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Research Ethics and Data Quality: The Implications of Informed Consent

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Patterns of research governance are changing rapidly in the field of social research. In current debates about these changes one issue of particular concern is the impact that new patterns of research governance will have on the quality of the data collected. The 'optimistic' scenario on this issue is that more ethical research practice will lead to better-quality data, but a more 'pessimistic' scenario exists in which the unintended outcome is poorer-quality data. Drawing on material from a study of researchers' experiences of dealing with the process of gaining informed consent from research participants, this article identifies the various ways in which the researchers position themselves in relation to the competing 'optimistic' and 'pessimistic' scenarios. It concludes by seeking to develop a synthesis of the two positions in which ethical research practice is treated neither as an automatic guarantee of, nor as an inevitable obstacle to, the collection of good-quality data.

Introduction

Gaining informed consent from people being researched has come to be regarded as a central element of the ethical conduct of research, and practice in this area is changing rapidly (Tinker & Coomber, 2004).[1] The principle of informed consent requires that prospective participants in research are provided with information about the project in which they are being invited to participate that is sufficiently full and accessible for their decision about whether to take part to be considered informed. It also requires that people in possession of this information consent freely to participation and have the

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opportunity to decline to take part or to withdraw from the study without such decisions triggering adverse consequences for them. These issues are particularly important in research involving members of groups that are commonly characterized as 'vulnerable' because of their perceived openness to coercion, exploitation or harm by more powerful others. Informed consent is one of the aspects of social research that has come in recent years to be subjected to increasingly rigorous monitoring and regulation by bodies concerned with research ethics, and it is also a part of the research process about which researchers themselves reflect regularly, and not merely as part of the procedures required to gain approval from ethics committees to proceed with research.

The implications of these developments in research practice for the quality of the data collected are a matter of continuing debate. Some researchers (Kent, Williamson, Goodenough, & Ashcroft, 2002) emphasize their potential to improve research findings while others (Coomber, 2002; Truman, 2003) lean towards opposite conclusions. The determination of what constitutes good-quality data is by no means straightforward, as Marsh's (1988, p. 26) and Silverman's (2000, ch. 3) discussions of reliability and validity demonstrate, but data can be more or less informative in terms of how extensive they are, how free they are from being merely artefacts of the research methods employed to generate them, and how far they can be regarded as authentic.

This paper reports on a project funded by the United Kingdom (UK) Economic and Social Research Council (ESRC) which sought to identify and disseminate best practice in relation to informed consent in research with six groups of 'vulnerable' people, on which basis more general conclusions could be drawn. The findings have relevance to ongoing discussions about the nature and consequences of the broad changes that are taking place in research governance and regulation in the UK. The project involved collecting data primarily through telephone interviews and focus groups with university-based and other social researchers and focused principally 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 reflects the assumed vulnerability of members of these groups within the research process. This focus exposes the issue of informed consent with particular clarity.

Thirty-one individual semi-structured interviews were conducted (29 by telephone and two face-to-face) 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 literature and web searches, our own knowledge of the area, and recommendations from other researchers approached to participate. Each of the six focus groups was conducted in an institution with recognized expertise in a topic area. These groups comprised experienced researchers and PhD students working in these broad areas ($n = 35$), and the topic guide was similar to that used for the interviews. The interviews and focus groups were designed to elicit information relating to researchers' views and practices around gaining informed consent from people involved in their research. To supplement our data, interested researchers were invited to respond to questions on the project website via email, and we received 12 such responses.

The interviews and focus groups were transcribed and entered into separate data sets in NVivo to allow thematic analysis to be undertaken. Broadly similar themes emerged across the two data sets. Analysis of email material was undertaken to supplement this process. It should be noted that the interviews, focus groups and emails provided us with researchers' opinions about informed consent and their accounts of how they handled the issues that it throws up, rather than detailed inventories of their actual practices. That said, our sense is that these accounts are authentic and that the researchers to whom we spoke are sufficiently reflexive about their practices to be unlikely to say one thing while doing another.

