

Ontario Health Team

Patient, Family and Caregiver Partnership and Engagement Strategy

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Introduction:

Through the formation of Ontario Health Teams, the Province is introducing a new model of healthcare delivery. A model designed to ensure that patients experience seamless transitions across different healthcare providers and in different healthcare settings. A model built on collaboration, partnership, trust, communication, and mutual respect between Patients, Families, Caregivers, Providers, and Communities. The way healthcare services are delivered and managed at the local level will be shaped through this collaboration.

The patient experience and outcomes are at the centre of healthcare delivery and must be the focus of those efforts to improve it.

Across various healthcare settings, the benefits achieved through patient, family, and caregiver partnership and co-design are well documented. As OHTs progress through their various stages of design, implementation, and ongoing evolution, the level of success and effectiveness achieved will be impacted by how effectively they engage with those key stakeholders.

A Patient, Family, and Caregiver Partnership and Engagement Strategy ("Engagement Strategy") for an OHT is intended to ensure that partnership, co-design and engagement with patients, families, caregivers, and the broader community are at the core of the OHT. These are not just activities that an OHT conducts, but a core element of its foundation, that will ultimately result in better patient outcomes.

The Engagement Strategy serves to outline the overarching principles that will guide the appropriate inclusion of these essential partners in all work of the OHT. This Engagement Strategy also demonstrates a level of commitment to patient, family, and caregiver partnership that is ongoing, and not a onetime exercise.

The purpose of this document is to provide a guiding framework, or vision, for the Burlington OHT's approach to Patient, Family, and Caregiver Partnership and Engagement. The implementation of the Engagement Strategy will be tracked and monitored through the Burlington OHT's ongoing reporting and performance monitoring processes. The specific engagement approach and activities will be developed and monitored at Burlington OHT committee level and reflected within specific project plans of the OHT.

Engagement – Overview

Patient Engagement means, family members and other informal caregivers, and health care professionals actively collaborating to improve health care quality in Ontario. 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.

When we say “patient”, we are referring to patients cared for in hospitals, people being cared for in their homes or through community programs, and residents living in long term care homes.

To align with the Ministry of Health’s common terminology, the term “patient” is used throughout this document to reference the individual receiving care or services. It is recognized, that depending on the specific care or services being delivered, it may be more appropriate to refer to these individuals as: “client”; “person”; “citizen”; or other description, as appropriate.

Element # 1: Strategic Goal

The Burlington OHT will strive to foster and embrace 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.

This strategic goal supports the vision of the Burlington OHT to co-create, with patients, families and caregivers, a patient and family-centred care delivery model that will wrap services around the patient. The model will be a primary care-led, home & community-focused system of integrated services designed to improve access and match care to need. Warm and timely transitions into and out of the hospital will occur when acute episodic care is required.

The successful implementation of this strategy should position the Burlington OHT as a leader in the ongoing effort to improve the local healthcare delivery model in Ontario, through meaningful patient, family, caregiver, and community engagement.

Element # 2: Guiding Principles

The Burlington OHT will advance patient engagement and patient-centred care guided by the core values outlined in the current **Patients Declaration of Values for Ontario** – see Appendix 1.

In an effort to maximize the mutual beneficial outcomes possible through a strong patient, family, and caregiver partnership, these core values will be supported through a focus on the principles of:

Partnership and Co-design –

Authentic, timely, and iterative engagement to inform meaningful and effective partnerships.

Learning –

All OHT activities will 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.

Empowerment – Patients, families and caregivers will be empowered to openly express their needs, perspectives, and concerns in a safe environment without fear of reprisal.

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.

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.

Respect – Health care professionals and organizations show respect for patient, family, and caregiver partners by actively demonstrating appreciation for their time, ideas, knowledge, lived experiences, worldviews, and cultural backgrounds; upholding safe spaces for engagement; and offering compensation for their time.

Element # 3: Engagement Domains and Approaches

The Burlington OHT and its members will identify areas in which engagement can occur with patients, families, and caregivers across various domains and throughout the various stages of the OHT's development. This engagement philosophy will be applied across various domains, including:

- **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.
- **Program and service design development and enhancement** - 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.
- **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.

