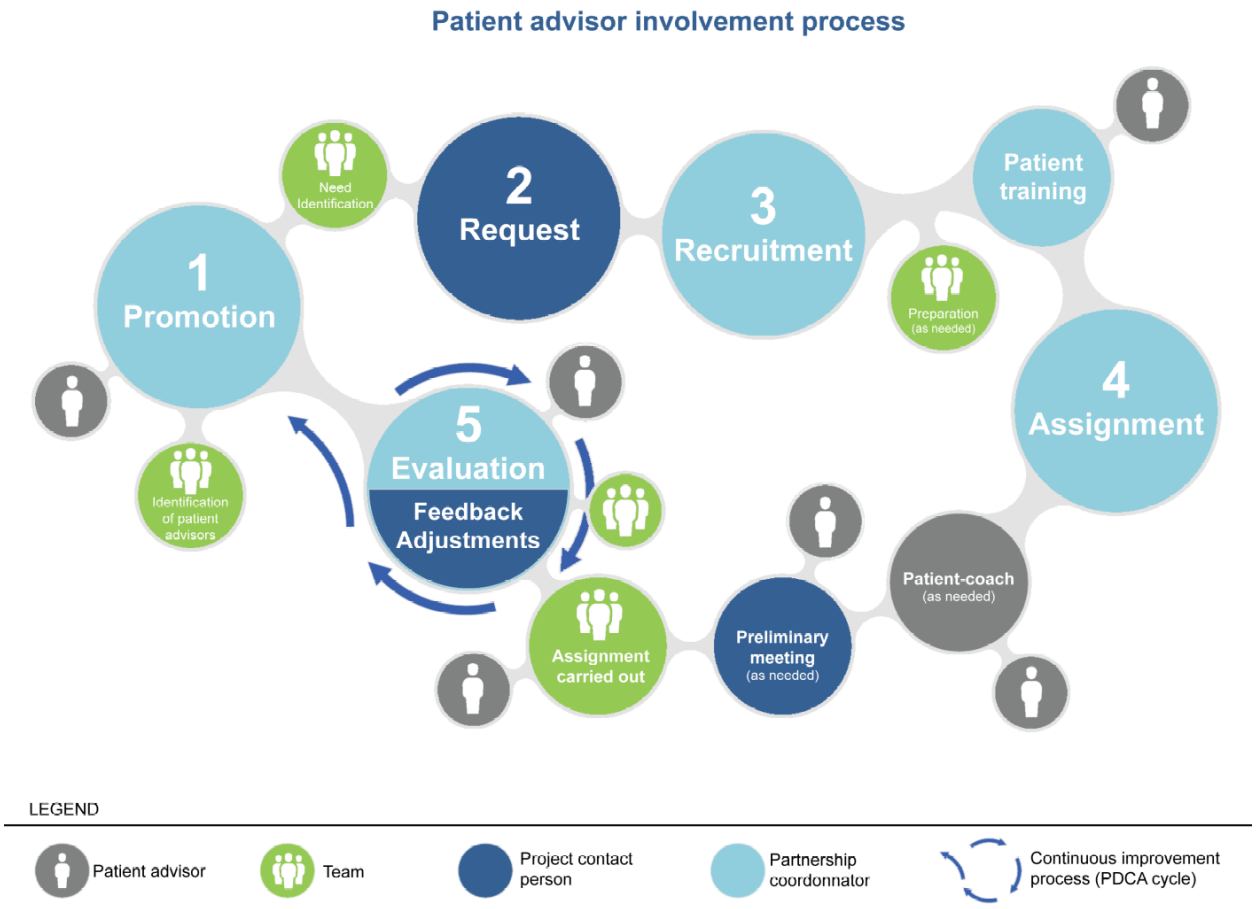
Infrastructure and resources

Aligning and embedding patient engagement in structures, policies, and processes helps achieve patient safety.

At the point of care, patient engagement can help patients and providers interact more effectively. Examples include policies for family presence, bedside shift reports, discharge planning, and care transitions.

At organization and system levels, patient engagement is stronger and more sustainable when it is in formal structures so patient partners can shape broader strategies. Their perspective is even more valuable when it impacts multiple organizations to enhance care transitions and coordination. Ideas include:

- Engaging patients in governance and decision-making (e.g., patient partners on boards, steering committees, and quality and safety committees, patient and family advisory councils or patient groups)[92]
- Engaging patients in co-designing formal processes to collect and include patient experience in decisions (e.g., reporting and learning structures that include patient feedback, compliments and complaints, and reported incidents)[93]
- Preparing people when they are healthy to understand the important role they play in achieving safe care-outcomes by learning, asking questions, and advocating for self and others



Patient engagement infrastructure and resources include:[94]

Organizational structures

To be effective, organizations should have formal structures that are accountable for patient engagement, such as:

- A dedicated office/department (e.g., patient experience)
- Within the quality and safety function/department
- Within the communications and public relations function/department
- A steering committee

When no formal organizational structure exists, organizations can build relationships with and gain support from external patient groups, like Patients for Patient Safety Canada, provincial quality councils or health authorities.

Staff position(s)

Many organizations have added one or more patient engagement specialist roles, commonly responsible for:[95]

- Recruiting, selecting, training, and supporting patient partners
- Setting up and supporting patient and family advisory councils
- Planning and implement engagement activities
- Developing and delivering training to patients and providers
- Monitoring and reporting on patient engagement

If there is no dedicated role to support patient engagement, staff with these responsibilities should be allocated dedicated time to carry out the work.[96] Patient partners often work alongside formal staff to co-lead patient engagement (e.g., as co-chairs).

Financial resources

Budgets and financial policies need to include patient engagement and compensation for patient partners. See the Change Foundation's Should Money Come into It? A Tool for Deciding Whether to Pay Patient-Engagement Participants and Saskatchewan Health's policy on Patient and Family Advisor Program Compensation and Reimbursement

Patient safety and patient engagement in care is supported by patient access to their health information which requires longer-term plans for investment.[97,98]

Human resources:

Human resource departments can promote patient engagement through recruitment, orientation and support to providers, leaders and staff by ensuring:[99,100,101]

- Job descriptions include basic patient engagement principles.
- Interview questions include patient engagement.
- Interview processes and panels include patient partners.
- Orientation includes patient engagement, patient experiences, and patient partners.
- Performance appraisals encourage continued skill development.
- Professional development opportunities on patient engagement are offered.

