

Ontario Health Teams
Patient, Family and Caregiver Partnership and
Engagement Strategy: Guidance Document

March 2021

Table of Contents

1) Introduction:	3
2) Requirements:.....	4
3) Developing, Validating and Confirming the OHT Patient, Family and Caregiver Partnership and Engagement Strategy	6
4) Summary:.....	8
5) Key Resources:.....	8
6) References:.....	8

Ontario Health Teams

Patient, Family and Caregiver Partnership and Engagement Strategy: Guidance Document

1) Introduction:

The 2019 *Ontario Health Teams: Guidance for Health Care Providers and Organizations* sets out that “Ontario Health Teams will uphold the principles of patient partnership, community engagement, and system co-design. Ontario Health Teams will be driven based on the needs of patients and communities. They will meaningfully engage and partner with patients, families, caregivers, and communities, based on a robust patient partnership model and community engagement strategy.”¹

To advance this foundational building block, the ministry has asked each OHT to create a Patient, Family and Caregiver Partnership and Engagement Strategy as a priority activity in their early formation.

A Patient, Family and Caregiver Partnership and Engagement Strategy for an OHT is intended to ensure that partnership, co-design and engagement with patients, families and caregivers are at the core of the OHT; these are not just activities that an OHT conducts, but the ethos of its foundation. The Patient, Family and Caregiver Partnership and Engagement Strategy will set out overarching principles that will guide the appropriate inclusion of these essential partners in all work of an OHT. It is expected that the Patient, Family and Caregiver Partnership and Engagement Strategy will be an ongoing demonstration of the OHT’s commitment to patient, family and caregiver partnership, not just a one-time perfunctory exercise.

Through the early implementation of OHTs, remarkable successes have been demonstrated in patient, family and caregiver partnership and co-design, and there remain ongoing opportunities to strengthen these efforts, share leading and innovative practices and maintain a consistent focus as more OHTs begin implementation, progress and evolve.

The purpose of this document is to provide a guiding framework for OHTs as they establish a Patient, Family and Caregiver Partnership and Engagement Strategy. In response to needs identified by OHTs, this document will profile leading practices, provide links to respected resources, and set out a streamlined validation and confirmation process.

2) Patient, Family and Caregiver Partnership and Engagement Strategy: Content

The Patient, Family and Caregiver Partnership and Engagement Strategy should clearly incorporate four foundational elements listed below. The inclusion of these elements will support a consistent focus and approach, while each OHT creates its unique strategy.

Element # 1: Strategic Goal
<p>Description: A high-level vision statement outlining what the OHT aims to achieve with respect to patient, family and caregiver engagement within its network over time.</p> <p>Example: A culture that is driven by the lived experience and unique local needs of patients, families and caregivers through partnering and co-design across all OHT activities.</p>
Element # 2: Guiding Principles
<p>Description: An outline of the core values, principles, and commitments that will serve as the foundation for the mutually beneficial outcomes that are possible through strong patient, family and caregiver partnership.</p> <p>These principles are not meant to be comprehensive, but rather to spark ongoing discussion and grounding in the commitments necessary to bring about effective and meaningful partnership within the OHT.</p> <p>Examples:</p> <p>Partnership and Co-design – Authentic, timely, and iterative engagement to inform meaningful and effective partnerships.²</p> <p>Learning – All OHT activities should include patient, family, caregiver, and provider partners who are ready and willing to learn from and about each other in a collaborative and bi-directional manner. Learnings may include other participants’ experiences and perspectives, facts about the issue at hand, or how the system and the care delivered within it may improve.²</p> <p>Empowerment – Patients, families and caregivers should be empowered to openly express their needs, perspectives and concerns in a safe environment without fear of reprisal.²</p> <p>Transparency – Transparency means that health care professionals and organizations are honest and forthcoming about their apprehensions, limitations, and knowledge gaps when it comes to engaging with patients, families and caregivers.²</p>

Responsiveness – Being responsive means that health care professionals and organizations act upon the voices and input of patients, their family and caregivers, and the public in ways that demonstrate the positive impact and value of these contributions.²

Respect – Health care professionals and organizations are asked to show respect for their patient, family and caregiver partners by actively demonstrating appreciation for their time, ideas, knowledge, lived experiences, worldviews and cultural backgrounds.²

Element # 3: Engagement Domains and Approaches

Description: Identification of areas in which engagement will occur across various stages and domains in OHT planning, implementation, and operations.

