



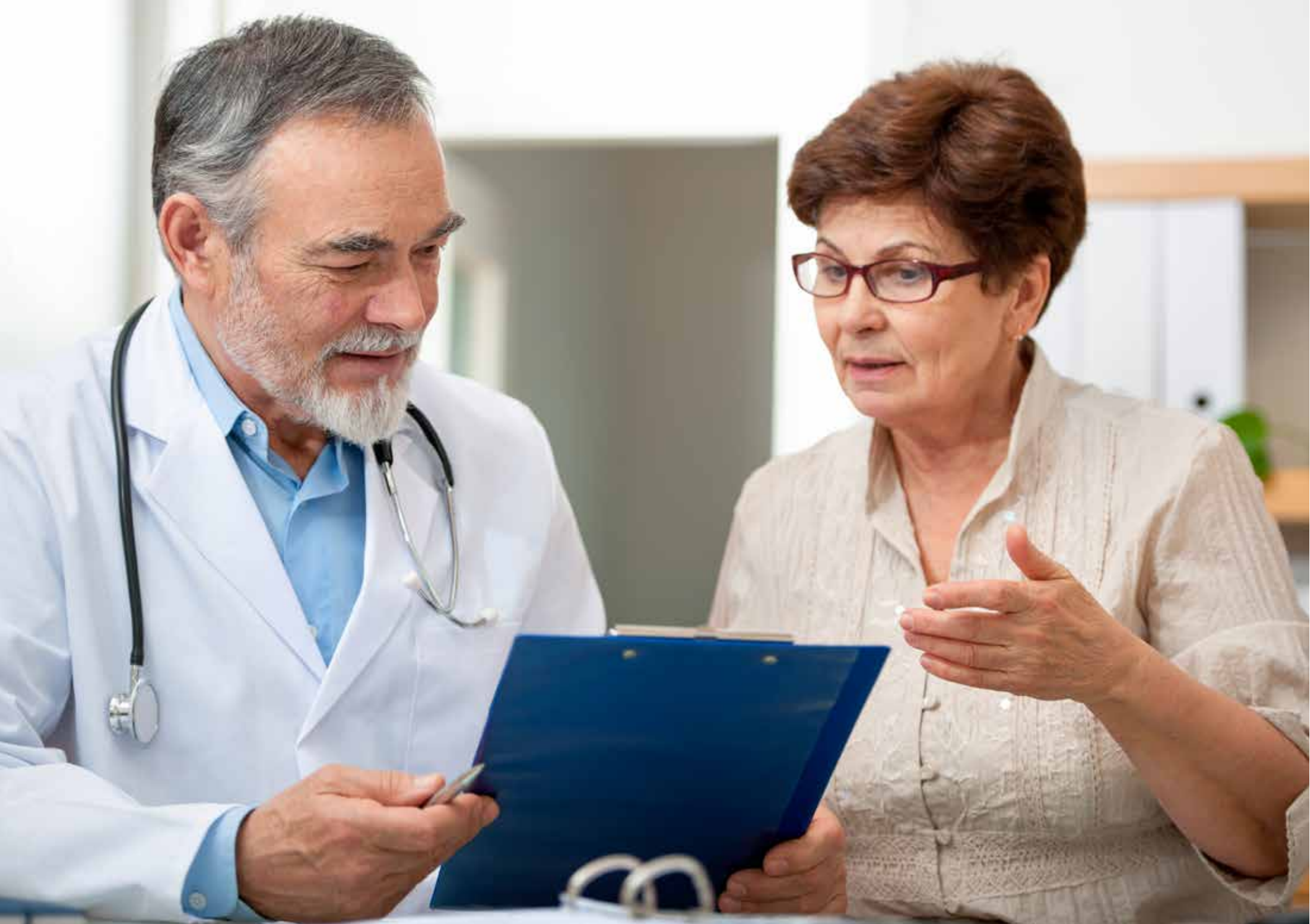
# Engaging with Patients and Caregivers about Patient Relations: A Guide for Hospitals





# Table of Contents

Executive summary . . . . .	5	Ways to engage . . . . .	19
Goals for Patient and Caregiver Engagement . . . . .	6	Assess your needs . . . . .	19
How this Guide can Help . . . . .	6	Include a variety of experiences and perspectives . . . . .	20
Introduction . . . . .	8	Choose a way to engage . . . . .	21
How to use this this guide . . . . .	8	Individual feedback . . . . .	22
Terminology . . . . .	9	Consider advanced practice . . . . .	26
Understand why to engage . . . . .	10	Keep in mind... . . . . .	26
Reasons to involve patients and caregivers . . . . .	10	Ensuring privacy . . . . .	28
New developments . . . . .	11	What you need to know . . . . .	28
Ready to engage . . . . .	12	Know your responsibilities . . . . .	29
Some things to consider . . . . .	12	Include privacy in your planning . . . . .	29
Ways to build your patient engagement team . . . . .	14	Other tips . . . . .	30
Consider joint leadership . . . . .	14	Document and report . . . . .	31
Involve patient advisors in planning . . . . .	15	Plan ahead . . . . .	31
Involve staff who will be affected . . . . .	15	Interim summary . . . . .	31
Questions to ask during the engagement . . . . .	16	Final report . . . . .	32
Find a focus for discussion . . . . .	16	Evolving your patient engagement process . . . . .	33
		Share your experiences with us . . . . .	34



# Executive Summary

Health Quality Ontario is pleased to present ***Engaging with Patients and Caregivers about Patient Relations: A Guide for Hospitals***, as part of our efforts to support quality improvement across Ontario's health system.

There is a growing recognition across the province that patient feedback, complaints and concerns can be a tremendous source of insight and a driver for positive change. As hospitals and other health service organizations receive and respond to complaints, they are able to track and identify key trends and opportunities for improvement. Many organizations are also leveraging their complaints data to inform annual quality improvement plans, meet accreditation requirements and drive other quality initiatives.

Regulation 188/15 under the *Excellent Care for All Act*, which came into effect September 1, 2015, builds on these trends to establish standards regarding hospital patient relations processes. This guide, ***Engaging with Patients and Caregivers about Patient Relations***, aims to give hospitals the tools they need to involve patients and caregivers in the development, maintenance and evaluation of their patient relations process, as specified in the regulation.

Health Quality Ontario's companion piece, [Ontario Regulation 188/15: Best Practices for Improving Patient Relations Processes in Ontario's Hospitals](#), provides an at-a-glance review of patient relations best practices and a guide to responding to the other stipulations of Regulation 188/15.

