GUIDELINE: Research involving Children and Young People
National Statement Chapter 4.2

INTRODUCTION

This guide has been prepared to help researchers design, plan and conduct ethical research involving children or young people. When designing your study you will need to consider the capacity of the child or young person to give informed consent and for autonomous decision-making throughout the research, their susceptibility to coercion and/or undue influence or persuasion from parents, other adults or peers, and the conflicting interests of the child/young person versus their parent. You will also need to consider any legal obligations that need to be met. Careful consideration should also be given to children’s communication and other age related needs at every stage of the project. As a guiding principle, research involving children and young people should only be conducted where:

- the research question posed is important to the health or well-being of children, even where the research may have no direct benefit for the individual child/young person involved;
- the participation of children is indispensable because information available from research on other individuals cannot answer the question posed in relation to children;
- the study method is appropriate for children; and
- the circumstances in which the research is conducted provide for the physical, emotional and psychological safety of the child.

It should also be noted that once ethics approval has been obtained from the HREC there is also a need for researchers to adopt a reflexive stance throughout the project and manage ethical issues as they arise. This may necessitate requests for modifications to be submitted.

INFORMED CONSENT

Consent vs Assent

It is essential in any research that the participants are given full information about the research in order to give their informed consent to take part.

Information presented to the child and parent should explain: the nature and purpose of the research; what will happen; what is being asked of the child; that the child can agree – or disagree to take part – without adverse consequences; and may withdraw at any time; and be given in clear language at a level that the child can understand, using visual aids if necessary. In addition to parental consent, the researchers should obtain assent from the child.

The University of Sydney HREC prefers that in all research involving children parental/guardian consent is also obtained. This does, however, depend on the context of the research and the maturity of the participants.

In longitudinal studies, provision should be made for obtaining consent from child participants again once they reach the legal age of consent.

Young people aged 16-18 with sufficient understanding may be able to give their full consent to participate in research independently of their parents and guardians. Children under 16 may be able to give their full consent providing they have been
provided independent advice, do not wish to involve their parents, and have sufficient maturity to understand the nature, purpose and likely outcome of the proposed research. A child’s level of maturity is to be adjudged weighing up individual and research related factors and circumstances.

Rather than focus on chronological age or age groups, it is more useful to concentrate on the level of risk associated with their participation. This may be related to the topic under investigation, the characteristics of the sample of children involved (i.e., if they have particular vulnerabilities), the context in which the research is taking place, the skills of the researchers involved, or the methods being used - and/or a combination of all these factors. For example, 14 year olds might be able to consent for themselves to a survey which asked questions which were of a non-sensitive nature. The same group of participants might require parental consent where individual interviews are involved and/or the nature of the questions are more intrusive or where the research likely holds long-term significance or impact.

“A review body may also approve research to which only the young person consents if it is satisfied that:

(a) he or she is mature enough to understand the relevant information and to give consent, although vulnerable because of relative immaturity in other respects;
(b) the research involves no more than low risk (see paragraph 2.1.6);
(c) the research aims to benefit the category of children or young people to which this participant belongs; and
(d) either
   (i) the young person is estranged or separated from parents or guardian, and provision is made to protect the young person’s safety, security and wellbeing in the conduct of the research (see paragraph 4.2.5). (In this case, although the child’s circumstances may mean he or she is at some risk, for example because of being homeless, the research itself must still be low risk); or
   (ii) it would be contrary to the best interests of the young person to seek consent from the parents, and provision is made to protect the young person’s safety, security and wellbeing in the conduct of the research (see paragraph 4.2.5).” National Statement 4.2.9

The consent process used may be governed by the setting of the study. In certain settings, such as hospital clinics or public schools, there may be policies mandating written consent or standing consent. Prior to submitting your ethics application, you should approach the key gate-keepers for the setting where your research will be conducted to gain an understanding of accepted practice and specific requirements.