The 'Optimistic' Scenario

There are several elements to the case that ethical research practice in relation to gaining the informed consent of research participants is integral to the collection of good-quality data in social research. From this viewpoint there is no conflict between researching ethically and researching effectively, and informed consent would be a desirable part of research practice even without the ethical and legal considerations that are also part of its rationale. Within this 'optimistic' scenario, the trend towards researchers paying more careful attention to the issue of informed consent is contributing to better research than that undertaken in the less closely monitored and regulated past. The key elements of the argument are that it does so because it helps to prepare researchers for the data collection process; because it helps to prepare research participants for the data collection process; and because it establishes a more equal relationship between researchers and research participants in which the latter can have confidence, as a result of which research participants will be more open and frank about the aspects of their lives that are being researched. There is a further argument that greater confidence on the part of people approached to participate in research ought to improve participation rates and thereby the ability to generalize findings.

The growth of regulation in research ethics has been the subject of extensive comment, and one commonly cited complaint relates to the requirement to gain ethical approval for proposed consent procedures before fieldwork can commence and the delay that this can cause. Reflecting on this point, an interviewee described one such delay on a project as 'a major nuisance' but then noted its unanticipated benefits: 'on the positive side … the fact that it got delayed actually did mean that we did spend a lot of time getting prepared which we wouldn't have done but for … having to get ethical approval', without which 'we'd have charged in and I think probably made various mistakes' (interviewee 12). Another interviewee made a similar observation about the benefits of delaying the commencement by graduate students of their fieldwork: 'it's actually very positive 'cause it really does make the students think about the ethics and to tackle some of the dilemmas before they actually get out in the field' (interviewee 17). The sense was that the process of gaining ethical approval has the potential to sharpen up the process of data collection by forcing researchers to clarify what their fieldwork is intended to achieve and how those objectives can best be pursued. A third

commented that the discussion of these issues in guidelines has the effect of encouraging 'researchers to think about the implications of their … actions'; in her view it is by no means common 'that researchers are prepared for what's going to happen to them in the field' (interviewee 15). To a fourth interviewee, seeking to circumvent this process smacked of regarding study participants 'just as research fodder' which she regarded as 'sloppy' research (interviewee 25). The issue was neatly summed up by the observation that 'actually thinking "well why do we want informed consent?"' contributes to researchers' 'reflective practice' (interviewee 4), in particular about the aspects of research relating to researchers' power.

The process of securing ethical approval encourages researchers to think hard about aspects of their research, such as the methods used to gain informed consent from research participants, for example by considering the best way to convey information about the study being undertaken. Informed consent can thus help to guard against what one email contributor called 'hit and run' research in which there is little or no accountability and where the quality of the data collected could be considered questionable on the grounds that research participants had not been given sufficient time to prepare. One interviewee identified it as 'good practice to try and get as much information to somebody in advance because … it gives them an opportunity to think it through but also obviously just to talk it through' (interviewee 6) with others such as friends and family members. One focus group member reported how the contact information he provided to prospective participants always made it explicit that it could be shown by the children '"to anyone you like"… to a friend, to a teacher, to anybody else' (focus group 5). Another interviewee supported her opinion that 'it is important to give people time' between first contact and data collection by noting that 'interviewing people who don't want to be interviewed … it's not a happy experience' (interviewee 19) and is therefore unlikely to generate good-quality data. Furthermore, research into which people are recruited hurriedly and without adequate preparation has the potential later to lead to retraction of what is said. This was the gist of the comment that it is important to give people time to collect their thoughts when they are being researched, because 'if people are rushed in an interview … they may well feel "well I didn't really mean that, I'd rather have a look of it and go back on it"' (interviewee 24). The ideal was identified as setting up 'a procedure whereby people feel they're able to say "no"' (interviewee 14); this gave confidence that people who opted to participate were appropriately interested and engaged. Recruitment of participants who were expected to participate immediately was identified by a school-based researcher as having the potential to produce 'absolute rubbish' (interviewee 13) on the completed questionnaires that she had seen administered in this way.

