

Consumer Advisory Panel Terms of Reference

Background

The Australasian Gastro-Intestinal Trials Group (AGITG) Consumer Advisory Panel (“Panel”) provides a mechanism for advice to be received by the AGITG on general research directions and priorities from a consumer perspective and to provide a means of identifying unmet needs in the community.

Role

The primary roles of the Panel are to provide the AGITG with a consumer perspective relating to:

1. Relevance of new clinical trial concepts including validity of the overall trial question;
2. Ease of understanding the concept lay summary, master Patient Information and Consent Forms and trial results lay summary;
3. Identifying gaps in research and new research questions;
4. Trial management (via Panel member participation on Trial Management Committees);
5. Grant applications (via Panel member participation as Associate Investigators);
6. Advising on patient recruitment strategies; and
7. Assisting with fundraising activities.

Members of the Panel may also choose to become involved in other activities including membership of AGITG Committees and/or Working Parties, advising on ways to increase the public profile of gastro-intestinal (GI) cancer, the importance of clinical trials and the work of the AGITG. Another area of potential involvement is in advising on/helping execute potential fundraising initiatives. The primary focus of the Panel however will be on the scientific activities outlined above but involvement in broader activities such as the GI Cancer Institute Gutsy Challenge and Engage programs is also expected.

Structure

The Panel is a committee of the AGITG Scientific Advisory Committee (SAC). Support will be provided to the Panel by the CEO and Clinical Research Manager.

Panel Chair

Following an Expression of Interest process a Chair and Deputy Chair will be appointed to the Panel by the SAC Chair.

Membership

Members of the Panel will be appointed, removed or replaced by the SAC Chair and Panel Chair.

The Panel will have a minimum of six members and a maximum of ten members.

Participation is voluntary and all approved reasonable out-of-pocket expenses will be reimbursed with any necessary travel/accommodation arranged by the AGITG Administration Team. The AGITG also currently offers Panel members a small payment (\$50) each year in recognition of and as a contribution towards their general out-of-pocket expenses.

The AGITG aims to have a mix of representation on the Panel as follows:

- Each of the GI cancers;
- Each of the mainland States; and
- GI cancer patients, survivors and carers (past or present).

Potential new members may be referred by existing members of the Panel, AGITG member clinicians or advertisements.

Interested consumers must submit a membership Expression of Interest which details:

1. Their experience of gastro-intestinal cancer as a patient, survivor or carer;
2. Their experience of clinical trial participation (if any);
3. Their involvement with other health related consumer groups;
4. Their reasons for wishing to join the Panel;
5. Whether they are willing to be involved in the promotion and understanding of clinical trials research;
6. Whether or not they have completed the “Developing Consumer Expertise to Participate in Research” online training modules on the Cancer Australia website (www.consumerlearning.canceraustralia.gov.au) and if such training has not been completed then their undertaking to complete such training within two months of being advised of their acceptance as a Panel member.
7. Their Curriculum Vitae.

New Panel members will be provided an Orientation Pack, which includes:

1. Panel Terms of Reference
2. Panel member contact details
3. Recent Panel minutes
4. Relevant AGITG operational and personnel information
5. AGITG Annual Report
6. List of AGITG Clinical Trials
7. List of commonly used abbreviations
8. Any other pertinent information

Essential Criteria

The essential criterion for a member of the Panel is to give unqualified support to the concept of clinical trials; of every person’s right to information concerning trials and their right to make a personal, informed choice. **As consumer advisers you are not asked for, nor do you necessarily have the expertise to comment on the scientific/medical merits of a trial.** Your role is to advise the AGITG on issues which may affect patients participating in the trial.

Besides the Cancer Australia training noted above all members of the Panel will be asked to undergo/undertake any additional training that is designed to inform and assist members on how to better perform their role as a member of the Panel.

Members of the Panel should be members of the AGITG.

Duration of Appointment

The Panel Chair and Deputy-Chair will be appointed for a period of three years. Retiring Chairs and Deputy-Chairs are eligible for re-appointment by the SAC Chair up to two terms in succession.

Membership of the Panel is for a period of three years. Retiring members are eligible for re-appointment by the SAC Chair and Panel Chair up to three terms in succession.

The Chair and Deputy-Chair may serve longer than three terms, if, at the end of the third term as member of the Panel they are mid-way through an appointment as Panel Chair or Deputy-Chair.

Meetings

The Panel will meet as required by teleconference and face-to-face but no less than two times per year. Face-to-face meetings are held coinciding with:

- Annual General Meeting and Open Working Parties meeting (held in May in Sydney)
- Annual Scientific Meeting (held in August to November in a different city each year)

All Panel members are invited to attend the AGITG meetings noted above.

Panel members are expected to attend at least 50% of face-to-face meetings held annually and participate in at least 75% of reviews (on-line and/or via teleconference).

A quorum of 50 percent members plus one additional member is required at meetings. If within 15 minutes from the time scheduled for the meeting a quorum is not present, the meeting shall be dissolved and stand adjourned to another time and place as the Panel Chair may determine or matters will be dealt with by circulating resolution.

Reporting

The Panel Chair is responsible for reporting Panel activities to the Board with support from the CEO and Clinical Research Manager. A written report will be provided at meetings of the Board, as appropriate.

Confidentiality and Conflict of Interest

Panel members will complete the AGITG Confidentiality & Conflict of Interest Declaration annually and update as needed. Members with a conflict of interest to declare in relation to new topics will make a declaration prior to the discussion.

Panel members are required to keep all matters confidential unless disclosure of matters discussed is required for the effective oversight of the activity.

Expectations of Members

It is recognised that Panel members are volunteers many with professional and/or family commitments, however, Panel members are all asked to be conscientious of their obligation/commitment regarding their participation in Panel activities and meetings.

Availability to attend and/or give presentations at other relevant meetings, forums and conferences is desirable.

Members' timely responses to various proposals, protocols and documents will also be sought throughout the year.