



Australian and New Zealand Intensive Care Research Centre

ANZIC RC Consumer and Community Connection Committee (ANZIC-RC-CONNECT) Terms of Reference

Version 2.0, 8th May 2025

Consumer engagement and involvement in research is essential to ensure that research meets the needs and expectations of the population included (DeBortoli et al., 2022). The National Health and Medical Research Council (NHMRC) describes that involvement of consumers and community should be in a minimum of four key phases; (1) determining research priorities; (2) development of research; (3) conduct of research including recruitment, consent and ethics and; (4) reporting including communications and publications (NHMRC, 2016). We have developed the Australian and New Zealand Intensive Care Research Centre (ANZIC RC) Consumer and Community Connection Committee to ensure consumer involvement and engagement in all aspects of critical care research associated with the Australian and New Zealand Intensive Care Research Centre (ANZIC-RC), School of Public Health and Preventive Medicine at Monash University and its partners. This process will be overseen by a Steering Committee.

Vision:

To promote active partnerships between consumers and researchers in critical care in Australia and New Zealand and facilitate research of the highest quality that is person centered, accessible and meaningful to consumers.

Aims of the ANZIC-RC Consumer and Community Connection Committee (CONNECT)

Partner in a meaningful and considered way

Ensure critical care research is underpinned by the needs and values of consumers.

Improve the profile of critical care research with consumers

Increase visibility, transparency, and enhance translation of research.

Establish a registry of consumers willing to connect

Involve consumers in activities surrounding:

- *Determining priorities*
- *Development of research*
- *Research conduct*
- *Reporting of research*

Provide training opportunities for consumers

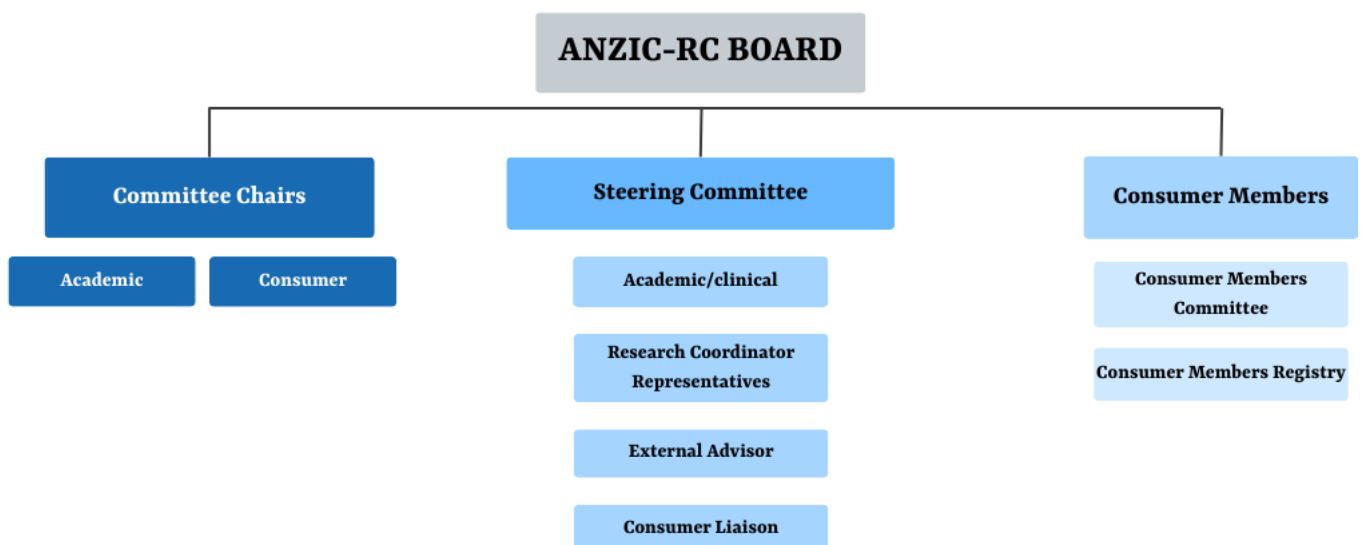
Promote interaction between consumers and researchers to share knowledge.



