

## **Multidisciplinary research ethics review: is it feasible?**

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(2006) *International Journal of Social Research Methodology: Theory and Practice*  
9: 405-417.

### **Abstract**

This paper reviews the currently rapid changes in research ethics governance affecting many kinds of social research. Arguments for and against single-discipline and multidisciplinary research ethics committees will be considered, with examples of how medical and social research ethics can inform one another. We conclude that the use of multidisciplinary research ethics committees, guidance and governance can be an effective and necessary part of social research methodology.

### **Introduction**

This paper reviews questions arising during rapid changes in research ethic governance. The changes are also evident in the related literature, in discussions at researchers' meetings, and in examples that many researchers sent us for our book on social research ethics (Alderson and Morrow, 2004).

Some authors and guidelines favour relying mainly on individual researchers' conscience, others also favour formal ethics peer review, guidance and governance. This paper reviews some of the history of medical and social research ethics and how they can each offer valuable insights and learn from one another. We summarise arguments for and against single-discipline and multidisciplinary research ethics committees (RECs), and consider why review by multidisciplinary RECs can be an effective and necessary part of social research methodology. We discuss current changes rather than offering detailed information about guidelines and governance. Some of these details are likely to have changed before this paper is published, so that our aim is to contribute generally to longstanding debates and gradual changes in attitudes and practices.

Social RECs are rapidly being established. Could multidisciplinary social RECs with lay members be more efficient than healthcare RECs: more cost and time effective, more appreciative of varying research methods and theories, more transparent and accountable? Could reputable social RECs be established, so that healthcare RECs need not duplicate their reviews of health-related protocols?

With inadequate planning and funding, support, training and time, multidisciplinary RECs are liable to be much less time- and cost-effective, less consensual and efficient than health care RECs. So at this important time of change and expansion, ways need to be found to involve social researchers in debating and planning effective methods of multidisciplinary ethics governance. The ESRC funded research (Webster *et al.* 2004) has stimulated important debates across the UK, to which this paper aims to contribute.

## Developments in research ethics

The millennium saw a rapid increase in research ethics activity. This was influenced by new ethical standards for research conducted in association with the National Health Service and the Social Services (DH 2001, 2003, 2004 with versions for Scotland and Northern Ireland). Standards were developed partly in responses to scandals associated with medical research, such as at Bristol Children's Hospital (Kennedy 2001). Guidelines have been written and revised, for example, in sociology and social research (SRA 2002; BSA 2002), psychology (BPS 2004), anthropology (ASA 1999); education (BERA 2004), social work (JUCSWEC 2002), medicine (WMA 2000; RCPCH 2000; BMA 2001; MRC 2004), nursing (NMC 2002), commercial research (MRS, 2004), by agencies for children and young people (Barnardo's nd; Children in Scotland 2002; NCH 2001; NCB 2003), funders (ESRC 2001, Lewis *et al.* 2003 2004; DH 2001, 2003; Nuffield 1999, 2002), and by most universities (Tinker and Coomber, 2004).

The new standards for research governance aim to set ethical and scientific standards, define ways to deliver standards, monitor and assess the arrangements, improve research quality, safeguard the public by promoting good practice, reduce and prevent poor practice and misconduct, and ensure that lessons are learnt from adverse incidents (DH 2003). RECs are important in all these processes. The government-led standards (DH 2003, 2004) are likely to spread into many other areas of social research for several reasons. Recent laws relating to research standards include the Human Rights Act 1998 and the Data Protection Act 1998. The 2004 Children Act connects all services for children very closely. There is uncertainty about where, for example, healthcare or social work research begins and ends (Butler 2002), and concern about unfair double standards between those participants who have formal ethical protections and others who do not (Lewis 2002). Many funders, universities and professional associations are requiring more formal standards. Some journals require evidence that authors have met formal ethics standards throughout their research projects before they will accept papers for publication (ICMJE, 2004).

