

Guidelines on Research Ethics for Projects with Children and Young People

Nathalie Noret, Faculty of Health and Life Sciences

Introduction

When conducting research with children and young people, the ethical issues that need to be addressed are similar to those outlined in most social and medical research guidelines. However, the way in which these ethical issues are tackled in practice can be very different (Greig et al, 2007; Tisdall et al, 2009). The following guidelines outline a set of procedures researchers may wish to consider when conducting research with such samples and should be read alongside the more generic York St. John University Guidelines on Ethics document. In line with the NCB (2003) and the UN Convention on the Rights of the Child (2008) definition, the term 'children and young people' refers to all persons under the age of 18 years.

Consent

Gaining consent for a child or young person to participate in research is often a more complex procedure when compared to gaining consent from other populations. Many researchers working with children and young people recognise the need to view them as autonomous individuals, capable of making their own decisions. However, in practice this is constrained by legislation which states that those under 18 are not legally competent to provide consent and that their decisions are often shaped and influenced by parents and other adult gatekeepers, such as teachers and social workers (Greig et al, 2007; Tisdall et al, 2009). In addition, an integral part of gaining consent is ensuring that participants are fully informed of, and understand the nature, purpose and outcomes of the research (Tisdall et al, 2009), which at times can pose difficulties, particularly when working with young children. Therefore, in practice, researchers are often required to gain consent from appropriate adults and also gain assent from the child or young person.

In terms of adult consent, researchers must first obtain consent from the relevant gatekeepers relevant to the study and involved in the child's life. If conducting research in a school or sports or community club setting, the researcher will need to obtain the consent of the person in charge of that setting, such as the head-teacher, sports coach or club leader. As with the issue of consent more generally, the researcher should outline the purpose of the project, what the involvement of the child and/or young person will be and the outcomes of the project. In practice, it is common to first seek consent from the organisation where participants will be recruited (such as the school) before gaining consent from the parents/guardians.

In terms of the specific issue of parental consent, the researcher(s) will need to consider the following:

- Does the research project require passive or active consent?

Active consent refers to the use of a consent form, whereby parents/guardians are required to sign and return a form indicating their consent for their child to participate in the study. Non-return of this slip is taken as an indication that the parent(s)/ guardian(s) do not want their child to participate in the study. Passive consent on the other hand, requires participants to return the slip only if they do not want their child to participate in the study. Non-return of the slip is then taken as consent for the child/young person to participate in the study (Ellickson & Hawes, 1989). The debate surrounding the use of active or passive consent when conducting research with children and young people has attracted much discussion in the research literature (See Jason et al, 2001, for a review). To date there is little consensus in the research literature or society ethical guidelines over which method should be employed.

Therefore, the YSJU ethics committee do not wish to advocate one particular approach. Rather, when reviewing proposals, the committee will consider the use of passive or active consent in the context of each individual project taking into consideration the following:

- *The age of the participants*; if the proposed project involves younger children where the issue of assent may be particularly difficult, the committee would advocate the use of active parental consent. If the project involves older children/young people the use of passive consent may be deemed appropriate.
- *The nature of the research*; if the project involves exploring particularly sensitive topics or a particularly intrusive method, the committee will advocate the use of a more active approach.
- *The location of the research*; if the project is to be conducted in a school or other community setting, whereby consent has also been sought from additional gatekeepers the use of passive consent will be deemed appropriate. However, when recruiting participants directly at home the use of active consent will be inevitable.

Once consent has been sought and gained from parents and other relevant gatekeepers the researchers are then required to obtain assent from the child/young person. Assent refers to a child/young person providing a signal that they are willing to participate in the project. This does not have to be signed or written assent, simply a signal that they are willing to take part (SRCD, 2009). When gaining assent from a child or young person the researcher(s) should consider the following:

- Ensure the information on the project is clear and written in a language appropriate for the sample. Participants should be provided with a written explanation of the research, in an age-appropriate format. The NCB (2003) guidelines provide a clear checklist of information that should be included when gaining consent.
- When in the planning stages of the research project, the researcher(s) may wish to consider piloting the consent information with a small sample to ensure that it is clear and easily understood.
- Verbal discussion of the research project alongside the written material is also advocated. This could be through a class discussion, an assembly or group meeting. If the research is to be conducted outside such a setting, the researcher may wish to consider reading through the consent material with the child before commencing the project.

Protection from harm: Risk, benefits and safeguarding children and young people during research

In line with the BERA (2004) guidelines, the best interests and rights of the child should be the primary consideration when conducting research with children and/or young people. As with all research, researchers have a duty to protect their participants from harm. When working with children and young people, researchers have a duty to ensure the method is appropriate and will not cause participants any physical or psychological harm (Alderson & Morrow, 2011). Alderson & Morrow (2011) outline how the issue of harm, risk and potential benefit should be discussed and addressed when planning a research project to be conducted with children and young people. In addition to reviewing research using the same method as conducted with adult participants, in terms of establishing the potential physical and psychological harm, additional factors should be explored. When exploring potential sources of harm that may result from the planned research project, researchers should consider the risk of:

- **Over-research**: Whether there is a chance that the children and/or young people are being asked to take part in too many studies. This is often the case with research conducted in schools when pupils are often asked to complete surveys.
- **Misunderstanding**: It is important that researchers pilot/test the information being used in the proposed study to ensure that it can be understood. The committee suggest that this should be done with all assent and debrief information in conjunction with any materials being used, such as questionnaires and experimental instructions. Misunderstanding questions and instructions could be a potential cause of distress in terms of causing anxiety or confusion.

