

## Ethical Guidance for Undertaking Research with Children and Young People

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### Contents

- [Introduction](#)
- [Choice](#)
- [Consent](#)
- [Risk, Harm and Distress](#)
- [Benefit](#)
- [Privacy and Confidentiality](#)
- [Dignity](#)
- [References and Further Reading](#)

### Introduction

Ethical principles aim to ensure that all aspects and stages of research conducted by and on behalf of Edge Hill University (whether by staff, students or associates), either with children and young people directly or through impact upon their lives, should ensure respect and fairness and protect vulnerable participants from potential harm. It is understood that research is undertaken to promote the general good.

This document should be read in conjunction with the [Edge Hill University Code of Practice for the Conduct of Research \(RO-GOV-01\)](#) and the [Edge Hill University Framework for Research Ethics \(RO-GOV-03\)](#).

This guidance document applies to all aspects and stages of research projects undertaken by those working on behalf of Edge Hill University that involve or impact upon the lives of children and young people.

It covers the following areas:

1. Choice
  2. Consent
  3. Risk, Harm and Distress
  4. Benefit
  5. Privacy and Confidentiality
  6. Dignity
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## Choice

[Contents →](#)

- Children and young people have the right to be informed, to express a view and to influence decisions.
- Information about research should be provided in a language style that is accessible to the specific age group of children from whom consent is sought.
- It should be clear that if a young person declines participation at any stage their relationship with those around them will not be affected.
- Children or young people should be provided with time to question about how participation in the research will affect them or their parent / guardian.
- Including minority groups in research is important and the information provided about research should be sensitive to the individual's culture or learning needs. Cultural sensitivity within the research process will attend to the need for interpreters, the language used in information sheets and a consideration of a range of issues (for example, religious fasts) that may affect the conduct of the research (for example, the study time line).

## Consent

[Contents →](#)

- Research with children and young people should be carried out with appropriate consent.
- Despite the absence of a law outlining the process for obtaining consent, the 'competence principle' demands that it must be established that an individual is competent to consent to research. This means that the researcher must ensure that the opportunity is given by which it can be established whether or not the individual has 'sufficient understanding and intelligence' to know what the research involves.
- Young people are normally presumed to be competent to give consent on attaining the age of 18. Exceptionally a child may be deemed Gillick<sup>1</sup> competent in which case "*Parental right yields to the child's right to make his own decisions when he reaches a sufficient understanding and intelligence to be capable of making up his own mind on the matter requiring decision.*"<sup>2</sup>
- The term Fraser competence is reserved for the special case of contraceptive advice to persons under the age of 16 whose consent alone may be acceptable.<sup>3</sup> In all other cases, if there is concern about whether the child is competent to consent for the research project the voluntary agreement of an adult parent / guardian should be sought before the child or young person becomes involved in research.

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<sup>1</sup> See [Gillick v West Norfolk & Wisbech Area Health Authority \[1985\] UKHL 7 \(17 October 1985\)](#) from the British and Irish Legal Information Institute (BAILII) website

<sup>2</sup> [http://www.nspcc.org.uk/inform/research/questions/gillick\\_wda61289.html#Further\\_reading](http://www.nspcc.org.uk/inform/research/questions/gillick_wda61289.html#Further_reading)

<sup>3</sup> Wheeler, R.(2006) Gillick or Fraser? A plea for consistency over competence in children: Gillick and Fraser are not interchangeable. *British Medical Journal*, 332 (8 April): 807.

- Young people are often invited to participate in research as members of cohorts, particularly in educational research. In such cases, persons in authority in schools, colleges and educational, sporting, youth work or other community settings may act as gatekeepers. The informed consent of the child and their legal carer must be ascertained by the gatekeeper.
- When consent for research is through a gatekeeper, the interests of the gatekeeper should also be taken into consideration.
- For research with individual children or young people, written consent should be obtained, but if the participant cannot sign, a mark on the document is acceptable.
- Consent for cohort research is sometimes assumed in the event of legal carers raising no objections within a reasonable time scale. This should only be the case where the research is non-intrusive and of low risk level. Ethics committees should not approve such a process if they have doubts about the potential welfare of any participant for whom consent is assumed through non-objection.
- It is important to note that there are additional strict guidelines for children who participate in clinical trials that must be adhered to.
- Ethics committees have a duty to satisfy themselves that those involved in securing consent are competent to do so.

## **Risk, Harm and Distress**

[Contents →](#)

- Historically children have been excluded from research that may have benefited them or other children because of a desire to protect them from harm and risk. There is a balance, however, to be struck between the risk of harm and the potential benefits to children through participation in research
- The response to risk of a child or a young person may be unpredictable and a procedure or research process that, 'bothers one child may not bother another'. All concerned in the process of the research need to identify what they understand as 'risks' that are involved for the child or young person because of their participation in the research project.
- Children and young people who are involved in illegal activities (for example, under age sex) will need special precautions to safeguard their participation in research. Those who are key workers for the child or young person may need to be consulted in anticipation of ethical dilemmas.
- Expectations must be carefully managed during the research process. The limitations of the research should be explained at the outset so that children or young people do not have hopes raised that issues or problems discussed in an interview will be resolved. The limitations of the researcher role must be clearly explained.
- Details of support services should be known to the researcher and available and accessible for the participant. Support during the research from a friend may assist the child or young person if sensitive issues are raised. The facility to debrief after participation should be made available where necessary.

