



GUIDE

Creating and
sustaining
patient and
family advisory
councils

Choosing Meaningful Projects

Let's make our health system healthier

Who is Health Quality Ontario?

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 it often falls short of being the best it can be. Plus certain vulnerable segments of the population are not receiving acceptable levels of attention. Our intent at Health Quality Ontario 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.

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Health Quality Ontario's Patient, Family and Public Engagement Program

At Health Quality Ontario, we believe that patient, family and public engagement is central to improving health care. Our patient engagement efforts are designed to encourage, enable and empower all Ontarians to be full participants in the care they receive – and to help patients, families and health professionals join hands together to improve Ontario's health system. Through our [patient engagement](#) program, patient and family volunteers contribute their ideas and priorities to all aspects of our work on health quality. We also support patients, families and providers on how to effectively engage with each other to meaningfully improve care, through our [online hub](#) of tools and resources, and through conferences and learning events.



Introduction

This is an exciting time for patient and family advisory councils across Ontario. With councils in all long-term care homes, many hospitals, and showing promising examples in other health sectors, patients and their families are poised to make significant contributions to improving the quality of care across our system.

At Health Quality Ontario, our goal is to help advisory councils get off to a good start and keep working well, focusing on meaningful projects that have a positive impact.

Do you serve on or support a patient and family advisory council?

Then this guide on *Choosing Meaningful Projects* is for you. It is part of a series of guides designed to provide you with practical tips and tools to help you address some of the challenges that patient and family advisory councils may face. The other guides include:

- Creating an Effective Terms of Reference
- Recruiting for diversity

For links to other resources available to help you create and sustain an effective patient and family advisory council, please visit Health Quality Ontario's website (www.hqontario.ca) and our hub of patient, engagement tools and resources that have been carefully gathered by Health Quality Ontario in consultation with patients and providers.

What's in a name?

Patient and family advisory councils go by various names, reflecting the variety of roles they can play within a health care organization. At any given health care organization they might be called a council, committee, forum, panel, network, roundtable or team. The Long-Term Care Act mandates that a resident's council is established in every long-term care home and that a family council is established, if requested by a family member of a resident or a person of importance to a resident. Over time, methods of engagement may change based on the culture of the organization, opportunities that arise and increasing support for your work. The key to these partnerships is that collaboration is meaningful for patient and family advisors and the organization. This requires leadership participation and organizational membership on the council so that goals are set, and decisions are made, that work for all involved. In these guides, we use the term "patient" to describe any type of person served by the health system and "family" to describe any individual who provides or has provided care or support to a patient or former patient.

These guides have been developed as a general resource. It is important to refer to the legislation for your sector (which can easily be accessed through your organization) to ensure you meet those requirements. As well, resources – like this guide developed by the [Ontario Association of Resident's Councils](#) – can help with understanding the resident and family council legislation in the Long-Term Care Act.

Choosing meaningful projects

Deciding what projects to take on, or establishing goals, is an important step for any patient and family advisory council. Creating opportunities for patients, families, staff and organizational leaders to make these decisions together is an important part of ensuring the work is meaningful to all.

Here is just a taste of the great work that some patient and family advisory councils have accomplished in Ontario:

- At [Thunder Bay Regional Health Sciences Centre](#), the patient and family advisory council proposed — and then helped to co-design — a new process to prepare children (and their parents) who are about to have surgery.*
- At [Bluewater Health](#) in Sarnia, patient and family advisors worked with staff in nutrition services and infection control to rewrite the policy on bringing food from home for patients. That project led to other involvement, such as the patient and family advisors testing new menu items.*
- The [South East Toronto Family Health Team](#)'s patient advisory council co-designed the organization's patient experience survey to ensure it asks patients about the things that are important to them. The council also helped design a survey for patients who have used the emergency department for care (instead of the family health team clinic).
- The [Mississauga-Halton Community Care Access Centre](#)'s patient and family Share Care Council provided their input on what patients need so they can be confident to leave hospital for home. Working with Trillium Health Partners, the council helped to design changes to Trillium's discharge process. Patients going through the re-designed discharge process had a 52 % reduction in hospital readmissions.

As these examples illustrate, there are many opportunities to involve patient and family advisors in projects that have a real impact on patient care and the delivery of health services.

How can your advisory council best decide what projects to take on?

Will they be philosophical topics such as looking at what your organization means by “patient-centred care”? Will they be hands-on issues, such as the comfort of seating in waiting areas or the signs that help people find their way throughout the building? Or will they be a combination of philosophical and hands-on? Listed below are a number of ways to get started in choosing the topics that will be the most meaningful to your council.

