

AMSANT Aboriginal Health Research Policy

Draft - June 2008

1. Preamble

AMSANT recognises the important role that research can play in achieving evidence-based improvement in Aboriginal health and health service delivery. As the peak body for Aboriginal community-controlled health services in the NT, AMSANT has a role in helping to facilitate effective and appropriate Aboriginal health research, particularly through the provision of advice and assistance to our members with respect to health research proposals.

2. Aims of this policy

The aims of this research policy are:

- a) To ensure that Aboriginal health research that AMSANT engages with is conducted according to appropriate principles, standards and processes; and that it provides maximum benefit to, and control by, Aboriginal people.
- b) To provide a set of protocols and processes to enable AMSANT to respond to requests for endorsement of, and/or participation and collaboration in, health research proposals.
- c) To outline AMSANT's role in providing information, advice and assistance to AMSANT members and affiliates with respect to health research proposals involving Aboriginal communities.

3. Principles

This policy is guided by the following principles:

Consent: Consultation, negotiation and free, prior and informed consent are the foundations of research with or about Aboriginal peoples.

Participation: Research should, to the maximum extent possible, include the involvement of the relevant Aboriginal communities, organisations and individuals in its design, execution, monitoring and evaluation.

Authority: Aboriginal community-controlled health service boards are the appropriate authorities and decision-makers in relation to determining the priorities and nature of health research and its control and coordination within the context of Aboriginal communities.

Research transfer: Research projects must include in their design and implementation, effective strategies for the transfer of knowledge and information related to the research to Aboriginal communities as well as to health services, governments and others who may use it. (See Section 9 for link to further information).

Cultural security: Health research must be culturally intelligible to Aboriginal people and must not compromise or endanger their legitimate cultural rights, values and expectations.

Cultural safety: The conduct of research must provide an environment which is spiritually, socially, emotionally and physically safe for people; where there is no assault, challenge or denial of their identity, of who they are and what they need.

Intellectual and cultural property rights: Researchers must respect the intellectual and cultural property rights of Aboriginal peoples in relation to knowledge, ideas, cultural

expressions and cultural materials and ensure that culturally-restricted and culturally-sensitive information is protected from inappropriate use or publication.

Ethical approval: Research proposals must obtain the approval of the relevant formal Ethics Committee/s.

Data management: The collection, use and storage of data related to health research must comply with the National Aboriginal and Torres Strait Islander Health Data Principles¹.

4. Research approvals scenarios

This policy addresses the following scenarios for requests regarding health research projects:

- a) External research concept or proposal where AMSANT and/or member/affiliate (i) endorsement; (ii) comment prior to development of the proposal; (iii) involvement in developing the proposal; or (iv) participation in carrying out the research, is sought.
- b) External research project where AMSANT assistance is sought to develop a research transfer proposal for completed external research findings;
- c) External researcher/s seeking access to Aboriginal opinion on existing research and/or authors;
- d) Internal research concept proposed by AMSANT.

5. Assessing health research proposals

In assessing or providing advice on the merits of a health research project proposal, AMSANT will give consideration to the following issues. The research proponents will be asked to respond in writing to these issues/questions using the pro-forma (attached), or, where agreed, in a verbal or other written form.

1. Have Aboriginal people been involved, or will they be involved, in the design, implementation, monitoring and evaluation of the project? Please provide details.
2. (a) What is the project's anticipated impact on health services and communities? (b) Is the project compatible with other projects/work of the health service/s? (c) Will the project cause disruption to the health service/s and/or community?
3. (a) What are the short and long-term benefits for Aboriginal people and health services? (b) Has the project evaluated and documented the likely health benefits of the research? (c) Will the project contribute to capacity building of the health service/s and community? (d) Does the project provide opportunities for the employment and training of Aboriginal people?
4. (a) Has the project considered the costs and expenses of the research for the health service/s and community members and has provision been made for reimbursement? (b) Does the project provide for reimbursement for community members acting as facilitators, informants and interpreters for their skills, time and expenses?
5. (a) Is the research methodology appropriate and does it adequately address the issues of cultural security and cultural safety? (b) Are there other specific aspects of the research which require special consideration? For example, does the project involve the collection of blood and tissue samples and have the relevant ethical and consent issues been addressed?

¹ http://www.aihw.gov.au/committees/nagatsihid/nagatsihid_data_principles.doc

6. Have community and individual consent issues been addressed? Please provide details.
7. Has the project received approval from the relevant formal Ethics Committee? Please provide details.
8. Has the project produced a comprehensive research transfer strategy (see under ‘Principles’), including providing feedback and access to research results? Please provide details.
9. Has the project addressed the issues of intellectual and cultural property rights? Please provide details.
10. How does the project comply with appropriate data management principles?
11. Does the project include adequate processes for the monitoring and evaluation of the research? Please provide details.
12. Is the time frame of the research achievable and appropriate?
13. Does the research project require a formal agreement or MOU with the relevant health service/s or AMSANT?