Both documents supplement the comprehensive Patient Relations Toolkit published by the Ontario Hospital Association . The Patient Relations Toolkit, which can be [downloaded on their website](#), is a complete guide to establishing a patient relations process, communicating about it, and reporting on it. Their toolkit contains specific examples of patient relations processes in hospitals across the province and other useful tools and resources.

In the meantime, below is more on engaging with patients and caregivers about patient relations. We hope it is helpful.

“ Developing and implementing a clear, transparent and accountable patient relations process is important for both patients and staff. If it is straightforward, it will be easy for patients to get their issues across and to help improve care across the hospital. If staff don't know what the process is, who to call, or where the accountability lies, it escalates patient anxiety and makes matters worse than they need to be. ”

– A Patient Advisor, Southern Ontario

## Goals for patient and caregiver engagement

Patient and caregiver engagement has an important role to play in developing, maintaining and improving patient relations processes. Hearing directly from patients and caregivers about the process of giving feedback can:

- Clarify how patients and their caregivers hope to be treated when they express feedback, concerns or complaints
- Increase a hospital's ability to communicate effectively and manage expectations around their patient relations process
- Identify process improvements that may allow hospitals to resolve more complaints at the source, reducing the need for escalation
- Improve both patient and staff satisfaction with the overall patient relations process
- Improve communication and relationships between patients, their caregivers, and hospital staff

## How this guide can help

This guide is intended to be a “how-to” for hospital staff who are responsible for engaging with patients and caregivers on what’s working well and what can be improved in their patient relations process. Often these will be staff working on quality improvement or patient experience initiatives, but may also include patient relations managers, unit managers and/or clinical leads.

The guide walks through the steps for leading an effective engagement process, including: addressing your organization’s concerns about engaging, identifying specific goals and objectives for engaging with patients, building a team to lead the work, selecting appropriate topics and engagement methods, reporting back and implementing change based on what you heard.

Each step is clearly identified, so that organizations with more experience engaging patient and family advisors can jump to the sections that are most relevant to them. For example, the guide reviews sample discussion questions and different engagement methods that can be a source of inspiration or can supplement engagement work that is already occurring. Organizations that are just beginning their patient engagement journey may find it worthwhile to review the preliminary sections on getting their organizations ready to engage and building a team to lead the work.

Table 2 on page 21 lists different methods for engaging. At a minimum, Health Quality Ontario recommends using one of the first three methods listed in the table to engage with patients and family caregivers about your patient relations process:

1. One-on-one debriefs with a sample of those who have gone through your patient relations process.
2. An evaluation survey for a larger sample of those who have gone through your patient relations process.
3. Discussions about your patient relations process with your patient and family advisors council, if you have one.

These methods provide a good place to start – and can help to identify key areas for improvement. However, it's important to note that no engagement method is perfect – different methods will allow you to ask different types of questions and engage with different populations. It is good practice to let your improvement goals inform the choice of engagement method(s).

Equally important from an engagement perspective is having a plan in place for how your hospital will take action based on the feedback received through patient and caregiver engagement. Effective engagement requires careful planning about where the feedback collected from patients and caregivers will go, and who will be responsible for implementing any recommendations that result. This guide provides suggestions for how to ensure patient and family feedback on your patient relations process can be carried forward to implementation.

As the provincial advisor on health care quality, Health Quality Ontario's goal is to support organizations in their quality improvement journey. We believe that patient and caregiver engagement has an important role to play in all aspects of quality improvement, including patient relations. We look forward to hearing from you about how patient and caregiver engagement has impacted your patient relations process and improved the quality of care within your organization.

# Introduction

Health care organizations in Ontario and elsewhere are seeking to improve how they approach patient relations: that is, how they receive and respond to patient and family caregiver feedback, concerns, and complaints about care.

Although organizations operate in varying circumstances and have different legal requirements, many face similar issues when seeking to improve patient relations. Common challenges include overcoming patient hesitation to voice concerns; helping front-line workers respond empathetically and participate in finding resolutions; ensuring effective communication; involving senior managers and organizational leadership; handling difficult situations; analyzing feedback; and tracking the implementation of recommended improvements.

This guide is designed to help hospitals improve patient relations efforts by engaging with patients and family caregivers. By listening to patients, hospitals can gain valuable insights they may not otherwise have considered.

In 2015, a new regulation was introduced under the Excellent Care for All Act that requires hospitals to “engage patients and their caregivers in designing, reviewing and maintaining ... processes for receiving, reviewing and attempting to resolve expeditiously complaints from patients and caregivers.”

The purpose of this guide is to provide hospitals with strategies for involving patients and caregivers as they work to improve their overall patient relations process.

## How to use this this guide

This guide is written for hospital staff who will be responsible for doing engagement with patient and family advisors on the patient complaints process. Most often, these will be staff who are working on quality improvement and patient experience projects, but may also include those who are directly responsible for receiving and responding to patient complaints, such as patient relations staff or unit managers.

If you are new to engaging with patient and family advisors about a quality or process improvement project, it may be helpful to start with the sections:

- Why to engage with patients and families.
- Getting ready to engage
- Ways to build your patient engagement team

These sections provide background that can help you clarify the goals and objectives for engaging, to identify and address any internal concerns or barriers to engagement, and to put together a team to help you get started. They also stress the importance of ensuring there is strong executive sponsorship for your project, which will be critical to implementing any recommended changes to your complaints process resulting from your patient and family engagement.



If your organization already has some experience working with Patient and Family Advisors on a quality improvement or patient experience project, you may wish to skim those early sections or jump directly to:

- Find a focus for discussion
- Ways to engage

These sections identify many different potential questions you could discuss with patients and their families, and cover different options for engaging with patients and families, depending on your goals and the time and resources you have available for this project.

In addition, all readers may find it useful to review the sections:

- How to build patient privacy measures into your engagement plan.
- How to summarize and share your findings so improvements can be made.
- Evolving your patient engagement program.

These sections focus on important considerations for protecting the privacy of the people you consult, and give some tips for moving forward from an initial consultation process to a cycle of engagement, change implementation, and further engagement.

## Terminology

In this guide, our focus is on hospital patient relations—on engaging patients and caregivers in improving how hospitals gather and respond to feedback, concerns, and complaints.

To ensure consistency with related materials from the Ontario Ministry of Health and Long-Term Care, the term *patient relations* is used to describe the concerns and complaints process in a variety of settings (hospital, long-term care and community care) and for a range of populations (patients, residents, clients, and their families and friends).