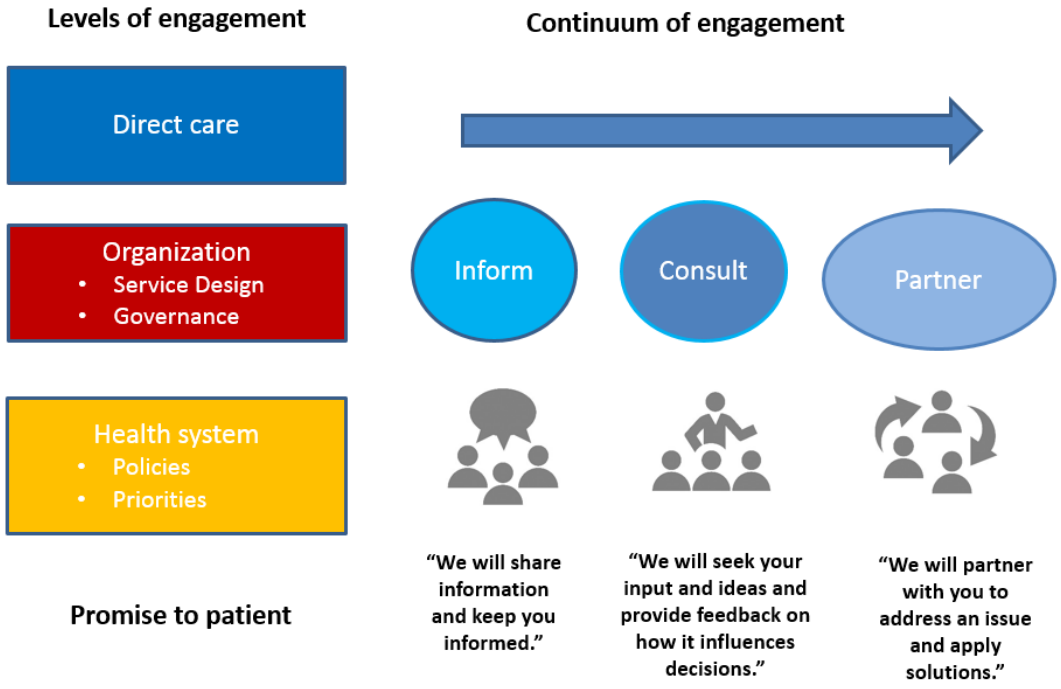
Patient engagement continuum

The engagement continuum ranges from low-level, where information is shared by providers with patients, to high-level

partnership, collaboration, and shared decision-making. All engagement levels are appropriate depending on the purpose of engagement. Patients, families, and patient partners should be determining together the most appropriate level of engagement.

Two patient engagement frameworks commonly used in the healthcare system in Canada are the Carman Framework, developed by the American Institutes for Research, and the International Association of Public Participation's Spectrum of Public Participation. Some Canadian provinces are using these frameworks or have developed their own, such as Health Quality Ontario's Patient Engagement Framework.

This graphic, with permission from Health Quality Ontario, was adapted from these three frameworks.



1.6. Summary – What you can do

Patients, families, and patient partners

- Learn about and use resources to help you have a safe care experience.
- Share your expectations and needs.
- Discuss your ideas for improving safety and listen to different perspectives.
- Ask about patient feedback surveys or formal compliments and complaints process.
- Learn:
  - Who is responsible for patient engagement
  - How the patient experience is included in services and care-design planning
  - How to connect with other patients and families
- Find out how to participate as a patient partner to make care safer for others:
  - Join a board or committee
  - Get involved in an improvement project or initiative
  - Help with the accreditation process

Providers, patient engagement specialists

- Learn about and use resources to engage patients for safe and quality care.
- Understand and apply leading patient engagement practices.
- Create an open, safe, and collaborative environment to share ideas or diverse perspectives.
- Set expectations for working together (e.g., roles, responsibilities, realistic goals).
- Know:
    - Who is responsible for patient engagement in your healthcare organization
    - How your healthcare organization brings the patient experience into services and care-design planning
    - How to connect with patient partners in the organization
- Look for or create opportunities for patient engagement in safety and quality improvement:
    - Ask patients and families about their care experience and seek out improvement ideas
    - Invite input on service planning or improvement projects. Test new ideas and monitor progress. Follow up on how the input was used and the project's results
    - Collaborate with patients and families on long-term improvement projects. Build in time to reflect on what is working well and what could be improved

Leaders

- Foster a culture of patient safety through patient engagement.
- Commit to patient and family-centred care and patient engagement by embedding it in the organization's vision, mission, principles, and strategies.
- Clearly link patient engagement with organizational strategies and patient safety.
- Walk the talk:
    - Champion new policies and processes that strengthen patient engagement.
    - Promote and support opportunities for patient partners to be meaningfully engaged.
    - Work towards patient engagement at all decision-making levels (e.g., boards, quality and safety committees, improvement teams, accreditation).
- Ensure sustainable structures and processes for patient engagement (recruit, orient, train).
- Create a mutual learning environment for patient and family partners, staff, and physicians.
- Provide opportunities for learning, testing, and adapting patient engagement best practices.

1.7. Practice example

Patient engagement on committees and initiatives – McGill University Health Centre

McGill University Health Centre's longstanding history of including patient representatives on organization-wide committees and the board of directors is summarized in Creating Engagement Capable Environments in Healthcare.[102] Since 2010, patient representatives participate on quality improvement teams with staff. Involving patients on quality improvement teams started with a pilot project on five units, where work was underway to strengthen patient care at the bedside.

This co-design approach spread to 19 units, with many newly developed or redesigned processes and materials (e.g., use of whiteboards to improve communication, better nursing hand-offs at shift change). Results from the pilot project with the first five units include:

- 60% decrease in medication incidents
- 8% increase in registered nurses' direct time in care
- Increased patient satisfaction
- Cost savings in equipment
- Decreased infection rates (25% for clostridium difficile and 26% for vancomycin-resistant enterococci)
- Improved team effectiveness
- Statistically significant reduction in nurses' voluntary turnover and overtime

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."[103]

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.[104] 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.[105]

Many studies have focused on how patients observe the way that care providers work.[106] Tools have been developed to guide patient observations for activities, such as hand washing,[107,108] medication delivery,[109,110] and patient identification.[111,112]

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.[113] The campaign helps patients engage with providers by asking three questions:[114]

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:[115,116, 117]

- 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:[118,119]

- 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.[120,121]

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.

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.[122] There are many barriers that might prevent a healthcare provider from disclosing a patient safety incident, including:[123]

- 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.[124] 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.

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*

Patient partners from Patients for Patient Safety Canada have shaped the *Canadian Disclosure Guidelines*[125] and the *Patient Safety and Incident Management Toolkit*.[126] 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.

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.

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

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.

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."[127]

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."[128]

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:[129]

- 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-judgemental
- Able to work collaboratively with other patients, families, and health care 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*[130]	
Committee/work group to develop patient and family educational materials, communication tools and signage	• 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	• 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	• 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	• 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	• 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.[131] Some of these examples are also used in other settings as they can be adapted from one health care setting to another.

