
Engaging Patient & Family Advisors on Committees

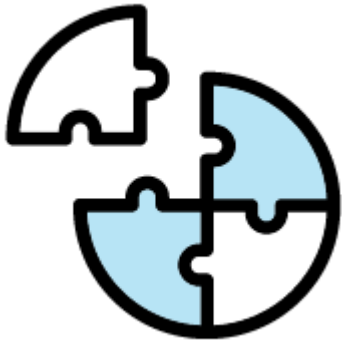


**Ontario
Health**



In this guide you'll find:

- 1 how to decide if committee engagement is the best choice for your engagement
- 2 how to start off on the right foot with patient & family advisor committee members so they can participate fully
- 3 steps to ensure patient & family advisor committee members feel engaged and supported



BEFORE YOU BEGIN

When and why should you engage patient & family advisors on a committee?

There are many impactful ways to gather input from patients and family advisors that offer broader perspectives and experiences **so before you even start**, consider if having patients on your committee is the best way to get their input and hear about their experiences. It can be a great way to engage but there are lots of other ways to get feedback and advice from a broader and more diverse range of patients.

Patient & family advisors on a committee can:

- ✔ bring a unique and valuable perspective committee work
- ✔ help the committee put a face to the numbers
- ✔ share experiences that the data can't tell us
- ✔ point to gaps in what *should* happen in patient care and what *actually* happens
- ✔ help the committee to think through how patients will be affected by decisions, policies and practices
- ✔ draw attention to the complex choices that patients and their families must make
- ✔ identify the steps in a patient's journey

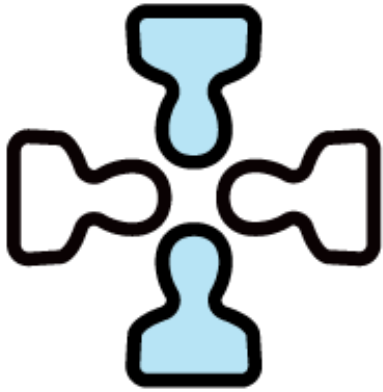


COMMITTEE GOALS

Here are some questions to consider before you engage patient & family advisors on your committee:

- Will patients be directly **impacted** by decisions made coming out of the committee?
- Is there a clear and obvious **role** for patients to contribute and participate?
- Is it a **topic** that is important to patients & caregivers?
- Will you and other committee members be able to ensure that patients are able to **participate fully** and understand the context and issues?
- Do you understand what patient advisors can **contribute** to this work? If not, feel free to talk to our team about the work of the committee to ensure it is a good approach.
- Do staff have the **capacity** to provide proper orientation and support to patients throughout the duration of the committee?
- Are there **issues** that patients could be speaking about at every meeting?
 - If no, consider doing one-off engagement activities like a focus group or survey.
 - If yes, there is a need for ongoing engagement on the committee.

Since engaging patient and family advisors on a committee requires time and resources from both staff and patient & caregiver advisors to contribute effectively it is important to be strategic and consider whether there might be higher impact approaches to getting patient perspectives on the topic or project.



WHO?


*Aim to get feedback from a diverse range of patients and caregivers, so that organizational and health system changes reflect the communities we serve. **An effective committee reflects the diversity of the people that you serve**—health care professionals, policy-makers, researchers, patients and families— and ensures that the decisions being made reflect and respond to a broad range of lived experiences and knowledge.*

Develop a list of **skills and desired perspectives and experiences** to include to maintain diversity of opinions, knowledge, geographic representation, etc. Consider who will be impacted by the initiative being worked on and who will be key to the initiative's success.

Reach out to your community- through partner organizations, caregiver & patient organizations or disease associations as well as healthcare delivery organizations that can act as key liaisons to introduce you to patients and caregivers.

Recruit a minimum of 2-3 patient participants. Having only one participant can place extra stress on individuals to be the lone voice from the patient or caregiver perspective and risks being tokenistic. A minimum of 2-3 participants encourages diversity, community and can support mentoring from more experienced participants.

Interviewing interested individuals will help you assess whether they are aligned with the goals of the committee and would be comfortable in that kind of role.



While it is important to recruit for diversity on committees, ensure you work on building the capacity of *all* committee members and staff leads to understand what some of the issues are for equity-deserving groups. It *should not* be left to people with lived experience of health inequities to be the ones to educate everyone else.



PREPARE

Patient & Family Advisors

In order to actively participate in meetings, patient and family advisors need to **understand the background and context** for discussion Meeting structures that you are very familiar with may be new for patient and family advisors. For example, who can approve minutes? What is a Terms of Reference?

Before their first meeting, help advisors understand the possibilities and limitations of the impact of their contributions. Not all advisors will know what actions Ontario Health can and cannot take in relation to the project they are discussing.

Make it clear to advisors that **asking questions** for clarity or more information is acceptable and expected.

Offer regular conversations ahead of or after meetings to help them feel more comfortable and participate more fully. If unsure, just ask participants what they need to successfully participate and make this an ongoing conversation.

