Protecting Human Subjects in Internet Research

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Abstract

The growth of the Internet as a research venue has led to practical, legal, and ethical problems regarding the protection of human subjects. Among these are difficulty in verifying subjects' identities, gaining informed consent, and assuring ethically-correct research. The authors summarize the current standards pertaining to the protection of human subjects in online research and present a set of guidelines for dealing ethically, legally, and practically with the issues of privacy and confidentiality, intellectual property, informed consent, and protection from harm. As computer-mediated communications merge and evolve, as the Internet becomes more and more a part of everyday life, and as standards for ethical and lawful online research are instituted, separate consideration of human subject protection issues in online research will become less important.

Keywords

Internet research, research ethics, protection of human subjects, informed consent, privacy, intellectual property

Practical, Legal, and Ethical Challenges

Researchers are increasingly turning to the World Wide Web as a convenient, ubiquitous laboratory for gathering data and conducting research (Buchanan, 2004; Reips, in press). There are many differences between conducting psychological research in a person-to-person setting and an online environment, yet the ethical and legal issues involving the protection of human subjects are the same. Researchers in the Information Age must face and deal responsibly with these issues.

While legal and ethical issues regarding the protection of human subjects participating in online research are essentially the same as those in real-world research, it is likely that the solutions to the ethical dilemmas created by online research will not be the same as those practiced in the laboratory. Solutions that work in the physical world require separate consideration and modification for virtual application.

Social scientists have expressed concern that applying a human-subject-protection model developed for science and medicine to the kinds of research conducted by psychologists, political scientists, and anthropologists was inappropriate even in the real-world environment (AAUP, 2000). Regulations developed for the real-world medical environment are even less appropriate when applied to social science research conducted in an online setting.

The set of United States regulations concerning the protection of human subjects is often referred to as "the Common Rule" (DHHS, 2001), and they are indeed the Common Rule for the United States. However, regulations and ethical standards exist in other parts of the world. Thus, the global nature of Internet research complicates the application of these guidelines. For example, contrasting the United States and Germany, Capurro and Pingle (2001) point out that the research traditions and fundamental ethical assumptions and views of personal data differ widely even within the Western philosophical tradition. The reason for this variation "is that the online medium transforms basic aspects of human existence, such as identity, language, confidentiality, that are at the core of any society and are protected in most countries by local law" (p. 6). They advocate moving from a "purely instrumental or moralist view" to an "ethics of care."

In this paper, the authors identify several key issues regarding the protection of human subjects in Internet-based research, describe the ethical and legal considerations related to these issues, summarize the present codes addressing these issues both in the United States and Europe, and provide a set of working guidelines for conducting ethical and lawful online research. These guidelines should have broad applicability regardless of the ethical system adopted.

Issues in Internet-Based Research

The commercialized Internet accessible through graphical web browsers is little more than a decade old, but Internet-enabled electronic communication and concomitant research venues have proliferated over that period of time. Computer-mediated communications include electronic mail, chatrooms, newsgroups, listservs, web-based experiments and surveys, message boards, threaded discussion forums, web logs (or blogs), and collaborative web sites. A fundamental issue is whether these venues are to be considered public or private. If they are public, the archived responses of individuals may be construed to be matters of public record, and few ethical considerations apply when the records of these responses are used in research.

If web-based venues are private, however, individuals' responses may be privileged and protected, and could only be used in research with clear protection of the identity, autonomy, and informed consent of the participant. The determination of "private information" by United States statute hinges on the individual participant's "reasonable expectation of privacy" (DHHS, 2001).

In an online environment one's level of technological sophistication could play a major role in determining perceptions of privacy. More experienced Internet us-

ers may be aware of the identifiable digital footprints left behind as they traverse the Internet, while neophytes may believe they are cloaked in electronic anonymity. Privacy, then, must involve more than an objective determination by the researcher alone. The same chatroom that a naïve participant perceives as limited to those actively engaged in discussion may be experienced as less isolated, more transparent, and publicly visible by another.

