

ALTERNATE LEVEL OF CARE (ALC) PATIENT AND CAREGIVER ADVISORY COUNCIL TERMS OF REFERENCE

Vision

Patients, families (herein called “caregivers”) and caregivers are partners with their health care providers and are engaged in all aspects of their healthcare.

Purpose

The Alternate Level of Care (ALC) Advisory Council (herein called the “*Council*”) serves as primary advocates for ALC patients and caregivers across Ontario. The *Council* will inform and respond to service and policy changes in ALC and co-design strategies to address issues *before* ALC, *during* ALC and *post* ALC.

The goal of the *Council* is to ensure the perspective of patients and caregivers is always considered and incorporated in their healthcare; and, to listen and learn from patients and caregivers with the aim to embed the patient voice throughout the ALC process.

Responsibilities and Opportunities

Person-Centred Care

- Advise the research team on meeting the needs of patients and caregivers with the Research Lead
- Provide a forum for patients and caregivers to identify opportunities to improve the quality of care and to participate in quality improvement initiatives for ALC
- Promote opportunities for collaboration among patients and caregivers and Research Lead
- Promote the inclusion of *all* voices

Role

- Review, comment on existing and/or emerging ALC strategies within Ontario
- Review of current processes and approaches of discharge planning, home care processes, LTC placement and efforts to engage and use community resources
- Identify the key factors and evaluate systemic gaps and issues that contribute to delayed hospital discharges/ALC days
- Identify factors that contribute to improved and appropriate utilization of hospital (acute, rehab and complex continuing care) and other sectors (community support agencies, supportive housing, home care, etc.)
- Make recommendations regarding ALC process changes within hospitals, regional planning bodies, the MOH (Ministry of Health), LTC (long term care) homes, and community services sectors.

Accountability and Reporting Relationships

- The *Council* communicates directly with the *Research Lead* who will be the acting liaison with members of the practice community and other researchers.
- The Research Lead is a member of the Council and supports the *Council* by attending meetings, assisting in preparing minutes and agendas, acting as a liaison with the research team and providing feedback from other members of the research team.

Members

The majority of *Council* members will be patients and caregivers empowering our community to champion patient and family engagement.

Members of the community with relevant experience (related to the mission of the Council) may, at the request of the Council, be invited to join the Council for a period of 1 year with ongoing membership determined on an annual basis.

Members of the *Council* makeup:

The majority of membership will be held by patients and caregivers

Total of at least 10 members made up of:

1 Chair

A minimum of 4 patients and maximum of 5

A minimum of 4 caregivers and maximum of 5

A minimum of 1 researcher

1 member of the community (practitioner, leader) may be invited to join

Decision-making: *The Council will strive for consensus and will use voting when there is no clear agreement. Voting will be made via a show of hands either in person or virtually (video meetings), or by secret ballot if requested. Once a decision is made, it is supported by the Council as a whole*

Quorum: A quorum of 50% +1 of all members is required to pass a decision

All members are expected to:

- Attend minimum of 70% of meetings per project period
- Provide insight and input to *Council* work
- Where possible, participate in projects between meetings
- Review pre-circulated materials and documentation
- Take on activities as determined by the *Council* and report back on progress
- Respect diversity and differing opinions
- Work collaboratively with Research Lead, stakeholders and other members of the public

- Respect privacy and confidentiality
- Provide constructive advice
- Represent caregivers as a well-informed participant

Term: Members are asked to participate for the period of [insert start and end date] or until projects are deemed complete. Members of the *Council* will initially serve for a two-year term [*a rotation schedule, in order that a new member comes in each year*) with a maximum 2 terms renewable, at the discretion of the Chair/Co-Chair prior to the start of a new fiscal year (April).

Selection: *Council members shall be selected from the public by the Chair/Co-Chair and Research Lead through word of mouth, referrals from healthcare professionals or Council members. The Council will strive to have a variation of patients and participants (deliberately seeking a representative group that varies by various dimensions including age, culture, and socio-economic status and other barriers).*

Patients and Family Members Qualifications:

- Must be a patient or a family member at a Toronto or broader healthcare facility within the last 2 years. One third (1/3) of council members must be current or have recent ALC.
- Respect diversity and differing opinions
- Work collaboratively with Research Lead, stakeholders and other members of the public
- Respect privacy and confidentiality
- Provide constructive advice
- Can represent patients and caregivers as a well-informed participant
- Be a collaborative and positive force for the enhancement of high-quality person-centred care

General requirements: Applicants must attend a screening interview, sign a confidentiality agreement and volunteer contract and attend a follow-up information session with the Chair

Reimbursement: *Council* members will be reimbursed for their expenses (such as transportation to and from meetings including TTC fare, taxi -where necessary- and parking) when funding is available.

Officers

The *Council* will elect a Chair or two Co-Chairs. One Co-Chair will be elected for a two-year term every year. [*a rotation schedule, in order that a new co-chair comes in each*

year]. Chairs can serve for a maximum 2 terms or longer at the approval and majority vote of the council members.

Roles and Responsibilities: The Chair/Co-Chairs will facilitate the conduct of meetings, liaise with the Research Lead and delegate responsibilities equitably to the members.

Qualifications:

- Understands the roles and responsibilities of the *Council*
- Provides democratic leadership for the *Council*
- Represents the collective voice of the *Council* inside the *Council* and in the community
- Works constructively with Research Lead and other *Council* members
- Is respectful of different opinions and supports the inclusion of all voices at the table

Duties:

- Call and chair meetings
- Develop the meeting agenda with the Research Lead
- Review and revise meeting minutes
- Communicate with *Council* members
- Write a final report at the end of each term summarizing the *Council's* activities and achievements
- Represent and speak on behalf of the *Council* at activities and events

Meetings

Frequency: The *Council* will meet at least 8 times/year or at the call of the Chair/Co-Chair. The *Council* will meet on a scheduled basis – monthly or as per agreement of the *Council* members, but no less than every two months.

Notice: Meetings will be scheduled in advance and notice will be made at meetings and followed up via email.

Minutes: All *Council's* related materials, inclusive of agendas will be pre-circulated in advance of *Council* meetings at a minimum of one week's notice. Minutes will be sent by email to all members of the *Council* by the Research Lead or Chair/Co-Chairs.

Records retention:

The *Council's* records are subject to the *Freedom of Information and Protection of Privacy Act* (FIPPA) and will be kept by the Research Lead.

Review

The *Council* will review these terms of reference at the commencement of each phase of the project or as requested by the Chair/Co-Chairs or *Council* membership. A review is required a minimum of once per year.
