OHT-N Experience Partner Council

Terms of Reference

Effective date: May 28, 2021

Context:

In its submission to become an Ontario Health Team (October 2019), Northumberland County partners showed an ardent commitment to the role patients and caregivers would have in the design and development of the Northumberland Team. This saw a submission that included: both patient and caregiver signatories; equitable inclusion of patients and caregivers across all committees and governance structures; a *Patient/Caregiver Partnership and Community Engagement Framework ;* and, the establishment of an overarching patient and caregiver advisory committee.

The *Engagement Framework* underpins the directions and decision-making for the Council, and is constructed around four pillars:

- Best practices for public participation recommended by the International Association of Public Participation (IAP2), and highlighted in RISE brief 5: *Community Engagement;*
- *Patient Declaration of Values for Ontario* (Appendix 1);
- Change Foundation's C.A.R.E. paradigm, detailing specific considerations for caregivers; and,
- Unique Northumberland experience respecting patient and caregiver contributions to local health and community care advancement.

Vision:

A broad and influential patient and caregiver voice working with the Ontario Health Team of Northumberland (OHT-N) to shape equitable and partner-driven health care delivery in Northumberland.

Purpose:

The OHT-N recognizes that patients/caregivers, by virtue of their journeys, can be natural leaders of service integration and system coordination. The purpose of the Experience Partner Council is therefore to:

- Bring to life the *Patient Declaration of Values for Ontario* in Northumberland.

- Provide patient/caregiver perspective and guidance as part of all OHT-N efforts to transform health and community care systems, with the goal of achieving Quadruple Aim outcomes, including:
  - improved patient and caregiver experience
  - improved patient population health outcomes
  - improved provider work-life experience, and
  - improved value, reducing the per capita cost of health care.

Working with the Collaboration Council, the Experienced Partner Council will have the following key functions and responsibilities:

Partnerships and Engagement/Community Impact
• Advance/broaden the partnership/leadership role that patients and caregivers assume in the design of the OHT-N and enhance health and community care in Northumberland, through a co-designed strategy. • Support OHT-N to advance engagement/participation of Home and Community Care and Public Health. • Support the development and implementation of marketing and communication plans coordinated with OHT-N and Priority Project leads. • Identify and assess prevailing patient/caregiver partnership frameworks and recommend as appropriate to the Collaboration Council. • Be the “positive” voice of the patient and caregiver that supports and “augments” the health and community care they receive from service providers. • Lead the recruiting of patients and caregivers, as required, for membership on all OHT-N Councils and Priority Projects, and engage/become involved in specific work projects, and system structures. • Monitor, support, and evaluate service user/patient engagement within the OHT-N and provide suggestions to improve.
Care Coordination
• Support the development, through co-design processes, of a wholistic view of healthcare, strategies, and the means for supporting the coordination of care for patients and caregivers across all service providers both within the OHT-N and beyond. • Explore how care coordination can be improved for patients and caregivers within the scope of all the Priority Projects. • Develop a vision of how continually increasing the base of caregivers/patients (i.e., volunteers) in OHT-N work towards system transformation can both advance quality and system sustainability (e.g., care coordination). • Work to improve care coordination for all system users, through formal patient/caregiver feedback mechanisms (including on-going acknowledgement), stories, value-stream mapping, and knowledge exchange processes.
Workplan/Activities
• “Living” workplan in keeping with the work of the OHT-N will guide and monitor Council efforts and directions. • On-going member orientation and education to ensure work is informed and current.

• Council activities flow through the workplan, ensuring coordination, documentation, and effectiveness. • Regional-based, community-led, co-design principles and practices determine/ shape delivery of health programs and services.
QI/Performance/Outcomes
• *Quadruple Aim* shapes planning, directions, decision making, evaluation. • The Council will support the quality improvement activities identified collectively by the OHT-N. • Coordinate Council work and directions with the Rapid-Improvement Support and Exchange (RISE) initiative established by the Province to provide support for rapid learning and improvement of OHTs, both in using a population-health management approach and in putting in place the eight OHT building blocks.

Membership:

- While acknowledged that most members will bring both patient and caregiver experience to the Council, efforts will be made to have a balance between those with overt patient experience and those with strong caregiver experience.
- Membership to represent as much of the diversity and population demographics (e.g., age, socio-economic, health, education) of Northumberland as possible.
- Membership term is three (3) years, with members committing to serve at least one (1) year.
- The number (or range of) of members on the Council is to be determined.
- Acting in an ex-officio capacity, at least one ‘communications/community engagement professional’ from the OHT-N will actively participate and contribute to all aspects of the Council's work.