Key Terms and Definitions:

- **Consumer:** For the purpose of this group, a 'consumer' is anyone who has been a patient with lived experience of being admitted to an intensive care unit, or a family member/whānau/care giver of someone who has been admitted to an intensive care unit within Australia or New Zealand.
- **Consumer Liaison Officer:** Person who provides a central point of communication between members of ANZIC-RC CONNECT and the consumer registry
- **Consumer Member Committee:** The advisory group of consumer member representatives who oversee the activities of the ANZIC-RC CONNECT from a consumer point of view.
- **Consumer Member Registry:** A group of people who have expressed interest in contributing to research activities conducted at ANZIC-RC.
- **ICU:** Intensive Care Unit
- **Steering committee:** The group of people who oversee the activities of ANZIC-RC CONNECT.
- **Researcher:** A person who conducts research (an original investigation undertaken to gain knowledge, understanding and insight). Researchers may be academics and/or clinicians.

CONNECT Governance and Structure:



1. Steering Committee

ANZIC-RC CONNECT is overseen by a steering committee (Figure 1) which reports to the ANZIC-RC board and aims to include the following representatives:

- Chair (professional)
- Chair (consumer)
- Academic/clinical member(s) (1 from New Zealand)
- Consumer member(s) (1 from New Zealand, 1 from Australia)
- Indigenous Researcher
- ANZIC-RC Senior Project Manager representative
- ICU Research Co-ordinator
- CONNECT Consumer Liaison Officer
- External member position(s) - those with consumer experience (academic or clinical) external to critical care

These positions will be rotational with a 2-year term. The exception is the first term (August 2022) which will be 4 years to establish the committee and processes.

The steering committee oversees activities of the ANZIC-RC CONNECT and the Member registry of interested consumers (patient or a family member/whānau/care giver) who would like to be offered opportunities to partner in research, and whom will also work alongside the steering committee and working party.

Steering committee meetings will be held three times per year. Decision-making in this committee will go ahead should there be a quorum (more than 50% of the committee). Meetings will run for 60 minutes.

2. Consumer Members

a. Consumer Member Committee

The ANZIC-RC CONNECT Consumer Member Committee comprises 7 consumer representatives with lived experience of intensive care. This committee oversees the activities of the ANZIC-RC CONNECT from a consumer perspective.

Committee Member responsibilities include attending consumer advisory meetings to provide guidance and insight on the consumer engagement processes at the ANZIC-RC. Attendance is either in-person or remotely (via Zoom).

Consumer Member Committee meetings will be held three times per year (and will be run for 60 minutes). Although attendance is generally restricted to this committee, the following groups are welcome to join and may be invited at specific times:

- Steering Committee
- ANZIC-RC Project Team members

b. Consumer Member Registry

Membership of the ANZIC-RC-CONNECT Member registry is limited to consumers with lived experience of intensive care within Australia or New Zealand. The registry is a list of consumers who have registered with CONNECT and have agreed to receive contact for potential research opportunities within the ANZIC-RC. An onboarding process is conducted when consumers join the Member Registry (Appendix A).

Registry Member responsibilities include:

- Attend meetings on project activities where interest has been expressed. Attendance is either in-person or remotely (via Zoom).
- Participate in a consumer orientation workshop (either via The Alfred Consumer Engagement process or via ANZIC-RC CONNECT)
- Respect the opinions and experiences of all committee members
- Members are expected to maintain confidentiality.

An update meeting for the Consumer Member Registry will be held twice per year at a minimum. Attendance at meetings will only be open to registry members, but occasionally the Steering Committee is welcome to invite any interested persons. The meetings will be face-to-face where possible but will also have access for virtual attendance via Zoom (and will be recorded). Meetings will run for 60 minutes.

