



Joint Community Advisory Group

Terms of Reference

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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 and PoCoG Joint Community Advisory Group (JCAG) is to provide a mechanism for community input on research activities and priorities for both Groups.

Key tasks include:

- 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 and PoCoG-supported studies
- Participating in working groups

We expect that JCAG 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 the PoCoG and 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

2. Structure

The JCAG shall consist of up to 12 community members and shall report to the relevant committee of both PC4 and PoCoG. The activities of the JCAG shall be shared amongst members with opportunities to attend workshops and participate in committee meetings where appropriate and supported by the Executive Offices of the Groups as required.

3. Meetings

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

4. Membership

4.1. New members

JCAG 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 JCAG
- Their curriculum vitae

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

- JCAG Terms of Reference (this document)
- JCAG Introductory Guide
- JCAG member contact details

- Recent JCAG minutes
- List of PoCoG and PC4 studies (available at <http://www.pocog.org.au/psd/psdstudies.aspx> and <http://pc4tg.com.au/-Current-Research-.html>)
- Any other information deemed necessary

4.2. Essential criteria

All members of the JCAG must be members of PC4 and PoCoG.

JCAG members are not eligible for membership of other committees of PC4 and PoCoG, other than as a JCAG representative.

4.3. Duration of appointment

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

4.4. Support for JCAG members

All members of the JCAG will be provided with appropriate learning opportunities. PC4 and PoCoG will endeavour to reimburse all travel expenses associated with members' participation on the JCAG. The PC4 and PoCoG Executive Offices will provide administrative support to JCAG members to minimise any other costs associated with JCAG participation.

5. Role of JCAG members

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

5.1. JCAG reviews

JCAG 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.

Documents not self-selected for review will be allocated to individual members by the Executive Officers 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 JCAG members will meet review deadlines or notify as early as possible to negotiate extra time or re-allocate proposals for review by other JCAG members if necessary.

The purpose of the JCAG review process is:

1. To provide a lay perspective on the impact of the proposal on participants
2. 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 JCAG 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 and PoCoG will implement organisational processes to ensure:

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

5.2. Participation in Group Activities

JCAG 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

These opportunities will be shared and may be allocated by:

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

5.3. Role of Peer Support Program

The aim of the PC4 and PoCoG Peer Support Program is to create supportive relationships between members of the JCAG.

The Peer Support Program is a semi-structured program that has a required minimum level of participation. Peer group members are paired based on geographical location, interests and experience. The specific rules of communication are agreed upon by the peer support pairs and recorded in a *Memorandum of Agreement* (MoA) valid for 12 months.

The Peer Support Program also incorporates an evaluation process in the form of a questionnaire. There are two points of evaluation that will give the peer support pairs the opportunity to renegotiate their MoA or request re-pairing.

6. Confidentiality and conflict of interest

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

6.1. Acting as a representative for the JCAG

When attending external meetings or activities on behalf of PC4 or PoCoG JCAG members are asked to reflect the Groups' goals and objectives and to respect the confidentiality of both Groups' documents unless disclosure has been authorised by the Executive Offices.

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

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

6.2. Breach of terms of reference and conflict resolution

Any matters of conflict or breach of terms of reference shall be referred to the Executive Officers of the Groups, who will resolve or escalate the matters internally as required.