



Terms of Reference – Patient and Caregiver Advisory Committee (PCAC)

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Contents

Purpose	1
Background	1
Core values	2
PCAC membership	2
Functions and responsibilities	3
Operations	4

Purpose

These terms of reference explain the structure of the SKIP Patient and Caregiver Advisory Committee (PCAC) and the roles that PCAC members play.

Background

What is SKIP?

The Solutions for Kids in Pain (SKIP) community consists of over 100 partner organizations, including hospitals, community groups, businesses, academic centres, and government institutions. All of these organizations support SKIP's vision of healthier Canadians through better pain management for children.

SKIP has an administrative centre in Halifax, Nova Scotia, and regional hubs in Alberta, Ontario, Quebec, and Nova Scotia. Each hub has a SKIP Hub Lead and Knowledge Broker who support [knowledge mobilization](#) and implementation of evidence-based solutions at institutions across their region. In other words, the SKIP Hub Lead and Knowledge Broker work to get the most current knowledge about children's pain to the people who need it, faster.

What is the PCAC?

The SKIP Patient and Caregiver Advisory Committee (PCAC) was established to build meaningful partnership with patients and caregivers and to ensure that SKIP's governance, committee structures, and knowledge mobilization activities are guided by the [Patients Included Ethics Charter](#).¹

¹ <https://patientsincluded.org/ethics/>



What is the Patients Included Ethics Charter?

The Patients Included Ethics Charter gives organizations a way to show their commitment to patients by involving patients in their work, giving patients the support they need to participate fully, and ensuring that patients are offered compensation. SKIP uses the charter as a guide for the minimum requirements for meaningful partnership practices. Where possible, SKIP aims to exceed those charter requirements.

Core values

Respect

Respect is the foundation of each PCAC core value. PCAC members treat other members with courtesy, patience, and kindness. Members are encouraged to participate in open and honest discussion, give constructive feedback, raise issues, and solve problems together in a compassionate way.

Belonging

The PCAC is a community of diverse people with diverse lived experiences who seek to truly see, hear, and include the members and the broader community we engage. The PCAC builds safe spaces where everyone has the support they need to be themselves.

Equity

Each PCAC member deserves access to opportunity, networks, resources, and supports that honour and respect their unique experiences and meet their needs.

Fun

Being a part of the PCAC is a shared experience where members are able to have fun, create bonds, and lighten heavy burdens through emotional support. Learning from others' experiences can be a productive, low-stress, and happy way of working toward shared goals.

PCAC membership

The PCAC membership consists of:

- 2 voting co-chairs appointed by the SKIP Leadership Team (Scientific Director, Director, and Associate Director) for a 4-year term,
- the SKIP Patient Partnership Advisor, who sits as a non-voting member and whose role is to report on the PCAC's activities to the SKIP Leadership Team, and
- 4 to 6 other voting members appointed by the SKIP Leadership Team for a 4-year term, based on a recommendation by the PCAC co-chairs and the SKIP Patient Partnership Advisor.

PCAC members should represent the diversity of the SKIP network and the lifespan of patient and caregiver members affected by pain.



Functions and responsibilities

What does the PCAC do?

The PCAC:

- gives guidance and input on SKIP's annual reporting to the Board of Directors and the Networks of Centres of Excellence (NCE), typically in spring, as it relates to outcomes of patient and caregiver partnership at SKIP;
- advises on the design and implementation of patient and caregiver partnership activities within SKIP, including:
 - evaluation (for example, reviewing our partnership practices, including how well our partnerships reflect the diversity of the people SKIP serves),
 - communications (for example, reviewing newsletters and social media messages), and
 - patient partnership resources on best practices for the SKIP network (for example, creating and updating patient partnership recruitment templates and onboarding resources);
- hosts a PCAC patient partnership priority-setting workshop each spring;
- works with the Managing Director and Leadership Team to integrate PCAC patient partnership priorities into SKIP network priorities each year; and
- reviews the PCAC Terms of Reference once a year and updates it as needed

What do PCAC members do?

Members are expected to²:

- declare all actual, potential, or perceived conflicts of interest (SKIP Conflict of Interest Declaration currently under review),
- respect confidentiality of all meetings,
- arrive prepared for meetings or notify the Patient Partnership Advisor if they cannot attend,
- participate in all meetings as health and other commitments permit. Members will be paid for missed meetings, and the PCAC will help them find other ways to contribute.
- draw upon their knowledge, networks, and experience to give input into discussions and decisions,
- work for the benefit of SKIP, independent of personal vested interests,
- promote ways to increase and improve patient and caregiver partnership, and
- ensure the PCAC follows its Terms of Reference.

² Adapted from Terms of Reference for Patient Advisory Committees, Université de Montreal Centre of Excellence for Partnership with Patients and the Public.



What does SKIP staff do to support the PCAC?

SKIP staff supports the PCAC by:

- scheduling meetings,
- sending meeting materials—including agenda, minutes, and documents for review—to PCAC members at least 1 week before each meeting,
- managing accommodation requests,
- managing compensation and helping members track their hours,
- helping the PCAC host its annual priority-setting workshop, and
- posting opportunities for new members to join the PCAC.

Contact SKIP staff through the Patient Partnership Advisor at [email here].

Operations

Meetings

- Quorum is equal to half of the membership of the PCAC.
- The co-chairs and SKIP staff co-create the agenda.
- The co-chairs decide how to facilitate the meetings, with support, as needed, from the Patient Partnership Advisor.
- SKIP staff record meeting minutes, including action items and decisions, and distribute this information to members.
- SKIP staff save approved minutes to SKIP organizational files.

Member compensation

- Members are compensated according to SKIP's patient [partner compensation guidelines](#) (\$1,500 each year for regular meetings and more for optional work).
- Members can choose to receive compensation annually or quarterly (at the end of March, June, September, and December).
- Members can decline compensation.
- Members may be offered training opportunities or other supports they need to contribute to the PCAC.

Member recruitment and onboarding

- Member recruitment will prioritize equity, diversity, and inclusion.
- To ensure representation and prevent power imbalances, recruitment will aim for a membership consisting of more patients than caregivers.
- SKIP staff will post opportunities to join the PCAC on the SKIP website and on SKIP social media. Anyone interested can fill out a short application form with optional demographic information and space to briefly talk about their patient engagement/partnership experience.



Demographic questions will be taken from the SKIP Patient Partner Recruitment Demographic Questions (under review).

- The co-chairs and Patient Partnership Advisor will review the application form to choose candidates for membership. The Patient Partner Advisor will contact candidates for an informal interview.
- Interview will be conducted with the Patient Partner Advisor and a PCAC Co-Chair
- The co-chairs and Patient Partnership Advisor will choose candidates to recommend to the SKIP Leadership Team for PCAC membership.
- The Patient Partnership Advisor will start the onboarding process as outlined in the Recruitment & Onboarding Guidelines (under review).

Member check-ins

- The Patient Partnership Advisor will check in with each PCAC member at least twice a year to ensure their needs are being met and that barriers to their participation are being addressed.