



Engaging with Patients and Caregivers about Quality Improvement

A Guide for Health Care Providers

Let's make our health system healthier

About Us

Health Quality Ontario is the provincial advisor on the quality of health care. We are motivated by a single-minded purpose: **Better health for all Ontarians.**

Who We Are.

We are a scientifically rigorous group with diverse areas of expertise. We strive for complete objectivity, and look at things from a vantage point that allows us to see the forest and the trees. We work in partnership with health care providers and organizations across the system, and engage with patients themselves, to help initiate substantial and sustainable change to the province's complex health system.

What We Do.

We define the meaning of quality as it pertains to health care, and provide strategic advice so all the parts of the system can improve. We also analyze virtually all aspects of Ontario's health care. This includes looking at the overall health of Ontarians, how well different areas of the system are working together, and most importantly, patient experience. We then produce comprehensive, objective reports based on data, facts and the voice of patients, caregivers and those who work each day in the health system. As well, we make recommendations on how to improve care using the best evidence. Finally, we support large scale quality improvements by working with our partners to facilitate ways for health care providers to learn from each other and share innovative approaches.

Why It Matters.

We recognize that, as a system, we have much to be proud of, but also that we often fall short of being the best we can be. Truth be told, there are instances where it's hard to evaluate the quality of the care and times when we don't know what the best care looks like. Last but not least, certain vulnerable segments of the population are not receiving acceptable levels of attention. Our intent is to continuously improve the quality of health care in this province regardless of who you are or where you live. We are driven by the desire to make the system better, and by the inarguable fact that better... has no limit.

Table of Contents

Introduction	4
Chapter 1. Getting Started: Planning and preparing to engage patients in your quality improvement initiative	8
Chapter 2. Working with patient advisors on quality improvement initiatives: Identifying the problem, understanding your system, and designing and testing solutions	20
Chapter 3. Following through and following up: Implementing, sustaining, and spreading changes	26
Chapter 4. How to engage patients in the development and review of your organization’s QIP.....	32
Glossary	36
References.....	37
Appendix 1. Get Involved in Quality Improvement: A Guide for Patients and Caregivers	38
Appendix 2. Introduction to Developing a Quality Improvement Plan: A Guide for Patients and Caregivers.....	41



Introduction

Patient engagement is an essential way of incorporating the voices of patients and caregivers (including family members) into decisions that will affect the care that patients receive. In particular, engaging patients and caregivers in the quality improvement process makes them active participants in improving the health care system and supports the transition to truly patient-centred care. Health care organizations across Ontario are increasingly seeking input from patients and caregivers to drive the improvement of the care that they provide, inform their annual Quality Improvement Plans, and meet accreditation requirements.

The benefits of patient engagement

Involving patients and caregivers directly in quality improvement processes can:

- Provide an important source of insight and ideas for quality improvement efforts¹⁻³
- Improve communication between patients and health care providers, leading to improved patient and provider satisfaction²
- Help health care providers embrace potential changes, as they are able to see them from the patients' perspectives¹
- Ensure that patients are full participants in decisions that affect them
- Empower patients to become involved in their own health care, rather than being passive participants^{4,5}
- Result in meaningful changes to health care services⁶

Involving patients and caregivers in quality improvement can benefit organizations of any size, from solo primary care practitioners to hospitals.

Patient engagement in quality improvement in Ontario

The increasing importance of patient engagement is now reflected in the legislation in Ontario, with the coming into effect of Regulation 187/15 under the *Excellent Care for All Act, 2010* on September 1, 2015. This regulation requires hospitals to engage patients in the development of their Quality Improvement Plans (QIPs), and further requires that their QIPs must contain a description of their patient engagement activities and how these activities inform the development of the QIP. Although these requirements apply only to hospitals at this point, patient engagement in quality improvement is a best practice that should be adopted by all health care organizations as they work to improve the quality of care that they provide.

A Definition of Patient Engagement

In the context of Ontario's health care system, the term *patient, public, and caregiver engagement* (abbreviated as *patient engagement* throughout this guide) refers to an activity that:

- a) Is primarily undertaken by a care provider, organization, or policy maker;
- b) Includes real contribution and participation from patients, caregivers, or members of the public;
- c) Results in improvements in the quality of care;
- d) Increases or sustains patient, caregiver, or public trust; and
- e) Uses the most appropriate public engagement approach or combination of approaches (sharing, consulting, deliberating, or collaborating) depending on the issue or situation.

Health Quality Ontario's Patient Engagement Framework

To help patients, health care professionals, organizations, planners, and policy-makers, Health Quality Ontario has created a Patient Engagement Framework to guide the approach for patient engagement to achieve better quality care.

This framework is a result of in-depth research and consultation with patients and professionals, and draws from a number of existing frameworks, including [Ontario's Public Engagement Framework](#).

Specifically, this framework has been created to unite the definition of patient engagement with guiding principles and enablers, and to define the three domains for engagement:

- 1) **Personal care and health decisions**, when patients and clinicians engage with each other to make shared decisions for the patient's care and health);
- 2) **Program and service design**, when organizations engage with patients to improve a specific program or service; and
- 3) For organizations, planners and policy-makers to engage with patients on **policy, strategy and governance** decisions.

Bottom line, the purpose of the framework is to help advance patient engagement in Ontario, as both a culture across all three domains and as a set of practices, and to help us achieve the vision of a highly engaged, patient-centred health care system, making decisions *with* patients.

Figure 1. Engaging Patients for Better Quality Care: Health Quality Ontario's Patient Engagement Framework

THE STRATEGIC GOAL

A strong culture of patient, caregiver and public engagement to support high quality health care

THE GUIDING PRINCIPLES

Partnership

Responsiveness

Empowerment

Learning

Transparency

Respect

ACROSS THESE DOMAINS

Personal care and health decisions

Program and service design

Policy, strategy and governance

ACROSS A SPECTRUM OF ENGAGEMENT METHODS

Share



Provide easy-to-understand health information

Consult



Get feedback on a health issue (e.g., policy or decision)

Deliberate



Discuss an issue and explore solutions

Collaborate



Partner to address an issue and apply solutions

ENABLED BY:

A culture of continuous quality improvement

Access to easy-to-understand health information

Commitment to health equity and cultural competence

Rigorous research and evaluation

How this guide can help

This guide has been designed to guide health care providers on how to engage patients in designing, carrying out, and communicating about their quality improvement initiatives, including how to engage patients in the preparation of their QIPs. Patient advisors may also find the entire guide helpful as an orientation when they join your organization's quality improvement efforts.

With this focus in mind, links are provided so that readers can access more detailed information on tools or techniques that they are interested in.

There are four chapters in this guide:

- [Chapter 1](#) instructs readers on how to get started with engaging patient advisors in quality improvement
- [Chapter 2](#) relates to what to do once the patient advisors are engaged as you design and test new changes for improvement
- [Chapter 3](#) relates to how to spread the successful changes
- [Chapter 4](#) describes how to engage patient advisors specifically in developing QIPs

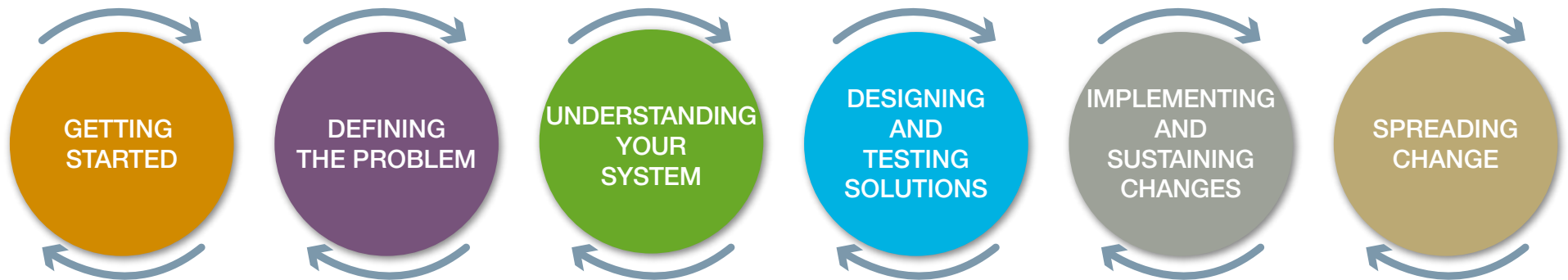


Figure 2. Health Quality Ontario's Quality Improvement Framework

This guide also contains two appendices that are written for patient advisors:

- [Appendix 1](#) provides an introduction to quality improvement for patient advisors who are considering becoming engaged in quality improvement
- [Appendix 2](#) provides an introduction for patient advisors as they become engaged in QIP development

This guide is not intended to be a comprehensive resource on how to conduct quality improvement initiatives – there are other resources that cover this. One excellent resource is Health Quality Ontario's Quality Improvement Framework (Figure 2).

This framework is referenced throughout the guide in boxes at the top of each chapter that summarize the steps in each phase of the framework. The text that follows focuses on how to engage patients in these steps. Refer to the [Quality Improvement Framework](#) on Health Quality Ontario's Quality Compass website for more details on any step of the quality improvement process.⁷



Chapter 1

Getting Started: Planning and preparing to engage patients in your quality improvement initiative

There is a lot of planning to be done as you get started on any quality improvement initiative, and especially so when patients will be engaged in the initiative. This section outlines the steps to getting started in engaging patients in quality improvement.



