

Guidance on Research being done with, or for, Organisations

Overarching Principle and Intent

The Western Sydney University HREC abides by the guidelines in the *National Statement on Ethical Conduct in Human Research* (2007) (The National Statement) and Western Sydney University policies including the *Research Code of Practice*, the *Intellectual Property Policy* and the *Data Management Policy* when reviewing all research proposals. Researchers should familiarise themselves with the National Statement and University policy.

Aims and Context for this Guidance Sheet

This guidance material aims to assist researchers to identify human research ethics issues when undertaking research which involves participants who have an existing relationship with an organisation. The organisation may be the conduit to the participants; the subject of the research; the funder/sponsor of the research; or a combination of these.

Scenarios include:

- The researcher may be **external** to the organisation and the research is
 - initiated by the researcher, or,
 - being done as a consultancy or otherwise initiated by the organisation.
- The researcher may be **internal** to the organisation, e.g. staff, and the research is about processes, including their own practices, within the organisation.
- The researcher may be doing research with his/her workplace clients.

Researchers need to be mindful that in a number of the above scenarios there may be an inherent conflict of interest for the organisation and for the researcher.

Ethics reviewers will consider issues such as how the research design:

- ensures the independence of the researcher, the research question and the research outcomes
- manages the role of the researcher in relation to other roles such as staff and/or professional, or contractor, and any resulting conflicts of interest
- manages the potential for, or any real, unequal relationship between the research participants and the organisation and/or researcher
- encompasses the principle of free and voluntary consent of research participants
- accounts for the potential for 'organisational gatekeeping' in relation to access to data and data sources, and
- accounts for any limitations to publication and report dissemination.

National Statement Principles

The National Statement is framed as a set of principles that should be applied to research design and practice. The following text about those principles has been drawn from Griffith University's *Research Ethics Manual Booklet 27 Unequal relationships and human research* and adapted for Western Sydney University ethics review.

"In the context of research involving organisations the following additional considerations may come into play: ¹

Merit and integrity

¹ Edited text from Griffith University's Research Ethics Manual Booklet 27 Unequal relationships and human research. The Booklet can be found under the Research Ethics Manual Tab, at http://www.westernsydney.edu.au/research/research_ethics_and_integrity/human_ethics

- Does the design of the research acknowledge the existing relationship and are there appropriate measures in place to ensure participation is voluntary?
- Have any conflicts of interest associated with the existing relationship been identified and addressed?; and
- Is it appropriate to encourage potential participants to consult with others before they agree to participate in the research or, if the participants are especially vulnerable, should an advocate or intermediary be appointed?

Respect for persons

- Extra care should be taken to ensure that respect for participants is given pre-eminence ahead of the research objectives.
- Special care should be taken to ensure the confidentiality of the information the researchers receive, especially where that information is a source of potential risk; and
- Consideration should be given to whether special consent arrangements are warranted.

Beneficence

- The presence of unequal relationships can raise special issues of risks to participants, whether the risk is real or perceived (e.g. impact upon employment, loss of service or treatment, impact upon personal relations). A research project must minimise these risks, discomfort and burdens to participants.
- Some participants (e.g. the patients of a specialist conducting research) may have unrealistic expectations with regards to the benefits of a project and this expectation needs to be managed; and
- Extra care should be taken to ensure individuals who decline to participate, or who withdraw consent, do not suffer any negative consequences (e.g. dismissal from employment, or poor therapeutic treatment).

Justice

- Some participant groups within, or connected to, organisations can be over-researched and more susceptible to the deleterious impacts of being over-researched. This should be carefully considered during the design and conduct of a project; and
- Every effort should be made to minimise the impacts of the inequality.”

Recruitment

Research that involves organisations often requires the researcher to liaise with the organisation to provide access to participants. Researchers need to consider whether an organisations ‘preferred’ method of recruitment might impair the research design e.g. resulting in not enough people, not accessing the people most able to provide the relevant data, not a broad enough range of input; sampling bias.

Researchers should also consider the privacy implications of any proposed recruitment method. For example, access to an organisations internal mailing list may put the organisation at odds with its own privacy policy and/or Privacy Legislation.

Likewise, the easiest or most obvious methods of recruitment e.g. having participants nominated by management, or snowball recruitment, may undermine the scope of the data collection and potentially the anonymity/confidentiality of participants.

Consent

Researchers need to show consideration for ensuring that the engagement between the researchers and the participants is open, is a voluntary choice for the participants, and best reflects the aims of the research, rather than being ‘sanctioned’ or tailored by the organisation.

Researchers should acknowledge that participants will be recruited and consented within an unequal relationship and their capacity to consent (to either say ‘yes’ or ‘no’ to participation) may be impaired by that inequality. Ensuring capacity will impact on:

- the degree of separation between the research activity and other activities that form part of the usual participant / organisation relationship
- the methods of initiating contact with potential participants
- how potential participants communicate their decision about participation to the researchers
- whether the decision to take part is obvious, or not, to others.

The following text, outlining typical strategies to address perceived pressure to take part in research, has been drawn from Griffith University's Research Ethics Manual Booklet 27 Unequal relationships and human research and adapted for Western Sydney University ethics review.

“Some typical strategies to address perceived pressure to take part in the research²

1. Participation is anonymous, so the researcher(s) / organisation will not know who participates, or the data is coded in such a way that participants will be anonymous
2. Recruitment is conducted by a third party.
3. The recruitment material includes a clear statement that participation will not impact upon standing / access to services / the relationship.
4. Potential participants are afforded time and space to consider their participation – rather than deciding immediately.
5. A clear distinction is made between the existing relationship and the research activity.”

