Guidance Paper 2: Obtaining Consent in Research involving Children – Understanding the Legal and Ethical Framework

This guidance paper describes the importance of obtaining consent from and on behalf of child participants involved in research. It is Guidance Paper 2 in the series *The Ethics of Research Involving Children: Common Questions, Potential Strategies and Useful Guidance*.

Ethical research considers the international and domestic law, as well as ethical and professional, obligations towards ensuring that participants provide valid consent. Issues around consent are paramount in research ethics applications. The law and ethics of consent are not just about ensuring that the child is fully aware of the implications of his or her involvement in the research and is kept safe (which might necessitate obtaining consent also from adults with parental responsibility); it is equally about ensuring that overly paternalistic approaches to consent are avoided, as such approaches may unintentionally undermine children's autonomy and prevent children from making decisions and expressing themselves on their own terms. As the ESRC notes in its ethical guidance:

> *"Researchers should consider the ethics implications of silencing and excluding children from research."*[1]

Beazley et al. (2009: 370) refer to this as children's right to be 'properly researched' which 'translates into: children being participants in research; using methods that make it easy for them to express their opinions, views and experiences; and being protected from harm'.[2]

1. Defining and understanding consent and assent for children's research

In basic terms, consent describes the 'informed and freely given "yes" or "no" to take part in research'.[3] It is the decision of an individual who is competent, who has been adequately informed, and who is free from undue influence. It may be written (on a consent form) or oral (recorded).

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[1] ESRC Guide: Research with Children and Young People, available at: https://esrc.ukri.org/funding/guidance-for-applicants/research-ethics/frequently-raised-topics/research-with-children-and-young-people/

[2] Beazley, H., Bessell, S., Ennew, J. and Waterson, R. (2009) 'The right to be properly researched: research with children in a messy, real world', Children's Geographies, 7(4) pp.365-378

[3] Alderson, P. and Morrow, G. (2011) The Ethics of Research with Children and Young People: A Practical Handbook (1st edition)

Consent is distinguishable from **assent**. The term 'assent' describes an expression of a willingness to participate in an activity or study by persons who are deemed unable to give legal consent on their own behalf.[4] In some contexts and jurisdictions, for example in many EU countries, assent is regarded as the principal means of engaging children in research because they are deemed not to have the capacity to consent. In these circumstances the consent of a responsible person (a parent, legal guardian, or carer - see below, section 3) is required along with the assent of the child. In essence, this amounts to:

- Permission from the parent/legal guardian for the child to participate; **and**
- An agreement from the child that they are happy to participate.

Conversely, if the child is deemed mature enough to consent on his or her own behalf, you may ask their parent/guardian to merely 'assent'. In essence, this amounts to:

- Permission from the child to engage them in the research; **and**
- An indication that the parents/legal guardian are happy for their child to participate.

Good practice in obtaining assent or consent for children in research

Having defined and differentiated assent and consent, it is fundamental to highlight what good practice in obtaining assent or consent from children and their parents looks like.

Assent

In so far as possible, the assent of all children who are not competent to consent on their own behalf should be sought.[5] Of course, where parents are providing informed consent they must be provided with complete but accessible information about the study and their child's participation, be given time to consider their decision, be able to ask questions, not in any way feel coerced and be aware of their rights and the rights of their child in respect of participating or not. Just because consent is provided by a parent, researchers must acknowledge that assent should still be approached in a similar way. You should not engage a child in research **solely** on the basis of their parent's/guardian's consent save for exceptional cases of clinical trials involving infants. This is confirmed by Alderson and Morrow (2020, p. 136), leading experts on the ethics of research involving children:

[4] See, A Greig and J Taylor, Doing Research with Children (1999, Sage Publications).
[5] Lambert, V. and Glacken, M., 2011. Engaging with children in research: Theoretical and practical implications of negotiating informed consent/assent. Nursing Ethics, 18(6), pp.781-801.

