

Research Ethics and Regulation in the UK:  
The Case of Informed Consent

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## Abstract

Patterns of research governance in the UK are changing rapidly in the field of social research with increasing regulation occurring through National Health Service Ethics Committees as well as the establishment of University Ethics Committees, which are themselves evolving as a result of pressure from statutory bodies, universities and research funders. In current debates about these changes, one issue of particular concern relates to the processes of gaining informed consent to study participation as well as, increasingly, to the ways data are used and stored. This paper draws on a study conducted in the UK which explored researchers' views of informed consent in social research conducted with research participants who are often constructed as 'vulnerable' in the research process because of their status or perceived ability to give informed consent. The sample included researchers conducting research with children, older people and people with a range of health problems. The move towards more formalised processes of consent is viewed as good ethical practice by some researchers and as having a positive impact on data quality. However, others view the increasing regulation of research as a source of concern in that it will impose specific methods of gaining consent on researchers which, it is feared, may be in conflict with researchers' specific research orientations and will prevent them from using their discretion in resolving the ethical dilemmas they encounter in their research. Particular tensions exist for those using participatory and ethnographic approaches. This paper will identify the various ways in which researchers in our study position themselves in relation to this issue. It will explore the ways in which ethical research practice in relation to informed consent is context specific and how such processes are neither a guarantee, nor an inevitable obstacle to, good quality data.

## **Background**

The ethical regulation of social research in the UK is in a state of flux with change occurring in response to a variety of institutional, legal, political and moral influences that are themselves evolving very rapidly. There has been an increasing concern with issues of research ethics in both social and medical research in the UK over the last five years. This concern was precipitated by public outcry following the scandals at Alder Hey Hospital in Liverpool and Bristol Children's Hospital where dead children's organs were retained for research without parental consent. These events, and a general sense of public concern, prompted the Department of Health to develop the Research Governance Framework (Department of Health 2001). The framework brings together various guidelines and statutes to provide a coherent and ethical context for research in health and social care.

The development of the Research Governance Framework has run parallel with changes in the management and organisation of NHS Research Ethics Committees. Local Research Ethics Committees (LRECs) were formed in the UK in early 1968 (these have a similar function to Institutional review Boards (IRBs) in North America although RECs do not have the force of law as IRBs do) to regulate medical research and to ensure adherence to these frameworks. The changes to LRECs have resulted in a more bureaucratic system of ethical approval with procedures that are onerous and time consuming and have been subject to much criticism from social researchers (see, for example, Truman, 2003; Ramcharan & Cutcliffe, 2001) and medical researchers (Mayor, 2004; Jamrozik, 2004; Jones & Bamford, 2004)<sup>1</sup>. Researchers conducting research in health and social care contexts are subject to regulation from NHS or

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<sup>1</sup> As a result of these criticisms an Advisory Committee has been formed and is due to report in March 2005 on how the system can be streamlined.

institutional Research Ethics Committees or Boards and these have a significant impact on the procedures researchers are able to adopt (see, [www.corec.org.uk](http://www.corec.org.uk); DoH, 2001), especially in relation to issues of informed consent.

The changes in ethical regulation in health and social care fields have impacted on social research more broadly (outside of the areas of health and social care).

Professional associations and research organisations have recently written or revised their ethical guidelines to ensure they meet with the current climate of concern relating to research ethics (see, for example, the Social Research Association ([www.the-sra.org.uk/Ethicals.htm](http://www.the-sra.org.uk/Ethicals.htm)), the British Sociological Association (BSA) ([www.britisoc.co.uk/library/ethicsguidelines2002.doc](http://www.britisoc.co.uk/library/ethicsguidelines2002.doc)), and the British Education Research Association ([www.bera.ac.uk/publications/guides.php](http://www.bera.ac.uk/publications/guides.php))<sup>2</sup>. However, ethical guidelines prepared by these organisations operate primarily on a system of self regulation; membership of these organisations is voluntary and the guidelines are not enforceable. In addition, they are intentionally vague and leave researchers able to interpret them in ways that fit the needs of the specific research they are undertaking and their own orientation to research ethics (see Smyth and Williamson, 2004:10). This has traditionally allowed social researchers to adopt a ‘situational relativist’ approach in which ethical decisions are made on the basis of the researcher’s moral stance and issues applicable to individual research projects (Small, 2001; Goodwin et al, 2003). This point is noted in the BSA statement of ethical practice (2002):

