DE MONTFORT UNIVERSITY LEICESTER

Research Services Directorate

ETHICAL CONSIDERATIONS FOR RESEARCH INVOLVING CHILDREN AND YOUNG PEOPLE

Created and Modified:	01 March 2022
Last Updated	01 March 2022
Author:	Susie Fowler
Originating Department:	Research Services Directorate
Approved by:	DMU Research Ethics Committee

DE MONTFORT UNIVERSITY

Ethical Considerations for Research Involving
Children and young People

Contents

1 Introduction

If research involves children and young people (CYP), many of the ethical considerations that apply to adults will still remain, however there are additional concerns that need to be addressed to ensure the protection of the CYP and integrity of the research project.

In England, Northern Ireland and Wales, a person is considered a child up to their 18th birthday, when they legally become an adult. Scotland is slightly different in that for most cases a person is still classed as a child up to 18, but there are some circumstances where this is reduced to 16. Should your research involve CYP in Scotland, please seek guidance from the relevant Scottish authorities.

The Economic and Social Research Council (ESRC) in ***Research with Children and Young People*** have set out ten points for consideration:

- Children's potential vulnerability to exploitation in interaction with adults, and adults' specific responsibilities towards children
- The differential power relationships between adult researcher and child participant, and how this may affect the child's right to withdraw or decline participating in research
- The role of adult gatekeepers in mediating access to children, with associated ethics issues in relation to informed consent
- The expectations of the child participants and their parents/carers, gatekeepers and whether the involvement in research is meaningful for the children
- The children's understanding of the purpose of the research and what they are contributing to
- Whether the information on the research and requested tasks is provided to the children in an accessible way
- Providing information on potential disclosure and breach of confidentiality and the reasons that this may occur
- Incentives and compensation for participation for children and young people, and how this may affect the principle of voluntary participation and freely-given informed consent
- Whether data deposit has been explained appropriately and in a way that children can understand
- Legal requirements of working with the specific population (including Disclosure and Barring Service clearance).

Additionally, The British Educational Research Association (BERA) in *Ethical Considerations for Educational Research,* sets out further regarding a researcher's responsibilities to participants:

> 'The Association expects researchers to be mindful of the ways in which structural inequalities – those, for example, associated with 'race', gender, LBGT+ issues and socio-economic status – affect all

> social relationships, including those that are formed in the course of research. Where relevant, attention should be paid to the ways in which such inequalities specifically affect children and young people, and their relationships. Sensitivity and attentiveness towards such structural issues are important aspects of researchers' responsibilities to participants at all stages of research, including reporting and publication.' (BERA 2018, p.6)

These guidelines hope to raise awareness of these potential areas for concern, with additional reading to be found at the end of the document.

2 Practical Considerations

2.1 Gatekeepers

The term 'gatekeeper' in the context of research refers to the person managing the environment in which the research is to take place (e.g. head teacher of a school) or the parent/carer of a CYP.

Parents/carers will naturally have a vested interest in any activities involving their children and will need to understand the validity of the research, as well as possibly having to provide consent. As such it is important to consider the following:

> 'BERA's principles of consent apply to children and young people as well as to adults. However, researchers may make different decisions as they deem appropriate for children and young people of different ages and capacities. BERA endorses the United Nations Convention on the Rights of the Child (UNCRC); the best interests of the child are the primary consideration, and children who are capable of forming their own views should be granted the right to express those views freely in all matters affecting them, commensurate with their age and maturity.
>
> Researchers following the UNCRC will take into account the rights and duties of those who have legal responsibility for children, such as those who act in guardianship (parents, for example) or as 'responsible others' (that is, those who have responsibility for the welfare and wellbeing of the participants, such as social workers). This may involve gaining the consent of those responsible for children, such as a parent or guardian.' (BERA, 2018, p.14-15, section 23 & 24)

When conducting research within a service/ school etc., the first priority is to gain approval from the person in overall management of the setting by providing full written details of the research proposal. Please also refer to Section 3.1 Consent and Gatekeepers. They will likely wish to see evidence of:

- Whether the project is of interest and value to their organisation
- Sight of ethical and safety reassurances

- Details relating to the level of burden the project is likely to put upon participants and staff
- Copies of any relevant DBS checks
- Sight of any additional documentation – relevant institutional policies and/ or guidelines
- Appropriate child protection procedures

It is important not to allow the gatekeeper to pressurise certain participants into being accepted into the study. They may have their own agenda and try to recommend only those who they feel would be most beneficial to their organisation's reputation.