Healthcare RECs have been reviewing protocols for over 70 years (McNeill 1993), although with gradually increasing critical scrutiny. Yet only recently, have RECs begun to monitor the progress of approved projects, apart from requiring annual reports and reports about major alterations to approved protocols. The *Research governance framework* (DH 2003, 2004) applies standards to social research that were intended in medical research to prevent severe and even lethal physical harm and potential litigation. The risks in social research are mainly social and emotional. Participants might feel deeply distressed and wronged by insensitive, intrusive or dishonest methods and by violations of confidentiality - risks that also apply in medical research. Indeed, highly publicised complaints about research into breast cancer and deceased babies' organs concerned, not the medical research itself, but the social circumstances when people were angry that they were not informed or asked to consent.

Medical research ethics has tended to be social, collective and political whereas, paradoxically, social researchers still tend to favour the personal ethics of 'self-regulation'. For example, the BSA's guidelines (2002) describe

only researchers' own individual ethics review, and do not mention RECs, neither does the ESRC (2001). Lewis's (2002) suggested methods of 'developing ethical practice, without the creation of RECs for social care' appeared to be generally supported at a reported sociology meeting (Glendenning and McKie 2003), although an earlier BSA meeting seemed to show more support for collective methods of research ethics review (Lyon 2002).

Accounts by social researchers, including those who advocate higher standards in social research ethics (Iphofen 2004), tend to emphasise problems rather than advantages of REC review (Truman 2003; Brindle 2005). The social research literature refers to the expense and time needed to complete the long REC forms and print many copies of them, especially the burden on small research agencies. It is difficult to plan and cost projects in detail in advance, and to allow for delays, problems, surprises and useful new openings that occur during a project. However, researchers already have to satisfy funders on these matters, and to inform potential participants in enough detail to enable them to decide whether to join a project. If the questions and methods alter during a project, participants can be re-informed – they may share in planning the changes.

A further serious problem was that occasionally researchers had to leave a project before data collection could begin and after months of delayed REC review. The timing for RECs was revised to prevent such problems. REC members may mistakenly approve poor and harmful projects, and nitpick over seemingly trivial points. Some RECs reject 'good' social research protocols (although it is hard to be certain whether the REC's decision was reasonable without seeing the protocol). REC members may have too little time and training to do their (unpaid) work properly. They may be dominated and misled by a few assertive members, or have ignorant prejudices against certain research methods. Sylvester and Green (2003) for example, described how RECs delayed research with people having palliative (terminal) care, and they warned that Masters students might have to do literature reviews instead of research with people because of REC barriers. However, perhaps literature reviews would be preferable to exposing both very ill vulnerable 'participants' and also Masters students to hurried and potentially unethical research routines, when courses seldom allow time for adequate ethics procedures. Doyal (2004) recommends that students' research projects, potentially valuable training for them, should be reviewed mainly for their scientific standards and less stringently for their ethical standards. This could be debated by social researchers; for example, might students be trained to follow sub-optimal ethics standards?

Despite the well-documented dangers of poorly regulated research and unaccountable researchers (Proctor 1988), for decades some doctors continued to resist ethics standards such as respect for informed consent, (for example, Tobias and Souhami 1993). Today, doctors are concerned about the very time-consuming REC forms, and also worry about counter-productive over-burdening of ethics governance with much other regulation unrelated to ethics (Jamrozik, 2004; Wald, 2005; Ward *et al.*, 2005). Yet scandals in medical research have encouraged medical researchers to value RECs as important protectors of participants and researchers, of reasonable ethical

standards, and of the good name of research itself. Complacent resistance is more often heard today in social rather than medical research debates.

The ESRC commissioned a review, and published a 7-page summary, which warns against 'ethical inflation' and imposed 'external drivers' that could 'restrict the conduct of important, high quality, social science research' (Lewis *et al.* 2003: 1, 3). The review expresses several concerns. Ethics 'embedded' in everyday research stands in opposition to overly prescriptive, imposed, 'highly formalised or bureaucratic ways of securing consent'. These ways are 'marginal to fostering relationships in which a process of *ongoing* ethical regard for participants could be sustained'. The ways conflict with what 'constitutes good (necessary, relevant) practice'. The authors advise that 'ethical vigilance' should be 'proportionate to the risks borne by research participants' (Lewis *et al.* 1993:4-5, their emphasis). They report a survey of social researchers who were asked for examples when 'good social science research was constrained by the inappropriate application of ethical guidelines devised for other research areas'. Respondents were not asked about possible gains for social research from ethics guidelines in other disciplines.

