

Research Governance Standard Operating Procedure

Guidance for obtaining consent for research with child participants in schools

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Disclaimer:

- When using this document ensure that the version you are using is the most up-to-date either by checking on the Research Governance webpages for any new versions or by contacting <u>rgoffice@sussex.ac.uk</u> to confirm the current version
- Staff and students may print off this document for training and reference purposes but are responsible for regularly checking for the current version. Any print-off of this document will be classed as uncontrolled
- Out of date documents must not be relied upon.

Version	Effective Date	Reason for Change
0.1	24/10/2014	N/A
0.2	01/10/2018	Reviewed and updated to reflect changes to data legislation and enhancements for increased clarity

1. Purpose

This document is intended to provide guidance to researchers in relation to:

(1) what procedures should be used to obtain consent for primary data collection from children and young people in schools, and

(2) when it is appropriate and acceptable for researchers to use "opt out" parent/carer permission (sometimes called parent/carer consent) procedures for primary data collection from children and young people in schools.

Having this guidance in place standardises the principles and expectations University Research Ethics Committees apply when reviewing proposals involving primary data collection from children and young people in schools.

1.1 Scope

Ethical research practice is situated in context, and therefore the most ethically appropriate course of action in any given study will depend on factors including the age of participants, the nature of the study, the expectations of the school, as well as cultural considerations. All researchers are expected to comply with the ethical code of conduct for their relevant professional body (e.g., ASA, 1999; BERA, 2018; BSA, 2017; BPS, 2018) as well as funder requirements (e.g., ESRC, 2012; EC guidelines). Beyond these general principles, the guidance contained in this document is relevant for:

- primary data collection which directly involves children and young people aged under 16 years in formal educational settings¹
- permissions for those with parental responsibility (parents/carers); and
- research in the UK and internationally.

The term "formal educational settings" is used here to refer to settings in the UK that are required to be registered with Ofsted as providers of childcare on non-domestic premises, primary schools, and secondary schools, and comparable institutions in other countries. For simplicity, these are referred to as 'schools' in this document and the relevant attachments.

¹ Exceptions will be made for those who are liable to be defined as 'vulnerable' under the terms of the Safeguarding Vulnerable Groups Act (2006) - <u>https://www.legislation.gov.uk/ukpga/2006/47/contents</u>

Guidance for obtaining consent for research with child participants in schools and use of "opt in" or "opt out" parent/carer permission procedures

Scope and definitions

This University Research Governance Committee guidance makes a distinction between *participant* consent – which must come from the child – and permissions to seek child consent from those with parental responsibility, including the parent/carer and the Head Teacher. The term "Head Teacher" is used to refer to people in comparable positions with different titles. Researchers applying for ethics approval or sponsorship approval from the University of Sussex are expected to adhere to this guidance, or to make a reasoned case for using alternative procedures, while taking account of factors with implications for the application of this guidance, including local cultural contexts, ages of children/young people involved, and the nature of the research.

All researchers are expected to comply with the ethical code of conduct for their relevant professional body (e.g., ASA, 1999; BERA, 2018; BSA, 2017; BPS, 2011), funder requirements (e.g., ESRC, 2012; EC guidelines) and the University's **Code of Practice for Research**. Beyond these general principles, the guidance contained in this document is relevant for:

- primary data collection which directly involves children and young people aged under 16 years in formal educational settings
- permissions for those with parental responsibility (parents/carers); and
- research in the UK and internationally.

The term "formal educational settings" is used here to refer to settings in the UK that are required to be registered with Ofsted as providers of childcare on non-domestic premises, primary schools, and secondary schools, and comparable institutions in other countries. For simplicity, these are referred to as 'schools' in this document and the relevant attachments.

Data collection in schools and the Data Protection Act (2018) (General Data Protection Regulation)

As a University researcher, all members of staff and students undertaking research activity should understand the limits and implications of current data legislation.

The Data Protection Act states that personal data must:

- be processed lawfully, fairly and in a transparent manner;

-be collected only for specified, explicit and legitimate purposes, and not be further processed in any manner incompatible with those;

-be adequate, relevant and limited to what is necessary in relation to the purposes for which it is processed;

-be accurate and, where necessary, kept up-to-date;

-not be kept as identifiable data for longer than necessary for the purposes concerned; and

-be processed securely.

Legal bases for conducting research using personal data:

In most circumstances the legal basis for using personal data for university research will be 'public task'.

By using 'public task' as the legal basis for taking personal data, the University ensures that as a publicly-funded organisation, it is through the exercising of official, public tasks that data is taken from people who have agreed to take part in research, and that the researcher is part of a reputable organisation that has a genuine reason to hold and use personal data.

This is **in addition** to the control given to participants through the consent expected as part of good research practice and expected by ethical review committees and processes. The process of ethical review acts as a safeguarding measure to protect the interests of research participants.

