Ontario Health Team of Northumberland
Experience Partner
Terms of Reference

Vision

The Ontario Health Team of Northumberland (OHT-N) Experience Partners are an active county-wide patient/client, family and caregiver-led team working through the OHT-N on decision-making and/or planning, design, governance or delivery of health and social care in Northumberland County.

Purpose

The OHT-N recognizes that patients, families, and caregivers, by virtue of their lived experience, have critical wisdom to share to advance service integration, innovation and system coordination. The purpose of the Experience Partner Council is therefore to:

- Bring to life the Patient, Family and Caregiver Declaration of Values for Ontario in Northumberland.
- Provide patient/client, family and caregiver perspectives and guidance to all OHT-N efforts to transform health and community care systems, with the goal of achieving progress along Quintuple Aim outcomes, including:
    - Enhancing patient experience
    - Improving population health outcomes
    - Improving better value
    - Enhancing frontline and provider experience
    - Advancing health equity

Accountability

The Experience Partners are accountable through the Experience Partner Council to the OHT-N Collaboration Council.

Term

These Terms of Reference are effective from April 2025. Moving forward, they will be ongoing until amended and/or terminated by agreement between parties with an annual review.

Responsibilities

Working with the Collaboration Council, the **Experience Partner Council** responsibilities will include the following:

- Advance understanding among and beyond OHT-N partners of why patients/clients, families and caregivers should be engaged as equal partners in program and system planning and support that work through recruitment, education, and engagement.
- Build, through a model offering different levels of engagement, the OHT-N's ability to effectively engage with diverse communities along a spectrum of participation, including equity deserving populations typically under-represented at system planning tables.
- Lead the recruitment and retention of patients/clients and caregivers to inform Experience Partner and OHT-N core areas of focus.

- Build linkages with patient experience communities of practice in Northumberland County, our Ontario Health East region, the province and beyond so we can learn from one another's experience and exchange tools and resources for mutual benefit.
- Monitor, support and evaluate engagement within the OHT-N and provide suggestions to improve.
- Bring Experience Partners together quarterly to standing meetings.

The **Experience Partner Project Pool** members' responsibilities will include the following:

- Participate in OHT-N projects by bringing lived and living experience perspectives to inform planning, implementation, and evaluation.
- Support meaningful integration of patient, family, and caregiver voices within project workstreams by providing insights, feedback, and recommendations.
- Amplify the voice of local patients and caregivers on project-specific initiatives.
- Assist with identifying gaps and opportunities within projects to enhance patient and caregiver engagement.
- Evaluate the effectiveness of their engagement within projects and share reflections with the Experience Partner Council and project teams to foster continuous improvement.
- Participate in quarterly Experience Partner meetings.

Membership

- In recognition of the broad spectrum of participation aspired to in the OHT-N's *Patient, Family and Caregiver Partnership and Community Engagement Framework*, patient, family and caregiver engagement will expand in 2025 from a small core Experience Partner Council drawn from OHT-N members to offer a broader model of engagement comprised of an expanded Experience Partner Council as well as a new Experience Partner Project Pool.
- While acknowledging that partners at the above levels of engagement will bring a mix of patient/client, family and caregiver experience to the Council, efforts will be made to consistently strive for a balance between those with overt patient experience and those with strong family/caregiver experience.
- Recruitment will be continuous and will seek to achieve diverse representation through method and opportunity.
- Acting in an ex officio capacity, the OHT-N Executive Lead, other OHT-N staff as appropriate and at least one (1) patient experience/communications/community engagement professional from the OHT-N Collaboration Council will continue to actively participate and contribute to all strategic aspects of the Council's work.

Duration of Service

Experience Partner Council – Patient/family/caregiver membership on the Experience Partner Council is expected to be for one (1) year, with the opportunity to renew membership on an annual basis for up to three (3) years with exceptions as appropriate. Membership terms on EPC patient, family, and caregiver communities and/or work groups will vary and be determined by the needs of the project and communicated at the time of recruitment. It is recognized that personal life circumstances may arise that require a pause. Special accommodations will be arranged as appropriate in discussion with the Experience Partner Chair/Co-Chair while being mindful of the need to maintain consistent patient/client, family, and caregiver representation.

Experience Partner Project Pool - Participation in the Experience Partner Project Pool is intended to be flexible and project-specific, recognizing that the level of engagement may vary based on the needs and timelines of individual initiatives. Experience partners will be recruited for defined project terms, which will be communicated at the time of recruitment. While some projects may require short-term involvement (e.g., one-time/ad hoc, a few months), others may span longer durations. Experience partners may participate in multiple projects simultaneously or sequentially, depending on their availability and interest. As with the Experience Partner Council, it is acknowledged that personal circumstances may arise that require a pause in participation. Special accommodations can be arranged to ensure continuity of patient, client, family, and caregiver representation while balancing individual capacity.

Chair/Co-Chairs

With Collaboration Council approval, the Experience Partner Council Chair/Co-Chair will rotate every two (2) years, with the opportunity to renew for one (1) additional year based on interest and capacity within the membership. While recognizing there will be overlap in experience, it is considered desirable that one Co-Chair bring a strong family/caregiver perspective and the other a patient/client perspective. Attention should be paid to staggered terms.

Individual Accountabilities

Involvement with other OHT-N Councils and projects

- The Chair/Co-Chairs of the Experience Partner Council will sit as a member of both the Collaboration Council and Governance Advisory Council. In cases where there is a Co-Chair, this responsibility can be shared.
- Where possible, there will be two (2) Experience Partner representatives on all OHT-N councils, working groups and ad hoc projects. This representation may come from the Experience Partner Council itself or, as appropriate, through the Experience Partner Project Pool.

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 Chair. 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 Chair. 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.

Decision Making

To the extent the Council makes decisions, unless otherwise specified in a decision framework adopted by unanimous agreement of the Experience Partner Council, decisions will be made by consensus (see Appendix I).

Consensus means that each member is prepared to support the Council's decision even if they do not agree with the decision/recommendation.

Meetings

- Regular meetings of the **Experience Partner Council** will usually be held monthly for a duration of two (2) hours. Meetings currently take place virtually. Additional meetings may be called if necessary.
- Members of the **Experience Partner Project Pool** will be invited on a quarterly basis to attend meetings of the Experience Partner Council.
- Quorum for Experience Partner Council meetings requires attendance of 50 per cent plus one member.
- On occasion, the Experience Partner Council may determine that an in-person meeting is appropriate. Where possible, arrangements will be made in such circumstances to make a virtual option available to those who are either unable or who choose not to attend in-person.
- The Experience Partner Council will review periodically the meeting format to determine if virtual meetings remain the most appropriate format. Meetings for working groups within the Experience Partner Project Pool will align with the requirements of the associated projects.

Attendance

Members will be expected to make best efforts to attend meetings regularly with the necessary preparation.

Amendment, Modification or Variation

These Terms of Reference may be amended, varied, or modified in writing after consultation and agreement by Experience Partner Council members. These Terms of Reference will be reviewed annually by the members of the Experience Partner Council and approved by the Collaboration Council.

Reimbursements

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

Appendix I: Patient, Family and Caregiver Declaration of Values

The Experience Partner Council of the Ontario Health Team of Northumberland endorses the Patient, Family and Caregiver Declaration of Values, and strives to advance the values within their work.

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 that health care providers will act with empathy, kindness and compassion.
2. We expect individualized care plans that acknowledge our unique physical, mental, emotional, cultural and spiritual 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 remains private, respected and protected.

Transparency

1. We expect that 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 that 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 that does not impact the quality of the care we receive.