The Ethics Rupture
Exploring Alternatives to Formal Research Ethics Review

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Contents

Acknowledgments ix

Introduction

The Ethics Rupture Summit in the Context of Current Trends in Research Ethics Review 5
WILL C. VAN DEN HOONAARD AND ANN HAMILTON

Part I: Strains in Research Ethics Review Processes

1. The Social Costs of Ethics Regulation 25
   ROBERT DINGWALL

2. Fieldwork Double-Bound in Human Research Ethics Reviews: Disciplinary Competence, or Regulatory Compliance and the Muting of Disciplinary Values 43
   RENA LEDERMAN

3. IRBan Renewal 73
   PATRICIA A. ADLER AND PETER ADLER

   LAURA STARK

5. Uncomfortable Truths, Ethics, and Qualitative Research: Escaping the Dominance of Informed Consent 106
   MARCO MARZANO

6. Assessing Risk in Psychological Research 119
   PATRICK O'NEILL


4 The Language of Law: How Research Ethics Review Creates Inequalities for Language Minorities

LAURA STARK

In 1974 the US Congress passed the National Research Act, and during the past 40 years the law has profoundly changed the conduct of research in the humanities, social sciences, and biomedicine. The law requires that scholars and scientists apply to research ethics review committees if they plan to study people (in whole or in part), and get committee approval before they start their work. Researchers' application materials must demonstrate (at least) two things to committee members and research administrators. First, the materials must show that researchers share committee members' sense of the risks and benefits of a given study and, second, that researchers intend to convey this information to the people they want to study through an informed consent process before they start the study. If researchers' formal compliance with the law is any indication, it seems that study participants are better informed and better protected than they were four decades ago.

Yet during these four decades, researchers have also explored a broader span of geopolitical settings, involved a wider range of participants in their studies, and used a greater variety of research methods in their work. At the same time, institutions have enforced regulations for human subjects research (HSR) in a wider array of disciplines (Schrag, 2010; Stark, 2007). As a result, researchers from medicine, the social sciences, and the humanities now commonly work in regions -- and with people -- using a variety of languages. In biomedical research alone, approximately half of the clinical trials registered with the US government in 2011 took place outside of the United States (Virk, 2011). During the past decade, the number of active investigators under the jurisdiction of the Food and Drug Administration (FDA) conducting research
outside of the United States has steadily increased, and over the same period the number of investigators conducting research within the United States has declined (Getz et al., 2009; for one compelling explanation, see Petryna, 2009). It is likely that a growing number of people enrolled in the remaining health research located in North America are non-native speakers of English: the US Census Bureau estimates that 20 per cent of its domestic population speaks a language other than English at home, and the Bureau expects the proportion will grow in the coming years (Shin and Kominski, 2010).

This confluence of dated regulations and expanded research settings has created a number of problems, one of which is a misalignment of languages among members of ethics review boards, researchers, and potential research participants. The intent of this chapter is to illustrate an emerging, systemic bias in research ethics review. The goal is not to be exhaustive or definitive in argument or demonstration, but to document a social and cultural shift that is currently taking shape and to consider some of its causes and consequences.

Both the legal crux of the problem is that regulations in the United States require that researchers apply for approval by their local Institutional Review Board (IRB) and that researchers accommodate the native languages of the people they hope to study. The working languages are not known for the more than 4,000 IRBs in the United States nor for the 2,000 IRBs registered with the US Office of Human Research Protections (OHRP) that operate outside of the United States. In this chapter, I present evidence and analysis from my long-term ethnographic study of three Institutional Review Boards in the United States, and for these boards English was the dominant language. Researchers who hope to get approval from Institutional Review Boards that use English as the dominant language must manage translation issues to study people who do not primarily or fluently speak English, as well as those who do not speak nor understand English at all. These researchers must either write the consent texts in English and then translate them for participants, or they must translate texts for the ethics review board into English from another language. Adding to the complication, studies often involve people who do not share a single language or dialect.

