

## **University Research Ethics Committee Guidance and Procedure: Research with Children and Young People**

### **1. Introduction**

This guidance is for UWE staff and students and highlights the specific factors for consideration in any research with or about children and young people. It must be read with the ethical research principles for research in general, guidance for research with human tissue, and the guidance for safeguarding of children and young people<sup>1</sup>. This guidance aims to reflect the different needs across all faculties and of our partners externally.

Throughout the research process these principles should underpin all activities:

- the rights of the child should be respected
- the agency of the child should be maintained
- the safety of the child should be secured.

Children and young people have an important and valued role to play in deciding research agendas, research questions, methods and outputs. All those undertaking research with children should be able to demonstrate that they have given due consideration to the three principles above in the selection of their aims and research questions, in the methods they intend to use and the mechanisms for analysis and reporting. All studies involving children should seek to be inclusive and accessible and pay due regard to the child's best interests, especially with respect to safeguarding the health and wellbeing of the child participant now and in their future.

'Children and young people' is the term used throughout. The upper age of childhood is defined according to purpose and the legal / policy context; this may be 16, 18 or 25 and is defined according to the capacity and vulnerability of the child and young person. The age and vulnerability of the child needs to be taken account of in planning and conducting the research.

'Research recognises the range of work defined by the use of a research question and use of research methodology and may include interventions/techniques/trials. Student research includes research carried out as part of a project or dissertation module where there is a research question and research methodology employed. Research is not practitioner training, a work placement, or reflective study of own practice, which is covered by other governance processes (for example in social work, nursing or education).

'Research with children' for this guidance means direct contact with children and

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<sup>1</sup> <http://www1.uwe.ac.uk/research/researchethics>;  
<http://www1.uwe.ac.uk/about/corporateinformation/policies.aspx>

young people by all means of access and communication, and, indirect contact where participants are asked about children and young people. 'Involving children and young people in research' is about their voice and might apply throughout the research process. Researchers also need to reflect on contexts in which children and young people are present, while not being the main participants in the research e.g. if the research takes place in a home or public place with children or young people's parents or carers. This guidance applies to the ethics their involvement can entail, but for further detailed guidance on such approaches other sources are suggested<sup>2</sup>.

## **2. Ethical Principles**

The overriding principle is that research is compliant with the requirements of the relevant professional body, is legal and supports the UN Convention on the Rights of the Child 1989<sup>3</sup>. The following principles are developed from those produced by leading children's research centres<sup>4</sup> and professional bodies<sup>5</sup>.

### **Beneficence**

- When children and young people participate in research, their interests must prevail over those of science, study and society where there is conflict.
- The purpose of the research is to obtain knowledge relevant to understanding and improving the well being of children and young people
- There must be a statement of risk that shows how an acceptable balance of risk and benefit for children and young people is assessed and managed.
- Researchers must take account of the particular and the cumulative impact of the research for children and young people including their participation in other research.
- Researchers must respect the need to provide accessible feedback to the children and young people throughout the study and where appropriate at the end of study findings.
- If the research is deemed to be of benefit to all children, it follows that it should

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<sup>2</sup> <https://www.ncb.org.uk/search/node/research> - see in particular guidance on consent

<sup>3</sup> <https://www.unicef.org.uk/what-we-do/un-convention-child-rights/>

<sup>4</sup> Medical Research Council, Ethics Guide: Medical Research involving children  
[www.mrc.ac.uk](http://www.mrc.ac.uk).

<http://www.rcpch.ac.uk/system/files/protected/page/ethics%20of%20research%20in%20Children%20-%20ADC%202000.pdf>

<sup>5</sup> The British Psychological Society, Code of Human Research Ethics:

<http://www.bps.org.uk/publications/policy-and-guidelines/research-guidelines-policy-documents/research-guidelines-poli>

The British Educational Research Association:

<https://www.bera.ac.uk/researchers-resources/resources-for-researchers>

include all children in the sample. If a group of children and young people are excluded, the research title needs to state the included group only, and there must be a rationale for exclusion. If specific groups are repeatedly excluded the research may be discriminatory and counter the first ethical principle regarding rights. It is therefore important to make exclusion visible and for reviewers to question this aims and research question.

