



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

Background

Consumer engagement and involvement are essential in the development of research projects. A process to support 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, is an important step to deliver research of the highest quality and impact. This process will be overseen by a Steering Committee.

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.

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:

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 or a family member/whānau/care giver of someone who has been admitted to an intensive care unit within Australia or New Zealand.
- ICU: Intensive Care Unit
- Member registry: A group of people who have expressed interest in contributing to research activities conducted at ANZIC-RC
- Consumer Liaison Officer: Person who provides a central point of communication between members of ANZIC-RC CONNECT and the consumer registry
- Steering committee: The group of people who oversee the activities of ANZIC-RC CONNECT

Governance and structure:

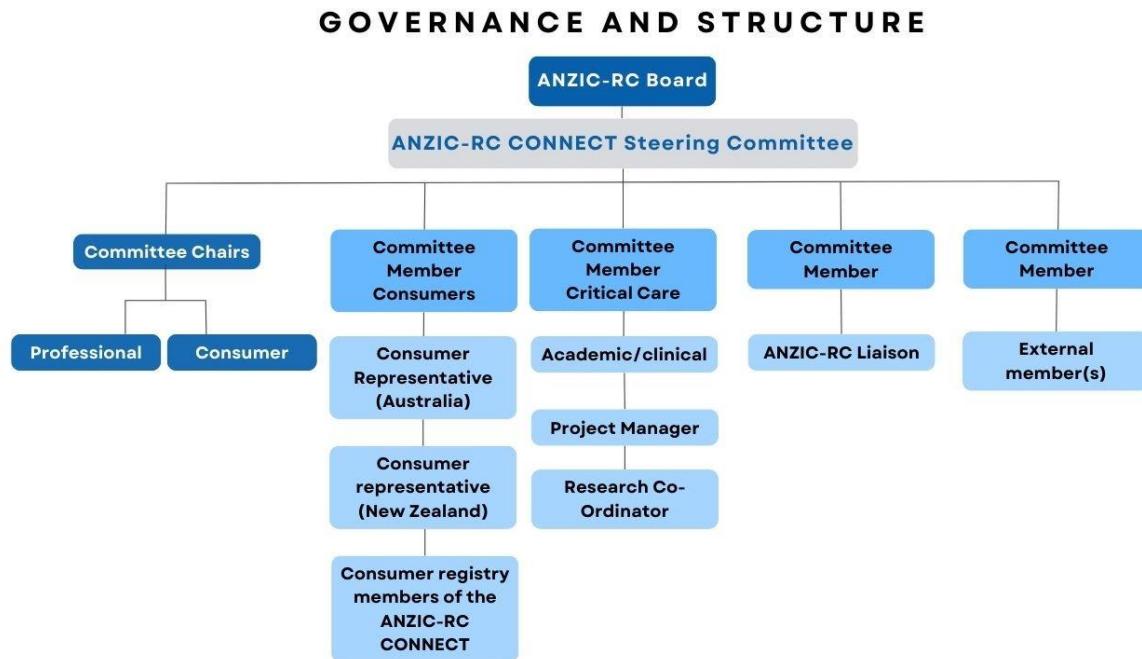
ANZIC-RC CONNECT will be overseen by a steering committee (Figure 1) which reports to the ANZIC-RC board and will include the following representatives:

- Chair (professional)
- Chair (consumer)
- Academic/clinical member(s) (1 from New Zealand)
- Consumer member(s) (1 from New Zealand, 1 from Australia)
- ANZIC-RC Project Manager representative
- ICU Research Co-ordinator
- ANZIC-RC 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 which will be 4 years to establish the committee and processes.

The steering committee will oversee 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.

Figure 1:



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.

Member registry:

Membership of the ANZIC-RC-CONNECT Member registry is limited to consumers with experience of intensive care within Australia or New Zealand.

Member responsibilities:

- Attend consumer advisory committee meetings, and 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.

ANZIC-RC CONNECT Liaison Officer:

The role of the ANZIC-RC CONNECT Liaison Officer will encompass the following responsibilities

- Maintenance of the Member Registry list

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- We request that members who wish to no longer be involved inform the ANZIC-RC CONNECT Liaison Officer
- Communicate with members and circulate any relevant documents or opportunities for engagement
- Arrange meetings
- Send reminders to members and follow up after meetings for feedback
- Create meeting agendas
- Send out meeting minutes
- Point of contact for the committee and Member Registry

Meetings:

Steering committee meetings will be held quarterly. The steering committee members will only go ahead with making decisions if we have a quorum (more than 50% of the committee).

Meetings of the wider ANZIC-RC CONNECT will be held as needed but at a minimum of twice per year. Attendance at meetings will only be open to registry members of ANZIC-RC CONNECT, but occasionally the Steering Committee is welcome to invite any interested persons. The meetings will be face-to-face where possible but also have access for virtual attendance via Zoom and will be recorded. Meetings will run for 60-90 minutes.

An agenda will be sent to members at least 48 hours before each meeting by the ANZIC-RC CONNECT Liaison Officer.

A meeting summary/minutes will be sent to committee members within 10 days after the meeting.

Communication:

Email will be the preferred method of contact. 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
2. The information circulated is confidential and should not be shared unless otherwise specified.

Circulating content to the email list:

Should a member want to circulate relevant material to all members of the group, it should be done via the ANZIC-RC CONNECT Liaison Officer who will distribute the material on behalf of the member.

Remuneration and reimbursement

This TOR document 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

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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 ANZIC-RC CONNECT Liaison Officer and Chair/s. Requests will be circulated to the steering committee and after review the ANZIC-RC CONNECT Liaison Officer will develop materials with the requesting researcher to be distributed or communicated ie. 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).