To analyse the causes and consequences of language mismatch, this chapter develops the concept of *monolingualism*, which is a person’s tendency to read, speak, and understand one language dominantly (if not exclusively). I treat monolingualism as a structural barrier in research ethics review – as a formal law, policy, or guideline in place to accomplish an explicit goal that simultaneously and systematically accomplishes other implicit ends with disproportionate and negative affects for some people. This chapter suggests a paradox of the law: the explicit goal of the US National Research Act is to protect research participants equitably, and yet the language of that law – as enacted during IRB meetings – is a structural barrier to the very protection that the law aims to achieve.

**Observing IRBs: New Approaches to “Empirical Ethics”**

In the past decades, social scientists have shown that ideas about right and wrong are not universal, but instead are the outcome of social processes that are located and generated within specific contexts and are constrained by the local techniques that evaluators conventionally use to make judgments. In short, people’s ideas about right and wrong reflect their communities’ habits, customs, and hierarchies. Building on this insight, scholars have explored how organizations “make ethical research,” including ethics review boards (Stark, 2012; Hedgecoe, 2008), data and safety monitoring boards (Keating and Cambrosio, 2009), and funding review panels (Lamont, 2010). My question is how ethics review boards in the United States do the work of making ethical research.

The premise of sociocultural approaches to studying bioethics is that legal and ethical terms derive their practical meaning and consequences from the way that individuals use and apply them in specific settings, in this case, during the course of IRB meetings. As a result, it is important to study the situations in which individuals enact rules and regulations because it is in these encounters that individuals give abstract rules concrete meaning.

Following this pragmatic approach, I analysed audio transcripts of IRB members’ discussions during their full-board meetings for one year (for details on methodology see Stark, 2012). I also observed their meetings and interviewed members of the three Institutional Review Boards between March 2004 and October 2005. To get a broad sense of problems and styles of work in boards reviewing human subjects research, I interviewed 20 IRB chairs at major research universities across the United States in 2003 and 2004 (Table 4.1).

For the interviews with IRB chairs, I drew a random sample of 20 per cent of the 151 universities (n = 30) categorized as “doctoral/research universities – extensive” according to the Carnegie Foundation for the
Table 4.1. Institutional Review Boards (IRBs) Observed

<table>
<thead>
<tr>
<th></th>
<th>Greenly IRB</th>
<th>Sander IRB</th>
<th>Adams Medical</th>
</tr>
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<tbody>
<tr>
<td>Duration of observations (months)</td>
<td>12</td>
<td>12</td>
<td>5</td>
</tr>
<tr>
<td>Meeting(s) per month (n)</td>
<td>1</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>New full-board protocols in period (n)*</td>
<td>40</td>
<td>20</td>
<td>60</td>
</tr>
<tr>
<td>IRB members</td>
<td></td>
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<tr>
<td>Community members (n)</td>
<td>2</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Faculty and administration (n)</td>
<td>12</td>
<td>11</td>
<td>9</td>
</tr>
</tbody>
</table>

Note: The meetings at Greenly IRB were recorded for 12 months and at Sander State IRB for 7 months. Field notes were taken during all of the board meetings. For a full description of research methods, see the appendix of L. Stark, *Behind Closed Doors: IRBs and the Making of Ethical Research* (Chicago: University of Chicago Press, 2012).

a The number of full-board protocols reviewed is rounded to protect the identities of the institutions. During the meetings, all of the boards also discussed expedited protocols, study amendments, and continuing reviews.

Advancement of Teaching (2001). Colloquially, these institutions are referred to as large research universities. I completed 20 interviews (a response rate of 67%), and used these interviews with this national sample to get a broad view of common issues and modes of operation of Institutional Review Boards in the United States. I also used the contacts I made through these interviews to select the boards that I subsequently observed.

