

ENGAGING PATIENTS IN PATIENT SAFETY

A CANADIAN GUIDE

Patient Engagement Action Team – February 2018



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

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



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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.”¹

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.^{2,3,4}

Evaluation involves systematically assessing an initiative’s design, implementation, and results to learn or influence decisions.⁵ 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.

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 of evaluation measures (adapted from [Alberta Health Services](#)):

Engagement process measures	Engagement outcome measures
<ul style="list-style-type: none"> • 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 	<ul style="list-style-type: none"> • 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 one to five, 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.⁶

More work is needed to develop and share practical tools for measuring engagement process quality and its impact on healthcare processes and health outcomes.^{7,8} 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:⁹

Components	Description	Examples
Purpose	<ul style="list-style-type: none"> Why are you conducting the evaluation and how will the results be used? 	<ul style="list-style-type: none"> Judge program merit or worth Improve programs Generate knowledge Increase engagement, motivation, and ownership Accreditation
Target audience(s)	<ul style="list-style-type: none"> Who are the intended recipients or users of the evaluation results? 	<ul style="list-style-type: none"> Patient partners Healthcare providers Board of directors
Participants	<ul style="list-style-type: none"> From whom will the data be collected? Who will conduct the evaluation? What preparation is needed for people to best fulfill their roles? 	<ul style="list-style-type: none"> Frequent users Frontline providers, patient, and family partners External evaluator
Evaluation questions and measures	<ul style="list-style-type: none"> 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.¹⁰ Consider ethical or privacy issues 	<ul style="list-style-type: none"> Did patients and families feel their perspectives were heard? What was their experience?
Methods and tools	<ul style="list-style-type: none"> 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? 	<ul style="list-style-type: none"> Surveys, interviews Interview script, survey tool
Data collection strategy	<ul style="list-style-type: none"> What data needs to be collected? When will it be collected and by whom? 	<ul style="list-style-type: none"> Observational data Patient narratives
Analysis	<ul style="list-style-type: none"> How will the data be analyzed? Is the amount of data to be collected manageable (i.e., only what can be used)? 	<ul style="list-style-type: none"> Text analytics. Thematic content analysis. Statistical analysis.
Result communications	<ul style="list-style-type: none"> Who is the target audience? How can results best be shared with the target audiences? 	<ul style="list-style-type: none"> Written report, infographic Presentation, workshop
Required resources	<ul style="list-style-type: none"> Determine and secure the resources needed for the evaluation This will also help verify the extent of the evaluation 	<ul style="list-style-type: none"> 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.¹¹ It may be used in a variety of healthcare organizations.¹² 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)
- M-P Pomey in collaboration with the integrated health center CIUSSS Mauricie-Centre-du-Quebec developed two questionnaires to evaluate patient advisors' participation. One for [healthcare providers](#)¹³ and one for [patient advisors](#).

The [Patient and Public Engagement Evaluation Toolkit](#)¹⁴ is a resource designed for practitioners of the health sector, produced after the completion of a rigorous systematic review of patient and public engagement evaluation tools. The searchable database includes a wide range of tools to assist in the evaluation of patient and public engagement initiatives, both in health research and in healthcare.

Additional examples of evaluation tools and resources are available [at Selected-Resources-to-support-Patient-Engagement-in-Patient-Safety](#).

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-centred care (PFCC) is being implemented in healthcare organizations.¹⁵

The American Institute for Research has developed an inventory of patient engagement measures, many of which are linked to PFCC.¹⁶ 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 ¹⁷	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 ¹⁸	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 ¹⁹	Providers
Communications	Clinicians invite patients and families to ask questions	Patient-Centered Care Improvement Guide Self-Assessment Tool ²⁰	Providers, although some 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 ²¹	Providers
Shared care planning and decision-making	Clinicians invite and welcome patients and families as partners in care planning and decision-making	CollaboRATE ²²	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.

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)²³
- 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 video²⁴
 - Ipads or postcards to gather feedback on key questions, such as:²⁵
 - 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?

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.²⁶ 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.²⁷ 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 dashboards²⁸ 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:²⁹

- 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 Ontario³⁰ 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.

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 Trust³¹ 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	<ul style="list-style-type: none"> • 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 	<ul style="list-style-type: none"> • 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. Remember to prepare patients and families to co-design and support evaluation. For example, Patients for Patient Safety Canada (PFPS) 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 PFPS](#), leads in the post-participation evaluation of PFPS, 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,³² engagement quality is assessed (at least in part) through the “integrity of design and process,” which includes these outcomes:³³

- 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.³⁴ 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 ³⁵	Providers
Participation in organizational partnerships	Patients and families help analyze a harmful patient safety incident.	Patient Engagement Survey ³⁶	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 ³⁷	Providers
Structures	Patients and families participate on committees, workgroups, and/or task forces.	Patient-Centered Care Improvement Guide Self-Assessment Tool ³⁸	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 Table³⁹ 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 Health⁴⁰ 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 evaluation⁴¹ 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 United States has developed [dashboards](#)⁴² (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:⁴³
 - 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 Survey⁴⁴ 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) ⁴⁵ is participatory culture—a significant factor that influences engagement processes.⁴⁶ It focuses on these prioritized outcomes:⁴⁷

- 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
<ul style="list-style-type: none"> • An explicit strategy guides the planning of public and patient engagement (PPE) activities • 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) 	<ul style="list-style-type: none"> • PPE reports are sent to relevant predetermined users in the organization (e.g., program 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

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

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 and appropriate orientation

Leaders

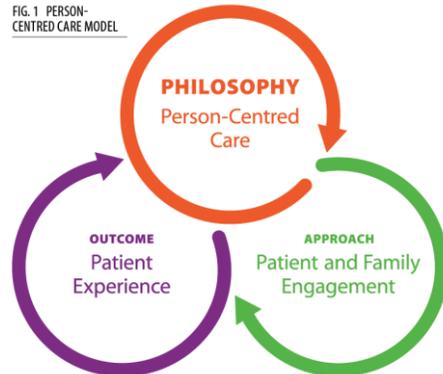
- Foster a learning culture that values monitoring and evaluation
- Educate the board and staff about standards for client and family-centred care
- Establish a baseline for measures in patient and family-centred care, and patient engagement using organizational assessment tools
- Include patient engagement, and patient and family-centred 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 example

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](#)⁴⁸ (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

Integration

- including PFAs as members of program committees or groups or on interview panels;
- changing how we communicate about our work, both internally and externally;
- increasing collaboration and interaction between patients, families, clinicians and the system;
- incorporating the voices of patients into our work;
- adding relevance for our key audiences – patients, their families and caregivers.

Work Impact

- making person-centred design and content changes to project materials;
- enhancing project design, planning, conceptualization and usability;
- modifying our data collection and methodologies;
- focusing our efforts on improving the patient experience and Person-Centred Care;
- identifying areas that require clarification and context.

Added Value

- raising awareness of the priorities of patients and their families;
- putting a face on the work that we do and increasing its meaningfulness;
- affirming and/or deepening our understanding of patients' experiences and needs;
- increasing our credibility with external stakeholders by including PFAC input;
- providing an opportunity to talk to patients and understand their experiences.

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