The third element of the argument that informed consent enhances data quality is that better data are likely to result where there is trust and rapport between researchers and participants. A minimum condition is that 'people … need to know that they're going to be safe in … an interview' (interviewee 31). This can be a crucial consideration in research with groups identified as vulnerable. One researcher with children made the general observation about trust that 'unless the research methodology itself has integrity and the relationship has integrity then … the data in many

ways is suspect' (interviewee 6). A researcher who had worked on a project with children aged 9–10 also highlighted the importance of establishing trust, mentioning that 'we found out that quite a few of them were a bit chary of being interviewed on their own but wouldn't mind being interviewed with friends so we … also put in the option of joint interviews' (interviewee 21), and the data generated were considered to be better because of the researcher's confidence that children had consented to the arrangements. Several interviewees attributed their sensitivity about the position of people being researched to their own experiences. One remarked that 'being on the other side of the fence … you do see things differently … I always try when I'm doing research to put myself in the other person's shoes' (interviewee 24). Another recalled how it had been 'uncomfortable' to be researched as part of a group to whom 'it certainly wasn't made explicit why or what was being … recorded … I think it's very important to be as explicit as you can about what you're doing and why' (interviewee 11). The implication drawn from such experiences was that people being researched who are unclear or anxious about some aspect of the research process are unlikely to be model participants.

The fourth reason for believing that informed consent promotes data quality is that it has a positive effect on participation rates: people will be willing to take part in research about which they receive convincing assurances. One interviewee referred to her organization's reputation for competent research as a positive influence when seeking agreement from people to participate in projects: 'we rarely come across problems with … getting informed consent, again because we … are well known for what we do and … we do explain in very great detail what we're doing' (interviewee 13). A researcher in the field of palliative care attributed a very high rate of recruitment to a particular study to 'being explicit … open about what it was we would do, why it was important to do it, what I was expecting their role to be, asking did they think that was appropriate, being prepared to shape it to fit with their values and their day-to-day working practices'. The other side of her argument was that bad practice can lead to suspicion on the part of respondents in future research projects, as she had found in another study in which people contacted 'were very cautious of my approach and request for them to participate in the study and that was because I felt they had been treated with little respect previously' (interviewee 11). In a similar vein, a focus group member argued that if social scientists 'can demonstrate that we're doing it sufficiently professionally … it's more likely to get co-operation of the wider public' (focus group 3). The adverse effect in the longer term on people's preparedness to talk to researchers was referred to by several interviewees when discussing covert research. As one put it:

> covert research … violates the … principle of informed consent, it violates the principle of voluntariness, it intrudes on people's right to privacy, it … potentially creates risks of … distress and humiliation to participants if they discover they've been researched without their permission, covertly, it can undermine their confidence and trust in other people, it can bring the … institution into disrepute. (Interviewee 27)

All of these points were regarded as likely to make it harder for researchers to find research participants.

The 'Pessimistic' Scenario

The 'optimistic' scenario that increased attention to informed consent is having a beneficial effect on data quality rests on several related arguments that, taken together, can be considered compelling. The remark that 'I think everyone agrees nowadays that consent is a good thing' (interviewee 7) might even be taken to imply that the debate has been settled. This would be an exaggeration, since our study identified various grounds on which researchers express reservations about the ways in which consent is handled, if not about the underlying principle of consent. These can be reconfigured into a more 'pessimistic' scenario in which data quality is held to suffer as a result of the processes put in place to gain informed consent. The key elements of this argument are that informed consent has an adverse effect on participation rates (in the extreme making some groups of people or some topics unresearchable); that the processes of gaining informed consent inhibit the development of the rapport 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 recognized not to be the intention of the move towards more ethical practices around informed consent, but rather are understood as unintended consequences.