Quality Improvement Check-In: Getting Started

Quality Improvement Check-Ins summarize the steps in each phase of the quality improvement cycle. To read about each phase in more detail, refer to Health Quality Ontario’s [Quality Improvement Framework](#).

During this phase, a quality improvement team is assembled and begins the journey of understanding what improvements should be made and how the team will know that their efforts have created a positive change. This stage involves planning how patients will be engaged in the quality improvement initiative and recruiting patient advisors to join the team. It is best practice to include a patient champion while assembling your team.

Quality phase: Getting started	Tips for engaging patients
Assemble a team/Quality Committee. Establish team roles and set group norms.	Engage a patient champion while choosing the members of your team. A more experienced champion can help you engage other patients and ensure that they feel comfortable. A single patient cannot represent all patient experiences; it is best to engage two or more patients on your team. Support staff in understanding that patients are experts in their own lived experience – this is their role.
Begin to plan your quality improvement initiative by identifying potential areas for improvement based on where concerns exist in the current state	Patient advisors will play a big part in identifying potential areas for improvement. This step may include consulting with the patient advisors who are part of your team/Quality Committee or reaching out to a larger number of patients through surveys, interviews, or focus groups.
Set overall goals/aims that you would like to achieve within specific timeframes	Be sure to clearly define the contributions of your patient advisors in advance to help you to reach your overall goals and support your advisors in knowing what to expect.

Key lessons: *It is important to set up a good foundation for how you will engage patients early in the process. Involving patients in quality improvement initiatives requires planning and consideration to ensure patients can participate. Think about when you will hold meetings with patient advisors – they may prefer to meet in the evenings or on weekends.*

Assembling a team/Quality Committee within your organization

Recruit team members within your organization

It helps to have a range of viewpoints as you think through the design and execution of your organization's engagement initiative. Include some of the following staff members on your organization's team:

- Staff with experience or expertise in quality improvement
- Staff with experience in partnering with patients
- Health care providers who will be impacted by the changes being implemented

Set roles for members from your organization

Setting roles for participants within your organization will help the process go much more smoothly for all involved. When working with patients, the following roles are of upmost importance:

- A logistical coordinator and administrative support person
- A single primary support person to act as patient liaison/relationship builder/recruiter; this person can assist patient advisors with questions and check in with them between meetings

Preparing your team and your organization to engage patients in quality improvement

The idea of engaging patients in your quality improvement initiatives must be supported by your team members as well as the leadership and other stakeholders in your organization.

The support of the leadership at your organization is essential to enable meaningful contributions from your patients. In addition to supporting the financial, logistical, and time commitments to complete the engagement as planned, the leadership should be committed to implementing suggestions or plans arising from the engagement. The leadership at your organization are in a unique position to help foster a culture of continuous quality improvement that incorporates patient engagement at its core.

Contact leadership in your organization to get their support regarding your general plan early, and keep them updated as you develop and refine the plan for your initiative.

Here's what you should discuss with the leadership at your organization:

- The overall plan and goals for the quality improvement initiative
- How you expect patient advisors to contribute to change
- The anticipated extent of participation by the patient advisors
- The resources (financial, logistical, time) that will be needed to complete the engagement as planned
- Any risks and benefits of the engagement, and plans on how to deal with them
- Expectation of leadership in supporting the initiative

Address potential barriers to patient engagement within your organization

Within organizations that are new to engaging with patients as advisors in their quality improvement work, there may be a number of questions and anxieties related to the process of engaging with patients. Table 2 presents common sources of concern or reluctance to engage that you may encounter within your organization, as well as how to address them.

Table 2. Barriers to engagement within your organization and how to address them

Concern or barrier	How to address the concern or barrier
<p>Inexperience/nervousness: Not all members of your organization involved in the initiative may have prior experience working or partnering with patients in this way.</p>	<p>Set defined roles for participants from your organization, and make sure that everyone feels comfortable with their roles (<i>see page 10 for discussion of roles</i>)</p>
<p>Skepticism about the utility of engagement: Some may be skeptical that engaging with patients will yield information or insights that will result in actionable change.⁵</p>	<p>Identify an explicit improvement goal that is meaningful to your organization as well as to patient advisors. All participants will be motivated and energized by a goal that will result in identifiable improvements.</p> <p>Try to begin with quality improvement initiatives that are relatable to patients (e.g., having them participate in the redesign of the waiting area, help to optimize way finding, or join a patient safety committee focused on hand hygiene or medication reconciliation) as opposed to more technical projects (e.g., optimizing the method for sterilizing surgical instruments).</p> <p>Remind the team that the success of the engagement activities will be evaluated throughout the process (e.g., through surveys and focus groups). You will keep using the engagement practices and models that work, and make adaptations to those that don't.</p> <p>Share examples of how patient engagement has benefited other units within your organization and peer organizations. Consider reaching out to staff who were involved in these projects to share their experiences.</p>
<p>Reluctance to expose deficiencies in your organization by engaging patients in the quality improvement process.⁵</p>	<p>Help your staff to see that patients actually experience these deficiencies and that you will be problem solving with them to address the issues. When you engage with patients, be honest and transparent, and help patients to understand the systems and restraints at play that they may not be familiar with.</p>
<p>Worry that conflicts will arise</p>	<p>Set up guiding principles for your team to help to reduce conflicts. Think about the potential points of conflict that may arise related to your specific project, and consider how you will address these. It's important to establish expectations in advance, set ground rules for participation and encourage healthy debate.</p>
<p>Fear of time commitment and competing priorities⁵</p>	<p>Plan the scope of the project so that it is manageable. Remember that you can scale up the project in the future. Engaging patient advisors in quality improvement initiatives doesn't always mean staff working more, but working differently.</p>
<p>Fear that you will not have the resources to implement suggested changes arising from the engagement</p>	<p>Discuss the resources available to you with your organization's leadership as well as front-line care providers who will be affected both before and during engagement. Be open with your patients about the resource limitations related to your project, and work within these limits.</p> <p>Remember that engagement does not have to be costly, but you should factor in expenses – often the cost of not engaging is much higher than covering patient advisors' parking fees or transportation costs.</p>

Remember that although the concerns listed in Table 2 are commonly expressed, evidence shows that few of these concerns are actually encountered in practice, and health care providers involved in patient engagement generally report positive results for their organizations.^{5,8} If some staff members are very nervous or apprehensive, it may help them to have the opportunity to be an observer on another team that is working with patients, or to get started with a small project. Typically, once staff experience patient engagement in action they are more optimistic about partnerships in the future. These staff can often become your best champions.

Planning your quality improvement initiative and approach to patient engagement

Identify potential areas for improvement

One of the first steps in the quality improvement process is to identify areas for improvement in the care you currently provide.

The decision of what to work on in your quality improvement initiatives can be influenced by a variety of inputs. Patients are one of the most important stakeholders in this decision, because they can best identify what they think is important to improve based on their experiences receiving care at your organization. Thus, a key role for patient advisors in the quality improvement process is to identify priority areas for improvement.

Once priority areas for improvement have been identified, patient advisors can be engaged to participate in designing, carrying out and communicating about the improvement initiatives.

Here are some examples of how priority areas for improvement may be identified:

- Results of patient experience surveys or other surveys
- Trends in complaints or concerns voiced by patients and caregivers
- Prioritization of areas for improvement by the organization's Patient and Family Advisory Council or Residents' Council
- Input from patient advisors involved in Quality Committees/Teams
- The organization's strategic plan
- The quality issues and indicators that will be the focus of the organization's annual QIP
- The results of annual Resident Quality Inspections in long-term care homes
- Accreditation processes that identify areas where an organization has not met standards
- Investigation of critical incidents reported by health care providers or patients
- Networks involving peer health care organizations or entire health care sectors (such as [Health Links](#))
- Comparative reports that show an organization's performance relative to other organizations in Ontario and across the country. These may include Health Quality Ontario's [Measuring Up](#), Data to Decisions reports for family health teams, or other reports used by your organization
- Areas for improvement related to accountability agreement targets and indicators with the Local Health Integration Networks

The focus of your efforts as well as how you chose this focus will inform which populations you wish to engage.

Engaging Patients to Identify Potential Areas for Improvement

The patients you engage with to identify potential areas for quality improvement will not necessarily be the same patients you will engage with to design and carry out the initiatives.

To identify priority areas for quality improvement, you should engage a larger number of patient advisors. This may be done as a survey, a focus group or town hall meeting, or in consultation with your organization's Patient and Family Advisory Council. Also review the complaints and concerns voiced by patients and families.

As you engage with patients to identify priority areas for quality improvement, offer them the chance to participate in the quality improvement initiatives that you will design to address the issues they identify as priorities. This is a great way to recruit interested patient advisors.

This guide largely focuses on engaging with patient advisors in designing and carrying out quality improvement initiatives, but it is essential that the patient voice is also incorporated in the identification of target areas for improvement.

Begin to set goals for the project and identify how your patient advisors will contribute

One of the most important steps in preparing for engagement is to set well-defined, achievable goals for the project. This will increase buy-in from participants and stakeholders from your organization as well as potential patient advisors. Start with general goals and refine them in collaboration with your patient advisors once they join your team.

It's important to define how your patient advisors will contribute to meeting these goals. If you are just starting out with a new team of patient advisors, choose a project that is focused on improving patients' experience; this will ensure that the project will resonate with patients and that their contribution will be unique and valued.

