If Research Oversight Is Inevitable, Can We Please Make It Realistic?
A Complaint, A Remedy, and A Research Agenda

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The Complaint
The Current Regime of Prospective Review is limited:
(1) To issues of risk and benefit within a community standard and
(2) To issues of consent
The current policy allows us to conflate and confuse bureaucratic regulation with the entire domain of research ethics.

Restating the Obvious
The regulation of research as a bureaucratic matter trivializes questions of research ethics for those of us involved in research that involves our active engagement in settings in which the primary data gathering technique is our skill in manipulating our relationships with our subjects

Case One
Researchers propose to use ethnographic methods tp investigate negotiations in a social service agency among case case-workers to understand better issues surrounding access to long-term mental health services.
The IRB decides because the subjects are vulnerable population, written consents are required not just from clients of the agency but everyone the researcher comes into contact with.
Has the IRB got it right?
Who are the subjects?
If the only identifier for clients is their signature on a consent form does the intended protection create unintended risks?

Case Two
An Assistant Professor teaching a course on Popular Culture has an assignment that each student describe one occasion of going out on Saturday night. Any activity in a public setting counts—a lecture, a church service or a rave. Student descriptions become research data.
The Course is not a requirement for the major. The course was reviewed by an IRB.
The Personnel Committee reviewing the untenured faculty member's dossier for re-appointment worries that the assignment is "risky".
A letter expressing concern for student welfare is entered in the faculty member's file.
What is going on here?
Who is being protected from what?
By what authority?

Case Three
At the Annual Sociology Meetings Three Years ago, I have a long talk with a friend from my graduate student cohort. She is the public member of a state medical board.

She has turned her membership into research. She has not informed other board members of this. She asks for advice. I suggest telling them and her university's IRB. At a conference last month, I saw her again. She was scheduled to talk in a session titled "fieldwork under fire." She still has not informed the board members of her research nor has she sought IRB approval. The fire is the requirement of IRB review.
Are the Research regulations the problem here?
Does it help to Know that the ASA Code of Ethics places great constraints on the conduct of deceptive research?

Case Four
An earnest graduate student with not much to recommend him proposes a participant observation study of a surgical residency. The topic of the research is to learn how error is recognized, categorized and managed during training.
The student proposes to live as close as possible the life of a surgical resident.
Everything else about procedures in the proposal is vague as this.
From whom and in what form is consent required?

Next To Last Case—I promise
A graduate student working with me is developing a proposal to look at "The Social Construction of Headache."
Prior to writing the proposal, she is invited to a conference of headache researchers in Rome.
Since the data she gathers at the conference may become part of the dissertation, I suggest that she inquire if IRB approval is necessary.
The IRB says since she lacks an hypothesis.
She needs not bother with consent formally or informally.
Does this make any sense?

Case The last
An anthropologist is conducting a study of homeless IVDUs in a major metropolitan area. The study has a photographic component. It has been approved by an IRB.
Should the anthropologist take pictures of theft (of municipal property) if this theft is a regular part of securing funds for drugs?
What should the anthropologist do when homeless IVDU's ask him for small amounts of money for buying heroin?

The Complaint Restated
The relationship between the bureaucratic regulations and the actual ethical issues we encounter is mysterious.
The model of a clinical trial with a discrete beginning, a specific intervention, a calculable risk/benefit ratio, and a clean clear endpoint does not fit inquiry that uses inductive methods.

Routine Confusions: IRB Side
Majority of IRB members drawn from medical schools
Most have little understanding of models of research that do not fit the "normal science" of RCT
Since most qualitative research looks so little like science—how can it have a benefit?
With no benefit, how can any risk no matter how minimal be justified
Routine Confusions: The Ethnographer's Side

Good God, these people do stuff that kills people, all I want to do is talk to them
What is this agonizing over consent? Without trust, there is no rapport, without rapport there is no consent—impossible to gather data without consent.
What harms can there be?

The Remedy: IRB Side
A little education and familiarity with inductive research methods in the social sciences would help.
Greater participation from social scientists in the process would certainly help.
An appeals process would make some sense as well.
The Remedy: The Researcher's Side.
Accept that the regulatory regime is a burden; clinical researchers feel the same way.
Learn the rules.
Draft detailed cover letters that instruct IRBs what procedures are appropriate and why. Refer back to the regulations in these cover letters.
The Research Agenda
We do not very much know about decision-making processes in IRBs.

We need studies that look at how risk and benefit are defined.
We need to look more closely at alternative models for research regulation

More Research: IRB Horror Stories
As soon as I convince someone to give me the money, I will collect "horror stories" from anthropologists and sociologists who have tangled with IRBs
Dual analysis
(1) concrete problems with procedural fixes
(2) "identity" tales—why we are different, why are work is special, why we are so misunderstood
The Research Agenda: Studies of Forbidden Knowledge
Flip side of science studies on production of knowledge
How do researchers learn what questions not to ask?
How do we study codes of conduct that are largely implicit?
How related to disciplinary mission?

The Research Agenda

Studies of Cleaned Data Sets vs. Fudged Data
There are rules about what is allowed and what is not in cleaning a data set for use
How are these rules taught?
How do they vary by discipline
Within disciplines, how do they vary by research method?

An Agenda for Candor as Well as Research
We serve neither ourselves no others by the flat insistence that we do no research that can do harm. Confront Squarely Two Dangers:
(1) foreseeable breaches of confidentiality and anonymity
(2) unforeseeable changes in political realities—regime changes, shifts in meanings of behavior, moral crusades

Universal Principles, Multi-National Corporations, National Bureaucracies, and Medically Naïve, Local Bodies:
Devries, Leeman, Petryna, and Bosk—multi national, multi-disciplinary group
Regulation of research—how do principles get translated as they move through levels of system?
What are operating understandings in different contexts?
What are tensions between local needs and
and principles of the privileged

The Paradigm Problem
J Bowyer Bell's The Secret History of the IRA has a four photograph sequence
Planning the raid
Loading the Car
The Target Before the Explosion
The Damage Done