I contacted three of the IRB chairs I had interviewed as part of the national sample to ask whether I could do long-term observations of their full-board meetings. I chose these three IRB chairs because their institutions were within 500 miles of my institution and because they encouraged the project. Thus, one limitation of my data – as indicated by the chairs’ willingness to let me, as an outside researcher, analyse the meetings – is that the board members were unusually eager to learn more about their own practices from a sociocultural perspective. Another way to think of this selection bias is to recognize that the boards I observed functioned well and were open to reflection about the way they made decisions; their practices were those of particularly self-aware and self-critical IRB members.

With their members’ consent, I attended the monthly full-board meetings of two Institutional Review Boards for one year between 2004 and 2005, and audio recorded most of the meetings. For five months I also observed but did not audio record the twice-monthly meetings of one Institutional Review Board at a medical school. The medical school board was one of several at a university that had additional ethics review boards for non-medical research. This Institutional Review Board, which I call Adams Medical Board, met every other week for three to four hours, during which I took field notes. I also interviewed 10 of the 11 regular members of the board, plus one non-voting administrator. The other two Institutional Review Boards that I observed were the only boards at universities without medical schools (although researchers conducted vaccine trials, physiology studies, and other medical research often in cooperation with local clinics and the schools’ infirmaries). At the board that I call Greenly IRB, members gave me permission to audio record their monthly meetings for one year. I supplemented these recordings with handwritten field notes and interviews with 11 of 14 board members. At the third IRB, Sander State IRB, members gave me permission to audio record their monthly meetings after my fifth month with the Board. Thus, I recorded meetings that averaged just under two hours in length for the remainder of the year (seven months) and continued taking field notes. I also interviewed the 12 regular members of the Sander State IRB during the course of the year. In sum, I supplemented my observations of meetings of three Institutional Review Boards with recorded interviews of 34 IRB members. I transcribed the audio recordings of these meetings and interviews, and analysed the transcripts using Atlas.ti, a software program for coding qualitative data that allows a flexible style of open coding without pre-established categories, helping researchers identify emergent phenomena.

Who Is at a Disadvantage in Human Subjects Review?

My study suggests that in North American boards, non-native English speakers – researchers and study participants – tend to be at a disadvantage in the ethics review process.2 The work of reviewing the ethics of human subjects research is simultaneously a practical and symbolic activity, and IRB members’ evaluations in the boards I observed affected both researchers and future research participants.

IRB members tend to concentrate their limited time on a review of researchers’ consent materials, perhaps with good reason. Participants, especially those with lower levels of education, find it difficult to understand and remember information about studies, even after a thorough
and sensitive consent process (Flory and Emanuel, 2004; Ballard et al., 2011). Part of the explicit task of IRB members is to judge how appropriate content materials are for a given group of participants — whether the materials are intended to be read or heard. To that end, IRB members use standardized tools aimed at improving the readability of consent documents by making the language more colloquial and pithy, while keeping the content legally valid and scientifically accurate.

Yet IRB members’ review of consent materials is a challenging task riddled with contradictions. During one IRB meeting, the board’s community member counted the syllables in a researcher’s consent form and observed that the word “institutional” itself has five syllables. Point taken: a proposed consent procedure that included telling participants that the study had been approved by the “institutional review board” could, in theory, stall IRB approval of the study because of the readability index. Nonetheless, there is a case to be made for simplifying consent materials. In another meeting I observed, board members suggested to the researcher, who was at the meeting, that he could better explain his research to participants, which is a regulatory requirement. The researcher did not see how he could be more clear. “I read through and honestly, I didn’t find big words,” the researcher explained. “I didn’t know what words were too big in the consent form.” IRB members offered specific suggestions for edits:

**DR MORRIS:** When I read these things that have four or more syllables, I get worried.

**PRIMARY INVESTIGATOR:** Oh, okay.

**DR MORRIS:** *(Quoting an example from the consent form)* “Excellerometers measure caloric expenditure.”

**PI:** Right.

**DR MORRIS:** That’s fine if I’m a graduate student in health science, but if I’m somebody else, I’m not sure I can understand what you mean.