Risks

Evidence of the identification, assessment and minimisation of risk to participants in the research design is a key principle in ethical review. Inevitably, some research questions are more sensitive or otherwise risky than others and some participant / organisational relationships are more vulnerable than others. But even in research that is not about these identifiably risky subjects or relationships, researchers need to be mindful about risks that are inherent because of an unequal relationship. Ethics applications which state that there is no risk for reasons such as ‘the participants are all professionals and they can decide if they want to take part’ may not show sufficient evidence of an understanding of the complex relationships that are the context for organisational research.

Risk to participants – from unequal or dependent relationships

The presence of an unequal relationship in a human research project can compound existing risks (in terms of likelihood of incidence or the severity of the harm) or introduce additional risks that would not have otherwise been present.

Examples of unequal relationships reviewed by the Western Sydney HREC:

- employers or supervisors and their employees
- educators and their students
- health care professionals, including psychiatrists and counsellors and their patients or clients
- carers and people with chronic conditions or disabilities, including long-term hospital patients, involuntary patients, or people in residential care or supported accommodation;
- service-providers (government or private) and especially vulnerable communities to whom the service is provided.

Researchers should show how they will manage existing risk and / or not introduce additional risk. They should have strategies that dissuade disclosures that may make the participant vulnerable.

For research projects which include data collected from clients of, or suppliers to, the organisation researchers need to consider whether there is the risk of reprisals because of participation or non-participation in the research. Researchers should consider whether there are repercussions for these clients or suppliers and whether there are risks in reporting issues or practices that may become evident from the research.

Risk to participants - from identification

Participants may be identifiable to others because of the group nature of the data collection method and/or because of the staff roles within the organisation that are the target of the recruitment. The researcher needs to consider how:

- they will mask participant identities and the comments made (data collected), which, by their nature, may indicate who made them

² Ibid

- the research results will be reported and to whom. Is the report for academic purposes and/or organisational purposes? Will there be more than one version and if so which goes where?

Researchers should consider the risks that may arise should one person say something that implicates others. This may be a risk for both the person who disclosed the information and for those the information is about. How will the researcher identify this type of disclosure and manage this risk?

If data is being collected by observation in the organisation researchers should consider whether people should be advised about the conditions under which the observation is being done.

For example:

- when and where will it occur?
- what form will it be in e.g. imagery or note taking?
- what records will be made?
- will people be identifiable in the data record?
- will everyone who is to be observed provide consent? What if some people object to the observation, don't consent to taking part in the observation?

How will these issues be managed?

Risk to participants - from distress

Some recounted experiences, or requests to recount experiences, can be difficult, even if not traumatic. Researchers should address these issues upfront and let people know what they can do should this arise e.g. tell the researcher to stop the interview; seek additional support or counselling. These details are usually provided in advance by the researcher in the participant information sheet.

Risk to participants – from captive relationships

Captive relationships are where potential participants are under the direct control of the researcher(s) / sponsor / organisation and they can order individuals to undertake an activity, even if the participants don't want to.

In some cases an ethics application for participants in this type of relationship will need to go to a designated, non-Western Sydney, HREC for review and ongoing monitoring, e.g. the Department of Defence HREC.

For more information see Section 7 of Griffith University's *Research Ethics Manual Booklet 27 Unequal relationships and human research*.³

Risk to the organisation - from adverse disclosures about processes and practices

During the process of the research the researcher may learn about conduct / behaviour / management processes that are at odds with policy or are illegal. Researchers need to show evidence they have considered how to manage this, for example, to whom issues will be reported. Participants need to know in advance what information will be reported. These disclosures may also be considered adverse events that need to be reported to the HREC in a timely manner.

Risk to the organisation - from data disclosure

Disclosure to the researcher - researchers should consider whether by being in the organisation there is the possibility of them gaining access to data that it is not appropriate for them to have, for example, because of privacy reasons. The application needs to explain how such possibilities will be minimised and what will be done should they occur.

Disclosure beyond the organisation - researchers should confirm with the organization, prior to commencing research, whether there will be any restrictions on data reporting and sharing. E.g. commercial in confidence data may be restricted. The researchers then need to show evidence of consideration for how this will impact on the research design, research reporting and publication verification requirements.

³ Ibid

Acknowledgement: *This material is an adaptation of Griffith University's research ethics arrangements.*

Human Research Ethics Guidance Documents available from Research Services

- Guidance for Researchers New to Human Ethics Review
- Guidance Human Research Ethics Protocols for Coursework Masters
- Guidance on Choosing the most appropriate PIS and Consent
- Guidance on Completing the Project Description
- Guidance on Creating Research Project Flyers
- Guidance on Data Storage and Retention Questions
- Guidance on Ethics Review Exemption
- Guidance on Issues with Informed Consent in Research
- Guidance on Levels of Risk and the Ethical Review Process
- Guidance on Making an Amendment to an Approved Project
- Guidance on Organisations in Research
- Guidance on Questions Related to Cultural Sensitivities
- Guidance on Questions Related to Restrictions on Publication of Results
- Guidance on Receiving and Responding to Ethics Committee Assessor Comments
- Guidance on Research Projects Seeking to use Western Sydney Staff as Participants
- Guidance on Reimbursements
- Guidance on The use of 'Opt Out' or Passive Consent in Human Research
- Guidance on Writing Participant Information Sheets and Consent Forms
- Guidance on Research Involving Young People
- Guidance on Research Projects and DFAT Advice
- Guidance on Using Focus Groups in Research

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