

SAAP Ethical Research Protocols

Coordination and Development Committee

Supported Accommodation Assistance Program

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Electronic copy of this document can be found at:

http://www.facsia.gov.au/internet/facsinternet.nsf/aboutfacs/programs/house-newsaap_research.htm

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CONTENTS

Glossary	4
1. Introduction	5
2. The SAAP Ethical Research Protocols	5
2.1 Research Categories.....	6
2.1.1 Research not subject to SAAP Ethical Research Review	6
2.1.2 Research subject to SAAP Ethical Research Review	6
Ethical Research Flowchart.....	7
3. SAAP Ethical Research Guidelines	8
3.1 Application	8
3.2 SAAP Ethical Principles and Guidelines.....	8
3.2.1 General Key Principles	8
3.2.2 Integrity, respect for persons, beneficence and justice	9
3.2.3 Informed Consent.....	9
3.2.4 Ethical review and conduct of research	10
3.3 Compliance with SAAP Ethical Research Protocols and Guidelines	10
3.3.1 Responsibilities of researchers carrying out research.....	10
4. Responsibilities of SAAP CAD and ISC research administrators.....	12
(SAAP research administrators)	12
5. Date of Implementation.....	12

Glossary

Australian Health Ethics Committee (AHEC): a principal committee of the National Health and Medical Research Council (NHMRC) established under the NHMRC Act 1992. The AHEC advises the NHMRC on ethical issues relating to health and develops guidelines for the conduct of medical research involving humans. The AHEC also assists Human Research Ethics Committees (HRECs) in institutions and organisations across Australia.

CAD: (SAAP) Coordination and Development Committee

De-identified samples or data: Data whose identifiers have been removed permanently or the data have never been identified. In some uses, the term ‘de-identified’ refers to data from which only names have been removed. Such data remain ‘potentially identifiable’.

Ethical Research Review: This includes approval of the research proposal before the research, monitoring the related research and handling complaints about the research by an ethical research supervisory body.

Ethical research supervisory body: a body established to ensure research complies with ethical research guidelines. Usually it takes the form of a Human Research Ethics Committee as outlined in Part 2 of the NHMRC *National Statement* on Ethical Conduct, at the NHMRC website <http://www.nhmrc.gov.au/publications/humans/part2.htm>.

ISC: (SAAP) Information Sub Committee

Human Research Ethics Committee (HREC): a body established by an institution or organisation to advise on ethical approval for research. The HREC’s role is to protect the welfare and rights of participants in research. The task of HRECs is to review proposals for research involving humans and to ensure that such research is soundly designed and conducted according to high ethical standards. Detailed guidelines on HRECs can be found in the *National Statement* on Ethical Conduct.

National Health and Medical Research Council (NHMRC): an independent statutory body within the portfolio of the Australian Minister for Health and Ageing. The NHMRC combines the roles and responsibilities of allocating Commonwealth funds for health and medical research, providing health advice, considering ethical issues in health and regulating sensitive medical research activities.

Professional: incorporates a number of values, including ethical behaviour, technical competence and continuous research and self-development.

Researcher: the individual or organisation or group that undertakes SAAP research.

SAAP Agency: a SAAP service delivery outlet, shop, or centre.

SAAP research administrator: An officer nominated to administer a SAAP research program.

SAAP research: Any research funded by SAAP and administered by the CAD whether with formal contract or not.

1. Introduction

This paper outlines the Supported Accommodation Assistance Program (SAAP) Ethical Research Protocols and Guidelines.

Research with people as participants has been required to conform to protocols on ethical research both overseas and in Australia. Ethical research protocols protect participants of research and researchers, enhance the quality of research and help in the continuing social support for research involving humans. In Australia, the *National Statement on Ethical Conduct in Research Involving Humans*¹ (hereafter *the National Statement*) developed by the *National Health and Medical Research Council* (NHMRC) of Australia has been accepted by many human research ethics committees as standard protocols for ethics in research involving humans.

This paper presents ethical research guidelines applicable specifically to SAAP research on homelessness and homeless people, which is administered by the SAAP *Co-ordination and Development Committee* (CAD) directly or indirectly through its *Information Subcommittee* (ISC). SAAP research is usually contracted to private researchers, companies, organisations, universities, SAAP agencies or partnerships between those groups (SAAP researchers).

