

Durham Regional Cancer Centre's Patient and Family Experience Advisory Council Terms of Reference

Purpose of the Patient and Family Experience Advisory Council

The Patient and Family Experience Advisory Council (PFEA Council) will contribute to the enhancement of person-centred care in the Durham Regional Cancer Centre (DRCC). Patient and Family Experience Advisors (PFEAs) bring knowledge and expertise about what it is like to be a patient or family member/partner-in-care receiving care and treatment at the DRCC. The PFEAC provides a forum for patients and their family members/partners-in-care to identify opportunities for improvement and to participate in quality improvement initiatives at the Durham Regional Cancer Centre. The PFEA Council's scope encompasses the entire continuum of cancer care provided by DRCC.

The Durham Regional Cancer Centre is committed to:

- Supporting a strong culture of patient, family member/partner-in-care engagement.
- Embedding Health Quality Ontario's Guiding Principles for Engagement* in all activities.
- Employing a range of engagement approaches.

*Health Quality Ontario's Guiding Principles for Engagement (2017):

Partnership – Meaningful patient engagement requires authentic, timely and mutually beneficial relationships forged between patients, their caregivers, health professionals and the organizations they work with.

Learning – All participants in patient engagement should expect to learn – about each other's perspectives and experiences, about facts on the issue(s) at hand, and about how things may improve and be better.

Empowerment – Patients and their caregivers need to feel empowered to openly express their needs, perspectives and concerns without fear of reprisal, and to make informed decisions with confidence.

Transparency – Transparency means that health care professionals and organizations are honest about their apprehensions, resource limitations, and knowledge gaps when it comes to engaging with patients and their caregivers.

Responsiveness - Being responsive means that health care professionals and organizations act upon the voices of patients, their caregivers and the general public in ways that demonstrate the positive impact of this input.

Respect: Health care professionals and organizations demonstrate respect for their patient and their caregiver by actively showing signs of appreciation for their time, ideas, lived experiences, various worldviews and cultural locations.

Responsibilities of PFEAs

- PFEAs must adhere to Lakeridge Health (LH) policies including, but not limited to the Confidentiality Agreement, Code of Conduct, Dress Code and Personal Hygiene, and Infection Protection and Control;
- PFEAs are responsible to prepare for meetings by familiarizing themselves with materials sent out prior to each meeting;
- PFEAs are responsible to attend regularly scheduled meetings;
- PFEAs may be asked to represent DRCC at an engagement session or meeting organized by Ontario Health – Cancer Care Ontario;
- PFEAs may choose to participate in an initiative or working group within LH. This is not an expectation or requirement of their role as an Advisor on the DRCC PFEA Council;

Accountability and reporting relationships

The Patient and Family Experience Advisory Council is accountable to the Leadership Team of the Durham Regional Cancer Centre. Reporting occurs with regular updates provided at the monthly meetings of the DRCC Quality Council. The Co-Chairs will share an annual report on DRCC PFEA activities with the DRCC Quality Council and the LH Patient Experience Program.

Whenever possible, agreement on any recommendation is by consensus of Advisors. If consensus is not achievable in the absence of members, the Co-chairs may decide based on a majority vote of the PFEA Council members in attendance at the meeting.

Working Groups established as needed to address specific issues, upon approval of the Co-Chairs. Individual PFEAs may choose to participate as an Advisor on initiatives or working groups outside of DRCC and LH. In this capacity, the Advisor's role reflects their experience with the health care system and not as a representative of DRCC or LH.

Membership of the PFEAC

Co-Chairs: PFEA Advisor from the Council
Patient Experience Lead/other member of the DRCC leadership team

The term for the PFEA Advisor Co-chair term is two years.

Members: Representatives from DRCC patient and/or family member/partner-in-care population with consideration given to equity in engagement. Ad hoc members may be invited to attend part or all of any meeting. This may include members of the DRCC leadership team, staff or physicians.

PFEAs are asked to commit to at least a one-year term, participating in a minimum of 4 meetings in a one- year period

Meeting schedule of the PFEA Council

The PFEA Council will meet up to six times per year, via video/teleconference or in-person when possible. PFEAs may be asked to review and provide feedback on documents circulated electronically between meetings.

Recruitment for the PFEA Council

Applications may be sought through a broad advertising campaign or by referral from a member of the healthcare team for patients or family members/partners-in-care who have experienced care at DRCC within the past 2 to 3 years

Co-Chairs of the PFEA Council will review applications and invite appropriate candidates to an interview. Co-Chairs will connect with the LH Patient Experience Program to support the LH process for volunteer onboarding

Terms of Reference review

The Terms of Reference will be reviewed bi-annually.

Last reviewed: October 2021