Examples of patient partner roles in primary care practices			
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 responses
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 7 to 15 patients who meet monthly or quarterly to discuss practice improvement	Bidirectional 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:[132]

- 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**
Patient engagement specialist Patient partnership program coordinator Patient and family-centred care coordinator Patient engagement advisor Patient experience lead Client and community relations coordinator	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-centered care. Through dialogue, everyone can learn about the concerns and develop a mutual understanding.[133]

Providers partnering with patients and families:[134]

- Believe the patient and family perspective matters
- Contribute to creating a trusting space for open and honest discussion
- Are respectful and non-judgemental
- 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

Patient engagement in safety and quality is still not common in every organization. There are challenges to overcoming resistance and concerns**.**

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

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.

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.[135]

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.[136]

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., story telling)

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 inclusion[137]

- 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 (e.g., short- or long-term contact with your organization or service)
- 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).[138]
    - 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.[139] 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:[140]

- 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.[141] 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 teams[142]	
Information to share	**Topics to cover**
Terms of reference	• Purpose • Goals and objectives • Duration (if not an ongoing committee, work group, or team) • Frequency of meetings • Confidentiality
Decision-making	• Process for setting the agenda • How decisions are made (e.g., rules, voting, consensus)
Membership	• List of members and their background • Roles and responsibilities (e.g., who chairs the meeting)
Background	• Accomplishments to date • Barriers • Record/minutes of recent meeting(s)
Progress	• Upcoming agenda items • Success measures

Checklist: preparing patient partners for work on committees, workgroups, and teams[142]	
	• Any priority shifts • Strategic objectives
Background information	• 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 committee[143]

- 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

Consider also:

- 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 partners[144]	
Consideration	**Description**
Link patient partner involvement to specific goals and objectives.	• 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.	• Concerns might be about:
	  ○ Health information privacy and confidentiality
	  ○ Fit and culture
	  ○ Impact on existing work processes
	• Keep communication channels open to:
	  ○ Catch any concerns early in the process

Preparing providers to work with patient partners[144]	
Consideration	**Description**
	○ Build a culture of transparency and acceptance
Provide a mechanism for ongoing feedback.	• Periodically check in with staff members to: ○ 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.[145] 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 quality[146]

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."[147]

Patient partners are linked to the following two safety and quality processes:[148]

- 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 approach[149] and be structured into an organization's quality and project management processes.[150]

Patient engagement in patient safety

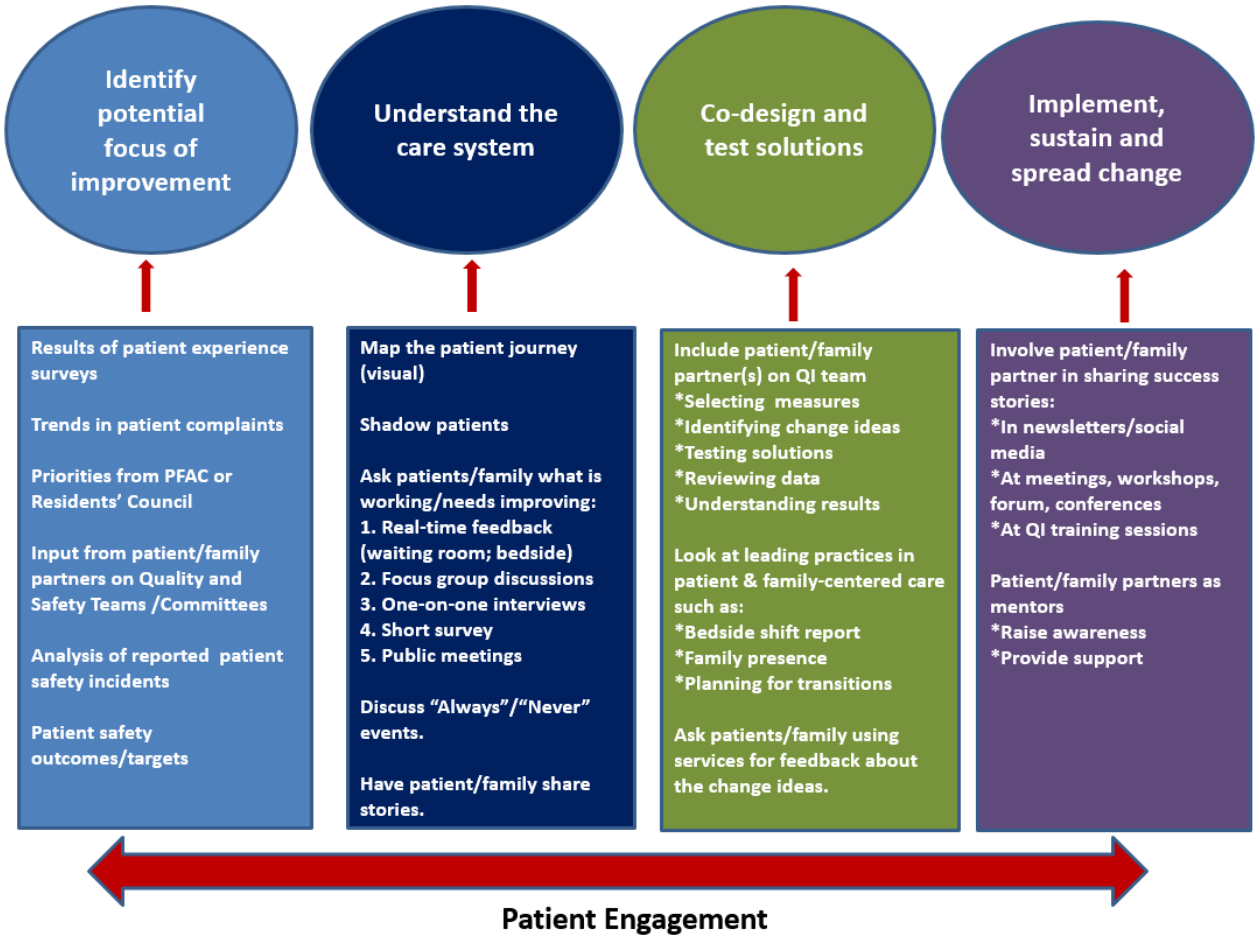
Patient engagement in preventing harm and maintaining care safety:[151]

- 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 health care services

Patient partners[152] 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 halls 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 (described in more detail later).



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.[153] 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 journey[154]. 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:[155]

- 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:[156]

- 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.[157]

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. [158,159] 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 brain[160] 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 evidence[31] 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 care[161] 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.[162] 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.[163]

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.[164] 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 fail 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."[165]

"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."[166]

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[167,168,169] 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 at al.[170] 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%)
- Safety policies/procedures (74%)
- Communication (64%)

Patients and families identified these factors from their own personal observations (32%), personal reasoning (11%), personal research (7%), record review (either their own medical records or reports they received in their own investigation (6%), and being told by a physician (5%). 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:[171]

- 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.[172] 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.[173]

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—whether 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 analysis[174]	
Concerns from providers	**Response from patient partners**
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? What if it hits too close to home for the patient partner? We don't want to make things harder for them. What if they feel scared it could happen to them or their family member?	"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 analysis[175]	
Patient family advisor	**Incident analysis team (lead or full team)**
• 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)	• 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 improvement[176]

- How at ease did you feel by joining the team?
    - 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?
    - 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 (e.g., background, context, team membership, goals, terms of reference, glossary).
    - 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. Never assume that everyone is comfortable asking questions or raising concerns. Explicitly invite every new patient partner to speak up and take time to address their points.
    - Check in with everyone regularly to see how patient 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 5 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% of PFAs in the organization were interested in participating.