When establishing contact with a service/ school etc. it is good practice to allocate one person from the research team (if applicable) to liaise and make arrangements. This can foster a good working relationship and minimise the possibility of any misunderstandings.

In certain circumstances, it may be necessary for the parent/carer/gatekeeper to be present during the research activity, however they must understand the importance of their neutrality and must refrain from attempts to influence the participants. For example:

- The child may request the presence of their parent/carer or the gatekeeper
- The research involves a CYP with disabilities who may have support or communication needs
- A group setting, such as a classroom, may require a teacher/ teaching assistance to be present to assist with discipline

There are some instances where the presence of the parent/carer/gatekeeper would be discouraged to minimise the likelihood of data being biased. For example:

- In a one-to-one interview, a CYP may feel pressured to give the answer they feel is socially correct, or feels the researcher/parent/carer/gatekeeper specifically wants to hear
- The CYP may feel unable or uncomfortable discussing personal information
- In a service related environment, if the gatekeeper is present, the CYP may not feel able to talk honestly regarding the service.

2.2 Location & Environment

It is important to be aware that the environment in which the research is being conducted may have an impact on the CYP and affect the responses they offer. Some settings may feel overly formal and imposing to a CYP. Additionally, conducting the research in the location the CYP normally attends to access a service may be confusing and, in a school setting, the CYP could feel pressured into giving the 'right' answer. It is a good idea to look for appropriate alternatives, if possible.

If you are intending to conduct research in a school or learning environment, it is important you also refer to the guidelines issued by BERA (British Educational Research Association) as these will help to shape your research ethics.

2.3 Power Balance

The CYP may automatically view the adult conducting the research as being a figure of authority and this power imbalance between researcher and the child participant may affect the data collected. It is important to be mindful of structural inequalities and issues of identity (BERA, 2018, p.6, section 2) so a conversation with school teachers/guardians etc., may be important in these circumstances. The researcher can try to minimise this effect by:

- Promoting a relaxed atmosphere
- Making sure that the CYP understands the session is not a test and that there are no right or wrong answers
- Dressing in a more informal manner
- Providing an informal seating/ room layout, rather than positioning behind a desk, as this automatically sets a barrier between researcher and CYP.

2.4 Providing Feedback

When providing feedback or informing the CYP about the outcomes of the research that they have been involved in, ensure an appropriate format is used and if possible produce two versions – one for the CYP and one for the parent/carer/gatekeeper.

Highlight those findings which will be of most interest to the CYP and always include a 'what happens next' section.

2.5 Accessibility, Inclusion and Diversity

There are some groups, as identified by the **UN Committee on the Rights of the Child**, who may not be in control of, or be able to fully access their rights and it is important to ensure that the research sample **does not exclude** these groups. An example would include sampling CYP via a school which means that any CYP not in mainstream education (e.g. home-schooled children) would be excluded. Other groups include:

- Very young children
- Young parents
- 16-18 year olds
- Black and minority ethnic CYP
- CYP with disabilities
- Those in public care
- Refugee/ asylum seekers
- Those in trouble with the law
- CYP living in poverty
- CYP affected by violence, abuse and/ or neglect
- Lesbian, gay, bisexual and transgender CYP
- Those from a traveller community

Research budgets may be an important issue if the sample contains participants whose first language is not English and a translator could not be afforded.

The exclusion of a particular group in the sample would need to be acknowledged along with any possible implications to the research findings.

2.6 Age

Research design will be affected by the age of the CYP participants. CYP of secondary school age will be able to interact with most methods that would be employed for adult participants, such as questionnaires or interviews. Those at primary school may not be able to interact and respond as well with formal, structured methods and settings (see BERA, p.15, section 25). If the study is aimed at very young children, additional considerations need to be taken into account in relation to the following:

- Ensure that the research project can be explained in such a way that it is understandable to the young child and that informed consent can be obtained
- The level to which the child can understand their contribution to the research must be clearly established
- Consider a multi-method approach and ways to supplement the data obtained from the child with information/ data gathered from adults/ gatekeepers known to them
- Consider employing a wide range of creative methods that will actively engage the child
- Taking into account children's ability to concentrate for periods of time, you may require a series of shorter sessions, rather than one longer one.
- Participation in the research must always be in the child's best interests.

Parents/carers and gatekeepers can be important during research involving very young children to help them understand the processes of data collection and help the child feel comfortable with the situation, but also to aid communication between the infant and the researcher. **Care must be taken to ensure that the adult does not influence the findings of the data collection.**

2.7 Disclosure Barring Service (DBS)

For any research involving vulnerable groups – CYP included – researchers will need to consider whether clearance will be required through the Disclosure and Barring Service (DBS).