The process of ethical review is one of the institutional measures that uphold the standards that are maintained for processing data.

Should personally identifiable data be taken from a School setting it is highly likely that a data sharing agreement will be required between the University and the School and you should contact the Research Governance Officer (<u>rgoffice@sussex.ac.uk</u>) for further guidance on this matter.

2.1 Criteria for requiring 'opt-in' parent/carer permission

The URGC has agreed that the default position for research involving primary data collection from participants aged under 16 years in schools should be for "**opt in**" parent/carer permission procedures to be used. However, recognising that this is not appropriate in all circumstances, it was agreed that opt-in parent/carer permission should be expected, unless researchers can **justify** using alternative procedures.

This does not mean that research involving children and young people in formal educational settings is automatically treated as "high risk", rather that all research must address procedures for obtaining permission from parents/carers *and* children and young people.

Situations in which "**opt out**" parent/carer permission procedures may be permissible include group testing/data collection on topics included on the standard school curriculum or class observation (such as that undertaken in the course of teachers' continuing professional development or similar). In such cases, Head Teachers must register their agreement to allow the application of "opt out" parent/carer permission procedures (see 2.4 below).

If the demands of children's participation:

- (a) are likely to entail a risk of distress or discomfort (however moderate or transient);
- (b) are sufficiently burdensome and/or intrusive that children are likely to need assistance from parents/carers in deciding whether to take part; or
- (c) are likely to be a cause of concern to parents/carers

then "**opt in**" parent/carer permission should be obtained in all but exceptional circumstances.

In cases where any of these criteria (a, b, or c) apply, but where the researchers feel that "opt in" parent/carer consent is *not* ethically appropriate, a case must be made for alternative procedures in the application to the C-REC. If researchers are unsure as to whether "opt out" parent/carer permission procedures may be permissible, then they should contact the Chair of the relevant Cross-School Research Ethics Committee (C-REC) or the University's Research Governance Officer prior to submitting their application for ethics approval.

Although the University is not in a position to direct individual schools' policies and practices, if the C-REC concludes that "opt in" parent/carer permission should be obtained, then this approach should be used, even if schools express a preference for use of "opt out" procedures. Whilst some schools (such as boarding schools) may act in *loco parentis*, the researcher should ensure that they understand clearly the limits of such responsibilities.

In all cases, school-children must be aware that data collected for the purpose of research will in no way impact on their grades. $^{\rm 2}$

Any exceptions to these principles should be considered by the C-REC Chair who (with at least another C-REC member) shall review the circumstances and advise. Resulting

² As a principle no child should miss out on an important aspect of their education as a result of taking part in the research. However, a further difficulty can arise when a research study stresses the possible benefits to be gained by taking part in the research. So, for example, if one class group take part in a research activity that brings about some benefit, it is unfair that class groups in the same year do not have equal access to these benefits. It is suggested therefore that if the research takes place in one group, at some point the same opportunity (or equivalent) is offered to others.

changes to approved applications will need to be approved by the submission of an amendment to the approving C-REC or SREO.

2.2 Children's Continued Informed consent

Children should be asked to give continued informed consent, in all but exceptional circumstances. Appropriate methods for obtaining and recording consent should be used. In order to give informed consent, children must be provided with information that is:

- sufficiently detailed in terms of its description of proposed methods; and
- presented in terms that are appropriate for their age and level of understanding.
- when working with young children thought should be given to how continued consent through the activity is monitored throughout the study

Children must also be given:

(a) information about how to obtain help/advice related to making a decision about participation from people other than the researchers (e.g., from parents/carers);
(b) sufficient time to make their own decision about participation; and clear means for communicating a desire not to take part or to withdraw from the research at any time (researchers should give examples of how this will be done). Templates for information sheets and consent forms are available on the research governance webpages www.sussex.ac.uk/staff/research/governance/apply. A template for Child Participant Information and Consent Form is also attached to this guidance.

Researchers must also identify signs that may indicate a child's unspoken desire to withdraw, and explain how they will respond if children show signs of discomfort or reluctance to continue³. If researchers do not usually work with children advice should be taken about the expectations of those that they will be working with. If children have intellectual disabilities and impaired cognitive abilities then it is important to be flexible and to devise ways of interacting that are appropriate to them to avoid the possibility of causing distress⁴.

2.3 Parents/Carers

In all but exceptional situations (see above), parents/carers (and/or others with parental responsibility such as social workers, on behalf of their local authority) should be given:

- (a) a sufficiently detailed description of the study including the information children will receive and requirements of children's participation - to enable a decision about whether or not to give permission for the child's consent to be sought;
- (b) sufficient time to consider whether they want their child to take part; and
- (c) clear and straightforward means for communicating a desire for their child to be invited take part or not (opt-in) or for the child not to take part (opt-out).