* These examples come from *The Change Foundation report, “Patient/Family Advisory Councils in Ontario Hospitals: At Work, In Play. Part 3: Examples: What the Councils Changed”* available at: www.changefoundation.ca.



Do a self-assessment

One way to get started is to do an assessment of different areas in your organization where patients and families may be involved and to co-create goals with the organization based on what you learn.

The Institute for Patient- and Family-Centered Care in the United States has developed a self-assessment tool to help organizations identify priorities for change and improvement. Completing this assessment with your advisory council, in partnership with your organization's senior leaders, could be a valuable exercise to help identify areas for your council to address. The tool is available free online at: <http://www.ipfcc.org/tools/downloads-tools.html>, and while the inventory is designed for hospitals, other types of health care organizations could easily adapt it.

Based on the Institute's tool, here are 10 key areas that your patient and family advisory council could explore. Within each, we have provided one example of a specific question to consider – to help spark ideas and to demonstrate how to bring focus to a broad topic. If you are just getting started, it's also helpful to focus on tangible, quick-wins and allow for training time to get council members up to speed.

- **Information and education for patients and families:** Do the organization's information materials reinforce the belief that patients and families are essential members of the health care team?
- **Patient and family support:** Are patients and families involved in developing, facilitating and evaluating any peer support programs offered by your organization?
- **Environment and design:** Do the building services and capital planning departments partner with patient and family advisors to ensure that their perspectives are included in all planning and redesign of the organization's physical space?
- **Patterns of care:** Are family members viewed as visitors or are they always welcomed to remain with the patient, such as during clinical discussions and shift changes? (For more on this topic, see "Better Together: Partnering with Families Campaign" from the Canadian Foundation for Healthcare Improvement, <http://www.cfhi-fcass.ca/WhatWeDo/better-together>)
- **Patient and family storytelling:** Are patients and families involved (through presenting their experiences, for example) in orientation and continuing education for employees, medical staff and the board of directors? (For more on this topic, see "Training and Family Storytellers and Patient and Family Faculty," <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3783065>.)
- **The organization's mission statement and definition of quality:** Were patients and families involved in defining quality and developing the mission and philosophy of care statements?
- **Measurement:** Are patients and families involved in developing the tools that measure patient and family experiences of care (including quality and safety)?
- **Charting and documentation:** Do patients and families (with the patient's consent) have easy access to their medical charts?
- **Human resources:** Are patient and family advisors involved in hiring practices, for example through developing questions about the interviewee's focus and experiences in patient- and family-centred care or patient engagement?
- **Leadership:** Do the leaders of the organization encourage and support collaboration with patients and families in strategic planning and facility planning? Leaders (For more on this topic, see the "Strategies for Leadership" toolkit, available at: <http://www.aha.org/advocacy-issues/quality/strategies-patientcentered.shtml>.)

Think “quality improvement”

Another way to ensure that your patient and family advisory council has an impact is to think of them as a potential partner in any work across the organization to improve the quality of care it provides. In essence, improving the quality of services and the experiences of patients and families is what these councils are all about.

Patient and family advisors can make valuable contributions in many aspects of quality improvement. For example, organizations are increasingly involving their advisory councils in creating their yearly quality improvement plans, helping the organization to identify priority areas for improvement. Other councils have helped to define “quality” at the organizational level, developing a declaration of patient values, or assisting in writing and updating patient safety policies. Some councils are also now involved in co-designing projects, working alongside health care providers to develop and test ideas for change that improve the quality of care and services.

One resource to help you get started in determining topics that would be meaningful to bring to your council is the Quality Compass, an online tool from Health Quality Ontario that provides evidence-based ideas to effect change and quality improvement on several priority topics across all health sectors (hospitals, long-term care homes, community care and primary care). In addition, it provides suggested tools to help fuel these changes and guidance on how to measure the success of these changes through specific indicators and targets.

Visit qualitycompass.hqontario.ca to see what topics and change ideas may be relevant for your organization and for your council to consider.



Build in time to learn

Learning is a key stage in any engagement process and should be a two-way process. Council meetings can be a forum for patient and family advisors to learn together about the different roles and activities in the organization, helping to inform the type of advice that council members may provide now or down the road. For example, inviting the director of a certain department or program to talk to the council about his or her responsibilities and challenges can help to identify opportunities where the council's input may have a positive impact.