## Consent

- Prior to participation, researchers must obtain voluntary informed consent or assent from each child/young person to participate in research if the age and capacity of the child means this possible<sup>6</sup>. The consent of the parents would normally also be sought in advance of approaching a child under 16yrs old. In other circumstances (for example clinical trials), a baby or a very young child, consent from their legal advocate (parent/guardian) may be sufficient on its own and is required where capacity to consent is clearly shown to have been explored and not found to be possible. NB. In the latter case the research may not be approved without reasons regarding beneficence and satisfactory risk assessment.
- In order for consent to be informed, the process and materials must be accessible and appropriate to the level of understanding of the child or young person.
- Researchers should be sensitive and attentive to children's ongoing consent which may be signalled verbally or non-verbally, for example through signs of distress, inattentiveness, boredom or noncompliance that may suggest that they are not wholly willing to continue with the data collection (See footnote 5, BPS p17).
- Hence, consent must be a continuous process without pressure that, of right, includes the opportunity to ask questions, decline and withdraw throughout the project.
- Consent should be documented in an auditable record (e.g., a written record or audio-recorded verbal consent).
- Consent should not only cover participation. It should clearly cover consent for use of data including any long terms plans for data use, plans to publish, archive data. Subsequent use of data by other researchers should be re-consented to reflect the child's developing understanding of access to data.
- Researchers should ensure that parents/guardians are informed about the nature of the study, given the opportunity to withdraw their child from the study or approve their participation on the basis of good practice, providing it does not conflict with the child or young person's interests but it is the child's consent that is necessary as above. Best practice would be not to go ahead

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<sup>6</sup> See [http://www.nspcc.org.uk/inform/research/questions/gillick\\_wda61289.html](http://www.nspcc.org.uk/inform/research/questions/gillick_wda61289.html)

with the study unless both the child and parent agreed to participation.

### **Confidentiality and Anonymity**

- Confidentiality of the data should be carefully maintained to safeguard and protect the child.
- No child or young person should be identified by information in writing, audio recording or images, unless there is a reasonable cause to suspect that the child is experiencing or is likely to experience harm, in which case the researcher should refer to and follow the UWE Safeguarding process promptly.
- Exceptions may be appropriate in instances where specific consent is obtained, such as a young people's film or where the child is a co-researcher. Care should be taken where a child's identity can be deduced from otherwise anonymous information. The generation, storage and transfer of digital images of children must comply with the law and the University Data Protection requirements.

### **3. The UWE Governance process**

**All UWE researchers, both staff and students, undertaking research with, or about children are required to have safeguarding training and be familiar with UWE policy and procedures relating to Safeguarding.** Students undertaking research activities with children as part of modules or other units of learning should have safeguarding training. This guidance should be included as part of the preparation curriculum. Supervisors of student projects are also required to have had safeguarding training. Safeguarding training for staff is provided via UWE Human Resources for further details contact Rachel Mylrea in Human Resources or Jayne Storey in Student and Partnership Services.

UWE has a module which it is expected that anyone conducting research with children should access and complete prior to starting their research:

<http://go.uwe.ac.uk/researchwithchildrencourse%20> Log in with your UWE user ID and password. Click on the enrol button.

- Researchers should be confident with safeguarding in order to recognise disclosure of harm or risk of harm, to know how to take action and report concern and ensure the safety of the child or young person within their research. They should be familiar with the safeguarding procedures within any setting where the research is being conducted in addition to UWE's own safeguarding policy procedures.
- If the researcher, or supervisor, wishes to raise any Safeguarding concerns during the research they should contact the Designated Safeguarding Officer in the setting where the research is being conducted and the Research Governance Manager in Research Administration [Ros.Rouse@uwe.ac.uk](mailto:Ros.Rouse@uwe.ac.uk) in accordance with UWE Safeguarding Policy and Procedures at

Safeguarding Policy – Staff

<https://docs.uwe.ac.uk/ou/hr/IntranetContent/Safeguarding%20children%20and%20Vulnerable%20adult%20policy.docx>

Safeguarding Policy – Students

<http://www2.uwe.ac.uk/services/Marketing/about-us/pdf/Policies/Safeguarding-Policy-and-Procedures%E2%80%93students.pdf>

- Depending on the research proposed, researchers may require a Disclosure and Barring Service (DBS) (formerly Criminal Records Bureau -CRB) check. Members of staff requiring DBS checks should contact Human Resources [hr@uwe.ac.uk](mailto:hr@uwe.ac.uk). DBS checks for students on designated courses are organised through Student and Partnership Services on admission but current students on taught programmes who require a DBS check should contact Rachel Cowie ([Rachel.Cowie@uwe.ac.uk](mailto:Rachel.Cowie@uwe.ac.uk)) in Corporate and Academic Services or Marisa Downham ([Marisa.Downham@uwe.ac.uk](mailto:Marisa.Downham@uwe.ac.uk)) in the Graduate School (research students).