‘The Association encourages members to use the statement [of ethical practice] to help educate themselves and their colleagues to behave ethically. ... [It] does not,

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<sup>2</sup> A list of guidelines for various professional and research organisations can be found at: [http://www.sociologyandsocialpolicy.soton.ac.uk/Proj/Informed\\_Consent/links.htm](http://www.sociologyandsocialpolicy.soton.ac.uk/Proj/Informed_Consent/links.htm)

therefore, provide a set of recipes for resolving ethical choices or dilemmas, but recognises that it will be necessary to make such choices on the basis of principles and values, and the (often conflicting) interests of those involved.’ (BSA, 2002).

The system of self regulation has been the traditional way that social researchers have managed issues of research ethics in the UK. Many social researchers have argued that ethical regulation does not necessarily translate well to social research, partly because the ethical dilemmas that arise in social research are context-specific (Punch, 1998; Swain et al, 1998; Small, 2001; Goodwin, et al, 2003). In addition, some social researchers argue that adhering to specific ethical rules in relation to research can affect the very issue that is being studied, such that it becomes impossible to conduct the research (Homan & Bulmer, 1982; Homan, 1991; Punch, 1998). This issue is particularly relevant to psychology experiments but is also relevant to research in sociology and anthropology, particularly ethnographic research. There is widespread debate about the basis for ethical decision making in social research, these include a commitment to participants’ rights (e.g., the protection of privacy); a commitment to ‘respect’ for participants; a commitment to knowledge (or the right for others to know e.g., how specific organisations operate); a commitment to the promotion of respect for social science (i.e., to avoid ‘spoiling the field’); and, protecting the researcher (e.g. from litigation) (see Alderson, 2004; Homan, 1991; Homan & Bulmer, 1982). All these issues are enshrined to some degree in the guidelines to which social researchers work.

However, this system of self regulation is currently under considerable challenge and it is unlikely that social researchers will be able to continue to self regulate their

ethical practice in the ways that they have hitherto. The ripples from the Research Governance Framework have impacted on other areas of research resulting in pressure from research funders (both Government and charities) for academic and research organisations to develop systems of ethical review for all research conducted with ‘human subjects’. Institutional Research Ethics Committees have increased in number in recent years with a recent survey indicating that most universities are aware of the need for such Committees and are beginning to put processes in place to ensure the ethical scrutiny of research involving ‘human subjects’ (see Tinker & Coomber, 2004). The Economic and Social Research Council (ESRC) (the Government funding body for social science research) are, at the time of writing, in the process of developing a Research Ethics Framework which will contain guidelines for ethical review (see: <http://www.york.ac.uk/res/ref/documents.htm>; [www.esrc.ac.uk/esrccontent/ourresearch/research\\_ethics\\_framework.asp](http://www.esrc.ac.uk/esrccontent/ourresearch/research_ethics_framework.asp)). This will mean that only research applications that have been through an ethical review committee will be eligible for ESRC funding and it will be expected that all institutions that want to apply for funding from the ESRC will have an appropriate ethics committee in place. Other funding bodies already have this stipulation and others are set to follow this. This prospect has been met with resistance by some social scientists (see, for example, Coomber, 2002), but others have identified the advantages of regulation and urged social researchers to become involved in the process of their development (Williamson et al 2002; <http://www.york.ac.uk/res/ref/index.htm>).

The issue of informed consent is central to ethical research practice. Informed consent is understood as ‘a procedure for ensuring that research participants

understand what is being done to them, the limits to their participation and awareness of any potential risks they incur' (Social Research Association, 2003:28).

