

# REDI HUMAN RESEARCH ETHICS

RESEARCH | ENGAGEMENT | DEVELOPMENT | INNOVATION

## Research Involving Young People

### Overview

The following document is intended to provide guidance to researchers on addressing the important issues that arise from research involving young people both in their project practice and their application for ethical approval of this research.

Research involving children or young people can give rise to ethical, moral, legal, institutional and practical challenges. When considering young people's involvement in research, areas of concern include whether potential participants are aged under 18, justification of their inclusion or exclusion, the consent process and whether there are any additional regulatory processes that need to be addressed.

Chapter 4.2 of the *National Statement* discusses research involving the participation of children or young people.

### The Inclusion or Exclusion of Young People in Research

In the case of all research, the benefits should outweigh the risks associated to any participant group. For young people specifically, the *National Statement* specifies that it is only ethically appropriate to include children in research under certain conditions. These include when the research is likely to make an important contribution to the body of knowledge in an area important to health, welfare or any other area of work related to children. Children's contribution must be considered indispensable to the research.

The Australian Human Rights Commission acknowledges the *International Convention on the Rights of the Child*. In summary this outlines that young people have the right to not be discriminated against, that they have the right to preserve their identity and that they are capable of forming their own views and have the right to express them. In practice researchers must be able to demonstrate that children and young people are safe, measures are taken to preserve or better their wellbeing and that the research is not contrary to their best interests.

### The Consent Process

Once it is determined that there will be participants aged under 18, researchers will need to consider who will consent and the most appropriate mechanism to achieve this.

### The young person as the principal consenting agent

As a general principle the decision of whether the young person can consent on their own behalf should be determined by (i) the age of the young person; (ii) the risks associated with the research and (iii) the degree to which additional regulatory requirements might apply.

In situations where a research team proposes relying on the young person as the principal consenting agent, the *National Statement* specifies that the research team must have a mechanism to assess the capacity of each individual participant to make an informed decision about their participation.

### Example 1: University students as participants

First year students are often asked to participate in research as part of their program of study. Many students are aged under 18, however the researcher can state that university students have the ability to consent and provide relevant reasoning for such. In this instance an information sheet and consent form is not required from the students' parent or guardian.

## **Example 2: School students as participants**

School students' participation even in what may be deemed low risk research requires both parental/guardian consent and consent from the young person themselves.

Section 4.2.9 of the *National Statement* provides an additional framework that can be used to justify treating the young person as the principal consenting agent. These provisions apply in circumstances where, for example, the young person is estranged from their parent/guardian, or where parent/guardian consent could be contrary to the best interests of the young person.

## **Parent/Guardian consent and young person assent**

In some situations it may not be possible to justify treating the young person as the primary consent agent or equal consenting agent with their parent/guardian. In this instance, it is still the view of the Human Research Ethics Committee (HREC) that a mechanism should be developed to obtain assent of the child or young person. At this University, many researchers use a 'Dialogue Sheet' to assist with this process. It is important to remember that whatever tool is used, it should be appropriate to the development level of the participants.

If the research team feels at least some of the potential participants would be capable of making a discerning decision about the project, it would be respectful to have two sets of informed consent materials – one addressed to the parent/guardian, the other addressed to the young person.

## **Special justification for not seeking parental/guardian consent**

There may be instances where a combination of the absence of significant risks or ethical issues, coupled with the capacity of the young person and the specifics of the project mean that researchers can justify not seeking consent from a parent/guardian. For example, where a young person has an estranged relationship, seeking consent from their parent/guardian may be contrary to the best interest of the young person and may put them at greater risk.

## **Gatekeeper' Approval**

There is a large amount of work involving children or young people where it is necessary to conduct this research in the context where the approval of an agency or organisation is required. Where this is the case, there may be additional approval processes required and appropriate consultation should also be made.

The most notable example is research to be undertaken with school aged students.

## **School-based research**

At Western Sydney University there are a number of researchers who work with schools in the local area. In addition to seeking ethical approval from Western's HREC, schools also have their own requirements. A list of NSW contacts and processes for State, Catholic and Independent Schools can be found through this link: [http://www.uws.edu.au/research/research\\_ethics\\_and\\_integrity/human\\_ethics](http://www.uws.edu.au/research/research_ethics_and_integrity/human_ethics)

Researchers must be clear in their research proposal in separating school and research activities. E.g. where a researcher is observing teaching style in the delivery of a program, the program itself is not necessarily the focus but rather the teacher. In this instance also, it is the HREC's view that teaching style cannot be observed without the learner – young people. As such, the appropriate information and consent process must also be afforded to the young people and not just the teacher.

In situations where a non-consenting student must be excluded from a school activity because of the degree to which the activity is combined with the research activity, or the student is amongst a minority of students excluded from a research activity conducted in regular class time, appropriate alternative arrangements must be made. These arrangements should provide an alternate learning activity of equal perceived worth and desirability. Again, both parents/guardians and the young people should be informed and consent to this process.

## **Regulatory frameworks**

It is the researcher's responsibility to ensure that the appropriate requirements are being addressed when conducting research in specific settings. A Working With Children Check is a requirement for people who work or volunteer in child-related work. The Working With Children Check is fully portable and can be used for any paid or unpaid child-related work in NSW as long as the individual remains cleared. Further information about the requirements and the process can be accessed through NSW Government Office of Children's Guardian - <http://www.kidsguardian.nsw.gov.au/working-with-children/working-with-children-check>

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#### **Human Research Ethics Guidance Documents available from REDI**

- Guidance for Researchers New to Human Ethics Review
- Guidance on Choosing the most appropriate PIS and Consent
- Guidance on Levels of Risk and the Ethical Review Process
- Guidance on Making an Amendment to an Approved Project
- 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 Data Storage and Retention Questions
- Guidance on Ethics Review Exemption
- Guidance on Research Involving Young People
- Guidance on Using Focus Groups in Research
- Guidance on Complaints
- Guidance on Research being done with, or for, Organisations

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