- Potential harm or distress caused by the questions being asked or procedure being followed.

Alderson & Morrow, (2011) suggest that these factors have the potential to cause emotional distress, feelings of embarrassments and have an impact on participants' self-esteem. It is important to note that it is not that research that poses a risk to children and/ young people should not be conducted, nor is it that all risks can be anticipated before the research commences; more that researchers should demonstrate and justify the need for the project, identify and outline the potential for risk and clearly state how this will be managed (Alderson & Morrow, 2011; ESRC, 2010).

Related to the issue of protection from harm is the legal requirement of child protection and how to safeguard children during research. For the purposes of this document, the Furey et al (2010) definition of safeguarding is adopted which defines safeguarding as:

1. *Protecting children from maltreatment*
2. *Preventing impairment of children's health or development*
3. *Ensuring that children are growing up in circumstances consistent with the provision of safe and effective care.*

In terms of safeguarding children in a research context, issues relating to the safety and well-being of children may be disclosed during the research process. Furey et al (2010) explain that this may involve reporting harm or the potential for harm to the research team. Therefore, before commencing a research project with children and/or young people, it is advised that the researcher considers the following points:

- One important aspect of safeguarding children and young people effectively is the ability to recognise issues defined as child protection issues and know how to respond to such issues effectively (Furey et al, 2010). The ethics committee advocates that any researcher wanting to conduct a research project with children and/or young people attend a suitable training event on Safeguarding, such as the North Yorkshire Safeguarding Children's Board E-Learning Basic Awareness Course and Child Protection.
 - The committee can discuss safeguarding issues with colleagues and signpost towards appropriate sources of support when making decisions about Child Protection issues and referral issues.
- It is a legal requirement for all organisations regarding children and young people to have a Safeguarding Policy. When working with such organisations it is important that researchers are aware of this policy and the process for reporting a child protection issue.
- If a researcher is recruiting children and young people at home, therefore not through a child/youth based organisation, it is advisable that they liaise with the local authority and are aware of local safeguarding policies and procedures.
- At the time of writing, the CRB process for working with children and young people is currently under review. The new Independent Safeguarding Authority (ISA) is now responsible for vetting and barring individuals working with vulnerable groups. It is currently unclear when individuals need to be vetted; however, the committee suggest that anyone wishing to conduct research with children and young people be vetted through the ISA (<http://www.isa.homeoffice.gov.uk/>).
- The committee wish to stress that at no point can anonymity and confidentiality be guaranteed when working with children and young people because of safeguarding requirements. Therefore, when planning a research project researchers are required to ensure that they are able to identify an individual participant should a child protection issue be disclosed.
 - The committee suggest the use of a coding system, assigning codes to individual participants names or by asking key indicator questions such as date of birth and house number, which can be used to identify an individual participant. If a child protection issue is disclosed this is then reported via the relevant process.

- The screening of data for the disclosure should be completed as soon as data are collected; this will of course depend on the method employed, i.e. if interviewing a child, this will involve immediate identification of a problem. However, if data are collected via questionnaire this would involve the researcher checking the questionnaires to ensure such an issue has not been reported.
- Once data have been screened, this identifying data should be removed from the dataset.
- When explaining a research project to participants, researchers should never promise anonymity or confidentiality. Instead, it should be explained, in an appropriate manner, that where possible this will be the case unless it is disclosed that the participant or another child are at risk of harm.

Additional Points

The additional issues such as participants' rights to withdraw, deception, use of incentives and debriefing are the same when working with a child/ youth sample, as outlined in the YSJU Ethics Guidelines document. However, researchers need to ensure that this information is communicated in a manner appropriate to the participants.

References

Alderson, P., & Morrow, V. (2011). *The Ethics of Research with Children and Young People: A Practical Handbook*. London: Sage.

British Educational Research Association (2004). *Revised Ethical Guidelines for Educational Research*. Cheshire: BERA.

Ellickson, P.L. and Hawes, J.A. (1989). An Assessment of Active Versus Passive Methods for Obtaining Parental Consent. *Education Review*, 13(1), 45-55.

Economic and Social Research Council (ESRC), (2010). *The Framework for Research Ethics*. Downloaded from:

http://www.esrc.ac.uk/images/Framework_for_Research_Ethics_tcm8-4586.pdf

Furey, R., Kay, J., Barley, R., Cripps, C., Shipton, L. and Steill, B. (2010). Developing ethical guidelines for safeguarding children during research. *Research Ethics Review*, 6(4), 120-127.

Greig, A., Taylor, J. and MacKay, T. (2007). *Doing Research With Children (2nd Ed.)*. London: Sage.

Jason, L.A., Pokorny, S. and Katz, R. (2001). Passive Versus Active Consent: A Case Study in School Settings. *Journal of Community Psychology*, 29(1), 53-68.

National Children's Bureau (2003). Guidelines for research. London: NCB.

Tisdall, E.K.M., Davis, J.M. and Gallagher, M. (2009). *Researching with Children and Young People: Research Design, Methods and Analysis*. London: Sage.

The Society for Research in Child Development (SRCD) (2007). SRCD Ethical Standards for Research with Children. Washington: SRCD.