Researchers are obviously subject to legal frameworks that influence, to varying degrees, how issues of informed consent are managed. This is particularly the case in research with children and people with 'incapacity' for whom parental or other adult consent is generally needed (see, Masson, 2004; Wiles et al, 2005). However, providing researchers work within the remit of the law (which has been interpreted widely by researchers) they have been free to adopt the procedures for consent that they choose or that the gatekeepers to their research participants stipulate. However, the increasing ethical regulation from research ethics committees means that researchers have less freedom to make decisions about how issues of informed consent will be managed. Researchers have noted that this may mean that more formal procedures of consent will need to be adopted which may put some people of participating (Wiles et al, 2004) and also may be inappropriate for some groups (Coomber, 2002) or some types of research (Holman & Bulmer, 1982; Scraton, 2004).

This paper draws on research conducted among researchers in the UK to explore their views of informed consent. The data are used here to explore our participants' views on the increasing formalisation of informed consent and its impact on the research process.

### **The study**

Before moving on to explore these issues, we will first outline the research study on which this paper is based. This paper draws on a research project, entitled 'Informed Consent and the Research Process' which was funded as part of the ESRC Research

Methods Programme. The rationale for undertaking the project was the increased attention that is being paid to the issue of informed consent in research, not least because of the broad changes that are taking place in research governance and regulation in the UK and the increasingly legally-oriented frameworks within which academic and social research organisations have to work (Truman, 2003; Tinker & Coomber, 2004). The focus of the study was to explore researchers' views and experiences of managing informed consent with the aim of developing resources for use by the social science community and encouraging debate on the topic.

The project involved collecting data primarily through telephone interviews and focus groups with academic and non-academic researchers and focused specifically, but not exclusively, on researchers who conduct qualitative research on or with children, young people, older people, people receiving palliative care, people with learning disabilities and people with mental health problems. The focus on these particular areas of research was made because of the assumed vulnerability of members of these groups within the research process, although we would argue that our study has implications for consent in social research more generally. Thirty-one individual telephone interviews were conducted with experienced researchers with reputations for work in these specific areas (n=24) or in research ethics more broadly (n=7). These individual 'experts' were identified through our own knowledge of the area, recommendations from other academics approached to participate, the literature and web searches. The six focus groups were conducted in six academic institutions which had recognised expertise in each of the topic areas. These groups comprised experienced researchers, academics and PhD students working in these broad areas (n= 35). The interviews and focus groups were designed to elicit information from



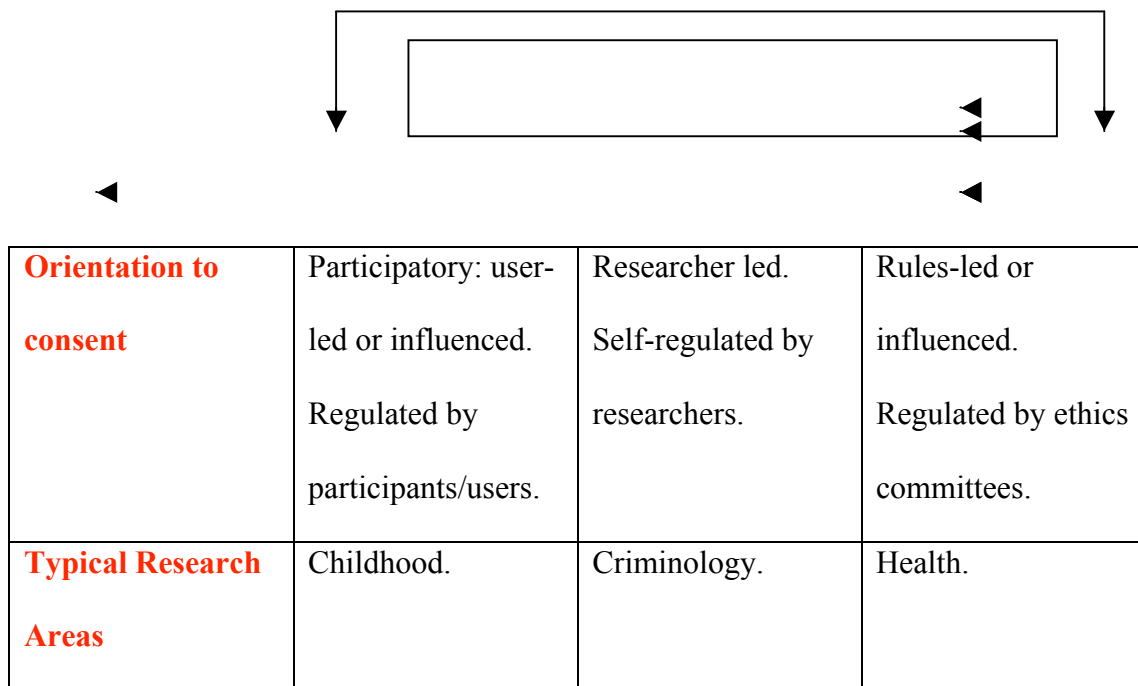
researchers relating to their views and practices around gaining informed consent from people involved in their research. To supplement our data, the project website invited interested researchers to email us their views on these issues and we also emailed 33 researchers inviting them to respond by email to these specific issues. The researchers contacted comprised those that we were unable to include in interviews or focus groups but would ideally have wanted to. We had responses from ten of these individuals.