Seattle Children's Hospital review of serious patient safety incidents – roles and responsibilities	
Roles	**Responsibilities**
Facilitator(s) of the RCA Staff of quality and safety team/ department	• 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	• 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	• 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	Those who can speak to similar events or experience in the care processes: • Review the case • Help determine the causes • May be responsible for owning action items
Patient engagement specialist	• 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

4. Evaluating patient engagement

"I'm always suspicious of a measurement approach that doesn't involve any opportunity for discussion with the respondent… there are some situations that just cannot be addressed by any survey… to hear about them, we just have to talk to people. It's all about connection—that's what's been lost and that's what needs to be restored."[177]

Methods to evaluate engagement processes and their impact are quite new in healthcare. Evaluating patient engagement efforts provides patients and families, healthcare providers, and organizations with information to recognize successes, identify improvements, and validate patient engagement as an input to decision-making. It also:

- Helps everyone involved reflect and learn from their engagement experience to make improvements, whether at the point of care or in organizational processes and planning
- Provides public accountability by ensuring that what is measured and reported matters to patients
- Builds evidence for patient care, engagement practices, and care outcomes that help shift individual behaviours and organizational processes. This supports investing in the people and structures needed for effective and purposeful engagement.

Evaluating patient engagement should include everyone's perspectives. Evaluation can take place at all levels in a healthcare organization and occurs at all stages of an initiative from planning to final analysis. This chapter covers the critical steps in planning for evaluation and provides measures and tools that can evaluate patient engagement at the point of care and organizational level, to help integrate patient engagement into the organization.

4.1 Introduction to evaluation

Patient engagement in the healthcare system is a relatively new development, though it is becoming more common. Methods to evaluate engagement processes and their impact are also quite new.[178,179,180]

Evaluation involves systematically assessing an initiative's design, implementation, and results to learn or influence decisions.[181] It requires collecting and analyzing information about the program's activities, characteristics, and outcomes. Collecting this information involves using predetermined measures, also called indicators in evaluation literature.

Patients and families participate on evaluation teams, committees, and improvement teams, to help develop surveys and other methods to evaluate their experiences. They are involved in all stages, supporting planning, developing tools, collecting information, and analyzing data.

Measures for evaluating patient engagement

At the most basic level, evaluation is trying to answer questions about:

- Process: How were patients and families engaged? What worked well? What needs to be improved? Was the engagement meaningful?
- Outcomes: What were the results of the engagement (e.g., tools, strategies, learning programs, policies)? Did clinical practices improve?
- Impact: How did engaging patients and families affect their care experience? What was the impact of patient engagement on safety and quality of care and health outcomes? Did it contribute to positive change?

Evaluation often starts by measuring process and making improvements to the initiative or activity. Over time, it is better able to assess outcomes and impacts.

Here are examples or evaluation measures (adapted from Alberta Health Services):

Engagement process measures	Engagement outcome measures
• Patient, family, and healthcare provider readiness to partner with each other • Representativeness (i.e., those participating in the evaluation are typically those involved in the program) • Diversity of views, opinions, and lived experiences • Early involvement • Clearly defined task(s), roles, and responsibilities • Decision-making process transparency • Patient, family, and healthcare provider satisfaction • Timeliness, participation rate, and costs • Effects of context and changing environment	• Influence on setting priorities and decisions • How well patients and families were heard and understood • Effect on attitude of patients and families and healthcare providers towards engagement • Overall engagement experience satisfaction • Engagement goal and promises met • What patients, families, and healthcare providers learned from each other • Effect on relationships, team effectiveness, and trust • Effects on context and changing environment • Unintended (positive and negative) consequences • Practice and clinical improvements (e.g., improved medication adherence, decreased hospital-acquired infections)

Context can be assessed from both a process and an outcome perspective. To illustrate, a significant patient safety incident that occurs midway through a process evaluating patient safety could affect both the evaluation and the outcomes. Assessing the social, cultural, and/or policy context, including predominant views towards patient engagement, may be important in understanding varying results across units or facilities. Differences in organizational arrangements (e.g., patient access to electronic health records, or whether families are considered “visitors”) may also be important.

It can be challenging to attribute outcome and impact changes entirely to patient engagement. There may be multiple initiatives going on that influence impacts, or the impact of engagement may be an intermediate step in achieving those outcomes. For example, partnering with patients on the care team or in a co-design process can generate possible solutions. These solutions then need to be implemented and tested and may lead to better results.

There are different interpretations about what is important to evaluate. Often both qualitative and quantitative measures are included. Quantitative measures, that focus on things that can be counted (e.g., number of participants, on a scale of 1 to 5, how satisfied are you with the hospital food?) tend to be more common. However, qualitative measures, that capture accounts of experiences, descriptions, observed behaviours (e.g., patient and health provider stories and experiences) are also important. Many patients and families want to provide fulsome and nuanced input (often through conversation), which most quantitative tools, such as surveys cannot accommodate. Both types are important. Numbers facilitate comparisons. Qualitative data offers detail and nuance, capturing contextual factors and variation. [182]

More work is needed to develop and share practical tools for measuring engagement process quality and its impact on healthcare processes and health outcomes.[183,184] Partnering patients and families with those responsible for monitoring and measuring patient- and family-centred care and patient engagement will make the information more meaningful and understandable.

Planning for evaluation

Considering evaluation at the earliest stage in planning helps clearly define an initiative’s objectives, and offers a shared understanding of success and how it will be assessed. This also ensures that evaluation data is collected throughout the process. An evaluation plan should be developed with patient partners as part of the project team whenever possible.

