

Original paper

# Meaningful consent to participate in social research on the part of people under the age of eighteen

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*This article describes changes in conventions among social scientists undertaking research with children and young people over the last decade, and discusses the legal position and aspects of the ethics of research with people under eighteen. It includes three brief case examples which illustrate the nature of the issues involved and ethics committees' responses to them, and concludes that although differences of opinion remain, a consensus is emerging about the need to let young people speak for themselves, subject to appropriate safeguards.*

## Introduction

Increasingly, university ethics committees are being asked to consider social science research proposals that involve research encounters with young people without formal parental consent. In most cases, these are carefully argued, well thought-out proposals: the research involves contact with young people in circumstances where parental consent is regarded as inadvisable or unnecessary. Professional opinion about parental consent issues in social work, youth justice and youth work agencies has been changing, and the law has also changed. In this fluid situation, the task of research ethics committees is complex. This article considers the principles involved and illustrates some ways in which they can be implemented, using case examples.

## The law in England and Wales

In a helpful review of the literature on informed consent in social research, Wiles et al [1] note that the Human Rights Act 1998 'protects the right to respect for private and family life and thus supports the need for consent to participate in research' where children and vulnerable adults are concerned. They also refer to the requirements of the Children Act 1989 which make it clear that confidentiality can be overridden if a child is identified as being in danger. The other, related area of law involved is case law on children's 'competence', and this is an extremely complex issue.

Researchers often refer to 'Gillick competence' in arguing that children can consent to participate in research and that parental consent is therefore unnecessary if the children concerned are deemed to be competent. The ruling in the Gillick case [2] related to children's competence to consent to medical treatment. The young people who were the subject of the case were ruled competent to obtain advice about contraception or to seek to be prescribed contraceptives. It is clear that this ruling also relates in certain circumstances to medical research, although the law has never been clarified in relation to children's competence to consent to involvement in medical research [3]. It might be regarded as stretching the analogy

too far to assume that Gillick competence necessarily applies to social scientific research, although Masson [4] states that the Gillick decision in the House of Lords applies to decisions about research participation in the absence of any other legal case covering specifically that issue.

It would seem that researchers could be the subject of legal action by or on behalf of a child to whom it was claimed that harm had been done by their involvement in research [4], although such a case has never arisen so far in England and Wales. Ethics committees are quite properly concerned to protect researchers and their parent institutions from legal action, as well as to protect research subjects from harm.

In general terms, children are increasingly seen as having rights and responsibilities of their own, and the law now 'limits the power that parents have over their mature children' [7], as a result of case law arising from the Children Act. Indeed, 'a parent cannot consent to research on behalf of a competent child' [7] because the child has the power to do so. Some researchers have argued that children are competent in the legal sense from around the age of nine, although children involved in research may have little real understanding of what happens to their contributions [8]. In disciplines specialising in research with children, such as youth work, there is an increasingly strong consensus that it is patronizing to seek parental consent as if this overrides children's own ability to consent to participate in research. Thus Masson [4] argues that

Where children can understand enough to distinguish research from other interventions, and to understand the impact on them of participating, it may be more ethical to act on their consent than to require the fully informed consent of a parent. Such an approach gives children the maximum opportunity to have their views and experiences recorded and avoids the exclusion of children whose parents would not respond to a request or would wish to control whom their child speaks to.

It may, however, be wise to seek consent from both the child and the parent or carer in more controversial research projects and in cases where the child's capacity to give informed consent is in doubt. In some cases it could still be argued that it would be harmful and against children's best interests to seek parental consent.

Another important legal issue is the protection of young respondents from contact with people who have criminal records, and it is now conventional to require research team members with access to children to be certified as conviction-free through the Criminal Records Bureau, although the fact that someone has no criminal convictions is little guarantee that they are safe to work with children. (The relevant legislation is the Police Act 1997). It may be that those appointing people to undertake research with children (particularly with younger children) should conduct rather more rigorous checks and interviews than normal [4].

Medical research is governed by European as well as domestic law, and is not discussed in this article. Masson summarizes the relevant legislation succinctly [4].

Alderson and Morrow [5] advise using a graduated approach, seeking parental consent in more contentious cases, in order to avoid the possibility of legal action. This approach is endorsed by some authorities in other jurisdictions: the American Sociological Association, for example, 'requires its members to obtain consent from both children and their guardians except where the research imposes minimal risk on participants, the research could not be conducted if consent were to be required, and the consent of the parent 'is not a reasonable requirement'...' [6].

If this graduated approach is accepted as a viable one, what principles should inform ethics committees' decision-making in such cases?

## **Ethical principles**

The principles involved in undertaking ethical research with young people are no different from those generally applied in judging the merits of applications by human research ethics committees:

consent must be fully informed, the research must do no harm, confidentiality must be protected, and so on. However, ethics committee members tend to be more concerned about ensuring that every angle is covered when research involves contact with young people – and this seems particularly appropriate in a climate where young people (who are, by definition, vulnerable in various ways) are treated as autonomous agents capable of making decisions about whether to participate in research, even though they may not fully understand the implications of doing so.