> *"Instead of referring to 'assent', we suggest that it is more logical to respect the consent of Gillick-competent children and young people, usually along with their parents' consent. This is sometimes possible from around 4 years of age if the children have relevant experience."*[6]

Researchers must explain at an appropriate level what participation involves using child-focused information. This should: explain what the research is for; emphasise that participation is voluntary; explain what will happen when a child participates; explain what choices a child has in terms of participation. Children should be able to have time to think about their decision and be able to ask questions that are answered honestly, in an appropriate environment and at a level that is understandable. Researchers still need to be aware that pressures of power differentials or context can induce children to agree verbally with things that they might in fact not be happy with. This requires the researcher to monitor a child's non-verbal behaviour and to be sensitive for signs that the child is not comfortable with the situation and decision. Finally, assent should be recorded as this is an integral part of the decision-making process.

Consent

Where a child is deemed competent to be able to give informed consent to participation in the research, they must be provided with complete but accessible information about the study and their participation, they must be given time to consider their decision, be able to ask questions, not in any way feel coerced and be aware of their rights in respect of participating or not. Children are not a homogenous group and researchers must consider the different levels of emotional and intellectual development when designing tailored information to aid understanding. This is where consultation with young people's advisory groups (explained in Guidance Paper 1) becomes invaluable. If a child is deemed competent then their consent must be authoritative but assent from parents is often seen as the responsible and most satisfactory addition to a competent child's consent.

Circumstances where parental consent may be problematic

In most cases, it is good practice for parents/legal guardians to be aware of and agree to their children's participation in research. However, if the child is deemed competent to consent on their own behalf, neither the consent nor the assent of the parents need necessarily be obtained. This is particularly relevant where, for example, the child is living independently (in secure or supported accommodation), or if the research touches on issues that the child wishes to discuss without their parents' knowledge (such as experiences of substance abuse, family abuse, or sexuality). The ESRC notes in its guidance (accessed 20 February 2023):

[6] Alderson, P. and Morrow, G. (2020) The Ethics of Research with Children and Young People: A Practical Handbook (2nd Edition) London: Sage, p.138

> *"Researchers should consider whether mature children can confirm consent without adult approval; for example, there may be circumstances where seeking consent from parents could jeopardise the research (for instance, in research into teenage sexuality or alcohol use). In such circumstances, researchers will need to regard the potential risk to the participants of the research as a priority."*[7]

These cases aside, it is usually advisable to encourage the child to at very least inform their parents of their participation in the research. This minimises the risk of creating any tensions or misunderstanding on the part of the parent (for example, parents may be concerned as to the whereabouts of their child during research meetings; or misunderstand the nature and aims of the research and how the data Is being used). Parental assent may also be of practical use (the child might need a lift to the research venue or access to the family computer to participate in the research).

Useful resources

- NSPCC 'Research with children: ethics, safety and avoiding harm. What to consider when conducting research involving children'. (NSPCC, June 2018).
- Nuffield Council on Bioethics, 'Research with children: ethical processes and challenges around the world'. (Nuffield Council, 2016)
- Alderson, P. and Morrow, G. (2020) *The Ethics of Research with Children and Young People*: A Practical Handbook (2nd Edition) London: Sage, Chapter 8

2. What is the legal position for children making decisions?

In general, when considering consent in children's research, we approach this from an ethical perspective because the **law on consent to research is uncertain**. However, it is helpful to be aware of the law regarding consent in England and Wales in other contexts. Much of this has been developed mainly in the context of consent to medical treatment, but the principles can support how we approach consent in research.

- Under the Family Law Reform Act 1969 (section 8) children aged 16 and over are presumed to have sufficient competence to consent to any surgical, medical and dental treatment. A person with parental responsibility can provide proxy consent for a child under 16 to such treatment.[8] For

[7] ESRC guidance, above note 1.
[8] The Children Act 1989, Section 1(1).

this reason, we might presume as researchers that all children under 16 are unable to give consent on their own behalf **but this is not legally correct**.

- The landmark legal decision in *Gillick v West Norfolk & Wisbech Area Health Authority* [1986] AC 112 decided that a **competent minor under the age of 16** can seek (medical) advice and treatment in her own right without the consent of her parents/legal guardian if she has **'sufficient understanding and intelligence to enable him or her to understand fully what is proposed'**. Subsequent cases have emphasised that competent children's freedom to consent to a particular course of treatment (or indeed, a refusal to be treated) on their own behalf is always subject to an assessment of whether or not that decision is in the child's best interests.

