

Durham Ontario Health Team

Regional Patient, Family and Care Partner Advisory Council

DRAFT TERMS OF REFERENCE – FINAL - as of September 28, 2022

REVIEW DATE: October 27, 2024

Purpose/Responsibility

The Durham Ontario Health Team (Durham OHT) Regional Patient, Family and Care Partner Advisory Council (PFCPAC) will work in collaboration with Durham OHT partners to ensure that engagement, partnering and co-design with patients⁽¹⁾, families and care partners⁽²⁾ are embedded in all Durham OHT activities in order to improve the system of health and social care and support for Durham Region residents.

Opportunities/Areas of Focus

PFCPAC members will be involved in a range of activities which includes, but is not limited to the following areas of focus:

- Collaborate with Durham OHT partners on the identification, prioritization, development, implementation and evaluation of all Durham OHT health and social care and support initiatives impacting Durham residents, including addressing barriers and gaps in the delivery of care and support;
- Support the Durham OHT as well as all those who provide health services in Durham Region in the use of the provincial [Patient, Family and Caregiver Declaration of Values](#) (PFCDV) to help guide service delivery in a way that is patient and family centred;
- Build a Durham OHT Patient, Family and Care Partner Community of Practice with Patient/Client and Family Advisory Committees from Durham OHT partner organizations, other Durham organizations delivering health and social care and support services and the broader community of Durham residents as a vehicle for sharing information with and consulting with Durham residents;
- Establish communication processes and platforms to actively engage the Community of Practice and the broader community of Durham patients, families and care partners in the work of the Durham OHT;
- Participate in Durham OHT governance and operational structures as members of the Durham OHT's Executive Leadership Table (ELT), Collaboration Council, additional Advisory Councils, Working Groups, and other groups as defined by the [Durham Ontario Health Team Patient, Family and Care Partner Partnership and Engagement Strategy](#);
- Support the development of Patient, Family and Care Partner Engagement resources for the use of Durham OHT organizations and their staff, and,
- Collaborate with the Durham OHT Project Management Office (PMO) in the establishment of key performance indicators (KPIs) for Durham OHT initiatives in order to measure patient, family and care partner engagement and health and social care and support experiences and outcomes.

⁽¹⁾ The use of the term patients refers to individuals accessing care and support in hospitals, primary care settings, community-based settings or in their homes, including long-term care.

⁽²⁾ The Terms of Reference refers to "care partners" in place of the Ministry's use of the term "caregivers" in recognition of the key role played by non-professional individuals who jointly partner with family and friends in their care journey.

Membership Criteria and Recruitment

The Durham OHT PFCPAC will be comprised of a maximum of thirteen (13) members. While acknowledged that most members will bring both patient/client and family/care partner experience to the PFCPAC, efforts will be made to have a balance between those with lived experience as a patient/client and those with lived experience as a family member/care partner.

The PFCPAC will endeavour to reflect the diversity of Durham region and social situations (i.e. access, education, income, food security, job security, housing security) affecting the daily life of Durham residents in its membership including, but not limited to, perspectives from:

- Black, Indigenous or Francophone Communities
- Lesbian, Gay, Bisexual, Transgender, Queer or Questioning and Two-Spirit (LGBTQ2S+) Communities
- New Immigrants Communities
- People with Disabilities
- People living with Mental Health and Addictions
- Residents of Urban/Rural/Remote Geographies

Preferred Skills and Competencies:

- An understanding and support of the [Durham Ontario Health Team Patient, Family and Care Partner Partnership and Engagement Strategy](#) and the provincial [Patient, Family and Caregiver Declaration of Values](#)
- An ability to take a system view of health and social care and support needs in Durham
- An ability to advise on behalf of all patients, families and care partners in addition to reflecting personal experiences.
- Respect for diversity and differing opinions
- An ability to work collaboratively and constructively with volunteers, staff, patients, families and care partners
- An ability to constructively participate in discussions
- Capacity to regularly attend PFCPAC meetings (approx. 2 hours each, held every 2 months) and other Durham OHT working group meetings (approx. 1.5 hours a month), as assigned/when required
- Commitment to prepare for meetings by engaging with the Community of Practice, reading minutes, agendas and any material provided in advance in order to be a well-informed participant
- Agreement to sign a privacy and confidentiality agreement

Term

- Membership on the PFCPAC will be for a two (2) year term with an annual evaluation based on feedback provided through a PFCPAC Evaluation Tool.
- Members can serve for a maximum of two (2) terms or no more than four (4) years.
- Members may apply to rejoin PFCPAC after a one (1) year absence.
- Recruitment will be based on a staggered and/or as needed approach in order to balance the PFCPAC with new and experienced members.