## **Findings**

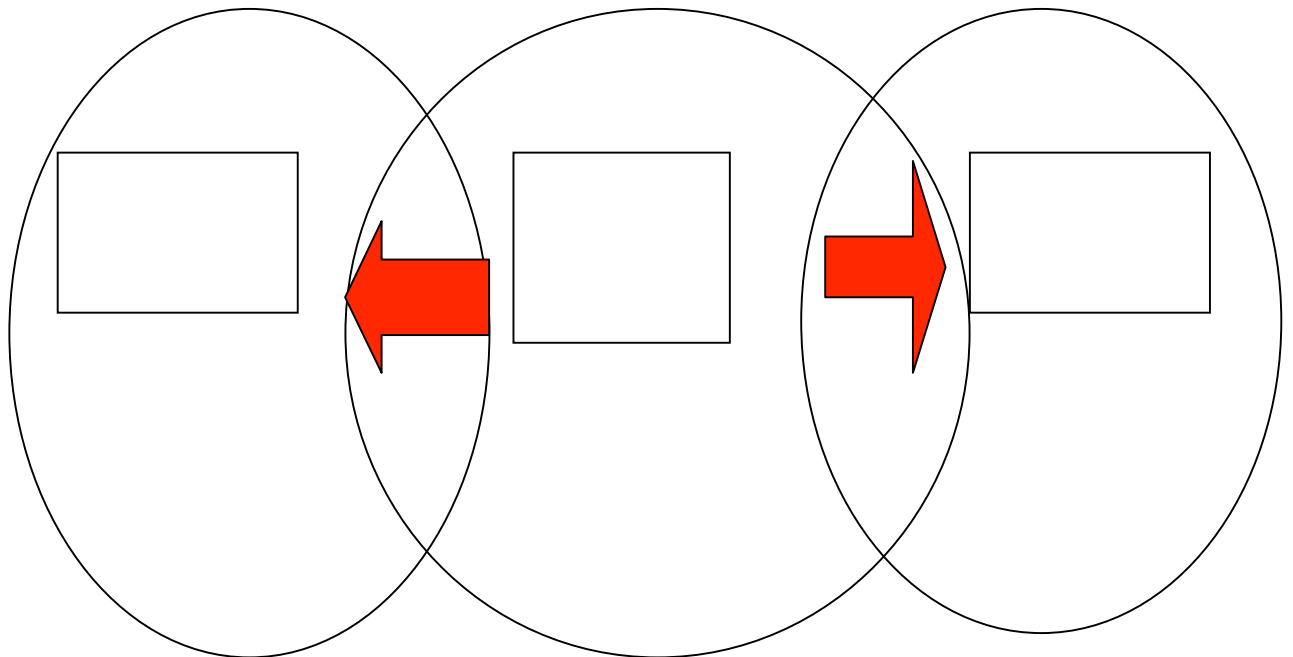
Informed consent is commonly understood as providing sufficient information to study participants to enable them to know what participating in research will entail. However, in practice this is not straightforward and involves researchers making judgements according to the specific contexts in which they work, the groups they work with, their disciplinary backgrounds and research approaches. In each of the areas from which our participants were drawn we found that approaches to consent, and to its increasing regulation, were, to some degree, specific to the research area. Most researchers viewed informed consent as necessary (i.e., were against the notion of covert research). However, while some researchers felt that improved processes of consent would improve the quality of research, others were concerned that increasing regulation may impose methods of gaining consent that may be in conflict with their area or disciplinary-specific research orientation and would have a potentially detrimental effect on the data collected and the research process more generally. Concerns were particularly expressed by researchers using participatory or ethnographic approaches. Those using participatory approaches view their approach to ethical issues in research and to consent more generally to be user-led i.e., they