Location of the ANZIC-RC CONNECT:

The ANZIC-RC is based within the School of Public Health and Preventive Medicine at Monash University, Melbourne, Australia. It is a leading critical care research methods center internationally and has significant links with all major stakeholder organizations in critical care in Australia and New Zealand. The establishment of ANZIC-RC CONNECT to engage in all research activities is a critical process with high priority.

CONNECT Liaison Officer:

The role of the CONNECT Liaison Officer encompasses the following responsibilities:

- Maintenance of the Consumer Member Committee and Consumer Member Registry.
 - o Annually, the Consumer Liaison Officer will seek confirmation from the Consumer Member Committee on membership renewal.
 - o In December annually, the Consumer Liaison Officer will seek confirmation from the Consumer Members in the Registry on remaining in the list.
 - o We request that members who wish to no longer be involved inform the CONNECT Liaison Officer.
- Communicate with members and circulate any relevant documents or opportunities for engagement
- Arrange meetings and send reminders to members and follow up after meetings for feedback
- Create meeting agendas and send out meeting minutes
 - o Meeting agendas will be sent at least 48 hours prior to the meeting.
 - o Meeting minutes will be sent out within 10 days following the meeting.

- Point of contact for the CONNECT Steering Committee, Consumer Member Committee, Consumer Member Registry and ANZIC-RC Project Team.

Communication:

Email is the preferred method of contact (anzic-rc.connect@monash.edu). It is essential that confidentiality be maintained due the sensitive nature of some things which may be shared. Members must agree on joining the group that:

1. The email list will not be used to promote or endorse commercial interest in any way or personal viewpoints that are not related to the work of CONNECT and/or the ANZIC-RC
2. The information circulated is confidential and should not be shared unless otherwise specified.

Circulating content to the email list:

Any form of communication must be circulated via the CONNECT Consumer Liaison.

- Should a member (from the Steering Committee, Consumer Member Committee or Consumer Member Registry) want to circulate relevant material to all members of the group, it should be done via the CONNECT Liaison Officer who will distribute the material on behalf of the member.
- Should an ANZIC-RC Project Team member share research opportunities requiring consumer engagement from CONNECT, the CONNECT Liaison Officer will provide a document to the Project Team Member outlining specific details regarding the project prior to sharing the research opportunity to the Consumer Member Registry (Appendix B).

Consumer Engagement Recognition

As a means of recognition and appreciation for the tremendous work and contribution conducted by the CONNECT Consumer Member Committee and the Consumer Member Registry, the following are offered:

- Acknowledgement of the consumer's involvement in published works (outlined in the "Authorship Contribution by Consumers" section below).
- A formal letter of thanks from the ANZIC-RC Project Team for the consumer's involvement in the research study.
- A Certificate of Appreciation (awarded annually).
- Providing a formal reference for the consumer.

Authorship Contribution by Consumers

The ANZIC-RC CONNECT recognizes the invaluable contribution and input given by the consumers. Therefore, should a consumer play a key role in the involvement of a research study and meet the requirements of authorship as outlined in the Recommendations for the Conduct, Reporting, Editing, and Publication of Scholarly Work in Medical Journals formulated by the International Committee of Medical Journal Editors (ICMJE), it is recommended that the consumer be offered authorship of the associated manuscript. The consumer may be

involved with research study design and methodology, and tasked with sharing key findings to the wider community. Additionally, the consumer may be asked by the researcher to provide feedback, commentary and advice during the drafting of the manuscript. Where a consumer does not meet the requirements for authorship per the ICMJE guideline, it is recommended they be listed as a contributor with their role defined in the Acknowledgements section of the manuscript.

