

# ENGAGING PATIENTS IN PATIENT SAFETY

A CANADIAN GUIDE

Patient Engagement Action Team – February 2018



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

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



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# TABLE OF CONTENTS

- 1. Engaging patients as partners ..... 4**
- 1.1 Why partner on patient safety and quality? ..... 4
- 1.2 Current state of patient engagement across Canada ..... 6
  - Patients and patient groups become trusted partners ..... 6
  - Grassroots efforts became embedded at all system levels ..... 7
  - Gaps in current practice ..... 8
- 1.3 Evidence of patient engagement benefits and impact ..... 9
  - How partnering with patients is making an impact ..... 9
  - Building stronger evidence for patient engagement ..... 11
- 1.4 Challenges and enablers to patient engagement ..... 11
  - Patient engagement challenges ..... 11
  - Patient engagement enablers ..... 13
  - Culture and leadership as patient engagement critical enablers ..... 14
- 1.5 Embedding and sustaining patient engagement ..... 16
  - Infrastructure and resources ..... 16
  - Patient engagement continuum ..... 18
- 1.6 Summary – What you can do ..... 19
  - Patients, families, and patient partners ..... 19
  - Providers, patient engagement specialists ..... 19
  - Leaders ..... 19
- 1.7 Practice example ..... 20
  - Patient engagement on committees and initiatives – McGill University Health Centre ..... 20
- Supporting References ..... 21**

# 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.”<sup>1</sup>

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 (eighth out of 11 countries), timeliness of care (11<sup>th</sup> out of 11), coordinated care (eighth out of 11), and safe care (10<sup>th</sup> out of 11). In 2014–2015, there was [at least one harmful incident for every 18 Canadian hospital stays](#) (138,000 out of 2.5 million hospital stays).<sup>2,3</sup>

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.<sup>7,8,9,10,11,12,13,14</sup>

Fundamentally, patients expect to be safe while receiving care. 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 value.

**Patient:** includes client, resident, person, individual, etc. and refers to those most impacted. [See Glossary.](#)

**Patient engagement:** an approach to involve patients, families and/or patient partners in:<sup>4</sup>

- 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<sup>5</sup> in ongoing, meaningful, constructive relationships at all system levels:

- Direct care
- Healthcare organization (service design, governance)
- Health system (setting priorities and policies)<sup>6</sup>

### 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<sup>15</sup> 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.”<sup>16</sup> Patients bring new, innovative approaches:<sup>17</sup>

- 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.<sup>18</sup>
- Engaged patients better understand and know more about their care, leading to better health service and resource use.<sup>19</sup>
- Partnering with patients in planning and designing healthcare services is an important way to improve care quality and accountability in the system.<sup>20</sup> 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.<sup>21,22</sup>

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



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

support patient engagement and shift to more patient-centred care.<sup>23</sup> 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

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.<sup>24</sup>

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.<sup>25</sup>

### 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.<sup>26</sup> 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 policymakers 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. Through meetings and building relationships, the

Canadian Patient Safety Institute 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.<sup>27,28,29,30,31</sup>

- 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.<sup>32</sup>
- The Canadian Patient Safety Institute's [National Patient Safety Consortium](#) identified patient engagement as a key focus area in the collective effort of key patient safety and quality organizations. The Canadian Patient Safety Institute has been modelling patient engagement in patient safety for more than a decade by ensuring that 100 per cent of programs are developed and delivered in partnership with patients. The Canadian Patient Safety Institute also develops specific [resources for patients and the public](#), and supports [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 and territorial levels, jurisdictions have 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.<sup>33</sup> These priorities continue to shape progressive change that embeds "Patient First" as a core value and focuses on improving the patient experience. The [Saskatchewan Health Quality Council's](#) number one priority is to integrate patients and families as partners in all aspects of healthcare.<sup>34</sup>
- [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.<sup>35</sup>
- Capital Health Authority in Nova Scotia (now the [Nova Scotia Health Authority](#)) introduced a policy<sup>36</sup> 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.<sup>37</sup>