Include the following components in an evaluation plan:[185]

Components	Description	Examples
Purpose	• Why are you conducting the evaluation and how will the results be used?	• Judge program merit or worth • Improve programs • Generate knowledge • Increase engagement, motivation, and ownership • Accreditation
Target audience(s)	• Who are the intended recipients or users of the evaluation results?	• Patient partners • Healthcare providers • Board of directors
Participants	• From whom will the data be collected? • Who will conduct the evaluation? • What preparation is needed for people to best fulfill their roles?	• Frequent users • Frontline providers, patient, and family partners • External evaluator
Evaluation questions and measures	• What questions will be asked? • What needs to be measured? How? • How will data be collected? • Use a logic model/theory of change/driver diagram to frame the questions.[186] • Consider ethical or privacy issues	• Did patients and families feel their perspectives were heard? • What was their experience?
Methods and tools	• What is the best approach to get the data? • What tools will help collect this data and what training may be required to use the tool?	• Surveys, interviews • Interview script, survey tool
Data collection strategy	• What data needs to be collected? • When will it be collected and by whom?	• Observational data • Patient narratives
Analysis	• How will the data be analyzed? • Is the amount of data to be collected manageable (i.e., only what can be used)?	• Text analytics • Thematic content analysis • Statistical analysis
Result communications	• Who is the target audience? • How can results best be shared with the target audiences?	• Written report, infographic • Presentation, workshop
Required resources	• Determine and secure the resources needed for the evaluation. • This will also help verify the extent of the evaluation.	• Time • Money • Expertise • Number of measures

Methods and tools for evaluating patient engagement

Many evaluation methods and tools exist, and some have been adapted for use in healthcare. Consider using validated tools where possible. These tools have been rigorously tested, and help ensure data collection consistency (e.g., if there are multiple evaluators). These tools also allow organizations to compare data and results across different projects, within the same or across different organizations.

Examples of tools include:

- The Public and Patient Engagement Evaluation Tool (PPEET), which measures the quality and impact of engagement, and is currently being tested.[187] It may be used in a variety of healthcare organizations.[188] Using three questionnaires, it measures four key elements of quality engagement:
    - Integrity of design and process

- Influence and impact
- Participatory culture
- Collaboration and common purpose

The three questionnaires target those who:

- Participate in patient and public engagement activities (e.g., patients, public)
- Plan and execute activities within organizations (e.g., patient engagement specialists)
- Create the vision and build capacity for engagement within their organization (e.g., leaders)

- The Evaluation Toolkit[189] project is a one-year collaborative project reviewing existing evaluation instruments to assess public and patient engagement in health research and health system transformation. It will produce an open access patient and public engagement evaluation toolkit by the summer of 2017.

4.2 Evaluating patient engagement at the point of care

Throughout this guide, two broad areas of patient engagement are considered, requiring different approaches for measurement and evaluation:

- Point-of-care engagement: How patients and families engage in their own care
- Organizational and unit-level engagement: Patient partners in committees, working groups, or processes aimed at improving quality and safety

Prepare patients and families for evaluation at the point of care so they understand why the data is collected, by whom, and how the findings will be used. Usually this information (and more) is included in the data collection tool, but giving them an opportunity to ask questions is usually helpful.

Measures and tools for evaluating patient engagement at the point of care

Much of the work to date developing point-of-care measures and tools originates from monitoring and evaluating how patient and family-centered care (PFCC) is being implemented in healthcare organizations.[190]

The American Institute for Research has developed an inventory of patient engagement measures, many of which are linked to PFCC.[191] The database presents different measurement areas and the tools used to gather information. Some measurement examples for point of care are included in the following table**.** Accreditation Canada's standards for client and family-centered care align closely with these broad measurement areas. Two examples are provided in the table and textbox below.

Excerpt – patient engagement measures inventory			
Measurement area	**Measurement examples**	**Measurement tool examples**	**Completed by**
Access to medical records	Provide patients with and inform them about mechanisms to access their medical information	PFCC Organizational Self-Assessment Tool[192]	Providers, although some questions could be adapted for patients to complete
Care processes	Conduct shift change report at the patient's bedside	Patient-Centered Care Improvement Guide Self-Assessment Tool[193]	Providers, although some questions could be adapted for patients to complete
Care transitions	Partner with patients to develop a discharge plan	IPFCC Hospital Self-Assessment Inventory[194]	Providers
Communicatio	Clinicians invite patients and	Patient-Centered Care	Providers, although some

Excerpt – patient engagement measures inventory			
Measurement area	**Measurement examples**	**Measurement tool examples**	**Completed by**
ns	families to ask questions	Improvement Guide Self-Assessment Tool[195]	questions could be adapted for patients to complete
Leadership support	Leaders provide resources (e.g., time, money, personnel) to support patient engagement	Checklist to Improve Effective Communication, Cultural Competence, and PFCC[196]	Providers
Shared care planning and decision-making	Clinicians invite and welcome patients and families as partners in care planning and decision-making	CollaboRATE[197]	Patients/families

Clients are able to access information in their records, including electronic medical/health records, in a routine, client-centred, and timely way. Planning for care transitions, including end of service, are identified in the care plan in partnership with the client and family.

Using patient experiences data to evaluate engagement at the point of care

Patient and family experience data contributes valuable information for patient engagement evaluation in patient safety. Formal and informal monitoring systems collect patient and family experience data and bring the information into planning and evaluation processes. One of the most common tools is the survey.

Several Canadian organizations have included questions related to patient safety in their patient experience survey. The Health Quality Council of Alberta Satisfaction and Experience with Healthcare Services Survey includes these questions:

- Based on your personal experiences in Alberta's health system within the past year, to what degree are you personally concerned that UNEXPECTED HARM could occur in the course of your care and treatment as a patient? (Participants respond using a scale of one to five, from “not at all concerned” to “very concerned.”)
- To the best of your knowledge, have you or a member of your immediate family experienced UNEXPECTED HARM while receiving healthcare in Alberta WITHIN THE PAST YEAR?
- Did this UNEXPECTED harm happen while receiving care for yourself, a family member, or both?
- Now please think about the UNEXPECTED harm that occurred MOST RECENTLY: Did the doctor or health professionals involved tell you that UNEXPECTED harm had occurred during your (or your family member’s) care or treatment?

The Canadian Institute of Health Information is currently testing out a new patient experience survey that includes Consumer Assessment of Healthcare Providers and Systems (CAHPS) measures plus additional Canadian measures.[198] Organizations that use these standard surveys can share their data and compare with other organizations or health regions. A national system is in place to share, analyze, and use this patient experience data to identify areas for improvement in the health system.[199] Here are some examples of patient experience survey measures from the Canadian Patient Experience Hospital Inpatient Survey:

- During this hospital stay, how often did nurses (doctors) listen carefully to you?
- During this hospital stay, how often did nurses (doctors) explain things in a way you could understand?
- Did you get the support you needed to help you with any anxieties, fears, or worries you had during this hospital stay?
- Were you involved as much as you wanted to be in decisions about your care and treatment?
- Were your family or friends involved as much as you wanted in decisions about your care and treatment?

The Institute for Patient and Family-Centered Care in the United States has developed one-page key measure dashboards[200] for patient and family-centered care (hospital or outpatient clinic). The dashboards show results from select standard survey questions and tools that measure how well the organization is advancing patient and family-centered care. Key patient safety and quality measures are also included (e.g., rates of incidents, hospital readmission rates, emergency department admission rates). Other key measures are listed as a "yes/no" checklist:[201]

- Discharge planning checklist
- Shift huddles and bedside shift report
- An accountable leader for patient engagement
- Patient engagement committee or patient partners on committees
- One or more patient representatives serving on the board of directors

Primary care providers can measure their patients' experiences in their practices with the Primary Care Patient Experience Survey. The survey was developed by Health Quality Ontario[202] in collaboration with the Association of Family Health Teams of Ontario, the Association of Ontario Health Centres, the Ontario College of Family Physicians, and the Ontario Medical Association.