The survey found 'a strong belief in the autonomy of the researcher to deploy her or his good professional judgement, albeit guided by the broad guidelines set by the researcher's discipline.' However, one controversial aspect of social research guidelines is that they permit covert research, which inevitably lacks consent (BPS 2004; BSA 2002) although the BSA is more cautious. Lewis *et al.* (2003:4) added, 'it was unexpected to find that a considerable number [of researchers] reported the absence of [consent] procedures'. The authors' surprise suggests greater faith in social researchers' self-regulation than tends to be shown in that of doctors or the police. In contrast, new guidance (DH 2003, 2004) emphasises expert and independent ethics review.

A subsequent ESRC-funded project to develop a framework for social science research ethics involved wider consultation, interviews, regional meetings, draft papers circulated for discussion, and a website ([www.york.ac.uk/res/ef](http://www.york.ac.uk/res/ef)) although, against ethical standards of transparency, the ESRC again vetoed the researchers' freedom to publish a final report. However, the second project has reported more support among social researchers for RECs and for ethics training (Webster *et al.* 2004; Boulton *et al.* 2004). The ESRC framework for social research ethics, due in March 2005, have not yet been published while this paper is being written.

Yet some social scientists appear to believe that formal guidelines and RECs 'invite the individual to surrender the moral conscience to a professional consensus' (Homan 1992:331). Others explore complicated reservations about bureaucratic ethics (Bauman 1993; Smyth and Williamson 2005). These important reservations imply that morality is wholly either a private or else a collective concern, instead of being a complicated combination, both socially constructed and negotiated in personal and political ways.

Researchers' critical theorising and analysis *about* ethics differs from their ethical standards *within* their research methodology and *towards* participants. To conceptualise ethics primarily as another discourse of power risks defending researchers' power and denying research participants' and others' attempts to criticise unethical research. Concern that RECs may undermine

researchers' personal moral responsibility illustrate the importance of expanding the theoretical, as well as practical, debates about social research ethics, considered, for example, by Smyth and Williamson (2005).

Healthcare researchers have increasingly accepted international standards in the *Declaration of Helsinki* (WMA, 1964, revised 1975, 1983, 1989, 2000). Medical consensus has been negotiated and sustained through formal tiers of numerous well-resourced and staffed medical associations from local to international levels. Pharmaceutical companies' funding and professionals' subscriptions have supported the medical meetings, ethics training, and the development of guidelines, RECs, and research governance, with helpful and harmful effects as frequently discussed in medical journals, for example, in the connections between excessive funding and fraud through all stages of medical research and publication (Sharev, 2003). These problems could either increase scepticism about smoke screens of medical ethics guidance and governance, or prompt still more formal effective controls. Although researchers understandably are concerned about the time and funds required by ethics governance, would they not consider this worthwhile if they saw their own ethical standards endorsed and equally required from their colleagues, in efforts to enhance the quality and reputation of social research?

### **Comprehensive research ethics and collegial approaches**

This section reviews further how social research ethics lacks both the generous funding and the multi-tiered cohesion of medical/healthcare research. Philosophy departments, many journals, MA courses and doctoral theses are dedicated to healthcare ethics, whereas there is relatively less social research ethics activity.

Social researchers often seem to be more concerned about differences than similarities between disciplines and theoretical perspectives - psychology and social policy, social work and anthropology, the sociologies of health and of education, economics and youth work, history and advocacy, qualitative and quantitative methods, positivism and post modernism. And yet healthcare researchers also cover a great range of specialties and methods from basic science to surgery, psychiatry to public health policy, preconception to post mortem but, as mentioned, they share a broad ethical common ground.