When we refer to patients, we are referring to all types of hospital patients (inpatients, outpatients, emergency department patients, rehabilitation patients, and others). We use the term caregivers to describe individuals such as family members and friends who have provided sustained care or support to a patient.

# Understand why to engage

## Key points

- Patients and caregivers are an important source of insight and ideas for quality improvement efforts.
- Working with patients and caregivers to improve your hospital's patient relations process has many benefits for your organization, and is a way of ensuring that patients are full participants in decisions that affect them.
- The 2010 Excellent Care for All Act requires that all Ontario hospitals have a patient relations process, and that they make information about that process available to the public.
- Engaging patients in designing, reviewing, and maintaining the patient relations process is part of a new set of Ontario [regulations](#).

## Reasons to involve patients and caregivers

Across Ontario, hospitals are increasingly engaging with patients and caregivers as an important driver for quality. Engaging with patients and caregivers can help to uncover new trends and opportunities for quality improvement, to improve patient experience and outcomes, and to design services that truly put patients at the centre of care. Many organizations are leveraging patient and caregiver input to inform annual quality improvement plans, meet accreditation requirements and drive other quality initiatives.

Engaging with patients and caregivers about something as sensitive as the process for handling patient concerns and complaints may seem challenging. But patient and caregiver engagement has an important role to play in developing, maintaining and improving patient relations processes. Hearing directly from patients and caregivers about your patient relations process can:

- Clarify how patients and their caregivers hope to be treated when they express feedback, concerns or complaints
- Increase a hospital's ability to communicate effectively and manage expectations around the patient relations process
- Identify process improvements that may allow hospitals to resolve more complaints at the source, reducing the need for escalation
- Improve both patient and staff satisfaction with the overall patient relations process
- Improve communication and relationships between patients, their caregivers, and hospital staff

As with any other engagement topic, talking with patients and caregivers about your patient relations process is really about building and sustaining good relationships, by working together to improve how health organizations provide

services and care. Receiving and resolving individual concerns and complaints is one important element of engagement, but involving patients and caregivers in the design, review and maintenance of the patient relations process can help ensure that they are full participants in decisions that affect them.

## New developments

The 2010 Excellent Care for All Act requires that all Ontario hospitals have a patient relations process, and that they make information about that process available to the public. Hospitals must also ensure that their process reflects the content of their patient declaration of values and that they consider patient relations and conduct patient engagement in the development of their quality improvement plans.

## New regulations for hospitals

In 2015, the Government of Ontario introduced new [regulations](#) that will affect how patient relations is handled across Ontario's hospitals. The new regulation requires each hospital to:

- Have processes in place for reviewing and resolving complaints made by patients and caregivers.
- Record, monitor, and analyze key information about each complaint, including the name of the complainant; the date and subject matter of the complaint; whether the complaint was resolved; and if it was, when and how that took place.
- Inform the complainant of the status of his or her complaint within 5 days of receipt and whenever he or she requests further information.
- Designate a patient relations delegate and make that person's contact information publicly available. (The patient relations delegate will be responsible for overseeing the patient relations process and for presenting aggregate patient relations data to the hospital's quality committee at least twice a year.)
- Engage patients in designing, reviewing, and maintaining the patient relations process.

## Other changes in patient relations

The Government of Ontario has also passed Bill 8—the Public Sector and MPP Accountability and Transparency Act—which includes a number of amendments to the Excellent Care for All Act that affect patient relations. Schedule 5 of Bill 8 has yet to be proclaimed and, as such, these amendments are not yet in force.

A **patient ombudsman** will be appointed whose role is to receive, investigate, seek resolution of, and respond to complaints from current and former patients and their caregivers of hospitals, long-term care homes, and community care access centres.

**Health Quality Ontario** will be given new responsibilities, including:

- Monitoring and reporting to the people of Ontario on the patient relations performance of hospitals, community care access centres, and long-term care homes.
- Supporting continuous quality improvement by promoting enhanced patient relations in health sector organizations, developing patient relations performance indicators and benchmarks for health sector organizations, and creating quality improvement supports and resources for health sector organizations, defined as hospitals, community care access centres, and long-term care homes.
- Supporting the patient ombudsman in carrying out his or her functions.

These changes and the new regulations are intended to place a special focus on improving how the patient relations process is managed across Ontario's health organizations. They have created an opportunity for hospitals to involve patients and caregivers in conversations about how to improve patient relations across the province. In so doing, they emphasize the role that patient relations can play in improving the quality of care across our health system.

# Ready to engage

## Key points

- Preparing your organization to engage with patients and caregivers as advisors is an important step in an effective engagement process
- Conduct conversations with senior leaders, your engagement planning team and hospital staff to develop strategies and build support for patient and caregiver engagement

## Some things to consider

As you consider the prospect of engaging with patients and family caregivers on your patient relations process, it's important to remember that individuals within your organization likely have different levels of personal and professional experience, and comfort working with patients and family caregivers.

Within organizations that are new to engaging with patients and caregivers as advisors, there may be a number of questions and anxieties related to patient and family engagement (particularly on a topic such as patient relations). This is okay and should only be expected.

Here are some of common questions and concerns about patient engagement that may be relevant to your organization:

- Not all members of your organization involved in this engagement process may have prior experience working/partnering with patients and/or caregivers (particularly individuals without clinical designations or involvement in the direct delivery of care).
- Individuals who are responsible for either documenting or responding to patient compliments, or in responding to compliments or complaints, may be cautious or apprehensive about engaging in a discussion about patient relations with a patient or caregiver.
- Individuals who have been involved in delivering care directly may be concerned about being challenged or hearing direct criticisms of the work of themselves, their colleagues or their unit.
- Some may be skeptical that engaging with patients and family caregivers will yield information or insights that will result in actionable change.

As you are getting ready to engage it is helpful to have conversations with staff at all levels to surface their concerns and to start to identify what can be achieved within the context of your organization's existing patient relations process, quality improvement practices, and resources available for this initiative.

Some ways to address common concerns include:

- Identify an explicit improvement goal for patient and family engagement that is meaningful to your organization as well as patient and family advisors. Engaging for its own sake can be valuable, but more people will be motivated and energized by a goal that will result in identifiable improvements.
- Clarify roles and responsibilities of all those on the planning team, and the scope of change the organization is willing to undertake. Consider asking someone who has experience leading quality improvement initiatives to facilitate (or co-facilitate) engagement activities. It may be valuable to have this person act as a neutral "third party".
- Identify potential conflict scenarios (e.g. "what if a patient or caregiver is still upset about an experience raising a complaint", "what if we receive patient or caregiver feedback that we can't take action on") and develop strategies for addressing them.
- Plan to discuss what's working well about the existing patient relations process, and/or to discuss the patient/family compliments process - to get patient and family feedback that identifies strengths your organization can build on.