- The 'Gillick' test has since been applied to many other areas of decision-making, and is certainly relevant to children's participation in research. As such, **a researcher is legally entitled to allow a child under 16 to participate in their study without their parent's or legal guardian's consent if he/she is satisfied that the child participant has sufficient understanding and maturity to understand the nature, purpose and likely outcome of the proposed research, and provided the child participation in the research is deemed to be in his or her best interests.**

- Under Article 8 of the EU General Data Protection Regulation 2018 (GDPR) researchers are required to get one parent's consent for children under the age of 13 if their personal data is being processed online (see further Guidance Paper 6).

It Is also worth bearing in mind the following legal provisions under the Mental Capacity Act 2005 for persons aged over 16:

- Under the Mental Capacity Act 2005, intrusive research (carried out without consent or in relation to a person who lacks capacity to consent) is **unlawful (s.30)** subject to some very narrow exceptions set out in s.31 where the risks are negligible compared to the potential benefits to the individual's health/condition.

- Section 32 of the Mental Capacity Act 2005 obliges researchers to consult with and obtain the consent of carers of those who do not have the capacity to consent on their own behalf.

- Section 33 of the Mental Capacity Act 2005 prohibits any research/intervention to which the person has or appears to have objected except 'where that is being done is intended to protect him/her from harm or to reduce or prevent pain or discomfort'. A further way this ought to be interpreted is that a young person can also request to be withdrawn from the project without delay unless this would pose a significant risk to that individual's health.

If researchers are seeking to recruit young people over the age of 16 who may lack capacity to provide valid informed consent, there are two ways this may be approached:

- The courts have held that parental consent for a person over the age of 16 will be legally valid, but **assent** for research from the young person would still be an ethical requirement.

- If assent cannot be obtained or the research is clinical, then an assessment of best interests decision under the Mental Capacity Act 2005 would be undertaken. This would involve consultation with those involved in the care of that young person to determine this.

For detailed guidance please see the Mental Capacity Act 2005[9] Code of Practice.

3. Determining 'capacity' and 'competence'

The challenge with legal and ethical guidance relating to consent is that it is often based on an assessment of children's capacity or competence, but how do we assess capacity or competence in a research context? Most researchers are not experts in child developmental psychology (and even in this discipline, approaches to determining competence or capacity are neither conclusive nor uncontested). So, assessments of children's competence and capacity to consent to research are by no means an exact science. Such assessments should, therefore, be made in light of the context of the research, a desire to protect and promote the child's rights and interests, and open, **informed discussion** with the child and any gatekeeper organisations that have assisted with their recruitment. Importantly:

> *"Researchers should not assume that children are necessarily vulnerable and incapable of providing consent because of their age. Researchers should consider children's competencies and vulnerabilities based on the purpose and context of the research as well as factors such as age, gender, socio-economic circumstances, and disability."*[10]

Researchers can commit to doing the following things to enhance children's competence or capacity to consent to and engage in research:

- Making sure that they, as researchers are creating the conditions (for example, a welcoming, safe environment) to optimise the child's chance of participating meaningfully and in an informed way in the research.

[9] Department for Constitutional Affairs. The Mental Capacity Act 2005 Code of Practice. Available from: https://www.gov.uk/government/publications/mental-capacity-act-code-of-practice
[10] ESRC guidance, above note.

- By providing **information** at various points during the research in an accessible way (orally and in writing) and ensuring that the child understands that information (see Annex 1 for a sample child friendly consent form).[11]

- Ensuring that the research team receives **appropriate training** in different methods of working with children.

- By working through **gatekeepers**, such as schools or youth workers, who have good knowledge of the child's abilities and understanding;

- If children and parents have literacy or language difficulties and are unable to consent in writing, their **consent can be audio-recorded** or simple touch-tap digital consent forms with more image-based options can be developed.

Although determining capacity or competence for children is not set out through an explicit framework, there are some legal pointers:

- Under the Mental Capacity Act 2005 (section 3[1]), there is a test for incapacity that involves four elements and that importantly has been used for children.[12] It requires that to make a decision an individual can:

    - understand information

    - Retain information

    - Use and weigh information and

    - Communicate a decision.

- Using the principles set out in Gillick, researchers should ensure that the child understands the risks and intended benefits to them or others of their participation in the research.

