Terms of Reference Template

Prepared by the AbSPORU Patient Engagement Team

This template was co-developed by the Alberta Strategy for Patient-Oriented Research (SPOR) SUPPORT Unit, Patient Engagement Team to assist research teams and other groups in the co-development of terms of reference for research project working groups or advisory councils.

A research team, working group or council TOR

- Is best co-developed at a first meeting with all members of the research team
- Is the overarching guiding document for the membership
- Provides background information about the research project, objectives and role of the working group or advisory council
- Must be agreed upon by all members before being finalized
- Serves as a reference document; and therefore
- Should be provided to all members both electronically, and in print, once co-developed
- This is a living document and should be reviewed on a regular basis. Each iterative version should be named differently with version number and date and all versions should be housed in a shared folder with access given to all members.
- It is important to use plain language where you can and write out ALL acronyms. Be consistent in the name of your group throughout the document, in your agendas and your notes and reports.

The next section consists of an editable document (including headers and footers).

Terms of Reference
[Your group, council, or committee name; (acronym if there is one)]

Background
Include the title of the project and explain about the project or activity.
- What is the background of the project?
- What is the question or problem being addressed?
- Why is this project necessary?
- Who does it hope to benefit and how?
- Who is funding the project?

Definitions
Patient and public members may not understand all the terms used to discuss the project. It is important to establish clear and understandable definitions when working together. A 'Definitions' section can help to clarify the more technical terms and acronyms that are used with the project and might be better situated at the end of this document.

> **Example:** Consider the broad, inclusive definition of "patient" given by the Canadian Institutes of Health Research (CIHR).
>
> Patient: An overarching term inclusive of individuals with lived experience of a health issue, either their own or that of a family member, caregiver, or friend.
> https://cihr-irsc.gc.ca/e/48413.html#a4

Purpose
This TOR serves as the guiding document for [group name]. The goals for this [group] are to
- Advise (project priorities, design, processes)
- Co-develop (educational materials, protocols, process guides)
- Guide (project priorities, design, processes)
- Provide (insights and feedback to the overall study)
- Other (participant recruitment, knowledge translation, dissemination, evaluation)

Membership
[THIS GROUP] consists of [how many people do you ideally want?] members. Membership will
- Represent multiple perspectives with respect to age, sex/gender/geographical location, health experience, health research experience, work, cultural and educational backgrounds as possible
- Discuss composition of the group i.e., patient partners, researchers, stakeholders, etc.
- Openly share their ideas and respect the perspectives and time of others
- Where will the membership list be housed? Who will maintain this?

Members will engage in

This is a good place to identify all working group and engagement opportunities that members will be offered. Please see Part II in this document for additional suggestions for engagement
https://cihr-irsc.gc.ca/e/51910.html

- Advising
- Brainstorming
- Collecting and analyzing data (i.e., conducting focus groups, interviews, thematic analysis, etc.)
- Connecting with other stakeholders
- Co-developing protocols/processes/educational tools
- Identifying research priorities
- Providing feedback/approving activities/documents
- Other

It is also a good place to identify training activities that will be offered (i.e., conducting interviews, facilitating focus groups, thematic analysis, NVIVO, etc.).

Expectations of members

The TOR should include clear expectations of the members about meeting attendance and outline any additional input or opportunities to collaborate.

- <u>Length of Project:</u> How often are meetings scheduled? How long will they last?
- <u>Attendance:</u> What commitment to meeting attendance are members making? Are meetings in person or online? Are meetings recorded for those unable to attend?
- <u>Agenda:</u> Will members be offered an opportunity to contribute to agenda items? When will this opportunity be extended (i.e., 2 weeks in advance of meeting)? When will the agenda be sent out (i.e., 1 week in advance of meeting)?
- <u>Co-chairs:</u> Will patient partner co-chairs be identified? What will their roles be – co-developing meeting agendas? Note taking? Will there be additional co-chair meetings? Is there one team member identified as a key contact person who will be responsible for sending all communication about meetings, notes, additional opportunities, etc.?
- <u>Notes:</u> How soon after the meeting will the notes be sent out? Will these be housed, with meeting recordings, in a shared drive?
- <u>Compensation and Reimbursement:</u> Is compensation being offered? How will this be covered? Are expenses anticipated? Will these be covered up front, if possible, to help avoid expense claim processes?
- <u>Term of Appointment:</u> What are the expected term lengths for members and co-chairs?

Decision Making

It is always a good idea to have conversations around decision making.

- How much decision-making power will the group have?
- Is there requirement for a quorum?
- Who else, external to the group, has influence in decision making?

Compensation and Reimbursement

Is compensation being offered? Which compensation guidelines are being used? What are the processes for offering compensation? Reimbursement of expenses? Who is the key contact person for compensation and reimbursement?

Stepping Down

What happens when members want to step down? What is the process for identifying and recruiting new members?

*Please note that this template is a guideline only. We encourage you to resource your membership and additional existing TORs to help inform the co-development of yours.

The AbSPORU Patient Engagement Team is here to help. Please reach out if you have questions or if you would like to learn more about our other supporting documents, resources and supports: peplatformab@gmail.com