



ETHICAL RESEARCH INVOLVING CHILDREN

Centre for Children
and Young People



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NEW ZEALAND

INFORMED CONSENT

Caregiver consent for child participation in research: Reaching and protecting the most vulnerable

Background context:

The Young Carers Study is a national study, designed in collaboration with Universities, the South African government, UNICEF, Save the Children and the National Action Committee for Children affected by HIV and AIDS. The study interviews 6000 children aged 10-17 years using a longitudinal design. It aims to identify the impacts of AIDS-orphanhood and caregiver AIDS-illness, as well as other risks such as abuse, on child outcomes. It also aims to identify services and programming that can help them. See www.youngcarers.org.za.

The ethical challenge:

Research examining child vulnerability has three – apparently corresponding - ethical requirements. The first is to protect children by ensuring that participating in research is their free and informed choice. This is usually addressed by providing clear written and verbal explanations of the research and its aims, and allowing children time to consider and ask questions about participation. The second ethical requirement is to ensure that it is in each child's best interests to participate in research. Because children are considered to be unable to make this decision alone, this usually requires that the researchers gain permission from the child's parent or legal guardian for the child to participate in the research. The third requirement is to ensure that the most vulnerable children are not excluded from taking part in research, so that the evidence-base on child vulnerability represents those children with the greatest need for assistance.

For a small but worrying group of children, these three ethical requirements are in direct conflict with each other, presenting researchers with a set of ethical dilemmas. In sub-Saharan Africa, the AIDS epidemic has left children living in child-headed and youth-headed households. These are homes where all the adults have died, and the oldest caregiver is a child themselves, or a sibling aged 18-25 years. In these situations there is no parent or legal guardian able to give consent for the child to participate. Our research also identified a group of children who very much wanted to participate in the research, but told our interviewers that their guardians would not let them participate because the guardians themselves were abusing the children, and did not want this to be exposed by the research. Finally, we found a small group of children whose guardians would not let them participate in the research because the guardians were involved in crimes such as drug dealing, and did not want this revealed through the research.

In these situations, gaining guardian consent was either impossible due to a lack of adult caregiver, or because adults were protecting their own interests at the expense of the children in their care. But these children represent some of the most vulnerable groups, and it was essential to include and represent their needs in the research.

Choices made:

The research team discussed this dilemma with a number of groups: NGOs working with vulnerable children and research ethics committees at Oxford University and South African universities. We also discussed the question with our Teen Advisory Group of South African children who help to make the research child-friendly. In addition, we reviewed legislation and literature around this area (see the South African Department of Health Research Ethics Guidelines 2004).

For these situations, we allowed children to identify another trusted adult, such as a teacher or social worker (in situations where caregivers were abusing or exploiting children) or an aunt or grandparent (in situations where children had no legal guardian) who could give consent for the children to participate. It should be noted that this approach was never used to get out of guardian consent just because it was convenient, and our research teams were trained carefully in this. If children did report any kind of abuse or exploitation, referrals were made to health and social services for them and with the child's full knowledge and consent.

Within the consent process it was also very important to ensure that children and adults truly understood all the information and expectations of research participation. Consent and information forms were read out in people's first languages, and were written in clear simple language without technical terms. At each stage in the research, children and their guardians or nominated adults were asked again for consent to participate.

Reflexive questions/considerations:

- Are there any particularly vulnerable groups of children who you want to make sure are included in your research?
- How can you approach these vulnerable groups without increasing their vulnerability?
- What are the laws about children's participation in research in the country where your study is taking place?
- What are levels of literacy in your research areas? How can you make sure that participants really understand the consent process?
- How can you involve children in planning your research and informed consent processes?
- What services are available in the area to help vulnerable children exposed by the research?

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