Please refer to the DMU Disclosure and Barring Checks Policy for full information on eligibility and applying for a DBS check. For Undergraduate and Taught Postgraduate students, this may be dealt with via their Faculty and initial enquiries should be made to the relevant Student Advice Centre.

3 Informed Consent

Informed consent is required from a parent or carer where it is viewed that a child is incapable of understanding the implications of taking part in a study or where the child is regarded as incompetent to consent. One parent can provide consent, but it is preferable to have consent from both where applicable. A child who is not capable of giving consent alone can still be involved in the decision-making process with others who are able in law, to provide consent. For the purpose of these guidelines, a CYP is anyone under the age of 18 and it is considered best practice to seek parental or carer consent. However, DMU acknowledges that there some circumstances in which it might be appropriate to waive the need for parental consent, or to seek informed consent directly from a CYP. Where such approach is being taken it must be fully justified in the researcher ethics application.

Although the power to consent, in law, is that of their parent(s) or legal guardian, the child's assent is advisable. Assent is difficult to define and is used in diverse ways, e.g. compliance by a child as young as three, through to the active agreement of a young teenager etc. Assent is agreement given by a child / young person, or others who are not legally empowered to give consent. It is important to provide children / young people with information that matches their capacity when seeking assent, and consider how best to record when assent is given. Researchers may also want to consider how they will respond to signs of dissent from the CYP. I

NB: 'While parental consent is required, a parent cannot consent *on behalf* of the child' (National Children's Bureau, 2011, p. 29)

It is also noteworthy that the person providing consent must have 'parental responsibility' (as defined in the Children Act, 1989), and it should not be assumed that a person responding to the term 'parent' has such status. Consent forms can be used to confirm the person giving consent has parental responsibility.

The National Children's Bureau (NCB) also set out possible exceptions and special circumstances around parent/carer consent, as follows:

Situation in which parental/carer consent *may* be required for CYP aged 16+

- You should always seek a parent or carer's consent if conducting an interview with a young person under the age of 18 in the family home.
- For particularly vulnerable 16-18-year olds (for example if they have a learning disability), or if the research is on an exceptionally sensitive or troubling topic, you may consider it appropriate to seek parental/carer consent.
- For looked-after CYP up to the age of 18, consent must be obtained from their social worker.

Situations in which parental/carer consent *may* be waived for CYP under 16

- If the research in question (often evaluation) is integral to a project, service or intervention that the child is already involved in, and parent or carers have already given consent for the child to participate in the project, then it may not be deemed necessary to additionally obtain consent for the child to participate

in the research/ evaluation. Seek clarification about the nature of consent already obtained from project staff, and consider the sensitivity of the research and the burden of participation before deciding whether it is appropriate to seek parental/carer consent. In such circumstances, you may consider informing parent/carers of their child's involvement in research either directly or through the organisation (a weak form of opt-out consent)

- If seeking parental consent would potentially breach a child's right to confidentiality, for example if they were using a service such as a drug treatment agency or sexual health service without their parent's knowledge, then it may be waived.

Further guidance on how to develop Participant Information Sheets/Consent documents for children can be found on The Health Research Authority (HRA) website.

Further information on this can be found in the 'Further Reading' at the end of the document.

It is essential to allow the CYP time to consider the participant information and talk through their decision with a trusted adult. Be available to discuss any concerns raised by the CYP. Consent should always be gained ahead of time prior to commencement of the study. NCB suggest the amount of time allowed can vary, depending on the age of the child – where a teenager may be expected to sign initial consent a week prior to the start of the study, it may be more appropriate to reduce this to a few days for CYP around 10 years and possibly less for those younger. Where consent is being given by a CYP, it is recommended that permission is also given by a responsible adult.

The CYP must understand that they are taking part in the study voluntarily, have the right to refuse to take part and can withdraw at any point, without consequence. Use regular reminders during the course of the data collection to reassure the CYP that the process can be stopped at any point if they feel uncomfortable. Setting up a system of cues can be a good way for the CYP to stop the process or ask a question.

If the research involves a group setting and participant information is provided to the group as a whole, each CYP is still required to provide individual informed consent.