Many healthcare RECs have members who are social researchers or who at least understand how to review research about very diverse topics, theories, methods, disciplines, and types of participants. The *British Medical Journal* has promoted qualitative and theoretical research in articles that explain their importance to readers (such as Mays and Pope 1996/2000; Alderson 1998), and increasingly publishes qualitative reports. Efficient multidisciplinary health RECs, and generic university social science and humanities RECs show they can provide a comprehensive, independent and expert review system. Some respondents have reported this in surveys by Webster *et al.* (2004) and Morrow and McNeish (2002). Single-discipline RECs, often dealing with applications from close colleagues, can find it harder to attain such critical independence.

Comprehensive healthcare RECs include 'lay' members (US 1977, 1978; Nicholson 1985). From their contrasting perspectives they can, for example,

challenge 'objective' concepts of risk and harm, and consider how personal estimations of risk can vary unpredictably (BPA 1992/RCPCH 2000; RCPCH 1997; BMA 2001). Lay people have also questioned the long-standing concept of 'therapeutic research', now abandoned in recent guidelines (WMA 2000; MRC 2004: 14). The term 'therapeutic research' confuses research (collecting and reporting data) with the treatment that is being investigated by the research to see whether it might be therapeutic.

The distinction between research and treatment is crucial in all research about services for several reasons. People who research their own discipline may assume that the service they offer is beneficial, instead of starting with the key research question: How do people receiving the service perceive and experience it? Practitioners owe a legal contractual duty of care to their clients/patients, whereas researchers' primary concern is to collect data, not to provide care. Edwards and Mauthner (2002) discuss valuable aspects of the protective ethic of care. There is, however, a risk of confusing the distinct roles of practitioner-care-givers with the researchers' role, whereas research ethics emphasises duties and dangers that are unique to the research. The research encounter is essentially a meeting between strangers. The following statement on social work ethics seems to blur the roles:

'Both the process of social work/care research, including the choice of methodology, and the use to which any findings might be put, should be congruent with the aims and values of social work practice and, where possible, seek to empower service users, promote their welfare and improve their access to economic and social capital on equal terms with other citizens' (Butler 2002:245).

This is a heavy burden for research. The statement does not explain how collecting and reporting data can meet the aims of social work/care (to provide a service) or directly 'empower' or benefit anyone. The research findings might one day help to improve policy and practice. The research encounter might indirectly offer participants some benefits, but that is not its aim or purpose. The belief or assurance that researchers directly help participants could undermine the key principle in research ethics: respect for freely given consent/refusal. This can occur if researchers, participants and gatekeepers mistakenly believe that the supposedly direct benefit of taking part in research should not be refused. Well meant 'caring' intentions have cloaked and excused harmful practices and research (Proctor 1988; Cooter 1992). Although modified by notions of inter-dependency, the ethic of care implicitly conceptualises the other person as dependent and needy of care, whereas medical ethics crucially emphasises the ethic of justice and respect for the person's independence from the researcher. This is an example of complex questions in research ethics to which social researchers contribute, complementing the more abstract impersonal approach of many bioethicists.

It is in doctors' financial and legal interests to develop firm ethics guidelines and governance, and to spend years developing and circulating drafts of guidelines that they eventually 'own', and that can protect them in the event of litigation. The medico-legal fraternity gains status and income when working on medico-legal-ethical cases and inquiries that further refine bioethics concepts, such as in the detailed medical ethics guidance that covers many

subgroups, such as children. So far, social research associations tend to use one set of fairly brief guidelines to cover all types of their research, and without publishing detailed supporting analysis.

### **How healthcare research ethics can inform social research ethics**

A review of the history and literature of healthcare research ethics suggests the following insights for social researchers to consider.

People play very different roles when they either receive services, such as healthcare or education, or else take part in research. It is vital to respect these practical and ethical differences.