A researcher in the field of ageing expressed the first strand of the 'pessimistic' scenario by noting that '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). A health researcher highlighted the dimension of ethnicity in this context by commenting that:

> 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)

The off-putting character of formal consent procedures led her to conclude that participation was more likely to come through informal personal contact, using a researcher from a similar ethnic background, in contexts where natural conversations might lead in due course to the question of participation in research being raised.

Along with ethnicity, social class was identified as a factor with a bearing on people's preparedness to consent to being researched. The interviewee who remarked that 'there's a high level of non-response in certain types of communities' had in mind the greater difficulties of gaining consent from people in poorer social groups, but he was also mindful that 'we don't have so many studies of … the powerful because they do tend to put up more restrictions in terms of what they might consent to' (interviewee 23); it can be difficult in areas such as financial matters to study up social hierarchies as well as to study down. Age was also mentioned, with several interviewees and focus group members commenting on how the requirement of parental or teacher consent for children to participate led to the exclusion of some children from research projects. A researcher recounted how

> sometimes schools will say "you can have those two people but not those two" … and it's often because somebody says "oh well, you know, that, that young person never says

> anything" or "oh they'll just swear all the time"… But I think in those circumstances where it's more they're just worried the young person will give a bad impression then I would often say "well it would be good to have them too". (Interviewee 6)

A focus group member noted that situations where children were required to have consent from both teachers and parents led to lower participation rates than situations in which teacher consent was deemed sufficient, mentioning a child who went so far as to forge their parent's signature in an effort to participate in a research project. Another member of this focus group argued that being required to gain the consent of both parents in post-divorce situations would work against the inclusion in research of 'children in a full range', and push researchers towards the 'safe' option talking only 'to very happy, highly articulate, middle-class children who you can meet through your friends' (focus group 5), an outcome that she strove to avoid. This sentiment was echoed in the related observation that 'people with dementia … are hugely under-represented because we can't get consent' and are thereby rendered 'hidden people' (focus group 3).

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 that research' (interviewee 26). 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 where we felt to go for a kind of absolutist position around informed consent basically made large-scale postal surveys not do-able' (interviewee 16). A third interviewee referred to colleagues in the USA with a shared interest in researching youth gangs who had concluded that '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' (interviewee 5). The question of research becoming unfeasible was raised in other discussions of the potentially adverse effects of informed consent. A specific example was provided by an email contributor, who felt that 'covert observation with no informed consent … can be justified', in cases like those where 'the researcher is in potential danger (e.g. observation of drug markets)… otherwise how can such research actually get done?'. One answer to this question was that more challenging research simply did not get done, at least in research undertaken by students whose tutors increasingly steer them towards topics that are 'as mundane and as normal everyday kind of things as possible' (interviewee 5). The comment that regulation has 'made it really quite difficult getting samples together. It's made it quite tough to do certain kinds of research' (interviewee 23) applies more broadly than in the field of ageing in which this particular researcher specialized. Another interviewee detected in the growth of regulation of research procedures 'a way of preventing us doing research … a bloody good stick to stop social scientists from finding out uncomfortable stuff' (interviewee 26), but her opinion that this was intentional was a minority view.

The second strand of the 'pessimistic' scenario, that the processes of gaining informed consent inhibit the development of the rapport necessary for generating authentic data, involved researchers reflecting on the impact of information sheets provided to potential participants. One expressed the concern that such information might 'lead people' (interviewee 15) into a narrower range of responses than they might otherwise have given, that is, it might put words into their mouths. Another 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). This issue led one focus group member to take great care 'not to let on too much about what you want to know' (focus group 3). Of course, by no means all researchers report this problem. One expressed concern that his results indicated insufficient attention on his part to informing participants about his study that had yielded 'bags of good data' (interviewee 23). Another expressed similar concern about the understandings of the research process of the deprived children who had provided her with 'wonderful data' (focus group 5). These concerns were echoed in the comment of another interviewee that what he called the 'best data', 'juicy data', (interviewee 28) tend to be generated by respondents who in the course of fieldwork have forgotten about the informed consent procedures established at the outset as the framework for the encounter.

