



GUIDE

Creating and
sustaining
patient and
family advisory
councils

Creating an Effective Terms of Reference

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 *Developing a Terms of Reference* 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:

- Recruiting for diversity
- Choosing meaningful projects

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 health care 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.

Creating an effective terms of reference

Once you have decided to start a patient and family advisory council, it's time to develop the group's terms of reference. A terms of reference document outlines the ways in which a group of people agree to work together to accomplish common goals. Your terms of reference is an important step in creating a shared set of expectations and building accountabilities for members, as well as explaining some of the supporting roles.

You don't need a lawyer to write the terms of reference for your patient and family advisory council. This guide includes key points to cover, a template you can use, and links to examples and more information.

What makes an effective terms of reference?

- It clearly describes the council's purpose, structure and operating rules.
- It defines roles and accountabilities for the council, senior leaders and support staff.
- It is collaboratively developed and it is approved by the whole council.
- It is easy to read and understand.
- It can change as the nature of the work of the council evolves.

Your council's terms of reference should answer these key questions

- **Mandate:** What is the purpose of your advisory council? What difference do you want this council to make?
 - o Include the council's mandate or mission statement. A good mandate will guide and focus the council's work. It clearly states the value that the advisory council brings to the organization and outlines the council's major goals.

- o See the sample mandate/purpose statement in this guide from the South East Toronto Family Health Team and the sample template at the back. See also the sidebar on "What kind of council are you?" for descriptions of the main types of patient and family advisory councils.

- **Accountability and reporting:** What is the council's relationship to your organization? For example, does the council make recommendations to your organization's Board of Directors, to the Chief Executive Officer (CEO) and to staff? What can the council expect from your senior leadership?
 - o It is considered a best practice for your council to have a direct relationship to the CEO, Executive Director or senior leadership team. You may also want to consider building in regular communication with the organization's board. Regular attendance and collaborative discussions with leadership enables the goals of the council to advance and be aligned with the strategic planning of the organization.
 - o At minimum, the organization should commit to listening and reporting back to the council in a transparent way. That means it doesn't have to take all of the council's advice but it should clearly communicate as to what ideas were acted on and why others were not.

- **Membership and structure:** Who can become a patient/family member of the council? How are they selected? Will the membership term be one year or several years? Which staff positions will be represented on the council? Consider:
 - o See Health Quality Ontario’s guide on [Recruiting for Diversity](#) to help you think about the different experiences you may want represented.
 - o It’s best to ensure that the majority of council members are patient and family advisors while ensuring the right staff are at the table to be able to affect change in the organization. This promotes a sense of ownership and underscores how the organization values their partnership. Leadership representation helps to create support for the goals of the council (including resources) while ensuring these goals also align with the work of the organization. In the Long-Term Care Act, staff members must be invited by the council.
 - o Most councils that have fixed terms for membership ask participants to commit for at least two or three years. Bringing in some new members every year helps to create a rolling balance of experience and fresh perspectives.
- **Roles and responsibilities:** Many organizations have found that it works well to have two patient and family advisors share the job of chairing the council. How will the co-chairs be elected? What are their responsibilities?
 - o **Common responsibilities for co-chairs include:** opening and closing meetings, developing meeting agendas in collaboration with support staff, communicating with council members and the organization’s leadership about council matters, representing and speaking on behalf of the council at special events.
 - o Co-chairs should be provided with training related to active listening, group facilitation (e.g. keeping a group focused and on-task, dealing with conflict, building consensus) and giving presentations.

SAMPLE MANDATE STATEMENTS

The Patient Advisory Council of the South East Toronto Family Health Team opens its terms of reference with these vision and purpose statements:

Vision: Families and patients are partners with their health care providers and are engaged in all aspects of their health care.

Purpose: The purpose of the South East Toronto Family Health Team’s (SETFHT) Patient Advisory Council (PAC) is to improve patient care experiences at SETFHT. The council serves in an advisory capacity, making recommendations on matters that impact the experience of patients and families at SETFHT. The PAC brings together individuals with a variety of experiences with SETFHT:

- To provide feedback on, and ideas for, initiatives and programs that enhance, ensure and embrace the model of patient-centred care;
- To be a collaborative, positive and rational force for the enhancement of high-quality patient-centred care at SETFHT; and
- To advance patient engagement and patient-centred care principles and practices at SETFHT.

For the full terms of reference for the South East Family Health Team Patient Advisory Council, see [here](#).



What is the role of the staff liaison?

As the key link between the advisory council and the organization, the staff liaison has a wide range of responsibilities to help the council develop and function well.

