CTTG Community Engagement Working Group
Terms of Reference

Roles and Responsibilities

The role of the Community Engagement Working group (CEWG) is to provide consultative advice to the CTTG transfusion medicine researchers during project development regarding the impact of research on community stakeholders (blood donors, transfusion recipients and Canadians at large), and engage community stakeholders individuals in transfusion research initiatives.

- Assist transfusion medicine researchers to identify appropriate community stakeholders to receive consultative feedback on specific research projects in an inclusive and ethical manner;
- Create a resource for researchers to guide impactful and appropriate community stakeholder engagement;
- Maintain a broad list of community stakeholders in transfusion medicine to facilitate community stakeholder linkages, including with other CTTG Working Groups;
- Develop a framework for community stakeholders to define their roles and expectations as participants in this and other CTTG Working Groups;
- Review and provide and feedback regarding stakeholder engagement and valued outcomes as they relate to applications for research finances/grants;
- Provide regular updates to the stakeholders who have given their input on the research progress;
- Liaise with the Knowledge Translation Subcommittee to ensure communication of research outcomes to stakeholders;
- Provide a conduit for community stakeholders to provide opinions about new research ideas and/or participate in the design and conduct of research projects.

Governance and Reporting Structure

The WG chair and vice-chair (or Co-Chairs) will report to the CTTG Steering Committee.

Expectations

Working group members are expected to attend and participate in regularly scheduled meetings. They are expected to respond to specific requests for input, advice, and requests for urgent meetings in a timely manner.

Working group members are also expected to help identify potential community stakeholders to participate in research project related feedback and contribute to development of Community Engagement Working Group resources.

Membership

- Chair and Vice-chair *or* Co-Chairs

  The chair and vice-chair (or Co-Chairs) will serve terms of 4 years, with a maximum of two consecutive terms.

- Members:

  The membership term is 4 years for the following, with the possibility for renewal for a second term:

  - Core (standing) Members (minimum numbers listed):
    - Transfusion Medicine Medical Professionals (e.g. physicians or nurses) – 3
    - Transfusion Medicine Trainee – 1
    - Blood operator donor engagement personnel – 1
    - Social Sciences expert (e.g. psychologist, sociologist) - 1

  The membership term is 2 years for the following, with the possibility for renewal for a second term:

  - Community Representatives, with pan-Canadian geographic representation (minimum numbers listed):
    - 1 donor, and
    - 2 transfusion recipients/family members of pediatric transfusion recipients

  Ad hoc Members:

  - Trainees in social sciences related specialties (e.g. health policy, medical sociology)

- Membership will be diverse in terms of lived experiences, geography, gender and cultural background. Perspectives from both Canadian Blood Services and Héma Québec will be represented.
- New members may be added at the decision of the Chair and Vice-Chair (or Co-Chairs) and Core Members, depending on the nature of research being discussed.

Remuneration:

- Membership participation is voluntary.
- Financial compensation is available to patient and donor representatives at a rate of $50/hour.
  - The remuneration value will be reassessed every 2 years (next due April 2026). Any potential increase in rate will require the approval of the CTTG Steering Committee.
- Professionals employed within transfusion medicine/blood services will not be remunerated.

Meetings

- WG meetings will occur on a regular basis (at least once every 3 months). Access to technology (device including an internet connection) is required to enable participation in virtual meetings.
- Quorum will be defined as attendance of 50% + 1 of membership (excluding the co-chairs).
- Meeting dates and agendas will be prepared by the Co-Chairs, who will prepare and ensure distribution of the agenda prior to each meeting. Distribution of meeting documents will ideally occur at least 48 hours prior to the meeting.
- In general meetings will be scheduled during a work-day (Monday-Friday between 8 am – 5 pm), with consideration of geographic time zones.

Decision Making

Decisions will be made by the WG through discussion and consensus. In the event that consensus cannot be reached, Co-chairs reserve the authority to present more than one option to the Steering Committee or make a decision on behalf of the group.

Members are encouraged to declare any relevant actual or perceived conflicts of interest and may choose to abstain from voting at any time.

Confidentiality

Members will keep confidential all information discussed at the WG meeting that is not available in the public domain.

Signature of a CTTG WG Participant Confidentiality Form will be required on an annual basis.

Date of CEWG Terms of Reference Approval: April 12, 2024
Date of Next Scheduled Review: 2 years (April 2026)

Chair: Dr. Michelle Zeller
Vice-Chair: Kelly Holloway