

Chapter 16

Online Research and Obtaining Human Subjects/IRB Approvals

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ABSTRACT

The development of digital computing and the growth of the Internet have opened up new opportunities to engage in online research. These online research practices involving human subjects, often involving relatively new technologies, can create tension between the online investigator and the Institutional Review Boards (IRBs) who are required to review and approve such research prior to data collection. This chapter aims to reduce this tension by discussing the associated ethics issues and applicable federal regulations, identifying specific concerns from the perspective of IRBs, and offering suggestions as to how best to address these concerns in applications in a way that can hopefully serve both the researcher and the review board.

PASSING REVIEW: ONLINE RESEARCH AND OBTAINING HUMAN SUBJECTS/IRB APPROVALS

Research ethics became a major concern in the middle of the 20th century, largely in response to growing awareness of the potential risks and harms faced by some participants epitomized by several scandals (Baker & McCullough, 2008). As a result, research involving human subjects is not merely required to be conducted in an ethical manor but often formally reviewed by an Institutional Review Board (IRB) prior to data collection. Such review boards are required for

federally funded research but also are used by research organizations inside and outside of the United States in order to ensure that research is conducted in such a way as to protect the rights of the participants.

IRBs are guided by a series of ethical concerns, and Federal and (sometime) state regulations designed to protect the rights of human subjects. New methods and procedures can become particularly problematic, as both researchers and IRBs seek to determine appropriate policies and standards while maintaining and protecting the rights of the populations under study. The rise of online research has been a recent example of old

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boards being faced with the challenge of reviewing new methods.

The Internet has opened the gates to a wealth of potential research observations and data collection methods. It has arguably allowed researchers access to much wider populations and large amounts of content and communication created by people. The nature of the Internet has also raised some troubling issues, related to its “public nature.” One aspect of that nature is the fact that most communication, content, and traffic on the Internet are public; moreover, the process of Internet communications includes address tags, which can be linked to sites and potentially individuals. This raises inherent questions about the potential for anonymity and confidentiality in online data collection. In addition, there is another “public” issue that arose very early in online research: for years, observations of normal public behaviors and content analysis (the observation and coding of published content) have been considered to not require IRB review. The problem has been that some researchers consider material public if they can find it on the Internet, but the participants may have thought that some level and expectation of privacy applied in private lists or discussion areas. The debate over whether certain materials are truly public or private has raged since some of the earliest online research, and forms one of the fundamental debates with IRBs.

The concern about ethics in online research is hardly new. A number of scholars have identified some of the emerging issues and problems (Jones, 1994; Frankel & Siang, 1999; Walther, 2002; Ess & Jones, 2004; Jones et al., 2004; Ess, 2007), and groups like the Association of Internet Researchers made developing their own ethics guidelines one of the first official acts of the association (Ess & Jones, 2004). Much more has been written in recent years about specific issues and problems. While many, starting with Jones (1994), found a certain tension between traditional research guidelines and online research practices, few addressed the issue of how to reduce the tension

and accomplish online research within the existing legal framework.

The tension may be compounded by the fact that both researcher and IRB members may lack familiarity with the specifics of Internet operations. The members of IRBs are representative of many disciplines, and also tend to be more senior scholars. Many may lack familiarity with the technical implications and nature of the Internet and various online research methods. This can lead to some confusion and a tendency to overprotect human subjects.

This chapter will try to help reduce the tension by taking a practical approach, with the hope of informing both researchers and IRBs about some of the human research ethics issues raised by online research methods, identifying the more specific concerns from the perspective of IRBs, and offering suggestions as to how to best address those issues and pass IRB review. While the concerns and issues associated with ethical research are global, this chapter will focus on the specifics of the U.S. regulations and IRB review process.

FEDERAL REGULATIONS REGARDING HUMAN RESEARCH

Institutional IRBs are given oversight over all research involving human subjects conducted under their auspices, or by their faculty or employees.¹ While the potential range and scope of human research is near boundless, there are three general classifications of data collection activities from an IRB perspective. First, there are research methods and activities that do not involve the collection of “research data from human subjects,” and thus are outside the review process. Second, there is research that is considered “exempt” from review, although one must realize that this exemption is only from full formal review (IRBs must still review such research proposals to validate that they are exempt). Finally, everything else is required to be reviewed, although the regulations

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