

## RESEARCH ETHICS: GUIDANCE NOTE ON RESEARCH INVOLVING CHILDREN

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### 1. Introduction

1.1 Research involving children and young people should only be conducted where:

- the research question posed is important to the health and well-being of children. However, a research procedure which is not intended directly to benefit the child subject is not necessarily either unethical or illegal. Such research includes observing and measuring normal development in controlled experiments;
- the participation of children is indispensable because information available from research on other individuals cannot answer the question posed in relation to children;
- the study method is appropriate for children;
- the circumstances in which the research is conducted provide for the physical, emotional and psychological safety of the child.

All proposals involving research on children should be initially submitted to the Departmental Research Ethics Committee (DREC).

### 2. Historical Background

2.1 The historical origin of current ethical principles for conducting research with children arises from the Nuremberg Trials, which took place after the Second World War, and the Nuremberg Code, which emerged from these. The Code sets out statements of certain moral, ethical and legal principles relating to research involving human subjects. Later, the emergence of the Declaration of Helsinki in 1964, most recently amended in 1989 and 1996, now includes an examination of the issue of children as research subjects in relation to informed consent<sup>1</sup>.

### 3. Declaration of Helsinki

3.1 The principles for conducting research contained in the Declaration of Helsinki apply to all human subjects, adults and children. For example, adequate information must be provided to the research participants, participation in the research must be freely volunteered, with the understanding that the participant can withdraw at any time, and in addition, informed consent should be obtained, preferably in writing. There is one section, which refers specifically to research

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<sup>1</sup> Anne Greig and Jane Taylor: Doing Research with Children (Sage Publications) 1999 p.148

with children and states: “when the subject is a minor, permission from the responsible relative replaces that of the participant in accordance with national legislation. Whenever the minor child is in fact able to give a consent, the minor’s consent must be obtained in addition to the consent of the minor’s legal guardian.”<sup>2</sup> The guidelines are clear that the consent of the child should be sought in addition to that of the responsible adult.

#### **4. Informed Consent**

##### **Consent and Children**

- 4.1 It is integral that the child has full information about the research in order to give their ‘informed consent’ to take part, and that consent is ‘freely volunteered’. The child should also know that ‘s/he can withdraw at any time’. The National Children’s Bureau have accepted these ethical principles but take them further in respect of research with children. Their ‘Guidelines for Research’<sup>3</sup> say that “*Careful thought needs to be given to translating this into practice when the participant is a child.*” Information presented to the child and parent, should explain: what will happen; what is being asked of the child; that the child can agree – or disagree to take part – without adverse consequences; and may withdraw at any time; and be given in clear language at a level that the child can understand, using visual aids if necessary.
- 4.2 A further consideration is the possible impact of the research on the child, at the time and at a later date. As the National Children’s Bureau Guidelines state “*This is particularly important where the participant has been discussing painful or difficult experiences.*” Their advice to researchers, prior to interviewing is, to gather information on local sources of help and have them available, if required, and to recognise the limitations of their own expertise and resist giving advice and support beyond their area of competence.
- 4.3 Young people aged 16-18 with sufficient understanding are able to give their full consent to participate in research independently of their parents and guardians. Children under 16 are able to give their full consent providing they have been counselled and do not wish to involve their parents and they have sufficient maturity to understand the nature, purpose and likely outcome of the proposed research.
- 4.4 In addition, participation in the research must always be in the child’s best interests. However, the University Research Ethics Committee would regard it as unwise for an investigator to allow the participation of a child in a project where parental consent was not forthcoming or a competent child was not in agreement.

##### **Parental Consent**

- 4.3 Parental consent is required 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. Although the child’s assent is advisable, the power to consent, in law, is that of his/her parents or legal guardian. Those

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<sup>2</sup> World Health Association: Declaration of Helsinki paras I.9,11

<sup>3</sup> National Children’s Bureau: Guidelines of Research London NCB 1993

acting for a child are only acting legally if participation in the project is of benefit to the child. If it is not, the parent or guardian could be said to be acting illegally.

- 4.4 One parent can give consent but it is preferable to have both. Where there is parental disagreement as to whether an 'incompetent' child should be volunteered for research, it is possible that one parent could apply to court to block the child's participation. The University Research Ethics Committee (UREC) may in such circumstances advise that where there is disagreement, the child should not be included in the research.

In cases where the study may involve participants who are particularly vulnerable or who may be unable to give informed consent (e.g. children with learning disabilities, emotional difficulties, problems with understanding and/or communication) then it may require the co-operation of a gatekeeper for initial access to the groups or individuals to be recruited (e.g. students at school where the Head teacher may need to give consent). This must be carefully considered and the protocols involved made explicit in the ethics approval application. The University Research Ethics Committee (UREC) will pay particular attention to this aspect.

## **5. Confidentiality Issues**

- 5.1 Confidentiality and anonymity must be explained in a way that children can understand. The researcher present at the interview is rarely the only person to see the results. It must therefore be made very clear who will have access to the data and what will happen to the data when the research is complete. Anonymity in the form of removing names and other identifying information should be explained. The extent of the anonymity and any potential areas where the confidentiality of the interview may be broken should be explained to the child at the outset of the interview. For example, the researcher has a duty to take steps to protect the child or other children, if they are considered to be 'at risk of significant harm'. The child needs to know what action may be taken in the event that s/he discloses that they or others are at risk of 'significant harm', or where the researcher observes or receives information of incidents likely to cause harm. Arrangements need to be made in advance, following professional advice, on agreed procedures in these cases, and for support for the child.
- 5.2 Information can be given about the storage of data and who will have access to it, and how it will be used, in the same clear language as used about the research. It can be argued that use by secondary researchers is not greatly different from that of primary researchers on the research team, who have not been directly involved in the collection of the data. Assurances can be given about the anonymity of the data, with the removal of names and any identifying information, to meet the concerns of the child and responsible adult. It is recommended that written information should always be provided for the child and responsible adult, and a contact telephone number, should they wish to contact the researchers.

## **6. Sources for Further Reading**

P.Alderson (1995) *'Listening to Children: Children, Ethics and Social Research'*, Barnardo's

Pia Christensen and Allison James (2000) '*Research with Children: Perspectives and Practices*', Falmer Press

Anne Greig and Jayne Taylor (1999) '*Doing Research with Children*', Sage Publications

National Children's Bureau: Guidelines for Research with Children, Library and Information Service including reading lists on '*Consent and Research related to Children*' and '*Ethics and Research and Children*'

Market Research Society: '*Guidelines for Research Among Children and Young People*' (January 2000)

British Psychological Society: '*Code of Human Research Ethics*', Section 10.1 (Leicester BPS 2010)