## Gaps in current practice

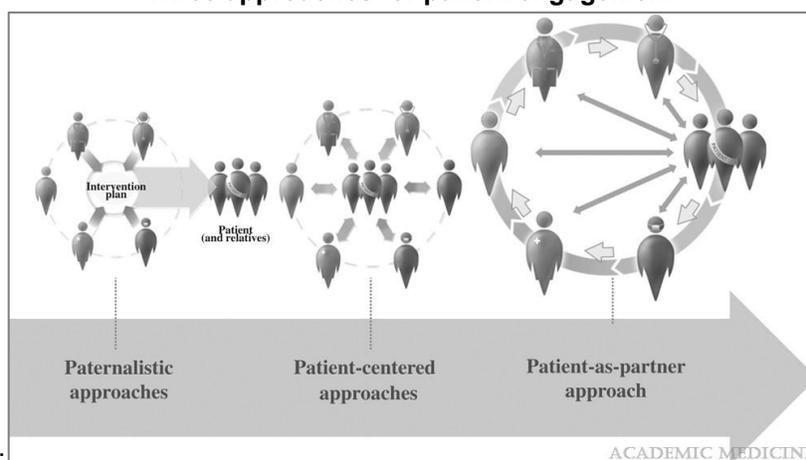
Despite progress, a [national consultation](#) in 2015 found that more needs to be done to increase patient engagement in organizations and the healthcare system.<sup>38</sup> The report found that providers and administrators in Canada's healthcare system acknowledge that patients—and their perspectives 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

To close the gap in practice, a good starting point is to understand the patient engagement approach currently used. According to the [Direction of Collaboration and Patient Partnership](#), University of Montreal, in paternalistic approaches, the work of healthcare professionals is centered on the intervention plan, and patients take little part. Patient-centred approaches put patients at the center of the healthcare professionals' work and concerns. In the patient-as-partner approach, patients are members of the health care team; like all other team members, they bring their unique expertise.

### Three approaches for patient engagement



© Direction of Collaboration and Patient Partnership, University of Montreal, 2013 (reproduced with permission). Source: [The Patient-as-Partner Approach in Health Care: A Conceptual Framework for a Necessary Transition](#). *Academic Medicine*:90(4):437-441, April 2015.

### 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.<sup>39,40,41</sup> 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)<sup>42</sup> 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.<sup>43,44</sup> 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.<sup>45,46</sup>

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.



#### 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.<sup>47,48</sup> 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	<ul style="list-style-type: none"> <li>Improved hand hygiene rates and reduced infection rates</li> <li>Better medication self-management<sup>49</sup></li> <li>Reduced patient safety incidents, such as medication errors or patient falls</li> <li>Increased identification of potential safety issues by patients and families that prevent safety events from occurring<sup>50,51</sup></li> </ul>
Patient and family-centred care	<ul style="list-style-type: none"> <li>Reduced anxiety and stress with the presence of family/supports</li> <li>Improved patient/provider communication</li> <li>Better understanding of health, options, and the care plan</li> <li>Improved patient satisfaction and care experience<sup>52</sup></li> </ul>
Coordination of care	<ul style="list-style-type: none"> <li>Better transition from hospital to home, discharge planning</li> <li>Improved interprofessional teamwork</li> </ul>
Equity	<ul style="list-style-type: none"> <li>Improved cultural awareness and consideration when providing services</li> </ul>
Health outcomes <sup>53</sup>	<ul style="list-style-type: none"> <li>Improved patient emotional health</li> <li>Better symptom resolution, functioning, pain control</li> <li>Improved physiologic measures, (e.g., blood pressure, blood sugar levels)</li> <li>Decreased death rate for people with chronic obstructive pulmonary disorder<sup>54</sup></li> </ul>