Remuneration and reimbursement

This Terms of Reference should be reviewed with the ANZIC-RC CONNECT Remuneration Guidelines. Remuneration may be provided as an honorarium payment where funding is available. It can be in the form of payment or a gift card/voucher and a range of options will be provided. There is no obligation to accept the honorarium offered. The honorarium payments are not subject to withholding tax or superannuation as there is no employer/employee between members of the Consumer Panel and the University. However, the ATO has indicated that payments may be subject to income tax in the recipient's hands where there is a connection to the recipient's income-producing activities (such as working in the health profession). We suggest that Panel members obtain their own taxation advice with regard to these payments.

Resources and training:

At commencement of the group an initial training session will be conducted for members of the ANZIC-RC CONNECT Member registry. As other opportunities arise (for example, commenting on grants, training will be provided where appropriate).

Requests for ANZIC-RC CONNECT Member registry to review or contribute to research processes:

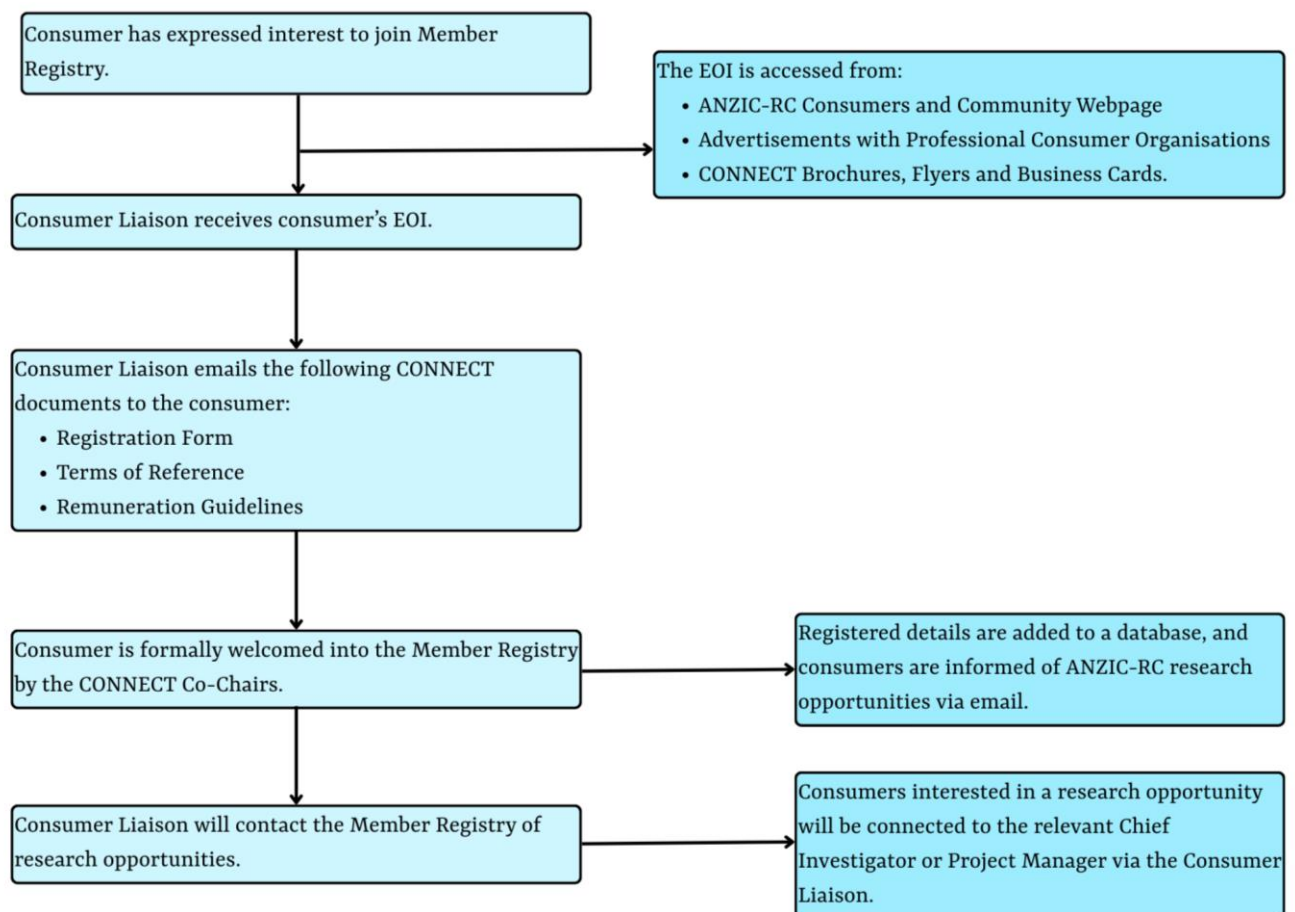
Requests for consumer input should be made in writing to the CONNECT Consumer Liaison Officer and Chair/s. Requests will be circulated to the steering committee and after review the CONNECT Consumer Liaison Officer will develop materials with the requesting researcher to be distributed or communicated i.e. EOI mail out, meeting with members of the ANZIC-RC CONNECT Member registry. It is the position of the ANZIC-RC board that any grant applications who will require ANZIC-RC CONNECT input for their project (if funded) should include appropriate reimbursement to consumers based on the level of engagement required (refer to the ANZIC-RC CONNECT Remuneration and Reimbursement Guideline V2 081123).