Long-standing concepts in medical ethics include justice, respecting autonomy, and attempting to avoid harm and to promote benefit (Beauchamp and Childress 2000). *Helsinki* sets standards for informed consent (such as to know the nature and purpose of the research, the means and methods, the risks, the right to refuse or to withdraw). Although these standards cannot necessarily provide clear solutions to ethical problems, they offer principled yet flexible criteria for assessing the ethics of any kind of research with any group of people. Uncertainty about interpretation is arguably a reason for having formal reviews and independent discussions to examine the complex arguments, instead of leaving individual researchers to decide alone.

RECs serve several vital purposes: to act as protective barriers between researchers and potential participants; to raise awareness about the importance and usefulness of ethics among research communities; to check whether and why the research is worth doing, and if the hoped-for benefits appear to justify any harms, risks or inconvenience to participants; to veto clearly unethical research; to see that the people invited to take part receive clear enough written and spoken information to enable them to express informed unpressured consent or refusal; to warn and advise about potential ethical problems that might be avoided or prevented; to check that certain groups are not over-researched upon, and that particular needs are met, such as for interpreters.

Besides scientific review by the funders (if any) and by medical research and development committees, RECs need to assess the basic science of each protocol in order to assess the basic ethical questions: Is the research worth doing? And do the hoped-for benefits appear to justify the risks and costs? RECs need to know, for example, whether the research duplicates previous work, whether the methods are likely to answer the research questions, such as if the sample size is large enough, and also how useful the research findings might be.

For these reasons of 'scientific expertise', it may be claimed that only specialists in the particular research discipline can be competent reviewers. However, the research can only be ethical if it is explained and justified clearly enough to enable anyone to give informed consent or refusal. RECs take the part of 'anyone', and consider how to address their views and possible misunderstandings and anxieties about risks. Multidisciplinary RECs that include 'lay' members (many of whom chair healthcare RECs) are better able to raise and debate such questions. West and Butler (2003) discuss these points and also describe how useful a multidisciplinary REC can be in probing such questions as how care relates to health research ethics review.

Research ethics involves the transfer of as much information and control as possible from researchers to participants, who may be far less confident and knowledgeable than the researchers. When 'lay' members speak for potential research participants on RECs, the discussions can involve some of this practical and symbolic transfer. 'Lay' people may ask seemingly naïve questions of the kind that participants might want to ask. Criticism that lay members are not 'representative' or elected ignores how professional REC members tend not to be representative either. In their task of imagining the views of potential participants, REC members' personal capacities may be more relevant to this than their professional qualifications.

Healthcare ethics has resources that social research, so far, does not have, such as the detailed guidelines mentioned earlier, the website for RECs (COREC 2005), that is partly informed by a forum for patients' self-help groups (Alderson 1994), and the monthly *Bulletin of Medical Ethics* distributed to healthcare RECs. These resources offer information about: methods of asking and analysing ethical questions; updates on the law and guidance on privacy, data protection and consent; ethical methods of selecting and accessing people, and of working with them throughout research projects; details of the information to give to potential participants and how to set this out in clear information sheets.

### **How social research ethics can inform healthcare research ethics**

Besides the transfer of information from healthcare to social research ethics, the opposite flow of knowledge is also worth considering. Social research ethics can contribute in several ways to medical ethics, which has been criticised for being too abstract and impersonal. The philosophical claim that it is necessary to clear away the contingent 'rubbish' of social experiences in order to see the ethical dilemmas clearly (Raphael 1976:8), is countered by the feminist philosopher's reply (with which many social researchers would agree) that ethical issues are constituted from this everyday 'rubbish' (Grimshaw 1986:31). Grounded in recorded experiences, social research ethics can introduce practical, realistic insights in new dimensions that tend to be ignored in abstract ethics.

The first dimension looks inwards into researchers' feelings - hopes and fears about their work, anxiety about mistakes, stress from lack of time and resources, shared satisfaction about new data and theories, as well as the hopes and fears of the participants. Although emotions can mislead and cloud judgement, there are great dangers for research subjects/participants if researchers forget empathy and pity. MacIntyre (1966:208) warns of the risks of becoming detached from our 'moral self constituted by responsibility'. We may be blindly obedient to rules instead of also carefully feeling a way forwards through unpredictable, ambiguous, negotiated interactions (Bauman 1993:11). It is ethical to support and debrief researchers during stressful, sensitive research, and reflexive sessions can inform the research analysis.