Informed consent can present obstacles to rapport between researchers and participants in other ways. One is the commencement of a research encounter with what can seem unnecessarily bureaucratic procedures. This was the view of the researcher in palliative care who said: '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). Another researcher in this field echoed this sentiment by saying '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). A youth researcher highlighted the similar danger of 'some people … you give them too much information and they're not informed, they're just befuddled' (interviewee 20) and an email contributor mentioned how participants could become 'bored with lengthy accounts of the research as a preamble'. Similar thinking lay behind the comment that 'you can overload people with information and … in doing so you can ruin the end of your study result' (interviewee 22). In short, information presented with the best of intentions to prospective participants in a project can still be 'rather forbidding' (interviewee 15). Similar concerns apply to the requirement to gain signed consent. Thus a researcher with children noted that 'when you're researching … very excluded groups, which typically I am, it's very threatening to ask someone to sign a form' (interviewee 4). Another interviewee felt that signed consent introduced a quasi-legal element to the relationship and risked putting participants 'in a bit more oppositional kind of frame'. A formalized procedure 'might seem a bit too formal … it might get in the way of establishing the good relationships you want', and is in any event no guarantee of 'honest

data' (interviewee 18). Signing a consent form before interviews thus has the potential to 'put people off quite severely' (interviewee 30), and is one of the aspects of informed consent that led a focus group member to wonder whether her procedures were 'making people now a bit more reticent about what they would have said quite freely before' (focus group 5).

Several interviewees and focus group members also flagged up the potential of informed consent procedures unintentionally to antagonize or alienate participants. In relation to things said at the outset by the researcher, one had come to the conclusion that it was 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). Another felt that '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 recognized as a potential obstacle to rapport. A health researcher was conscious that 'if you start to continuously remind people about the research that affects the dynamics' (interviewee 14), while a focus group member conducting field work that involved meeting with respondents with learning disabilities on several occasions and who 'made a point of saying "is it ok for me to speak to you to-day?"' reported that 'people were getting irritated with "well yes, you asked me that before"' (focus group 2). Formalized procedures thus had the potential to generate obstacles to positive research situations, and the view that 'At the end of the day it's about the relationships you create in the field and that's what matters' (interviewee18) led to a widely expressed preference for a pragmatic and flexible approach to consent issues.

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 as the third broad strand of the 'pessimistic' scenario. The time required to gain consent features prominently in the comments of several interviewees, such as the researcher with children whose experience was that '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' (interviewee 6). A researcher in palliative care reflected on her work involving people who are very ill and spoke of being aware 'that 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). Another researcher in the same field complained of 'losing data' (interviewee 22) through people telling their stories before all the preliminaries had been gone through. This echoed the account of the researcher with older people whose participants had responded to the initial information about the project by in the interim 'rehearsing what they were going to say and it was all tumbling out and sometimes it didn't come out in the interview because they'd already rehearsed it in their minds and, and said it to me before I'd put the tape on' (focus group 3).

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 in order to check that they consent to the use of the data that they contain. In some instances participants sought to make merely stylistic alterations to what they had said, but more serious difficulties arise where changes desired by participants go further than corrections to grammar into changed meanings. One interviewee raised as a question the issue of what a researcher should do if they 'transcribe verbatim an interview and show it to the respondent who says "I didn't say that" and, you know, you gently say well it's on tape and they say "well I didn't mean it"' (interviewee 15). When discussing this issue, another interviewee commented 'that is a difficult area, very difficult if people are trying to change things afterwards. Maybe the first reaction was the right one' (interviewee 24). The commitment to 'send transcripts back to people for accuracy' (interviewee 3) 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 to meet concerns that at the time of data collection people may not fully appreciate what they are consenting. This is certainly the implication of the view that 'as a profession, we are slightly duplicitous … the people who haven't done research don't really understand how their information's going to be used and I think we do use their information … in ways that they probably wouldn't like' (interviewee 4).