develop partnerships with potential participants to ensure that participants' views are respected (Alderson, 2004; Thomas & O'Kane, 1998). Those using ethnographic approaches often view their approach to ethical issues in research to be researcher-led or self-regulated, partly because the notion of informed consent in ethnographic work is often difficult to achieve (see Homan & Bulmer, 1982). Figures 1 and 2 illustrate these views. The objections raised by these groups of researchers to increasing regulation around informed consent are outlined below.

**Figure 1: Researchers' Orientations to Consent**



**Figure 2: Tensions in the Increasing Regulation of Research Ethics**



While a number of our research participants were of the view that ‘everyone agrees nowadays that consent is a good thing’ (interviewee 7), our study identified various grounds on which researchers express reservations. Researchers, especially those working in participatory and ethnographic paradigms viewed the increasing regulation, especially around informed consent, impacted negatively on the research process. The key concerns were that: informed consent has an adverse effect on people’s willingness to participate in research (in the extreme making some groups of people or some topics unresearchable); that the processes of gaining informed consent inhibits relationships between participants and researcher which are necessary for the

collection of authentic data; and, that the quality of the data collected suffers as a result of the practical arrangements for gaining consent. These impacts are generally recognised not to be the *intention* of the move towards more ethical practices around informed consent, but rather are understood as a series of unintended consequences.

#### Adverse effect on participation

Formalised consent procedures are seen by some researchers as resulting in some groups being excluded from research. There was a fear that because of greater regulation especially around research with so-called vulnerable groups, research with these groups would not take place:

‘there’s a danger that we’re going to exclude so-called vulnerable groups because we make doing research with them so difficult’ (interviewee 16).

‘people with dementia... are hugely under-represented because we can’t get consent .. they become hidden people from research’ (focus group 3).

Conducting research with specific ethnic groups was also identified as problematic because formalised procedures don’t take into account the ways in which ethnic minority families can most appropriately be accessed:

‘in terms of a fairly patriarchal household consent was.... on some occasions derived through the.... male head of the household or consent was often refused via the male head of the household. So one problem with consent I think is about... it does have

some relationship to power dynamics within the household... And I think that's a particular problem with... certain minority ethnic communities' (interviewee 23).

'the whole notion of informed consent is based upon this middle-class western sort of stereotypical concept of autonomy... And while we've gone to enormous lengths to get information translated into Urdu, Punjabi and things like that we're still finding that response rates for this type of mechanism are extremely poor' (interviewee 14).

Age was also mentioned, with several interviewees and focus group members commenting on how the requirement of parental or teachers' consent for children to participate led to the exclusion of some children from research projects:

'one child who tried very hard to be interviewed and could not be interviewed because his parents hadn't returned a form and, and his teacher knew that. The second week I was in the school this child brought in a signed form which the teacher asked to see and said "that's not your parent's signature is it?" you know, so this poor child... was saying in lots of ways "I would like to talk to this person" and couldn't because of this consent process' (focus group 5).

In the extreme, the requirement of parental consent made some projects unfeasible, as in the case of one interviewee's PhD student who had contacted young gay men through clubs but was required by an ethics committee to gain their parents' consent for them to be interviewed, as a result of which he actually couldn't do the research. Similar reasoning about the inapplicability of seeking consent from parents for research into aspects of their children's lives about which they may not know led to

the abandonment of plans to conduct a postal survey of school children related to alcohol consumption. A third interviewee noted how research into youth gangs had become impossible to do:

‘you could never do this kind of research any more because parental consent worked against children’s interests in situations where most of the parents don’t know they’re in gangs and if they did the young person in question could actually run a risk of abuse or certainly alienation from the family if they did’ (interviewee 5).