Additional measurement tools and methods

Surveys are a primary source of quantitative data and highlight key improvement areas. While they can tell you *what* people think and experience, they do not necessarily tell you *why*. It is usually not possible to ask follow-up questions to better understand a patient's responses. Using a mix of measures (both quantitative and qualitative) and tools provides for more robust evaluation findings.

Qualitative data, to better understand patient engagement experience nuances, is collected in different ways. Patients (and/or PFAs and volunteers) sometimes play an active role in collecting this data. Collection methods include:

- One-on-one interviews (e.g., Patient Family Voices Volunteers interview and document patient and family perceptions of their hospital care experience)[203]
- Focus group discussions (e.g., Small groups gather to discuss and explore their views in detail, providing an opportunity to listen to a range of opinions and experiences)
- Direct patient engagement observations at the point of care, sometimes using video[204]
- Ipads or postcards to gather feedback on key questions, such as:[205]
    - Please share one positive example from your recent office visit/hospital experience.
    - Please share one example that could have been improved.
    - If you could make one change in the care you received, what would it be?

Patients Canada is currently developing key performance targets to measure patient and caregiver experiences and identify improvement areas that can lead to more patient-centred care in the healthcare system.[206] This work uses stories or narratives of a patient's experience.

Enhancing quality and safety monitoring processes

Regular processes for partnering with patients and families to monitor and evaluate quality and safety can be enhanced if they consider patient experience data and other measures of patient engagement.

The Health Research and Education Trust[207] developed a Leadership Resource for Patient and Family Engagement Strategies, which describes practical examples of patient engagement linked to measures and outcomes. While largely quantitative measures are provided as examples, the following table (adapted) provides a good link between engagement, measures, and outcomes or improvements.

Description/process	Measurement	Outcomes
Patients and families participate in rounds; orders and discharge paperwork are clarified; patients and families are involved in decisions	• Percentage of patients and families that participate in rounds • Number of stories in which new information is discovered from patient and family • Length of time for rounds • Patient and family satisfaction scores • Staff satisfaction scores • Length of stay	• Decrease in length of stay • Increase in satisfaction scores • Decrease in readmissions rate, safety outcomes • Change in percentage of near misses versus harmful incidents

4.3 Evaluating patient engagement at the organizational level

It is also important to measure patient engagement quality and impact at the organization and system levels. This includes patient and family advisory councils, patient and family committees, and working groups or teams at various organization levels serving different purposes (e.g., service design, policy-making, quality improvement, and safety).

Patients and families are also engaging as partners in the evaluation process to help identify appropriate measures, develop and implement measure tools, analyze findings, etc. For example, Cancer Care Ontario worked in partnership with patient family advisors to develop and test an evidence-based advisor survey to measure the advisor experience.

Remember to prepare patients and families to co-design and support evaluation. For example, Patients for Patient Safety Canada (PFPSC) volunteers selected for evaluation committees are oriented by staff to the specific task and to the team. Evaluations they contribute to include: advisors to the independent evaluation of PFPSC, leads in the post-participation evaluation of PFPSC, members of the Evaluation Action Team mandated to evaluate the National Patient Safety Consortium and the Integrated Patient Safety Action Plan.

Measures and tools for evaluating patient engagement at the organizational level

Patient engagement evaluation at this level can easily draw from the broader field of public engagement, which includes but is not specific to patient engagement.

Quantitative measures often track what is being done, including the number of patients and families engaged, the number and type of activities where patients or family were engaged, or the number of requests for patient partners.

To understand if the engagement was meaningful to participants, evaluate if engagement process goals were achieved, and track and understand engagement quality. Achieving meaningful engagement requires that participants:

- Know the purpose for their involvement
- Have good and comprehensive information to support their participation
- Can freely voice their ideas and concerns
- Know what will happen with their input
- Have evidence of the commitment of decision-makers to respect their input
- Are informed about the decisions made, and how their involvement informed these decisions.

In the PPEET,[208] engagement quality is assessed (at least in part) through the "integrity of design and process," which includes these outcomes:[209]

- Public and Patient Engagement (PPE) participants represent the diverse range of views of those most affected by the decision.
- Participants have access to supports that enable participation, such as:

  - Meeting-related expenses
  - Compensation, where possible
  - Comfortable, non-threatening, and convenient activity locations, amenities, times, and days
  - Relevant information, produced at an appropriate education level
- Clear, two-way communication exists between organizers and participants:
  - Process and objectives are clearly communicated.
  - Participants understand how their input will be used.
  - The outputs of the PPE activity process are reported to participants, including how their input will be used in the decision.

These are evaluated through the participant and project questionnaires. Respondents use a five-point to scale to rate measures, such as:

- Participant questionnaire
  - I had enough information to contribute to the topic being discussed.
  - I was able to express my views freely.
  - I think this activity will make a difference.

- Project questionnaire
  - The project plan had a clear strategy to identify and recruit those most affected by the decision.
  - The project plan included a clear statement about how goals and expectations for the PPE activity would be shared with participants.
  - The project plan indicated how PPE input would be used.

More organizations are measuring not just how many people are involved, but also who is involved. Collecting information such as age, language, and cultural background helps monitor perspective diversity and sets targets for more equitable engagement. This includes engaging those who are more vulnerable and marginalized or where there might be barriers to their engagement (e.g., language).

The American Institute for Research has developed an inventory of patient engagement measures.[210] The database presents different measurement areas tools to gather information. Some measurement examples for the organizational level are included in the following table.

Excerpt – patient engagement measures inventory			
Measurement area	**Measure example**	**Measurement tool examples**	**Completed by**
Leadership support	Leaders provide resources (in the form of time, money, personnel) to support patient engagement	Checklist to Improve Effective Communication, Cultural Competence, and PFCC[211]	Providers
Participation in organizational partnerships	Patients and families help analyze a harmful patient safety incident	Patient Engagement Survey[212]	Senior leaders (e.g., CEO, CNO), although some questions could be adapted for patients to complete
Policies	Patient partners help develop, implement, and evaluate a hospital's family presence policy	Better Together Partnering with Families – Organizational Self-Assessment[213]	Providers

Structures	Patients and families participate on committees, workgroups, and/or task forces	Patient-Centered Care Improvement Guide Self-Assessment Tool[214]	Providers, although some questions could be adapted for patients to complete

Comprehensive orientation provided to new team members and client and family representatives. Services are co-designed with clients and families, partners, and the community.