Governance and Council Structure:

Accountability and Reporting

The Experience Partner Council will be a partner to – as well as accountable to (including reporting) – the OHT-N Collaboration Council.

Any work groups established to support the work of the Experience Partner Council will be accountable to the Experience Partner Council.

The Experience Partner Council has an overall implied responsibility to the full breadth of all communities served by the OHT-N.

Decision-Making/Consensus

Experience Partner Council decisions will be made by consensus (see Appendix 2).

Quorum

Quorum for meetings requires attendance of 50 per cent plus one of Experience Partner Council Membership.

Involvement with other OHT-N Councils and Projects

- The chairs of the Experience Partner Council will sit as members of both the Collaboration Council and the Governance Advisory Council.
- Where possible, at least one Experience Partner Council member will sit on each of the three (3) Year One Priority Project Teams, the Digital Project Team, and the Facilitation Council.
- The Collaboration Council will look to the Experience Partner Council for patient and caregiver representation on various short-term, and sometimes longer, projects and initiatives. To the extent practicable for members, best efforts to support the Collaboration Council with EPC representation will be provided.

Confidentiality

Instances may occur – for example, in the planning phases of a particular program or activity – when information shared with Experience Partners should remain internal to the Experience Partner Council and/or broader OHT-N tables. All efforts will be made to expressly highlight those instances for Experience Partners. When in doubt, members are expected to err on the side of caution and await external OHT-N communication prior to sharing information, or to seek clarification via the Experience Partner Council Co-Chairs. A designated spokesperson serves as the OHT-N's public representative on formal announcements.

Conflict of Interest

Experience Partners are expected to fulfill the duties of their volunteer role in a professional, ethical, and competent manner and avoid any real or perceived conflict of interest. Experience Partners have an obligation to declare a personal or pecuniary interest that could raise a *conflict of interest* concern at the earliest opportunity to the Experience Partner Council Co-Chairs. Each Experience Partner has an ongoing obligation to disclose any actual, potential or perceived conflict of interest arising at any point during the term of their appointment in regard to any matter under discussion by the Council or related to the Council's mandate.

Meeting Frequency

Meetings will be held monthly for a duration of two (2) hours. Teleconference and/or videoconferencing technologies will be available options.

Attendance Expectations

Members will be expected to make best efforts to attend meetings regularly.

Members may attend meetings in person, by video or telephone conferencing.

Reimbursements

The OHT-N will reimburse members for out-of-pocket expenditures incurred by members related to Council business, specifically for mileage and parking. Pre-approval will be required for reimbursement of other expenditures (e.g., childcare, caregiver support, printing costs, travel and costs related to attending educational/promotional events).

Co-chairs
The Council will elect new co-chairs annually.

While recognizing there will be overlap in experience, it is considered desirable that one co-chair bring a strong caregiver perspective and the other a patient perspective.

Appendix I: Patient Declaration of Values

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.

Appendix II: Consensus Model for Decision-Making

The simplest and most basic definition of consensus is, "**general agreement about something"** (Soanes, C. and Hawker, S., ed., The Compact Oxford English Dictionary of Current English. 3rd ed. Oxford University Press, 2005.)

In this approach, people are not simply for or against a decision. They have the option to situate themselves on a scale that lets them express their individual opinion more clearly. This model is usually used with a round, so that everyone in the meeting is given the opportunity to state where they are at, according to the following six levels:

1. Full support
2. Acceptable
3. Support with reservations
4. I cannot do this, but I can live with it and will not block it
5. Need more information or more discussion
6. Cannot support it, cannot accept it, or cannot allow the group to support this

If everyone is at level 4 or above (3, 2, or 1), then, by definition, consensus has been reached.

If someone is at level 2, 3 or 4, they have the option of explaining their reservations. These can be addressed at the meeting, if the group feels this is necessary or will be helpful. Conversation about reservations is not an absolute necessity in achieving consensus if everyone is already at 4 or higher, but it usually improves the strength of the recommendation or suggestions being discussed.

If someone is at level 5, they have the obligation to explain what information or discussion they require from the group. If someone is at level 6, it is important for them to try to offer a solution that can accommodate their needs, and the needs of the rest of the group.

In addressing someone's reservation, it is important to ask everyone for possible solutions. The person expressing the concern and the rest of the group have the responsibility of finding a solution.