³ In the case of children with PMLD or autism etc. it is almost impossible for the researcher to know and understand the body language or other signs which children might exhibit showing that they are becoming uncomfortable. It is suggested that any research activity carried out with such participants takes place in full view of an adult with detailed knowledge of the child who can therefore step in and act as the voice of the child.

⁴ The British Psychological Society's Practice Guidelines provides useful principles to apply when undertaking research with participants whose on-going consent is more difficult to ascertain. BPS Practice Guidelines (2017) - https://www.bps.org.uk/news-and-policy/practice-guidelines

Researchers must confirm that the procedures they propose to use for communication with parents/carers are appropriate and acceptable for the school and are in line with standard means of communication used by the school.

2.4 Educational settings

The University will approve the use of "opt-out" parent/carer permission procedures if the project is not deemed to necessitate opt-in consent/permission (taking account of the criteria noted in this guidance), providing:

- the Head Teacher or nominated other member of staff provides written confirmation that he/she has been fully informed about the research, has reviewed all materials/ questions/ anticipated topics to be used/covered, and confirms that these do not raise significant concerns about anticipated risks;
- this confirmation from the school is conveyed to students and parents/carers on information sheets and consent/permission forms; and
- the information sheet for parents/carers meets the criteria detailed above under 2.3.

2.5 Limits to Confidentiality – Duty of Care

Whilst, as a principle, researchers will seek to respect the confidentiality of information received from participants, this has to be balanced by the duty of care⁵ that a researcher holds from their position of relative privilege and as a professional bound by the ethical codes of their discipline.

In some instances there will be legal requirements relating to specific legislation such as the **Crime and Disorder Act** (1998) or the **Anti-Terrorism, Crime and Security Act** (2001) that can require individuals to hand over information to a public authority in defined circumstances. Other legislation (such as the 2006 **Safeguarding Vulnerable Groups Act** (2006)) can also apply and the onus is on the principal investigator to inform themselves or seek assistance in understanding what the implications may be if working in areas that may lead to safeguarding disclosures that may need breaking confidentiality to protect those who might otherwise be I.

As part of the consent process, researchers are advised to inform participants, the circumstances that may lead to confidentiality being broken. Plans should be made so that researchers have support if faced with making decisions of this nature. The Research Ethics Guidebook advises:

'If at all possible, individual researchers should not have to make the decision to breach confidentiality on their own – systems should include provision for the researcher to consult with a supervisor, project director, or another experienced researchers (and, if necessary, to make contact outside office hours).'

2.6 Procedures

The templates attached to this guidance should be used to allow Head Teachers to confirm their satisfaction with the use of "opt in" or "opt out" parent/carer permission. These templates can be used for an informed consent method, however if there is a justifiable reason not to use such templates e.g. if the research involves individuals with low literacy levels or where a form is inappropriate, other methods can be considered during ethical review. In addition to this form, the application for ethical approval should include the letter to be sent to the Head Teacher requesting the involvement of his/her school. That letter should:

⁵ http://www.ethicsguidebook.ac.uk/Limits-of-confidentiality-a-duty-of-care-97

(1) provide a rationale for the study,

(2) describe the requirements of schools and children involved in the study, and

(3) explain the arrangements for obtaining child consent, and parent/carer permission (if this is required).

Researchers hoping to use "opt-out" parent/carer permission processes must justify this in their application. They must also prepare the following supporting documents:

(1) an information sheet and permission form for parents/carers (see templates available here: <u>http://www.sussex.ac.uk/staff/research/governance/apply</u>).

(2) an information and consent form for children written in age-appropriate language (see template available here

http://www.sussex.ac.uk/staff/research/governance/apply).

(3) a form for the school Head Teacher to complete to indicate her/his approval of the use of "opt-out" parent/carer permission procedures that addresses the points set out in section 2.4 (see template attached to guidance and available here:

http://www.sussex.ac.uk/staff/research/governance/apply

TEMPLATE FORM FOR HEAD TEACHER [opt in]

Project name: [insert study name]

Approved by: University of Sussex [**insert committee name**] Cross-Schools Research Ethics Committee – email: [**xxxxxxx**@sussex.ac.uk]

Researchers are required to abide by ethical guidelines when working in schools. These cover topics such as gaining appropriate consent, permitting children to withdraw from the study, and keeping data confidential.

We would be grateful if you could check and sign the following sheet to show that you approve of the research procedures for this study.

Names of researchers visiting the school: [insert researcher name(s)]

Supervisor name, telephone number and email address: [insert details]

Period of visits: [insert details]

Classes/year groups visited: [insert details]

Brief description of procedure:

Parents/carers will be sent an information letter with details of the study and a permission slip to be signed and returned in order for their child(ren) to participate in the study. Parents/carers should be given at least two weeks to read and respond to this letter.