#### Adverse effect on researcher-participant relationships

Researchers viewed formal information sheets and the need to have signed consent forms, which are a requirement by most ethics committees, as having a negative impact on potential participants. The concern was expressed that formal information sheets might lead people into a narrower range of responses than they might otherwise have given. One researcher related the problem to the classic case of participants responding to the fact of being studied:

‘it raises.... the Hawthorne effect doesn’t it? So you get the kind of behaviour they think you want them to perform’ (interviewee 25).

There are other ways that informed consent can present an obstacle to rapport between researchers and participants. One is the commencement of a research encounter with what can seem unnecessarily bureaucratic procedures:

‘When you come into their house they don’t want you to say “now we have a whole bunch of paperwork to do”.... that interrupts the natural flow of a conversation.... just confronting these people with a whole load of paperwork.... isn’t part of the deal’ (interviewee 22).

‘we’re now required to write every single detail in terms of what this research is about... what the effects of it might be, that in itself can be a potential barrier to people wanting to take part in the research.... sometimes I think we can give them overload.... as opposed to really making better research’ (interviewee 10).

‘some people.... you give them too much information and they’re not informed, they’re just befuddled’ (interviewee 20).

Similar concerns apply to the requirement to gain signed consent. Consent forms were seen as problematic, especially when conducting research with some groups who might view such forms as threatening, this includes research into illegal activities or where disclosure of information can put participants at risk from physical harm or censure from others (e.g., in the case of domestic violence or where people are involved in activities of which their parents, spouses or others are not aware) .

‘when you’re researching.... very excluded groups, which typically I am, it’s very threatening to ask someone to sign a form’ (interviewee 4).

‘It introduces a quasi-legal element to the relationship and risks putting participants in a bit more oppositional kind of frame. A formalised procedure sometimes seems a bit

too formal... it can get in the way of establishing the good relationships you want and in any case is no guarantee of honest data' (interviewee 18).

Several interviewees and focus group members also flagged up the potential of informed consent procedures to unintentionally antagonise or alienate participants. In relation to things said at the outset by the researcher one had come to the conclusion that warning people that the interview might be distressing or seeking to ensure that people had understood the information felt rather patronising:

'its not necessarily appropriate to say "you might find this interview distressing" because... people can decide that for themselves and it does sound a bit patronising... [and] it's very difficult to anticipate what might cause distress' (interviewee 15).

'it gets to the point of [being] pretty patronising if you're going to start saying "do you understand about this study?" because they do because otherwise they wouldn't be taking part in it' (interviewee 22).

The recognition that consent is on-going has rightly led researchers to re-visit the issue with participants at various points of the research process, but this has also come to be recognised as a potential obstacle to rapport:

'if you start to continuously remind people about the research that affects the dynamics' (interviewee 14)



‘I made a point of saying “is it ok for me to speak to you to-day?” and people were getting irritated with “well yes, you asked me that before”’ (focus group 2).

#### Adverse effects on data collection

The view that the quality of the data collected suffers as a result of the practical arrangements for gaining consent follows on from this point. The time required to gain consent features prominently in the comments of several interviewees who worked in educational settings and who had limited time made available in the school day in which to conduct research:

‘just getting people to think through the implications of... taking part... it’s time consuming and it doesn’t always fit in with the way in which we have to do research ’cause we don’t always have that... time’. (interviewee 6).

‘ the potential that exists to mess up maybe quite a short session with talk, talk, talk, talk, talk about all these things before you actually get going’ (interviewee 2).

Researchers in palliative care expressed similar views:

‘the time that it takes to work through the consent form is actually time that’s being taken away from the opportunity that I have to gather information from them for research purposes... compromising the information that we can gather in the period of time that you’re with them’ (interviewee 11).

The potential to lose data through informed consent procedures could take other forms. One of these mentioned by several interviewees relates to research participants being shown transcripts of data relating to them and seeking to change it. In some instances requests from participants to change what they had said were stylistic but which don't change the meaning of what is said. More serious difficulties arise where changes desired by participants go further than corrections to grammar into changed meanings. The commitment to send transcripts back to people for accuracy can even lead to the withdrawal of a participant's data altogether, and although this appears to be extremely rare at present it has the potential to become less so as post-fieldwork consultation increases.

