

Terms of Reference v2.0

Consumer, Carer and Community Engagement in Research (C3ER) Sub-group

CHS Consumer, Carer and Community Engagement in Research C3ER (C3ER)	
1. Purpose	The Consumer, Carer and Community Engagement in Research (C3ER) is a sub-group of the Clinical Research Management Group (CRMG). It brings lived experience of research* participation and partnerships into how Canberra Health Services (CHS) designs, governs, delivers and reports its research, including clinical trials. C3ER advises on the research participant and partnership experience. Its work covers research accessibility, informed consent, recruitment and retention, participant-facing information, feedback and complaints, and quality improvement. C3ER supports CHS to meet its obligations under the National Clinical Trials Governance Framework (NCTGF) and National Safety and Quality in Health Services (NSQHS) Standard 2 (Partnering with Consumers). *It is anticipated that C3ER will initially focus on CHS-affiliated clinical trial research in 2027, with its scope expanding to encompass all CHS research from 2028. This timing aligns with the anticipated release of the third edition of the National Safety and Quality Health Service (NSQHS) Standards in 2028.
2. Membership	Chair Director, Consumer, Carer and Community Partnerships in Research, Research Ethics and Governance Office (REGO). The Chair is responsible for: • Creating a welcoming, inclusive environment for all members and attendees • Running effective meetings, including open discussion, clear decisions and follow-up on actions • Setting the agenda for each meeting with the Deputy Chair and members, including reviewing papers before circulation • Ensuring members have timely, accurate and clear information • Summing up discussion and directing it towards a consensus view • Linking the C3ER to the CHS Partnering with Consumers and Carers Committee, and the CHS Consumer and Carer Advisory Group

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Deputy Chair*

TBC

The Deputy Chair is responsible for:

- Supporting the Chair
- Undertaking the duties of the Chair when they are absent

Ex officio members

Ex officio members attend to ensure ongoing consideration of National Clinical Trials Governance Framework (NCTGF) and accreditation requirements. They do not count towards quorum and may nominate a delegate to attend on their behalf:

- Senior Officer Grade A, Research Ethics and Governance Office, or delegate
- Quality Program Manager, Clinical Trials, or delegate

Members

The C3ER will include:

- Four consumer and carer representatives, at least two of whom have taken part in a CHS-affiliated research project
- Aboriginal and Torres Strait Islander representation, through the Aboriginal and Torres Strait Islander Wellbeing Office or a community-nominated representative
- Culturally and linguistically diverse inclusion representation (CHS staff)
- Disability and accessibility representation (CHS staff)
- Two research-active clinical or operational representatives (CHS staff)
- Research Officer, Health Care Consumers' Association (HCCA).

Members are responsible for:

- Reading papers before the meeting
- Bringing their knowledge and experience to the discussion
- Participating under a principle of equal voice, and making room for others to be heard
- Contributing to actions arising from discussions and decisions
- Sharing perspectives from their communities, networks and lived experience where applicable
- Submitting agenda items to the Secretariat at least two weeks before the meeting, for the Chair's approval

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	Proxies are accepted at the discretion of the Chair. Members brief their own proxies. Secretariat The Chair holds the secretariat function, supported by REGO. The Secretariat is responsible for: • Working with the Chair and Deputy Chair so members have timely, accurate and clear information • Scheduling meetings in advance • Circulating papers five working days before each meeting • Recording minutes and preparing a summary of outcomes for members, CRMG and the agreed communication cascade
3. Membership particulars	Recruitment • Consumer, carer and staff members will be recruited through an open expression of interest, supported by direct approaches to people with relevant experience, including former C3ER members and consumers identified by CHS clinical trial co-ordinators who have previously expressed interest. • HCCA and CHS consumer networks will help promote the expression of interest • Reimbursement will be offered to consumer and carer members in line with CHS procedures Term • The Chair of the CRMG appoints members • Members serve a two-year term, with a maximum of two consecutive terms • The Chair may invite guests to present on themes and items within the scope of the Group
4. Scope of Group	Scope and Functions The annual work program will explicitly map discussion topics and recommendations to relevant NCTGF actions and NSQHS Standard 2 requirements. In particular, C3ER provides advice on research conducted within CHS. Its functions include advising on: • Community awareness, trust and confidence in clinical research

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	• Consumer and carer involvement in research protocol review, design and development (also known as Consumer and Carer Research Partnerships / Partnering with Consumers and Carers in Research). • Participant recruitment and retention • Informed consent processes • Accessibility, inclusivity and cultural safety in research • Participant-facing information, communication and engagement • Dissemination of research findings to participants and the broader community • Participant feedback, complaints management and quality improvement processes • Evaluation of participant experience and other research quality measures • Clinical research workforce education and development informed by participant feedback and experience Membership Membership comprises individuals with lived and living experience as research participants, carers and community members. Sponsors, referring clinicians, research support services and other research stakeholders may be invited to attend meetings or contribute to discussions where relevant to specific agenda items. Such participants are not members of C3ER and do not hold standing membership.
5. Frequency of meetings and papers	• The C3ER meets for 90 minutes on the fourth Wednesday of each month, from 10:00 am to 11:30 am, excluding December and January, and more often if the Chair calls an additional meeting • Meetings are scheduled opposite the Risk Sub-Group so members can attend both • Each meeting follows a standing agenda and carries one discussion focus, covering a stage of the participant journey and the accreditation requirements for that stage • Agendas and papers will be circulated at least five working days before the meeting

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	• Meetings will be recorded for minute taking only, and recordings deleted once minutes are endorsed • Minutes will be shared with members and relevant governance groups • Decision-making will aim for consensus, with respectful consideration of differing views • Conflicts of interest will be managed under CHS policy • Consumer and carer members will receive induction and ongoing support tailored to their needs
6. Quorum	Fifty per cent of core membership plus one, including: • The Chair or Deputy Chair • Two consumer, carer or community representatives • One CHS representative other than the Chair Ex officio members and guests do not count towards quorum.
7. Reporting responsibilities	C3ER reports to the CRMG. The C3ER provides updates and reports to other governance bodies as directed by the CRMG.
8. C3ER Sub-groups	There are no formal sub-groups of C3ER. Working groups may be established as needed.
9. Authorisation and decision-making	C3ER provides its decisions to the CRMG as recommendations. The CRMG is the authorised decision-making body.
10. Changes to the Terms of Reference	The Terms of Reference will be reviewed every 12 months, or more often as required. The CRMG endorses the Terms of Reference.
11. Evaluation	The C3ER's function and impact will be reviewed annually. Evaluation criteria will include representation, relevance, influence on research processes and member satisfaction. Findings will inform changes to how C3ER works and to consumer, carer and community involvement across CHS research.