

# Partnering in Co-design for Health

## MAOHT Patient, Family and Caregiver Engagement - FAQs

The Muskoka and Area Ontario Health Team (MAOHT) is committed to people-centered care and the principles of patient, family and caregiver partnership, community engagement and healthcare system co-design to meet the needs of its diverse population.

The underpinning of this commitment is outlined in the Patient, Family, Caregiver Engagement and Partnership Strategy. The Strategy is a framework consisting of four elements:

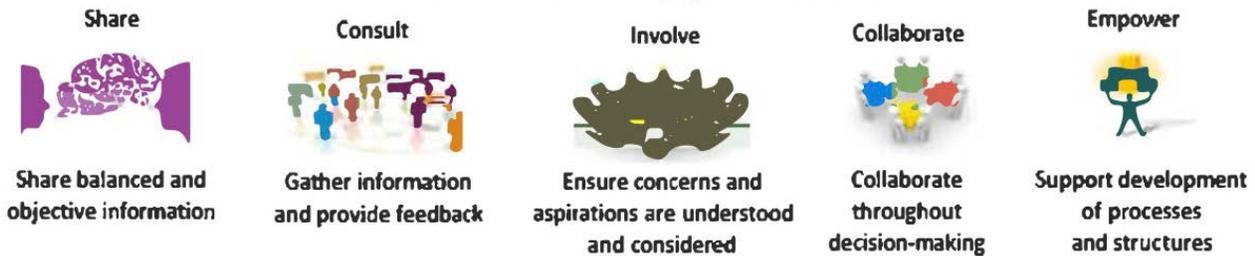
- Strategic Goals
- Guiding Principles
- Engagement Areas and Approaches
- Foundations

The framework is designed to guide MAOHT Partners in ensuring the lived experiences and expertise of patients, families, and caregivers are embedded in all MAOHT processes, practices, and policies to create a more integrated health care system resulting in better health outcomes for our community.

### The Engagement Continuum



#### Across a Spectrum of Engagement Approaches



**Keep informed**



**Seek input**



**Partner  
in decision making  
and co-design**

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### 1. Who is a Patient\*, Family and Caregiver?

In the PFC Engagement and Partnership strategy, a patient\* means:

- “A current user/consumer of the healthcare system, or people who are not yet users/consumers of the healthcare system but could or should be.”

\* Refers to patients/clients/participants/persons accessing service/persons with lived experience.

Based on the Vanier Institute of the Family, our modified definition of “family” is:

- “Any combination of two or more persons who are bound together over time by ties of mutual consent, birth and/or adoption or placement.”
- “Inclusive of diverse family structures including (but not limited to) single parents, same-sex couples, stepfamilies, married or common-law couples (with or without children), skip-generation families and more.”

The Ontario Caregiver Organization (OCO) defines a “caregiver” as:

- Ordinary people who provide physical and emotional support to a family member, partner, friend, or neighbour.

### 2. Who is the Patient, Family, Caregiver Partners Advisory Committee and why are they important?

- Patient, Family, Caregiver Partners Advisory Committees (PFCPAC) are one of many mechanisms Ontario Health has implemented to learn from the experience of patients and families.
- PFCPAC committees are a key component of the Ontario Health Team Structure and are mandatory.
- Ontario Health states that PFC partnership and engagement is a critical success factor in the development and continuation of OHT’s.
- The role of the PFCPAC is to provide co-design, advice, and recommendations.

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### 3. What are the benefits of Patient, Family, Caregiver Partners Advisory Committee involvement?

- Improved patient experience
- Gain important perspectives and insights
- Improved health care quality/patient safety
- Advocacy of all patients, families, and caregivers

### 4. What is Patient Engagement?

- “Patients, family members, and other informal caregivers, and health care professionals actively collaborating to improve health care quality.” It includes individual health care professionals, health care organizations, and the province partnering with patients and their loved ones in different ways to understand their experiences, preferences, and needs, and respond to them.” (Health Quality Ontario: Ontario’s Patient Engagement Framework)
- “The act of involving the patient and their family in decision-making, design, planning, delivery and evaluation of health services at all system levels. When patients are actively engaged, they can become informed decision-makers in their own care and help improve the overall health care system. When health care providers listen to and work with patients and family members, programs, service delivery, and policy can be improved by their first-hand knowledge, insight, and experience.” (BC Patient Safety & Quality Council: Patient Voices Network)

### 5. What is Co-Design?

- “Co-design is an approach that enables health care providers and people with lived experience (or other service users) to co-design care pathways, programs and services, health priorities, policies, and plans, together in partnership.
  - **Participation:** Co-design is a collaborative process in which you invite everyone who may impact the person with lived experience or be impacted by their care – the entire care team.
  - **Development:** Co-design is dynamic and adaptive. It evolves and adapts for context, environment, and people’s needs.
  - **Ownership and Power:** Co-design shifts power and ownership so it is shared, and everyone’s voice is equal at the table.