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 social research involves people talking about their relationships with others, from whom consent has not been gained. One view on this was that requiring the consent of everyone mentioned in an interview would be impossible: 'you don't know who it's going to be … so you couldn't do it' (interviewee 29). Commenting on data derived from interviews with families about social services provision, another interviewee took the view that 'you don't need informed consent from the people that they're talking about' as these data were not about identifiable individuals, but the issue of where to draw the line in relation to whose consent is needed when they are mentioned in research data was acknowledged to be 'a really good question' (interviewee 27). Another way of stating the problem is that informed consent is typically operationalized as the consent of individuals and that this stands in tension with people's interconnectedness with a potentially huge network of others. As one interviewee observed, 'for people who want to work with communities, for example, or community groups, as action researchers, this very individualized model is very problematic' (interviewee 16), because in talking about their community involvement people inevitably talk about others whose consent has not been sought.

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)

Observational studies throw up the further difficulty that

> 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)

Recognition that 'ethnography using covert research has produced some very, very interesting results … really, really interesting stuff' (interviewee 9) sensitizes researchers to what insistence on informed consent in its strict interpretation rules out, and there is a clear sense that it is not only famously problematic studies such as Laud Humphreys's *Tearoom Trade* (Humphreys, 1970) that would be prohibited by such a stance.

Discussion

The 'optimistic' and 'pessimistic' scenarios set out above are composite constructions from the opinions contained in the data collected in our study, and the participants in our study do not fall neatly into two opposing camps of 'optimists' and 'pessimists'. Despite the fact that researchers in the field of health typically have greater experience of dealing with regulation by research ethics committees than do researchers in some other areas, they did not constitute a distinct group of optimists or pessimists. The opinions of many of the participants in our study span both scenarios. This is unsurprising given the frequency with which issues surrounding informed consent were described by our participants as 'tricky', reflecting their complexity and the political nature of the decisions that they entail. This is also consistent with the prevailing view among participants that informed consent is much more a matter of striking balances between competing ideals than it is about following a set body of rules (Wiles, Crow, Charles, & Heath, 2006). Van den Hoonaard's metaphor of researchers 'walking the tightrope' is apposite here (Van den Hoonard, 2002).

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 whatever their preferences, as a condition of the research being allowed to proceed. 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.[2] What is new is that research is being conducted (Tinker & Coomber, 2004) in an increasingly regulated environment in which expectations on researchers in relation to their practices around informed consent are growing apace. 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 confused, risky, harmful, exploitative or coercive. If, in addition, participation rates increase as a result of these changes, then what has been outlined above as the 'optimistic' scenario is further reinforced. However, a more 'pessimistic' scenario can also be presented in which current changes in relation to informed consent have the opposite effect on data quality. 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 characterized by less rather than more rapport, and if the pursuit of informed consent leads to data being patchy and distorted.

The reality currently lies somewhere between the two positions, and is likely to continue to do so. 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 characterized as 'vulnerable' means that our findings cannot be generalized 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 in the 'pessimistic' scenario. The second conclusion is that changes to research governance are understandable responses to the twin problems of research participants being provided with too little information (which risks participants being deceived or manipulated) and of too little attention being paid to consent issues (which risks

participants being coerced). There are, however, also problems associated with participants being provided with *too much* information (which risks research being delayed, participants' thinking being moulded, and participants becoming alienated) and with *too much* attention being paid to consent procedures (which risks narrowing of research agendas if certain social groups or topics become unresearchable). 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. Researchers' reflections on their experiences of how 'informed consent' works in practice and on the potential to improve that practice need to be fed into the developing field of research governance. This article is intended to contribute to this process.

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Notes

[1] See also these websites: http://www.york.ac.uk/res/ref/documents.htm; www.esrc.ac.uk/esrc-content/ourresearch/research_ethics_framework.asp

[2] See http://www.sociologyandsocialpolicy.soton.ac.uk/Proj/Informed_Consent/Resources.htm

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