The second dimension looks around at the numerous practical problems constantly arising during research projects. These tend to be omitted in published research papers, partly for lack of space. Reviewing these problems, Hallowell *et al.* (2005:142) contend that social research 'is first and



foremost a moral activity' about human relationships, a complicated balancing between many opposing options and minefields. They conclude (2005:151) that at every stage ethical research relies on codes, RECs, researchers' good intentions, 'all of these things and more'. Ethics connects to researchers' skill when they respect participants' views, evaluate their own work, and try to raise standards. Ethics also involves attempts to avoid abusing power discrepancies, both between researchers and participants, and within research teams. Caution is particularly necessary with the least visible, and therefore most potent, forms of power (Lukes 2005). Hence the importance of transparency and the explicit consent process, besides watching for cues that participants may feel too intimidated to refuse or withdraw.

The third dimension is the broader political and economic context that influences the types of research that can - or cannot - attract funds, and support from policy makers and other influential groups. The political dimension raises numerous questions about the contributions that social research should make to society. Medical ethics tends to concentrate on the central data-collecting stages of research, and to overlook political and economic questions often embedded in earlier planning stages (choice of topic, samples, questions, funders) and in the later dissemination. Our book divides research projects into ten stages, and reviews ethical and political questions that arise at each stage (Alderson and Morrow 2004). For example, what impact might the final research reports have, not only on participants, but also on the welfare and reputation of the larger groups they represent, such as asylum seekers, or other socially excluded groups? Should researchers be responsible for trying to prevent their findings from being misapplied or misreported in stigmatising ways? And how far should these concerns guide and even constrain practical research decisions?

## **Conclusion**

The conclusion summarises some of the main points in this paper and considers ways forward for social research ethics. The previous section ended with questions. The question format helps to adapt and connect the general guidance and governance to specific research issues. Approaches of shared inquiry, rather than rigid prescription, can rely partly on the personal agency of each researcher and REC member. We suggest that researchers' own good intentions are necessary but not sufficient. They also need to refer to long-standing principles of justice, avoiding harm, and respecting participants' views and informed consent. Healthcare RECs recognise that ethics is a private concern and is also social, political and collective, if researchers are to be fair and accountable. Researchers have reported examples (some in the literature, others are personal communications) of healthcare RECs that manage to:

- take realistic account of everyday difficulties in research;
- avoid being too prescriptive, formal, imposed and bureaucratic;
- respect researchers' and teams' individual responsibility;
- promote 'good' research practice;
- appreciate many kinds of research methods and disciplines.

Healthcare RECs' requirements for 'patient information sheets' could benefit all forms of research with people.

To achieve high standards, social research ethics requires greater recognition as a public, social, negotiated and political matter, as well as a personal and private one. The growing interest, activity and literature concerning social research ethics provide a start. One means of promoting shared objectives could be to establish a multidisciplinary national forum. The forum could set certain standards to protect researchers, participants and RECs quasi-legally, which individuals and local RECs cannot achieve alone. For example, outstanding questions that need to be agreed nationally range from, 'When can researchers rely on children's consent without needing their parents' permission?' to 'How can personal privacy be respected in family genome research?' A respected social research forum could cover the range of related agencies, funders, disciplines and methods, to debate problems, develop consensus and promote higher standards of research ethics 'literacy' and governance. Meanwhile, rather than asking whether multidisciplinary RECs can work, we have to question how much longer social research can continue without them.

### **Acknowledgements**

We are grateful to all the researchers who sent us examples of ethical aspects of their work, to Di McNeish and Helen MacDougall, to three anonymous reviewers, and to Barnardo's for funding the project on 'Ethics, social research and consulting with children and young people'. This paper expresses our views and not necessarily the views of Barnardo's.

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