

# Bureaucracies of Mass Deception: IRBs and the Ethics of Ethnographic Research

Charles L. Bosk, University of Pennsylvania, and  
Raymond G. De Vries, St. Olaf College

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## Background

There is a need to identify the ethical principles that will serve as guidelines for the protection of human subjects of biomedical and behavioral research.

- Meetings were held in 2003 to discuss “best practices.”
  - The goal was to put out a set of procedures and to distribute them as a set of guidelines for those with responsibility for administration and compliance with federal regulations.
  - No matter how sensible, adequate and non-intrusive, the guidelines will be resented by social scientists who don’t want regulations on the proper ethical conduct of qualitative, ethnographic researchers.
  - This article attempts to illustrate why there is such resentment.
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## Reasons for Resentment

Social scientists resent an attempt to create best practices guidelines for several reasons:

1. Social and behavioral research encompasses too vast an amount of ground to cover with a single set of regulations.
2. Qualitative research is underrepresented in the membership of the working group deciding the best practices.
3. To title the conference IRB (Institutional Review Board) Best Practices . . . is to link the regulation of social science research with the current regulatory regimes of clinical medicine, supported by rationales from evidence-based medicine and not from the qualitative view – a big problem.
4. As opposed to clinical trials, ethnographic research consists of the relationships forged with those people whose life-world needs to be understood.
5. To the degree that one can restate a disciplinary curiosity as a set of testable propositions, these are likely to be trivial.
6. The procedures cannot be stated formally. Social scientists want to know how they make sense of their world, how they navigate in it, and how understanding their world helps to better understand the world around us.
7. Questions to be asked are not known in advance and how deep the inquiry will delve isn’t known until it is in process.
8. Subjects can’t be informed in advance of the risks or benefits because one doesn’t know in advance what one will find.

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- Confidentiality** IRBs also review proposals to make sure that confidentiality and anonymity of study subjects is adequately safeguarded.
- This is not so easily done in qualitative research when one is dealing with descriptions and statements of subjects who may be recognized by peers and others, even if not named.
    1. If such regulations are stretched too far it does not permit ethnographic work in public domains where it can be hamstrung by overly rigid insistence on confidentiality and anonymity.
    2. Consent forms would not work with the type of social research proposed especially when studying illiterate peoples.
  - Social scientists and behavioral scientists do not want regulations that require prospective review of research projects and they believe that such review does nothing more than hinder the pace of research.
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- Why the Fight?** Both the complaints and calls for resistance seem peculiar on several counts:
- Some of the complaints are inaccurately strident.
    1. Some say it's a violation of their First Amendment rights and others see investigative journalists having a free rein when it comes to informed consent or confidentiality. (Perhaps scientists *should* be held to a higher standard.)
  - How much good IRBs accomplish, how much harm they prevent, remain open questions – how procedures might evolve so that they better meet the realities and contingencies of social and behavioral research is certainly an open question.
  - None of the social scientists truly object to the goals of IRB research – all wish subjects to be treated with respect, protected from harm, and saved from embarrassing exposure.
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- What's Needed?** What's needed are some constructive suggestions for making the system work better.
- We need to educate IRB members about the nature of qualitative social science research.
  - We need to do a better job of educating ourselves about the regulations.
  - We need to explore the different ways that the system can be streamlined and made more efficient.

- It is in the above spirit that the following suggestions are offered:
  1. Encourage more and better studies of how IRBs work.
  2. Increase social scientist participation on IRBs.
  3. Increase social scientist's knowledge of IRB rules.
  4. Educate IRB members in the methods and theories of qualitative research.
  5. Have in place a speedy appeals process.
  6. Explore other ways of organizing review of social science research.

**Note:** Social scientists can find ways to work within the system at the same time that they work to change it.

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## **Conclusion**

The review process may impose more harm than benefit, but it's hard to imagine turning back now.

- The entire process seems to impose fewer burdens than what is actually complained about.
- A spirit of cooperation is the way to respond to those who have volunteered or been pressured to perform this onerous task.
- The problem with IRBs and qualitative research is that they are such a distraction from the real difficulties faced by social scientists – the real ethical dilemmas – that we may end up not discussing the serious and elemental because we are so busy with the procedural and the bureaucratic.

**Note:** The authors do not think that the system of perspective review does much to protect subjects from harm or guarantee ethical conduct of researchers.