Next review of this document: 1st May 2026

References

- DeBortoli, E., Soyer, H. P., Milne, D., Dissanayaka, N., Gartner, C., Holt, J., Rae, K., Robison, L., Wallingford, C. K., & McInerney-Leo, A. M. (2022). Measurable outcomes of consumer engagement in health research: A scoping review. *Frontiers in Public Health*, 10, 994547.
- NHMRC. (2016). Statement on consumer and community involvement in health and medical research. Consumers Health Forum of Australia,

APPENDIX A: Onboarding Process of the CONNECT Consumers Flowchart



APPENDIX B: CONNECT Project Information Form (for ANZIC-RC Project Team)

<p>ANZIC-RC CONNECT Project Information Form</p> <p>Dear ANZIC-RC Project Team Member,</p> <p>Please fill this form to provide all information about your project and what consumer engagement input is required.</p> <p>Once this form is submitted, the Consumer Liaison and Co-Chairs will review this information. Once the review is completed, you will be notified via email and the CONNECT Terms of Reference, Remuneration Guidelines and the consumer's completed Honorary Panel Form will be provided to you. Thereafter, the Consumer Liaison will connect you to the consumer member(s) who expressed their interest.</p> <p>Please ensure you engage with the consumer accordingly as per the CONNECT Terms of Reference and Remuneration Guidelines. It is in the position of the ANZIC-RC Board that any grant application who will require CONNECT consumer input for their project (if funded) should include appropriate reimbursement to consumers based on the level of engagement outlined in the CONNECT Remuneration Guidelines.</p> <p>The name, email address and photo associated with your Google Account will be recorded when you upload files and submit this form</p> <p><small>* Indicates required question</small></p>	<p>Summarised Project Description *</p> <p>Your answer</p>
<p>Project Team Member Name *</p> <p>Your answer</p>	<p>What kind of consumer engagement do you require? Please provide a description of the activities. *</p> <p>Your answer</p>
<p>Email Address *</p> <p>Your answer</p>	<p>What kind of consumers would you require? Please outline your selection criteria. *</p> <p>Your answer</p>
<p>ANZIC-RC Project Name *</p> <p>Your answer</p>	<p>Please indicate the time commitment of the consumer. *</p> <p>Your answer</p>
	<p>How often will your team communicate with the consumer? How often will meetings be held? *</p> <p>Your answer</p>
	<p>Will the consumer be remunerated? *</p> <p>Your answer</p>
	<p>Please provide any supporting documentation about this project (such as a Terms of Reference specifying consumer input etc). *</p>

