

# ALIA ethics requirements and guidelines

Research involving humans should always comply with current ethical standards. In Australia, the ethical standards for such research are set by the National Health and Medical Research Council (the NHMRC) National Statement on Ethical Conduct in Human Research and those proposing to carry out research should be familiar with the ethics sections of the publications of the National Health and Medical Research Council (NHMRC).

It is important to consider the ethical implications of conducting research. Much of the research conducted in library and information studies involves humans and would be classed as 'low risk'. However, it is the responsibility of the researcher and ALIA to ensure that any research funded by the Association meets national ethical guidelines.

Research that involves low or negligible risk is research where participants have the potential to suffer no harm, but where there is potential to suffer only inconvenience or discomfort. (See National Statement on Ethical Conduct in Human Research, Section 2). There is no objective measure of risk that covers all situations. Different people interpret harm and risk in different ways. When considering the harm that may result from your research (for participants, researchers, the public etc) take into account the following types of harm: psychological, physical, privacy infringement, "labelling" [reputation] and economic.

## Participant recruitment

Recruitment of participants must not involve coercion. Participation must be voluntary. If contact details are needed, the researcher must have authorised access to the contact details of participants (eg participant's organisation or person with duty of care responsibilities may need to provide authorisation). See the References section to access a copy of the <u>NHMRC National</u> <u>Statement on Ethical Conduct in Human Research</u>.

# Giving informed Consent

An information sheet and consent form must be provided to participants in all but exceptional circumstances. In preparing these documents reference should be made to the <u>NHMRC</u> <u>National Statement on Ethical Conduct in Human Research</u> (see paragraph on Consent 2.2).

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Respect for human beings involves giving due scope to people's capacity to make their own decisions. In the research context, this normally requires that participation be the result of a choice made by participants – commonly known as 'the requirement for consent".

This requirement has the following conditions: consent should be a voluntary choice, and should be based on sufficient information and adequate understanding of both the proposed research and the implications of participation in it.

Other main points to note from the National Statement are listed below:

- A participant may refuse to participate without giving a reason or justification (paragraph 2.2.19).
- A participant's consent must be clearly established, and the consent of all properly interested parties obtained (paragraph 2.2.12). When appropriate, consent may need to be sought at both an individual and an organisation level.
- Consent must not be the subject of coercion or to any inducement or influence which could impair its voluntary character (paragraph 2.2.9).
- Circumstances in which consent from participants may not be necessary include: the use of non-identifiable data, observational research in public places, or the use of anonymous surveys (paragraph 2.3).
- A participant must be free at any time to withdraw consent to further involvement in the research.

## Information sheet

Participants must be given an information sheet, unless they are incapable of understanding written information, for example, young school children, or if it is culturally inappropriate. A consent form (see below) may not be required if participation is completely anonymous (no personal details recorded) and information is not sensitive (ie unlikely to cause embarrassment, pain, distress, emotional or spiritual discomfort).

The main purpose of the information sheet is to provide participants with a plain language statement describing the aims of the project and the nature of involvement of participants. Participants should be clearly informed of their rights and any risks associated with participation. At all times the researcher must observe the welfare of the participants and respect the dignity and personal privacy of the individual. An information sheet **must** include the following:

- The aims of the project;
- A description of what will be required of the participants (include details of amount of time required of participants);
- A statement which addresses confidentiality and security of information. Details of who will have access to personal information and the purpose(s) for which participant information will be used, including whether participants would be potentially identifiable in any published material;

- A statement that advises participation is completely voluntary; participants are at liberty to withdraw at any time without prejudice or negative consequences; non-participation will not affect an individual's rights/access to other services/care (eg in the case of patients);
- Any risks/benefits to participants;
- The contact details of the investigator(s) should the participant require further information;
- The contact details of ALIA, should participants wish to make a complaint on ethical grounds;
- Confirmation that the project has been approved by ALIA.