6. AMSANT protocols with respect to members/affiliates

AMSANT will adhere to the following protocols with respect to providing information, advice and assistance to members/affiliates on health research proposals:

- a) Upon receiving a request involving a health research proposal pertaining to a particular community or communities, AMSANT will advise the proponent to forward the request to the relevant member/affiliate health service/s.
- b) AMSANT will endeavour to provide in a timely manner, advice to the relevant member/affiliate health service/s on the compliance of the research proposal with respect to the criteria and issues detailed in Section 5.
- c) AMSANT will endeavour to provide assistance to members/affiliates, where requested, to help enable the members/affiliates to participate in or engage with, a health research project.
- d) AMSANT’s endorsement of research does not in any way bind its members or affiliates. Members and affiliates are free to refuse to endorse or engage with research projects as they see fit.

7. AMSANT internal processes with respect to research proposals

- a) External requests involving health research will be forwarded for consideration to AMSANT’s Public Health Advisory Group (PHAG).
- b) Where necessary in the opinion of the EO or PHAG, research proposals will be referred through the EO to the AMSANT Board for further consideration.
- c) Research proposals will be assessed by relevant staff using the criteria outlined in Section 5 and the results forwarded to the EO who will engage the Board or other parties as relevant.

8. Research contracts, agreements and MOUs

Where considered necessary a research contract/agreement/MOU should be drawn up prior to the commencement of the research. Such documents should include:

- a) The obligations of each of the parties, including with respect to communication, participation, consent, research methodology, monetary and in-kind costs and employment and training.
- b) Details relating to principles of data ownership and management, intellectual property, art copyright, publications, including conference presentations, cultural security and cultural safety, and research transfer.
- c) The views of the relevant Ethics Committee/s should be taken into account.
- d) AMSANT and/or health service boards which are parties to the document should retain the right to request modifications to the proposal, request more detail, refuse the right of publication and/or request regular reports on work in progress.
- e) Conference papers and material for publication should be reviewed and approved by AMSANT and/or health service boards or person nominated by them before presentation, publication or submitting as a thesis. Papers, reports, theses, etc. must appropriately acknowledge the health service in a manner acceptable to the health service board.

9. Resources and further information

Guidelines and Principles

Approach to Research – CRCAH website:

<http://www.crcah.org.au/research/approachtoresearch.html>

Research Transfer – CRCAH website:

<http://www.crcah.org.au/research/researchtransfer.html>

Guideline for Ethical Research in Indigenous Studies – AIATSIS (2000):

http://www.aiatsis.gov.au/_data/assets/pdf_file/2290/ethics_guidelines.pdf

Keeping Research on Track – A Guide for Aboriginal and Torres Strait Islander peoples about health research ethics – NHMRC (2006):

<http://www.nhmrc.gov.au/publications/synopses/e65syn.htm>

Values and Ethics - Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research – NHMRC (2003):

<http://www.nhmrc.gov.au/publications/synopses/e52syn.htm>

National Statement on Ethical Conduct in Human Research – NHMRC (2007) – Ch 4.7:

http://www.nhmrc.gov.au/publications/2007_humans/section4.7.htm

National Aboriginal and Torres Strait Islander Health Data Principles – AHMRC (2006):

http://www.aihw.gov.au/committees/nagatsihid/nagatsihid_data_principles.doc

Ethics Committees

(Information on ethics committees can be found at <http://www.menzies.edu.au>)

The Human Research Ethics Committee of NT Department of Health and Community Services and Menzies School of Health Research. Considers applications for research in the Top End of the Northern Territory. Email: ethics@menzies.edu.au

Central Australian Human Research Ethics Committee. Considers applications for research in Central Australia. Email: cahrec@nt.gov.au

AMSANT Pro-Forma for Assessing Health Research Proposals
 (Please see *AMSANT Aboriginal Health Research Policy* for further information)

Question	Response (Applicant to provide details)	OFFICE USE ONLY Response OK?: y / n Comment / further action
1. Have Aboriginal people been involved, or will they be involved, in the design, implementation, monitoring and evaluation of the project? Please provide details.		
2. (a) What is the project's anticipated impact on health services and communities? (b) Is the project compatible with other projects/work of the health service/s? (c) Will the project cause disruption to the health service/s and/or community?		
3. (a) What are the short and long-term benefits for Aboriginal people and health services? (b) Has the project evaluated and documented the likely health benefits of the research? (c) Will the project contribute to capacity building of the health service/s and community? (d) Does the project provide opportunities for the employment and training of Aboriginal people?		
4. (a) Has the project considered the costs and expenses of the research for the health service/s and community members and has provision been made for reimbursement? (b) Does the project provide for reimbursement for community members acting as facilitators, informants and interpreters for their skills, time and expenses?		
5. (a) Is the research methodology appropriate and does it adequately address the issues of cultural security and cultural safety? (b) Are there other specific		

aspects of the research which require special consideration? For example, does the project involve the collection of blood and tissue samples and have the relevant ethical and consent issues been addressed?		
6. Have community and individual consent issues been addressed? Please provide details.		
7. Has the project received approval from the relevant formal Ethics Committee? Please provide details.		
8. Has the project produced a comprehensive research transfer strategy (see Section 3 'Principles'), including providing feedback and access to research results? Please provide details.		
9. Has the project addressed the issues of intellectual and cultural property rights? Please provide details.		
10. How does the project comply with appropriate data management principles?		
11. Does the project include adequate processes for the monitoring and evaluation of the research? Please provide details.		
12. Is the time frame of the research achievable and appropriate?		
13. Does the research project require a formal agreement or MOU with the relevant health service/s or AMSANT?		