

TOGA supports and shares the vision outlined in the NHMRC Statement on Consumer and Community Engagement in Health and Medical Research. This vision emphasises forging partnerships among consumers, community members, researchers, and research organisations to enhance the health and well-being of Australians through medical researchⁱ

TOGA recognises that the involvementⁱⁱ of consumers and community members significantly enhances health research, including its relevance, design, execution, benefits and translation. TOGA also recognises the importance of a partnership with consumer representatives founded on mutual trust and a shared belief in the value of research, and the need for and provision of resources and training to optimise this involvement.

TOGA advocates for consumer involvement and community engagement in thoracic cancer research, encompassing:

- Collaborative identification of research priorities
- Collaborative review and endorsement of research concepts
- Joint project design with researchers
- Development of research materials to be delivered to patients such as consent forms, information sheets and research advertisements
- Periodic meetings to update consumers involved in the project on research progress, seeking lived experience expertise where relevant
- Participation in reviewing and editing research results summaries and their implications for policy and practice
- Manuscript authorship consistent with the ICMJE¹ principles
- Advocacy for research to improve healthcare and public awareness of thoracic cancers
- Involvement in the allocation and assessment of grant funding

TOGA endorses key principles of community and consumer involvement including:

- Where possible, inclusion of consumers with relevant but diverse lived experience of thoracic cancer
- Early planning for involvement from project initiation
- Clear delineation of roles and responsibilities of consumers and community members, ensuring their meaningful and rigorous contributions to the research process

¹ International Committee of Medical Journal Editors. Recommendations for the conduct, reporting editing, and publication of scholarly work in medical journals. <http://www.icmje.org> Updated December 2018. Accessed 10 July 2019.

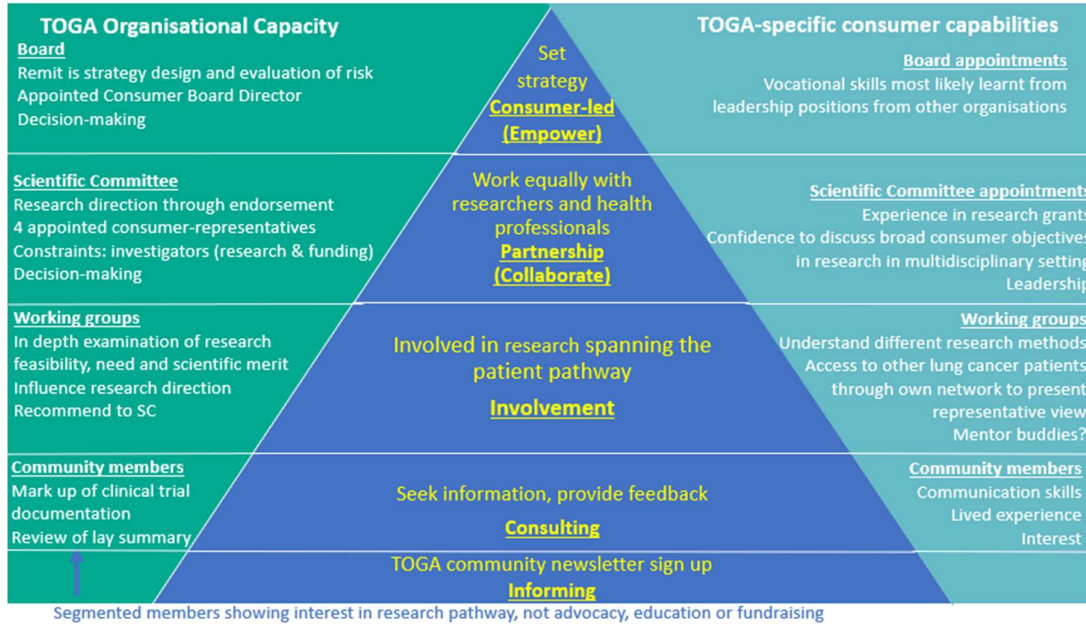
- Provision of training and support to enable effective collaboration between consumers, community members, and researchers
- Fair and appropriate recognition and acknowledgment of the contributions made by consumers and community members

In its approach to involving consumers and community members in research design, TOGA adheres to several strategies:

- Opportunities for all interested TOGA community members to be further involved in developing research
- Early integration of consumers and community members into research project design and other aspects of the research project
- Establishing clear roles and responsibilities agreed upon at the project's outset
- Ensuring meaningful engagement, where consumer and community involvement is collaborative and researchers work in partnership with consumers.
- Providing necessary training and support for effective collaboration among stakeholders
- Offering appropriate recognition and acknowledgment of consumer and community contributions
- Integrated consumer representatives through the organisation's research development and peer-review and decision-making committees as well as dedicated opportunities for consumer feedback on research proposals
- Consumer involvement in decisions regarding allocation of donations raised from the thoracic cancer community
- Evaluate and report on consumer and community involvement in practices and processes alongside other academic metrics of success

This collaborative approach ensures that TOGA activities remain relevant, impactful, and resonate with the communities it aims to serve.

Figure 1: Organisational Capacity and Corresponding Capabilities for involvement of consumers in TOGA. Working groups and community members levels are open to all interested TOGA community members. Specific training is defined for each level, and comprises a combination of internal TOGA resources and experience gained from TOGA and wider sector consumer involvement opportunities.



ⁱ National Health and Medical Research Council, Consumers Health Forum of Australia, 2016. Statement on Consumer and Community Involvement in Health and Medical Research. Accessed 6 January 2024: <https://www.nhmrc.gov.au/about-us/publications/statement-consumer-and-community-involvement-health-and-medical-research>

ⁱⁱ TOGA has adopted the definition of involvement from the ACTA Consumer Involvement toolkit, where **Involvement** is when consumers and community representatives actively work with researchers to help shape decisions about health research priorities and research design.