

Patient / Family / Caregiver Advisory Group - Framework

Purpose: To outline a framework for the Huron Perth and Area Ontario Health Team (HPA-OHT) Patient, Family, Caregiver Advisory Group (“Patient Partners”).

- **OHT Commitment:** People will partner together for effective decision making
- **OHT Commitment:** We will embrace change to enrich the lives of citizens and put community health outcomes first

Vision for the Patient Advisory Council – *While the vision of this group will be built with patient partners at the table, the HPA-OHT commits to broaden and deepen our work based on what patients/families and caregivers are experiencing.*

Proposed Framework

This framework is based upon the principles of **Patient Declaration of Values for Ontario** (Appendix 1). Established in 2019, the Declaration is grounded in respect and dignity, empathy and compassion, accountability, transparency, equity and engagement.

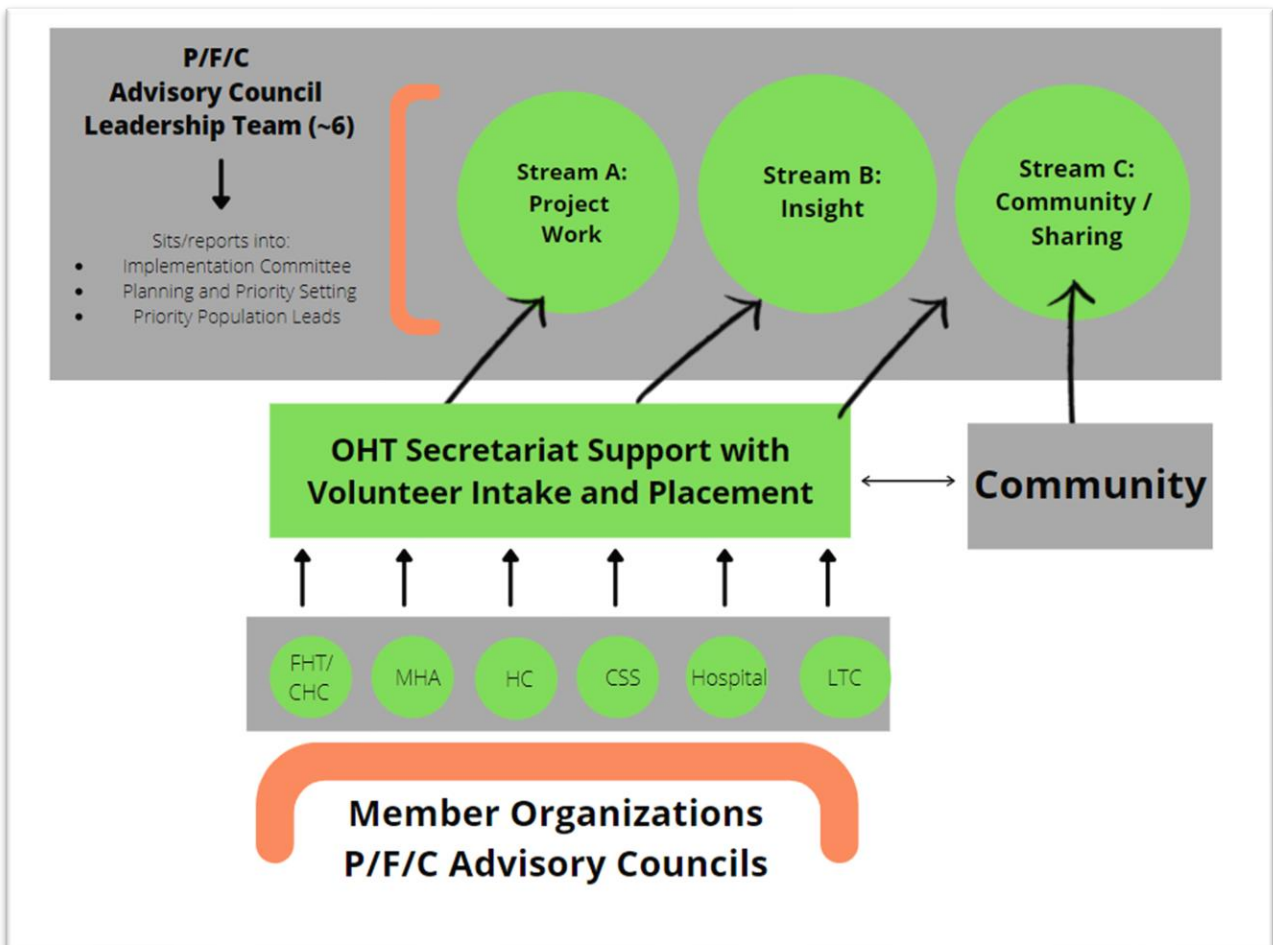
The reference to equity and engagement specifically states that patients, “expect that we will have opportunities to be included in health care policy development and program design at local, regional and provincial levels of the health care system.”