**PI:** I’ll have you sit in on one of my classes! *(Laughing)*.

**DR MORRIS:** But that’s what I’m saying. Just make the words so that a person can understand them. *(Giving an example)* I hate the word “discontinue.” That is “stop.” I know I harp on people about this, but I really think you can apply simple language for big words and make it a lot easier for people to understand.

**PI:** Alright.

**PROFESSOR HARPER:** Another one, is “muscular skeletal.” We can put a simple word in instead. I can’t even say “musculoo,” “muscular

skeletal.” That’s just a bad word. Like “excellerometer.” You can put simpler words in there to tell what that means. I’m from the [named department]; we don’t have vocabularies either. Little words work.

**DR MORGAN:** Everyone gets caught in their own technical jargon, but unless you’re actually confined to that population of people who can say “Ah, it sounds good,” it is hard to see that. Participants might wonder: does an excellerometer, for example, have electrodes stuck into it?

**PI:** How about “motion detectors”?

**DR MORGAN:** Yes.

**ANOTHER IRB MEMBER:** Sure. *(Field notes, SG, Nov.)*

IRB members have the potential to accomplish practical good for research participants through their review of consent materials. To be sure, they do not always accomplish this goal in part because of the very guidelines they are supposed to follow to ensure participants’ protection. Yet in the Institutional Review Board I studied, the board members’ review of materials benefited English-language participants almost exclusively.

IRB members tend to focus on consent forms precisely because the material is consequential for participants, but my research raises questions about the biases and blind spots in the review process. A community member on another board explained that “an important part of my function” is to read consent forms to make sure participants will “understand.” She said, “If it’s not understandable to me, who’s well educated, then I figure somebody with an eighth grade education will not understand it and I will definitely raise that concern” *(Field notes, C3)*. Yet this board member spoke only English. As a result, she could only ensure that participants who shared her language would understand the materials. Likewise, a clinician who also served on this board mentioned the importance of community members, including the volunteer quoted above, in judging the readability of consent documents. However, this IRB member observed that the board had never included a person who spoke Spanish, even though the university ran many community studies in the Spanish-speaking enclaves that surround the hospital setting being studied *(Field notes, C6)*.

During meetings, IRB members discussed language issues on rare occasions. The silence on this topic was all the more apparent because of the large number of researchers who proposed studies with subjects who were not native English speakers. On one of the occasions when IRB members did recognize differences in language they did so
by praising one board member’s idiosyncratic strength, rather than
by reflecting on the board’s homogeneity overall and the limits that
this homogeneity set. For the study, the researcher had a consent form
translated into Spanish for the people she planned to enroll, and she
was also in the process of hiring people to conduct Spanish-language
interviews in a nearby city. The researcher herself did not speak Span-
ish. For the consent translation, the researcher depended on a consul-
tant, and she was unable to judge the quality of the translation prior
to the IRB review, which she attended. As a result, she could neither
confirm nor refute one IRB member’s opinion that “the Spanish con-
sent [was] bad.” The IRB member claimed, referring to the section on
risks, “It says here I’m afraid my friends will relax me” (Field notes,
NG, Dec.). Moreover, the researcher was unable to discuss the best way
to revise the materials, or to serve as a trustworthy judge of a fresh
translation (from a consultant) that IRB members requested before they
would approve the study.

These examples suggest that the practical benefits of reviewing
human subjects materials privilege participants who share the domi-
nant language of IRB members. In doing so, this disparity perpetuates
a pattern in research more broadly. Traditionally, anglophone research,
and medical research in particular, has worked to the greater advan-
tage of people with strong English literacy. Similarly, English-speaking
research participants would seem more likely to comprehend consent
procedures and to get more intelligible consent documents (via
researchers) from Institutional Review Boards that share their language.

