Ross Coomber (2002) 'Signing your life away?: Why Research Ethics Committees (REC) shouldn't always require written confirmation that participants in research have been informed of the aims of a study and their rights - the case of criminal populations. (Commentary)'
Sociological Research Online, vol. 7, no. 1,
<http://www.socresonline.org.uk/7/1/coomber.html>

To cite articles published in Sociological Research Online, please reference the above information and include paragraph numbers if necessary

Received: 21/3/2002  Accepted: 7/5/2002  Published: 31/5/2002

Abstract

This brief commentary discusses the problematic incursion of Research Ethics Committees on social research, particularly on those groups who wish (and/or indeed it is vital for their safety) to remain anonymous. It is argued that REC's, often ignorant of social science methodology, commonly attempt to impose restrictions on research and researchers that contradict their own ethical guidelines and expose them to unreasonable risk. It is further pointed out that REC's are as yet not fully established within all UK institutions but fear of litigation will mean that those who do not already have them fully in place either have some form of REC in embryonic structure or are looking to implement REC's in the near future. It is in this context that it is argued we as social scientists should be helping to actively shape the workings of incumbent and emerging REC's in order to protect research, researchers, research participants and the integrity of what REC's actually do.

Keywords:
Protecting Research; Research Ethics; Research Ethics Committees

Discussion

1.1
The structure and origin of much that makes up university REC's approach to research ethics is historically rooted in the invasive research of medics and others who do research 'on' subjects perhaps involving them in surgical procedures, drug trials or experiments that may be a physical or psychological danger to them. Abuses by a minority of researchers led to the development of procedures that sought to mitigate against such abuse. Although it is the case that approval of medical and/or health related research has been processed by REC's for some time and those institutions containing medical schools; or 'health' schools were first to develop the model it is only recently that social science proposals, particularly where the research is clearly non-invasive, such as social surveys, have also been expected to be passed by REC's. Not surprisingly then, given that an extant model exists, based on protecting participants from invasive procedure, many institutions adopt that model first and apply its principles more widely. The resultant format is thus one that heavily reflects concerns about invasive (physical or mental) research and seeks to a) make sure that the research proposals passed by the committee are appropriate and safe, and b) that the prospective participants are fully appraised of the research and of their rights.
(e.g. to anonymity or to stop the research at any time without prejudice). The method increasingly used to achieve the second of these concerns is that of the signed consent form. However as the Social Research Association’s ethics guidelines point out:

‘In order to protect the researcher from accusations of failing to secure informed consent a practice has grown of having subjects sign a consent form. While this may serve as some indication that the subject understands some of the implications of their consent to participate it may also compromise principles of confidentiality and anonymity – equally valuable an obligation to subjects (see clause 4.7). Signed consent forms might only be appropriate for longitudinal and/or more intrusive studies’ (SRA 2002)

1.2

That REC’s seek to protect individuals from research or researchers that might unintentionally (or even knowingly) do them harm or indeed to protect the employing institution from lawsuits is of course laudable. The means through which this protection is sought however is often inappropriate because it is not in the interests of those participating in the research or those carrying it out. Individuals committing acts of illegality shouldn’t be asked to sign a declaration to this effect and as a consequence open themselves up to the potential of investigation and prosecution by the criminal justice system. Likewise, some individuals may want to protect their identities from even the researcher (for whatever reason) and requiring them to divulge it may well run counter to other important ethical requirements the committee is there to protect. Asking for criminal populations to sign a declaration that they understand the research and have been informed of their rights in relation to participating in it is also not in the interest of researchers involved in the research as they may be forced to be complicit in the prosecution of research participants (Coomber 2002, Dixon 1998). It’s not just REC’s that have this responsibility but we as social scientists (be we sociologists, criminologists, historians, psychologists or anthropologists) also have a professional responsibility to our research participants. Ethics guidance provided by the British Sociological Association provides a generic statement that clarifies the point:

‘[social scientists] have a responsibility to ensure that the physical, social and psychological well-being of research participants is not adversely affected by the research. They should strive to protect the rights of those they study, their interests, sensitivities and privacy’ (British Sociological Association 2002)