HPA OHT commits that participation by patient partners will look different based on the individual, and that true engagement comes in varying forms. To garner this engagement – we will facilitate a range of accessible ways of participating to meet patients where they are comfortable, how they want to contribute and support them in whichever path they chose!

The proposed engagement methods align with building authentic relationships. According to the Ontario Centre of Excellence for Child and Youth Mental Health, **Hart’s Ladder** (Appendix 2) is a child/youth/adult decision-making model that represents methods of engagement that truly invite engagement at the highest level. It moves beyond patients simply being informed of decisions to a more inclusive engagement of shared decisions and patient partner initiated and directed work.

For the purposes of this framework, the Hart's Ladder model was adapted with patient partners in mind to ensure co-development and decision-making level of engagement in the HPA OHT.

Please find below a framework for P/F/C engagement within the HPA OHT. Additional details to understand this diagram found below.



The diagram above is comprised of three main elements with details below:

1. **Advisory Councils already in existence**
2. **A HPA OHT P/F/C Leadership Team**
3. **Three Involvement Streams (A, B, C)**

1. OHT Member Advisory Councils (in existence)

HPA OHT members offer an enormous network to connect and learn from patient partners. Many of the sectors have long standing P/F/C Advisory Councils already established. The opportunity to connect with established Councils, and their seasoned volunteers, will help pull together a system-level volunteer network more expediently and with expertise across all sectors.

The HPA OHT will collaborate with Sector Leads to connect with Patient Advisory Councils and offer a selection of access points for patient engagement in HPA OHT work. The access points for patient engagement are split into three streams that patients may cross between at any time as needs fluctuate for patients and the HPA OHT.

2. A P/F/C Leadership Team

The P/F/C Leadership Team will be comprised of six members who commit to a three-year term. Will look to keep 6 members as a “Leadership Team” to work with the OHT Secretariat staff in building forward this engagement practice. Two members of the P/F/C Leadership team will be participants at the major HPA OHT Accountability Structures; Implementation Committee and Planning and Priority Setting. At each of these Structures, one of the P/F/C members will serve as Co-Chair as per the Terms of Reference for each Accountability Structure.

3. Three Involvement Streams (A, B, C)

HPA OHT is committed to co-development, patient partner led initiatives and decision-making at all levels as seen in the Hart’s Ladder model. The involvement streams are accessible engagement tools that align with the model. All involvement streams will be supported with education, offered by HPA OHT, to build understanding and capacity of positive communication skills and awareness of the **Code of Conduct** for patient partners.

Stream A – OHT Project Work

- These patient partners commit numerous hours of in-person or virtual meeting participation and reading, co-writing and reviewing documents for co-development, patient partner led initiatives and decision-making related to priority projects for population health and/or HPA OHT collaboration work in communications, digital and diversity/equity/inclusion groups.
- In-person and virtual meetings occur during regular business hours, Monday through Fridays with opportunity to review materials sent via email anytime.
- Open for candidates who wish to submit an application, complete the interview process and agree to on-boarding process and sign commitments. (More information below on Intake Process for this Stream).

Stream B – OHT Insight

- These patient partners engage via phone, email or online engagement.
- With the exception of phone engagement, this work is virtual and could be done any time of the day. An online tool to support this form of accessibility may be Bang The Table (a virtual community engagement tool)
- Allows for flexibility and does not require any in-person meetings or events.
- 24/7 virtual engagement invites unlimited patient partners.
- Opportunity exists to collaborate with municipalities, work places and Perth Huron United Way to support engagement of vulnerable populations who may not be comfortable using or have no/limited access/capacity to use the Internet.
- Open to any patient partner in Huron or Perth.