Knowledgeable, computer-savvy researchers cannot assume that their own perceptions of privacy or lack of it are shared by research participants. Some writers dismiss the issue, describing expectations of privacy as "misplaced" (Walther, 2001). Others describe such beliefs as naïve or unrealistic. Simply dismissing the privacy expectations of naïve subjects as unrealistic begs the question of who is really naïve. It is also possible that the experimental context may alter expectations regarding privacy. For instance, while one would normally not take candy from strangers, one might feel safe taking it from an experimenter. Online, one might feel safer typing in a credit card number on a secure bank web site than on a general site. In the same fashion, subjects might feel that their responses were protected from scrutiny on a web site devoted to an experimental survey.

A second major issue in Internet-based research is the ability of both researchers and subjects to assume anonymous or pseudonymous identities online (Amber, 2000; Frankel & Siang, 1999). This ability to assume or fabricate identity complicates matters regarding informed consent, correct identification of research participants, and protection of underage subjects. There are further ethical implications regarding the integrity of results if the gender, age, and other aspects of identity are uncertain or inaccurate. In the online venue, experimenters often cannot be sure they are even dealing with a single individual, as typists could change without the experimenter's knowledge. A student taking an online test or participating in a survey an online experiment could easily have a parent or another student nearby to provide answers or assistance. The most extreme case would involve an experimenter involved in the naturalistic observation of an individual who did not exist at all. White cites the "Kaycee Nicole" case involving the young girl whose web log documented her fight against cancer. "Readers were shocked to tears" to find she had died and "even more shocked to learn she had never existed" (White, 2001).

Considering the many different Internet venues, it may be convenient to distinguish among three kinds of online psychological research. First, there is experimental research that involves the collection of survey or experimental data via electronic means, whether by electronic mail or via a web site. Normally, survey researchers and web experimenters collect only enough personal information to confirm the identity and the informed consent of participants, and individual participants' responses are typically not reported except as part of an aggregate. A second kind of Internet-based research includes the analysis of online, public documents treated as texts or archives (Knobel, 2003). Third, online research can refer to the study of "Internet-worked cyberspaces" (Knobel, 2003). This third category would include the study of web sites, online chat spaces, instant messaging, e-mail discussion lists, and other kinds of computer-mediated communication (Knobel, 2003).

Protecting Personal Privacy

At the one extreme, some researchers apparently believe that they can freely use information gathered from online public communication sources as long as participants are not person-

ally identified (see for example Denzin, 1999). Such researchers state that information gathered by lurking passively in an Internet chatroom, for example, is a matter of public record. Indeed, the collection and analysis of such publicly available information may be justified without consent under strict circumstances (Bruckman, 2002). In some cases the researcher goes beyond observation to create the virtual environment and may even create virtual confederates who react to the subject in preprogrammed ways (see for example Williams, Cheung & Choi, 2000). At the other extreme, many researchers are taking precautions to ensure that participants in online research are fully informed and give their voluntary consent to the use of their responses in research studies.

After World War II, the Nuremberg Code established the foundation for modern ethical standards for psychological and medical research using human subjects (Gravetter & Gorzano, 2003; Graziano & Raulin, 2000; Katz, 1972). Ethical guidelines for the use and treatment of human subjects embody principles requiring protection from harm, informed consent, and confidentiality.

The primary codes in the United States presently regulating online psychological research are the American Psychological Association Ethics Code (APA, 2002), the U.S. Department of Health and Human Service's Protection of Human Subjects (DHHS, 2001), and the DHHS Health Insurance Portability and Accountability (HIPAA) Act (DHHS, 2003). Additional protection is provided by the Children's Online Privacy Protection (COPPA) Act (FTC, 1998) and the Gramm-Leach-Bliley Act (FTC, 1999). Collectively, these codes are intended to:

• Protect the privacy and confidentiality of individuals and their personally identifiable medical and financial records.

• Ensure that individuals who give consent to have personally identifiable information collected, transmitted, and stored electronically have been fully informed.

• Ensure that no personal information is collected from children under the age of 13 years without informed parental permission.

As well, the Association of Internet Researchers (AoIR) is developing a code of values that all Internet researchers would be expected to uphold when conducting online research. The AoIR is also pursuing clarification and education regarding the ethical dimensions of human-subjects research (AoIR, 2001) and has recently released a set of recommendations for ethical decision making and Internet research (Ess, 2002).

