

1. Tagline **Find important information here on [ethical considerations relating to] RESEARCH WITH CHILDREN AND YOUNG PEOPLE**
2. Brief intro
Involving children in research is essential to ensure that this addresses their unique needs and has a benefit to them. Researchers should also consider the ethics implications of silencing and excluding children from research about their views, experiences and participation.
- While it is often not scientific or ethical to apply the findings from adult research to children, many of the ethics considerations that are relevant to adults also apply to children and young people.
- Researchers should always ensure that risk and harm in research involving children and young people is minimised and put adequate safeguards in place for all of those involved.
3. High level principles / considerations
Children should be included as active participants in research even if their ability to express their views and needs, make independent decisions or confirm consent is limited due to their age, competency or stage of development. Researchers should consider children's competencies and potential vulnerabilities based on the purpose and context of the research as well as factors such as age, gender, socio-economic circumstances, and disability. Adult researchers can reduce the vulnerability of children in research by offering appropriate support and working with children.
- In developing and conducting research involving children, researchers should consider the following:
- The research aims must be relevant to children
 - The research offer should be 'fair', with a balance of risks and benefits when viewed from the perspective of children and their parents/carers
 - The expectations of child participants and their parents/carers (or gatekeepers) when choosing to take part in research
 - How to best support children and their parents/carers to make shared decisions about taking part in research
 - Whether involvement in research is in the child's immediate and longer-term interests, and meaningful for the child.
 - The use of 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
 - Research is a partnership with the child and/or family, who should be kept informed and given the opportunity to consent at different stages of the project.

Safeguarding children

Children are potentially vulnerable to exploitation in interaction with adults, and adults' have specific responsibilities towards children.

Researchers working with children in health and social care settings should have appropriate training in child protection and understand when and how to raise a concern. Researchers have a responsibility to ensure

they have procedures in place at the outset of a study to manage any safeguarding concerns that may arise.

In most cases, researchers working with children and young people will need to secure [Disclosure and Barring Service \(DBS\) clearance](#). The DBS offers organisations a means to check the criminal record of researchers to ensure that they are suitable for work with these groups.

Consent

Children should be provided with information about the research in a way that they can understand, including information to explain when potential disclosure (for example for child protection reasons) might be needed. Children should also receive age-appropriate information about the uses of their personal data.

A child's ability to give consent depends on their capacity to understand what is proposed and to weigh up the risks and benefits. Where assent or consent for research is sought from children aged under 16 years it is good practice to also secure consent from a parent or carer. If a child is under the age of 16 years and they are taking part in a clinical trial of an investigational medicinal product (CTIMP) then consent from a parent or adult with parental responsibility is required by law. Research involving looked-after children also raises complex consent and legal issues, and these should be thoroughly investigated in the context of any proposed research.

Researchers should be aware that the differential power relationship between adult researcher and child participant may affect the child's choice to withdraw or decline participation in research. It is therefore important to ensure that children and young people have the time and opportunity to seek support when making decisions about taking part in research. Children and their parents/carers should be supported to make shared decisions about consent in the interests of the child. Researchers should always respect a child's refusal to participate or continue to participate and, if a child becomes upset, should accept this as a valid refusal.

Researchers may need to consider whether mature children can consent without adult approval in some circumstances, for example where seeking consent from parents could jeopardise research into teenage sexuality or alcohol use.

4. Brief explainer against each document / link

Further information

Key resources

- [UKRI Preventing harm in research and innovation](#)
- [Health Research Authority: Research Involving Children](#)
- [NSPCC: Research with children: ethics, safety and avoiding harm](#)
- [NSPCC: Child protection system in the UK](#)
- [UKCDR Guidance for Safeguarding in International Development Research](#)
- [Disclosure and Barring Service \(DBS\) \(Gov.uk website\)](#)
- [Ethical Research Involving Children \(ERIC\)](#)

<http://www.rcpch.ac.uk/cyp-research-charter>

- Guidance prepared by young people for researchers highlighting how they would like to be involved and considered during the research process

RCPCH resources list

<https://www.rcpch.ac.uk/resources/research-charter-resources>

Legal/Ethics

UKRI/RCUK Schools Policy

<https://www.ukri.org/files/legacy/scisoc/schoolspolicy-pdf/>

- Schools policy/guidance for researchers and teachers

HRA

<https://www.hra.nhs.uk/planning-and-improving-research/policies-standards-legislation/research-involving-children/>

- Specific webpage and materials for Scotland
- Legal framework: CTIMP, non-CTIMPs, over and under 16 years, Gillick competence, assent/consent, lack of capacity

Paediatric CTIMP: https://ec.europa.eu/health/sites/health/files/files/eudralex/vol-10/ethical_considerations_en.pdf

NSPCC

<https://learning.nspcc.org.uk/research-resources/briefings/research-with-children-ethics-safety-avoiding-harm>

- Ethics of involving children in research covers:
 - how to obtain informed consent, retrospective
 - inclusiveness
 - incentives
 - how to manage the risk of harm to participants: stress, distress
 - complaints
 - what to do with the information gathered during the research; confidentiality and disclosure of abuse

NIHR

<https://www.nihr.ac.uk/documents/children-payment-for-participation-report/12085>

- specific report and guidance relevant to payment for participation by children

PPI/co-production with children

Children's Research Centre

<http://wels.open.ac.uk/research/childrens-research-centre>

- [OU initiative to teach children about research and involve them in it](#)

National Youth Agency

<http://www.nya.org.uk/wp-content/uploads/2014/06/YRN-session-1.pdf>

- [Resources for children developing research projects – Young Researcher Network toolkit – introducing CYP to research](#)

GenerationR Alliance Young People's Advisory Groups (YPAGs)

<https://generationr.org.uk/>

- [funded by NIHR;](#)
- [network of YPAGs](#)
- [detailed information about who should give consent and different circumstances](#)

http://generationr.org.uk/wp-content/uploads/2014/10/starchild.full_.pdf

- [GenR is a member of the international iCAN network](#)

<https://www.icanresearch.org/>

Ethical Research Involving Children (ERIC)

<https://childethics.com/>

- UNICEF funded
- evidence-informed guidance for researchers wishing to ensure their research respects the rights, dignity and wellbeing of CYP

DECIPHER

<https://decipher.uk.net/>

- [PH research centre in Cardiff](#)
- [Undertakes research with CYP in schools, etc](#)
- [PPI experience](#)

Save the Children

<https://www.savethechildren.org.uk/content/dam/global/reports/education-and-child-protection/so-you-want-to-involve-children-in-research.pdf>

- Specific advice about involving children in research about violence against children

BANNAR

<http://bannar.org.uk/default%20documents/Working%20with%20young%20people%20in%20research%20updated%20Dec%202018.pdf>

- YOURR Project: YP Opinions underpinning rheumatology research
- Resource with wider relevance for PPI with CYP

National Children's Bureau

<https://www.ncb.org.uk/resources-publications/guidelines-research-children-and-young-people>

- Principles of involving children, guidance and practical tips – in several sections;
- Experienced authors; detailed practical guidance and case studies;
- Not specific for health research

INVOLVE

<http://www.invo.org.uk/wp-content/uploads/2016/01/involvingcyp-tips-keyissues-january2016.pdf>

- tips for involving children