In the same way, council members may want to consider developing presentations for staff and leaders of the organization to inform them about the council's work and their roles as patient and family advisors. Council members can act as faculty in ongoing staff education initiatives, particularly training related to patient and family centred care. Regular dialogue between staff, patients and family members outside of clinical settings can help to build a support for patient engagement among an organization's staff, and sustain a culture of patient and family centred care.



We encourage you to reach out to the organizations highlighted in these resources to hear about their lessons learned, to build a network of colleagues, and to learn first-hand how their councils are working (perhaps by attending a meeting of their patient and family advisory council or by meeting with their co-chairs and staff liaison).

Learn from other organizations

Many organizations across Ontario have established patient and family advisory councils and are sharing examples of the contributions their councils have made. Here are a few resources that can spark additional ideas for topics or projects your council may wish to tackle:

- Patient/Family Advisory Councils in Ontario Hospitals: At Work, In Play. Part 3: Examples: What the Councils Changed from The Change Foundation. Available at: www.changefoundation.ca
- Achieving Patient Experience Excellence in Ontario: An Idea Book, Engaging Patients and Families from the Ontario Hospital Association. Available at: www.oha.com.

Health Quality Ontario's annual conference workshops on patient and family engagement:

- [Patient Engagement in Action: Putting Patients, Families, and Caregivers at the Centre of the Circle of Care](#)
- [Engaging the Vulnerable in the Quality Agenda](#)
- [Building a strong and engaged patient and family advisory community](#)
- [Patients and Providers Working Together – Easier Said Than Done](#)
- Improving Care Through Patient Engagement and Empowerment
- [Learning from the Patient and Family Advisor Experience](#)
- [Metrics: the Patient and Family Advisors' Key to Success](#)
- Best Practices in Patient Relations: Partnering with Patients to Improve Experiences

Lay the groundwork for projects to succeed: thoughts for your staff liason

As you identify areas or projects for your council to focus on, it's important to take some time to explore your organization's readiness to work with a patient and family advisory council. The impact and success of your council's efforts will depend on partnering effectively with people across your organization.

Have staff throughout the organization embraced the idea of working with your council or is there some reluctance? Do some question the value of patients and families providing feedback in their area of work?

It's common that people may have questions or concerns about the best ways to engage with patient and family advisors. This is part of the learning process that organizations go through as they start to work with patient and family advisors.



Preparations like these will give you important insight into which parts of your organization may be most open to working with the patient and family advisory council, which in turn, will help the council focus its efforts and manage expectations.

To help get everyone on the same page, we recommend you:

- Ask senior leaders for their priorities for patient, family and public engagement. This will likely create an instant advantage: you already have support for these ideas right from the top. Find a way for senior leaders to regularly attend council meetings to obtain feedback and partner with council members on their goals.
- Identify the staff who are likely to be most affected by your council's findings and recommendations. This may not be obvious from the outset, but with a little probing you can determine the right people to involve early on and often – which will be key to the success of any project.
- Make sure there is regular communication between those who lead and support the council, and colleagues who may be affected by the council's work. Joining regular huddles or other staff meetings to introduce new council projects is a good way to signal the organization's support for council work. Bring patient and family council members into these meetings and discussions as much as possible to create an environment of shared decision-making and planning

Start small and stay focused

Our final words of advice for how to choose projects that will be meaningful and have an impact are: start small and stay focused. Many of the projects highlighted in this guide took many months of work on the part of the council and others, so it's important not to tackle too much at once. By focusing on one project or topic that inspires and motivates both patient and family advisors and the people who work in an organization, you can dramatically increase the chances of your council's success.

For more information

“Appendix A. Working With Patient and Family Advisors on Short-Term Projects” in “Working With Patients and Families as Advisors: Implementation Handbook” from the Agency for Healthcare Research and Quality. This appendix includes detailed instructions on three suggested initial activities to conduct with patient and family advisors. Available at: <http://www.ahrq.gov/professionals/systems/hospital/engagingfamilies/strategy1/index.html>.

“Patient- and Family-Centered Care: A Hospital Self-Assessment Inventory” from the Institute for Patient- and Family-Centered Care. Available at: <http://www.ipfcc.org/tools/downloads-tools.html>

Share your experiences

We encourage you to share the results of your work – with council members, other patients and families, and staff from across your organization.

At Health Quality Ontario we are always eager to hear about your experiences with patient and family engagement, and any lessons learned. In addition, we welcome input on how these guides can be improved to help ensure the tools and resources we are providing are relevant and helpful.

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