- Research with young people may also pose a risk of harm or distress to the researcher, or other workers with access to the data. This is a particular risk in qualitative research where data may have an emotional content through the disclosure of distressing aspects of children's lives. Such risk should be anticipated and structures to support those affected by such processes as the coding of interviews should be available.
- Researchers who work directly with children or young people must undergo security screening, for example, through enhanced Criminal Records Bureau (CRB) clearance. In the case of foreign nationals undertaking research, the equivalent clearance must be obtained from the relevant government or agency, and the additional time in obtaining such clearance needs to be taken account of in planning the research.
- As a potentially vulnerable and relatively powerless group in society children are often not in a position to challenge potential misrepresentations of themselves in research. This should be taken into consideration when developing mechanisms for the involvement of children and young people in research, particularly in terms of a dissemination strategy.
- The following are some questions that may help guide the researcher in the assessment of harm and distress:
  - How severe may the harms associated with the research process and procedures be?
  - How likely are the harms to occur?
  - How invasive or intrusive is the research? (Note that these concepts would be applied just as much to the possibility of social/psychological invasion and intrusion as physical)
  - Might adverse effects be brief or long-lasting, immediate or not evident until years later?
  - Are a few children drawn into many research studies because they are available?
  - Might an effect not regarded as adverse at the time of the research become so in the future when the child is older?

## **Benefit**

[Contents →](#)

- The research may not benefit the participant directly but have a recognized benefit for other children and young people in the future.
- The following are some questions that may help guide the researcher in the assessment of harm and distress:
  - How significant, severe or how common is the phenomenon that the research aims to address?
  - How is the knowledge gained likely to be used?
  - Will the research benefit the child participant or other children?
  - Will the potential benefit be limited because of expense or difficult access?
  - Is there a less intrusive research method that could be used?
  - Are the benefits immediate, brief, long lasting or not evident until years later?
  - Should a wider range of children be offered the potential benefit of participating in the research?

## Privacy and Confidentiality

[Contents →](#)

- A consideration of best interests may mean that the child or young person may be encouraged by the researcher to include their parent or guardian. However, if competent children do not want to involve their parent / guardian this should be respected.
- Any decision to disclose confidential information to a third party must be explained to the competent child before disclosure.
- Research data given in confidence may be liable to a court subpoena and research participants should be informed of this fact in relevant circumstances.
- In the case of medical research, general practitioners may need to be informed if the research is related to the child's or young person's health care. The consent form should request consent to inform and update the child's GP of the participant's involvement in the research. If the child or young person resists information being provided to the parent, guardian or GP when deemed necessary the researcher must refer back to the ethics committee that assessed the protocol for research.
- Researchers have responsibilities within the context of safeguarding children if they have reasonable cause for concern that a child is suffering harm. In this case, the researcher has a responsibility to liaise urgently with social services or the clinical carers of the child or young person. Relaying sensitive information should be discussed with the child by the researcher prior to disclosure.
- When personal records are explored retrospectively (for example in public health research) data protection issues need to be adhered to. Research data should be stored securely and adhere to the Data Protection Act (1998).

## Dignity

[Contents →](#)

- Dignity should be preserved for all involved in research. Therefore, the researcher needs to minimize any inconvenience, intrusion, embarrassment, coercion or distress within the design of the protocol.
- Researchers should be sensitive to cultural issues, concerns and values that the child or young person may hold. For example, the acknowledgement of religious fasts should be taken into consideration.
- Where the child displays special needs, information should be provided in an appropriate format and the skills of a specialist colleague may be required as a facilitator or as an advocate.
- Disparity between the power and status of the researcher and the participant child(ren) or young person(s) should be addressed within the research design.
- Researchers should acknowledge the participants and dignify their involvement by routinely providing feedback about the research.

## References and Further Reading

[Contents →](#)

### ***Child-Centred Research Ethical Codes***

Centre for Children and Young People (2006) *CCYP: Code of Ethical Research Practice*, Southern Cross University, NSW, Australia, available at: <http://ccyp.scu.edu.au/index.php/6/?hl=ethical+practice>

Children's Research Centre (2006) *Ethical Guidelines*, Trinity College, Dublin, available at: <http://www.tcd.ie/childrensresearchcentre/about/ethics.php>

United Nations (1989) *United Nations Convention on the Rights of the Child*, available at: <http://www.unicef.org/crc/>

### ***Relevant Professional Organisations Ethical Codes***

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