Co-Chairs

- Co-chairs shall serve for a maximum of two (2) terms (maximum 4 years).
- To support its initial establishment, the inaugural PFCPAC co-chairs will be appointed through the Durham OHT ELT, one to serve one (1) year and one to serve two (2) years.
- At the end of the appointment period(s) the PFCPAC will elect its co-chairs from amongst its membership by majority vote of the council.
- Elections will be staggered to lessen the impact of turnover on the council and create less potential disruption.
- Co-chairs will be expected to:
 - provide democratic leadership for the PFCPAC members
 - represent the collective voice of the PFCPAC at Durham OHT leadership tables, with the Community of Practice and in the broader community
 - work constructively with OHT organizational staff, the Durham PMO and other PFCPAC members
 - call and chair meetings
 - develop meeting packages with the support of the Durham OHT PMO
 - communicate with council members
 - respect differences and support the inclusion of all voices at the table
 - support the development of an annual report summarizing the PFCPAC members' activities and achievements during the year

Meetings

- PFCPAC meetings will be held every two months for a duration of two (2) hours each or based on a schedule determined by the Council.
- Work Group meetings will be held as determined by the applicable work group.
- Dates and times of PFCPAC meetings for the year will be determined in advance.
- Face-to-face meetings will be the preferred method for meeting when permitted; however, to support accessibility, teleconference, videoconference and other methods will also be available.
- Agendas, minutes and other reading material will be posted to a PFCPAC collaborative workspace or sent by fax, mail or email in advance of the meetings
- Administrative support will be provided by the Durham OHT PMO
- Quorum is represented by 50% +1 of the Council members.

- For a meeting to go forward as planned there must be quorum and one (1) co-chair present.
- The PFCPAC will strive for consensus in all its decision making – See Appendix 2.
- If consensus is not achievable, decisions will be made by majority vote of a quorum. A quorum will consist of 50 per cent plus one of the membership.

Council accountability and reporting relationships

- The PFCPAC Co-Chairs will represent the PFCPAC by reporting to the Durham OHT Executive Leadership Table and Durham OHT Collaboration Council.
- The PFCPAC will work in partnership with the Durham PMO to action its Opportunities/Areas of Focus.
- PFCPAC members will represent the PFCPAC and the Community of Practice at Durham OHT Working Groups.

Durham OHT Project Management Office (Backbone Team) Liaison Role

A leadership resource from the Durham OHT Backbone Team will attend PFCPAC meetings as a non-voting member. This resource will also work in partnership with PFCPAC Co-Chairs:

- In the development of council meeting agendas and securing of required presenters
- In ensuring that engagement and partnering with patients, families and care partners are the building blocks of all Durham OHT activities.
- In identifying opportunities for partnering and engaging with council members in Durham OHT working groups and other Durham OHT activities.
- In providing updates to council members on the work of the Durham OHT.
- In providing guidance to the Durham OHT Backbone Team resource providing support to the PFCPAC whose role includes minute taking, distribution of internal and external correspondence, preparation of internal and external reports, including annual reports, in consultation with co-chairs and OHT Backbone Team leadership resource.

Recognition and Support

- In recognition of the value of Patient, Family and Care Partner Advisors, PFCPAC members will be offered a financial honorarium for their participation on the Durham OHT PFCPAC and other Durham OHT governance and operational structures based on their role/time commitment – see Appendix 3.
- PFCPAC members will also be reimbursed for pre-approved expenses incurred as per Lakeridge Health's *Travel, Conference and Hospitality Expense Policy*.
- Lakeridge Health will not be responsible for any expenses incurred by council members that are not pre-approved in writing by the Durham OHT PMO.
- Durham OHT partner organizations may offer in-kind support to PFCPAC members to support their full participation in Durham OHT work, if required.

Ethical Framework and Conflict of Interest

PFCPAC members are required to fulfill the duties of their appointment in a professional, ethical and competent manner and avoid any real or perceived conflict of interest as stated in the conflict of interest agreement.

- PFCPAC members have an obligation to declare a personal or financial interest that could raise a conflict of interest concern at the earliest opportunity to the co-chairs.
- Each PFCPAC member has an ongoing obligation to disclose any actual, potential or perceived conflict of interest arising at any point during a member's term of appointment in regard to any matter under discussion by the PFCPAC or related to the PFCPA's purpose/responsibility.

