Consent in school-based research involving children and young people: a survey of research from systematic reviews

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Abstract

This study examines the way that consent is reported for participation in school-based research involving children or young people aged from 5 to 16. Databases containing descriptions of research identified during systematic reviews were surveyed to determine to what extent consent is sought, and from whom, and to see whether reporting varied by study characteristics such as the age of participants, the country in which the research was carried out, research design and substantive area of study.

Of a total of 489 studies in school settings involving children or young people, less than a third (n=145:30%) reported seeking consent. Only one in seven (n=66:13%) sought consent from children or young people themselves. Consent was reported significantly more frequently in studies sourced from health promotion reviews, when compared to those sourced from education reviews.

Codes of practice indicate that researchers should seek consent from research participants. This study demonstrates that these principles often are not reflected in practice.

Background

Current codes of practice indicate that education researchers should seek consent from research participants and should aim to inform participants about the possible consequences for them of taking part in the research [1, 2]. The recently updated Ethical Guidelines from the British Educational Research Association [2], for example, make it clear that participants should be asked for their consent before the research gets under way and that, where the participant is not judged to be able to give consent, researchers should seek the 'collaboration and approval' of those in a guardianship role. Guidelines from the English Royal College of Paediatrics and Child Health [3] include the principle that children of school age should be asked for consent, even where parents have agreed to the child's participation. A similar recommendation is made in the code of the British Sociological Association [4].

This paper arose from an initiative concerned with systematic research synthesis in the social sciences. Since 1993 the Evidence for Policy and Practice Information and Co-ordinating Centre (EPPI-Centre) at the Institute of Education, University of London, has built up detailed databases of research identified during the production of systematic reviews in education, health promotion and other areas of social policy. A previous analysis of 215 health promotion studies included on one of these databases found that only 45 (21%) of studies gave clear information about the extent to which participants had consented to take part in research [5]. In a second analysis of the research included in two reviews of health promotion interventions for young people, under a third of studies reported seeking participant consent [6]. These findings led us to explore the issue of consent reporting in social science research further.

The EPPI-Centre databases now include records of over 20,000 studies. These relate both to evaluations of interventions and to other kinds of research, such as studies of people's experiences and views. All the records have coding that describes substantive characteristics such as study type, country, age of participant and study setting. A sub-set of over a thousand studies included in the in-depth stages of systematic reviews has been coded in more detail. This detail includes whether consent was reported to have been sought or consent reporting was judged by reviewers as either unclear, ‘not stated’, or not applicable. Study coding is done by researchers who are part of review groups collaborating with the Centre [see 7] and by staff at the EPPI-Centre.

To increase the reliability of data extractions, reviewers working on a review first apply codes independently in pairs, and then compare coding so as to reach consensus. Coding guidelines, containing detailed explanations and definitions, are used to help ensure that codes are applied in a consistent and meaningful way. For review groups that are working collaboratively with the EPPI-Centre, quality assurance work within review teams is supplemented by independent coding by staff at the Centre on a sample of studies.

Methods

Searches were run of EPPI-Centre review databases in August 2004 using the Centre's EPPI-Reviewer software [8] to identify studies meeting the following criteria:

1) participants aged between 5 and 10 and/or between 11 and 16 years; and

2) conducted in either a primary/elementary and/or a secondary school; and.

3) coded by reviewers to provide detail of consent reporting.

Within this set of studies, further searches were run to identify whether authors reported seeking consent or permission, and if so, from whom they reported seeking consent. Codes distinguished between the seeking of consent from study participants and the seeking of consent or permission from others, such as parents, teachers or school heads. Two other relevant codes were available: 'consent not stated or unclear' and 'consent not applicable'. When the latter had been applied to a study, we examined the reviewers' description of their rationale for this coding decision. We also examined the frequency of reporting of consent procedure by:

- the age of participants (did reporting differ when participants were of primary/elementary school age, as opposed to being of secondary school age?);
- the year of publication (did reporting differ for studies published earlier rather than later (we took the arbitrary date of 1991));
- the country of study;

- study topic (did reporting differ if the study had been reviewed for a systematic review of policy or practice in education or of policy or practice in health promotion?);
- study type (did reporting differ between intervention evaluations and other kinds of study?);
- evaluation design (for those studies that were evaluations, did reporting differ between those studies that used randomization to produce equivalent comparison groups and those that did not use a randomized controlled trial (RCT) design?).

Results

Out of the 1,122 studies with detailed coding that were on the database at that time, 525 met this study's inclusion criteria. In all these individual studies, children or young people (aged 5-16) participated in research conducted in a primary/ elementary and/or secondary school setting.

