Consumer Panel
Terms of Reference

Committee Name

Thoracic Oncology Group of Australasia (TOGA) Consumer Panel, hereafter referred to as 'CP'.

Foreword

TOGA recognises the value of consumers, patients, and caregivers being involved in all aspects of research that relates to them, including research priority setting.

Purpose

The primary purpose of the CP is to bring together TOGA community members involved in research or in review of material for research studies that are provided to patients.

TOGA Consumer involvement in research operates according to the TOGA Position Statement "Consumer and Community Involvement in Thoracic Cancer Research", and subsequent amendments.

Members of the CP may also choose to become involved in other activities including, but not limited to, membership of TOGA Committees and/or Working Groups, involvement in fundraising initiatives or review of awards.

Expressions of Interest

Expressions of Interest will be extended to the TOGA community membership to join the CP when a CP member completes their term.

Expressions of interest may also be invited by the TOGA Operations Unit where the CP does not adequately reflect TOGA's research directions, or where the TOGA Operations Unit or CP Chair identifies an individual whose experience, expertise or perspective would make a valuable contribution to the Panel.

Essential criteria

The essential criterion for a member of the CP is their commitment to clinical trials as a key strategy for improving the outcomes of those affected by cancer. This includes supporting and promoting every person's right to information concerning trials and their right to make a personal, informed choice. As consumer advisers they are not asked to provide, nor expected to have, specific expertise about the scientific or medical merits of a trial. CP members are asked to provide the perspective of someone who has been through a similar or related experience.

Members of the CP must be members of TOGA.

Selection Process

An informal discussion will be held between the candidate and TOGA CEO (or TOGA representative), and optional attendance by an experienced consumer representative, to ensure there is alignment in the expectations and activities of consumer involvement.

Where a consumer representative participates in the informal discussion, the TOGA CEO and consumer representative will consider whether the individual should be recommended for appointment to the CP; otherwise the CEO (or delegate) will make this recommendation. Any recommendation will be submitted to the TOGA Board of Directors.

Terms

Consumer Panel members may serve terms of 2 years with no maximum number of terms. When a CP member is interested in completing another term, they should respond to the EOI process, and their name will be forwarded to the Board of Directors for appointment.

Appointment

The TOGA Board of Directors reserves the right to not renew terms, or not appoint candidates, even if there are vacant positions. The number of appointed CP members will not exceed 15.

Induction

All members of the CP will be asked to undergo/undertake any training that is designed to inform and assist members on how to better perform their role as a member of the CP.

Initial suggested training is the Cancer Australia training for consumer involvement in the cancer cooperative clinical trial groups and consumer involvement training provided by Telethon Kids.

https://consumerlearning.canceraustralia.gov.au/

https://training.telethonkids.org.au/courses/consumer-introduction/

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

- CP Terms of Reference
- TOGA Code of Conduct
- CP member contact details
- Relevant TOGA operational and personnel information
- List of TOGA clinical Trials
- List of commonly used abbreviations
- Any other pertinent information

Every effort will be made to assign new CP members to an experienced CP member ‘buddy’ who can provide mentorship and guidance during the initial involvement activities.

Review of clinical trial concepts

Prior to working groups an ‘open meeting’ of the CP will be held, where any member of the TOGA Community Membership can attend. A TOGA staff member will cover the concepts to be presented at working groups, covering the concept in more detailed and lay language than the working group presentation, to facilitate understanding.

For involvement in very early concept design and review and recommendations for TOGA endorsement, consumer representatives should join TOGA working groups https://thoraciconcology.org.au/working-group/.

Once concepts reach a more mature stage (eg protocol), members of the CP will be invited to provide feedback on a research design during a meeting with the lead investigator. Prior to the meeting, the written concept will be circulated as pre-reading. It is estimated that these opportunities arise approximately once/year.

The TOGA study chair or lead researcher will be expected to present a verbal outline of the clinical trial concept at the meeting and be available to answer questions on the research. The consumer representatives may choose to conduct further discussion on the concept without the study chair present and submit written feedback or may choose for the study chair to remain for the discussion and receive direct communication regarding the consumer views.

Involvement in research projects and grant applications

Periodically, TOGA receives requests from researchers to identify consumer representatives who are willing to be involved in research projects or grant applications. These may or may not be TOGA-endorsed projects, but it is important to note that TOGA has no ability to define consumer involvement for these research projects. These opportunities will be circulated to the CP and interested consumer representatives asked to express interest to the researcher directly.