1.3

In the current legal framework that circumscribes research in the UK researchers can be summoned to give evidence and to produce their research data, including identifier information about those who participated in the research. International reciprocation treaties mean that the criminal justice system in countries such as the US may also request such information. In an era where research is increasingly being carried out over the Internet and WWW, participants in our research may come from more than one country, so even if the UK doesn’t tend to pursue research in this way (at the moment) others may. Asking participants to sign a form admitting to illegal acts therefore actually contradicts other aspects of most REC criteria rendering them, in certain circumstances, inconsistent and inappropriate.

1.4

Casual conversations with research colleagues in different institutions around the UK made me aware that REC’s commonly ask for conditions on research which are inappropriate, that these conditions are often applied because there is a failure to grasp either the research methodology involved (ethnographic and other qualitative research confuses the `scientists’ on REC’s) or that the guidelines that apply to medical and other `invasive’ research may not be totally appropriate for research on criminal populations and/or those
wishing to ensure their anonymity. In other words ethics guidelines tend to be implemented as though they apply equally to all research and there is suspicion of those who suggest they are inappropriate.

1.5

Concerned about this issue I contacted various colleagues based in 22 universities (both `old' and `new') around the UK who undertake work on persons involved in criminal activities to enquire into REC requirements and approaches to research involving such individuals. The response was enlightening. I was surprised to find that some reported their universities as either not yet having fully functional REC's (but fully expecting their imminent arrival) or not yet having one established at all. For those who carried out research directly with criminal populations and who had functioning REC's all had had the requirement to obtain signed confirmation from those being researched that they understood the research and what their rights were in relation to it. Only one of the responses, of an admittedly unrepresentative and ad-hoc sample, reported that their REC had been flexible in the application of its regulations. The others reported `conforming' in order to get the research approved but also as a consequence acknowledged that what the REC wanted was not what they got as will be explained below. One reported it being a requirement on some studies but not others although they expected it to soon become the norm. In the near future it is probable that all research carried out in universities in the UK involving people will have to be passed by REC's and the likely trajectory of practice, if left unquestioned, will be to follow the medical model that is so often implemented without question and imposed on social scientific research as though unproblematic. In fact one major funder, The Wellcome Trust, has recently declared that it will not fund research to any institution that does not have its own `published standards of good research practice' and `approval from the appropriate research ethics committee' (Wellcome Trust 2000). Other funding bodies either already require REC approved proposals or are likely to follow the lead towards it as a requirement. It is unlikely therefore that any major research institution will not have fully functioning REC's in place in the very near future.

1.6

It is the opinion of this researcher that REC's should make it a requirement for participants to be appropriately informed, as at present, for participants to be appraised of their rights, as at present, and for participants to have to indicate that they consent to the research, again as is the case at present. This was also the clear position of all of the researchers contacted that offered a view. What REC's need to accept is that it is not desirable to have participants in research on illegal behaviour to sign a consent form – they merely need indicate to the researcher that they have been appraised of, and consent to, the research. For those REC's that need some form of `concrete' proof that consent has been given respondents could be given code numbers and be asked to provide verbal consent which is voice recorded. Recording verbal consent may not always be appropriate however[1] and the researcher's word may have to be sufficient and REC's may need to accept the assurance of the researcher that this will be or has been carried out.

1.7

This may raise an objection that researchers cannot be trusted to do this and that it is (on occasion) in the researcher's interest not to fully inform a potential participant and/or seek overt consent[2]. These are the very reasons why REC's came into existence. What needs to be addressed here is what happens in practice already and what is desired by ethical idealism. At present a number of techniques are utilised by researchers to satisfy both their REC requirements and the research participants. REC's want a signed form (and so may Finance Offices but this is a different issue and one that can be resolved differently[3]); participants don't want to sign them (and usually won't, at least not with a meaningful signature). The researcher is thus left with a real dilemma. By even asking some individuals (e.g. drug dealers) to sign such a form the researcher is in serious danger of
losing some of the (probably slight) credibility he/she may have managed to build up with the participant. At worst the potential participant will simply up and walk. To avoid this dilemma (and more importantly incriminating the participant) the researcher will suggest to the participant that as they [the researcher] doesn't know their identity `you can sign anything you want, I won't know the difference' (or, more commonly, the interviewee will work this out for themselves) – enter `Mickey Mouse', `Elvis Presley', `John Smith'. The resultant signed consent form is thus worthless in any meaningful sense. As one of the researchers commented:

`Yes, I have had that situation. We were doing research with street and sauna working prostitutes and so anonymity is a big concern. We had to collect the consent but it was taken in the extreme and as might be expected resulted in lots of MM's [Mickey Mouse's]. Talk about adhering to the form of the thing whilst being bereft of meaning!'

1.8

Is this a problem? Not, I would argue for the research, the researcher or the participant. It is a problem however for REC's. By asking for a procedure to be carried out that is not in the interests of anyone involved they create a structure whereby researchers, acting (reasonably and appropriately) in the interests of the participants are forced to play a game with REC's in order to get approval of the research project. Consent forms are signed (as is required) but they are rarely signed with a true name and the objective of the signing has been lost. This is what actually happens and any pragmatic policy that is not merely symbolic needs to address what happens in reality. Ethics Committees, as they so often have to, need to acknowledge the difference between types of research and in the case of those who may not wish to sign a declaration of criminal undertakings or indeed of legal but socially condemned activities they need to assess the research not on signed consent but also on the likelihood of harm accruing from the research as a result of the research.

1.9

REC's should not reject research proposals that do not plan to use signed consent forms on that basis alone. If a research proposal indicates that harm resulting from the research and its methodology is unlikely then consideration of broader issues is necessary. As stated at the beginning of this discussion this restriction itself may be likely to create the greatest risk of harm to the participant by laying them open to criminal proceedings. Indeed it should be the job of the REC to actually question whether research planning to use signed consent forms is using an appropriate approach to collecting consent. REC's also need to face up to the fact that falsely signed consent forms, that almost inevitably result from research on those involved in criminal activities or who wish to remain anonymous are no proof that any participant has in fact been in receipt of the information the `signed' form suggests they have. In this sense REC's are already forced to trust the activities of the researcher as the researcher may choose to skip this procedure and sign the forms themselves at a later time.

* The Future – what should be done?

2.1

It is suggested that social scientists should undertake at least three approaches to help improve the performance of REC's and ensure that future research proposals are not unreasonably restricted by standardized procedures. To begin with we can be pro-active towards those REC's that are fully formed by tabling a motion to discuss the issue around anonymity and pointing out the contradiction in the existing model and asking for the guidelines of the institution at hand to be amended to incorporate a recognition that social science research may operate differently to other research involving human `subjects'. Secondly but similarly, in those institutions where REC's are in emergent form the opportunity to feed into the way that the REC is to operate may be more straightforward.
Find out who is chairing the working party or the incumbent committee and again ask for the issue to be discussed. Finally, organisations such as the British Sociological Association and related bodies could take the issue in hand, extend on their published research ethics guidelines and pro-actively circulate a memorandum to REC’s around the UK pointing out the anomalies, taking a policy stance in relation to the issue and requesting that the issue be considered and REC guidelines be amended appropriately. If we do not act on this issue research will continue to be restricted, our research participants will potentially be put at risk and researchers will continue to play unwanted games.

Notes

1 Many interviews are recorded but many are not. Circumstances sometimes make it difficult to record information and not all participants agree to being recorded

2 For example when the researcher wants to hide the objectives of the research from the participant. It is rarely the case however that a researcher cannot still provide satisfactory protection to a participant

3 Finance Officers may ask for signed forms for interview payments. With a fully informed understanding of the research process Ethics Committees could easily circumvent this requirement by allowing different rules to be implemented. Again, researchers would have to be trusted to some extent.

References


Copyright Sociological Research Online, 2002