Examples of good projects include those that involve improving transitions of care (e.g., working with patients to understand gaps) or improving communications with patients (e.g., developing materials to be given to patients with a chronic disease; creating case studies to help care providers practice their communication skills). On the other hand, highly technical projects (e.g., refining specifications for equipment standards) may not resonate with patients, and their potential contributions to such projects may be unclear.¹ Avoid engaging patients about a problem when decisions have already been made or when there is no room for flexibility in decision-making – this can be viewed as tokenism. Over time, you and your patient advisors will become more comfortable with creating meaningful partnership opportunities in all your activities.

Choose a method of engagement

There are many different methods for engaging patients, and each one has its 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:

- **What phase are you at in planning the quality improvement initiative?** Consider how to engage patients to help choose a focus for your quality improvement efforts (Getting Started) versus asking them to help develop and implement a specific quality improvement initiative (Designing and Testing Solutions; Implementing and Sustaining Changes).
- **What is the focus you have chosen?** For example, if your focus is on improving communication with patients, what methods will allow you to investigate patient experiences and explore communication alternatives with patients?
- **Who are the patients you most need to hear from?** For example, if you are focused on reducing barriers to providing input, you will want a method that allows you to engage with people who may have perceived or experienced those barriers.
- **How extensive do you expect the engagement to be?** Your methods should provide a reasonable opportunity for patients to share their experiences, expectations, and perspectives, and comment on the issues on which you are seeking feedback.
- **What can be accomplished with the time, money, in-kind resources, and organizational commitment you have available?** Be realistic about your engagement strategy and be clear about what patient advisors can expect.

Table 1. Suggested Methods for Patient Engagement

Method of Engagement	When to use	Examples	Resources and notes
<p>One-on-one debriefs/interviews</p>	<ul style="list-style-type: none"> To identify priority areas for quality improvement To explore a single issues or range of issues with a single patient or caregiver 	<ul style="list-style-type: none"> Ask patients after appointments/ during care what could be improved Set up interviews with patients who have encountered problems or have expressed new ideas to hear their stories and opinions on how to avoid such problems in the future 	<p>Resources</p> <ul style="list-style-type: none"> Refer to Health Quality Ontario’s checklists, Supporting Patients and Caregivers to Share Their Stories and Communicating Clearly with Patient and Caregiver Advisors Consider using Emotional Touchpoints methodology, developed by the National Health System in the United Kingdom, to guide interviews. Interviews are just one step in the process prior to co-design <p>Notes</p> <ul style="list-style-type: none"> Interviews can lead to opportunities to co-design quality improvement initiatives in the future Consider whether another staff member may be best to conduct these debriefs to ensure open and honest feedback is obtained Develop a systematic way of collecting information and sharing results in advance of starting your project. Build in processes to involve patients in the development of the interview questions, and analyze results within privacy and confidentiality limits

Method of Engagement	When to use	Examples	Resources and notes
<p>Surveys and feedback forms</p>	<ul style="list-style-type: none"> To receive systematic feedback from a larger population 	<ul style="list-style-type: none"> Conduct an open-ended survey asking patients about which aspects of their care they would most like to be improved Conduct a survey to determine the most popular options for choice of foods when reviewing food service in hospitals or long-term care homes. This may be an organizational survey and/or a more informal “intercept”/“real-time” survey at the point of care to capture responses 	<p>Resources</p> <ul style="list-style-type: none"> Refer to the Primary Care Patient Experience Survey developed by Health Quality Ontario and collaborators Refer to the Ontario Hospital Association’s Recommended Patient Survey Instruments <p>Notes</p> <ul style="list-style-type: none"> For best results, include patient advisors in the development of survey questions, survey distribution/dissemination, and analysis of survey results. Asking some standard questions during a clinical encounter can provide real-time information that can be captured and useful for quality improvement (e.g., Ask Me Three)

Method of Engagement	When to use	Examples	Resources and notes
Discussions with Patient and Family Advisory Councils	<ul style="list-style-type: none"> • To identify priority areas for quality improvement • To discuss approaches to other patient engagement methods 	<ul style="list-style-type: none"> • Involve the Patient and Family Advisory Council in the development of your Quality Improvement Plan • Involve the Patient and Family Advisory Council in building your organization's strategic plan • Ask the Patient and Family Advisory Council to become a partner on a key organizational quality improvement priority • Ask the Patient and Family Advisory Council for input on how you will conduct your other patient engagement efforts 	Resources <ul style="list-style-type: none"> • Refer to the Agency for Healthcare Research and Quality's Working With Patient and Families as Advisors: Implementation Handbook for information on generating a Patient and Family Advisory Council • Refer to Health Quality Ontario's three mini-guides on creating and sustaining patient and family advisory councils: Recruiting for Diversity, Creating an Effective Terms of Reference, and Choosing Meaningful Projects
Focus groups/other public meetings (one time)	<ul style="list-style-type: none"> • To identify priority areas for quality improvement • To identify general approaches to a particular problem • To extend invitations to participate in quality improvements projects resulting from the focus group/meeting 	<ul style="list-style-type: none"> • Conduct a focus group with people who have been bereaved to identify areas for improvement in palliative care 	Resources <ul style="list-style-type: none"> • Refer to the University of Wisconsin's Focus Groups: A Guide to Learning the Needs of Those We Serve for information on when to use focus groups and how to conduct them
Meetings with patient and caregiver groups	<ul style="list-style-type: none"> • To identify priority areas for quality improvement for specific populations • To recruit patient advisors to a quality improvement team 	<ul style="list-style-type: none"> • Hold a meeting with a support group for patients with chronic kidney disease to determine how to improve patient experience at the dialysis clinic 	Resources <ul style="list-style-type: none"> • Contact Ontario 211 or refer to thehealthline.ca to identify patient and caregiver groups in your community

Method of Engagement	When to use	Examples	Resources and notes
Teams/task forces for specific quality improvement projects	<ul style="list-style-type: none"> To develop and implement a specific quality improvement project in partnership with patient advisors 	<ul style="list-style-type: none"> Form a team to revise the format of treatment information provided to patients on discharge Form a team to improve an important quality issue, e.g., increase uptake of cancer screening by targeting communications to populations with poor uptake 	<p>Resources</p> <ul style="list-style-type: none"> Refer to the Institute for Patient and Family-Centred Care's Tips for Group Leaders and Facilitators on Involving Patients and Families on Committees and Task Forces
Quality committees or other groups that discuss quality issues	<ul style="list-style-type: none"> To collaborate on driving the entire quality improvement process, from identifying priority areas to developing and implementing specific projects 	<ul style="list-style-type: none"> Include patients on existing quality committees or other groups that discuss quality issues 	<p>Resources</p> <ul style="list-style-type: none"> Refer to Health Quality Ontario's checklist, Chairing Meetings with Patient and Caregiver Advisors Refer to the Institute for Patient and Family-Centred Care's Tips for Group Leaders and Facilitators on Involving Patients and Families on Committees and Task Forces
Patients as mentors	<ul style="list-style-type: none"> To provide skilled support and mentorship to other patient advisors To raise awareness among patients and caregivers about a quality improvement initiative 	<ul style="list-style-type: none"> Consider recruiting participants as part of a person-to-person awareness-raising campaign. Enlist health care providers 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 your chosen quality improvement initiative. Peer mentors can be matched with new advisors and provide them with guidance and support 	<p>Resources</p> <ul style="list-style-type: none"> Refer to the Institute for Patient and Family Centred Care's resources about peer mentoring

This list is not exhaustive. For more resources on patient engagement methods and practices, visit [Health Quality Ontario's growing online hub](#) of leading patient engagement tools and resources. The library offers you a range of tools and resources to help you plan, do and evaluate patient engagement in your quality improvement work.

One resource that includes many examples of successful practices in patient engagement in Ontario is Health Quality Ontario's report, [Engaging with Patients: Stories and Successes from the 2015/16 Quality Improvement Plans](#). This report summarizes the practices related to patient engagement described in the 2015/16 QIPs submitted by hospitals, interprofessional primary care organizations, long-term care homes, and community care access centres across Ontario.

Another valuable resource is the landmark work done over the past five years in Ontario by the Change Foundation through their PANORAMA project. PANORAMA was a standing panel of 31 Ontario residents exchanging views, experiences and advice that helped The Change Foundation in its work to improve the patient/caregiver experience. Refer to [Rules of Engagement: Lessons from PANORAMA](#) for a robust list of methods of engagement, each described in detail. The Change Foundation also hosts a [Caregiver Resource Hub](#) that includes many useful resources.

Plan carefully to protect patient advisors' privacy

When you engage patients in some aspects of quality improvement, you will hear their personal stories and experiences. These stories may be considered personal health information, and you will need to ensure they are treated as such. If applicable, we encourage health care organizations to consult their legal teams and privacy officers before engaging with patients in order to clarify their privacy obligations and requirements.

Ask some key questions while planning your engagement efforts:

- **Determine what personal health information, if any, 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.
- **De-identify the information or aggregate it before putting it in your report.** For example, in a one-on-one debrief with patient advisors, or during group discussions, you may be able to note themes and comments rather than attributing feedback to a specific patient. Feedback surveys can be conducted anonymously.
- **Decide how you will use the patient information, and with whom you will 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 health care providers, or as a means of responding to someone about a specific complaint.
- **If you intend to use identifiable information, obtain patient consent for all of the ways you may use that information.** For example, if you want to share a patient story in a board meeting or in health care provider training materials, describe these plans on the consent form so that patients are aware of the different ways their story will be shared. It is also best practice to follow up and ask permission each time you intend to use their story, even if you already have written consent.
- **Communicate clearly with patients about what information will be shared, with whom, and for what purpose** Patients may be concerned about information getting back to their provider and how this might impact their care. In addition to obtaining written consent from patients, you should have a full discussion of any concerns they may have around these issues. Remind patient advisors that they can withdraw their consent at any time.