Differentiating between these domains will help OHTs to pinpoint priorities for engagement.² It will also assist OHTs in considering these domains holistically in order to develop a comprehensive approach to engagement activities across the OHT at large.² Examples should be provided to reflect how engagement approaches will appropriately align with the identified domains.

Examples:

Policy, Strategy, and System Level Discussions – Engaging in broad domains of policy and strategy means the OHT and its members work together with patients, families and caregivers to enable system-level changes. This can include driving more accountable health priorities, plans and policies.² By embedding patient, family and caregiver partners within collaborative decision-making structures, OHTs will be enabled to foster a culture of system co-design that is more likely to be long-standing and effective.

Program and Service Design – Engaging in the domain of organizational program and service design means that the OHT initiates engagement activities that partner with patients, families and caregivers for the purpose of improving specific health programs, services, or other organization-wide projects such as quality and safety improvement initiatives.² These activities may be ad-hoc or time-limited and draw upon the unique experiences of patients, families and caregivers in relation to the service being redesigned.

Personal Care and Health Decisions – Engaging in the domain of personal care and health decisions means health care professionals partner with patients, families and caregivers in processes of shared decision-making and care.²

Element # 4: Enablers

Description: Identification of key enablers that will facilitate meaningful patient, family and caregiver partnership and co-design within the OHT. OHTs are asked to consider the examples below and those that may be unique to their partnerships.

A Culture of Continuous Quality Improvement – An ongoing commitment from OHT partners / members to continuously improve – and to use the experiences, perspectives and needs of patients, families and caregivers to identify and implement continuous improvement activities.²

Ongoing Orientation, Education and Communication – Providing patients, families and caregivers with ongoing training, support, tools, and resources to enable them to meaningfully contribute in their role as partners/advisors. An ongoing commitment to creating an environment for advisors to thrive includes thoughtful consideration to onboarding new advisors into existing structures, the use of inclusive/non-exclusionary language, creating respectful environments for patients, families and caregivers to share their lived/living experiences, etc.

Commitment to Diversity, Inclusion, Health Equity and Cultural Competence – Engaging patients, families and caregivers through the lens of health equity means health care professionals, planners, and organizations have a responsibility to engage with – and respond to – the unique needs of Indigenous, Black, or other racialized, and/or Francophone patients, families or caregivers who have long been disadvantaged by the health system. It also requires a concerted effort to include and highlight voices of a diverse range of populations.

Minimizing Barriers – Considering and addressing barriers to participation such as financial and logistical (i.e. time and length of meetings); minimizing any chronic/systemic barriers related to factors such as race and disability; addressing barriers to participation through other enablers such as education, resources, training, technology support, etc.

Skillset Matching – Ensuring that the right patient, family and caregiver advisors are sought for the diverse spectrum of work (i.e. various domains of engagement) that can occur within OHTs. Advisors with specific lived experience, knowledge, and advisory skillsets will be better positioned to contribute meaningfully when matched with the appropriate role or capacity.

Rigorous Research and Evaluation – Evaluating the process, outputs, and impacts of engagement activities to demonstrate value and build a case for new and improved ways of partnering with patients, families, and caregivers.²

3) Developing, Validating and Confirming the OHT Patient, Family and Caregiver Partnership and Engagement Strategy

OHTs should ensure that the design and development of their OHT Patient, Family, and Caregiver Partnership and Engagement Strategies are appropriately informed by those with firsthand experience of the health system. This includes recognizing and respecting patient, family and caregiver advisors as equal partners and including them early in planning and designing of the strategy.