As in the United States, other countries have sought to create ethical standards for online research. These countries include Canada, Germany (Capurro & Pingle, 2001), Norway (NESH, 2001), and Sweden, among others. The European Commission's Information Society Technologies Programme (IST, 2004) has produced a code of practice for socio-economic research in the European community. As indicated by Capurro and Pingle (2001) and Ess (2002), the European perspective on Internet research ethics is more typically deontological than that of researchers in the North America, and particularly the United States, whose views are more typically utilitarian.

Regardless of the global source of data collected and the ethical system adopted, three primary and transcendent principles emerge regarding the protection of human subject, whether the research is conducted in a laboratory or on the Internet. These principles originally delineated in the Belmont Report (NIH, 1979) are autonomy or respect for persons, beneficence, and justice (Frankel & Siang, 1999). The principle of autonomy dictates that the individual should be respected, and that in most cases, he or she must give informed consent to voluntary par-

ticipation in any research activity. Furthermore, the individual's privacy should be reasonably protected. As described by the Belmont Report, two moral requirements are involved in respect for persons "to acknowledge autonomy and to protect those with diminished autonomy." The principle of beneficence requires that the research should produce a benefit—whether to the general good or to the specific individuals who participate, or both. This benefit must outweigh the potential risks associated with the research. The Belmont Report cautions that "hard cases" arise where general good and individual participant risk are both involved. Finally, justice demands that subjects be treated fairly, and that they have the opportunity to withdraw voluntarily from the study at any time without fear of consequence. Justice further involves fair or representative selection of research subjects without discrimination against particular classes due to convenience or manipulability.

Ethical Challenges of Internet Research

The application of these human-subject-protection principles, however, is complicated in online research because the researcher and the subject are not usually face-to-face. Specifically, the Association of Internet Researchers has identified some distinctive challenges of Internet-based research (AoIR, 2001 and Knobel, 2003). Below, the authors present, discuss, and expand the list of Internet-research challenges:

• Greater risk to individual privacy and confidentiality because of greater accessibility of information about individuals, groups, and their communications—and in ways that would prevent subjects from knowing that their behaviors and communications are being observed and recorded (e.g., in a large-scale analysis of postings and exchanges in a USENET newsgroup archive, in a chatroom, etc.). Individuals often have unrealistic, even illusory, expectations concerning their anonymity on the Internet. The truth belies these expectations. Not only are server logs with computer users' Internet Protocol (IP) addresses maintained and backed up to tape and disk, but persistent identifiers (cookies) and other traces of online activity, for example lists of visited web sites, may be recorded as well. Some of these personally-identifiable records may go into additional storage as electronic or hard copy information, which increases the risk of identity capture and exposure in the future. Individuals' responses to questionnaires or surveys, including sensitive personal or financial information, could conceivably be intercepted at various points as they travel across the Internet. When responding to a paper-and-pencil survey, an individual may feel reasonably sure that a questionnaire sent through the postal service will not be opened and read. However, it is debatable as to whether the same individual could be equally confident that e-mail sent from an office computer or a networked computer laboratory would not be intercepted or recorded. Hidden Trojans, worms, or undetected keystroke counting mechanisms could increase the likelihood of survey responses containing sensitive personal information falling into unintended hands even if the survey itself were later to be sent via encrypted processes.

• Greater difficulty of ascertaining identities because of the use of pseudonyms, multiple online identities, etc. As previously mentioned, many individuals adopt pseudonymous identities on the Internet, and often individuals adopt completely false identities. Ascertaining the true identity of research participants requires the collection of personally-identifiable information, yet such information poses a risk to individual privacy, as noted above. Reciprocally, potential subjects may have difficulty

in determining if the individual soliciting research participants is a bona fide researcher whose research is for a legitimate scientific purpose.