However you present your findings, remember to take steps to ensure that you have patients' permission in writing if they are going to be identified, and that they understand and appreciate any possible implications of this information being shared.

Recruiting patients to be involved

You should already have an idea of your target population by the time you are ready to reach out and begin recruiting patient advisors. Thus, your means of extending the invitation to participate will depend on your target population.

How to reach out

Clear communication via multiple methods will go a long way to ensure that patients feel welcome and are prepared to participate. Consider the following methods:

- Written material (e.g., posters, handouts, a notice in a newsletter)
- Phone calls
- Emails
- In-person invitations from care providers
- In-person invitations from volunteers
- Social media

In your invitations to participants, provide an overview of the goals of the project or initiative, the specific contributions expected from participants, and the time commitment required. Be careful with patient advisor contact information on email distribution lists.

Recruiting for diversity

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

For some quality improvement projects, specific skill sets may be required, such as the ability to read or computer skills. However, effective engagement is optimized if the participants reflect the diversity of your target population for engagement. Diverse representation ensures that the decisions being made reflect and respond to a broad range of lived experiences. Refer to Health Quality Ontario's guide to [Recruiting for Diversity](#) for helpful tips and practices. The Ministry of Health and Long-Term Care's [Health Equity Impact Assessment Tool](#) can also help to guide this discussion.

Consider recruiting experienced participants

Consider recruiting one or more participants who have previous experience acting as advisors. In particular, advisors who have experience working with a leadership role or who have worked on quality committees/quality initiatives and understand process improvement would be a good choice to co-lead your team. 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 caregivers. They may also be able to act as mentors for less experienced advisors on the team.



Chapter 2

Working with patient advisors on quality improvement initiatives: Identifying the problem, understanding your system, and designing and testing solutions

This section includes a practical explanation of what to do once you have identified your team members, engaged the patient advisors who will be on your team, and begun to identify your area of focus for quality improvement. During this part of the initiative, you will follow three steps in the Quality Improvement Framework, along with your patient advisors: Defining the Problem, Understanding your System, and Designing and Testing Solutions.



Quality Improvement Framework Check-In: Defining the Problem, Understanding your System, and Designing and Testing Solutions

Quality Improvement Check-Ins summarize the steps in each phase of the quality improvement cycle. To read about each phase in more detail, refer to Health Quality Ontario’s [Quality Improvement Framework](#).

Phase 2. Defining the problem: During this phase, your team will delve deeper into the systems and processes related to the concerns identified in Phase 1, and will determine the underlying problems that contribute to these concerns.

Quality phase: Defining the problem	Tips for engaging patients
Fully explore concerns identified in Phase 1 and highlight where the current state does not meet the needs of your patients	Collect patient stories surrounding the concerns you have identified. Ask patients what outcomes are important to them and try to identify why these outcomes were not attained
Create a map of the current process (visual tool)	It is important to involve patients in creating this process map as there may be significant contrast between provider and patient perspectives. Patients’ process steps start earlier and end later than providers’
Create a measurement plan and begin collecting data	Share the data “story” with patients as it develops

Key lessons: *Patients play a valuable role in identifying why the current state is not working for them. They can also provide input on processes that provide value or do not provide value. Discussion of both [Always Events](#) and [Never Events](#) (i.e., things that should always happen or never happen) often resonates with patients and may provide useful feedback at this stage.*

Phase 3. Understanding your system: During this phase, teams collect and analyze data related to the problems identified in Phase 2. As the team learns about the performance of its system, it will also identify clues about the barriers to better performance that exist within the system.

Quality phase: Understanding your system	Tips for engaging patients
Analyze and interpret data relating to areas for improvement, establishing a baseline	Patients can help to identify “pain points” and provide context for the data. Clinicians will also gain a better understanding of the data by considering the patient experience.
Identify/brainstorm change ideas to be tested	Include patients fully in this step. Ensure that patient suggestions are anonymously recorded and that you can demonstrate how they have been addressed or incorporated in your plan
Prioritize the change ideas with the most benefit (including likelihood of stability) for the least burden	Capturing the patient’s perspective of what change is most important is key while considering resources. Often patient suggestions are the “low-hanging fruit”

Key lessons: *Patients are a great source of change ideas. You may want to consult with patients who have been involved where things did not go well to get their opinions on what could be done to avoid this in the future. It is important to respect patients’ perspectives and communicate if suggestions are made that are not within the scope of the project or are not feasible.*

Phase 4. Designing and testing solutions: Once there is a clear understanding of the opportunities for improvement, teams can begin developing plans and testing ideas. This is an exciting phase that provides teams the opportunity to exercise creativity and challenge the status quo by trying different improvement ideas.

Quality phase: Designing and testing solutions	Tips for engaging patients
Obtain senior leadership approval for the changes planned	Clearly outline patients’ needs that are driving this change. Consider a powerful patient story/presentation by a patient relating to the initiative
Begin quality improvement activities (i.e., testing change ideas)	Ensure interested patients are involved. Work closely with patients and share stories to motivate the team. Using role play and simulation when testing change ideas can help predict outcomes
Establish ongoing data collection, analysis, interpretation, and communication mechanisms to monitor and share progress and impact	Working with patients changes how clinicians communicate about their work. Patients may play a lesser role in the data collection, depending on the project, but will want to be closely informed of the results. Consider using visual displays of data so that patient advisors can also be involved in tracking improvements

Key lessons: *Patients are important in the testing of changes to ensure that the changes being tested are meaningful to the patients being impacted. This may be an opportunity to involve new patients in on-the-ground testing of ideas.*

Helping your patient advisors prepare to work on quality improvement initiatives

Educate your patient advisors

Patient advisors need to be provided with background information if they are going to partner or co-lead a quality improvement initiative. Remember that your patient advisors are experts in their own lived experience, but may not necessarily be experts in health policy or quality improvement science. Provide them with background readings to prepare for any meetings, being sure to provide any materials far enough in advance that they will have time to read them, and offer to review these materials with them. Less experienced members of the team from within your organization may also find the same training and support to be useful.

- In collaboration with our patient advisors, Health Quality Ontario has produced a short tip sheet for patients and caregivers on getting involved in quality improvement. This is provided as Appendix 1 in this guide. Consider distributing this to your patient advisors when they join your team.
- Present your patients with an introduction to quality improvement, focusing on the methodology that will be used in your project (e.g., Lean, Six Sigma). Consider sending a link to Dr Mike Evans' [video introduction to quality improvement in health care](#) or Health Quality Ontario's [Quality Improvement Framework](#).
- Consider introducing the six dimensions of quality health care – safe, effective, patient-centred, timely, efficient, and equitable – and working together to identify which dimension your quality improvement effort will/should improve. Research has shown that the dimensions of care are best explained to patients by organizing them into three simplified domains of quality.⁹ The following were offered as an example:
 - o Care that protects patients from unintended outcomes and does not cause harm (safe care)
 - o Care that is proven to work or get results (effective; efficient)
 - o Care that is responsive to a patient's needs and preferences (patient-centered, timely, and equitable)

- If your initiative will be included in your organization's QIP, educate your patient advisors on QIPs. An introduction to QIPs intended for patient advisors is presented in Appendix 2.
- Provide any necessary information related to your specific quality improvement initiative, if you have already chosen one.

Allow for multiple channels of communication throughout the engagement process

Patient advisors may have questions or feedback that they wish to discuss outside of a group setting, and it's important to allow them this opportunity. Share the email address and telephone number of the point person on your team with your patient advisors (with consent), and let them know that questions or feedback are welcome at any time. The point person can involve the other members of the team if the conversation relates to their role.

Tips for organizing meetings to involve, collaborate with, and partner with patients

Partnering with patient advisors will enable your organization to plan a more meaningful and effective engagement process. But if you have not worked with patients 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 patient advisors and health care providers to work together successfully.

Address potential barriers

- **Financial:**
 - o Financial barriers should be removed to enable patient advisors from all backgrounds to be involved in the project. This may include covering child or elder care, parking, travel, and accommodation. Prepare the organization to support this work with the appropriate policies and procedures so that patients who choose to become involved have a clear understanding of the nature of the support you can provide.

- **Timing:**
 - Plan meetings at convenient times. Evenings and weekends often work better than regular working hours, but it's always best to work with your advisors to find the best times for everyone.
 - Consider lengths of meetings – do not overtax patients with a long session, and include lots of breaks.
- **Accessibility:**
 - Ensure that meeting locations are physically accessible.
 - Offer supports for those who may be hearing or visually impaired.
 - Ensure that translation services are available if they are needed.
 - Simplify written materials for ease of reading and comprehension.
 - Refer to the Government of Ontario's [resources](#) for planning an accessible meeting.
 - Offer the ability to participate remotely.
 - Be mindful of furniture (desks, chairs, computer screens) that may be perceived as a barrier between participants.

