Social Science Data Reuse and Institutional Review Boards: A Pilot Study of Stakeholders’ Opinions

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Background
- This study, conducted at a large research university, assessed the opinions of IRB members and social science researchers about data sharing and archiving.
- It particularly focuses on possible ethical issues or other real or perceived barriers to full utilization of digital data repositories by examining potential users’ attitudes towards digital repositories.
- It should be considered a pilot study due to the small samples and exploratory methods.

Methods
A Survey
- Of social/behavioral science researchers across the university, including doctoral students and faculty, included multiple choice and free response sections
- 74 surveys completed (700 emails sent out)

B Interviews
- Of IRB members
- 5 members of a social/behavioral IRB interviewed

C Content analysis
- Of previously approved IRB applications, coded according to their language about future plans for data
- 93 blank informed consent documents from 2008 “approved” IRB applications examined

Key Findings

A Of researchers...
- 84.9% had never archived data; 77.8% said they would consider doing so
- 61.6% thought the IRB would approve a study that included a plan to archive de-identified data for future use; 31.5% didn’t know
- Most weren’t comfortable archiving data based on what they said in their last IRB application

B Of IRB members...
- Most were generally supportive of data archiving
- 4 of 5 preferred to see data archiving plans explicitly indicated on IRB applications
- All mentioned “anonymity,” “confidentiality,” “de-identification,” and “informed consent”

C Coded blank informed consent forms (n=93)

Discussion
- Language used on IRB applications (as well as language that is not used), and the underlying ethics of the issue seem to be barriers to data archiving.
- Neither researchers nor IRB members give significant thought to data archiving in early stages of social/behavioral science research. Neither group is clear on the “rules” or if there are any.
- Social/behavioral researchers and IRB members are both interested in protecting subjects and upholding professional ethics.
- There is evidence that social/behavioral IRBs have and will approve applications that include data archiving plans.

Limitations
- Study was conducted at a single university
- Small sample size for interviews
- Very low survey response (possibly explained by those not requiring IRB approval)
- Possible over-representation of Information & Library Science researchers who might be more aware of or supportive of data repositories

Recommendations
- Early intervention by repositories
- Discussion within IRBs on how data archiving in social/behavioral science should be handled
- Guidance provided by IRBs and repositories
- Continued education and research

Cited
Full report is available at http://sils.unc.edu/itrc/mpi/
See also: Davis & Connolly (2007), Foster & Gibbons (2005), Green & Gutmann (2007), Markey, et al. (2007), and Witkowski & Alter (2009)