[11] See also the templates suggested by Alderson and Morrow in Chapter 8 of their ethics handbook, above note 6. Note that the samples provided are merely examples. Researchers should avoid the temptation to merely copy and paste from these and, instead, think carefully about how your research can be explained to children. The University of Liverpool Young Persons Advisory Group (YPAG) can offer feedback and advice on any draft child friendly information that you create. See Guidance Paper 1 for further details of how to consult with the YPAG.
[12] Re S (Child as parent: Adoption: Consent) [2017] EWHC 2729 (Fam)

4. Why obtaining consent from the child participant reinforces their rights

Obtaining the consent of a child participant, whatever their age or maturity, is in keeping with the UK's obligations under the UN Convention on the Rights of the Child 1989 (UNCRC), an international human rights treaty that has been binding on the UK since 1991. This asserts that the child who is capable of forming his or her own views has the right to express those views freely in all matters affecting them. **Article 13** of the UNCRC further states that:

> *"The child shall have the right to freedom of expression; this right shall include freedom to seek, receive and impart information and ideas of all kinds, regardless of frontiers, either orally, in writing or in print, in the form of art, or through any other media of the child's choice."*

These obligations promote participatory standards and a positive, respectful tone for the whole relationship between researchers and participants.

It is useful to regard consent and assent as an **ongoing process** rather than simply a 'yes' or 'no' at the beginning of the research. Guidance issued by The Council for International Organizations of Medical Sciences states that consent should be a 'meaningful process' involving participants 'in an early and sustained manner in the design, development, implementation…and monitoring of research, and in the dissemination of its results'.[13]

With this in mind, researchers should build into their research opportunities for participants to reaffirm their consent at different points. This might be at the beginning of a new phase in the work, at the point of data analysis or just before dissemination of the results. Such consent should be informed by up to date information about the nature of the new phase/the results that will be reported. **Renewing consent** at these different stages allows the potential participant to take ownership of their participation and to remain engaged in the project. Respect for children's consent also minimises the likelihood of overlooking any risks that children may be exposed as a result of their participation in the project as it progresses.

[13] (CIOMS) (2016) International Ethical Guidelines for Biomedical Research Involving Human Subjects. Geneva: CIOMS, p.33, cited in Alderson and Morrow, above note 6 at p. 156

Key considerations for obtaining consent from and for children participating in research

Having explained what good practice looks like for obtaining consent or assent from children participating in research, we now set out some key considerations for researchers. These considerations will aid researchers in approaching the consent checklist in the next section.

- It is important to recognise that power relationships exist between children, as well as between adults and children, and this can impact on the equality of children's participation in research, both in terms of access to and actual participation during research projects. The nature of power relations between adults and children means that it can be difficult to ascertain that children's consent is given freely. Approaches to consent, as well as research design, can be employed as a way of minimising power imbalances and supporting children's participation. The order in which consent is gained, as well as from whom, should be considered carefully.

- It is fundamental that the approach to consent that is adopted is tailored to the specific considerations of the participants. For example, children of different ages may benefit from different – or a combination of – ways of presenting information on the study, such as audio, visual, pictorial explanations of the study. In some circumstances it may be appropriate to audio-record consent. In other circumstances, signed consent forms may be more appropriate. Researchers should consult the guidance resources highlighted in these papers when considering approaches to consenting children.

- Certain forms of data, such as audio and visual data, are considered to be highly sensitive, and specific consent should be sought for the processing of this type of data. It will be important to take steps to ensure that children understand how their audio or visual data will be used (see Guidance Paper 6).

- Respecting individual privacy and confidentiality in the context of focus group can be challenging and requires careful reflection; particularly for research which draws on internet chat rooms and blogs. It is important that the consent process is explicit on the risks and expectations involved in such studies (see Guidance Paper 3 and Guidance Paper 4).

- Dissent, or the participant's refusal to participate in, or withdrawal from, the research much be respected. Researchers should consider issues such as how the process for gaining children's informed consent can allow for dissent at different stages of a project.

5. Consent checklist

The following a list of some of the factors that you need to consider when determining issues of consent to research. Note the shift in emphasis away from the child 'proving' that they have the maturity and capacity to consent towards *you*, as researchers, creating the conditions under which the child can safely and meaningfully consent.