- o The staff liaison is a key communication link to the organization and provides partnership and support on a number of activities, including agenda co-development, preparing presenters so both council members and presenters find it meaningful, and coordinating or facilitating training the co-chairs for their roles. On occasion, the staff liaison serves as a committee co-chair alongside a patient/family co-chair.
- o Your terms of reference can set out specific roles for council members, such as providing secretariat support for the council. The staff liaison should be also responsible for distributing and following up on minutes of council meetings, after they have been reviewed and approved by the co-chairs.
- o In addition to the staff liaison, and depending on the council's mandate or focus, you may also want to include staff who work on quality improvement, patient/client experience, communications or other groups that expect to have regular interaction with the council.
- o For more on this topic, see “Staff Liaison to Patient and Family Advisory Councils and Other Collaborative Endeavors” from the Institute for Patient- and Family-Centered Care at: http://www.ipfcc.org/advance/Staff_Liaison.pdf.

What is expected of the patient and family members on the council?

This part of the terms of reference is an opportunity to describe the qualities and behaviours that will help the council be productive and effective.

- o You might include behaviours like being a good listener and being open to hearing the perspectives of others. You might also consider qualities or roles such as the ability to represent the concerns of patients and families and share personal experiences in ways that others can learn from.

WHAT KIND OF COUNCIL ARE YOU?

A patient and family advisory council can have a broad purpose or a more specific one. Your council likely fits into one of these four types:

- **Organizational:** These councils have an ongoing role of providing advice from the patient and public perspective. Top executives of the organization may sit on the council. For example, the [Kingston General Hospital Patient and Family Advisory Council](#) includes the chief nursing executive (and other staff) and is broadly tasked with identifying opportunities to improve patient experience and quality of care.
- **Task:** Task-focused councils are created for a specific purpose, such as to help the organization review and redesign one aspect of care. An example is the Ottawa Hospital's Patients' Reference Panel on Cancer Program Transformation, which ran for several months in 2011. It developed guiding values from the patient and family perspective and produced a report with many recommendations on ways to improve the program.
- **Condition:** These councils focus on concerns unique to the treatment and care for specific physical or mental health conditions. For example, the Renal Patient and Family Advisory Council of London Health Sciences Centre provides a voice for patients and families affected by chronic kidney disease and contributes to the development of policies and programs related to their care.
- **Constituency:** These councils work on issues faced by a group with a distinct set of concerns, regardless of their health problem. This may be an age group such as children or youth who use the organization's service. Or it could be a broader group that faces distinct challenges. For example, Alberta Health Services convenes a Wisdom Council including community elders and traditional healers who advise the ministry on Aboriginal health priorities and service delivery at a system level.

What is expected of staff or clinician members?

Staff or clinician members are an important partner for any council and the terms of reference should outline the key roles and qualities that these members bring to the table, including:

- o Encourage staff engagement and partnership with the advisory council at all levels of organization
- o Understand the roles, responsibilities, challenges and opportunities for point-of-care staff in partnering with patient and family advisors
- o Promote staff buy-in and share council discussions with others to further the council's goals
- o Contribute to two-way information sharing
- **Meetings:** How often will the council meet? Will decisions be made by consensus or by voting?
 - o Consensus is a process in which the group seeks agreement on a decision through discussion. Consensus means that all members can support the decision, even if the decision is not everyone's preferred solution. This may involve compromising on timelines or on the overall goal of a project.
 - o Some patient and family advisory councils state that they strive for consensus and that they vote on a decision only when they cannot reach a consensus.

- **Money:** Will volunteers be reimbursed for expenses, such as child care, parking or other travel costs? Will they be paid for their time as well?
 - o The Change Foundation has developed a question-and-answer tool to help organizations decide whether or not to pay patient-engagement participants. See “Should Money Come Into It?” at www.changefoundation.ca/library/money-it-tool-deciding-pay-patient-engagement-participants/.
- **Review:** Will the terms of reference be reviewed on a regular schedule, such as every two years? The review schedule might depend on the length of the membership term and turnover of members.

For more information

“Working With Patients and Families as Advisors: Implementation Handbook” from the Agency for Healthcare Research and Quality. Available at: <http://www.ahrq.gov/professionals/systems/hospital/engagingfamilies/strategy1/index.html>. See especially Appendix B. Establishing and Working With Patient and Family Advisory Councils.

