



**Adopted: October 2009**

**Review: September 2011**

## **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 NT based formal Ethics Committee/s<sup>1</sup>.

*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 Principles<sup>2</sup>.

#### **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.

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<sup>1</sup> The NHMRC has introduced a new policy (Harmonization of MultiCentre Ethical Review) which will mean that research based in multiple jurisdictions may only have to obtain ethics review in one state. AMSANT believes that Aboriginal primary health research conducted in the NT should be reviewed by a NT based ethics committee (either the Top End and/ or the Central Australian ethics committee) given that these NT committees have local knowledge and experience which will inform their decisions. AMSANT will only consider research for review if it is or will be submitted to a NT based ethics committee. AMSANT also suggests that ACCHSs consider that one of their criteria for participation in a research proposal should be that it has been reviewed by a NT ethics committee

<sup>2</sup> [http://www.aihw.gov.au/committees/nagatsihid/nagatsihid\\_data\\_principles.doc](http://www.aihw.gov.au/committees/nagatsihid/nagatsihid_data_principles.doc)



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- 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 (a) design, (b) implementation, and (c) 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. What are the risks of the project to Aboriginal people and health services?
5. (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?
6. (a) Is the research methodology appropriate? (b) Does it adequately address the issues of cultural security and cultural safety? (c) 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?



7. Have community and individual consent issues been addressed? Please provide details.
8. Has the project received approval from the relevant NT based formal Ethics Committee? Please provide details. (NB multi site research projects may not need to seek approval from a NT based committee. However, AMSANT will request that local ethical review occurs).
9. Has the project produced a comprehensive research transfer strategy (see under 'Principles'), including providing feedback and access to research results? Please provide details.
10. Has the project addressed the issues of intellectual and cultural property rights? Please provide details.
11. How does the project comply with appropriate data management principles?
12. Does the project include adequate processes for the monitoring and evaluation of the research? Please provide details.
13. Is the time frame of the research achievable and appropriate?
14. Does the research project require a formal agreement or MOU with the relevant health service/s or AMSANT?

It is important that researchers provide information to AMSANT in a timely manner so that this process can be undertaken. If the timelines are short ( e.g less than 7 weeks ) , AMSANT may not be able to assess the research proposal.

**6. Additional criteria when a request is made for AMSANT to be a partner in a research proposal.**

AMSANT is frequently asked to be a partner in research proposals. For AMSANT to be fully engaged in a partnership arrangement , the following criteria would need to be satisfied

- a) AMSANT is able to negotiate the level of involvement in the research process and is considered an equal with other partners.
- b) AMSANT has been involved in the development of the research proposal in a meaningful way from an early stage and the contribution of AMSANT

is acknowledged in the research submission and other material produced from the research partnership ( peer reviewed papers, conference presentations, government reports etc).

- c) There are opportunities for appropriate people within the membership and secretariat of AMSANT to be involved in the research team including being investigators in the project. This will ensure that the research team includes people with direct links to the sector and appropriate primary health care expertise.
- d) There are mechanisms identified in the proposal to provide capacity for AMSANT and ACCHSs to engage in the research at each stage of the process and increase the skill base within their organizations . This should include the identification of resources that will support the community controlled sector.
- e) There is an agreed plan for dissemination of results back to ACCHSs and communities.
- f) AMSANT is involved in decisions about seeking funding from government sources in research partnerships. This will prevent AMSANT being involved in partnerships where researchers are in direct competition with the community controlled sector for funds directed towards service support and primary health care delivery.

## **7. 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) At the same time, 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.



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- 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.



## **8. 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.

## **9. 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>



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*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](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](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](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](mailto:ethics@menzies.edu.au)

*Central Australian Human Research Ethics Committee.* Considers applications for research in Central Australia. Email: [cahrec@nt.gov.au](mailto:cahrec@nt.gov.au)



**AMSANT Pro-Forma for Assessing Health Research Proposals**

(See *AMSANT Aboriginal Health Research Policy* for further information)

**Instructions**

This Pro-forma is to be filled out by organisations or individuals seeking support, feedback or engagement with respect to health research projects involving Aboriginal communities in the Northern Territory.

A completed pro-forma together with a covering letter outlining the purpose and nature of the request should be forwarded to AMSANT’s Executive Officer at:

Post: The Executive Officer      Fax: (08) 89814825      Email: John.Paterson@amsant.org.au  
AMSANT  
GPO Box 1624  
Darwin NT 0801

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 a) design, b) implementation, and c) 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?		



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<p>3. (a) What are the short and long-term benefits for Aboriginal people and health services?</p> <p>(b) Has the project evaluated and documented the likely health benefits of the research?</p> <p>(c) Will the project contribute to capacity building of the health service/s and community?</p> <p>(d) Does the project provide opportunities for the employment and training of Aboriginal people?</p>		
<p>4. What are the risks of the project to Aboriginal people and health services?</p>		
<p>5. (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?</p> <p>(b) Does the project provide for reimbursement for community members acting as facilitators, informants and interpreters for their skills, time and expenses?</p>		
<p>6. (a) Is the research methodology appropriate?</p> <p>(b) Does it adequately address the issues of cultural security and cultural safety?</p> <p>(c) 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?</p>		
<p>7. Have community and individual consent issues been addressed? Please provide details.</p>		



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<p>8. Has the project received approval from the relevant formal Ethics Committee? Please provide details.</p>		
<p>9. Has the project produced a comprehensive research transfer strategy (see Section 3 'Principles'), including providing feedback and access to research results? Please provide details.</p>		
<p>10. Has the project addressed the issues of intellectual and cultural property rights? Please provide details.</p>		
<p>11. How does the project comply with appropriate data management principles?</p>		
<p>12. Does the project include adequate processes for the monitoring and evaluation of the research? Please provide details.</p>		
<p>13. Is the time frame of the research achievable and appropriate?</p>		
<p>14. Does the research project require a formal agreement or MOU with the relevant health service/s or AMSANT?</p>		
<p>15. Which Aboriginal Medical Services have you, or will you be, approaching with respect to the research?</p>		