Be sure to discuss any concerns or issues with your organization's senior leadership, the engagement planning team, and any staff groups who may be impacted by changes to the patient relations process. Having these discussions before you engage will help to clarify the parameters for your engagement process and to develop your organization's support for engaging with patients, families and the public about your patient relations process.

Before you engage, it is also important to discuss what will happen after your engagement process occurs – including what resources are available to implement possible recommendations, so that everyone involved understands the parameters for their efforts. By gaining the support of your organization's leadership and identifying who is responsible for taking action, you can make the best use of the time and goodwill of both patients/ caregivers and staff within the organization.

# Ways to build your patient engagement team

## Key points

- Consider building a team that involves a staff member who works on patient experience and quality improvement, as well as staff who are responsible for patient relations
- If possible, include an experienced patient or family advisor as part of your planning team, or consult with your hospital's patient and family advisory council.
- Involve key staff members who are likely to be most affected by the findings and recommendations of the engagement initiative.

## Consider joint leadership

It helps to have a range of viewpoints as you think through the design and execution of your hospital's engagement initiative. Consider building a team that is co-led by:

- A staff member who is not directly involved in patient relations—typically someone who is involved in quality improvement or patient experience, who is not as heavily invested in the current approaches and can provide an outside perspective.
- A staff member from your patient relations office or program who can speak knowledgeably about the hospital's practices.
- If available, one or more patient and family advisors who have experience working on quality committees and quality initiatives, and who understand process improvement. These advisors will understand the purpose of your engagement process and can help design a process that meets the needs of other patients and their families.

Consider involving point of care staff in your engagement team as well. These members of the team will add great value to this work as they can add context about the environment or competing priorities, contributing to everyone having a broad understanding of the different factors that might lead into the patient relations process. They will also be important when trying to implement changes. Their experience in engaging with patients at the point of care may also be a benefit to other team members with less familiarity/experience with patient/caregiver engagement.

## Involve patient advisors in planning

In addition to inviting a patient advisor to co-lead the team, you may wish to include additional patient or caregiver advisors on your planning team, and/or actively consult with your hospital's patient and family advisory council, if it has one. Experienced patient and caregiver advisors will be able to offer important insights and input into how other patients and families will respond to your engagement efforts.

## Involve staff who will be affected

Some staff members are likely to be more affected by your findings and recommendations than others; patient relations specialists, the chief of medicine, the chief of nursing, and heads of nonclinical programs such as security, housekeeping, and food services may all have a stake in proposed changes to the patient relations process. You will need their commitment to the initiative to ensure that recommendations are implemented. They may not all need to be involved in the planning and execution of your patient engagement initiative, but they should be consulted early in the process and updated along the way.

## PARTNERING WITH PATIENTS

Partnering with patient or family advisors will enable your organization to plan a more meaningful and effective engagement process. But if you have not worked with patients or family advisors in this kind of partnership role before, the prospect may seem challenging.

In practice, there are a few simple things that will go a long way to helping a team of patients, caregivers and hospital staff to work together successfully:

- Keep the atmosphere informal and friendly. Welcome individual team members one by one to establish a personal connection.
- Be clear about the roles, responsibilities and time commitment expected of all team members, and the value that each team member will add.
- Take time to get to know each other, tell stories and share information about where you are coming from, in order to build good personal relationships on your team.
- Engage in joint learning as a team – about how your organization's patient relations process works, patient relations best practices, and the hopes and concerns that the team has about the work ahead.
- Avoid the use of titles, acronyms and medical or administrative terminology as much as possible.
- Make time to invite patient and caregiver questions and input periodically throughout every meeting.
- Conduct debriefs with patient and family advisors after meetings are complete to find out if they need further information or support to participate fully.

# Questions to ask during the engagement

## Key points

- If your hospital is already aware of a particular issue, consider focusing your engagement initiative on that topic and potential related changes. Alternatively, you might decide to focus on a particular area of care (for example, the emergency department or intensive care).
- Avoid choosing an issue with your patient relations process that you already know how to resolve.

## Find a focus for discussion

You may not need to engage with patients and caregivers about every facet of patient relations at your hospital. In fact, a clear and focused discussion on an important topic may be all that is needed to satisfy participants and generate helpful feedback on your patient relations process. Consider asking yourself the following:

- What aspects of this hospital's patient relations approach are we most open to changing?
- What aspects of this hospital's patient relations approach are patients most likely to want changed?

As a starting point, you may wish to focus your patient and caregiver consultation process on any steps or changes you have in mind that will ensure you meet Ontario's new [regulation](#) for hospital patient relations processes.

If your hospital is already aware of a particular issue, consider focusing your engagement initiative on that topic and potential related changes. If you have a patient and family advisory council, consider asking them what they think your focus should be.

Alternatively, you might decide to focus on a particular area of care—the emergency department, the intensive care unit, or the outpatient clinics, for example—and examine how patient relations can be improved in that setting.

Or, you might decide to ask patients and caregivers to take a big-picture view and consider all aspects of patient relations at your hospital. If you haven't yet identified a particular issue to examine, a broader consultation may help you determine priorities for improvement.



Table 1 provides some suggested questions to use as the focus of your engagement initiative.

**TABLE 1: SUGGESTED QUESTIONS**

- What barriers to patients and their families experience that stop them from coming forward with concerns and/or complaints?
- What can we do to help patients and their families better understand what to expect from their care and what to do when care doesn't meet those expectations?
- What can we do to encourage patients and their families to share positive and negative feedback? What tools would patients and families be most likely to use to provide feedback? How can we make patients and families more comfortable with providing negative feedback?
- How can health care providers encourage patients and families to share feedback? How do patients and families want their health care providers to respond when they share negative feedback?
- How should we treat different types of negative feedback? What should be different about how the hospital responds to feedback about the following:
  - The wait for care
  - The safety of care
  - The quality of treatments
  - The interactions with their care team
  - The cleanliness, comfort, and privacy of the hospital environment
  - The handling of discharges or transfers
- When should a care team call in a manager or patient relations specialist to help address a concern or complaint? When should a manager or patient relations specialist call in a hospital executive?
- What support should we give patients when they are making a formal complaint?
- When people give us negative feedback, what information should we collect? Are we currently collecting and analyzing the right information?
- What kind of communication should patients and families receive while we are investigating a complaint?
- What kind of communication should patients and families receive once we are finished an investigation? Are current means of communication in line with what you expect?
- What should be done when a patient or family member is dissatisfied with the hospital's response to their concern?
- What does success look like from a patient/family caregiver perspective? How would patients and families measure the success of a patient relations process?