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- **Outcomes and Intent:** Co-design has a practical focus. It also recognizes that the process itself will have a collateral impact such as improving relationships and communications. The very act of asking and listening to someone share what matters most to them builds trust.” (The Change Foundation, The 101 of Engagement and Co-design, A Step-by-Step Guide, Volume 1, v 2.0, Aug. 2020)

### 6. Why is Co-Design important?

- Co-design and engagement are key ingredients to advancing meaningful change.
- There is a growing body of evidence that shows co-design improves how patients, families and caregivers experience care, the relationship between patients and providers, and how service is delivered.
- The Ministry of Health requires a “demonstrated history of meaningful patient, family and caregiver engagement” as an essential component for system change to models of integrated care.

### 7. What is the Role of a Patient, Family, Caregiver Partner?

- PFC partners are essential advisors that share their own lived experience or reflect broader community perspective.
- “They provide guidance into the discussion and decision-making for co-design of policies and programs that can help improve the health of all Ontarians.
- Bring a unique and valuable perspective to this system-level work.
- Help the committee put a face to the numbers and share experiences that the data can’t tell us.
- Advise the committee on how to redesign and plan services through the lens of a patient or caregiver.
- Guide the committee to consider what the other steps in a patient’s journey might be and understand the complex choices that patients and their families must make.” (Participating on a Committee at Ontario Health: A Resource for Patient & Family Advisors. Ontario Health, pg. 2)
- Identify and make recommendations of improving the care experiences for all patients/family/caregivers.
- Discuss and plan changes to improve the delivery of health services with a quality and safety lens.

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### 8. How will Patient, Family, Caregiver Partners Advisory Committee members provide input?

- Bring lived experience, knowledge, expertise, and insights to help identify the challenges and identify opportunities to improve the health care programs and services.
- “Be direct, clear and focus on resolving problems.
- Will tie personal lived experience, those identified in the community, or that of a family member to the larger issues in the project or committee.
- Will provide clear and constructive feedback to help improve and guide change in healthcare programs and services for everyone in Ontario.” (Participating on a Committee at Ontario Health: A Resource for Patient & Family Advisors. Ontario Health, pg. 4 & 6)
- During the meeting or afterwards, will seek clarification or provide additional feedback/comments to the project lead.
- Will keep information they hear private and confidential.

### 9. What are some typical questions that Patient, Family, Caregiver Partners Advisory Committee Members will ask?

- What is the scope and goals of the project or committee and what are the deadlines/timelines?
- “Can you provide definitions of medical terms and acronyms?
- Will ask the chair, what kind of feedback are you looking for from us?
- To ensure understanding, will clarify with “Let me make sure I understand this correctly, I heard you say... or ask, “Can you walk me through this so I can picture it?”
- How is this decision going to affect patients? Have you spoken to other patients directly influenced by this?
- What other ways will you consult with patients and families beyond this committee?” (Participating on a Committee at Ontario Health: A Resource for Patient & Family Advisors. Ontario Health, pg. 5)

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### 10. What is the role of a Chair/Co-Chair (of a Committee, Working Group, Task Force) as it relates to PFC participation?

➤ Prior to meetings:

- Understand and apply the PFC Engagement and Partnership Strategy, PFC Declaration of Values, the Community Engagement Policy and the principles of co-design.
- Meet with PFPCAC member before first meeting to explore where the member can contribute and provide an overview of the project.
- Plan and host a group orientation: discuss reason for group, roles, expectations, key issues, relevant background information, ground rules, creating safe space, and process if someone gets triggered.
- Provide opportunities for involvement from project initiation (i.e., funding application process, committee, and sub-group formation) and throughout project duration (i.e., concrete tasks).
- Provide materials well in advance including membership of group, medical terms, and list of project related acronyms, and to give adequate preparation time. Consider that the complexity of the materials will require a steep learning curve for group members.
- Be available to reach out to the PFPCAC to respond to questions.
- Consider the timing, pace and complexity of the project – are there opportunities for members to provide meaningful feedback?

➤ Advice for initiatives during meetings:

- At the first meeting, or when new members join, have all members introduce themselves explaining their background, role and how they can contribute; ensure everyone enters full name on screen.
- Limit and explain acronyms so that PFPCAC members can fully understand the discussion.
- Ensure voice of all members have been heard, there is opportunity for input, decision-making and co-design.
- Record the meetings (provide minutes and if possible, audio record) so that members can access the information after the meeting.

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- Provide feedback and conduct an evaluation:
  - Follow-up on questions and suggestions
  - Consider a standing item on agenda to ensure everyone has been engaged and had the opportunity to contribute. Host a “Check-in” before the end of the meeting.
  - Ensure there is a formal evaluation of group process and individual contribution. Consider implementation of a scoresheet (self and peer evaluation) that would be co-developed with input from PFCPAC and other committee members.
  - Ensure mechanism for gathering feedback (e.g., during meetings and also after meetings for those who want more time to think about their perspectives, etc.) and to provide the opportunity for members to evaluate the meeting.
  - Confirm that the PFCPAC lived experience is valued before a recommendation goes forward.
  - Ask: How is the process working for everyone? How is the co-design process going? Is it effective?
  - Regularly ensure time of meetings works for the group.
  - Assess and evaluate the process, outputs and impact of engagement activities.
- When a PFCPAC member can't join at the beginning of a WG that the Chair and PFCPAC member work together to ensure an orientation occurs.
- Assess impact of work:
  - Recognize and close loop on results and outcome of work.
  - Measure and report on progress.
- Celebrate successes.