Forty four of the 525 studies had been coded by reviewers as ‘consent not applicable’. In some of these cases, for example studies using routinely collected data such as examination results or established assessment procedures, children or young people would be relatively unaffected by participation. We judged that 36 of the 44 studies were appropriately labelled as ‘consent not applicable’. However, 8 of the 44 involved the use of self-report questionnaires or novel educational interventions; we reclassified these as ‘consent not stated or unclear’. Thus, the

analysis that follows is based on 489 studies. Of these, 395 reported evaluations of interventions and 94 were other types of study.

Table 1 about here

Table 1 shows that the majority (n=344: 70%) of the studies did not report on consent or reported in a way that was unclear. Only around one in seven of the total (n=66: 13%) reported that consent had been sought from children or young people themselves. Authors' reports indicated that teachers and parents were more likely to be asked for consent or permission for children or young people's participation than were children or young people themselves. Table 1 also shows that there was no difference in the reporting of consent procedures between studies with participants in primary schools and those studies focused solely on secondary schools, nor between studies reported before 1991 and after.

Table 2 about here

Table 2 shows that the 489 studies consisted of 277 that had been part of reviews on educational topics and 212 that had been part of reviews focused on health promotion. The education review topics included the effects of differing school size, teaching approaches and forms of assessment, as well as studies of processes associated with teaching and learning. Health promotion topics covered intervention effectiveness related to smoking cessation, peer-led health initiatives, healthy eating, physical activity and sexual health, as well as studies of children's and young people's views in these areas. As can be seen in Table 2, consent was found to be

reported more frequently in studies sourced from health promotion reviews, when compared to those sourced from education reviews. Authors of health promotion studies were twice as likely as authors of education studies to report that they had sought consent from someone; they were also more likely to report seeking consent from children or young people themselves.

Table 3 about here

Table 3 gives the breakdown for study type and for different evaluation designs. Reporting of consent was similar for evaluations and for other study types. Just under a third (N=123: 31%) of the 395 evaluations used a randomized controlled trial design. There was a tendency for RCTs to report consent more than other evaluation designs.

Discussion

This paper reports an analysis of what authors of research papers say about consent; it is not a general discussion of the considerable literature on consent to participate in research. The analysis reported in this paper examined the description of consent procedures in a set of studies which had been coded for inclusion in systematic syntheses of educational and health promotion research. The studies examined in the paper are not a random sample of the available literature, but were selected to fit the criteria for the individual systematic reviews in which they were included. However, there is no reason to suppose that these studies are unrepresentative in any way with respect to the issues which are the focus of this paper.

Our analysis shows that reporting the consent of children and young people to take part in school-based research is the exception rather than the rule. Only one in ten education studies and one in five school-based health promotion studies reported seeking children and young people's consent. Fewer than a third of studies reported consent procedures clearly. We do not know whether this was because most authors failed to report the details of consent procedures, or because consent had not, in fact, been sought.

Consent from research participants is considered good in itself, a recognition of the human value of being involved and consulted about what is done to and with us [9]. The recommendation that consent should be sought from children and young people wherever possible is there, not only to protect the researched and the researcher, but also to increase openness and to empower the 'subjects' of research [10]. It is also important for readers of research reports to know how consent was obtained and from whom, because this is part of understanding the strength and nature of research findings.

Our data do not allow us to estimate the proportion of studies where consent was sought from research participants but not reported. It may be that, in many of the studies in the databases we looked at, researchers gained access to school settings, and this permission was treated as a form of consent for the research. Working with the 'gatekeepers' who are necessarily involved in research access to children and young people in school settings presents a number of challenges for researchers. As well as limiting or denying access, gatekeepers can bypass

individual consent from children and young people by assuming that such consent is not required [11]. School staff may set up the interaction between researchers and potential participants in such a way that there is no opportunity to ask for consent, or for participants to choose to withdraw. Such methods may include data collection sessions supervised by teachers and/or with a lack of privacy for participants.

Although the comparison of education and health promotion research reported here is a relatively artificial one (many 'education' studies measure health outcomes, and many 'health' studies are also concerned with cognitive gains and other educational outcomes), the finding that education-focused research reports on consent procedures less often than health promotion-focused research is an interesting one. Many factors may contribute to this picture. There may be different requirements from journals about the reporting of consent and ethics approval, and from research funders about the seeking of consent and the approval of research ethics committees. Researchers working in health promotion may have been more heavily influenced by the move towards the tightening of consent and other ethics procedures in medical research, especially in experimental research [12]. This is supported by the tendency we found for consent reporting to be higher in evaluation studies using an RCT design. There may be a perception that research in schools does not require consent in the same way that is required for medical research with children and young people, because research in educational settings may be seen as harmless [13]. This view predominates in qualitative research which is common in education, despite evidence that research participants may be at risk of significant harm in many qualitative research studies [14]. The argument that participants in education research are somehow protected from the adverse consequences that

can accrue to those who take part in research in other settings may be changing in the context of an active debate about ethical standards in social research and the role of independent scrutiny [eg. 15-17]. Unravelling differences between the 'cultures' of educational and health promotion research with respect to consent would be helped if studies were coded according to any disciplinary affiliations reported by study authors.

