Terms of Reference (ToR) Template

This template was developed by the Patient Engagement (PE) Platform of the Alberta Strategy for Patient-Oriented Research (SPOR) Support for People and Patient-Oriented Research and Trials (SUPPORT) Unit (AbSPORU) to assist research teams and other groups in the co-development of terms of reference with their stakeholders and in particular their patient / public members.

A research team, working group, or committee ToR

- is best co-developed at the first meeting, with all members of the research team, working group, or committee—all stakeholders;

- is the overarching guiding document for the Membership;

- provides background information about the research or other undertaking to the team, group or committee;

- includes "ground rules" and expectations;

- 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 developed.

Note: It is important to use plain language where you can, and to explain all acronyms—even "common" ones. Your ToR should be short, concise but comprehensive, and easy to understand—generally following a Grade 8 reading level (modern standard).

The next section consists of an editable ToR document.

Terms of Reference

[Your team, group, council, or committee name]

Background

In this section, you should provide the Membership with background information about the project, study, or undertaking.

What are the basics of the initiative?

- When did it begin?
- Why is it happening?
- Where will it happen?
- Who is funding it?
- What is the question or problem being addressed?
- Who else would have an interest in the project?

Definitions

Patient and public members may not understand some of the terms used to discuss the initiative (e.g., clinical trial, CIHR, atherosclerosis, intersectionality, working group). Technical terms should always be explained in "lay" or easy-to-understand language. A "Definitions" section can help clarify the more technical term and acronyms that are integral to the project.

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 personal experience of a health issue and informal caregivers, including family and friends. http://www.cihr-irsc.gc.ca/e/48413.html#a4

This definition could be altered by the actual committee or group members to best suit everyone; for example,

Patients: Individuals with personal experience of a health situation, and informal caregivers, including family and friends.

Purpose

This ToR serves as the guiding document for [GROUP NAME]. The goals for [THIS GROUP] are to

- develop?
- guide?
- advise?
- provide?
- announce?
- other?

Members will engage in

- advising?
- Identifying priorities?
- brainstorming?
- providing feedback?
- reviewing documents?
- developing protocols?
- collecting and analyzing data?
- connecting with other stakeholders?
- approving activities or documents?
- other?

Membership

[THIS GROUP] consists of [how many people do you ideally want?] members. The patient / public members

- are diverse with respect to their age, sex / gender, geographical locale, ethnicity, health experiences, work, cultural and educational backgrounds, and volunteer / caregiver experiences, as appropriate to the project.
- openly and candidly share their ideas with [GROUP].
- respect the opinions and time of others.

Stepping Down

What happens when members want to step down? How are patient / public members replaced?

Note: In the case of research, the foundational group of researchers should be part of the final research team, along with patient / public members and other stakeholders, such as those dealing with policy. Having researchers, clinicians, and patient / public members working together from the start makes for more meaningful engagement and improved learning opportunities for all.

Confidentiality

The importance of trust and confidentiality of information are very important and can be addressed in this section.

- Will members agree to the open sharing of emails or will group emails be sent using the bcc function?
- Is the membership expected to keep meeting information confidential? Some? All?

Expectations: Meeting Attendance, Time Commitment, Etc.

The ToR should include text that makes very clear how much time members are anticipated to need to commit for this work. If members are expected to use email and teleconferencing, they must have access to and experience with such systems, and may need support in this area.

Note: The research team or group should always identify a study or project contact person as the liaison between patient / public members and researchers or institutional members. This person is the individual that all team members can call for information about meetings, or as an emergency contact.

- Attendance: What commitment to meeting attendance are members making? Are meetings face-to-face only? (or with a teleconference option)? What happens when people miss meetings?
- Agenda: When will the meeting agenda be sent to the Membership? Can members add items to the agenda?
- Preparation: What is the usual preparation time for the meetings?
- Conduct of Meeting: Who will chair the meeting? What, if any, rules of order will apply?
- Minutes / Notes: Will minutes or notes of meetings be kept? If so, will they be distributed among the Membership?
- Length of Project: How many meetings? Over what period of time? How long are meetings?

- <u>Compensation and Reimbursement</u>: How are each of these issues addressed? (see below)
- <u>Term of Appointment </u>(if relevant)

Note: Consider and discuss whether patients, public members, researchers, or institutional members have other expectations unique to their specific roles.

Decision Making

It is always a good idea to clarify decision-making power, so no one is confused about who has final say.

- How much decision-making power will the group have?

- Who has the ultimate authority to make final decisions?

- Who else, external to the group, is involved in decision making?

Reimbursement of Expenses and Compensation for Time

Use this section to address how you will handle members' expenses and compensation. Will the group have sufficient funding to be in a position to reimburse and offer compensation to members for their participation?

Note: A draft compensation document has been developed by the AbSPORU PE Platform that we are hopeful will be approved by AbSPORU. Also, check with your funding agency or institution for guidelines about expenses, compensation, and honoraria. Some patient / public members may decline compensation.

It is common for patient / public members to be reimbursed for out-of-pocket expenses (i.e., parking, travel, child care, etc.). Will the members be offered reimbursement for out-of-pocket expenses? If so, how will members apply for reimbursement?

Other Meeting Expenses

- We suggest that you always provide a snack or meal during meetings.

*** Please note that this template is a guideline only.
Your Membership will be in the best position to contribute to the ToR.
Usually, Terms of Reference documents are "living documents" that can evolve
throughout the life-cycle of the committee or group and project. ***