Confidentiality and Ontario's Freedom of Information and Protection of Privacy Act (FIPPA)

- Each PFCPAC member will be required to sign a confidentiality agreement.
- All confidential information, including notes written by individual members in connection with their work on behalf of the Durham OHT, is subject to the provisions of Ontario's [Freedom of Information and Protection of Privacy Act, R.S.O. 1990, c.F.31](#) and may be subject to disclosure in accordance with the Act.
- All PFCPAC discussions are considered public information unless specifically noted by the Durham OHT PMO representative and marked as confidential.
- Discretion is required by all PFCPAC members when commenting on issues that have been discussed at meetings.
- Consistent messaging that reflects the values and principles of the collaborative process, the Durham OHT and the needs of their community, will be developed by the PFCPAC for use by its members.

Ownership of Council Materials

All confidential information, including all work materials produced by the PFCPAC, shall be and remain the sole property of the Durham OHT PMO. PFCPAC materials are not to be shared with other stakeholders, unless there is expressed permission to do so.

Records retention

PFCPAC records are subject to the [Freedom of Information and Protection of Privacy Act, R.S.O. 1990, c.F.31](#)) and are governed by the Durham OHT *Records Retention Policy* - pending.

Review

The PFCPAC will review these terms of reference every two (2) years during the month of October. The document will be noted as approved every two years and indicated on the document.

Appendix 1 – References

- [Durham Ontario Health Team Patient, Family and Care Partner Partnership and Engagement Strategy](#)
- [Experience-Based Co-Design \(EBCD\)](#)
- [Patient, Family and Caregiver Declaration of Values](#)

Appendix 2: Consensus Model for Decision-Making used with the permission of the [Northumberland Ontario Health Team](#)

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.

Appendix 3 – Recognition and Support of Durham OHT Patient,
Family, and Care Partner Advisors

Recognition and Support of Durham OHT Patient, Family
and Care Partner Advisors

Manual:
Section:
Developed by:
Approved by:
Cross Reference to:

Document No:
Original Date: January 11, 2022
Revision Date(s): **March 25, 2022**
Review Date:

Document Applies to: All patients, family members and care partners volunteering as members of the Durham OHT Regional Patient, Family and Care Partner Advisory Council (PFCPAC) and/or a Durham OHT Working Group.

Accountability Framework

This policy outlines the process, rules and principles for the recognition and support of patients, families and care partner advisers while volunteering as members of the Durham OHT Regional Patient, Family and Care Partner Advisory Council (PFCPAC) and/or as members of a Durham OHT Working Group.

The expected outcome is to demonstrate the value of patient, family and care partner advisors by:

- Offering patients, family members and care partners a financial honorarium based on their role/time commitment.
- Offering patients, family members and care partners in-kind support from Durham OHT organizations to support their full participation in Durham OHT work,

Policy

PFCPAC Co-Chairs

- Durham OHT Regional Patient Family and Care Partner Advisory Council co-chairs will be offered an annual honorarium to a maximum of \$3,000 based on the expectation that they will be providing approximately 125 hours of volunteer service in a calendar year.
 - The 125 hours is comprised of six (6) 2-hour PFCPAC meetings, six (6) 30-minute preparation periods and six (6) 30-minute follow-up periods; six (6) 2-hour Project Management Office meetings; bi-weekly 1-hour meeting attendance at the Executive Leadership Table; monthly 1.5 meeting attendance at the Collaboration Council and, 1-hour a week miscellaneous work as a PFCPAC co-chair.

PFCPAC Members – excluding the Co-Chairs

- Durham OHT Regional Patient, Family and Care Partner Advisory Council members will be offered an annual honorarium to a maximum of \$350 (a maximum of \$87.50 per quarter) based on the expectation that they will be providing 18 hours of volunteer service in a calendar year as members of the PFCPAC.
 - The 18 hours is comprised of six (6) 2-hour PFCPAC meetings, six (6) 30 minute preparation periods and six (6) 30 minute follow-up periods.

Patient, Family and Care Partner advisors who are members of a Working Group

- Patient, Family and Care Partner advisors who are members of a Working Group, as defined by the Durham OHT, and who volunteer to work/attend meetings, including preparatory work, two or more hours per month, will be offered an annual honorarium \$500 (\$125.00 per quarter) for each.
 - It is expected that an advisor will be engaged in a maximum of three different Working Groups. Any exception will need to be approved by the PFCPAC Co-chairs.