## Avoid potential pitfalls

Focus is important, but don't narrow your focus so much that patients and caregivers can't contribute what they think is most important. If you are aware of a major issue of concern that patients and caregivers are likely to bring up, focus your engagement initiative in a way that allows them to discuss it and give you their input into the hospital's overall patient relations process at the same time. If you have a good reason to put a particular patient/caregiver priority to the side, be sure to explain why you have decided to do so.

Try not to focus your engagement initiative on an issue you already know how to resolve. Participants are likely to be frustrated if you have a plan of action and are simply coming to them for a stamp of approval.

# Ways to engage

## Key points

- Assess your needs ahead of time and choose a method that aligns with your focus and resources.
- Include a variety of experiences and perspectives; find ways of involving people who may otherwise face barriers to participation.
- Consider using one or more methods to engage with patients and caregivers. Each method has its own benefits and drawbacks; by using more than one, you may uncover findings that you would not otherwise have been aware of.

## Assess your needs

There are many different methods for engaging patients and their caregivers, and each one has strengths and limitations. Before choosing a method, it can be helpful to ask a few key questions in order to narrow down which methods might be most appropriate for your organization and the issues you wish to tackle. These questions include:

- **Who are the patients and caregivers you most need to hear from?** For example, if you are focused on reducing barriers to making complaints, you will want a method that allows you to engage with people who may have perceived or experienced those barriers, including some who have never made a complaint.
- **What is the focus you have chosen?** For example, if your focus is on improving communication with complainants, what methods will allow you to investigate patient experiences and explore communication alternatives with patients and caregivers?
- **How extensive do you expect the discussion to be?** Patients and caregivers may have experienced real hardship as a result of a problem they encountered, whether they raised a concern or not. Your methods should provide a reasonable opportunity for them to share their experiences, expectations, and perspectives, in addition to commenting on the issues for which you are seeking feedback.
- **What can be accomplished with the time, money, in-kind resources, and organizational commitment you have available?** Avoid methods that will overtax you and your team, or that are so extensive that it is difficult to manage expectations.

## Include a variety of experiences and perspectives

Paradoxically, many of the most “open” methods of reaching and recruiting participants (posters and handouts, for example) engage with only a sliver of the patient and caregiver population – those who have the time and capacity to put themselves forward as volunteers. While it’s good practice to include a way for any interested individual to find out about your engagement initiative, be sure also to find ways of involving those who may otherwise face barriers to participation.

It’s often these individuals and communities who face unacknowledged challenges when trying to raise a concern, make a complaint, or provide critical feedback. Active, targeted methods of recruitment can help build a diverse participant pool.

If your organization is unsure about how to recruit patients and caregivers from specific populations you wish to engage, consider reaching out or partnering with local community organizations or social service agencies to recruit people who may face barriers to participation, such as those from cultural or linguistic minority groups, people with lower incomes, parents of young children, people with disabilities, or the frail elderly. Community and social service organizations that work regularly with these populations can provide valuable insight into how to reach out effectively and reduce barriers to participation.

If you do not have regular contact with organizations in your local community, 211 Ontario (<http://www.211ontario.ca/>) can connect you with community and social services across the province. Simply visit the website, type in your organization’s postal code and the kind of service or community resource you are looking for, and you can view a list of community contacts near you.

## Choose a way to engage

Table 2 summarizes some of the methods you can use to engage with patients and caregivers, and the sections that follow provide more detail

about each method. Consider using one or more of the ideas below as part of your initiative. Each method has its own benefits and drawbacks; by using more than one, you may uncover findings that you would not otherwise have been aware of.

<b>TABLE 2: SUGGESTED METHODS</b>		
<b>Method</b>	<b>When to use</b>	<b>Resources needed</b>
<b><i>Individual feedback</i></b>		
One-on-one debriefs	<ul style="list-style-type: none"> <li>To explore a broad range of issues with a single patient or caregiver</li> </ul>	<ul style="list-style-type: none"> <li>Staff interviewer (someone not involved in the complaints process)</li> <li>Private meeting location</li> <li>Emotional Touchpoint cards (optional; see main text for description)</li> <li>Patient diary (optional; see main text for description)</li> </ul>
Evaluation surveys	<ul style="list-style-type: none"> <li>To receive systematic feedback from a larger number of people on your complaints process or other specific patient relations activities</li> </ul>	<ul style="list-style-type: none"> <li>Survey that can be answered on paper, by phone, and/or online</li> <li>Volunteer(s) or staff member(s) to administer the survey</li> <li>Staff member to review and report on findings</li> </ul>
<b><i>Group discussions</i></b>		
Discussions with patient and family advisory councils	<ul style="list-style-type: none"> <li>To get preliminary input</li> <li>To initiate an extensive investigation of the hospital's patient relations process</li> </ul>	<ul style="list-style-type: none"> <li>Patient and family advisory council</li> <li>Meeting location</li> <li>Neutral facilitator</li> </ul>
Visits with patient and caregiver groups	<ul style="list-style-type: none"> <li>To engage with particular communities of patients/caregivers</li> <li>To explore particular issues or aspects of your patient relations process</li> </ul>	<ul style="list-style-type: none"> <li>Contact and meeting information for patient support groups, community centres, social agencies, and other groups</li> <li>Staff member(s) to conduct visits</li> </ul>
Additional meetings	<ul style="list-style-type: none"> <li>To engage patients who are already interested in your area of focus</li> </ul>	<ul style="list-style-type: none"> <li>Meeting location</li> <li>Meeting facilitator</li> </ul>

## Individual feedback

### One-on-one debriefs

If you are planning to review your formal complaint process, consider offering all recent complainants the chance to debrief and identify what could have been improved. There are many different ways to conduct a debrief (see below), and all of them lend themselves well to an engagement initiative that explores a broad range of issues.

### Open-ended debriefs

Open-ended debriefs give patients and caregivers the chance to tell their stories with encouragement and minimal interruption. The interviewer (we suggest it be a member of your organization who was not involved in the complaint process so that they have some distance from the issue and can be seen as objective, and who has experience hosting these types of debriefs) encourages patients and caregivers to tell their stories. This is then followed by a period of conversation in which the interviewer seeks to clarify the details of the story (without interrogating the person telling the story); clarify why the person acted the way they did; explore how they would have liked things to be different; and asks the person telling the story to provide specific recommendations for change.

