

AGITG Consumer Advisory Panel

Terms of Reference

Background

The Australasian Gastro-Intestinal Trials Group (AGITG) Consumer Advisory Panel (CAP) was formed in 2008 to provide a mechanism for advice to be received on general research directions and priorities from a consumer perspective including identifying unmet needs in the community.

Key activities include the review of specific clinical trial concepts from consumers' perspective including validity of overall trial question and comments and suggestions regarding the Patient Information and Consent Form (PICF) and other issues such as identifying new research questions.

Members of the CAP may also choose to become involved in other activities including 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 will be on the scientific activities outlined above but involvement in broader activities could be considered by the CAP in the future.

Goals

The primary goals of the CAP are to provide the AGITG with a consumer perspective on issues about clinical trials including:

- Relevance of new clinical trial concepts and protocols under consideration of the Scientific Advisory Committee (SAC);
- Ease of understanding patient information and consent forms;
- Identifying gaps in research;
- Advising on patient recruitment strategies.

Structure

The CAP is a sub-committee of the Scientific Advisory Committee. The Panel will be facilitated by the Chair of the CAP with support from the Executive Officer and other staff as required.

Following a recommendation from the CAP, the Chair of the SAC will appoint the Chair of the CAP for a three year period. Retiring Chairs are eligible for re-election.

The CAP will meet prior to SAC meetings (3 – 4 times per year) to review new concepts and provide feedback from the patients perspective. Feedback will be provided to the Operations Executive Committee via the Executive Officer. Feedback will be provided to the SAC by the CAP Chair.

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Membership

Participation is voluntary and all expenses will be reimbursed.

New members may be sourced via existing members of the CAP and AGITG member clinicians and must submit a membership application which details:

1. Their experience of gastro-intestinal cancer;
2. Their experience of clinical trial participation (if any);
3. Their involvement with other consumer groups;
4. Their reasons for wishing to join the CAP;
5. Whether they are willing to be involved in the promotion and understanding of clinical trials research;
6. Their Curriculum Vitae.

Essential Criteria

The essential criterion for a member of the CAP 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.

All members of the CAP will be asked to undergo training provided by the Cancer Council Australia and Cancer Voices that is designed to inform consumers on how to identify research priorities and provide background to clinical trials.

Members of the CAP should be members of the AGITG.

Duration of Appointment

Membership of the CAP is initially for a three (3) year period. At the end of that time membership of the CAP may be renewed after reapplication.

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Confidentiality and Conflict of Interest

CAP members contribute because of their personal experience with gastro-intestinal cancer and if applicable as clinical trial participants and not as members of any other group. CAP members must respect the confidentiality requested by the researchers when reviewing documents, and must disclose any conflict of interest in any matters being considered by the CAP.

Expectations of Members

It is recognised that CAP members are volunteers with professional and family commitments, however, CAP members are all asked to be conscientious regarding their participation in CAP activities and meetings.

CAP meetings will be held three (3) times per year. The meetings are to be held in advance of SAC meetings at the following times:

- Mid-late February
- Mid-late April in advance of the Annual General Meeting and open Scientific Advisory Committee meeting (held in May each year)
- September/October in advance of the SAC meeting coinciding with the Annual Scientific Meeting (ASM).

All CAP members will be invited to attend the Annual Scientific Meeting of the AGITG.

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.

All new CAP members are also required to sign a Confidentiality Undertaking and are furnished with an Orientation Pack, which includes:

1. CAP Terms of Reference
2. CAP member contact details
3. Recent CAP minutes
4. Relevant AGITG operational and personnel information
5. AGITG Annual Report

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6. List of AGITG Clinical Trials
7. List of commonly used abbreviations
8. Any other pertinent information