Before beginning any data collection session, the researchers will stress to the children that there are no right or wrong answers to the questions; rather, they are just interested in the children's views. Children will be asked if they would like to take part in the study, and given the option to withdraw from the study at any point. They will be told that they can skip over any questions they do not wish to answer.

The research will take place ... [insert details], as agreed with staff on the days of data collection. Children will ... [insert details].

Consent procedure

Parents will be sent an information letter about the study with a permission form that they must return in order for their child to be asked to participate in the study. Children will also be asked for [**verbal/written**] consent to participate in the study after receiving an initial briefing on the nature of the study and the procedures involved.

Please sign below to confirm that you:

- understand the requirements of children who take part in the research
- have received detailed descriptions of the methods and materials to be used
- give approval for the research to take place at your school.

Name of school:	
Name of [Head Teacher]:	
Signature:	
Date:	

TEMPLATE FORM FOR HEAD TEACHER [opt out]

Project name: [insert study name]

Approved by: University of Sussex [**insert committee name**] Cross-Schools Research Ethics Committee – email: [**xxxxxxx**@sussex.ac.uk]

Researchers are required to abide by ethical guidelines when working in schools. These cover topics such as gaining appropriate consent, permitting children to withdraw from the study, and keeping data confidential.

We would be grateful if you could check and sign the following sheet to show that you approve of the research procedures for this study.

Names of researchers visiting the school: [insert researcher name(s)]

Supervisor name, telephone number and email address: [insert details]

Period of visits: [insert details]

Classes/year groups visited: [insert details]

Brief description of procedure:

Parents/carers will be sent an information letter with details of the study and a form to be signed and returned if they do not wish for their child(ren) to participate in the study. Parents/carers should be given at least two weeks to read and respond to this letter.

Before beginning any data collection session, the researchers will stress to the children that there are no right or wrong answers to the questions; rather, they are just interested in the children's views. Children will be asked if they would like to take part in the study, and given the option to withdraw from the study at any point. They will be told that they can skip over any questions they do not wish to answer.

The research will take place ... [insert details], as agreed with staff on the days of data collection. Children will ... [insert details].

Consent procedure

Parents will be sent an information letter about the study with a form that they must return if they do not wish for their child to be asked to participate in the study. Children will also be asked for [**verbal/written**] consent to participate in the study after receiving an initial briefing on the nature of the study and the procedures involved.

Please sign below to confirm that you:

- understand the requirements of study participants
- have received detailed descriptions of the methods and materials to be used
- have undertaken a full review of the study, including all materials to be used
- give approval for the research to take place at your school.

Name of school:	
Name of [Head Teacher]:	
Signature:	
Date:	

CHILD PARTICIPANT INFORMATION AND CONSENT FORM TEMPLATE

The participant information sheet, covering letter or leaflet should be printed on University of Sussex headed paper, (where appropriate) with full contact details of the researcher, the supervisor if the researcher is a student and the details of how to contact the Research Ethics Committee that approved the study. Consent forms should normally contain the following information

** Depending on the age and capacity of the child or young person, this information may be presented as a form for them to read and complete, or as a "script" to be read to them

PLEASE DELETE THE SECTIONS OF THIS TEMPLATE WHICH ARE NOT RELEVANT TO YOUR STUDY

Study title

The title should be simple, self-explanatory, and age appropriate.

Invitation paragraph

This should explain that the individual is being asked to take part in a research study. The following is an example of how this may be phrased:

'You are being invited to take part in a research study. Before you decide whether or not to take part, it is important for you to understand why the research is being done and what it will involve'.

Why have I been invited to participate?

**You should explain how the child was chosen to take part in the study. You should state that the child's parent/carer has given permission for her/him to be asked to take part in the study. **

Do I have to take part?

You should explain that taking part in the research is entirely voluntary, and that just because a parent/carer has given permission for them to be invited to take part, they do not have to. For example, you could say: -

'It is up to you to decide whether or not to take part. If you decide to take part you are still free to withdraw at any time and without giving a reason'.

If your study involves the recruitment of students/pupils you must explain that by choosing to either take part or not take part in the study will have no impact on their marks, assessments or future studies.

What will happen to me if I take part?

You should explain your methods of data collection, including what the individual will be asked to do, and how much time will be involved. This should be presented using ageappropriate language and concepts. You should explain if any rewards for participation are to be offered

Who will see what I say/do?

You should explain that none of the personal information collected about the individual will be shared with parents or teachers, and that it will only be available to the researchers.

What should I do if I want to take part?

Do you understand what you will be asked to do?

yes / no

Do you have any questions about what will happen or why?	yes / no
Do you want to stay and do the activities I have described?	yes / no

[When appropriate, the child should complete the section below] Name Date

References

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