My interviews with members Institutional Review Boards suggested
that the breakdown in language happened in translations, and that the
direction of translation might be part of the problem. Because research-
ers are required to submit both foreign-language and English-language
versions of the consent materials, they tend to write in English and
have the foreign-language consent materials translated. During one
meeting, a board member’s idea for how a researcher might improve
the foreign-language consent materials pointed to the root of the prob-
lem: “Translating English-language consent forms into Spanish is a
problem for many IRBs,” the board member observed. “There has to
be a computer program that can do consent translations” (Field notes,
AM, Mar.). Poor-quality translation of consent materials is a pervasive
problem in research. Yet IRB members, like many researchers, lack the
language skills needed to remedy the problem and—more significantly—to recognize problems with translated materials.

In sum, my empirical study of Institutional Review Boards suggests
that the ethics review process creates social disparities based on lan-
guage, and that these disparities stem from IRB members’ tendency to
evaluate only those application materials that they can read. IRB meet-
ings were patterned around biases in board members’ language skills,
and as a result only writing and speech that was conducted in the domi-
nant language of IRB members was open to evaluation. IRB members
changed—and one hopes, improved—consent materials most often for
future participants who shared the board’s dominant language. When
consent materials were written in a language other than English, board
members tacitly trusted the skill of the translator without requiring
information about the qualifications of the translator. Thus any prac-
tical benefit of IRB review, such as improved consent materials, may
neglect speakers of non-dominant languages.

Monolingualism and Its Implications

Scholars have used two approaches to study language mismatch: lan-
guage concordance and poststructural monolingualism. Both approaches
acknowledge that language communities map onto regional and cul-
tural communities. Because of this feature of language, people who
share a language often share the resonances and implicit meanings of
words. They get the joke, so to speak, but also tend to miss the political
undergirding of language.

These two approaches build on different assumptions about how
language works (including verbal language and symbolic language,
e.g., sign language as well as spoken language), and about what lan-
guages accomplish unintentionally. As a result, they imply different
political and practical responses. First, researchers in health fields
have used the term language concordance to study accuracy in linguistic
translation. Conceptual and evaluative words, such as fair and justice,
are freighted with connotations and histories, and therefore have a
range of resonances across language groups. Scholars have shown the
special difficulty, even impossibility, of capturing the precise meaning of
abstract terms across languages (Tang et al., 2011; Viruell-Fuentes
et al., 2011), though language mismatch can also be strategically use-
ful in some circumstances (Ribeiro, 2006). The imperatives of research
ethics and regulation, however, require that people communicate and
develop a shared understanding of abstract terms, such as rights and
respect.
The implication is that scholars should work harder to make translations as accurate as possible, ideally by involving people from appropriate language communities or by involving members of the actual audience (e.g., research participants) in an ongoing communication process. This latter approach creates a puzzle because regulations concerning human subjects research in many countries require researchers to create texts and scripts before they begin their studies. Still, funders and research institutions have (paradoxically) turned language concordance into a metric of success—a quantitative measure assessing the quality of language, which monitors can track and researchers can compare over time. Scholars who use fieldwork in their research have advocated and developed approaches to work within this communication paradox (Miller et al., 2007).

By contrast, the approach of structural monolingualism considers the assumptions that individuals make about people whose language is different from their own. This marks a niggling but important distinction between the two approaches: whereas language concordance is concerned with (different) languages and the process of translation, monolingualism is concerned with (language) difference and the production of political inequality. Philosopher Jacques Derrida developed a theory of monolingualism in the 1990s, and took seriously the claim that people think in languages. Because language is verbal and conceptual, one’s language organizes both the attributes associated with different social groups and the patterns of chauvinism that result from people’s linguistic affinities and familiarities.

Scholars working on structural monolingualism tend to assume that people’s thoughts are organized into two categories: what I am and what other people are (Derrida 1998). Some people may be the same as who I am (e.g., Canadian, gay, black, male). People who are not the same as I am are not simply members of any number of alternative, precise categories (e.g., American, straight, white, female). They are “other” than I am; they are different.