There is, however, an irony in the situation in which young people are deemed competent to consent to receive services, but may at times be ‘protected’ from taking part in evaluative research aimed at improving those same services (see case example 3 below; note also the comments about differing ages of consent in case example 2).

In any event, research ought to be ethically informed, and to go beyond what is legally required in terms of protecting those being researched from harm. Confidentiality and anonymity as they are understood in the social science research context need to be clearly explained to young people before they become involved in research, and this must include the circumstances in which the paramount welfare of the child overrides confidentiality obligations. The obvious examples are where a researcher is informed about possible child abuse or a medical condition which has not been disclosed to the parents. Breaching promised confidentiality is not a step to be taken lightly, and researchers need to pass information to the relevant authorities rather than trying to deal with it themselves, not least because ‘their conversation could later be used as testimony in a court setting’ in child abuse cases [4]. This applies even in cases where the researcher is qualified in counselling or social work: the boundaries between the researcher role and other roles should not be allowed to become blurred. A researcher cannot instantly stop being a researcher in order to counsel a distressed interviewee, although these boundaries may be particularly blurred in the case of practitioner-researchers working within their own organizations.

Young people also need to be made aware of the researcher’s position on reporting possible criminal conduct. Some researchers working with young offenders have qualified their promise of confidentiality to participants by saying from the outset that this would not apply if serious criminal conduct was disclosed – but a problem then arises in defining ‘serious’. Yates [9] gives the example of witnessing young people ‘rallying’ what he suspected were stolen cars at high speed and seeing individual young people driving although they were too young to do so. He had to balance the possible danger to himself (and his ability to continue the research) if he informed on the young people, the potential danger to the professionals who had vouched for him to the young people being researched, and the likelihood that the police would take any action if they were informed (in an area festooned with CCTV cameras but rarely the subject of police attention in the case of volume crime). He decided it was not ‘my duty to inform on routine criminal acts’ [9]. Other researchers might have taken the view that seeing young people he suspected were driving stolen cars was sufficiently serious to merit reporting to the police regardless of the consequences for the researcher, his sponsors or the research project.

Additional issues arise in relation to research with victims of crime or abuse. If they are interviewed pre-trial, there may be concerns about ‘contamination’ of their evidence (although the rules relating to child witnesses are changing rapidly, along with the practices of agencies such as the Crown Prosecution Service) and researchers need to proceed with considerable caution [10].

In general, research involving victims and vulnerable people may require consideration of their support needs should they become distressed as a result of their participation in the research. Some researchers are content to provide leaflets giving information about the support services available, or to have these available in case they are needed [11] while others are more proactive in ensuring that support is available immediately after interviews by making arrangements for a volunteer from a support agency to be present in case their help is required. However, other experts in the field take the view that no special issues are raised in the course

of researching victims of crime: victims are not necessarily particularly needy or vulnerable, and as research subjects they need only be treated with the same respect and sensitivity as anyone else [12]. Indeed, they may even pose a threat to researchers' safety [12]: stereotyped thinking about victims can blind us to such dangers.

There may also be a need to avoid researching some areas altogether at times: several researchers refer to the likelihood that 'people who live in high-crime areas can feel victimized by ... research' [12; see also 9]. Research on members of subordinate groups needs to be sensitive to the danger of over-researching the residents of particular areas or institutions. This is an issue which is touched upon in the British Society of Criminology's Code of Ethics for criminological researchers, although not specifically with reference to young people [13]. Researchers need to use their power responsibly, and to bear in mind how it might be used by others, including the media.

It is apparent from the discussion above that opinions and practices in relation to research with young people vary widely. The law gives some guidance and professional codes of ethics offer further assistance – but they are usually prefaced by a warning to the effect that no code of ethics can provide all the answers. Adequate training in research ethics in the context in which the research is undertaken, and a sufficient grounding in thinking ethically, are clearly very important in a rapidly changing research environment. Research with young people also raises particular methodological issues which are outside the scope of this paper, but which have been discussed in some detail elsewhere [11, 14, 15]. The case examples below illustrate some of the ways in which the issues discussed above may be addressed in practice.

### **Case example 1**

A psychology PhD student proposes to interview young prisoners aged 14-17 about their offending behaviour and its antecedents. She is informed by the prison that there is no need for parental consent for one-to-one interviews because the prison acts in loco parentis and has no objection to the interviews taking place. The university ethics committee is not content with this, in view of the vulnerability of the young people being interviewed; the sensitivity of the subject being researched; the confidentiality issues arising from the notion of the prison as a 'substitute parent'; and the difficulty of offering them appropriate support in the closed and inhumane setting of a young offender institution if the interview upsets them. The student is therefore encouraged to seek parental consent before undertaking the interviews. However, her supervisor and the contact at the prison both feel that the parents of young prisoners are unlikely to respond to letters asking for consent, and it emerges that some of the young people are estranged from their parents or carers or do not wish such contacts to be made. A compromise proposal is therefore made to the university ethics committee: the student would like to write to the prisoners' parents/carers about the research, enclosing an information sheet and a form declining consent for the young person to take part in the study. The letter will say that consent is assumed unless a reply is received by a specified date. This is agreed, the letters are sent out, and no replies are received. The research goes ahead on the basis of informed consent by the young people themselves.

