



# Partnering in Co-design for Health

## MAOHT Patient, Family and Caregiver Engagement - FAQs

---

### 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, your 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

# Partnering in Co-design for Health

## MAOHT Patient, Family and Caregiver Engagement - FAQs

---

### 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 patient 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” 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 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 design care pathways, programs and services, health priorities, policies, and plans, together in partnership.

- o **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.
- o **Development:** Co-design is dynamic and adaptive. It evolves and adapts for context, environment, and people’s needs.
- o **Ownership and Power:** Co-design shifts power and ownership so it is shared, and everyone’s voice is equal at the table.

**Partnering in Co-design for Health**  
**MAOHT Patient, Family and Caregiver Engagement -**

## Partnering in Co-design for Health

### MAOHT Patient, Family and Caregiver Engagement - FAQs

---

#### 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 programs and services.

“Be direct, clear and focus on resolving problems.”

Will use personal lived experience, those identified in the community 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. 46)

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, 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)

## Partnering in Co-design for Health

### MAOHT Patient, Family and Caregiver Engagement - FAQs

---

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

¾ Prior to meetings

Understand and apply the PFC Engagement and Partnership Strategy, PFC Declaration of Values, the Community Engagement Policy and the principles of coc

# Partnering in Co-design for Health

## MAOHT Patient, Family and Caregiver Engagement - FAQs

---

Provide feedback and conduct a reevaluation

- o Follow-up on questions and suggestions
- o 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.
- o 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 PFC PAC and other committee members.
- o 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.
- o Confirm that the PFC PAC lived experience is valued before a recommendation goes forward.
- o Ask: How is the process working for everyone? How is the design process going? Is it effective?
- o Regularly ensure time of meetings works for the group.
- o Assess and evaluate the process, outputs and impact of engagement activities.

When a PFC PAC member can't join at the beginning of a WG that the Chair and PFC PAC member work together to ensure an orientation occurs

Assess impact of work

- o Recognize and close loop on results and outcome of work
- o Measure and report on progress

Celebrate successes.

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

Understand and apply the principles of creation and co-design - see PFC Engagement and Partnership Strategy and the Ontario PFC Declaration of Values.

Understand the role of PFC PAC member.

Support PFC PAC member (

## Partnering in Co-design for Health

### MAOHT Patient, Family and Caregiver Engagement - FAQs

---

#### 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 and social context of patients and families (e.g., 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?



# Partnering in Co-design for Health

MAOHT