“Creating Patient and Family Advisory Councils” from the Institute for Patient- and Family-Centered Care. Available at: http://www.ipfcc.org/advance/Advisory_Councils.pdf

“Supporting Your Home’s Residents’ Council: A Resource Guide for Residents’ Council Leadership and Staff Assistants” from the Ontario Association of Residents’ Councils. <http://www.ontarc.com/products.html>

A terms of reference template

Use and adapt this template to create your council's terms of reference.*

Click [here](#) to download a Word version of the template

[organization name and logo]
[name of your advisory council]

TERMS OF REFERENCE

Purpose

[Insert your purpose / mandate / mission statement. Include an inspiring vision of the way that patient engagement can transform health care and briefly describe the council's broad purpose. For examples, see the "Sample mandate statements" section of this guide]

Responsibilities and opportunities

- *[List the council's key roles; use active words to inspire action, such as:]*
- To advise *[the organization or program]* on meeting the needs of patients and families through teamwork with staff
- To advance patient engagement and patient-centred care in all services provided at *[organization]*
- To provide a forum for patients and families to identify opportunities to improve the quality of care and to participate in quality improvement initiatives at *[organization]*
- To promote opportunities for collaboration among patients, families and staff at *[organization]*
- To promote the inclusion of all voices in health care decision-making

* This template is based on the terms of reference of the Family Advisory Committee of Holland Bloorview Kids Rehabilitation Hospital. We thank them for permission to adapt their terms of reference for this guide.

Accountability and reporting relationships

The *[council name]* communicates directly with the *[senior leaders who are responsible for listening to and working with the council, e.g. the President and CEO]*.

The staff liaison for *[the council]* supports the council by *[insert a brief overview of the liaison's role]*.

Members

Members of the council will include *[List numbers for each type of member or the proportion of public and staff positions on the council. Refer to legislation for guidance]*.

- *X patient/family representatives*
- *X senior management representative(s)*
- *X clinical representatives*
- *1 staff liaison]*

All members are expected to: *[List basic responsibilities, such as:*

- *Participate in at least X meetings per year of X-X hours each*
- *Participate in projects between meetings [Estimate this time commitment if possible]*
- *Inform the co-chairs or staff liaison if they will miss a meeting*

Term: Members are asked to participate for X years, from *[months that your meeting year runs, e.g. September 1 to August 31]*. Members can serve for X terms. *[Describe your process for balancing new and experienced membership.]*

Selection: *[Briefly describe your process for selecting public members, e.g. who is responsible]*

Patients and family members

Qualifications:

- A patient or family member of a patient at *[organization]* in the past *[X]* years
- *[key qualities that you want to see in council members, for example:]*
- Respects diversity and differing opinions
- Works collaboratively with staff and other members of the public
- Respects privacy and confidentiality
- Provides constructive advice
- Can represent families as a well-informed participant

General requirements:

- Attend a screening interview
- Sign a confidentiality agreement and volunteer contract
- Attend a *[orientation, information, training sessions]*
- *[Other requirements, such as for any volunteer in your organization]*

Reimbursement and compensation:

- *[Briefly describe your reimbursement and compensation policy; refer to more detailed information available from staff liaison if needed]*

Staff and board members

- *[List the specific staff positions, including board of directors/trustees members, represented on the council]*

Officers

Co-chairs

[Describe your election/selection process and whether co-chairs will be public members or a combination of public and staff members, for example;]

The *[council]* will elect two co-chairs from among its patient and family members – or may choose to elect one staff co-chair and one patient/family co-chair. One co-chair will be elected for a two-year term every year at *[which month]* meeting. *[This is an example of a rotation schedule, so that a new co-chair comes in each year]*. Chairs can serve for a maximum X terms.

Qualifications:

[List requirements or key qualities such as:]

- An understanding of the roles and responsibilities of the *[patient and family advisory council]*
- Ability to provide democratic leadership for the council
- Ability to represent the collective voice of the council inside *[the organization]* and in the community
- Desire to work constructively with staff and other council members
- Is respectful of difference and supports the inclusion of all voices at the table

Duties:

- Call and chair meetings
- Develop the meeting agenda with the staff liaison
- Review and revise meeting minutes
- Communicate with council members
- Confer with the CEO and senior management on matters related to the council's work
- Write an annual report summarizing the council's activities and achievements during the year
- Represent and speak on behalf of the *[council]* at *[types of activities that the co-chair may participate in]*

[repeat for vice-chair or past chair if your council has those positions]

Meetings

Frequency: The *[council name]* will meet at least X times a year.

Notice: *[Describe how meetings will be publicized]*

Decision-making: *[Describe how the group will make decisions, e.g. will strive for consensus and will use voting when there is no clear agreement]*

Quorum: At least XX% of the voting members must be present for a vote to take place.

Voting: *[How will you vote? e.g. a show of hands or by secret ballot if requested]*

The staff liaison will send the minutes out within XX weeks of each meeting.

Minutes will be sent by email to:

- All members of the *[council]*
- *[others who will get the minutes]*
- *[others on request]*

Records retention

The *[council's]* records are subject to the *Freedom of Information and Protection of Privacy Act (FIPPA)* and are governed by *[the organization's]* Records Retention Policy.

Review

The council will review these terms of reference every X years by *[date]* and approve any revisions.

Share your experiences with us

Health Quality Ontario is 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.

Please contact us:

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