Consumer representatives who attend working group meetings should identify themselves to researchers independently if they wish to be involved in a particular project.

Communication of Consumer Priorities

In recognition of the importance of communicating consumer priorities, prior to design of research, the TOGA CP will meet annually with key researchers to outline their priorities and receive feedback eg Think Tank priority setting exercises. Ideally, this will result in jointly agreed priorities for design of research concepts.

Expectations of members and TOGA

CP members are expected to treat others in a way that is polite, respectful, transparent, and culturally sensitive.

TOGA respects and understands that CP members are volunteers, many with personal, professional and/or family commitments. TOGA appreciates that participation in CP is voluntary, and recognises that from time to time, CP members' personal circumstances may prevent them from taking on additional duties or active participation in assigned roles. TOGA understands that this does not indicate a lack of interest in TOGA's activities or in continuing a role on the CP.

Chairperson/s

Following an Expression of Interest process among CP members and any noted endorsement by members of the CP, the Chairperson of the CP shall be appointed by the TOGA Board. The Chairperson shall preside over all CP meetings. The Chairperson will be appointed for a two-year term and may be reappointed for one additional two-year term following a further EOI process.

The Board may appoint a Deputy Chairperson from within the TOGA community membership or CP to support leadership continuity and succession planning. The appointment will be for a two-year term. The appointee may serve one further two-year term, subject to a new Expression of Interest process, with a maximum of two consecutive terms. For avoidance of doubt, the Deputy Chair does not necessarily become the Chair.

To promote continuity and stability of leadership, Chairperson and Deputy Chairperson appointments will be staggered wherever practicable. The commencement years of their respective two-year terms should alternate to avoid concurrent term completion.

The Chairperson(s) will develop meeting agendas in collaboration with the TOGA Operations Office.

The Chairperson(s) will also work with the TOGA Operations Office to:

- Ensure updates from the CP are provided to each Scientific Committee (SC) meeting; and
- Review and advise on opportunities proposed for dissemination to the broader TOGA consumer membership and/or CP, ensuring relevance, appropriateness, and alignment with TOGA's objectives, including study participation opportunities and roles on external consumer advisory groups.

If the CP Chair is unavailable, the CP may nominate a Chair in their absence. In the absence of a Chair (or Deputy Chair), a representative from the TOGA Operations Office will assume the role on an interim basis until a Consumer Chair is appointed or available to fulfil the responsibilities of the position.

If the Chair, Deputy, CP and Board of Directors all agree that two CP co-chairs, is preferable the Chair and Deputy, with no change to the appointment process, can be so named.

Decision making

The purpose of the CP lends to minimal decision-making. In general, the CP will adopt a consensus approach when establishing recommendations, where a majority of members agree, with the remainder content to give way. Any objections will be noted in the minutes. However in the instance that the CP needs to make a decision to progress and cannot agree, and the Chair and Deputy cannot agree to determine the vote, the decision will be forwarded to the Scientific Committee or TOGA Board of Directors to determine the final direction.

Meetings

The CP will meet as required by videoconference approximately two to four times/year, interfacing with the TOGA Scientific Committee agenda and other key TOGA initiatives likely to benefit from consumer involvement.

An agenda for the meeting will be prepared by the Chair and TOGA CEO, following a call for items approximately 21 days in advance of the meeting. Items not advised in advance will not be discussed at the meeting. The agenda will include, but is not limited to:

- Declaration of conflicts of interest
- Acceptance of previous meeting minutes
- Welcome to new members
- Lessons learned and consumer involvement experiences
- Training requirements
- An update on the TOGA clinical trial program
- Dates of next meetings
- Other business

Reporting

TOGA will evaluate and report on consumer and community involvement in research involvement alongside other academic metrics of success.

Budget and expenses

The cost of administration for the CP will be managed by the TOGA CEO. Funding to attend the ASM will be subject to the TOGA Travel Grant Policy, and not all CP members will be automatically funded to attend the ASM.

Confidentiality and conflict of interest

CP members will complete the 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.

CP members are required to keep all matters confidential unless disclosure of matters discussed is required for the effective oversight of the activity. The TOGA Confidentiality Statement will be signed by each member upon appointment to the CP.

Grievance procedure

Complaints in relation to the activities and operation of the CP should be made in writing to the TOGA CEO. The complaint will be considered by three TOGA members free of conflicts, nominated by the TOGA CEO/TOGA Chair. The decision whether to table the complaint at a CP meeting will be at the discretion of these three nominated members who consider the complaint. Regardless of whether the complaint is tabled at a meeting or resolved out of meeting, the complaint and the outcome of the deliberations should be minuted and communicated to the complainant by letter. The resolution of the complaint should also be recorded in the minutes.