3.1 Consent and Gatekeepers

In order to fully comply with the principles of voluntary informed consent, this should be obtained from the CYP. Where a research project involves CYP in an environment protected by a gatekeeper (school etc.) it may be that the CYP initially receives information regarding the research from the gatekeeper. The researcher should be alert to any underlying pressures that could be put upon the CYP to participate (or not) and make sure the gatekeeper is briefed around the importance of voluntary consent from the CYP.

If a CYP is unable to give informed consent (e.g. babies), this should be sought from the parents/carers and measures implemented to agree signals that may indicate the child wishes to withdraw.

You should take into consideration the ethical guidelines issued by the British Educational Research Association (BERA), specifically sections 23-26 which follow Article 12 of the United Nations Convention on the Rights of the Child (UNCRC):

1. Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child.
2. For this purpose, the child shall in particular be provided the opportunity to be heard in any judicial and administrative proceedings affecting the child, either directly, or through a representative or an appropriate body, in a manner consistent with the procedural rules of national law.

Thus, if the CYP are considered too young to be able to understand and provide informed consent themselves, assistance should be given in order that the CYP is able to *assent* to taking part in the research with consent being provided by those who have legal responsibility for the child. This could be those acting in guardianship (parents/carers), or as responsible others (those with responsibility for the wellbeing and welfare of the CYP such as social workers).

It may also be appropriate to consider using opt-in or opt-out procedures, where appropriate in the context of the research – see BERA guidance Section 26.

4 Safeguarding

The **DMU Safeguarding Policy** should be referred to in respect of the institutions guidance, alongside other relevant legislation and guidelines.

Unfortunately, there are times during a project that the researcher may come into contact with CYP who are at risk of significant harm. Therefore, when working with CYP as research participants, it is important that the researcher is fully aware of their responsibilities towards the CYP and any key guidance/ legislation on their professional duty to report concerns of this nature. The research team should be prepared for the potential disclosure of any safeguarding concerns.

It is important to be alert to any potential signs of neglect or disclosure of abuse, even though this may present a conflict in relation to maintaining anonymity, *if* information is disclosed that indicates possible harm to a CYP.

A further consideration is the possible impact of the research on the child, at the time and at a later date. This is particularly important where the CYP has been discussing painful or difficult experiences

If safeguarding issues are raised, confidentiality cannot be guaranteed. It is important that the CYP or their parent/carer is made aware of the limits of confidentiality

during the information sharing and informed consent process at the start of the research project and reminded throughout any interview sessions. This may present moral dilemmas if the researcher becomes aware of safeguarding issues – researchers have a duty to protect the CYP, but need to be mindful of the legalities of breaking confidentiality in relation to data protection laws. The Data Protection Act is not a barrier to sharing information but provides a framework to ensure that personal information about living persons is shared appropriately.

More information can be found on the DMU Safeguarding webpages.

4.1 Reporting Concerns

If research is being conducted at an establishment (e.g. school) *away* from DMU, the organisation involved will have its own procedures pertaining to safeguarding and these should be followed, if there are any safeguarding concerns.

If the research is taking place on DMU campus, or in a context where no safeguarding policy is in place, please refer to the **DMU Safeguarding Policy** for guidance on reporting concerns.

NB: There is nothing within the DMU policies which prevents members of staff reporting safeguarding concerns directly to the police or social services, however if this is the chosen course of action, you should always inform the designated Safeguarding Co-ordinator that you have done so, in order that a central record can be created.

Ideally, if it is known that children (or vulnerable adults) are likely to be involved in the research, it may be more practical from a safeguarding perspective to complete the research on DMU premises, or within an organisation which has a Safeguarding policy in place. If there is a valid reason why this cannot occur, greater consideration should be afforded during the risk assessment and ethical approval processes.

5 External Agency Authorisation

Where research involves the study of CYP who are accessing various services (e.g. NHS or Local Authority), additional permissions and/ or approval may be required, as below:

5.1 Children and Family Court Advisory and Support Service (CAFCASS)

Approval for research involving CAFCASS will need to be sought from CAFCASS Research Governance Committee.

5.2 Local Authority Children's Services

If research involves participants who are accessing Local Authority Children's Services, additional approval forms may also be required from the Association of Directors of Children's Services (ADCS) – see below, the local authority research governance team **PLUS** permission must be sought from the service you wish to

recruit the sample from.

5.3 Association of Directors of Children's Services (ADCS)

ADCS review the worthiness of projects and to ensure that the main concerns of the departments involved are reflected. Applications can be made via the ADCS website and maybe subject to a fee (dependant on the type and size of the research). Further guidelines and the application form can be accessed here, and where needed approval must be sought before approaching any children's services.