Disclosure and Barring Policy – Staff

<https://docs.uwe.ac.uk/ou/hr/IntranetContent/DBS%20Disclosures%20Policy.docx>

Disclosure and Barring Policy – Students

<http://www2.uwe.ac.uk/services/Marketing/about-us/pdf/Policies/Disclosure-and-Barring-policy.pdf>

- Adherence to this guidance and these policies and procedures will also safeguard the researcher in case of false allegations.

#### **4. Applying for Research Ethics Approval**

**All research with children as defined above requires ethical approval** in accordance with UWE's Research Ethics Policy and Procedure and the Operating Procedures for Ethics Review of Student Research Projects. Both may be found at: <http://www1.uwe.ac.uk/research/researchethics>. Thus all research with children requires the completion of an application for ethical approval whether or not it is deemed low risk or high risk (see below).

- UWE has module on safeguarding and research with children which is available for staff and students and is essential for those undertaking research or supervising studies which involve research with children:

##### Research with Children online course

An online course on how to conduct research that involves children and young people: doing ethical research and keeping children safe.

1. Go to [Research with Children](#)

2. Log in with your UWE user ID and password

3. Click on the enrol button

- Research with children involving NHS healthcare settings will require approval by an NHS Research Ethics Committee in accordance with the Department of Health Research Governance Framework. See <http://www.hra.nhs.uk/>. If the

research being conducted by a member of staff or student falls within this Framework and NHS REC approval is being sought the research also requires approval from a UWE REC but this does not normally require a separate application. Please see separate guidance on 'Sponsorship of Research at UWE' and the Operating Procedures for Ethics Review of Student Research Projects at <http://www1.uwe.ac.uk/research/researchethics>.

- Research with children and adults in social care settings may require approval from the National Social Care Research Ethics Committee. See <http://www.hra.nhs.uk/resources/research-legislation-and-governance/questions-and-answers-mental-capacity-act-2005/>. As above, the research also requires approval from a UWE REC but this does not normally require a separate application. Please see separate guidance on 'Sponsorship of Research at UWE' (<http://www1.uwe.ac.uk/research/researchethics/guidance.aspx>).
- For other research with children, the level of ethical scrutiny will be commensurate with the level of risk associated with the project.
  - For staff and doctoral students, applications for ethical approval should be submitted to the appropriate Faculty Research Ethics Committee (FREC). At least one of the FREC scrutineers of any research with or about children should have been trained in child safeguarding.
  - For undergraduate and masters students, their application will be first scrutinised by their supervisor (who should have safeguarding training). Those projects considered to constitute a high risk (see next section) to the child, or where there is any question about the level of risk, will be forwarded to the appropriate Faculty Research Ethics Committee for full scrutiny. Those considered to be low risk (see next section) can be approved by the supervisor.
- High risk research includes research where the student (or members of the research team) proposes direct contact with children either face-to-face or virtual, and where there is unsupervised access to children, or where the research deals with on-line materials and on-line contact with children. High risk research includes research where there is potential harm from taking part and this could be on the body, emotional and material.
- Low risk research includes research where the student has had formal training regarding interaction with children, where there is direct supervision of contact time by someone with training in safeguarding and working with children, where, for example, the purpose is purely to listen or to observe the children.
- Researchers must submit evidence with their research ethics application of an up to date DBS clearance. This should take the form of an email from the relevant countersignatory confirming that the researcher has a valid DBS check for working with children and/or vulnerable adults. It is the responsibility of the applicant to provide this information.
- For further advice on applying for ethics approval students should contact their supervisor in the first instance. For additional advice staff and students

may wish to contact their Departmental Ethics Advisor or Associate Head of Department for RKE both of whom are normally members of the Faculty Research Ethics Committee<sup>7</sup>.

- The University Research Ethics Committees (ie, including FRECs) should make resources available to researchers and welcome queries regarding the particular challenges of research with children.
- A Support Plan should be included in the research information for participants, that explains that a child's distress or disengagement may signal a wish not to participate that will be respected, and, should include a statement regarding response to disclosure of harm and risk of harm.

UREC Working Group on Research with Children  
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<sup>7</sup> In Departments where these formal roles do not exist this will be the Department representatives on Faculty Research Ethics Committee.