

Patient Engagement Forum: Terms of Reference

Purpose

The Patient Engagement Forum is designed to bring together a broad cross-section of patient organizations who can better provide Canadian Blood Services with perspectives and first-hand insights and feedback on issues of importance to those that use the products and services facilitated by the organization.

It provides a venue for Canadian Blood Services to engage patient organizations more frequently, more inclusively and in more robust ways and to help better appreciate what stakeholders are hearing from patients, what issues and concerns are emerging, and what we could be doing differently to best meet patient needs. Topics for discussion include operational or strategic topics related to patient care identified by members and Canadian Blood Services.

Objectives

1. Provide patients and patient organizations with regular briefings from Canadian Blood Services on operations and priorities, with an opportunity to ask questions in response.
2. Listen to and better understand patient perspectives and concerns.
3. Engage Forum members on key health policy issues and directions.
4. Involve senior Canadian Blood Services executive and board members so they hear patient organization perspectives first-hand.

Membership

Membership is limited to patient organizations who represent people who receive medicinal products or services through Canadian Blood Services and have patients and/or caregivers as members. This includes federal national organizations, organizations that represent a significant regional patient community, and umbrella associations of patient organizations. Up to one provincial or territorial members of a national organization may also join as a member, subject to the agreement of the national office.

Members may participate in either the Blood, Plasma, or Stem Cell meetings (whichever is applicable) as well as in joint sessions of the full Forum. Where appropriate, members may participate in the meetings of more than one community.

Each member organization should select a principal representative to take part in meetings. They may also, when necessary, have a second attendee take part.

The member representative(s) should be able to speak on behalf of their organization and have a sense of the lived experiences of the patients the organization represents. It would also be

helpful to understand the bigger picture challenges and successes the patient community experiences.

The representative should be comfortable enough with technology that they can participate fully in our virtual meetings, and they should have a mechanism where they can report back or raise any relevant matters with other interested members of their organization. From time to time, they may be asked to collect additional insights from their organization (or have similar asks of Canadian Blood Services) so they should be equipped and able to do so.

They should feel comfortable engaging with Canadian Blood Services and with representatives of other patient communities and sharing their perspectives and opinions.

There is no term limit on members' participation, though they can be changed at the member organization's discretion.

Meetings

There will be two series of Forum meetings each year – one in the spring and again in the fall. Each series will consist of one meeting for each of the product member communities (blood, plasma, stem cells), and one joint session with all members.

Specific meeting dates will be selected after input from patient group members. Agendas for the meetings will be designed collaboratively with the membership and reflect discussion topics or questions of interest to members or Canadian Blood Services. Agendas and any pre-meeting materials will be distributed to allow sufficient time for participants to arrive prepared.

The Forum is a safe place where members and Canadian Blood Services staff can express different perspectives but in a respectful that meets [Shared Commitments for Safe Engagement](#).

Following each series of meetings, members will be invited to provide feedback to Canadian Blood Services. This feedback will be reviewed carefully and acted upon whenever possible.

Meetings will take place virtually, using Microsoft Teams.

Reports

Following each series of Forum meeting, a summary report will be distributed to members promptly. Members are invited to review reports and identify any errors or omissions. Reports will also include a description of feedback received.

Action or follow-up items will be tracked, and progress reported back to members. Efforts will also be made to update members on how their input has impacted relevant decisions made by Canadian Blood Services.