



COMMUNITY ADVISORY GROUP
TERMS OF REFERENCE
2020-2023

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Acknowledgement

The document is based on the Terms of Reference of the AGITG Consumer Advisory Panel and was informed by processes from the following groups:

- Australia New Zealand Breast Cancer Trials Group (ANZBCTG)
- Australia New Zealand Gynaecological Oncology Group (ANZGOG)
- Australia New Zealand Urogenital and Prostate (ANZUP)

1. PURPOSE

The purpose of the PC4 Community Advisory Group (CAG) is to provide a mechanism for community input on research activities and priorities for PC4.

Key tasks include:

- Provide input into the strategic plan and research priorities of PC4
- Reviewing research concepts and protocols from the community perspective, including the relevance of the overall research question
- Reviewing information sheets and consent forms of PC4 supported studies
- Participating in working groups
- Acting as consumer Associate Investigators for PC4 supported studies
- Facilitating recruitment of new consumers for PC4 supported studies

We expect that CAG members will also be involved in other activities including:

- Facilitating links with the community and cancer community/consumer groups
- Raising awareness and advocating for community priorities among PC4 members
- Advising on ways to increase public awareness of the importance of clinical trials
- Advocating participation in research and clinical trials to consumers
- Contributing to or initiating community projects and activities
- Promote PC4 and PC4 supported studies as a consumer media representative on different platforms including print media, radio, online, TV and social media

2. STRUCTURE

The PC4 consumer advisory group is the core feature of the PC4 consumer engagement model. This group represents the formal aspect of consumer engagement in the development of PC4 research. As a minimum, 2 consumers represent the broader group on the PC4 Advisory Committee and Scientific Committee. The CAG consists of up to 12 community members. The activities of the CAG shall be shared amongst members with opportunities to attend workshops and participate in committee meetings where appropriate and supported by the PC4 Office as required.

3. MEETINGS

The meetings of the CAG will be held not less than twice per year, with at least one being a face-to-face meeting. Face-to-face attendance is voluntary but desirable. Teleconferencing facilities will be provided by PC4 to enable members to participate. Each member of the CAG will be required to attend at least one meeting per year, either in person or via teleconference.

4. MEMBERSHIP

4.1. NEW MEMBERS

CAG membership will reflect a diversity of skills, experiences, demographics and location.

New members shall be required to submit an application with details of:

- Their experience with cancer
- Their experience with clinical trials or studies
- Their involvement with other community/consumer groups
- The reasons for wanting to join the CAG
- Their curriculum vitae

Upon appointment new members of the CAG shall be provided with access to:

- CAG Terms of Reference (this document)
- CAG Introductory Guide
- CAG member contact details
- Recent CAG minutes
- List of PC4 studies (available at <http://pc4tg.com.au/about-us/pc4-research/>)
- Any other information deemed necessary

4.2. ESSENTIAL CRITERIA

All members of the CAG must be members of PC4. CAG members are not eligible for membership of other committees of PC4, other than as a CAG representative.

4.3. DURATION OF APPOINTMENT

Membership of the CAG is for a term of three years. Membership may be renewed upon reapplication. Terms of the CAG may be staggered by offering renewal options of one to three years to avoid the complete renewal of the committee in any one year.

4.4. WITHDRAWAL FROM CAG

Due to changes in circumstances CAG members may wish to terminate their membership before their current term is completed. Members wishing to resign from CAG should email the National Manager of PC4.

4.5. SUPPORT FOR CAG MEMBERS

All members of the CAG will be provided with appropriate learning opportunities. PC4 will endeavour to reimburse all travel expenses associated with members' participation in consumer activities related to the CAG. The PC4 Office will provide administrative support to CAG members to minimise any other costs associated with CAG participation.

5. ROLE OF CAG MEMBERS

PC4 recognise that members of the CAG are volunteers with professional, personal and family commitments and shall endeavour to accommodate any personal circumstances to a reasonable extent.