CP members should not contact the Chair of TOGA directly. In the instance where the TOGA CEO is considered to be in conflict, the complaint can be sent to info@thoraciconcology.org.au

References

National Framework for Consumer Involvement in Cancer Control. Cancer Australia and Cancer Voices Australia (2011). Cancer Australia,Canberra, ACT.

Committee Terms of Reference. Guidance for CTNs, May 2019. Australian Clinical Trials Alliance (2019) Melbourne, VIC.

Statement on Consumer and Community involvement in Health and Medical Research, National Health and Medical Research Council (2026), Consumers Health Forum of Australia.

TOGA Position Statement “Consumer and Community Involvement in Thoracic Cancer Research”

Review and approval

The Terms of Reference for the CP shall be reviewed by the committee and approved by the Thoracic Oncology Group of Australasia Board every 3 years.

Name of the document	TOGA CP Terms of Reference
Version	6
Replaces	Version 4.0, March 2025
Reviewed by and date	23 September 2026
Approved by and date	23 September 2026
Next review date	23 September 2029

Document History

Version	Date	Status	Key changes
2.0	8 December 2021	Approved by TOGA Board	Established the Consumer Panel under a broad remit. Included Consumer Panel Co-Chairs appointed by the Board, with Co-Chairs providing updates directly to the Board.
3.0	15 May 2024	Approved by TOGA Board following consideration of draft version 2.3 and a minor subsequent wording amendment	Revised the purpose of the Consumer Panel to bring together TOGA community members to provide lived-experience perspectives on developing research. The Panel's reporting line was changed to the Scientific Committee, consistent with this research-focused role. Detailed consumer input into individual research concepts was to occur through TOGA Working Group meetings, which are open to all TOGA community members. Formal Co-Chair positions were removed. The Executive Officer chaired meetings unless a consumer member volunteered to chair. The revised role did not require a formal decision-making process.
4.0	25 September 2024	Approved by TOGA Board as draft version 3.2 and subsequently issued as version 4.0	Introduced a formal Consumer Panel Chair position, with expressions of interest sought from Consumer Panel members and appointment made by the Board. Introduced a decision-making process. Established a mechanism for communicating Consumer Panel research priorities through engagement with the Scientific Committee.

Version	Date	Status	Key changes
4.0	July 2025	Governance change implemented without amendment to the Terms of Reference	A Consumer Panel Co-Chair was appointed. This governance change was not incorporated into the approved Terms of Reference at the time.
6.0	23 September 2026	Approved by TOGA Board	Terms of Reference reviewed and revised to reflect current Consumer Panel governance and operating arrangements, including formalisation of the Co-Chair role, introduction of terms, expansion of concept review discussions to include TOGA Community members and other amendments arising from the review.

APPENDIX 1 Expression of interest form

TOGA Consumer Panel (CP) has been established to provide a structure for consumer representatives and TOGA Community Members to be involved in research.

This application form will help provide us with information about you that will help TOGA ensure your interests and those of TOGA are aligned.

Pending mutual agreement regarding your involvement, we will invite you to join TOGA and formally become a member of the CP. The CP meets approx. twice per year to welcome new members, to share experiences and learnings from involvement in research and to discuss any training or mentoring needs.

Invitations to review research will be sent out by email with interested consumers/community members to self-nominate. As a guide to time commitment, each concept takes around 3 hours, each consent form around 2 hours, each lay summary around 1 hour, and a grant application 1-2 days. Not all members need to review every item, but as a guide, you would be expected to review around 3 items per year.

Thank you for your interest in joining the TOGA CP. Please fill in this application form and send it to TOGA at info@thoraciconcology.org.au

To discuss this in any way and for more information please contact:

Megan Sanders

TOGA CEO

megan.sanders@thoraciconcology.org.au

Thank you for your interest in joining TOGA.