Setting the atmosphere during the meeting(s)

- Keep the atmosphere informal and friendly.
- Avoid the use of titles, acronyms, and medical or administrative terminology as much as possible.
- At the beginning of the meeting, ask individual team members to introduce themselves and describe who they are and why they are participating. Do not forget that, as the health care provider, you are a key member of the team and should include yourself in the introductions.
- Take the time to get to know each other, tell stories, and share information about where you are coming from in order to build positive personal relationships on your team.
- 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 their caregivers.
- Create a meeting environment that allows space for everyone at the table to contribute.
- Build an agenda that includes discussion around patient experience and better quality of care.

- Engage in joint learning as a team – about how your organization's quality improvement process works, quality improvement best practices, and the hopes and concerns that the team has about the work ahead.
- Make time to discuss privacy concerns in person. You may need to reiterate to your advisors that their personal information will not be shared without their permission, and that they should not share others' stories outside of the group.

Check in frequently

- Continuously evaluate your engagement process as it plays out.
- Keep checking in on skill sets and team building; identify gaps and strengthen them.
- Assess whether the right people are on the team and resources are assigned appropriately.
- Ask participants frequently whether they have any questions or would like more information on a particular topic.
- Consider pre-meeting briefs and post-meeting debriefs to ensure patients' needs are being met and questions are being addressed.

Avoid potential pitfalls

- Focus is important, but don't narrow your focus so much that patients can't contribute what they think is most important. If you are aware of a major issue or concern that patient advisors are likely to bring up, focus your engagement initiative in a way that allows them to discuss it. If you have a good reason to put a particular 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 "rubber stamp".
- Avoid becoming defensive. Health care providers should help clarify misunderstandings and offer explanations when asked, but such explanations must be provided carefully to create an environment that welcomes feedback.

Address conflicts of interest

Recognizing that patient advisors have interests outside of your project, it is possible that you may encounter perceived or actual conflicts of interest during your engagement efforts. Remind participants that they should be acting transparently, in good faith, and leave aside personal interests in order to advance the public interest. Ask participants to take steps to avoid conflicts of interest, and promptly disclose any conflicts that they may have. Should a conflict be identified, it should be addressed quickly, and may need to include the advisor stepping away from the improvement activity.

Provide feedback on whether patients' input will be incorporated

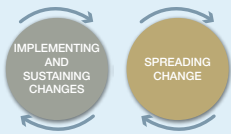
Be open with patients before, during, and after the engagement process about what feedback will be incorporated and what will not. It is fine to share with them that, although some of their suggestions may be good ideas, they will not be implemented due to financial or other resource constraints. More experienced advisors will expect that, at some point, feasibility, costs, and restraints will need to be considered, and are often the team members to bring this up.



Chapter 3

Following through and following up: Implementing, sustaining, and spreading changes

Once you have generated ideas, implemented change ideas and demonstrated that they have resulted in improvement, it is now time to formally implement and sustain the changes locally and begin spreading them – that is, working to implement the initiative on a broader scale (e.g., in other units, departments, practices, etc).



Quality Improvement Framework Check-In: Phases 5 and 6

Quality Improvement Check-Ins summarize the steps in each phase of the quality improvement cycle. To read about each step in more detail, refer to Health Quality Ontario's [Quality Improvement Framework](#).

Phase 5. Implementing and sustaining changes: Once your team has trialed your improvement ideas through small tests of change, have demonstrated improvement in different scenarios and have a high degree of confidence that the changes are indeed an improvement, you are ready to progress to Implementing and Sustaining Changes. During this phase, change ideas are formally implemented into everyday practice in the unit or department where the work is done.

Quality phase: Implementing and sustaining changes	Tips for engaging patients
Develop a sustainability plan	Patients continue to be key stakeholders and can influence the success of the plan
Formalize and standardize changes and document new processes	Involve patients in the development of patient-friendly materials
Share new processes creatively, widely, regularly, and often	Patients can play a role as peer teachers. Testimonials and recognition for the work that the patient advisors have done is also important

Key lessons: *Engagement may begin to wane in this phase. Be sure to keep in regular contact with the patients who were involved in Phases 1 through 3 and will be interested in the implementation of the project. Consider conducting a focus group or a check-in to test if the implementation is going as planned from patient's perspective.*

Phase 6. Spreading change: During this phase, successful change ideas are implemented on a broader scale.

Quality phase: Spreading change	Tips for engaging patients
Create and implement a spread plan. Start the spread with units eager for the change to build momentum and provide examples to individuals or departments with the most barriers	Providing patients' perspectives on the importance of the change can help health care providers to overcome barriers to adopting changes
Communicate changes	Patient participants can be great ambassadors for spread, sharing the impact of the project, and making an emotional connection through stories and examples
Create a measurement plan for spread	Patients who remain interested and invested in the project will be enthusiastic about measuring spread

Key lessons: *Patient advisors will bring other skills in addition to their expertise in their experience that may be useful while spreading change. The patients that were involved in the improvement initiative will often become your organization's biggest supporters when it comes to communicating to spread change.*

Tips for evolving your patient engagement process as the quality improvement initiative matures

The improvement team needs to pause, celebrate, and explore the strengths and weaknesses of the initial engagement. With the experience of the project, the team and patient advisors who have been involved may be ready for a more robust and mature approach.

This can also be a key time to reach out to current and new members, both health care providers and patients, to establish continued interest, test the waters in case the team is fatigued, or look for people with new skill sets that are needed to move forward.

- Some members will be ready to retire from the initiative (both staff and patients).
- Some may want to step back or be involved in a different way in spreading the initiative (both staff and patients).
- Does the team need some focused training to achieve the scale up? What is the inventory of skill sets and resources on the existing team, and are there any gaps?
- Consider the readiness of the organization and the patient advisors involved to increase the participation from patients in the ongoing development of the initiative given the new parameters, and determine the need for new membership.
- Are there new skill sets needed to move forward? It may be necessary to adjust the recruiting strategy for both staff and patient advisors on the team.
- Send regular updates to participants to reaffirm that your organization takes their feedback seriously.
- Commit to re-engagement in the future, and to adding new methods of engagement.
- Members who are no longer active can continue to provide valuable feedback and advice on an ad hoc basis. Ensure that you have their input and offer them opportunities to remain involved.

Evaluate your work and commit to re-engagement

Be sure to take time in the six months after the engagement initiative to gather your team, review activities, celebrate achievements, discuss shortcomings, and brainstorm about further improvements. This includes taking the opportunity to ask advisors about their experiences as patient advisors, and whether they felt their time was used well. To capture this experience, refer to a helpful evaluation called the [Public and Patient Engagement Evaluation Tool](#) (PPEET), developed by the PPEET Research Practice collaborative, a pan-Canadian partnership of practitioners and researchers that is funded by the Canadian Institutes of Health Research.

Quality is a journey and requires ongoing monitoring and course correction. Make sure to document your suggestions so that the evolving team can learn from the work. Participants often deeply appreciate updates every four to six months, and sending updates can help reaffirm that your organization takes their feedback seriously.

Commit to re-engagement at some point in the future, and re-confirm with leadership at your organization that they are supportive of this. 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 organization's patient and caregiver advisory council about how any changes you have implemented are working. When you do re-engage with patient advisors about your organization's approach to quality improvement, it may be tempting to simply repeat the methods you developed the first time around, but try to avoid this and add a new method of engagement. The chance that you'll learn something new increases greatly when you engage with patient advisors in a new way.

Report on your results

Plan ahead

You will need to work out in advance how the results of your engagement initiative will be documented and shared within the organization, with the patient advisors who participated in your initiative, and potentially with the broader community served by your organization. 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. Plan to share your results even if the project was not successful in achieving your original goals – the lessons you learned are important as well.

Final report

Consider releasing a short summary report that describes how your organization has involved patients in your quality improvement initiatives. This communicating of results keeps the momentum going for further improvements that are generated through the engagement of patients. You could also highlight any future opportunities for involvement here. This can be a stand-alone report, or an article in your organization's newsletter or on its website. You may wish to include the following sections in the report:

- Provide a short introduction that thanks participants, describes how your organization values patient/caregiver input, and highlights what was learned during the process.
- Describe how you engaged with patient advisors, including the methods you chose and the steps you took.
- Summarize the issues raised, lessons learned, and recommendations put forward. It is okay to describe conflicting perspectives that were not resolved during the process.
- Explain the actions your organization 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).

Case Example: Health Quality Ontario's experience with engaging patients to prepare this Guide

To illustrate how some of the steps and concepts in this toolkit can be applied, Health Quality Ontario has included a case example of how patients were involved in the development of this guide.

Background: This Guide was conceived as a collaborative effort between two separate branches of Health Quality Ontario: the Quality Improvement Plan Program and the Patient, Public and Caregiver Engagement department. A working group was formed, consisting of six Health Quality Ontario employees. Collectively, the working group decided that it was important to engage and collaborate with patient advisors in the development of this Guide. The decision to engage patient advisors in writing this Guide was supported by management and leadership at all levels of Health Quality Ontario.

The goal: To co-write a concise and instructive Guide that is informed by examples and experiences from QIPs and from patient advisors' experiences, and would be useful for staff involved in engaging patients in quality improvement and the development of the QIPs.

The aim of engaging patients in the development of this guide was to ensure that we have a product that, if followed by care providers, would result in an engagement experience that would be successful from the view of patient advisors as well as health care providers.

The specific markers of success we were aiming for were:

- **Informative:** We aimed to provide a guide that would be useful to the field as they embark on engaging patients in quality improvement, with specific guidance for QIPs.
- **Clear:** We aimed to write at a language level appropriate for any health care provider, regardless of their level of experience with engagement or quality improvement.
- **Useful:** We wanted to produce a document that the reader would share with others, particularly staff teams and patient advisors involved in quality improvement.