### 11. What is the role of Other Group Members?

- Understand and apply the principles of co-creation and co-design - see PFC Engagement and Partnership Strategy and the Ontario PFC Declaration of Values.
- Understand the role of PFCPAC member.
- Support PFCPAC member (i.e., make them feel welcome, recognize their contribution, help them learn and understand issues, be aware of teaching opportunities).
- Seek out and value the PFCPAC members' lived experience and expertise.
- Limit and explain acronyms so that PFCPAC members can fully understand the discussion.
- Ensure the privacy and confidentiality of shared lived experience of PFCPAC members.

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### 12. How can Equity, Diversity, and Inclusion in Engagement be addressed?

- Ensure that issues related to equity, diversity, and inclusion are considered when exploring solutions.
- “Be aware of and take responsibility for your own world view, cultural teachings, and privileges.
- Understand the barriers within the community.
- Be aware of the policies, historical and current events, politics and social context of patients and families (i.e., the Black Lives Matter movement, the discovery of unmarked graves at Residential Schools, Muskoka Pride, diverse groups in Muskoka, Poverty, etc.).
- Work towards trusting and respectful relationships, and reciprocal collaboration with all committee members.” (Participating on a Committee at Ontario Health: A Resource for Patient & Family Advisors. Ontario Health, pg. 7)

### 13. How do we create Safe Spaces in engagement?

Co-create a safe space by demonstrating empathy and compassion. Encourage self-care and foster wellness support:

- **“We will acknowledge that these conversations can be triggering!** All members must acknowledge that what they say might be triggering:
  - Even when we follow our Code of Conduct.
  - Even though we approach this in a trauma informed way.
  - Even though we have co-created safe space.
- **We will reaffirm our commitment to each other and invite each other to take care of themselves as they need to throughout the conversation.**
  - We will offer a quick break if things get heavy.
  - We will remind each other to take care.
- **We will acknowledge when a conversation may have taken emotional energy and may have affected us.**
  - We will invite people to take a brief grounding exercise to bring themselves to present.
  - We will do a “check out” to move the conversational focus somewhere else (e.g., what is one thing people are taking away and one thing for self-care).
  - We will share resources with each other.”

(Moving forward together: Transforming care through partnership and engagement. Minister of Health’s Patient and Family Advisory Council, Annual Report 2021-22, pg. 19)

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### 14. What is the Patient, Family and Caregiver Declaration of Values (PFCDOV) and how does it help guide PFC engagement?

[Patient, Family and Caregiver Declaration of Values for Ontario](#) is also foundational to PFC engagement, partnership, and co-design. The purpose of the PFCDOV is to articulate patient, family and caregiver expectations of Ontario's health care system. The Declaration is intended to serve as a compass for the individuals and organizations who are involved in health care delivery and reflects a summary of the principles and values that patients, families and caregivers note as important to them. It is meant to create a partnership between individuals interacting with the health care system including patient, family and caregivers and those who provide health services.

The PFCDOV should be used by providers across the health care system in addition to patients, families, and caregivers to inform partnership in care.

The MAOHT Alliance Council has endorsed both the PFC Engagement and Partnership Strategy and the Patient, Family and Caregiver Declaration of Values for Ontario.

### Resources

- [Algoma OHT's Community Partnership Toolkit](#)
- [BC Patient Safety & Quality Council: Patient Voices Network](#)
- [Chairing Meetings with Patient and Caregiver Advisors: A Best Practice Checklist for Health Care Professionals. Health Quality Ontario](#)
- [Definition of Family - The Vanier Institute of the Family / L'Institut Vanier de la famille](#)
- [Encourage Self Care & Foster Wellness Support from Minister of Health's PFAC](#)
- [Health Quality Ontario: Ontario's Patient Engagement Framework](#)
- MAOHT Collaboration Steering Committee – Etiquette for Effective Meetings (on agendas)
- [MAOHT's PFC Engagement and Partnership Strategy \(Definitions in Appendix\)](#)
- [Participating on a Committee at Ontario Health: A Resource for Patient & Family Advisors. Ontario Health](#)
- [Patient, Family and Caregiver Declaration of Values for Ontario](#)
- [Principles for Authentic Engagement](#)
- [Rules of Engagement. Caregiver Perspectives on Meaningful Engagement. The Ontario Caregiver Organization](#)
- [The Change Foundation, The 101 of Engagement and Co-design, A Step-by-Step Guide, Volume 1, v 2.0, Aug. 2020.](#)
- [The Ontario Caregiver Organization](#)

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#### More Information

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