Researchers should not, however, be discouraged from undertaking research with minors who are, for example, not living with their natural parents due to family breakdown or who may be refugees or are otherwise vulnerable. Avoiding research with or excluding such groups of children prevents them from having a voice in research that could potentially be of benefit to them and in policy development.

“Opt in” versus “Opt Out” Consent

“Opt Out” or passive consent refers to a form of consent whereby parents are provided with information about a research project and are asked to sign and return a form if they do not wish their child to take part in the research. Parents who do not return the form are assumed
to have consented to their child’s participation. The HREC generally prefers active consent, as this guarantees that parents have been given the opportunity to provide informed consent but passive consent may be appropriate and more practical in some contexts.

If you would like to use a passive consent process, you will need to provide a justification for using this approach, with consideration of how informed consent will be achieved in this context. The HREC will be concerned that:

- Parents have received the relevant information (the researchers have used appropriate strategies to deliver the information about the research to parents).
- Parents have acknowledged the information or have been provided with a reasonable amount of time to consider their child’s participation and to indicate they do not wish their child to participate.
- Parents have been provided with opportunities to review the research materials and/or to discuss their child’s involvement in the research with the researchers (or the school/pre-school/child care Director/Principal, if appropriate).
- Parents with low literacy or English proficiency levels have been provided with information about the research in an appropriate format.

In assessing whether passive consent could be used the HREC may take into account

- The age and maturity of young participants
- The type of research activity undertaken
- The nature of the research
- The risks of participation in the research.

When considering a passive approach to consent, we recommend you refer to section 2.3.6 of the National Statement. Some key conditions highlighted in the National Statement include: that the research involves no more than low risk; the benefits of the project outweigh any risks associated with not seeking consent; the use of explicit consent is likely to result in a low participation rate that would compromise the research findings; and participants have been given information about the project and the chance to opt-out if they desire.

See also the guidance on this issue in the Ethical Research Involving Children document: Informed Consent.

THE RIGHT TO WITHDRAW

All participants have the right to withdraw from your research at any time, even if they have agreed to participate and are not required to provide reasons or an explanation for their withdrawal. You must make it clear to all participants that they have this right even if, for example, parents have given consent to the young person’s participation. This may be especially important in some settings, for example schools, where students are routinely following instructions by teachers.
RESEARCH IN SCHOOLS

Researchers should follow the relevant guideline. All research in schools requires the permission of the School Principal. Research conducted in public schools and in Catholic schools requires SERAP and CEO approval respectively.

COERCION

You should ensure that children do not feel pressured or influenced in any way to take part in research due to a power imbalance between the children participants and/or any adults involved in decision-making about children's participation in research. Real or perceived coercion may also exist between teachers and students. A child or young person may naturally try to please a parent or teacher and may therefore agree to take part in research even if they have some doubts. Pressure from peers should also be avoided.

Researchers should err on the side of providing an appropriate Participant Information Statement and Participant Consent Form for children as young as possible, or should have other procedures for informing children such as a class presentation. Opportunities for children to ask questions or seek clarification on any aspect of the research should also be facilitated.

The HREC considers it a sign of respect for young participants that they are informed of the research in an appropriate way and given the opportunity to provide acknowledgement and assent.

CONFLICTS OF INTEREST

Researchers should carefully consider any conflict of interest between parents/carers and children. Parents may, for example, wish to know how children have performed in any testing or what views they expressed in an interview. The children may be happy to take part in research but may not wish to know how they have performed in relation to their peers, and may be concerned about their parents or others knowing what they have said.

Some organisations may have a vested interest in asking children to participate in research, for example those trialling new comprehension tests. Clinical Trials involving children and young people in particular require careful consideration to balance any Risks and Benefits.