Organizing open-ended debriefs with patients and caregivers can be a simple way to gain a wide range of insights into your hospital's approach to patient relations. Even just a few debriefs can provide a considerable amount of insight, because they are about more than just listening to stories; they are about giving patients and caregivers the opportunity to recommend ways of addressing the issues they describe.

### Emotional Touchpoint debriefs

The “Emotional Touchpoint” methodology has emerged as a particularly effective way of holding structured but open-ended debriefs on health care topics. In this situation, a staff member prepares a general set of laminated cards, each one representing a different possible “touchpoint” during the issue under discussion: moments that may have had particular emotional or narrative importance in the patient's experience. The staff member also prepares a set of emotion cards using words and/or images.

The participant is then presented with the two sets of cards (along with some blank cards so they can make additions) and asked to identify some touchpoints he or she would like to talk about. The participant can also select emotion cards to help describe his or her experiences at each touchpoint, giving the interviewer opportunities to follow up about why participants felt the way they did and what could have been done differently.

This method is effective because discussing a range of emotions in a systematic way allows health care providers to gain a balanced picture about the highs and lows of that experience. Emotional Touchpoints allow service users and providers together to identify areas of an experience that may be improved, as well as areas that are already having a positive impact on the patient or caregiver.

More information about Emotional Touchpoints can be found here: [http://www.scottishhealthcouncil.org/patient\\_public\\_participation/participation\\_toolkit/emotional\\_touchpoints.aspx](http://www.scottishhealthcouncil.org/patient_public_participation/participation_toolkit/emotional_touchpoints.aspx)

## Patient diary

Another technique to use during a debrief is a patient diary. This method is useful for learning how patients and caregivers raise questions, concerns, and complaints, and how they might be encouraged to speak up. Try giving a small diary to returning patients and patients who will be admitted for a length of time, and ask them and/or their family members to note their experiences if problems arise. Ask them to jot down answers to five simple questions that are formatted into the diary:

- What was the problem with the care you were getting?
- What did you decide to do about this problem?
- Why did you decide to do that?
- What happened next?
- Were you satisfied with what happened?

During a debrief later, you can then ask these patients or caregivers to discuss their diaries, encouraging them to focus on when they were most and least satisfied with the response to the issue they were facing. You can then use those examples to ask participants what your hospital should be doing differently.

## Evaluation surveys

Some health care organizations have begun asking all complainants to complete a short survey about their experiences and provide suggestions for improvement. Although this method provides information only from those who raise formal complaints, it can help identify ways of improving this important aspect of patient relations.

The survey should be broad enough to cover the most important aspects of a complainant's experience. It can also include questions that focus on specific issues you have identified. Make sure to include at least two open-ended questions: one asking for recommendations about how to improve the process, and another for respondents to provide feedback in greater detail if they choose. Open-ended questions allow participants to add any information they feel is relevant and has not been covered in the survey.

The Western Australian Health Complaints Management Toolkit is a helpful starting point for anyone looking to develop a patient relations evaluation survey. It contains a sample complaint evaluation survey form and includes some good basic questions that apply to most hospital patient relations processes. It can be found in Microsoft Word format here: <http://www.health.wa.gov.au/circularsnew/attachments/1015.docx>

You may want to ask questions about patient complaints and concerns as part of broader follow-up surveys on patient experience or satisfaction with your hospital's care. Adding questions about concerns and complaints to a broader survey will allow you to get input from those who may have concerns or feedback but have decided not to voice them via the patient relations process.

Depending on the resources available to you, you may consider asking people to fill out the survey on paper, online, over the phone, or in person. Administering surveys on paper or online is more confidential and cost-effective, but you may receive fewer responses depending on how you are able to distribute the survey. Phone or in-person surveys require more staff or volunteer time to administer, but may be appreciated by patients and caregivers as a way of showing that your organization is actively inviting their feedback. Consider training volunteers or staff who are not part of your patient relations team to hold these conversations as a way of preserving neutrality and confidentiality.

One risk with all survey methods is they can come across as disconnected from subsequent changes to the patient relations process; you may want to give respondents the option of requesting individual follow-up from a staff member, or receiving a summary report of the survey's findings. These kinds of actions help to distinguish true engagement from simple research and promote positive ongoing relationships between your hospital and the patients and communities it serves.

### Group discussions

Engaging with groups of patients and caregivers can be worthwhile because it allows individual participants to see how their perspective and stories are similar or different from those of others, and to develop shared recommendations that reflect a range of experiences and expectations. Group discussions also allow you to reach people who have only considered making a complaint and people who have not yet had a reason to make a complaint.

### Discussions with patient and family advisory councils

If you have one or more patient and family advisory councils at your hospital, be sure to speak with this important constituency about your patient relations process.

If you plan on engaging with patients and caregivers outside of the patient and family advisory council, we recommend you still have a short, two-part discussion with the council to get their preliminary input on your hospital's approach to patient relations and consult them about your approach to patient engagement. Meeting with your patient and family advisory council is a good way to test out discussion questions for use with other groups, and to get ideas about whom to include in additional consultations.

Alternatively, you may wish to meet with your patient and family advisory council for an extensive discussion about patient relations:

1. Start with a short, simple presentation about the hospital's responsibilities with respect to patient relations and provide some basic statistics (for example, the number of complaints in the past 3 years, the most common types of complaints, the longest time it took to resolve a complaint). This sort of introduction will help group members relate their own experiences to the bigger picture, understand the volume of complaints you receive, and better grasp some of the constraints your hospital faces.
2. Have participants work together to map the process of raising and addressing concerns and complaints. Work through the process three times: first, have a knowledgeable staff person describe in general terms what should happen; next, participants who are comfortable doing so can describe what happened to them; then, participants can work together to describe what they would have liked to happen. This may require a few hours to complete successfully.



3. Discuss one or two personal stories. Before the meeting begins, you may wish to identify volunteer(s) who are willing to share their experiences and ask them to write out their story in advance. Alternatively, you might consider presenting one or two anonymous cases that highlight the issue you're interested in. Then, give each participant a few minutes to share his or her reflections, one at a time, without interruptions (with the ability to opt out). After that, the facilitator guides the group through four short discussion rounds of:

- **What?** Clarify the details of the story (being careful to avoid interrogating the storyteller).
- **Why?** Consider why things in the story occurred the way they did, and why certain things worked and certain things didn't.
- **How else?** Consider alternatives: how could this story have gone differently? What realistic actions could your hospital have taken to realize a different outcome?
- **Now what?** Have participants point out the most important suggestions. What should your hospital focus on?