Select quality areas	Example of improvements
Effectiveness and appropriateness	<ul style="list-style-type: none"> <li>Improved care and service delivery after co-design with patients, (e.g., staff wearing identification badges, purposeful hourly rounding at the bedside)</li> <li>Reduced rates of preventable readmissions to hospital<sup>55</sup></li> <li>Reduced lengths of stay in hospital<sup>56</sup></li> </ul>
Efficiency	<ul style="list-style-type: none"> <li>Lower costs per patient stay in hospital</li> <li>Better staff recruitment and retention and staffing mix</li> <li>Lower medical and legal costs from law suits against the provider/organization</li> </ul>

### Impact on patient safety

Studies show that patients and families can provide unique safety information and be valuable partners in safety surveillance.<sup>57,58,59,60</sup> 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 per cent, and harmful patient safety incidents increased by 10 per cent.

Evidence proves that involving patients can help improve infection control (e.g., their own hand hygiene, the hand hygiene of their providers).<sup>61</sup> 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.<sup>62,63</sup> 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.<sup>64</sup> 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<sup>65</sup>. 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.<sup>66</sup> 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.<sup>67</sup> 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.<sup>68</sup>

### **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.<sup>69</sup>

## **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.”<sup>70</sup>

### **Patient engagement challenges**

Some common challenges related to patient engagement in general are also common to patient engagement in patient safety. They include:<sup>71,72,73</sup>

- 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 resources
- 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.<sup>74</sup> 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:<sup>48</sup>

- 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

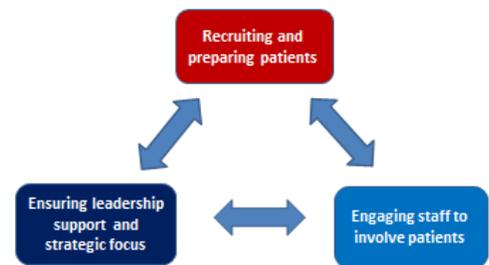
Finally, organizational patient safety performance targets and incentives may not always be consistent with patient engagement.

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

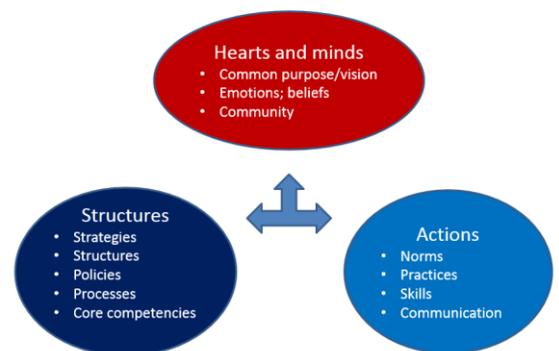
Based on a research and practice review, researchers found three tightly linked factors that reinforce each other to enable patient engagement:<sup>75</sup>

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:<sup>76</sup>

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.<sup>77</sup> 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.



Other influences: culture/society, legislation, standards, health professional regulations

There are specific, interconnected factors that enable patient engagement in patient safety, influenced by a culture of safety. To enable patient engagement, organizations should:<sup>78</sup>

- 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.”<sup>79</sup>

### 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.<sup>80,81</sup> Organizations should combine improvement efforts in safety and quality with patient engagement to include every aspect of care and every strategy.<sup>82,83</sup>

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:<sup>84</sup>

- 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:<sup>85,86</sup>

- 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:<sup>87,88</sup>

- 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<sup>89</sup>
- 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)

For patient and family-centred care strategies to be properly developed and implemented, healthcare organizations should strive towards:<sup>90</sup>

- 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



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

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)<sup>91</sup> 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.