Patient partner engagement at the organizational or unit level often requires ongoing and long-term collaboration. The Evaluate Team Collaboration Skills tool provided in A Resource Toolkit for Engaging Patient and Families at the Planning Table[215] evaluates collaboration quality and how it changes over time. It assesses respect and diversity, structure of participation, and trust on a five-point scale as shown in this trust scale:

Domain	Old ways	First steps	Making headway	Picking up speed	Strong momentum
Trust	I think that others' intents are self-serving. I am afraid to say what I think.	I'm observing and assessing the safety of the group, such as people's attitudes and non-verbal communication, and whether I have peers here.	I'm experiencing dialogue, which gives me the opportunity to hear others' views. I don't think the group punishes people who express contrary opinions.	I mostly trust the good intentions and motives of others in the group. I am coming to believe in the value of what we can learn from each other.	I realize that the best resolutions require everyone's contributions and expertise.

Self-assessment tools are also useful. For example, Spectrum Health[216] developed a goal-setting tool to help patient and family advisory councils (PFACs) reflect on their work during the previous year and set goals for the coming year. Spectrum Health is an integrated health system in the United States, with 17 active PFACs that incorporate patient and family perspectives when planning how care should be provided.

- Using a 10-point rating scale, PFAC members used a self-assessment tool to individually and collectively rank where they felt the PFAC was collaborating effectively (meetings, PFAC members, health leaders engaged with the PFAC, and alignment of PFAC goals with key organizational strategies and service goals).
- The assessment results helped the PFAC plan for improvements and refine their goals for the coming year.

Multifaceted approaches to evaluating patient engagement are also used. A variety of methods and tools were used in the evaluation[217] of the two-year engagement project, Partners Advancing Transitions in Healthcare (PATH):

- These included observational data, surveys, focus groups, interviews, and patient-reported outcomes using a technology tool.
- One method used was social network analysis, which mapped the social networks of all the PATH partners (patients, family caregivers, partner organizations and providers), showing connections and relationships prior to the establishment of PATH (e.g., at the proposal stage) and six months later.
- The results showed how much more interconnected people became over the course of the PATH project, with patients and family caregivers reporting almost 10 times as many connections on average compared to partner organizations and providers.

4.4 Evaluating patient engagement integration into an organization

As organizations embed engagement into the way they work, evaluating progress is critical. Keeping it on leadership's radar is also important. One way to do that is to embed it into existing performance metrics (dashboard or other) or corporate level metrics. For example, the Institute for Patient and Family-Centered Care in the U.S. has developed dashboards[218] (one-page graphic summaries) of key measures for patient and family-centered care—for the hospital or outpatient clinic.

- Process measures for engagement of patient and family advisors (PFAs) include number of advisors, hours contributed by PFAs, dollar value of their time, and number and type of committees and teams with PFAs.
- Other key measures of good patient engagement practice are in a "yes/no" checklist:[219]
    - Appointment of an accountable leader for patient engagement
    - Patient engagement committee or PFAs on committees
    - One or more patient representatives serving on the board of directors.

The Health Research and Educational Trust Patient and Family Engagement Survey[220] suggests the following measures be used regularly to track patient engagement implementation strategies and organizational impact in hospitals:

- The number of advisory councils across the hospital
- Ratio of patient and family members to staff on advisory councils
- Number of patient partners serving on committees or quality improvement (QI) teams
- Number of staff trained in partnering with families
- Number of staff trained in communicating to support patient engagement
- Changes in patients' ratings of hospital care as patient engagement strategies are implemented
- Changes in clinical process and outcomes as patient engagement strategies are implemented
- Changes in market or financial performance as patient engagement strategies are implemented

These measures point to the importance of organizational culture and the role it plays in engagement processes.

One of the four elements of quality engagement assessed on the public and patient engagement evaluation tool (PPEET) [221] is participatory culture—a significant factor that influences engagement processes.[222] It focuses on these prioritized outcomes:[223]

- The organization promotes and supports ongoing quality public engagement in strategic planning, policy, and service delivery by embedding PPE values and principles in the organization's philosophy and structure.
- Organizational leaders and managers have received training in PPE.
- PPE practice is being implemented in service and policy work and is part of standardized business and planning processes.

These are evaluated through an organizational questionnaire for senior leaders within the organization (e.g., board members, executive team, department leads, managers, senior project leads and/or project sponsors, and organization partners). Respondents use a five-point to scale to rate measures, such as:

- The organization seeks public and patient input when considering patient safety and quality of care.
- A commitment to PPE values and principles is in key organizational documents (e.g., mission and vision, strategy, etc.).
- Comprehensive PPE training and materials are available to support staff.
- Organizational leaders ensure that public and patient input is used in service planning and decision-making.

Other dimensions of the organization questionnaire include:

Policies and practices that support PPE planning and implementation	Influence and impact
• An explicit strategy guides the planning of public and patient engagement (PPE) activities.	• PPE reports are sent to relevant predetermined users in the organization (e.g., program

• The organization has explicit strategies for identifying and recruiting relevant public and patient participants depending on the engagement activity. • There is direct resourcing for PPE within the organization (e.g., through dedicated PPE unit and/or staff).	manager, senior management, board members). • Organizational leaders or program areas report using input from PPE activities. • I am aware of PPE activities that have influenced relevant Board decisions.

4.5 Summary – what you can do

Patients, families, and patient partners

Patients and families can ask how to share feedback, experience, and ideas about patient engagement and patient safety by:

- Completing a survey
- Agreeing to be interviewed to share your story
- Participating in a focus group discussion
- Participating in a community meeting or forum to share your experience
- Reading documents

Patient partners can ask how patient engagement influences patient safety across the organization and/or system by:

- Exploring how decisions will impact patients and families
- Describing what success looks like for patients and families
- Checking if patient experience data is being considered in planning and decision-making
- Suggesting other ways to monitor and evaluate patient engagement
- Asking when and how the learning about engagement activity results will be shared
- Reflecting on your own participation in the process
- Obtaining your engagement results
- Asking if there is an evaluation plan for patient engagement and how to get involved
- Suggesting that the patient and family advisory council assess how it is working together and achieving its goals

Providers and patient engagement specialists

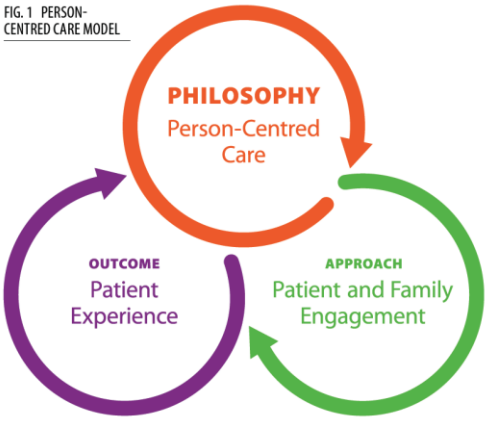
- Reflect on your own experience with patient engagement and what could be improved.
- Regularly review patient experience data to identify improvement opportunities.
- Develop an evaluation plan for engagement. Determine which measures can be linked to and inform the organization's overall evaluation strategy and dashboards.
- Invite and encourage patient partners to give their perspectives on how to define and evaluate success.
    - Ensure that measurement/evaluation is a regular agenda item.
- Produce an annual report that summarizes patient engagement processes and outcomes.
- Close the loop with the patient partners by communicating how their feedback was used, actions taken, and any follow-up steps.
- If you are responsible for monitoring or evaluating a safety or improvement project:
    - Ensure a good fit between patient partners and the evaluation work and team
    - Describe the patient partner role in the evaluation committee and project team
    - Provide background information about the topic or area evaluated
    - Provide orientation to the methodology used, including common terms and definitions, specific tools and strategies, and ways to display data