Stream C – OHT Community / Sharing

- These patient partners will work to engage within at their convenience in their personal and/or work lives.
- These patient partners offer a connection to patients who are experiencing vulnerabilities that limit their access to Stream A or B, yet are invaluable to the work of co-development and partnership for their health care systems.
- An example of community sharing is through seasonal Community Conversations that are facilitated by patients with logistical support from the HPA OHT Secretariat. The Conversations could focus on a priority population project, a specific proposed system improvement or a listening exercise to collect patient concerns.
- Open to any patient partner in Huron or Perth.

Volunteer Intake Process for Stream A and P/F/C Leadership Team Members

Continuous process, quarterly outreach.

1. Volunteer candidates complete an application and submit to P/F/C Leadership Team. Leadership Team is available to support candidate application with HPA OHT support, such as translation services.
2. A sub-committee, minimum 3 members, conducts volunteer candidate interviews and brings forth recommendation to entire Leadership Team that includes appropriate Stream for volunteer engagement. HPA OHT Secretariat supports logistics of interviews and contacting approved or declined candidates, if needed. The sub-committee uses a diversity/equity/inclusion lens that accompanies a matrix of required capacities to engage at this level. i.e. sector, location, etc.

3. Volunteers must complete an on-boarding process and review/sign Code of Conduct, Confidentiality Agreement and Statement of Understanding of the Terms of Reference and the Conflict Resolution Process.
4. Volunteers will be added to the HPA OHT contact mailing list and introduced to their HPA OHT project/group contact. It is at this point that they will commence engagement. i.e. receive email information and invitations to meetings to access engagement opportunities

Next Steps

With the support of the HPA OHT Secretariat, the P/F/C Leadership team will complete the following tasks by March 31, 2022:

- Finalize and adopt the P/F/C Network Framework
- Create and adopt P/F/C Leadership Team Terms of Reference
- Create Volunteer Documents
 - Volunteer Candidate Application Form
 - Standard Volunteer Candidate Interview Questions
 - Volunteer Welcome Package
 - Code of Conduct
 - Conflict Resolution Process
 - Confidentiality Agreement
 - Statement of Understanding of Terms of Reference
 - HPA OHT Web Page content for P/F/C Leadership Team
- Collaborate with HPA OHT Communication Advisory Group to create annual communications plan to community

Appendix A

Patient Declaration of Values for Ontario

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 families and caregivers be treated with respect and seen as valuable contributors to the care team.
5. We expect that our personal health information belongs to us, and that it remain private, respected and protected.

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 and assumptions.
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.

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 values the experiences of patients, families and caregivers and incorporates this knowledge into policy, planning and decision making.
4. We expect that patient/family 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.

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.

Equity and Engagement

1. We expect equal and fair access to the health care system and services for all regardless of language, place of origin, background, age, gender identity, sexual orientation, ability, marital or family status, education, ethnicity, race, religion, socioeconomic status or location within Ontario.
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.

Note: The purpose of this Patient Declaration of Values, drafted by the Minister's Patient and Family Advisory Council in consultation with Ontarians, is to articulate patients' and caregivers' 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 and reflects a summary of the principles and values that patients and caregivers



say are important to them. The Declaration is not intended to establish, alter or affect any legal rights or obligations, and must be interpreted in a manner that is consistent with applicable law.


Ontario Ministry of Health. (October 15, 2019). Retrieved from <https://www.ontario.ca/page/patient-declaration-values-ontario>

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Appendix B



Co-Development & Partnership
Co-development and/or leadership in all projects, services and processes that impact or interest patients.

Consulted
Patients provide input and are advised how their input impacts decisions made by others.

Informed
Patients receive communication to inform them about priorities, services or policy changes. Patients do not contribute to the process.

Tokenism
Patients are included for the sake checking a box, especially those with diverse identities.

Decoration
Patients are at the table with little or no influence or decision making capacity.

Manipulation
Patients are directed by others without thoughtful opportunities to engage

Inspired by Hart's Ladder of Engagement