The participants in SAAP research are often the homeless people who seek help from SAAP agencies. Many of those people are vulnerable and disadvantaged particularly given their physical and psychological conditions (eg. stress due to domestic violence). Research with those people could aggravate their stress. In addition, they may be under the risk of real physical and/or emotional harm even when they are accommodated in a SAAP agency.

SAAP agencies, which are involved in research, are often staffed by workers for whom research may represent an intrusion in their work or life. Further, SAAP staff may be subject to violence or threats of violence connected to their work and consequently may wish to maintain privacy.

2. The SAAP Ethical Research Protocols

All SAAP research projects are subject to SAAP ethical research protocols. Some are subject to ethical research review by an ethical research supervisory body and required to observe the ethical principles as stated in the *National Statement*. Some are not subject to ethical research review but researchers must be aware of and adhere to ethical principles in the *National Statement* (for example principle 1.1 regarding integrity in research) as appropriate².

All SAAP research proposal documents must contain a statement of whether the research is subject to SAAP Ethical Research Review as identified under sub section 2.1.2.

All SAAP research proposals and research projects, which are subject to SAAP Ethical Research Review, will follow SAAP Ethical Research Guidelines set out in section 3.

A flowchart on page 7 summarises the key steps in the SAAP ethical research protocols.

¹ An electronic copy can be found at <http://www.nhmrc.gov.au/publications/synopses/e35syn.htm>

² A general guide to conduct research consistent with the *National Statement* can be found in the JOINT NHMRC/AVCC STATEMENT AND GUIDELINES ON RESEARCH PRACTICE (1997) at <http://www.nhmrc.gov.au/funding/policy/researchprac.htm>. This guide is being revised in 2005.

2.1 Research Categories

2.1.1 Research not subject to SAAP Ethical Research Review

- Research and evaluation projects that interrogate, analyse or model aggregate and de-identified data (such as those in the SAAP National Data Collection reports or published information) do not require ethical research review approval. (The processes of collection of data, release and distribution of information or reports have already been subject to ethical review).
- Research and evaluation projects that do not deal with identifiable human data and include theoretical research and literature research.

Where during the course of using or manipulating de-identified or aggregated data or data sets, the researcher locates data, the dissemination or publication of which could identify or lead to identification of a particular small number of people, by personal characteristics or geographic locations, the researcher should not publish those data or the findings on those data unless the responsible SAAP research administrator agrees after ascertaining the circumstances for the publication³.

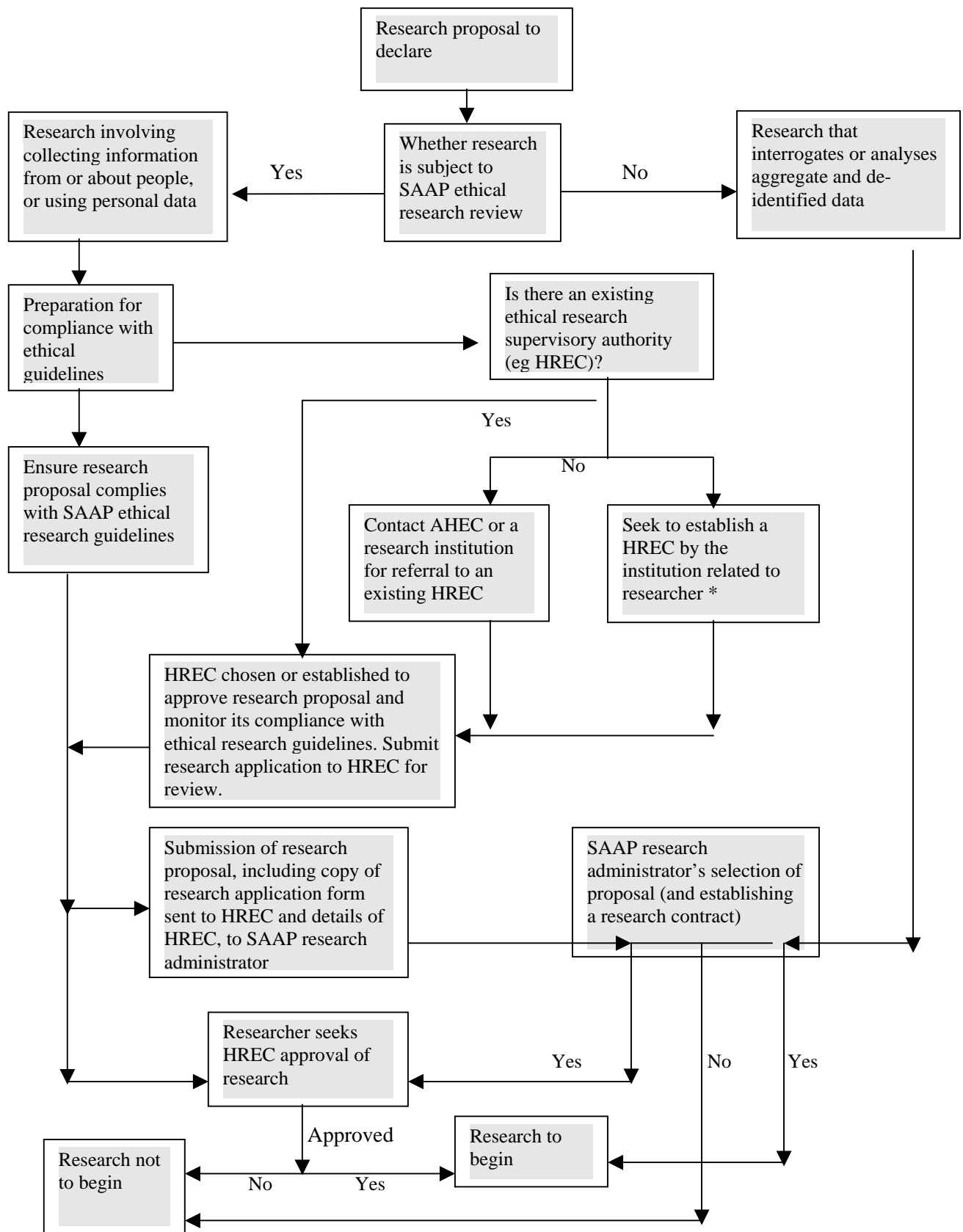
2.1.2 Research subject to SAAP Ethical Research Review

