

Patient and Community Engagement in Research Committee (PCERC)

Terms of Reference

Purpose

Patients and communities who experience disproportionate burdens of illness due to social inequities, including racism, socioeconomic position, invisible disability and barriers to accessing quality healthcare, have been historically discriminated against in research. Meaningful efforts to engage patients and communities in the design and implementation of research are important to redress historical harms and shape a path to reducing health inequities. It is important to engage communities, and excluded sub-groups within communities, to ensure we are reaching people with unmet healthcare needs due to access barriers.

Opportunities for patient and community engagement in basic science may be more limited than in the clinical setting but are nevertheless imperative for the development of therapies. Patient and community perspectives can help to shape research priorities and ultimately improve outcomes for patients, communities and families. Engagement at this fundamental stage of research can help researchers to more closely examine the scientific problems they are trying to solve, ultimately resulting in therapies that are accessible and inclusive.

Mandate

At Unity Health Toronto, we are committed to serve Toronto's diverse urban communities and democratize access to high-quality care for people experiencing marginalization.

The mandate of the Patient and Community Engagement in Research Committee (PCERC) is to:

- a) implement innovative models of engagement with our patients and community stakeholders through multi-level capacity building;
- b) prioritize equity in our frameworks and processes and strive for reciprocal value generation with our patient and community partners; and,
- c) apply dedicated resourcing and create consistent, mutually beneficial and lasting structures to respect and cultivate this relationship with our most valued partners.

PCERC provides advice to the Research Leadership Committee on the existing opportunities and barriers related to patient and community engagement in the design and implementation of research, and supports the research community by developing resources and organizing learning events.

Objectives

PCERC will:

- Establish institutional structures for equitable and ethical patient, family and community engagement in the design and implementation of research and innovation, in close collaboration with the Unity Health Toronto Patient Experience and Community Engagement Office and the Care Experience Institute.
- Integrate the design and implementation of research and innovation into select priority areas of the Care Experience Institute, which align with our scientific pillars, as a means to understand and create the very best care experiences for Unity Health Toronto patients and families.
- Co-create best practices and build the research community's capacity for partnering with patients, families and communities in different research contexts, defining specific approaches for value generation and harm prevention.
- Forge strategic partnerships with patient and community groups and organizations whose needs and expertise align with our research foci.

Membership

PCERC membership includes representatives from Unity Health's scientists, trainees, research employees, and **at least four** patient or community advisors/partners. A **minimum of 8 and maximum of 18 members** will be selected with the intention of having a gender-balanced and diverse group. Each member will commit a **minimum of two years** as member. The membership status and function of PCERC will be reviewed every two years to ensure alignment with the intended purpose. PCERC will be considered ongoing with rotating membership.

PCERC is chaired by Dr. Patricia O'Campo and is supported by the Office of the Vice-President, Research & Innovation team.

Meeting Procedures

PCERC will convene **monthly** for **60-90 minutes** (depending on the need), with additional meetings scheduled as required on an ad-hoc basis. The Office of the Vice-President, Research & Innovation team will schedule the meetings and facilitate the minutes in accordance with a format agreed upon in advance.

Quorum will be obtained through the presence of **50% plus one** of the total Committee membership, including the chair and **at least two patient or community partners**. PCERC will conduct its business based on the membership present. If quorum is not achieved, opportunity will be given for members to provide input on business and participate in decision-making in absentia. **Decisions** will be carried by consensus of the committee. If consensus is not obtained, decisions will be put to vote and carried with 50% plus one of the membership present.

Confidentiality

All information, discussion and comments during the PCERC meetings are considered confidential, and must not be shared with anyone outside the committee. Meeting material is provided to the PCERC members in confidence and should be kept in a secure place, and not be accessible to others.

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