Embedding patient, family, and caregiver partners within collaborative decision-making structures of the OHT – project teams, committees, etc. will foster a culture of system co-design that is more likely to be long-standing and effective. Efforts will be made to ensure a wide spectrum of engagement approaches are deployed, including:

- **Share** - Provide easy-to- understand health information
- **Consult** - Get feedback on a health issue (e.g., policy or decision)
- **Deliberate** - Discuss an issue and explore solutions
- **Collaborate** - Jointly identify an issue and explore, develop, and evaluate solutions

Element # 4: Enablers

The following key enablers will facilitate meaningful patient, family and caregiver partnership and co-design within the Burlington OHT:

A culture of continuous 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

Ongoing orientation, education, and communication – Providing patients, families and caregivers with ongoing training, support, tools, and resources to enable them to meaningfully contribute to 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/nonexclusionary 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.

Burlington OHT - Patient, Family, and Caregiver Engagement Strategy

The Strategic Goal

The Burlington OHT will embrace 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.

The Guiding Principles

Partnership & co-design	Learning	Empowerment
Transparency	Responsiveness	Respect

Across these domains

Personal care & health decisions	Program & service design	Policy, strategy & system level discussions
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Using a wide Spectrum of Engagement Approaches

Share	Consult	Deliberate	Collaborate
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Enabled by:

A culture of continuous improvement	Commitment to health equity and cultural compliance
Access to easy-to-understand health information	Rigorous research and evaluation
Minimizing barriers	Skillset matching

Appendix 1 – Patient, Family and Caregiver Declaration of Values for Ontario – July 2021

Accountability

1. We expect open and seamless communication about our care.
2. We expect that everyone on our care team will be accountable and supported to carry out their roles and responsibilities effectively.
3. We expect a health care culture that demonstrates that it values the experiences of patients, families and caregivers and incorporates this knowledge into policy, planning and decision making.
4. We expect that patient, family and caregiver experiences and outcomes will drive the accountability of the health care system and those who deliver services, programs and care within it.
5. We expect that health care providers will act with integrity by acknowledging their abilities, biases, and limitations.
6. We expect health care providers to comply with their professional responsibilities and to deliver safe care.

Empathy and Compassion

1. We expect health care providers will act with empathy, kindness, and compassion.
2. We expect individualized care plans that acknowledge our unique physical, mental, and emotional needs.
3. We expect that we will be treated in a manner free from stigma, assumptions, bias and blame.
4. We expect health care system providers and leaders will understand that their words, actions, and decisions strongly impact the lives of patients, families and caregivers.

Equity and Engagement

1. We expect equal and fair access to the health care system and services for all regardless of ability, race, ethnicity, language, background, place of origin, gender identity, sexual orientation, age, religion, socioeconomic status, education or location within Ontario. We further expect equal and fair access to health care services for people with disabilities and those who have historically faced stigmatization.
2. We expect that we will have opportunities to be included in health care policy development and program design at local, regional, and provincial levels of the health care system.
3. We expect an awareness of and efforts to eliminate systemic racism and discrimination, including identification and removal of systemic barriers that contribute to inequitable health care outcomes (with particular attention to those most adversely impacted by systemic racism).

Respect and Dignity

1. We expect that our individual identity, beliefs, history, culture, and ability will be respected in our care.
2. We expect health care providers will introduce themselves and identify their role in our care.
3. We expect that we will be recognized as part of the care team, to be fully informed about our condition, and have the right to make choices in our care.
4. We expect that patients, families and caregivers be treated with respect and considered valuable partners on the care team.
5. We expect that our personal health information belongs to us, and that it remain private, respected and protected.

Transparency

1. We expect we will be proactively and meaningfully involved in conversations about our care, considering options for our care, and decisions about our care.
2. We expect our health records will be accurate, complete, available, and accessible across the provincial health system at our request.
3. We expect a transparent, clear and fair process to express a complaint, concern, or compliment about our care and that it not impact the quality of the care we receive.