Importantly, categories are always formed in relation to each other—as binaries—and they inevitably fall into hierarchies. Categories, according to structural monolingualism, can never be exactly even. One always must be better or worse, superior or inferior, and these relations, Derrida pointed out, map on to people’s political intuitions. At the basic level, patterns of discrimination are built into the language communities that frame people’s thinking and as a result embed assumptions about what is natural. Similar cases have been made for gender and sexuality (e.g., Schiebinger, 2004), which has fuelled gender studies and queer theory since poststructuralism (Butler, 2006).

Structural monolingualism is not fatalistic about human prejudice, though. The approach acknowledges that inherent human prejudices can be managed and mitigated. The first step is to develop attention to the issue in specific social settings. This chapter holds up IRB meetings as just such an exemplary setting.

These two approaches to the study of language mismatch point to the source of problems in research ethics review and attune observers to solutions. It is common to assume that research review committees strengthen (or at least do not diminish) the comprehensibility of consent materials for research participants. To be sure, many researchers challenge the notion that IRB members’ editorial changes to consent materials make substantial improvements, an issue I discuss elsewhere (Stark, 2013). Still some researchers have come to rely on review committees to provide “helpful insight into potentially problematic phrases or words, and to ensure that the documents will be well understood by study participants” (Virk, 2011: 4).

Poor translation of study materials is common in research, and this problem undermines the stated aim of regulating human subjects research: to protect participants. This is a quandary because language barriers are a key contributor to low participation rates of many minority groups in research, including qualitative studies (Gee et al., 2010; Swanson and Ward, 1995). To take an example from health research, the most influential group-specific social factor contributing to the low participation rates of Latinas in breast cancer clinical trials was a lack of English proficiency (Borrayo et al., 2005).

Regulations do not require that individuals who translate materials and lead the consent process share the language or dialect of study participants. Scholars such as Karen Virk (2011) have argued that the consent process in particular is a serious barrier because members of many racial and ethnic minority groups lack strong skills in the language of governance. But there is another way to think about the language mismatch: namely, that many members of ethics review boards and researchers lack skill in the languages spoken by research participants.

Conclusion: The Many Languages of the Law

The increasingly global context of research has enhanced the need to understand how people communicate in research ethics review—how
The implication is that scholars should work harder to make translations as accurate as possible, ideally by involving people from appropriate language communities or by involving members of the actual audience (e.g., research participants) in an ongoing communication process. This latter approach creates a puzzle because regulations concerning human subjects research in many countries require researchers to create texts and scripts before they begin their studies. Still, funders and research institutions have (paradoxically) turned language concordance into a metric of success – a quantitative measure assessing the quality of language, which monitors can track and researchers can compare over time. Scholars who use fieldwork in their research have advocated and developed approaches to work within this communication paradox (Miller et al., 2007).

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Conclusion: The Many Languages of the Law

The increasingly global context of research has enhanced the need to understand how people communicate in research ethics review – how
research regulations, effort could productively be directed towards reforming practices of IRB deliberation and at incorporating language experts or members of a variety of language communities into the review process (Kithinji and Kass, 2010; Miller et al., 2007). The protections put in place for research participants during the 1970s fit awkwardly in the twenty-first century research environment; it is time to broaden the imaginations of researchers and policymakers regarding risks to both researchers and participants who are embedded in multiple language communities.

NOTES

2 I discuss language mismatch among ethics board members and researchers elsewhere (Stark, 2013).
3 In general, there is work to be done on the question of whom IRB members imagine when they think of future research participants, a practice that I call "seeing like a subject" (Stark, 2012).
4 For example, the September and March meetings of Sander Sate involved lengthy discussions of translating consent forms (regarding types and delays in approval). It was explicit, though it did not seem peculiar to board members that all translations were from English into the non-English language.
5 It is important to note Derrida argued that a person’s dominant language also creates alienation of a speaker with herself.

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