### **Case example 2**

A criminology PhD student proposes to undertake ethnographic research on an urban housing estate, aimed at establishing the processes through which young males in such a setting go in order to 'achieve adult masculinity'. This will be done using semi-structured interviews with young men of 12-18, which will be tape-recorded and transcribed. Access is to be achieved through sponsorship by professionals working on the estate, and then by a snowballing process once some interviews have been secured. The student is aware of potential risks to himself as an outsider on the estate, risks to the young people when they speak of criminal and anti-social activities which may not have come to the attention of the authorities, and a number of possible threats to the

completion of the project in such a setting. He has read the relevant methodological literature and thinks it inappropriate to seek parental consent for his interviews with young people who in many cases are old enough to serve in the armed forces and all of whom are old enough to go to prison. However, the university ethics committee views the research as unorthodox and risky, and the supervisory team agrees. The research might pose substantial risks for the researcher, the university and the young people. The committee requires that parental consent be sought, and also makes a number of suggestions regarding the security of the data once they are collected. The student contacts the parents concerned personally, providing an information sheet and a consent form, after an introductory period of overt participant observation to establish a degree of trust among residents of the estate. One family declines consent, and their son is omitted from the research; others agree and the research goes ahead. Informed consent is also sought from the young people who are the subjects of the study.

### Case example 3

A permanent member of staff and established researcher is commissioned to undertake an evaluation of a local authority teenage pregnancy prevention strategy. This involves interviewing young people aged fourteen and fifteen about sex education and sexual health projects. A lawyer advises that signed parental consent forms are required for each interview because those involved are under eighteen. The university ethics committee takes the view that this is over-cautious in view of the relatively low risk to the young people, and it is agreed that parents will be *informed* about the research, but young people's own consent is sufficient.

### Concluding comments

Since the early 1990s, the climate of opinion in respect of social science research with children has changed enormously. Children are no longer viewed as inarticulate or as uniquely in need of protection from researchers: they are now increasingly seen as 'highly informed experts on their daily life' [5] and this has influenced attitudes towards issues of consent and risk. Although differences of opinion remain, a consensus is emerging about the need to let young people speak for themselves, subject to appropriate safeguards. However, this consensus among social scientists may need some explanation and justification to risk-averse human research ethics committees.

*Acknowledgements:* I am grateful to Jennie Fleming, Mike Semenchuk and Joe Yates for their comments on earlier drafts of this article.

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### References

1. Wiles R, Heath S, Crow G, Charles V. Informed consent in social research: a literature review. NRCM Methods Review Papers NRCM/001. Southampton: ESRC National Centre for Research Methods, 2005.
2. *Gillick v West Norfolk and Wisbech AHA*. 1985. 3 All ER 402. 1986 AC 112, House of Lords
3. Eckstein S. Training for research ethics committees in the UK. *Indian J Med Ethics* 9 (2) 2001; <http://www.issuesinmedicalethics.org/0920a056.html>
4. Masson J. The legal context. In Fraser S, Lewis V, Ding S, Kellet M, Robinson C (eds) *Doing research with children and young people*. London: Sage, 2004
5. Alderson P, Morrow V. *Ethics, social research and consulting with children and young people*. Ilford: Barnardo's, 2004.
6. Israel M. *Ethics and the governance of criminological research in Australia*. Sydney, New South Wales: NSW Bureau of Crime Statistics and Research, 2004.
7. Masson J. *Researching children's perspectives: legal issues*. In Lewis A, Lindsay G. *Researching children's perspectives*. Buckingham: Open University Press, 2000
8. Goodenough T, Williamson E, Kent J, Ashcroft R. Ethical protection in research: including children in the debate. In Smyth M, Williamson E (eds.) *Researchers and their 'subjects'*. Bristol: Policy Press, 2004.

9. Yates J. Criminological ethnography: risks, dilemmas and their negotiation. *Br J Commun Just* 3 (1) 2004 19-31.
10. Williams B. Counselling in legal settings: provision for jury members, vulnerable witnesses and victims of crime' In P Jenkins (ed.) *Legal issues in counselling and psychotherapy*. London: Sage, 2002.
11. France A. Young people. In Fraser S, Lewis V, Ding S, Kellet M, Robinson C (eds) *Doing research with children and young people*. London: Sage, 2004.
12. Walklate S. Researching victims In King R D, Wincup E (eds.) *Doing research on crime and justice*. Oxford: Oxford University Press, 2000 183-201.
13. British Society of Criminology. Code of Ethics for Researchers in the Field of Criminology at <http://www.britisoccrim.org>.
14. Morrow V, Richards M. The ethics of social research with children: an overview. *Children and Society* 10 (2) 1996 90-105.
15. Coyne I T. Researching children: some methodological and ethical considerations. *Journal of Clinical Nursing* 7 1998 409-16.