

# CADTH Patient Community Liaison Forum

## Terms of Reference

### Purpose

The CADTH Patient Community Liaison Forum is a voluntary group, comprising representatives from patient group umbrella organizations and CADTH. Its purpose is to provide a means to share information and collaborate on broad issues that generally apply (high-level policy and process issues) to CADTH work and patient groups. It is not a decision-making body, nor does it act as an ombudsman for patient groups. Its objectives include but are not limited to:

- fostering improved collaboration, engagement, and mutual understanding among members
- assisting in identifying priorities for patient input-related activities (e.g., training, dealing with conflict of interest requirements, feedback to patient groups, etc.)
- sharing learnings and experiences about involving patient groups in health technology assessment
- fostering communications among Liaison Forum members
- facilitating the sharing of information, as appropriate, with and from patient groups.

While this forum currently focuses on CADTH–patient group interactions related to drugs, this could expand to include non-drug health technologies in the future.

### Membership

Membership in the Liaison Forum is voluntary. Liaison Forum members may invite new members, as appropriate, to join the group. Members will include:

- representatives from CADTH
- representatives from patient group coalitions/umbrella organizations (note: the coalitions/umbrella organizations represent patient groups that are not specific for any one disease or condition and are geographically broad).

Members will be designated by their respective organizations to participate based on their knowledge and experience with current or emerging issues relevant to the interests of this Liaison Forum. Each participating organization in the Liaison Forum will designate two members to ensure active participation in forum meetings.

### Officers

The Liaison Forum Chair will rotate among members each meeting — a roster will be established at the beginning of the year.

The Chair will facilitate open and effective communication, and will ensure issues and thoughts are raised and recorded.

## **Meetings**

Meetings will be held three to four times per year, generally by teleconference. A face-to-face meeting will be held once per year. Dates for meetings will be arranged well in advance. Additional teleconferences will be scheduled, as required.

Meeting agendas will be developed by the Liaison Forum Chair in consultation with forum members. The agenda will be divided into CADTH and non-CADTH sections.

A common list of actions will be maintained.

## **Secretariat**

CADTH will provide secretariat support for the Liaison Forum.

The responsibilities of the secretariat include:

- arrange logistics for teleconference meetings (and in-person meetings, if scheduled)
- provide specific secretariat functions — issue calls for meetings; prepare and distribute documentation, including agenda, list of action items, etc.
- solicit agenda items from members and work with the Liaison Forum Chair to develop the meeting agenda
- facilitate interaction between the Liaison Forum and CADTH as appropriate.

## **Expenses**

Members are responsible for arranging and paying for their travel, accommodations, and expenses to attend face-to-face forum meetings when they occur.

## **Transparency**

All participants will make reasonable efforts to ensure that any discussions and materials brought to Liaison Forum meetings are available to share publicly. From time to time, it may be necessary to deem a document as internal to the Liaison Forum. In the event that one or more members of the Liaison Forum deem particular materials or discussions “internal” or “sensitive,” any external distribution must be discussed and agreed to by the participants before it can occur.