Identifying which populations to engage: We wanted to include some more experienced patient advisors, who could share their experiences with both successful and unsuccessful engagement initiatives, as well as some patient advisors with less experience being engaged, who could share their input on the engagement process, any barriers they may have encountered, or perceived barriers they may have.

Recruiting advisors: Patient advisors interested in working with Health Quality Ontario can submit an [Expression of Interest](#) on our website. Our team members contacted individuals who had expressed interest to ask whether they would like to be part of this project. We conducted standardized interviews with all individuals who expressed interest (n=27) to explain the scope of the project, and 20 agreed to participate.

Choosing methods of engagement (Figure 3):

- **Online meetings:** We decided that the bulk of our engagement would be in the form of online meetings. Internally, Health Quality Ontario uses online meetings quite frequently, so the team was

comfortable hosting meetings via webinar. Using online meetings is also more convenient for participants, since they can avoid travelling.

- **Telephone and email feedback:** We made sure to let advisors know that we are available by telephone or email throughout the process if they were unable to make a meeting yet still wished to contribute, or if they were wary of sharing any feedback or questions in front of a group.
- **In-person meeting:** We planned a single in-person meeting once we had a solid draft of the Guide to share how their feedback had been incorporated and to receive additional feedback.
- **Follow-up:** We kept patient advisors up to date on the progress of the Guide by webinar and email, and distributed a PDF version of the Guide following completion of the design process.



Figure 3. The process of engaging patients in the development of this Guide

- Most of the twenty advisors participated in at least one of the online sessions to develop the guide
- A few people were not able to attend any sessions, but provided feedback on the developing guide by email

- Eight advisors participated in an all-day workshop where we refined the guide and explored the extent to which the material was perceived to be informative, concise, and shareable

How our advisors contributed

Our patient advisors provided feedback on the structure of the Guide; ensured that the information provided was relevant for advisors and that the most important points were emphasized accordingly; ensured that plain language was used in the appendixes that are meant for use by patient advisors; and suggested additional content to be added (including additional methods of engagement and potential pitfalls).

Lessons learned

- We found that holding briefings before and after meetings to consider individual needs of participants was helpful
- Some reflective participants would provide feedback after the meetings
- We needed to train attendees to use the webinar software, but once they were familiar with the program there were few technical problems
- We relied on administrative support to help organize travel and accommodations for advisors for the in-person meeting
- We needed to mail some materials out rather than sending them only via email

Check in: after workshop debrief:

Advisor comments

- “I feel more optimistic about the health care system because of this experience.”

- “I’ve never felt more welcome in any project than I have in this one. I’ve rarely gone to a meeting where I’ve been as interested in a topic as this one. I feel like I know so much more now than I did when I arrived.”
- “Please be sure to keep us involved”
- “Would appreciate follow-up on next steps”
- “I’m so impressed by this organization’s passion for patient engagement – it’s clearly not just a job.”

Staff comments

“I was impressed with the contributions to the Guide and really appreciated the constructive criticism we received.”

If you would like to learn more about how we engaged patients in this project, contact Engagement@HQOntario.ca.





Chapter 4

How to engage patients in the development and review of your organization's QIP

This chapter discusses how to engage patients in the development and review of the QIP. This is an important aspect of engaging patients in quality improvement.

As mentioned, hospitals in Ontario are now required to both engage patients in the development of their QIPs as well as describe their engagement practices in their QIPs. The Ontario Hospital Association has developed a useful guidance document for hospitals as they work on this, titled [Engaging Patients and Caregivers in QIP Preparation](#). Organizations in other sectors of the health care system are also increasingly engaging their patients in the development of their QIPs.

Patient advisors can contribute to the development of all three of these aspects of the QIP:

- Patient advisors who have been involved in quality improvement projects can help to write the description in the Progress Report. Patients' contributions should also be described under comments column in the progress report.
- Patient advisors can help to develop the Narrative section. They will have helped to select the organization's priorities for quality improvement, and can also help summarize how they and other advisors have been involved in the organization's quality improvement activities.
- Patient advisors can help to identify priorities for improvement, provide input into the targets for improvement and help to develop the change ideas to go in the Workplan.

Here are some ways to engage patient advisors in the development of your organization's QIP:

- Include patient advisors on the Quality Committee responsible for developing the QIP and that reports to the Board
- Involve existing patient groups in the development of the QIP
 - Share progress on your QIP and request guidance from your organization's Patient and Family Advisory Council or other patient groups
- Build towards the Patient and Family Advisory Council and/or other patient groups having equal voice and weight in developing the QIP
 - Some organizations have their Patient and Family Advisory Council sign off on the QIP before submission, similar to how the Board of organizations must sign off on the QIP

- Hold focus groups or town halls to share the QIP to a wider audience of patient advisors
- Involve patient advisors in planning and executing the quality improvement activities described as change ideas in the QIP

Overview of QIPs

QIPs include three sections:

The **Progress Report** links the previous year's QIP with the coming year's QIP and should be integral to your organization's ongoing monitoring efforts throughout the year. The Progress Report is intended to help the organization gain insight into how effective the change ideas tested were in achieving established targets and describe how they were refined to make progress toward set targets.

The **Narrative** section allows your organization to provide context and set the stage for the commitments being made in the QIP being developed for the upcoming year. The Narrative should be easily understood by all audiences, including the public, and includes a space for organizations to specifically describe their patient engagement work.

The **Workplan** is the portion of your QIP that identifies the quality issues, indicators, targets for improvement, and specific change ideas that your organization will be testing over the coming year.

QIPs are submitted through Health Quality Ontario's online submission system, **QIP Navigator**.



Getting Started

One of the first steps to preparing a QIP is to organize ongoing Quality Improvement Committee meetings to discuss the development and implementation of the QIP in your organization.

While the development of the QIP is an ongoing process, the 'new' QIP season typically begins in the fall, when Health Quality Ontario introduces the new priority quality issues and corresponding indicators for the coming year. This is a natural choice for when to bring new patient advisors on board as part of your Quality Improvement Committee. As part of the Quality Improvement Committee, your patient advisors will participate in all aspects of developing and implementing your QIP.

While your organization will still be working on implementing change ideas from the previous QIP at this time, you should start thinking about selecting the priority issues for the coming year in the fall. Input from patient advisors will be very important for selecting these priorities. In addition to input from the patient advisors who are participating in developing and implementing your QIP, remember to review data from patient experience surveys and data on complaints to inform your selection of priority issues to work on.

At the first meeting with the patient advisors, share your most recently submitted QIP. If the data are available, review your current progress on the selected indicators. Make sure to give your patient advisors the opportunity to ask questions about these documents as they learn more about the QIPs.

Accessing Health Quality Ontario's Resources

Consider signing up for Health Quality Ontario's webinars for your sector, which take place throughout the fall and winter. Multiple different webinars are offered, focused on topics such as summaries of each sector's QIP submissions from the previous year; how to set targets for improvement; introducing the priority issues and indicators for each sector; and how to address key issues such as equity and integration of care. Patient advisors may also be interested in these [webinars](#), so be sure to pass along the information and offer them the chance to participate.



Defining the Problem

Begin to measure data and explore the gap between your current state and where you'd like to be. Reach out to patients to collect stories of their experiences related to these issues – patients have a valuable role in identifying why the current state is not working for them. Create a Measurement Plan to determine how progress will be tracked. For some indicators, data on your organization's performance will be uploaded to the QIP submission system, QIP Navigator, by Health Quality Ontario – log in to Navigator to review these data and ensure that your measurements are aligned with the performance or consider the performance cited for the indicator. For instance, you may be using more current data than is in the QIP; reflect this in your plan.



Understanding your System

Begin to analyze the data your team has collected that relates to the priority areas. Begin to set targets for the coming year using information from sources such as evidence-based literature, service accountability agreements, current provincial data such as that provided in [Measuring Up](#), and your organization's historical data. Be sure to share the above-mentioned documents and discuss what targets resonate with your patient advisors.

Brainstorm improvement opportunities and change ideas that you will test over the coming year. Begin writing the Narrative portion of your QIP, in collaboration with your patient advisors. This section should reveal a true commitment to quality improvement and patient engagement, and should be written in language that resonates with patients, caregivers, and the public.



Designing and Testing Solutions

Refine the change ideas that you have generated and write them up as improvement initiatives in your QIP. If patient advisors will be included in implementing, sustaining and spreading these change ideas, be sure to include descriptions of how they will be engaged. Write up your change ideas in the Workplan section of the QIP. Once the Workplan is completed, take the necessary steps to have the QIP reviewed, approved, and submitted to Health Quality Ontario by April 1 each year.

Begin testing the change ideas described in your QIP. Keep patient advisors involved in the testing of change ideas, checking in regularly to ensure that the changes are resonating with them. Share your results widely, including stories of challenges and successes. Set up measurement systems to continuously monitor progress.



Implementing and Sustaining Changes

Formalize and standardize successful change ideas into policies/procedures, orientation documents, job descriptions, and education programs. Document new processes. Continue to adhere to your ongoing measurement plan to track performance. Discuss lessons learned with staff and patient/family councils. Share improvement stories and evaluate their impact and any feedback from patients. Create a plan for spreading changes that have been successful – for example, to other units, departments, or practices – and continue to monitor your progress toward the goals in the QIP.



