

Ethical considerations for research with CALD Populations and Vulnerable Groups

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Overview

- Planning
- Collaboration and partners
- Ethics
- Logistics
- Resources

Planning:

Should I be including CALD populations?

- Relevant evidence
- Prevalence of the condition in that community
- What's in it for me???
- Support networks – bilingual staff
- Outcome Measures and Tools – what already exists? Be practical
- Be aware that consenting will take time
- Be creative
- Apply for funding (Factor the costs for interpreters and translation)

Partnerships: Collaboration with the community

- Include consumer in the planning stage
- Local community leaders
- NGO
- Consumer and Community Participation Council
- Health consumers NSW website <http://www.hcnsw.org.au/>
- NSW Multicultural Health Communication Service
<https://www.mhcs.health.nsw.gov.au/>

Partnerships: Multicultural Health / Health Promotion Service / Refugee Health / STARTTS

- Link with district wide organisations
- Consultation or advice on:
 - Communication strategies
 - Implementation of strategies in communities
 - Networking opportunities
 - Issues of importance on prevention, population health, refugee health
- Consultation and engagement critical in the early planning phase to support feasibility and design considerations

Partnerships:

Multicultural Health / Health Promotion Service / Refugee Health / STARTTS

Contacts:

- Health Promotion Service:
https://www.swslhd.health.nsw.gov.au/populationhealth/PH_Promotion/default.html
Mandy Williams - Director Health Promotion Service / Phone: 02 8738 5910
Email: mandy.williams@sswahs.nsw.gov.au
- Multicultural Health: Balwinder Sidhu: Deputy Director Multicultural Health Strategy & Equity/ Balwinder.Sidhu@health.nsw.gov.au
- SWSLHD Refugee Health Service:
<https://www.swslhd.health.nsw.gov.au/refugee/contact.html> / SWSLHD-RefugeeHealth@health.nsw.gov.au
- STARTTS: <https://www.startts.org.au/research/> Email: STTS-Research@health.nsw.gov.au

Partnerships:

SWSLHD Health Language Services

- Health Language Services (HLS) is a 24-hour multilingual and sign interpreter service.
- SWSLHD HREC recommends speaking with Language Services before submitting the Ethics Application to obtain specified advice. There may be a need for fees depending on the level of involvement of the interpreters for the project.
- Contact: Director, Katina Varelis - Phone 8738 6801
- e-mail (non-urgent only): Interpreters.Bookings@sswahs.nsw.gov.au
- <https://www.swslhd.health.nsw.gov.au/services/Interpreter/>

Ethical Considerations – National Statement

- **Respect** for human beings is a recognition of their intrinsic value. In human research, this recognition includes abiding by the values of **research merit and integrity, justice and beneficence**. Respect also requires having due regard for the welfare, beliefs, perceptions, customs and cultural heritage, both individual and collective, of those involved in research.
- Researchers and their institutions should **respect the privacy, confidentiality and cultural sensitivities** of the participants and, where relevant, of their communities.
- Any specific **agreements** made with the participants or the community **should be fulfilled**.
- **Consent**: using tools and language that are **appropriate, respectful and relevant** to the research design, objectives, potential participants and context, including relevant cultural sensibilities.
- **Data**: Data and information may be of cultural, historical or other significance such that they should be **retained** beyond the minimum retention period. Disposing of these data or information without consideration of these factors violates the ethical principle of respect. These matters should be appropriately addressed in the research plan and in consent processes and documentation.

The Application: Addressing the ethics

- Ongoing engagement
- Tools and literacy of population
- Recruitment and consenting
 - Describe - Who How and When
 - Needs to address the power relationships
 - NAATI certified interpreters required
 - NAATI certification for translated documents. Translation certificates are required to be submitted to the Ethics Committee. This can be done via Amendment after the English Master versions have been approved by the Ethics Committee.
- Ethical considerations such as cultural factors e.g. respect, religion, values, beliefs, understanding of the research, minimizing distress and increasing trust with participants
- Feedback at end of research (improve research participation)
- Have your draft protocol reviewed by the Ethics Office

Ethical Considerations: Consent

- Translation of study documents for participants who speak a language other than English
 - NAATI accredited translator
 - Translation certificate provided to the ethics office
 - <https://www.swslhd.health.nsw.gov.au/services/Interpreter/translation.html>
- Interpreter requirement:
 - Project and consent discussions should take place with the participation of an accredited interpreter who will countersign the consent document to confirm

Where it is not feasible to translate a PISCF (due to practical, resources, time or literacy concerns), more detailed discussion between the participant, carer/family and research team needs to occur with an accredited interpreter

Use of informal interpreter – Family or staff members who do not have a role on the project are not appropriate for research processes.

PIS and Consent Form

- Make it simple
- Use pictures
- Add link to a website if required
- Use lay language
- Language is culturally respectful and easily understood
- Review for readability (year 6-7)
- Reviewed by a bilingual worker/relevant consumer from the cultural background being recruited to.

Project Implementation: Logistics

- Allow time for translations
- Allow time for booking of Interpreters – time and processes
- Be patient
- Look for efficiencies
- Address confidentiality and privacy concerns
- Address possible negative perceptions towards
 - Participating in research
 - Discuss with family
 - Signing a consent form

Other resources

- **Ingham Institute (Videos and research papers)**
<https://www.inghaminstitute.org.au/resource/the-importance-of-involving-diverse-populations-in-research/#>
- **Link to NHMRC statement and section for vulnerable populations**
<https://www.nhmrc.gov.au/book/section-4-ethical-considerations-specific-participants>
- **Cochrane guide to working with Consumers**
<https://www.youtube.com/watch?v=d-xnPWt98KU>
- **Multilingual Mental Health Assessment Tools**
<https://www.dhi.health.nsw.gov.au/transcultural-mental-health-centre-tmhc/health-professionals/cross-cultural-mental-health-care-a-resource-kit-for-gps-and-health-professionals/multilingual-assessment-tools>

Questions