SAAP research or evaluation projects which involve collecting information from or about people, or use personal data which have already been collected (eg file notes) or contain an ability to identify people or cause risk/harm from dissemination of results will be subject to ethical research review. Such projects include:

- conducting paper based or electronic surveys of humans;
- oral interviews, focus groups or interviews conducted electronically;
- case studies, observation and recording by any means of human and cultural activities;
- using human data from records, individuals or collectives;
- changes to collection of data sets;
- data linkages and changes to data linkages; and
- testing responses to experimental conditions.

³ Principle 11 of the Information Privacy Principles does not allow a record keeper to disclose personal information records except in limited circumstances such as ‘...(b) the individual concerned has consented to the disclosure;’.

Ethical Research Flowchart



* It could take time and resources to establish an ethical research supervisory body

3. SAAP Ethical Research Guidelines

3.1 Application

All SAAP research proposals and researches that are subject to SAAP Ethical Research Review must adopt the following.

3.2 SAAP Ethical Principles and Guidelines

3.2.1 General Key Principles

SAAP researchers must follow guidelines of ethical conduct consistent with those in *the National Statement* as applicable to the research, and uphold the key principles contained in Part 1 of the *National Statement* and expanded in subsections 3.2.2, 3.2.3 and 3.2.4 of these SAAP Ethical Research Protocols. The key principles⁴ are summarised as follows:

□ *Integrity, respect for persons, beneficence and justice*

Integrity is expressed in a commitment to honest and ethical conduct of research and dissemination and communication of the results.

Respect for persons is expressed as regard for the welfare, rights, beliefs, perceptions, customs and cultural heritage, both individual and collective, of persons involved in research.

Beneficence is expressed in researchers' responsibility to minimise risks of harm or discomfort to participants in research projects.

Justice requires a fair distribution of the benefits and burdens of participation in research and, for any research participant, a balance of burdens and benefits.

□ *Consent*

Researchers must obtain informed consent from subjects in research before conducting research. Informed consent must be clearly established, for example through documents.

□ *Research merit and safety*

The research must be justifiable in terms of its potential contribution to knowledge and is based on a thorough prior investigation of current literature and previous studies.

All research proposals must be designed to ensure that any risks of discomfort or harm to participants are balanced by the likely benefit.

Research must be conducted or supervised by persons with experience, qualifications and competence.