Spreading Change

Document your system for monitoring performance and the achievement of any commitments/priorities established in the QIP. Implement your plan for spreading successful changes. Communicate broadly, including by posting your QIP on your organization's home page and referring patients to the document. Your patient advisors may be champions of your successes and integral to your communications about your successes. As you implement change ideas and process measures throughout the year, update your working copy of your Progress Report, comparing it against the previous year's QIP priorities and targets. Indicate which change ideas have been implemented, what lessons were learned, and how your patient advisors contributed.

Glossary

For Ontario's health care system, the term **patient, public, and caregiver engagement** (abbreviated as **patient engagement** throughout this guide) refers to an activity that:

- a) Is primarily undertaken by a care provider, organization or policy maker;
- b) Includes real contribution and participation from patients, caregivers, or members of the public;
- c) Results in improvements in the quality of care;
- d) Increases or sustains patient, caregiver, or public trust; and
- e) Uses the most appropriate public engagement approach or combination of approaches (sharing, consulting, deliberating, or collaborating) depending on the issue or situation.

In this guide, we will use the term 'patient engagement' rather than 'patient, public, and caregiver engagement', in the interest of brevity.

Quality in the context of health care has been defined as "The degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge."¹⁰ From this definition follow the six components of high-quality health care: *safe, effective, patient-centred, efficient, timely, and equitable*.¹¹ These six components of high-quality health care are also at the heart of [Quality Matters: Realizing Excellent Care for All](#), Health Quality Ontario's vision for achieving a quality health system.

Quality improvement can be defined as a systematic approach to making changes that lead to better patient outcomes (health), stronger system performance (care), and enhanced professional development. It draws on the combined and continuous efforts of all stakeholders – health care providers, patients and their families, researchers, planners, and educators – to make better and sustained improvements.¹²

A **Quality Improvement Plan (QIP)** is a formal blueprint on how a health care organization will address quality issues and meet its quality improvement goals. Hospitals, interprofessional primary care organizations, community care access centres, and long-term care homes are required – either by the *Excellent Care for All Act, 2010* or by their funding or accountability agreements – to create a Quality Improvement Plan every year. Each organization develops a plan including specific targets and actions that reflect the province's health care improvement priorities, as well as the quality issues that are locally relevant. The plans have three components – the progress report, the narrative and the work plan – which together reflect on the quality improvement activities and achievements of the previous year, provide context about the organization and outline steps for the year ahead. All QIPs are publicly posted on Health Quality Ontario's [QIP Navigator website](#).

A **patient advisor** is a person who has been a patient, the family member of a patient or the caregiver of a patient, and is partnering with staff at a health care organization to provide input into policies, programs, and practices that affect patient care and services. Patient advisors ensure that the voice of the patient is heard and influences planning and decision making on issues that affect patient care.¹³

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Appendix 1

Get Involved in Quality Improvement:



A Guide for Patients and Caregivers

What is Quality Improvement?

Quality improvement is the process that health care organizations (like hospitals or your family doctor's office) use to improve how they plan and give care to patients and their caregivers.

- Many health care organizations have teams that focus on quality improvement. Visit the [Health Quality Ontario](#) website to watch a video to learn more about Quality Improvement, and who may be part of it.
- Quality improvement always starts with health care organizations choosing one issue or problem to focus on. For example, a hospital may use a quality improvement process to reduce wait times in a clinic.
- There are a few models for doing quality improvement. To learn more about how they all work, visit the [Department of Community and Family Medicine, Duke University School of Medicine](#) website.

Why should you get involved in quality improvement?

Quality improvement can be done through projects or committees. It's a key way to improve the patient experience, health outcomes and health care staff training. As someone with first-hand experience in getting care or caring for a loved one, you can have a big part to play.

You are an expert in your health experiences, and bring valued insights to the table. By taking part in quality improvement, you are using your experience to help fix a problem. Your voice can improve the health system for future patients and caregivers.

How can you get involved in a quality improvement project?

If you or your family member or loved one have received care at a health care organization and want to get involved in improving the care that they provide, reach out to them to offer your services as a patient advisor.

- Ask someone who works there (for example, your doctor or nurse, or a receptionist) for information about how to get involved. If it is a larger organization, you may be directed to another department, such as the Patient Relations department.
- Check the organization's website to see if there is any information about getting involved.
- Contact the organization's Patient and Family Advisory Council, if they have one, and ask about opportunities to work on quality improvement

How you can be involved: Key questions for staff

When you find a quality improvement project you want to be involved in, it's important to be clear on what your role will be. While some staff may be experienced on how to partner with patients in quality improvement, some may not be. Being prepared with what to ask can help the partnership grow and help your journey as a patient advisor. Just think – you, too, can provide education and support to the staff.

Below is a list of key questions to ask quality improvement staff. Ask the questions to help you plan for, work on and follow up with quality improvement projects.

Plan for quality improvement – Ask staff these questions to help you plan for quality improvement, and decide when to be involved:

1. What is the main issue or problem, and goals for improvement?

Every quality improvement project has a clear focus and goals. You may be helping to define these if you are involved in the very early stages of a project, or they may already have been determined. Either way, it's important that you understand what these are, and think about whether you agree with them.

2. Who are the people involved and what are their roles? What will my role be?

Get to know all the people involved, and the many roles they play. Talk with staff and agree on your own role, tasks and amount of time you invest.

3. Will expenses related to my participation be covered by the organization?

Discuss with the organization to find out whether they will provide patients with coverage for their transit, food during meetings, or with support for other needs.

Doing Quality Improvement – Ask these questions to be involved in the ways you prefer:

1. Where can I get education, training and staff support about this topic?

Doing quality improvement can be hard if it's new to you. Ask staff for education and training, or to be matched with a quality improvement expert or peer mentor to help you through the process. Remember that the staff you're working with may also be new to working on quality improvement projects.

2. What are the quality improvement milestones or timelines?

"Milestones" are key events or achievements during a project. They are a good way to tell if a project is reaching its goals. Project timelines will let you know how long you will be involved.

3. How many quality improvement cycles will there be?

Quality improvement occurs over time. Quality improvement staff use [run charts](#) and other tools to track change over many cycles. It's important to ask staff how many [cycles](#) a project may take. This will give you a sense of how long it may take for your input to lead to improvement.

Follow-Up – Ask these questions to stay linked to the quality improvement project, even after you are involved.

1. What is the main issue or problem, and goals for improvement?

Quality improvement staff have a duty to let you know the final results of a project. If they don't follow up, you can ask them for an update. Ask questions to find out how your input was used.

2. What role will patients and caregivers play in spreading improvements?

The first goal of quality improvement is to solve a problem. The second goal is to [spread](#) the solution to other, common sites. There may be a chance for you, or other patients and caregivers, to help spread improvements.

Important Things to Know:

- **Be Mindful of Privacy** – A lot of details are shared during QIP meetings. If you want to share details about your experiences that should not be recorded or repeated outside of a meeting, make this clear beforehand. Staff may ask you to sign a confidentiality (privacy) agreement before you can access some of the information about the organization. This means you will be asked not to share any private details that you learn during meetings.
- **Not All Input Is Used** – Your input is meaningful. But it's important to know that health care organizations may be limited in what they can do with it. Not all of your input will be used as part of the quality improvement project.
- **Be Patient** – It may be a long time before you see results from the time and effort you put in. But know that your steady input is leading to improvements that will be seen over time.

Health Quality Ontario www.hqontario.ca/quality-improvement/what-is-quality-improvement

Department of Community and Family Medicine, Duke University School of Medicine
www.patientsafetypeduhs.duke.edu/module_a/introduction/introduction.html

Run Charts www.ihl.org/resources/Pages/Tools/RunChart.aspx

Cycles www.institute.nhs.uk/quality_and_service_improvement_tools/quality_and_service_improvement_tools/plan_do_study_act.html

Spread www.ihl.org/resources/Pages/HowtoImprove/ScienceofImprovementSpreadingChanges.aspx

If you have any questions or comments, or would like more details on this topic,
contact engagement@hqontario.ca.

For related tools and resources visit Health Quality Ontario's Patient,
Caregiver and Public Engagement Hub:

<http://www.hqontario.ca/Engaging-Patients/Patient-Engagement-Tools-and-Resources>

Appendix 2

Introduction to Developing a Quality Improvement Plan:



A Guide for Patients and Caregivers

What is a Quality Improvement Plan?

A Quality Improvement Plan (QIP) is a health care organization's formal plan to improve the care they provide to patients and their caregivers. Hospitals, long-term care homes, certain primary care organizations, and organizations that provide home care are legally required to submit a QIP to Health Quality Ontario each year by April 1st.

Each year, Health Quality Ontario asks the organizations that submit QIPs to focus on a handful of key issues that are priorities in Ontario, such as ensuring patients have timely access to care and ensuring patients are satisfied with the care they have received.

Health Quality Ontario provides specific measures, or *indicators*, that organizations can use to track their performance on these key issues over time. Examples of these indicators include the length of time patients spend waiting in the emergency department, and the results of surveying patients about their satisfaction with the care they have received. Health care organizations can also choose to work on improving on other indicators representing issues that are important for them and their patients.

There are opportunities for you to get involved in developing a QIP for a health care organization that has provided treatment to you or a loved one. By getting involved, you can help decide on what needs to be improved and how it should be done.

What does a Quality Improvement Plan look like?