• Greater challenges to researchers because of increased difficulty in obtaining informed consent. The aforementioned identity issues have obvious implications for informed consent. Identity is linked to the subject's actual and legal ability to give consent. Questions of competence, comprehension, and age arise. Researchers are challenged to gain informed consent while protecting the subject's privacy. Because the researcher's contact with the subject is electronically-mediated, the documentation of truly informed consent becomes problematic. There are significant trust issues for the subject as well as the researcher. Many potential participants having read of various nefarious Internet schemes may suspect the motives of the "researcher" and believe that the "research" is not what it is purported to be. Such individuals may be hesitant to volunteer or to be completely forthcoming in their responses. This hesitation may increase with the sensitivity of the subject matter and the likelihood of negative repercussions if a breach of confidentiality should occur. In a fashion similar to the findings of research concerning volunteer subjects and demand characteristics in real-world experiments (Rosenthal & Rosnow, 1975; Orne, 1962), individuals willing to volunteer for online research may differ not only from the general population but may also differ from the virtual population of Internet users as well.

• Greater difficulty in discerning ethically-correct approaches because of greater diversity of research venues and the global reach of the media involved. As previously stated, computer-mediated communication engages people from different cultural and legal settings in an increasingly diverse set of research venues. The applicability of various state, federal, and international codes is problematic at best.

• Difficulties in obtaining representative samples due to the economic "digital divide."* The population of individuals using the Internet is better educated and economically more advantaged than the population as a whole, and is grossly overrepresented by North Americans. This has implications for the previously explicated principle of justice. Yet on the other hand, the Internet is less geographically circumscribed than most other research venues, and if used properly, could afford samples with greater cultural diversity.

• Difficulties dealing with potential harm due to the absence of face-to-face contact. This issue is especially troublesome when subject matter, questionnaire items, or experimental manipulations have the potential to result in psychological distress for participants. Debriefing without direct contact with the participant makes assessment of individual reactions and selection of appropriate interventions difficult (Kraut, 2003). Protective debriefing may be more difficult because the subject could leave the experimental space with the click of a button prior to the end of the experiment. This could be an even larger issue in an experiment involving deception such as the social ostracism experiment of Williams, Cheung, and Choi (2000) where the subject might never know the nature of deception.

Intellectual Property Issues

In addition to the ethical issues involved with online data

* Note: The previous four challenges were identified by the AoIR Ethics Working Committee and are presented with adaptation and elaboration by the present authors. These last two points are added by the present authors.

collection, there is another issue regarding intellectual property, namely the question of whether a subject's responses to an online data collection device such as a survey or the records in a web-based journal are behavioral responses or in fact original works of authorship. If such responses are considered behavioral signs or samples, as is usually the case in psychological research, copyright considerations hardly apply. If, on the other hand, they are considered original works, they are de facto copyrighted under the U.S. Copyright laws whether or not they display a copyright symbol (U.S. Copyright Office, 2003). As such, these materials could only be used with the express written consent of the copyright owner.

Similarly, the European community has sought to apply harmonize copyright standards across member countries via the recently enacted Directive on the Harmonisation of Copyright and Related Rights in the Information Society (IST, 2004).

The Future and Internet Research

Online research is married to the technology that enables it. Even now the virtual world resembles the real world more and more as desktop video conferencing, file sharing, audio instant messaging, text messages, cell phones with built-in video cameras, and other computer-mediated communication become more prevalent and blur the distinction between online and face-to-face interactions. The technologies themselves are merging; with the dividing lines between telephone, Internet, and television blurring even more as each of the media take advantage of the technology offered by the others.

Computer-mediated communication technologies are not only merging, but also evolving. Collaborative workspaces, virtual organizations, electronic commerce, and online courses and degrees all create interesting and important research questions. Moreover, researchers are not always passive observers. The growth of the Internet has led to the involvement of researchers as participants themselves in Internet-based groups. Such participation may involve different roles such as facilitator, advisor, peer member, or even service provider (Humphreys, Winzelberg, & Klaw, 2000). Disclosure as to the particular role(s) being performed is obviously dictated. As the Internet continues to become a part of everyday life, and as technologies merge and come to resemble real world research contexts, the differences between online and laboratory ethical strictures will likely contract if not collapse. Global communication technology, along with global research venues and subject pools, will increasingly necessitate sensitivity to diverse cross-cultural conceptions and traditions regarding privacy and the integrity of individuals. Notions of beneficence and justice must be interpreted in a broader context. In the meantime, working solutions and guidelines should be implemented to address current ethical dilemmas in online research.

Some Proposed Guidelines for Conducting Ethical Online Research

While ethical standards regarding Internet-based psychological research are currently incomplete at best and contradictory at worst, the authors' recommendations should assist researchers in conducting ethical and lawful online studies.