5.1. RESEARCH PRIORITISATION AND STRATEGIC PLANNING

The views of the CAG are represented by two members on both the Scientific and Advisory Committee. CAG representatives on these committees are responsible for sharing the CAGs position on areas of research priority and strategic activities related to consumer engagement.

5.2. CAG REVIEWS –WORKSHOPS

PC4 holds two regular workshops, a Concept Development and a Peer Review Workshop. CAG members are encouraged to contribute to reviewing as many documents (concepts, protocols, Participant Information Sheets, Consent Forms, etc.) as their time permits. Documents will be circulated to all and all contributions, including 'no further comments' are valuable. Two members of the CAG attend the workshop face-to-face based on availability and interest.

Documents not self-selected for review will be allocated to individual members by the Executive Office based on participation to date, expertise and area of interest. Mandatory allocations will be restricted, at this point in time, to a maximum of two per member per year.

It is expected that CAG members will meet review deadlines or notify as early as possible to negotiate extra time or re-allocate proposals for review by other CAG members if necessary.

The purpose of the CAG review process is:

1. To provide a lay perspective on the impact of the proposal on participants
2. To provide a lay perspective on the quality of a grant application and how well it meets the needs of the public and possible participants
3. To ensure Participant Information Sheets and Consent Forms enable potential participants to make an informed choice whether to join the research study. Feedback on grammar and spelling is appropriate for these documents

It is expected that CAG members would only object to approval/endorsement/support of a study or concept if it does not concord with the aims of the respective Group or if there are ethical flaws from the reviewer's perspective.

PC4 has implemented organisational processes to ensure:

- Suggestions from the CAG and external consumer groups on priorities for research are presented to researchers
- There is a mechanism for feedback from the researchers to the CAG

5.3. PARTICIPATION IN RESEARCH GROUP ACTIVITIES

CAG members may be invited to participate in a number of Group activities, including:

- Contributing to committee or working group meetings
- Participating in workshops (for health professionals and consumers)
- Joining a research team as an investigator

- Being a community advocate to help disseminate results of PC4 supported studies

These opportunities will be shared and may be allocated by:

- Continuing participation in an established role
- An expression of interest from the CAG member/s
- An invitation from the Group

5.4. IDENTIFYING NEW CONSUMERS

As part of PC4's tiered consumer engagement approach, members of the CAG may be asked to help identify appropriate new consumers to engage with PC4 Research Group Activities. CAG members may leverage their existing networks to contact consumers that may be interested in:

- Contributing to working group meetings
- Participating in workshops (for health professionals and consumers)
- Joining a research team as an investigator
- Joining a research team as a steering committee member

6. CODE OF CONDUCT

CAG members are expected to abide by the University of Melbourne Code of Conduct. It is expected that CAG communication is not offensive, harassing or discriminatory in any way and that CAG members act fairly, reasonably and treat fellow CAG members and PC4 members with respect, courtesy and sensitivity.

6.1. CONFIDENTIALITY AND CONFLICT OF INTEREST

CAG members are asked to contribute as individuals with an interest or experience in cancer, and not as representatives of another group or organisation. CAG members must treat all documents, be it research or governance documents, as confidential. CAG members must disclose any conflict of interest in any matters being considered by the CAG. All CAG members shall be required to sign a Confidentiality Agreement and contact details release form.

6.2. ACTING AS A REPRESENTATIVE FOR THE CAG

When attending external meetings or activities on behalf of PC4, CAG members are asked to reflect PC4's goals and objectives and to respect the confidentiality of PC4 unless disclosure has been authorised by the National Manager.

CAG members are encouraged to represent the CAG at external meetings or activities and are required to:

- Inform the National Manager of this prior to the event taking place.
- Use approved media communications resources (PowerPoint presentation, brochures, flyers, etc) provided by the National Manager

6.3. BREACH OF TERMS OF REFERENCE AND CONFLICT RESOLUTION

Any matters of conflict or breach of terms of reference shall be referred to the National Manager and Director, who will resolve or escalate the matters internally as required. Final outcomes of any matters of conflict or breach of terms are at the discretion of the National Manager and Director of PC4.