There are three parts to a QIP:

1. The Progress Report: A report on progress from the previous year's plan
2. The Narrative: A brief summary of the plan
3. The Workplan (that is, the plan itself), which includes:
 - o The indicators that the organization will be working on
 - o How they are currently doing on these indicators
 - o Targets for what kind of improvement they would like to see
 - o Ideas on how they are going to improve to reach these targets

All QIPs are publicly posted. You can browse the QIPs of the organizations you are interested in by visiting Health Quality Ontario's [QIP Navigator website](#).

An example of how a QIP can help us improve on an important health care quality issue

Imagine your family doctor is part of a family health team. You have a scrape on your leg that is sore and oozing, and you're worried that it might be infected. You would like to be seen as soon as possible. You call your family health team to get an appointment, but the next available appointment is a week away.

The next day, you feel even worse, so you go to the emergency department. When you finally are seen, they diagnose you with an infection, prescribe antibiotics, and send you home.

The Issue: Timely access to primary care.

In this situation, it would have been best for you to see your family doctor quickly to get the antibiotics you needed.

By patients seeing their family doctor or appropriate provider in a timely fashion, it can prevent them from getting sicker and requiring more extensive care. The family doctor knows the patient's history and can consider other factors that might be important to the outcome of care.

Patient advisors who are part of the Quality Committee at your family health team report that the issue of timely access is important to them.

In this example, two of the six doctors have already implemented changes to improve timely access to care, with good results. The Quality Committee decides to focus the improvement work so that all doctors on the team use these principles so that any patient needing care can receive care in a timely manner.

The indicator: One indicator that is often used to track performance on this issue is based on a survey question about patients' perceptions of timely access:

The last time you were sick or were concerned you had a health problem, how many days did it take from when you first tried to see your doctor or nurse practitioner to when you actually saw him/her or someone else in their office?

- Same day
- Next day
- 2 – 19 days (enter number of days: _____)
- 20 or more days
- Not applicable (don't know/refused)

Your family health team includes this question on surveys it gives to patients throughout the year. When the Quality Committee first writes the QIP, they record how they are doing on the indicator at that time and set a target for improvement over the coming year. They find that 45% of their patients were able to receive an appointment on the same day or next day when they needed one. Since this data is available for each doctor in the clinic, they can provide feedback to individual physicians.

The Quality Committee might set a target to improve by 20% in one year (so go from 45% to 57% of patients reporting that they received an appointment on the same day or the next day). To reach this target, they will come up with one or more change ideas to improve their performance.

The change idea:

Change ideas refer to the approaches an organization uses to improve care. There are many different change ideas that could be used to improve timely access to care.

The Quality Committee decides that they will pair the physicians who have already implemented changes to improve timely access to care with physicians who have not yet tried this change. They will measure extent to which all physicians in the office are adopting advanced access scheduling and the number of appointments for each physician's schedule available for same day access.

They will continue to survey patients throughout the year and see how this change is affecting the indicator.

Why should you get involved in Quality Improvement Plans?

QIPs are designed to improve care and outcomes and to create a system that provides care **with** patients. As of September 1, 2015, all hospitals are required to work with patients to develop their QIPs. And although this is not required for other types of health care organizations, many of them are beginning to engage patients in the development of their QIPs as well.

As someone with first-hand experience in receiving care or caring for a loved one, your active participation in developing the QIP is important to ensure that the health care organization includes ideas that will improve the patient experience.

You are an expert in your health experiences, and bring valued insights to the table. By participating in developing an organization's QIP, you are using your expertise to help fix a problem. Your voice can improve the health system for future patients and caregivers.

How you can be involved: Key orientation questions

Deciding on improvement priorities and establishing goals is an important step for a health care organization. Organizations will look to engage with you, often through established formats such as patient councils, town halls, or focus groups. When you are involved in developing the QIP, it is important to be clear on what projects would be most meaningful to you so your ideas may be considered for inclusion. Below is a list of key questions to ask staff. Ask the questions to help you plan for important projects that have a positive impact.

Get ready for Quality Improvement Planning – Ask staff these questions to help you plan for developing the QIP, and decide when to be involved:

Where can I get education, training and staff support?

- QIPs include provincial as well as local priorities. Ask staff for education and training on the provincial requirements for the QIP. You may also want to be matched with a QIP expert or peer mentor to help you through the process.

Who are the people involved and what are their roles?

- Get to know all the people involved, and the many roles they play. Talk with staff and agree on your role, tasks, and amount of time you invest.

Developing QIPs – If you will be part of the team responsible for developing a QIP, consider these questions to ensure meaningful projects are being included and patient needs are being addressed:

What is the timeline for developing a QIP? What are some milestones on this timeline?

- Milestones are key events or achievements that will occur over the course of development of a QIP. Talk to the team about the timeline to develop the QIP and the important milestones on this timeline. This will help give you an idea of the time commitment that might be required at different stages of development.

One important milestone is when the QIP is approved by the Board before submission. This will occur before (but close to) submission. Another significant milestone is April 1st of each year – this is the date when the completed QIP must be submitted to Health Quality Ontario.

What issues related to care are important to improve on this year?

- You can make a big difference by identifying the issues that you think should be targeted for improvement. These may be selected from the list of key provincial issues (and their corresponding indicators), or they may be other issues specific to the organization that you are aware of or feel would be important to address. It's important for you to weigh in on what the organization will be working on over the coming year because you are the one that has experienced the care or services being delivered.

What are some goals for improvement?

- Every quality improvement project needs a clear focus and goals. Once the issues and problems to be worked on are identified, you can help to identify goals that you think will make a real difference to patients.

What changes can we make to ensure a positive outcome?

- Health care organizations may have some ideas on how they can go about achieving the goals that have been set. Listen to their ideas to see if they resonate with you. Your experience and insight can help an organization identify what needs to be done differently.

Follow-Up – Ask these questions to stay linked to the QIP, even after you are involved.

When and how often can I expect updates?

- QIP staff should follow up to let you know what the final plan looks like. If they don't follow up, you can ask them for an update. Ask questions to find out how your input was used. The organization should also publicly post the QIP on their website.

What role will patients and caregivers play in executing the improvement projects?

- Some of you may want to continue on with implementing a project. Let the staff know. You can make a valuable contribution by working alongside health care providers to test ideas for change.
- The first goal of quality improvement is to solve a problem. There may be a chance for you, or other patients and caregivers, to help organizational leaders make decisions to ensure the work is meaningful to all.

Important Things to Know:

- **Be Mindful of Privacy** – A lot of details are shared during QIP meetings. If you want to share details about your experiences that should not be recorded or repeated outside of a meeting, make this clear beforehand. Staff may ask you to sign a confidentiality (privacy) agreement before you can access some of the information about the organization. This means you will be asked not to share any private details that you learn during meetings.
- **Not All Input Is Used** – Your input is meaningful. But it's important to know that health organizations may be limited in what they can do with it. Not all of your input will be used as part of the QIP.
- **Be Patient** – It may be a long time before you see results from the time and effort you put in. But know that your steady input is leading to improvements that will be seen over time.

Reviewing Quality Improvement Plans

Ideally, you will be involved early in the process of creating a QIP. However, sometimes patient advisors may be asked to review a QIP when it is nearly completed. Here are some key points to consider as you review a QIP that has already been written.

Progress report

- As you read the progress report, can you identify where the organization made progress and where they encountered challenges?
- Does the Progress Report include descriptions of any lessons learned over the previous year?
- Do the topics resonate for you from your personal experience or an experience you've heard about?

Narrative

- Is the Narrative section easily understandable to patients, caregivers, family and the public?
- Does the Narrative section show the organization's vision for improving the quality of care that they provide?
- Does the Narrative section make the reader feel hopeful and excited about the ways in which the organization will be improving over the coming year?
- Does the Narrative section show the organization's commitment to patient engagement and patient-centred care?
 - o Would a patient, caregiver, or family member reading the document see a potential role for themselves in the organization's work on quality improvement?

Workplan

- Do you think that the targets that have been set will inspire the organization to achieve improvement?
- Will the planned improvement initiative(s) described improve the quality of care received by patients at the organization?
- Are there examples where the planned improvement initiative(s) include plans to involve patient advisors?
 - If not, why not? Can you suggest ideas for how patient advisors can contribute to the initiatives described?

The entire QIP

- Overall, does the QIP show the organization's commitment to improving the quality of care provided?
- Is it clear that the organization is building on lessons learned (as described in the Progress Report)?
- Are there any areas for improvement that you feel are missing in the QIP that should be addressed?

Glossary

Quality Improvement Plan (QIP): A QIP is a health care organization's formal plan to improve the care they provide to patients and their caregivers. Hospitals, long-term care homes, certain primary care organizations, and community care access centres (which provide home care) are legally required to submit a QIP to Health Quality Ontario each year by April 1st.

Indicator: A specific measurement that is used to track performance on quality issues over time. An example of an indicator is the percent of patients who reported that they were able to get an appointment with their primary care provider the same or next day when they needed it.

Quality issue: An aspect of care for which there is room for improvement across Ontario. An example of a quality issue is timely access to care.

Change idea: A specific approach that an organization will use to try to improve its performance on an indicator.

QIP Navigator website: <https://qipnavigator.hqontario.ca/Resources/PostedQIPs.aspx>

If you have any questions or comments, or would like more details on this topic, contact engagement@hqontario.ca.

For related tools and resources visit Health Quality Ontario's Patient, Caregiver and Public Engagement Hub:

<http://www.hqontario.ca/Engaging-Patients/Patient-Engagement-Tools-and-Resources>

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