⁴ Researchers should consult the NHMRC at <http://www.nhmrc.gov.au/publications/synopses/e35syn.htm> to ensure full coverage of the *National Statement* and any updates as it may be reviewed from time to time

□ Ethical Review and conduct of research

Research projects involving humans must not be undertaken or funded unless a *Human Research Ethics Committee (HREC)* has granted approval.

A researcher must ensure that the privacy, confidentiality and cultural sensitivities of the research participants are respected.

Researchers would find detailed commentaries on the application of the *National Statement* principles in the *Human Research Ethics Handbook*, which can be found at <http://www.nhmrc.gov.au/publications/synopses/e42syn.htm>.

The SAAP Ethical Research Guidelines expand on aspects of three of the above principles:

3.2.2 Integrity, respect for persons, beneficence and justice

Researchers need to be aware that they could have a duty of care towards homeless persons and SAAP workers when researching or involving them. This duty of care could arise because there is a possible risk of harm that the research may cause directly or indirectly to homeless persons and SAAP workers (outlined in the Introduction to this document).

As Indigenous persons make up a significant proportion of homeless persons, researchers need to be familiar with the principles in the *National Statement* dealing with Aboriginal and Torres Strait Islander Health Research⁵ and apply them as appropriate.

Researchers should be professional⁶ in dealing with homeless persons or SAAP workers that are participants in research. For example a professional researcher would have the skill to carry out research using methods that would not cause undue stress on the participant.

3.2.3 Informed Consent

Before a research begins, researchers must provide information to participants and any SAAP agency involved in the research so that participants understand:

- the ethical research guidelines applicable to the research and in accordance with the SAAP Ethical Research Guidelines;
- the purpose, scope, duration, methods, expected outcomes, requirements, benefits and risks of the research to subject persons or SAAP agencies involved as applicable; and

⁵ A guide on how to conduct ethical research dealing with Aborigines and Torres Strait Islander is the Values and Ethics - Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research which can be found at <http://www.nhmrc.gov.au/publications/synopses/e52syn.htm>

⁶ Examples of professional conduct for researchers in social work can be found in the *Australasian Association of Social Workers Code of Ethics*, which can be found at http://www.aasw.asn.au/adobe/about/Code_of_Ethics_2002.pdf, the *Code of Professional Behaviour of the Market Research Society of Australia*, at http://www.mrsa.com.au/files/Code_Behaviour.pdf, and the Australian Psychological Society's Codes of Ethics, at http://www.psychology.org.au/aps/ethics/code_of_ethics.pdf

- the rights of subjects including to seek help while participating in research, to end participation in research, to report and complain to a research ethics supervisory body and details of how to contact it;

Researchers also need to obtain the participants' informed consent⁷ to participate in the research. This is also necessary where the research has a participant who is a minor⁸ that is accompanied by an adult who has exercised care or guardianship over the minor. The researcher must obtain consent both from the minor and the adult before researching the subject

3.2.4 Ethical review and conduct of research

Privacy principles in these SAAP Ethical Research Guidelines extend beyond individuals to include SAAP agencies or service delivery outlets. This ensures that individuals cannot be traced through their personal details or through identification of the related SAAP agencies or service delivery outlets except in limited circumstances permitted under the Australian Government Information Privacy Principles⁹. Those circumstances include those under Information Privacy Principles 10 and 11 where the person consents to the use of their personal information. When intending to publish personal, agency details or identifiable data, researchers should talk to the SAAP research administrator. Researchers must ensure

- the privacy of individual subjects and SAAP agencies or service outlets involved in the research is protected. In general, protection of privacy must follow the Australian Government Information Privacy Principles.
- that electronic or hard copies of records do not enable the identification of any individual or SAAP agency or service outlet who is a participant in or is involved in the research.
- they disclose the names and organisation of persons conducting the research and their contact details to participants and SAAP agencies or service outlets involved in research and ensure a private and safe environment to conduct the research with subjects.

3.3 Compliance with SAAP Ethical Research Protocols and Guidelines

3.3.1 Responsibilities of researchers carrying out research

Where research proposals and projects are subject to Ethical Research Review, SAAP researchers are to ensure¹⁰:

⁷ Examples of guidelines to obtain informed consent and informed consent sample forms can be found at: <http://www.research.unimelb.edu.au/humanethics/processes/applicprocedure/consent/> and <http://www.usyd.edu.au/ethics/human/sample/sample7.html>

⁸ In this paper, a minor is a person who is less than 18 year old and has sufficient competence to make the decision to participate in research.

