



IRBs and Internet Research Ethics

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It was the best of times,
it was the worst of times....

Growing Use and Awareness of Internet-Based Research

- Documented evidence:
 - 25% increase in online psych experiments from 2001-2002 (Peden and Flashinski, 2003)
- Anecdotal evidence:
 - Serving on UWM's IRB for 4 years, at least 2 Internet-based research protocols each month compared to 1-2 per year
- Emergence of significant documents (Frankel and Siang, 1999; AoIR "Ethical Decision-Making," 2002; growing literature, albeit scattered across disciplines; two books in 2003...)

IRB Training?

Formal

- NIH computer-based modules and sessions
- Public Responsibility in Medicine and Research IRB 101 sessions (participation typically voluntary)
- Many institutional training sessions springing up, eg, Protecting Human Subjects in the 21st Century: Issues in Social & Behavioral Research; some contain brief mentions of Internet research ethics
- Administrators typically get the Frankel and Siang report and some information on security issues in web surveys
- Informal
 - Learning as we go along; one board member “teaches” the others; “We don’t even know what questions to ask... .” (IP, encryption, cookies, server logs, firewalls, etc)

A decorative graphic on the left side of the slide, consisting of two overlapping circles. The top circle is a dark teal color, and the bottom circle is a lighter, semi-transparent teal color.

IRB Training?

- At many institutions, completion of a human subjects tutorial is now “required”
- Some institutions issuing specific Internet-based research protocol guidelines
- Personal note—lots of disgruntled academics vis-à-vis Internet research policy!



Major Issues

- Three guiding principles of research ethics:
 - Justice, beneficence, autonomy
- Translating these to Internet spaces? Reviewing protocols demands a careful look at:



Issues in Internet Research for IRB Review

○ Recruitment

- fair? legitimate? integrity of research?
- Public and private spaces?
- Is Internet-based the best approach or a convenience for researcher?

Issues in Internet Research for IRB Review

- Security issues and privacy
 - Is there a truly secure online interaction? What type of Internet location/medium is safest? Is an “anonymous” survey possible? How will subjects/participants be protected? Is encryption enough? Ownership and stewardship of data? How long does e-data last? What about SurveyShare, Zoomerang, et al?
 - *“Panelists should be aware, however, that in responding to surveys or survey invitations that they may be disclosing their own personally identifiable information to Members. The security and privacy protections in place on this Site and through the Service do not cover this type of transfer or disclosure of personal information. Panelists responding to surveys or survey invitations are solely responsible for the content of their responses.”*

Issues in Internet Research for IRB Review

○ Informed Consent

- Debate over public and private spaces; is IC necessary? The processual nature of IC? Potential conflict between waiving IC and beneficence (will something from a public space come back to haunt us; use of archived quotes never intended to be used in research?)? Verification of understanding? Click boxes? Blanket statements necessary (*"I understand that online communications may be at greater risk for hacking, intrusions, and other violations. Despite these possibilities, I consent to participate"*)?

Researcher Naiveté?

- “Responses are stored on the survey share server (right on www.surveymshare.com). They can only be accessed by me, as I'm the only one who knows the password that allows me to access the survey maintenance section.” (From SurveyShare Privacy policy-- “SurveyShare has access to your survey contents purely for purposes of backup.... ”)
- “As an instructor, I have permission to read all student posts made to the password-protected site...and use [them in analysis]...” (What about those non-consenting students' posts?)
- “I have published fairly extensively on online cultures, so I have a pretty good sense of what IRB rules apply or might apply in a given research situation.”

Are There Exceptions?

- Course management systems?
 - *"[Internet research guidelines make a] number of assumptions about Internet research that do not apply to simple, low-risk research projects which are using the campus' course management system."*

A Few Web Resources

- NIH module: <http://www.nihtraining.com/ohsrsite/IRBCBT/intro.html>
- Collaborative IRB Training Initiative: <http://www.miami.edu/citireg/>
- UW Human Subjects Tutorial: <http://info.gradsch.wisc.edu/research/compliance/humansubjects/tutorial/>
- Frankel and Siang Report: <http://www.aaas.org/spp/sfrr/projects/intres/main.htm>
- AoIR Report:
<http://www.aoir.org/reports/ethics.pdf>
- CEPE 2001 Panel: http://www.nyu.edu/projects/nissenbaum/projects_ethics.html
- Barak's Internet Research Bibliography: <http://construct.haifa.ac.il/~azy/refmetho.htm>



The first step in the evolution of ethics is a sense of solidarity with other human beings.

Albert Schweitzer, Nobel Peace Prize-winning doctor and theologian