- **Legality:** am I acting in a way that is legally as well as ethically correct when it comes to obtaining consent, informing parents and enabling the child to withdraw consent?
- **Information:** have I presented the research in such a way that potential participants can fully understand the nature of the research and the implications of their involvement at all stages of the project? Is the information appropriate for the different ages of children who may participate? Have I developed multiple information formats to acknowledge the different ages of potential participants?
- **Understanding:** How do I go about checking that child participants understand the nature and implications of their involvement in the research?
- **Withdrawal from the study:** Have I made it clear to the participants and their parents that they can withdraw from the study at any time, and explained how they go about withdrawing?
- **Consent of parents:** Have I identified whether parents are consenting or assenting for their child to participate in the research? Is this a study where parental assent may not be in the competent child's best interests?
- **Complaints:** Does the child know who to contact and how if they are concerned about any aspect of the research?
- **Are my research expectations reasonable?:** is the child participant being asked to take part in too many meetings/for too long? This may be the case when a child is required to complete a long survey or attend long sessions that disrupt their other commitments.
- **Do I view consent as an ongoing process?:** what measures have I put in place to ensure that the child is continually updated and given the opportunity to consent to different stages/aspects of the research?

Useful resources

- K Tisdall, Researching with *Young People: Research Design, Methods and Analysis*, (2009, Sage Publications).
- *The research ethics guidebook: a resource for social scientists* (ESRC, RDI and Institute of Education, London)
- Nuffield Council on Bioethics (2015): *Children and Clinical research: ethical issues*
- Johnson, V., Hart, R. and Colwell, J. *Steps for Engaging Young Children in Research Vol 1: The Guide*, (2014, Education Research Centre, University of Brighton)
- Johnson, V., Hart, R. and Colwell, J. *Steps for Engaging Young Children in Research Vol 2: The Toolkit*, (2014, Education Research Centre, University of Brighton)

Supplementary support examples

The examples below are intended to demonstrate how written consent can be presented and obtained. We include them to support researchers in developing their own – ideally within a more appealing format or branding – rather than as any sort of template.

Annex 1a: Sample Child Friendly Consent Form for Competent Children

UNIVERSITY OF LIVERPOOL
European Children's Rights Unit

Phase 2 Online Consultation - Consent Form for Young Participants

This consent form must be filled in by all those who want to take part in the XXXX Project. Please read the Information Sheet for more information about the project before you sign this form.

I consent to taking part in an online meeting as part of the XXXX Project	☐
I understand that this will involve me attending 1 online (zoom) meetings in June 2020 and giving feedback on some materials created by X	☐
I consent to being audio-recorded during those meetings.	☐
I understand that the research team will not pass on any personal details (such as my name/address etc) to anyone in X	☐
I understand that the information and suggestions I give will be used by X to create child friendly information about the X	☐
I confirm that the research team is allowed to use my feedback in later training and research materials	☐
I understand that I can change my mind and decide that I no longer want to take part in the meeting at any time. I can ask that none of my feedback is used by anyone, and that all of my personal details are deleted by the research team. I will **not** have to pay back any of the money I have received for taking part.	☐

Name of Participant: _____

Date: _____

Signature: _____

Name of researcher: _____

Date: _____

Signature: _____

Annex 1b: Sample Parental/Guardian Consent Form

Consent Form for Parents/Guardians of Under 16s

This consent form must be completed by the parents or guardians of all under 16s who wish to take part in X Project. Please read the Information Sheet for more information about the project before you sign this form. Please note that the child must have consented to participating in this project prior to you giving consent.

Name of Child Participant: _____

I consent to the above young person taking part in group meetings as part of the X Project	☐
I understand that this will involve them attending 2 meetings and giving feedback about X	☐
I consent to them being audio-recorded during those meetings.	☐
I understand that the research team will not pass on any of their personal details (such as my name/address etc)	☐
I understand that the information and suggestions that they provide will be used by X to create child friendly information about X	☐
I confirm that the research team is permitted to use their feedback in later training and research materials	☐
I understand that they can change their mind and decide to no longer take part in the project at any time. They can ask that none of their feedback will be used by anyone, and that any personal details are deleted by the research team. They will **not** have to pay back any of the money received for taking part.	☐

Name of Parent/guardian: _____

Date: _____

Signature: _____