## Consent Form

A consent form would normally include the details listed below:

- Title of project
- Statements of confirmation, such as -
  - "I have been informed of and understand the purposes of the study."
  - "I have been given an opportunity to ask questions."
  - "I understand I can withdraw at any time without prejudice."
  - "Any information which might potentially identify me will not be used in published material."
  - "I agree to participate in the study as outlined to me."
- Name and contact details of the researcher, the principal supervisor (if applicable) or an ALIA contact (ie ALIA Chief Executive Officer and Chair of the Research Advisory Committee). The participant should be able to contact someone other than the researcher.
- Name of participant, signature and date.
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### Use of sensitive tests

- Researchers have a duty of care if their research uncovers information about individual subjects that has a bearing on their wellbeing. If the data are valid at the individual level, the researcher has a duty of care to those discovered to be at risk.
- Diagnostic tests (eg IQ tests) should only be used if they are specific to the research questions asked. Diagnostic tests should only be analysed by persons with the appropriate qualifications and competence to interpret the results.
- If the instrument used in collecting information from the participant is a diagnostic test, and has been collected by someone professionally able to interpret it diagnostically, then the duty of care may require feedback to the individual concerned or to someone responsible for the individual (eg parents) if the individual is identified as being at risk.

- If the instrument is not diagnostic, but is still indicative or raises concerns about the individual's wellbeing (eg traits, states, conditions or tendencies), then feedback may still be necessary if a participant's score is extreme.
- If the instrument is non-diagnostic or non-indicative, it is recommended that data should be collected in ways that would not allow an individual's score to be identified, ie it has to be collected anonymously or the scores need to be de-identified.
- If information is collected anonymously, the information sheet should state clearly that individual scores will not be identifiable or made available for any purpose. If information is not collected anonymously, the researcher should "inform potential subjects of the possibility of diagnosis and the way the results will be handled. In particular, the researcher must outline to whom and how results, which indicate that the subject of the research is 'at risk', will be communicated."
- Where feedback to an individual or carer of the individual is warranted, extreme care is necessary to avoid possible negative consequences such as 'false alarms'.
- The researcher's duty of care to participants pertains only to the information that is central to the purpose of the research.

## Notes for researchers

Confidentiality The applicant must indicate in detail how confidentiality and privacy will be maintained. Relevant details must be included in the information sheet for participants and ethics application form. For example, what procedures and safeguards will be employed. Who will have access to the data? How will it be stored? In which format? When will it be destroyed? etc. A simple statement of intent to maintain confidentiality is not sufficient.

Anonymity and Identity of Participants Researchers have a responsibility to take all reasonable steps to protect participants' privacy and to inform participants fully, prior to participation, of any possible risks regarding identification in published material. Researchers should take care to anonymise participant data, and where possible offer participants the opportunity to access any publications resulting from your research.

Recruitment The applicant must demonstrate that there is no possibility of undue influence on potential participants through eg power relations such as that between librarian and client.

Risks/Benefits The proposed benefits of the study must outweigh any potential risk, and any such risks to participants must be minimised and fully communicated to participants before consent is obtained.

Adequacy of Method Applicants should ensure that proposals provide sufficient detail in order to demonstrate to the Committee that the project is justified, relevant and that all methods are clearly outlined.

Invasive surveys and other techniques Any proposals involving surveys that could be construed as invading personal privacy etc, should automatically be referred to ALIA in order to be vetted by a suitably qualified expert.

External Institutional Approval Proposals that require external institutional approval, ie approval from institutions associated with the research, must attach confirmation of that institution's ethics approval.

## Reference publications and websites

Applicants should refer to the following publications where applicable to assist with their application:

• NHMRC, "National Statement on Ethical Conduct in Human Research"

http://www.nhmrc.gov.au/publications/synopses/e72syn.htm

• Joint NHMRC/Universities Australia "Australian Code for the Responsible Conduct of Research"

#### http://www.nhmrc.gov.au/publications/synopses/r39syn.htm

Where a researcher would like to use data that has already been collected by a Commonwealth agency, the researcher will need to consult the following publication:

• NHMRC "Guidelines under Section 95 of the Privacy Act 1988"

http://www.nhmrc.gov.au/publications/synopses/e43syn.htm

• NHMRC "Standardised Participant Information and Consent Forms"

#### https://hrep.nhmrc.gov.au/toolbox/standardised-forms

Other resources

• The Australian Privacy Commissioners Website

#### http://www.privacy.gov.au/

• Australian Association for Research in Education (AARE), Code of Ethics (pp1-5)

#### http://www.swin.edu.au/aare/

• NHMRC "Guidelines on Ethical Matters in Aboriginal and Torres Strait Islander Health Research"

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

• Oral History Association of Australia "Guidelines of Ethical Practice"

http://www.ohaa.net.au/guidelines.htm