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Inclusive research practices with Culturally and Linguistically Diverse (CALD) populations

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Purpose of document:

This document guides ANZCA CTN-affiliated research teams in designing and conducting culturally inclusive and accessible clinical research. It offers practical strategies to support meaningful participation of Culturally and Linguistically Diverse (CALD) communities, informed by expert advice, community input, and national recommendations.

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Version	Contributors	Reviewed/Approved	Date Approved by ARCN Sub-Committee & CTN Executive	Changes
1.0	Anna Parker Dr Tuong Phan Gillian Ormond Karen Goulding	Tracy Hess Samantha Ryan A/Prof Stefan Dieleman	1/8/25	Creation

Inclusive research practices with Culturally and Linguistically Diverse (CALD) populations

This document is based on the CTN educational session: "The challenge and necessity of enrolling from CALD populations" by Ms Anna Parker and Dr Tuong Phan and updated in 2025 with recommendations from the Federation of Ethnic Communities Councils of Australia (FECCA).

1. Purpose and scope

This document helps ANZCA CTN-affiliated research teams design and conduct culturally safe, inclusive, and accessible trials that are representative of Australia and New Zealand's population diversity. It is based on many years of experience with research and consumer engagement, addressing both systemic underrepresentation and the practical hurdles to engaging CALD participants.

2. Why CALD inclusion matters

- Equity: ensures all patient groups benefit from and contribute to research.
- Generalisability: research findings are valid across diverse populations.
- Health outcomes: addresses disparities in access to cutting-edge treatments.
- Policy alignment: supports national and state goals (e.g. Victorian Cancer Plan).

3. Barriers to CALD participation in research

- Language barriers (low English proficiency; lack of interpreters or translated materials).
- Cultural norms (family- or community-based decision making; mistrust of formal documentation).
- Health literacy (low awareness of research processes, rights, and ethics).
- Staff assumptions (e.g., assuming recruitment will be "too hard" or take too long).
- Limited research engagement (researchers not having necessary cultural competence or strategies to engage with CALD communities).

4. Key principles for inclusive research

- Respect cultural preferences and family-based decision-making.
- Simplify complex trial language and consent forms.
- Localise resources based on community demographics.
- Engage with CALD communities proactively—not only at recruitment.
- Collaborate with linguists, clinicians, and community champions.
- Create a safe research environment where participants feel secure and valued.

5. Practical strategies for CALD inclusion

a. Design phase

- Choose outcome measures that do not depend on language (e.g., days alive out of hospital vs. Hospital Utilisation and Resource Allocation System (HURAS)).
- Budget for translation and cultural tailoring of study materials such as Patient Information and Consent Forms (PICFs).
- Plan for verbal consent or alternate models where culturally appropriate.

b. Recruitment

- Provide translated resources early (pre-admission clinics, outpatient areas).
- Share translated videos or show in pre-admission settings.
- Consider phone/video calls to walk through materials with interpreters or bilingual staff.

c. Consent process

- Offer verbal consent (especially if written signatures are culturally sensitive) (ensure ethics approval for this is obtained).
- Include interpreters and allow family involvement.
- Use plain language aligned with health literacy principles.

d. Follow-up and retention

- Maintain contact with participants via preferred communication methods.
- Offer translated outcome measures (e.g., World Health Organisation (WHO) surveys validated in multiple languages).

6. Tools and resources

a. CALD research videos

Short videos explaining the research process are now available in:

- English
- Italian
- Vietnamese
- Mandarin
- Greek (in production)

These are based on Part A of the National Participant Information and Consent Form and are designed to be:

- Shared via email or SMS.
- Played in clinics or waiting rooms.
- Used alongside interpreters for information sessions.

b. Awareness posters and TV displays

Sites are encouraged to promote research participation using:

- Research posters in multiple languages.
- Screens in pre-admission clinics.
- Flyers or QR codes linking to videos.

c. Stakeholder collaboration

- Partner with departments of linguistics, multicultural health units, and local CALD leaders.
- Co-design resources with community feedback.

7. Ethical considerations

- Align inclusivity with national statements on research ethics.
- Ensure that CALD patients are not excluded due to operational constraints.
- Consent models (written, verbal) should be clearly discussed with the Human Research Ethics Committee (HREC) and tailored per population group.

8. Funding and trial design considerations

- Justify inclusive design in grant applications.
- Seek supplementary funding for translation, video production, and interpreter costs.
- Build CALD considerations into endpoint selection (e.g., use validated multilingual Patient Reported Outcome Measures (PROMs) where relevant).

9. Cultural sensitivity beyond language

- Language is only one barrier; mistrust of systems, previous experiences, or misunderstanding of the role of research can deter participation. Consider alternative consent documentation methods (ensure ethics approval for this).
- Deliver resources in context—not just as a link, but in-person where possible.
- CALD-focused trials should consider co-design with community groups and trial coordinators who reflect the population.

10. Future directions and local implementation

- Encourage local champions (clinical staff, bilingual researchers, or community workers) to tailor efforts per region. Explore Aboriginal and Torres Strait Islander research partnerships.
- Use terms like "clinical research" or "medical research" over "clinical trials" where appropriate. The term "trial" may feel cold or intimidating.
- Frame research as part of routine care and quality improvement to improve uptake, not experimentation.
- Work with ethnic community organisations (e.g. FECCA) to distribute materials.

11. National Recommendations for Inclusive Research (FECCA, 2024)

In 2024, FECCA publicly called for a national reform of health and medical research practices to prioritise CALD inclusion. Their recommendations stress the importance of cultural safety, shared governance with community leaders, and adequate resourcing to overcome structural barriers. These align closely with ANZCA CTN's commitment to ethical and equitable research practices and underscore the need for broader integration of CALD-inclusive strategies in study design, funding applications, and implementation phases.

Key recommendations include:

1. Mandate CALD representation in research design

- Research funding bodies should require evidence of CALD-inclusive design from inception.
- This includes cultural risk assessments, not just language translations.

2. Engage CALD consumers in governance

- Research advisory panels should include multicultural health experts or community representatives.
- Co-design should move beyond consultation and into shared decision-making.

3. Prioritise cultural safety

- Researchers must be trained in cultural humility and unconscious bias, especially when interacting with vulnerable groups.
- Ensure consent processes are trauma-informed and context-aware: Approach consent with sensitivity to participants' past experiences and current circumstances. Use clear, respectful language, promote a sense of safety and choice, and adapt communication to the cultural, emotional, and environmental context of each individual.

4. Resource CALD participation

- Projects must budget for interpreters, translations, outreach, and follow-up in appropriate languages and formats.
- Emphasise multimodal communication (videos, graphics, community champions).

5. Integrate research with service delivery

- Clinical trials and research must be presented as part of routine care to avoid perceptions of experimentation.
- CALD engagement should happen early and often—not just at the point of consent.

These recommendations reinforce ANZCA CTN's commitment to equitable, representative, and community-informed research.

12. Conclusion

Culturally inclusive research improves not only the representativeness of data but the ethical standing and social value of our clinical studies. By embedding CALD engagement strategies early in research planning, ANZCA CTN sites can help lead a more inclusive, equitable research culture across Australia and New Zealand.