Guideline 1
Internet research should conform to legal requirements. It is

assumed here that ethical research will also be research that is lawful. For the purposes of these guidelines, United States regulations are the starting point of legal reference. International research will have the more complicated problem of conforming to more than one set of regulations. It is particularly important that international and cross-cultural research have specific and detailed informed consent so that consent is based on fact rather than cultural expectation or researchers' assumptions.

Guideline 2
Public matter can be quoted or analyzed without consent under the following strict conditions (adapted from Bruckman, 2002):
1. The material is publicly archived and readily available.
2. No password is required to access the material.
3. The material is not sensitive in nature.
4. No stated site policy prohibits the use of the material.

In all other cases, consent should be obtained before the research is conducted. It should be noted that in the United States, when human subjects are involved, the decision to waive consent is no longer that of the researcher alone. Consent must be waived by the appropriate Intuitional Review Board (IRB) using procedures and guidelines described in the Federal regulations.

Guideline 3
Gain informed consent without disrupting online activity. Participants in psychological research, whether the research is conducted online or in person, have a reasonable expectation of privacy. The gaining of informed consent should allow participants to verify that they understand the purpose of the research and the means taken to protect their privacy and confidentiality. In addition, wherever the use of online communication involves intellectual property, the ownership of that property should be identified, and the permission of the copyright holder should be obtained before the material is used in research. Some Internet writings are clearly meant to be publications or at least works of original authorship. Other writings, such as casual instant messages or chatroom comments more closely resemble conversation where privacy expectations are different. There is a full continuum of examples and expectation between these extremes. Researchers should be aware of where their research stands on that continuum. When in doubt the consent or permission of the research participant is in order.

Electronic forms of gaining consent may be appropriate if the subject is fully informed and is over the age of 18 years, and the potential risk to the subject is low (Bruckman, 2002). In other conditions, it is usually advisable to obtain signatures on paper to document informed consent. The nature of gaining consent, whether electronic or paper-based, should be minimally disruptive to participants' online activity. In recognition of the COPPA requirements in the United States, the participation of children under the age of 13 years in research should be granted by informed parental permission. Where feasible the child participant additionally should be asked for consent. It may be difficult to ascertain the subject's age with absolute confidence. However, the experimenter should make every effort to do so given the limitations of the online research venue. Asking for date of birth, in addition to age, and the use of other verifying information may help ensure the process.

As part of informing consent and protecting underage children, researchers should routinely post privacy policies on web sites used for data collection purposes. Active rather than passive consent processes are preferred. In some cases the consent

could take the form of agreeing that entry into a chatroom constitutes entry into a public forum where behavior may be monitored, observed, and reported elsewhere or even used for research. Online, individuals frequently simply click through or agree to privacy statements without reading them. It may be advisable as well for researchers to require participants to answer a series of objective questions about the research to document their informed consent. Obviously, there will be a tradeoff between the use of questions to verify understanding and minimizing disruption.

Guideline 4

Protect the identities and confidentiality of online subjects. As part of informed consent, subjects should be made aware of the researcher's intentions regarding the degree of revelation of their identities, and should give permission for the use of both names and pseudonyms. The strictest standards of confidentiality should be applied. Identities of subjects should be separated from their responses wherever and whenever possible.

Guideline 5

Practice disclosure. The researcher should disclose the purpose of his/her study, the methods of collecting data, and plans for analyzing and reporting data. If there are incentives for participation, they should be explained, and should not constitute enticement or coercion. Rarely would Internet-based researchers need to resort to deception to achieve their research goals (Frankel & Siang, 1999), so the use of deception in online research should be avoided or kept to an absolute minimum. To the extent possible, researchers should follow the same standards for debriefing subjects in online research as those for real-world studies. In cases where a subject may elect to leave a site prematurely, the debriefing frame should be a required part of the exit procedure.

Guideline 6

Use technological solutions to technology-caused problems such as electronic links to identity. Kraut (2003) suggests transmitting and storing identifiers separately from the data, in effect disconnecting the identifiers from the data, using session cookies to tie together responses and storing them somewhere other than on the same disk or file as the data, identifying the participant only for the duration of the session, avoiding e-mailed responses which involve identifiers, and possibly even encrypting the data. It is important to recognize that confidential data stored in networked commuters, especially in widely accessible computer labs, may be at great risk for outside access, therefore storage on removable disks or CDs is preferable.