⁹ The Australian government Information Privacy Principles can be found in Appendix 2 of the *National Statement on Ethical Conduct* at <http://www.nhmrc.gov.au/publications/humans/appndix2.htm>

¹⁰ SAAP researchers could discuss compliance with SAAP ethical research guidelines with SAAP research administrators before submitting research proposal.

- they are familiar with the SAAP Ethical Research Protocols, the *National Statement* and related documents; and
- they discuss with SAAP research administrators any issues of compliance with SAAP Ethical Research Guidelines where research methods change.

SAAP researchers should also ensure:

- SAAP research proposal and contractual documents outline how the research will comply with SAAP Ethical Research Guidelines. This includes details of:
 - how informed consent will be obtained as under subsection 3.2.3 of the SAAP Ethical Research Guidelines;
 - ethical research supervisory body, usually a committee, such as a HREC. Details of such committee would include, for example, name, composition and contact details of the committee and whether the committee is currently registered with the *Australian Health Ethics Committee (AHEC)*¹¹. Otherwise further required details would include constitution, relationship to researchers, responsibility and power, qualification of members, procedures such as research approval, monitoring and complaints, and indemnity for the ethical research supervisory body. A guide to the establishment and powers of the ethical research supervisory authority can be found in Part 2 of the *National Statement*.

Part 2 of the *National Statement* also contains guidance to researchers without affiliation to an institution or organisation with a HREC. ‘2.4 *Researchers without affiliation to an institution or organisation with an HREC must ensure that the project is approved by an established HREC. There should be an agreement between the institution or organisation and researchers that defines the approval, conduct and monitoring of research, and who carries legal responsibility for it.*’.

The AHEC secretariat could refer researchers to a HREC registered with the AHEC, for ethical review of a research proposal. The HREC may charge a fee to the researcher. The issues involved in fees for ethical consideration of research proposals are discussed in *NHMRC Information Sheet 4: AHEC Information for HRECs: February 2000 - Fees for Ethical Consideration of Research Proposals*.

- they seek approval for ethical review of the research by an ethical research supervisory body and advise the result to the SAAP research administrator at the latest four weeks after the SAAP research administrator has approved the proposal or before the research contract is entered; and
- SAAP Ethical Research Guidelines are observed until research finalisation and/or reporting/publication.

¹¹ The Australian Health Ethics Committee (AHEC) is a principal committee of the National Health and Medical Research Council (NHMRC) established under the NHMRC Act 1992. Details about the AHEC can be found at <http://www.nhmrc.gov.au/about/committees/ahec/index.htm>. In 2004, AHEC provided assistance to over 200 HRECs in institutions and organisations across Australia. The task of HRECs is to review proposals for research involving humans and to ensure that such research is soundly designed and conducted according to high ethical standards.

4. Responsibilities of SAAP CAD and ISC research administrators (SAAP research administrators)

SAAP research administrators are to ensure that:

- SAAP Ethical Research Protocols are published in hard copies and electronically, particularly on SAAP Information Management Website¹² or any other related electronic locations.
- All SAAP research publicity, tender and Expression of Interest documents outline the requirement for compliance with SAAP Ethical Research Protocols.
- All SAAP research proposals and SAAP research contracts subject to SAAP Ethical Research Review are to provide details of arrangements to ascertain research's compliance with SAAP Ethical Research Guidelines until finalisation and or reporting/publication of the research.
- Where the research project is subject to SAAP Ethical Research Review, SAAP research administrators must be satisfied with the researcher's arrangements to follow the SAAP Ethical Research Guidelines, and with the capacity of the ethical research supervisory body such as, HREC, to supervise the research, before a contract for SAAP research is entered into or a SAAP research is undertaken (where there is no contract).
- SAAP research contracts will not be established if the researcher of research subject to SAAP Ethical Research Review cannot obtain ethical research approval by an ethical research supervisory body.

5. Date of Implementation

The SAAP Ethical Research Protocols and Guidelines apply from 1 October 2005 to all research contracted or undertaken without contract from that date.

¹² The SAAP Information Management website aims to encourage information management by SAAP stakeholders through showcasing SAAP quality research and data. It can be found at http://www.facsia.gov.au/internet/facsinternet.nsf/aboutfacs/programs/house-newsaap_nav.htm