Finally in relation to the adverse effect on data quality of putting informed consent into practice are matters concerned with how far to take the commitment to use only those data for which consent has been gained. A good deal of research involves people talking about their relationships with others, from whom consent hasn't been gained, and one view on this was that requiring the consent of everyone mentioned in an interview would be impossible. A related issue concerns gaining consent from all participants in observational or ethnographic research where it is often impossible to get consent from everyone in a particular setting. One researcher noted:

'one can do covert research without intending to... The status of those data where, you know, you might not even know the person's name, you might overhear things, you might be, people might know about your research and not be participants but talk to you about their own experiences and those of other people. I mean what do you say at the end of the conversation? "Do you mind if I rush off and write it all down and

would you sign an informed consent form?" It's very, very problematic but then drawing boundaries around a field in which one is immersed so that the only data are those formally collected is very difficult' (interviewee 15).

More hypothetically the case of classroom observation was raised:

'if you're doing something with the class and you... agree that every individual in the class had to be asked to take part and if one person doesn't want to take part what... do you do with that data? Or, you know, if one person then wants to withdraw from a group discussion... what do you do? You can't, it's a group discussion and the other people in the group have responded to you then you can't easily withdraw the individual's comment because they're part of what made the rest of the group happen' (interviewee 27).

## **Conclusion**

Prospective participants in research are generally considered to be entitled to be provided with information about the projects in which they may take part but that information needs to be presented in a form that is manageable and meaningful to them and within timeframes that suit them. Information can be more or less excessive, more or less opaque, and more or less untimely, and it is readily apparent from our respondents' accounts that researchers err on one or other side of what is ideal in these respects more often than they achieve perfection. It is also readily apparent that regulation of researchers by ethics committees, funding bodies, research population gatekeepers and other interested parties plays a significant part in producing this outcome. In other words, shortcomings in relation to researchers' practices around

information are by no means the result of researchers' judgements alone, because often research practice in relation to information is imposed on researchers regardless of their preferences. The same point can be made about consent, regarding decisions about whose consent is required, what form that consent takes and how long it is understood to endure. Consent can be sought from individuals alone or in addition from relevant others, it can be signed or verbal, it can be through opting in or opting out, and it can be more or less frequently re-confirmed at various stages of the research process.

The fact that researchers face a number of difficult decisions around informed consent is nothing new, as our annotated bibliography of relevant literature has revealed ([http://www.sociologyandsocialpolicy.soton.ac.uk/Proj/Informed\\_Consent/Resources.htm](http://www.sociologyandsocialpolicy.soton.ac.uk/Proj/Informed_Consent/Resources.htm)). What is new is that research is being conducted in an increasingly regulated environment in which expectations on researchers in relation to their practices around informed consent are growing apace (Tinker and Coomber 2004). There are several reasons to believe that these changes will have a beneficial effect on the quality of data generated if as a result researchers are more reflective about their practices, research participants are better prepared for their involvement, and relationships between researchers and participants in their studies are mutually empowering rather than risky, harmful, exploitative and coercive. However, a more 'pessimistic' scenario can also be presented in which current changes in relation to informed consent have the opposite effect. This will be the outcome if the more regulated environment sees participation rates fall (in the extreme to zero as certain areas become unresearchable), if researcher-participant relationships become characterised by less

rather than more rapport, and if the pursuit of informed consent leads to data being patchy and distorted.

The reality lies somewhere between the two positions. Ethical research practice is neither an automatic guarantee of, nor an inevitable obstacle to, the collection of good quality data. Precisely how the situation unfolds will vary considerably from one field of research to another, depending for example on whether the subject matter involves activities about which participants are reticent to see disclosure because they involve criminality or some other aspect of deviance (Coomber 2002). There will also be variation according to the extent to which the subject matter of research is individual or collective, and according to whether individuals are deemed 'competent' (Masson 2004). Our research focus on groups of people commonly characterised as 'vulnerable' means that our findings cannot be generalised to relate to informed consent in every case, but they do point towards two broad conclusions. One is that the results of the current drive towards greater regulation will not be determined by the fact that they are motivated by good intentions; these alone cannot prevent the range of unintended consequences outlined above. It follows that the rigidity of standardized regulation will need to be tempered by a degree of flexibility according to the characteristics of specific research contexts.

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