Again, such a discussion may take a few hours to complete, so be sure to plan accordingly and record the results as you go.

*Note: if you decide to focus your engagement initiative on a conversation with your Patient and Family Advisory Council, you should choose at least one other method to complement their feedback. Advisory Council members are likely to be more confident advocates than the average patient; their needs and expectations for how concerns, complaints, and critical feedback are handled may differ from those of other patients.*

### Visits with patient and caregiver groups

The benefit of this method is that you can engage with members of pre-organized groups during their established meeting times, finding patients and caregivers where they are.

These groups may gather at your hospital (a chemotherapy support group or a diabetes education group, for example) or you may need to seek them out in the community. Self-organizing patient and family support groups such as those from Alzheimer's Canada are worth considering; organizations that serve particular communities or subsections of your patient population (for example, community health centres or nonprofit social service agencies) may also be useful avenues for connecting with the patients whose input you seek. By selecting a range of groups to visit, you can invite many different participants to offer feedback. Reaching out to groups outside the hospital also allows you to establish or strengthen your relationships with these organizations and the broader community.

You will likely have only a short time with participants: 45 minutes is probably the shortest amount of time for a successful conversation; 60 to 75 minutes is better. Start with a short presentation (5 to 8 minutes) that describes your hospital's patient relations process. Provide essential information, but do not overwhelm participants with detail or advocate for the existing process. Avoid using acronyms, replace health care jargon with plain language descriptions, and acknowledge a range of potential perspectives and experiences.

After your presentation, have an open discussion with group members about their experiences and suggested improvements, allowing the group to focus on areas that are most interesting to them.

## Additional meetings

You might consider hosting one or more meetings for patients or caregivers who want to discuss the topics you've decided to focus on. The benefit of this method is that it engages those who are already interested in the chosen topic. A roundtable meeting format is most suitable for this open method. Start with a short presentation of your hospital's approach to patient relations and then break into groups of four to seven at separate tables. With each group led by a staff facilitator, discuss patients' reactions, experiences, perspectives, and recommendations.

If your focus is the formal complaint process, consider hosting a small, targeted meeting of people who have gone through the process in the recent past. You may want to try to recruit representatives from communities that are less likely to participate, but make sure you keep the meetings small: no more than six patients or caregivers in each. Start by quickly presenting the legal requirements and any relevant statistics about your hospital's patient relations process; then ask people to share aspects of their experience that could have been improved. Careful facilitation can guide the discussion from the sharing of experiences, to exploration of how participants would have changed things, to specific recommendations for your hospital to implement.

If your focus is on encouraging patients and caregivers to offer feedback, consider recruiting participants as part of a person-to-person awareness-raising campaign. Enlist staff and volunteers to strike up conversations in waiting areas and during rounds, or set up a booth in the entrance area or cafeteria to inform people about how to raise concerns, make complaints, or provide feedback. Then, have staff or volunteers pass along information about a meeting to discuss patient relations. You might also ask coordinators of patient support groups and staff members who are in regular contact with patients to encourage one or two of their patients to attend the meeting (although the individuals they choose are more likely to be confident advocates). If you are planning well in advance, consider posting a standing

offer to involve interested individuals in the next review of the patient relations process. Include registration information, and then organize a meeting once enough people have expressed interest.

## Consider advanced practice

If you are deeply invested in exploring substantial changes to the way your hospital approaches patient relations, and if you have significant resources available for your project, consider using a process called experience-based co-design. This method builds on the Emotional Touchpoint method described above and involves the creation of a short edited film reflecting on your patient relations process, using patient interviews. The film is shown to staff and patients, conveying in an impactful way how patients experience the process. Staff and patients are then brought together to explore the results of the interviews and work in small, mixed groups to identify and implement improvements. A complete guide to experience-based co-design can be found here: <http://www.kingsfund.org.uk/projects/ebcd>

## Keep in mind...

Regardless of the option you choose, be sure to do the following:

- Affirm that differences in perspectives and opinions are welcome.
- Assure participants that sharing their perspectives and opinions will not affect current or future treatment for themselves or family members.
- Seek consent to collect and use the information that patients and caregivers are sharing; see Ensuring privacy for more details.
- Confirm that personal information will not be shared; in a meeting, ask everyone to acknowledge that they will maintain the privacy of any personal information shared in the meeting.
- Avoid becoming defensive. Staff should help clarify misunderstandings and offer explanations when asked, but such explanations must be

provided carefully to create an environment that welcomes feedback. Bring in a staff member who is not involved in patient relations to help prevent defensiveness from developing.

- Make efforts to address potential barriers, and let participants know that accommodations are available.
  - **Finances:** cover travel expenses and the cost of child- or elder care.
  - **Timing:** plan meetings at convenient times; evenings and weekends are often better than regular work hours.
  - **Accessibility:** ensure that meeting locations are physically accessible; offer supports for those who may be hearing or visually impaired; use translation services if they are available at your facility; simplify written materials for those with low literacy. See the Government of Ontario's checklist for planning an accessible meeting: [http://www.mcass.gov.on.ca/en/mcass/programs/accessibility/understanding\\_accessibility/planning\\_meeting.aspx](http://www.mcass.gov.on.ca/en/mcass/programs/accessibility/understanding_accessibility/planning_meeting.aspx)

# Ensuring privacy

## Key points

- Personal health information can be anything related to an individual's physical or mental health, such as family health history or information about the provision of health care.
- Hospitals have responsibilities under the [Personal Health Information Protection Act](#) and the [Freedom of Information and Protection of Privacy Act](#).
- Each hospital should consult with its legal advisor(s) and privacy officer to determine any legal requirements regarding the collection and use of personal health information in the context of patient engagement
- When engaging with patients, it is considered best practice to obtain their consent ahead of time to any collection, use, or disclosure of their personal health information, and to abide by requests to revoke that consent at any time.
- When planning your patient engagement approach, think about how you will present your findings and what format they will take, to determine what form(s) of consent you will need.

## What you need to know

Once you have chosen a focus and method(s) for engagement, it is very important to plan for how you will maintain the privacy of the information that patients and caregivers will share with you. When you engage patients in improvements to patient relations, you will hear their personal stories and experiences. These stories may be considered personal health information, and you will need to ensure they are kept confidential.

This section describes best practices related to the collection and use of personal health information that may be disclosed in the context of patient engagement activities. These best practices are not a substitute for legal advice regarding the obligations of your organization. We encourage all hospitals to contact their legal teams and privacy officers in order to clarify their privacy obligations and requirements when conducting patient engagement.