Each OHT must document their Patient Partnership and Engagement Strategy in writing using the OHT’s chosen format and style. The Patient Partnership and Engagement Strategy must be endorsed by OHT members, specifically the patient, family and caregiver working structures established by the OHT. Endorsement through established patient, family and caregiver structures (or advisors within other structures if the OHT has elected to embed patients, families and caregivers within all structures rather than create a standalone PFAC) will affirm the co-design principle used to support its development.

Once complete, OHTs are required to post their respective Patient, Family and Caregiver Partnership and Engagement Strategy online so that it will be accessible to members of the public. OHTs will also be required to confirm that they have developed their strategy in accordance with this guidance document through the ministry’s quarterly reporting process.

Snapshot: Learnings to Date

Through OHT implementation to date (and previous patient, family and caregiver partnership engagement initiatives across the province), a number of leading practices have emerged that foster a culture of system co-design, these include:

- Establishing a dedicated resource or staff to lead patient, family and caregiver activities within the OHT (including leading engagement efforts).
- Integrating patients, families and caregivers in working and decision-making structures, including as co-chairs.
- Including more than one patient, family or caregiver partner in working structures (preferably three, at least two).
- Evaluating training and orientation to ensure that patients, families and caregivers feel comfortable, well supported and prepared to advise.
- Supporting long-term, sustainable patient, family and caregiver partnership through mentorship, which can also assist in smooth and effective onboarding.
- Ensuring that even through challenging or unpredictable times, patient, family and caregiver partnership and co-design are maintained.
- Concerted efforts are continuously invested in bringing a diversity of patient, family and caregiver voices to the table, including those from Indigenous, Black or other racialized, and Francophone communities.

4) Summary:

Transformation of health care in Ontario will be driven by the needs of patients, families and caregivers. The development of the Patient, Family and Caregiver Partnership and Engagement Strategy by OHTs will be an integral step to advancing a patient-centred health system. As OHTs develop their strategies, teams should incorporate opportunities for engagement at all stages, recognize and address barriers to equitable participation, and use co-design methodology to guide planning.

As OHTs mature, these strategies will lay the foundation for patients to be partners in designing, implementing and evaluating strategies, policies, programs, and services within their OHT to meet the unique needs of their local populations. OHTs should understand this exercise as the beginning of a process that will evolve over time and should commit to renewing their strategy on a regular basis.

5) Key Resources:

Equity in Engagement Framework (Ontario Health)	Link
Ladder of Engagement (National Health Services)	Link
Ontario’s Patient Engagement Framework (Health Quality Ontario)	Link
Patient Declaration of Values for Ontario (Government of Ontario)	Link
Patient Partnering Tools and Resources (Health Quality Ontario)	Link
Rules of Engagement (The Change Foundation)	Link
The 101 of Engagement and Co-Design – A Step by Step Guide (The Change Foundation)	Link
Toolkit: Sharing Your Personal Journey for Public Speaking and/or Advisory Engagement. An Expertise for Co-Designing Person Directed Services & System Transformation. (Support House)	Link

For more resources to support OHT patient, family and caregiver engagement efforts, please visit the RISE website at: <https://www.mcmasterforum.org/rise>

6) References:

- 1) Government of Ontario. (n.d.) Ontario Health Teams: Guidance for Health Care Providers and Organizations. Retrieved March 12, 2021, from https://health.gov.on.ca/en/pro/programs/connectedcare/oht/docs/guidance_doc_en.pdf

- 2) Health Quality Ontario. (n.d.) Ontario's Patient Engagement Framework: Creating a strong culture of patient engagement to support high quality health care. Retrieved March 12, 2021, from <https://www.hqontario.ca/Portals/0/documents/pe/ontario-patient-engagement-framework-en.pdf>