LEGAL OBLIGATIONS

Working with Children Check

It is mandatory for all researchers who will have contact with minors under the age of 18 to have applied for clearance to work with children under the following University policies:

Working with Children Policy 2014
Working with Children Procedures 2014
The process for applying for a new Working With Children Check is detailed on our website: Legislation relating to Human Ethics

The University of Sydney HREC requires that researchers conducting research with children in overseas countries which do not mandate clearance to work with children must nevertheless comply with relevant Australian Legislation. Researchers must also familiarise themselves with and comply with any other local requirements when research is conducted overseas.

**Mandatory Reporting and Duty of Care**

The advice received from HR and the Office of General Counsel is that, generally, researchers are not subject to mandatory reporting, unless they are in one of the designated categories eg teacher, school counsellor, psychologist, and clinician. However, although not obliged to supply information there may be a moral and ethical obligation on individuals to report information as they see fit. This comes down to what researchers *ought* to do in some contexts rather than what they *must* do in others (e.g. as a teacher/researcher). You may find it useful to consult the mandatory reporting guidelines which give details and checklists of what information should be reported and how this should be done.

**Keep Them Safe Website**

When deciding to report information this should be done in an informed way. For example, it may not be appropriate to make a report on children aged 16 and above. Consideration may also need to be given to children other than the primary participant. There may be potential for ongoing risk to other minors and implications for other children and young people. For example, an interview with young people leaving care at 18 may disclose that a young person has been sexually abused by a foster carer. Other children may therefore be at risk in that situation. The duty of care is not necessarily just about the child participants themselves.

You should also consider the need for timely advice to be given, noting that data analysis can often take place months after the original interviews. Consider your responsibility when information is found out some years down the track. If you are asking questions which might elicit responses of concern, then you may have an obligation to review those responses as early as possible so that appropriate action can be taken. Understandably, some of these decisions will come down to the judgement of the individual researchers.

In the case of schools, reporting should usually be made to the School Principal or School Counsellor. Other institutions may have a Child Protection Officer. It may be appropriate to report concerns to parents but this should be given careful consideration. In the case of homeless children, an appropriate agency could be contacted.

**PRIVACY AND CONFIDENTIALITY**

You need to tell your research participants whether what they tell you will remain confidential to you as the researcher (and your research team). This means ensuring they are never identifiable to anyone, and that you cannot tell anyone who has/has not been involved in your research other than as required by law. Confidentiality also has practical implications
for your research; for example, you must not write participant’s names or any other identifying information about them on any notes you take. Instead, you need to give them an anonymous identification code. Some research is carried out with the intention of naming individuals; this is acceptable in some circumstances and must be made explicit from the outset.

It is difficult to be specific regarding the age range where parents providing information about their children without their children’s assent or permission is appropriate. While children are in primary school (up to the age of 12 in Australia), most parents would expect to be informed of research and consulted about what information should be included. High school pupils might be expected to be more autonomous. As with assent, this issue is dependent on content and context.

See also Ethical Guidance: Privacy and Confidentiality

PHOTOGRAPHY AND VIDEOTAPING

If you plan to take photos or videos of your participants, remember that this means they will be identifiable even if you do not name them. You will need to justify the necessity for photographs or videos in your application and seek specific consent in the Participant Information Statement and Participant Consent Form.

PROVIDING FEEDBACK TO PARENTS AND CHILDREN

You should consider the best format for providing general feedback to participants. Any feedback should be age appropriate. A wiki or Reddit type age appropriate internet group may have the advantage of generating dialogue however, the need to maintain anonymity and confidentiality need to be considered. Teenage participants may be happy to receive letters in the regular mail - this may be seen as a more individualised approach.

Any feedback provided to participants may have the added advantage of informing the research and may assist the interpretation of the data.

The main consideration is that the information is very clear in the Participant Information Statement on what feedback will be made available and how this will be delivered. You should ensure the transparency of the information.

The Participant Information Statement should also be very clear about whether feedback will be provided to participants and parents or only to one of these groups.

For more information please consult Chapter 4.2 of the National Statement