### WHAT IS PERSONAL HEALTH INFORMATION?

Personal health information can be anything related to an individual's physical or mental health, including family health history or information about the provision of health care. For example, when a patient talks about an experience with a particular health care provider, a diagnosis, or how a particular lab test was administered, he or she is disclosing personal health information. If you can identify the person to whom the health information relates, or could reasonably link the person to the information using the details provided, it is most likely personal health information and must be protected under privacy legislation.

## Know your responsibilities

A health information custodian is a person or organization who has custody or control of personal health information as part of their powers or duties (with some exclusions).<sup>1</sup> Hospitals are considered health information custodians and have responsibilities under the [Personal Health Information Protection Act, 2004](#), when they collect, use, or disclose personal health information.

Hospitals are also subject to the [Freedom of Information and Protection of Privacy Act](#), and any information they collect may be the subject to an access-to-information request. Your hospital's privacy officer can direct you to the policies that apply to your organization.

The most important thing to remember is that in the context of engagement, it is best practice to let the patient decide what personal health information you collect, how you use it, and whom you share it with. You can affirm this principle by getting a patient's consent before you collect, use, or disclose their personal health information, and by affirming their ability to revoke that consent at any time.

<sup>1</sup>See s.3, *Personal Health Information Protection Act, 2004*.

## Include privacy in your planning

While you are planning your patient engagement initiative, think about how you will present your findings and what form they will take. Ask some key questions:

- **What personal health information do you need to collect for a successful engagement initiative?** To minimize risk, it is always best to collect as little identifiable personal health information as possible.
- **Can you de-identify the information or aggregate it before putting it in your report?** For example, in a one-on-one debrief with patients and caregivers, or during group discussions, you may be able to note themes and comments rather than attributing feedback to a specific patient. Complaint evaluation surveys can be conducted anonymously.
- **How will you use the patient information, and with whom will you share it?** For example, if you will be creating reports for your senior management team, consider ahead of time the information you will want to include. You may also want to use patient feedback in public marketing materials, in training materials for staff, or as a means of responding to someone about a specific complaint.
- **How will you protect patients' identities?** If you intend to use identifiable information, make sure you have obtained patient consent for each way you plan to use the information. For example, if you want to share a patient story in a board meeting or in staff training materials, describe these plans on the consent form so that patients are aware of the different ways their story will be shared.

However you present your findings, remember to take steps to ensure that if patients are going to be identified, you have their permission in writing.

## Other tips

- It is considered best practice to ask for permission to contact a patient or caregiver before you invite them to any kind of engagement process.
- Where caregivers want to share information about a patient, it is good practice to get the patient's consent or verify that the caregiver has the ability to provide consent on behalf of the patient.
- If you plan to make recordings (audio or video), make sure that patients and caregivers are made aware of this fact and that you get their signed consent agreeing to the recording. The consent form should describe how the recording will be used.
- Ensure that you have a secure file storage location. If information is stored electronically, access to the folder should be limited to those who require the information. If information is stored on paper, make sure the filing cabinet is locked.
- Track consent forms and verify that you have patients' consent before using any information you have already collected.
- Once you have a plan for patient engagement, consult your privacy officer to ensure your organization is fulfilling its obligations under the *Personal Health Information Protection Act* and/or the *Freedom of Information and Protection of Privacy Act*.

# Document and report

## Key points

- Prepare an interim summary that goes to the internal recipients you identified at the planning stage. The recipients should then discuss your findings and determine actions to be taken.
- When actions have been approved by senior leaders, release a short final report to the people who participated in your engagement process, that describes the engagement process, the lessons learned, and the actions your hospital plans to take in response.

## Plan ahead

You will need to work out in advance how the results of your engagement initiative will be documented and shared within the hospital, with the patients and caregivers who participated in your initiative, and potentially with the broader community served by your hospital. Engagement initiatives are different from other forms of qualitative research, partly because they include an up-front commitment to share information about the process and the results with participants and potentially, with the public.

## Interim summary

Once your engagement activities are complete, prepare an interim summary that goes to the internal recipients you identified at the planning stage. This summary should describe the process and results of your engagement initiative. The recipients should then discuss your findings and determine actions to be taken. Often the best way forward is for hospitals to agree to achievable “first steps,” with a general commitment to revisit the recommendations (and possibly engage with patients and caregivers again) once those first steps have been achieved.

## Final report

When actions have been approved by senior leaders, release a short summary report that describes the engagement process, the lessons learned, and the actions your hospital plans to take in response. This can be a stand-alone report, an article in your hospital's newsletter or on its website. You may wish to use a simple four-part structure for the report:

- Provide a short introduction that thanks participants, describes how your hospital values patient/caregiver input, and highlights what was learned during the process.
- Describe how you engaged with patients and caregivers: the methods you chose and the steps you took.
- Summarize the issues raised, lessons learned, and recommendations put forward. It is OK to describe conflicting perspectives that were not resolved during the engagement.
- Explain the actions your hospital will take in the near future and provide timelines if possible. Point out that not every recommendation can be implemented right away, and that you will revisit remaining recommendations in the future (committing to future consultation is a good way to maintain trust).



# Evolving your patient engagement process

## Key points

- Gather your team for a review 6 months after the engagement initiative.
- Send regular updates to participants to reaffirm that your hospital takes their feedback seriously.
- Commit to re-engagement in the future, and to adding new methods of engagement.

## Evaluate your work and commit to re-engagement

Be sure to take time in the 6 months after the engagement initiative to gather your team, review activities, discuss shortcomings, and brainstorm potential improvements. Make sure to document your suggestions so that whoever is responsible next time can learn from them.

Participants often deeply appreciate updates every 4 to 6 months, and sending updates can help reaffirm that your hospital takes their feedback seriously.

Commit to re-engagement at some point in the future. This isn't meant to be onerous; depending on the size of your initiative, it might be reasonable to wait a number of years before making another significant effort to approach patients and caregivers. However, if you plan to wait a while, consider an interim check-in of some sort with your hospital's patient and family advisory council about how any changes you have implemented are working.

When you do re-engage with patients and caregivers about your hospital's approach to patient relations, it may be tempting to simply repeat the methods you developed the first time around, but try to avoid this and at least add a new method of engagement. The chance that you'll learn something new increases greatly when you engage with patients and caregivers in a new way.

## Share your experiences with us

We are eager to hear how you have decided to engage patients and their caregivers in efforts to improve patient relations at your hospital, and what additions or modifications you would make to this guide based on your experience. Please reach out—we promise to follow up!

**Contact us:**

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