

Aboriginal Health & Research Ethics Committee

The Aboriginal Health Research & Ethics Committee (AHREC) promotes and supports quality research which will benefit Aboriginal people.

The Committee was established in 1986, following concerns by the then Aboriginal Health Organisation of South Australia, about the increasing number of research proposals and research being conducted in Aboriginal communities in South Australia.

Its objective is to monitor and coordinate medical and health research in Aboriginal communities in South Australia, to offer advice to communities on the ethics, methodology and potential benefits of research proposals and to review research needs of Aboriginal communities in order to determine priorities for research.

Proposals to conduct health-related research involving Aboriginal people or communities in South Australia need to be submitted to the AHREC even if approval has been or will be obtained from the researcher's institution. The AHREC is recognised by the National Health and Medical Research Council as a Research Ethics Committee.

For further information contact Senior Research & Ethics Officer on telephone (08) 8132 6700 or alwin.chong@ahcsa.org.au

Function

The Aboriginal Health & Research Ethics Committee exists to:

- To review research needs of the Aboriginal community in conjunction with community controlled health services in order to determine priorities for research.
- To assess research proposals submitted by individuals and organisations in order to determine their appropriateness and benefit to the Aboriginal community.
- To assist in the organisation and implementation of research projects in the Aboriginal community.

Research Checklist

The following checklist has been adapted by the AHREC from the National Health and Medical Research Council's (NH&MRC) publication Guidelines on Ethical Matters in Aboriginal & Torres Strait Islander Health Research (March 1991), and the inaugural bulletin of the Aboriginal Health Research Ethics Committee of SA (1989). Please consult the NH&MRC publication for further details as this is not an exhaustive coverage of the issues, tel: 1800 658 616 or <http://www.health.gov.au/nhmrc/index.htm>

Consultation

- Appropriate literature searches have been/will be completed. (Libraries are available in several Aboriginal organisations as well as the Department of Human Services).
- Advice has been, or will be sought, from State/Federal/local Aboriginal agencies (especially community controlled health service, wherever appropriate, and the AHREC) prior to the design of the project proposal.
- The appropriate approval has been, or will be, obtained from Aboriginal agencies with regard to both the usefulness of the proposed research, and the sensitivity to the political and cultural situation of the community(ies) concerned, prior to any detailed discussions about research methods or ethical considerations.

- Wherever possible, written consent should be obtained from both individual participants or subjects and the relevant community elders and/or leaders and/or community-recognised spokespersons.
- Informed Consent must be based upon a clear simply worded but comprehensive Information Statement given to each participant or expressed in a medium that will be clearly understood by participants.

Community Involvement & Particular Local, Cultural Considerations

- Ideally your project should evolve from a collaborative approach to project design with at least one Aboriginal group/organisation. Questions to consider include: has the relevant community received an offer of involvement in the conduct of the research? At what level? (eg co-investigator, research officer, project officer, or research assistant). It should also be noted that this necessitates budgeting to take account of appropriate payment for any assistance.
- Any particular cultural and social needs should be taken into account in the research design and methodology. This includes awareness of the relevant workloads of existing staff that may become involved in aspects of this research. Talking to Aboriginal organisations is vital to preliminary discussions on all such issues rather than reliance on text books on Aboriginal people or health.
- Community resources used in the conduct of research should be appropriately costed and a process for reimbursement needs to be identified in the research application.
- The Researchers must recognise the community's right to further information, and accept that changes to procedures or methods require further negotiations and consent. (The AHREC may also need to be approached for approval if any changes are proposed).

Sample Storage & Destruction

This is a particularly sensitive matter, which should be discussed with the AHREC prior to forming your proposal. Further permission will need to be obtained if personal information or blood or tissue samples are to be used for purposes other than those detailed in the application. Agreement must be reached concerning details pertaining to the return of identifiable raw data or sample(s), and secure storage. This agreement will probably need to be in writing such as in the form of a research contract.

Ownership of Data & Reporting Results

- Prior to any publication or presentation of research findings, they should be confidentially conveyed to participants (with counselling when appropriate) and a 'Summary of Findings' should be reported to the whole community through appropriate community agencies in whatever form they deem appropriate.
- Results must not be published revealing any participant's identity or any community without written permission.
- Pictorial material must only be created, produced or used with consent and must be handled in accordance with the community's wishes.
- Aboriginal assistants or contributors should, wherever practical, be involved in preparation of publications and should be acknowledged (in accordance with NH&MRC Statement of Scientific Practice).
- Co-authorship of publications with Aboriginal people should be arranged wherever appropriate.

Principles

The rights of individual patients or subjects or participants take precedence over the expected benefits to human knowledge, academic institutions or the wider community.

Only Research deemed to benefit the (relevant) Aboriginal community will be supported.

Approval & Application Form

Formal, written recommendation to conduct health related research with Aboriginal people is required from the AHREC prior to any such research in South Australia, even if ethical approval has already been obtained from other sources.

Proposals are itemised to the AHREC agenda on receipt and will not be dealt with until future meetings. The recommendation, however, remains subject to the final decision of the particular Aboriginal community(ies) involved.

Researchers should realise that many communities are quite small and feel that too much research has been going on and that it rarely seems to make a difference to their lives. Community leaders are often busy or short-staffed and poorly resourced. All research plans, therefore, must be progressed with a great deal of sensitivity and a willingness to listen and to work with communities at their pace.

Researchers should talk to key statewide Aboriginal organisations (including AHCSA) before approaching community members or leaders.

An Application Form is available on www.ahcsa.org.au

Meeting Dates

The AHREC meets on the first Thursday of every month except January. Meetings are held in the AHCSA Boardroom, 78 Fullarton Road, Norwood SA 5067 and commence at 5.30pm.

Research Proposals must be submitted at least seven days prior to the next meeting to be itemised on the agenda.