The analysis reported in this paper shows that, of those studies where a consent procedure of some sort was reported, over half (79/145: 55%) described consent only from someone other than the school student (Table 1). According to these figures, children and young people involved in school-based research are usually not asked for consent. One factor operating here may be the dominant educational theory that children are incompetent to consent because of their developmental immaturity [18]. The health promotion studies in our analysis were slightly more likely to report consent from children and young people themselves (17% in health promotion studies, 11% in education studies, Table 2). But the view that consent from children is not necessary has also been prominent in medical research [19]. Where consent is sought on their behalf from others, some of this is likely to be the common practice of passive parental consent that has been challenged on various grounds [20].

We would recommend that researchers should report on the way that ethical issues were dealt with in a project, including how and from whom consent for the research was sought. There are some very good examples in journal articles of detailed reporting of the process of consent and how this process works throughout the

study [eg. 10, 21, 22]. The challenge is to make sure that the key information is included in all types of journal articles, even those that do not usually include reflection on methods, or those where there are space restrictions. This is part of the general move needed to improve the way that educational and social research is reported [23].

The variation in reporting seen in this study also indicates a need for the relevant professional bodies to clarify their ethical guidance for research so that it takes specific account of the rights of children and young people. In the meantime, local examples of guidance [24] provide a starting point for critical and reflective thinking on the issue.

The EPPI-Centre was established in 1993 to address the need for a systematic approach to the organization and review of evidence-based work on social interventions. The work and publications of the Centre engage health and education policy makers, practitioners and service users in discussions about how researchers can make their work more relevant and how to use research findings. Frequently, reviewers note how the act of describing and appraising research raises their own awareness of limitations in the way in which research is conducted. This study illustrates how such reviews can provide useful evidence about the conduct of research, as well as substantive findings. It indicates that the reporting of consent procedures for school-based research involving children and young people is one area where research has, more often than not, failed to meet standards of good practice.

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Competing interests

None

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Table 1. Reporting of consent procedures by age of participants and publication date (N=489)

	All studies		Age of participants				Publication date			
Type of consent reporting	Total		secondary only		primary		before 1991		1991 and after	
	N	%	N	%	N	%	N	%	N	%
Clear reporting of consent procedures	145	30	78	29	67	30	35	29	110	30
sought from children/ young people	66	14	36	13	30	13	14	11	52	14
sought from other but not from children/ young people	79	16	42	16	37	17	21	18	58	16
No consent reporting or reporting unclear	344	70	189	71	155	70	85	71	259	70
TOTAL	489	100	267	100	222	100	120	100	369	100

* EPPI-Coding systems have not always distinguished between a lack of consent reporting or unclear reporting. When they have distinguished between them, the great majority have been coded as not reported.
** A further 36 studies had been judged as “consent not applicable”. These included studies based on routinely collected data such as exam results, where it could be argued that participants would otherwise be unaffected by participation.

Table 2 Reporting of consent procedures by country studied and review topic (N=489)

			Country studied						Review topic			
Type of consent reporting	Total		USA		UK		Other		Education		Health promotion	
	N	%	N	%	N	%	N	%	N	%	N	%
Clear reporting of consent procedures	145	30	84	34	44	30	17	18	56	20	89	42
sought from children/ young people	66	13	39	16	17	11	10	11	31	11	35	17
sought from other but not from children/ young people	79	16	45	18	27	18	7	7	25	9	54	25
No consent reporting or reporting unclear	344	70	163	66	104	70	77	82	221	80	123	58
TOTAL	489	100	247	100	148	100	94	100	277	100	212	100

Table 3. Reporting of consent procedures: i) by study type (N=489); and ii) by evaluation design (N=395).

Type of consent reporting	Total		Study type				Evaluation design			
			evaluation		other study type		RCT design		not RCT design	
	N	%	N	%	N	%	N	%	N	%
Clear reporting of consent procedures	145	30	117	30	28	30	44	36	73	27
consent sought from children/ young people	66	13	56	14	10	11	21	17	35	13
consent sought from other but not from children/ young people	79	16	61	15	18	19	23	19	38	14
No consent reporting or reporting unclear	344	70	278	70	66	70	79	64	199	73
TOTAL	489	100	395	100	94	100	123	100	272	100