Expenses and In-Kind Supports

- All PFCPAC members and Patient, Family and Care Partner advisors will be reimbursed for pre-approved business expenses incurred as per Lakeridge Health's *Travel, Conference and Hospitality Expense Policy*.
- Durham OHT partner organizations may offer in-kind support to PFCPAC members and Patient, Family and Care Partner advisors to support their full participation in Durham OHT work, if required.

Process

- Volunteers who are also employed by Durham OHT organizations, will not be offered the honorarium if the hours of their PFCPAC participation and/or representation as a PFCP advisor on a Durham OHT Working Group is also being compensated by their employer.
- The Durham PMO will administer the honorariums which will be paid out semi-annually in June and December.
- The Durham PMO will work with the Finance Department at Lakeridge Health to process the honorariums.
- It will be the responsibility of each PFCPAC member to report any honorarium received to the Canada Revenue Agency.
- The Durham PMO and PFCPAC co-chairs will work with Durham OHT organizations to identify any in-kind supports that could be offered to PFCPAC members to support their participation. This may include assisted transportation, caregiver respite, computer equipment or other services.
- The Durham PMO will support PFCPAC members to claim applicable personal business expenses.

Appendix 4 – Confidentiality Agreement
DURHAM ONTARIO HEALTH TEAM

STATEMENT OF CONFIDENTIALITY
PATIENT, FAMILY AND CARE PARTNER ADVISORY COUNCIL
(PFCPAC) MEMBER

Name: _____

Date: _____

(Please Print in Full, Last Name, First Name)

Affiliation with Durham Ontario Health Team (OHT): _____

I agree that I will observe and comply with the following Durham OHT confidentiality and privacy policies and procedures.

I understand that I will encounter confidential information in my role with Durham OHT. This information will not be accessed, used or disclosed for purposes other than for which the information is intended and for which I am authorized.

I understand that when I am accessing any information within or external to the organization in the course of my role, that I am a representative of the Durham OHT and will at all times represent the Durham OHT in a manner consistent with the Mission, Philosophy and Values of the OHT.

I agree to treat electronic information, hard copy records, financial records, personnel information and all other information as confidential.

I understand that my information is equivalent to my signature and will take all reasonable steps necessary to safeguard my access from disclosure to others.

I understand that the use of my access will be strictly limited to accessing information on the basis of a need to know for or performance of my duties.

If I have reason to believe that the confidentiality of the access to the Durham OHT Virtual Collaborative Workspace has been violated, I will contact the Durham OHT Strategic Implementation Lead immediately for reassignment of a new password and/or access and to mitigate risks.

I understand that if I breach this Agreement, it will cause my removal from all activities with the Durham OHT.

I understand and agree that the duty to maintain the confidentiality of the confidential information shall continue after my working relationship with the Durham OHT is terminated.

Name: _____

Signature:

DATE: _____

Witness: _____

Witness Name: _____

23 June 2022

DURHAM ONTARIO HEALTH TEAM

Conflict of Interest Disclosure Statement

Patient, Family and Care Partner Advisory Council (PFCPAC) Member

Any member of the Patient, Family and Care Partner Advisory Council has a real or perceived conflict of interest when the member or their relatives, close associates or personal friends have a financial or other interest in the outcome of the work being performed.

A real or perceived conflict of interest occurs when a member of the Patient, Family and Care Partner Advisory Council (PFCPAC) has:

- a) a personal or professional interest in a specific outcome;
- b) a spouse or other family member who will benefit from a specific outcome; or
- c) any other interest that could be perceived as a threat to the independence or objectivity of the Patient, Family and Care Partner Advisory Council member performing a duty or function.

Declaration

I _____ Print First and Last Name _____, as a member of _____
declare

Select one of the following:

- Absence from conflict of interest

I have no financial or other interest in the outcome of the work of the Durham Ontario Health Team, Patient, Family and Care Partner Advisory Council (PFCPAC).

I further declare that should a conflict of interest arise in the future during the course of this work, I will fully disclose the circumstances in writing and without delay to the PFCPAC.

- Real or perceived conflict of interest

Description and nature of conflict(s):

I will maintain my objectivity, conducting my work in accordance with my Code of Ethics and standards of practice.

In addition, I will take the following steps to mitigate the real or perceived conflict(s) I have disclosed, to ensure the public interest remains paramount:

Signature:

Witnessed by:

X _____

X _____

Print name: _____

Print name: _____

Date: _____

Appendix 6 – Patient, Family, and Care Partner Evaluation Tool - Pending