Leaders

- Foster a learning culture that values monitoring and evaluation at all levels to improve quality and safety.
- Educate the board and staff about Accreditation Canada standards for client and family-centered care.
- Specify behaviours, actions, policies, and procedures that support patient engagement.
- Establish a baseline for measures in patient and family-centered care, and patient engagement using organizational assessment tools.
- Include patient engagement, and patient and family-centered care key performance targets in organizational performance measures.
- Integrate patient engagement evaluation into protocols, charters or terms of reference for committees that develop policy, redesign care processes, or improve quality and safety.
- Support measuring patient engagement quality and impact during planning, bringing in the perspectives of all involved (e.g., patients and family, providers, decision-makers).

4.6 Practice examples

Evaluating a provincial advisory council and advisor experience – Cancer Care Ontario



"We asked ourselves whether patients can have an influence on the cancer and renal systems at a strategic level. The answer is yes, they can."

Cancer Care Ontario[224] (CCO) uses patient engagement to implement patient and family-centred care within the organization and its services. In their report, Improving Ontario's Health System through Patient Engagement, CCO demonstrated what patient engagement looks like, why it is important, and the value they have seen so far.

Setting up a patient and family advisory council was a key strategy to engage patients and families at the strategic level in the organization. To assess the impact of PFAC feedback, CCO used a structured debrief interview with people (CCO program member or other individuals) after they had made a presentation to the PFAC. They asked the following questions in the interviews:

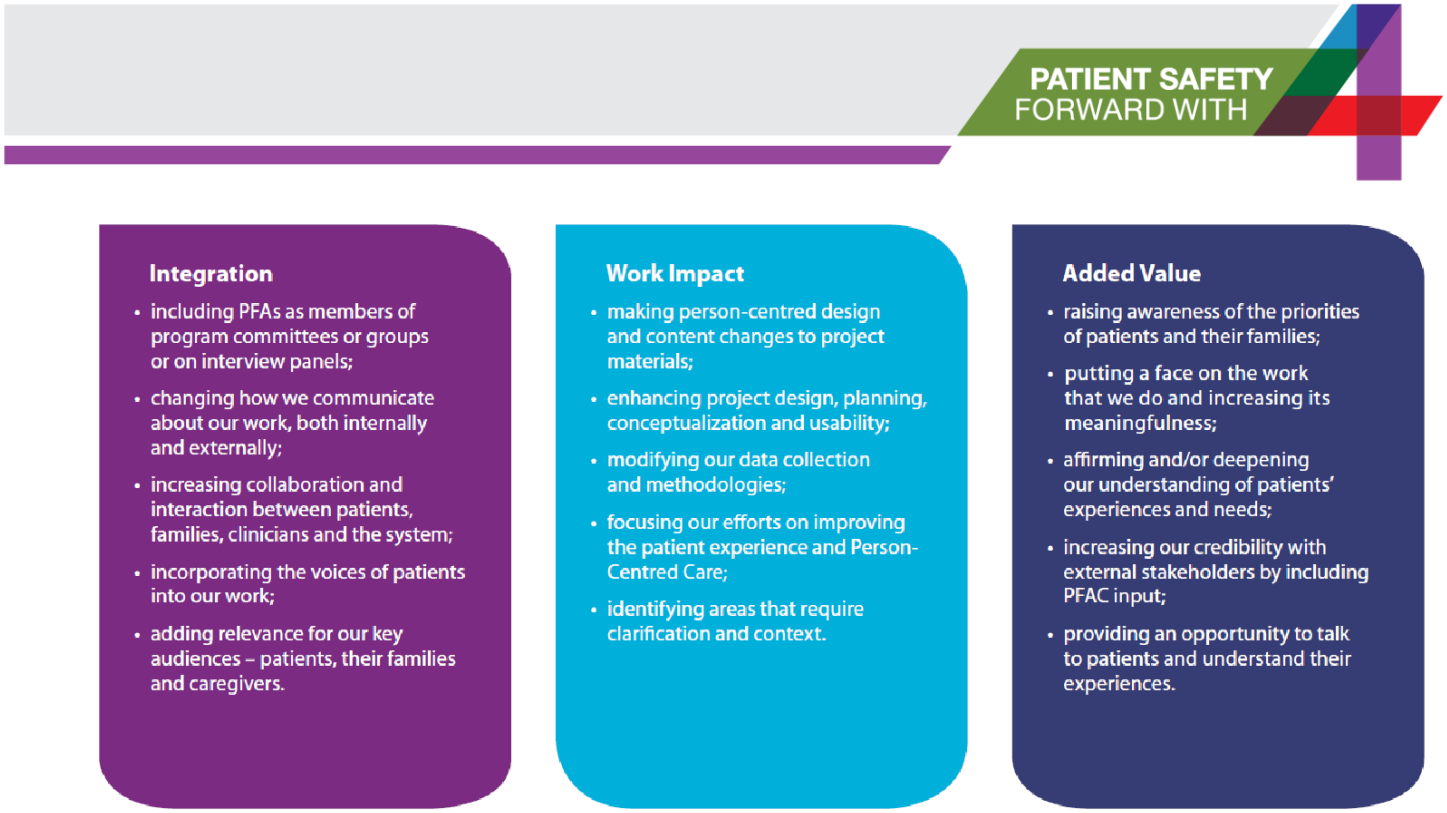
- How did you incorporate the input and feedback received from the PFAC (after your presentation)?
- Have those interactions changed the course of your work?
- How would you describe the value of having the PFAC input into your work?

The responses were grouped by impact into three areas: integration, work impact, and added value see table below). Understanding the effects of PFAC feedback in transforming healthcare design, delivery, and evaluation is invaluable when measuring patient engagement at the system level.

CCO was recognized for partnering with patient family advisors to develop and test an evidence-based advisor survey to measure the advisor experience. The goals of the project were to:

- Monitor and identify process improvements for engaging advisors on an ongoing basis
- Provide a standardized tool to the regional programs to assess their own advisor engagement and report their progress at a provincial level
- Create a quarterly survey tool for CCO and the Ontario Renal Network to administer to their current advisors and use the data to report on the organization's corporate balance scorecard.

Perspectives of CCO program representatives on the impact of CCO PFAC



CCO also developed surveys to help measure advisor experiences.

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