If less than three services are involved in the research project, ADCS approval is not required, and the local authority can be approached directly.

5.4 Health Research Authority (HRA)

For any health and social care research involving NHS service uses or patients and any carers/ relatives, the HRA have approval processes in place which also generally include an ethical application/ approval. Applications are made via IRAS. For further information and detailed guidance, please click here.

6 Ethics Application

When writing your ethics application, you must consider and include the following:

- Clear justification as to why you want to do research with CYP. (E.g., can the information available from the research be sought from individuals other than CYP?)
- As CYP as classed as vulnerable (being under the age of 18), details of how they will be protected
- Details of what support is in place for any disclosure that may be made to you during the course of your data collection
- How you intend to approach/ recruit
- Describe the process that will be used to obtain and record consent from the parent/guardian and to gain assent from the participants, or justification as to why parental assent may not be required for those aged 16/17
- How will feedback be provided to CYP and parents/carers either during or at the end of the project
- Whether a DBS check is required
- How the circumstances in which the research is being conducted provides for the physical, emotional and psychological safety of the child
- How the study method is appropriate for children.

7 References and Further Reading

In formulating this document, the University has been informed by:

- British Educational Research Association [BERA] (2018) *Ethical Guidelines for Educational Research*, fourth edition, London. https://www.bera.ac.uk/resources/all-publications/resources-for-researchers
- The Children Act, 1989 https://www.legislation.gov.uk/ukpga/1989/41/contents
- Department for Education, HM Government, *Working Together to Safeguard Children* (2018) https://www.gov.uk/government/publications/working-together-to-safeguard-children--2
- Economic & Social Research Council, *Research with Children and Young People*, https://esrc.ukri.org/funding/guidance-for-applicants/research-ethics/frequently-raised-topics/research-with-children-and-young-people/
- Health Research Authority Home - Consent and Participant information sheet preparation guidance. (hra-decisiontools.org.uk)
- National Children's Bureau, *Guidelines of Research with Children and Young People*, (2011) Guidelines for Research with Children and Young People (ncb.org.uk)
- The Research Ethics Guidebook, *Research with Children* Research with children (ethicsguidebook.ac.uk)
- The Research Ethics Guidebook, *Does your Research involve Children or Children's Services?* Does your research involve children or Children's Services? (ethicsguidebook.ac.uk)
- UNICEF UK, *The United Nations Convention on the Rights of the Child,* (1990) https://www.unicef.org.uk/what-we-do/un-convention-child-rights/
- NSPCC - Research with children: ethics, safety and avoiding harm

Further Reading

- General Medical Council, *Good Practice in Research and consent to Research (*p. 9 – Areas requiring special consideration) https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/good-practice-in-research
- Health Research Authority, Research Involving Children https://www.hra.nhs.uk/planning-and-improving-research/policies-standards-legislation/research-involving-children/
- INVOLVE, National Institute for Health Research, *Involving children and young people in research: top tips and essential key issues for researchers* (2016). Eastleigh: INVOLVE involvingcyp-tips-keyissues-January2016.pdf
- McCarthy, K. N., Ryan, N. C., Darragh T O'Shea, Doran, K., Greene, R., Livingstone, V., . . . Dempsey, E. M. (2019). Parental opinion of consent in neonatal research. *Archives of Disease in Childhood. Fetal and Neonatal Edition,104*(4) https://www.proquest.com/docview/2243272122?accountid=10472

- NSPCC, *Research with children: ethics, safety and avoiding harm* https://learning.nspcc.org.uk/research-resources/briefings/research-with-children-ethics-safety-avoiding-harm/
- Sheffield Hallam University, *Guidance for Obtaining Consent to Undertake Research with Children in Schools* (2016). Sheffield: University Research Ethics Committee. https://www.sheffield.ac.uk/rs/ethicsandintegrity/ethicspolicy/further-guidance/special-guidance/papers
- Unicef, *Ethical Research Involving Children* (2013). Florence https://www.unicef-irc.org/publications/706-ethical-research-involving-children.html
- University Medical Centre Groningen – The Beatrix Children's Hospital, *Research in newborn infants. Ethical Aspects, recruitment and informed consent.* https://www.ema.europa.eu/documents/presentation/research-newborn-infants-ethical-aspects-recruitment-informed-consent-pieter-jj-sauer_en.pdf

8 Document Version Control & Update Information

Version	Date	Updates	Changes made by
0.1	01.03.2022	Final Version	S.Fowler (Research Services)