Try creating annotated meeting agendas that also include: key decisions that need to be made and **explicit opportunities for comments** or questions from advisors.

Consider having a patient co-chair to help balance out the leadership of the committee. Having co-leadership of the committee allows for diverse perspectives and styles and limits the influence of an individual's perspective on the direction of the committee's work.



PREPARE

Committee chair(s), staff leads & all committee members

It may be new for the chair or committee members to be supporting and collaborating with patient and family advisors on a committee. Ensure everyone understands that, like health care professionals, patients and caregivers have valuable expertise to share that's rooted in their experiences with the health system.

Set the stage for a safe meeting space by helping all committee members understand the importance of having patient advisors on the committee as well as the specific needs they may have in order to fully participate. Be clear on how patient and family advisors add value to your committee.

At the first meeting with patient and family advisors have the chair **ask all participants to do roundtable introductions**, asking everyone to share their name, profession or area of interest, and one reason they're attending the meeting. This benefits not just the patients, but all committee members who may not know each other. **Taking time** to understand who the advisors are and the unique experiences and expertise they have to offer **helps build trust** across the committee.

The most important thing you can do to ensure the success of the committee is by creating a space (virtual or in-person) that **feels safe for people to participate** in. Let the entire committee know that they can speak openly and offer dissenting opinions. Even small gestures like the chair greeting each attendee by name at the beginning of each meeting can help build trust and create an inclusive space for all participants.



DISCUSS

Sometimes it can be difficult for advisors to know how to participate or what kind of input to share. Try to facilitate the discussion to draw out advisors and ensure all voices are brought into the conversation.

Balance participation—keep track of who is talking and who isn't. When meetings also include health care professionals, try to make sure they don't take up too much space in discussions. It's important that advisors feel comfortable on the committee to speak up and move the conversation forward.

Ask participants to **tackle a question in pairs**. Try to mix groups so they include one advisor and one health care professional.

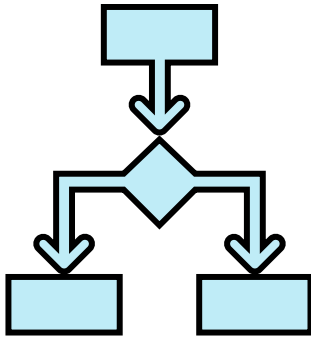
Ask participants to **take a moment to reflect** on a question or issue independently before taking turns responding.

Ask open-ended questions that prompt long responses.

Avoid breaking long silences. Silence often helps participants gather their thoughts before speaking. Wait at least five to seven seconds before breaking silence.

Navigate interruptions—step in quickly to ensure that all voices are heard.

When discussion veers off track, try to refocus and **use a “parking lot”** to keep track of unrelated issues and topics and reassure participants that you'll return to them.



DECIDE

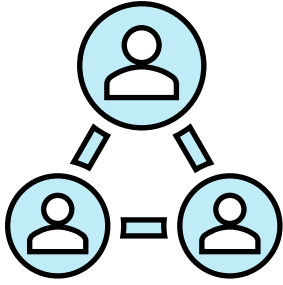
Focus on Key Decisions. As discussion unfolds, pause to take stock of the key decisions that need to be made and whether you're on track to make them. Remind the committee of these decisions so they can focus their contributions constructively.

Keep Discussion On Track. Discussions can sometimes veer off track, especially when advisors are sharing sensitive health experiences. When this happens, take a moment to validate the advisor's experience,. Prevent discussion from centering on the experiences of any one person.

Create a list of follow-up actions as a group and identify who will respond to each decision or task. Invite patient advisors to lead some of the action items without being too pushy. This helps to **build a shared sense of ownership** and accountability over the meeting.

Offer options for patient advisors to provide feedback to staff or co-chairs after each committee meeting ends: some people are not on-the-spot thinkers but require some time for reflection. You can also offer the option to provide feedback afterwards in an email.

Close the meeting by revisiting the key decisions you set out to make. Acknowledge the specific contributions of the patient advisors so that they feel valued.



FOLLOW-UP

Patient and family advisors want to **see impact and action** come from the ideas and experiences they share with you. They want to know their participation has meaning and brings value to the work.

Remember to **circle back** to patient and family advisors to let them know what you did with their feedback and the impact their participation had.

Following-up with the advisors demonstrates a genuine commitment to seeing them succeed and shows an attitude of wanting to learn and make improvements.

Share minutes or a summary shortly after the meeting. Include details on any actions or responses that you or your organization are prepared to take in response to what you heard. Ask the advisors to **review and respond** to the summary and fill-in any details you may have missed.

If patients or caregivers miss meetings, offer a quick phone call so they can **get caught up**, offer a **chance to contribute** to that topic, and **be prepared** for the next meeting.

Be proactive in reaching out to advisors about their experience of being on the committee—to ensure that improvements can be made on an ongoing basis, rather than hearing back at the end of a participant's tenure, or at the annual committee evaluation (ask us for resources for evaluation).