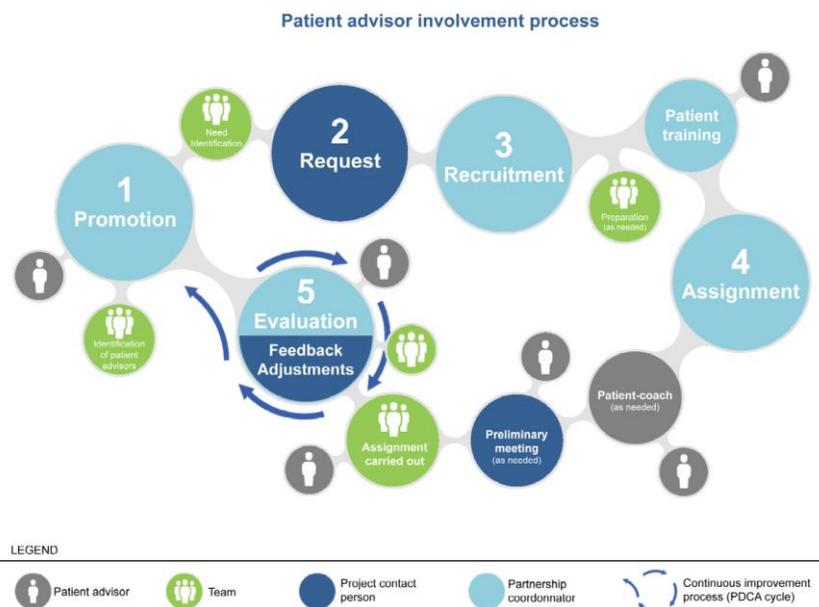
## 1.5 Embedding and sustaining patient engagement

### 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)<sup>92</sup>
- 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)<sup>93</sup>
- 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 other



Patient engagement infrastructure and resources include:<sup>94</sup>

### **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:<sup>95</sup>

- 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.<sup>96</sup> 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.<sup>97,98</sup>

### **Human resources**

Human resource departments can promote patient engagement through recruitment, orientation and support to providers, leaders and staff by ensuring:<sup>99,100,101</sup>

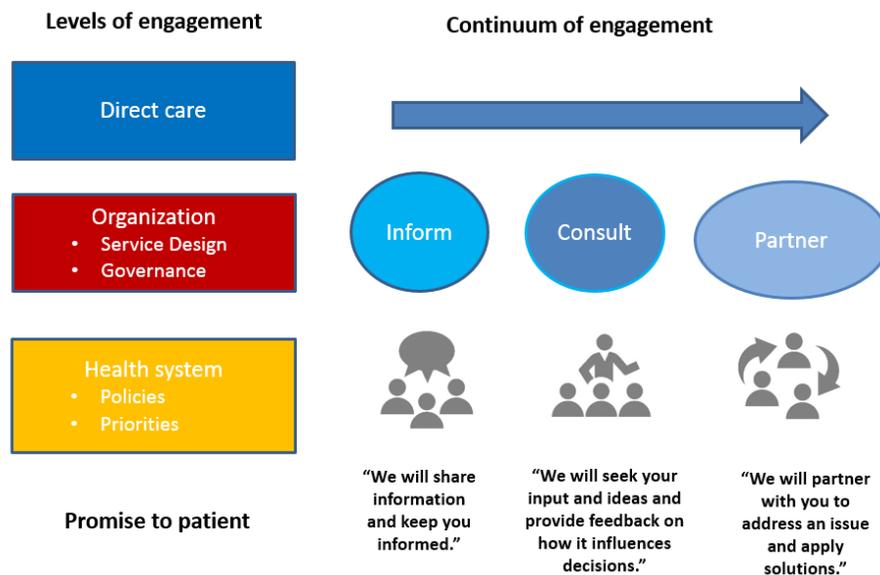
- Job descriptions include basic patient engagement principles
- Interview questions include patient engagement
- Interview processes and panels include patient partners
- Orientation includes patient engagement, patient experiences, and patient partners
- Performance appraisals encourage continued skill 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 the [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](#).<sup>102</sup> 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 per cent decrease in medication incidents.
- 8 per cent increase in registered nurses' direct time in care.
- Increased patient satisfaction.
- Cost savings in equipment.
- Decreased infection rates (25 per cent for clostridium difficile and 26 per cent for vancomycin-resistant enterococci).
- Improved team effectiveness.
- Statistically significant reduction in nurses' voluntary turnover and overtime.

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