It is generally recognized that in online survey research it is better to e-mail a link to a web site where one can respond to the questionnaire in relative anonymity than it is to e-mail the questionnaire itself and require it to be returned by email with the commensurate links to identifiers. Commercial survey sites are available that will post questionnaires for a fee. These services vary in the degree to which anonymity and confidentiality are protected, so careful attention should be made to each site's privacy policies.

Guideline 7

Consult with the appropriate Institutional Research Board(s) (IRB) and follow their recommendations and directives. IRB members vary in their knowledge of and sensitivity to online research issues. The online researcher should maintain two-way communication with the expedited reviewer(s) and

those on the IRB with knowledge of online research. It is quite possible that more than one institution's IRB may be involved when conducting research across institutions. It is the researcher's responsibility to seek approval from each. If the researcher has doubts concerning IRB jurisdiction, the Office for Protection From Risks, Protection of Human Subjects can be contacted directly. Federal regulations set a floor on what research activities may be permissible. Institutions are encouraged to elaborate these regulations to further protect the research participants under their care, and to address other ethical concerns. Thus, it is likely that restrictions on Internet and other forms of human subject research are tighter at some institutions than others. Thus researchers may find what is permissible in one place may be disallowed in another either for ethical or practical reasons. In some cases it is necessary for the researcher to seek institutional permission when using the institution's e-mail to contact or solicit employees, students, or other individuals for research. Institutional consent may be further needed when the research involves that institution.

Below, the authors provide a tabular summary of their proposed guidelines for conducting ethical online research:

SUMMARY

Guideline 1. Internet research should conform to legal requirements.
Guideline 2. Public matter can be quoted or analyzed without consent under the following strict conditions (adapted from Bruckman, 2002):
• The information is publicly archived and readily available.
• No password is required to access the information.
• The material is not sensitive in nature.
• No stated site policy prohibits the use of the material.
Guideline 3. Gain informed consent without disrupting online activity.
Guideline 4. Protect the identities and confidentiality of online subjects.
Guideline 5. Practice disclosure.
Guideline 6. Use technological solutions to problems caused by technology such as electronic links to participants' identities.
Guideline 7. Consult with the appropriate Institutional Review Boards and follow their recommendations and directives.

Table 1. Summary of Proposed Guidelines for Ethical Internet Research

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Conclusion

The growing use of the Internet as a worldwide research laboratory brings with it a number of practical, ethical, and legal challenges. Chief among these are the difficulty in obtaining truly informed consent, the protection of research participants' privacy and confidentiality, difficulty in verifying participants' identities, difficulty in choosing ethically-correct approaches, problems in obtaining representative samples, and difficulties in protecting subjects from potential harm and providing appropriate debriefing. Additionally, difficulties regarding the perception of privacy and intellectual property currently obfuscate understanding of the best practices for ethical research and protection of subjects' expectations of reasonable privacy.

Ethical codes for human subjects' protection in an online environment are in a state of flux, with standards currently being developed simultaneously around the globe. As these standards are eventually integrated, the ethical issues should be clarified, and widely-accepted approaches for dealing with them should

be forthcoming. In the interim, the authors propose a set of working guidelines that should suffice to ensure that online research is conducted ethically and lawfully. These guidelines include consideration of what constitutes public matter that can be accessed and researched without consent, gaining informed consent in all other cases, protecting the privacy and confidentiality of online subjects, practicing disclosure, using technology to address technology-created ethical issues, and gaining appropriate institutional permission for conducting the research.

Researchers should be aware of the evolutionary nature of technology. Today's solutions may differ from tomorrow's, though basic ethical principles will still apply. Technology's relatively rapid movement and evolution makes it necessary for online researchers to stay abreast of advances in online research techniques and concomitant threats to privacy of human subjects. The protections of newer technologies should be employed as they become available. The authors anticipate that as the virtual environment comes to resemble the real world and is more thoroughly integrated into it, the distinctive nature of conducting research online will be lessened and online research will come to resemble more and more the conduct of face-to-face research.

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