Yours sincerely

Megan Sanders

Thoracic Oncology Group Australasia

Consumer Panel
Terms of Reference

Applicant details	
Surname	**Given Name**
Email	
Address	
Phone	

Lung cancer/Mesothelioma ('Thoracic cancer') Connection:

- ☐ I have or had lung cancer/mesothelioma
- ☐ My family member has or had lung cancer/mesothelioma
- ☐ My family member died of lung cancer/mesothelioma

Time since diagnosis

- ☐ <1 year
- ☐ 2-4 years
- ☐ 5-7 years
- ☐ 8-10 years
- ☐ 11+ years

Applicant experience

1. **What is your experience in consumer advocacy or representation?**
   - ☐ Sharing your personal story publicly
   - ☐ Working with researchers
   - ☐ Working with research funders (e.g. grant reviews)
   - ☐ Working with healthcare providers (e.g. hospitals)
   - ☐ Fundraising for lung cancer research or advocacy organisations
   - ☐ Attending lung cancer scientific meetings or conferences
   - ☐ Organising educational events for the community
   - ☐ Actively participating in online lung cancer communities
   - ☐ Other: _____

2. **Are you prepared to liaise with thoracic cancer clinicians and researchers?** ☐ Yes ☐ No

3. **Are you prepared to attend meetings remotely (by phone or virtual/online)?** ☐ Yes ☐ No

4. **Please provide your social media links:**
   - **Twitter:**
   - **Facebook:**
   - **Instagram:**
   - **Blog/website:**
   - **Other:**
   - ☐ **Not on social media**

Applicant interest

5. **How did you find out about the TOGA Consumer Panel?**
   - ☐ Word of mouth
   - ☐ TOGA's website
   - ☐ Clinician or medical team
   - ☐ Another organisation: _____
   - ☐ Other: _____

6. **Why are you expressing interest in joining the TOGA Consumer Panel?**

7. **The TOGA working groups are the structure for review and input into early design of concepts. Please indicate the working groups you would like to join.**

   - ☐ **Translational Research Working Group**
   - ☐ **Supportive care research concept development working group**
   - ☐ **SCLC/Mesothelioma research concept development working group**
   - ☐ **Advanced NSCLC research concept development working group**
   - ☐ **Early-stage NSCLC (incl I-IIIB) research concept development working group**

Please email if you would like more detail on these areas.

Declaration

By signing this form:

I authorise the Thoracic Oncology Group of Australasia Ltd ('TOGA') to collect my personal information and handle them in accordance with the *Privacy Act 1988* (Cth) and the TOGA Privacy Policy. More information about how information is handled by TOGA can be found in our privacy policy (available at https://thoraciconcology.org.au/terms-conditions-privacy-policy/).

I wish to join the TOGA Consumer Panel, and I declare that to the best of my knowledge the information supplied within this application and any supporting document is correct.

Signature _____

Name _____

Date _____

Office use

Notes

Applicant is member of TOGA	**Y/N**	**Date joined:**
Progress invitation to CP	**Y/N**	**Reason if No**

APPENDIX 2 Confidentiality agreement

(1) I,_____(*name*),

_____(*position*) of,

_____(*organisation)*

_____(*address*),

acknowledge the confidential nature of all activities of the TOGA CP, including all discussions, whether by verbal, written or electronic means and all associated documents.

(2) It is agreed that I will not supply details or copies of documents to any third party outside the CP except as outlined in the working group Terms of Reference or agreed to in writing by the CP

(3) I understand that my obligations under this agreement continue to have full force and effect when I am no longer a member of the CP.

Signature Date: ___/___/___

SIGNED on behalf of TOGA by

Position:

Signature Date: ___/___/___

APPENDIX 3 POSITION DESCRIPTION OF TOGA CONSUMER REPRESENTATIVE

DUTIES:

- To provide feedback on research proposals and clinical trial documentation provided to consumers utilising lived experience of thoracic cancer.
- To undertake all background reading
- To be conscious of issues of diversity and representation and actively consider broader views – understanding and being conscious of the nature and limits of your specific personal experience and point of view and to consider a diversity of consumer needs and interests beyond these limits
- Familiarity with TOGA's Vision, Mission and Strategic Plan
- Adhere to TOGA Code of Conduct
- Attendance at training or seminars and/or participation in other development activities is strongly encouraged to support full and active participation in this role

EXPERIENCE:

- A personal experience of cancer as a patient, a person who has cared for another with cancer, or a family member or friend
- Membership of other consumer groups that enables a diverse and representative view to be brought to the review of research
- Written and verbal communication skills

CONFIDENTIALITY AGREEMENT:
Written declarations of confidentiality will be completed on appointment to the CP.

CONFLICT OF INTEREST:
Written declarations of interest/s that may give rise to a conflict will be submitted annually as per TOGA's policy. This is affirmed at every meeting, as well as an opportunity to declare any new interests that may give rise to a conflict.