The Ethics of Internet Research

By

Susan G. Williams MSN, RN

CITATION

Abstract

Research conducted on the internet is a cost effective form of recruitment, data collection, and analysis. Researchers can access individuals worldwide for studies in remote areas where there is a lack of or inability to conduct research. With this opportunity come ethical concerns such as determining a safe environment to take a survey, research in a virtual environment, data security, confidentiality, and performing secondary analysis on archived support group information. Researchers should be aware of laws regarding minors and respect the core ethical principles of beneficence, respect for persons and justice. Institutional Review Boards at institutions conducting this type of research need specific guidelines for researchers to follow in order to maintain the integrity of research. It is important for future nurse researchers to incorporate new therapeutic models and specific steps to protect the public when participating in internet research.

Key Words: internet, research, ethics, data collection

Introduction

The Internet or World Wide Web is changing the way people function on a daily basis. As of September 2010, 76% of Americans had either a laptop or desktop computer (Pew Internet American Life Project, 2010). Smith (2011) identifies that 35% of Americans own a smart phone in a study conducted by the Pew Internet American Life Project. Similarly, Kim (2011) states that "by the end of 2014, one in every three Americans, or 90 million users is expected to have a tablet" (p.1). This capability to communicate with others online has opened many opportunities for a researcher to recruit study participants and to collect data (Longo, 2010). An example of this technology is tracking the progress of clients with chronic illnesses or following clients involved in longitudinal research studies (MobileActive.org, 2012). As this type of "web-based" research grows, researchers will face ethical concerns that are different from traditional research ethical issues (Denissen, Neumann & Van Zalk, 2010). The purpose of this article is to discuss the topic of internet research and the ethical issues that emerge because of this process. The review of literature will present different views of this area of research and specific

ethical concerns. The article will include strategies to address these ethical issues and the status and future directions of internet research.

Literature Review

A search on CINAHL was performed using the search terms internet, research, and ethics. The search was limited to the last 6 years and yielded 75 articles. Both full text and peer-reviewed studies with references were included. The author selected ten articles that specifically addressed the topic of ethical issues related to internet research and presented both positive and negative aspects of this type of research. Other articles came from various sources including but not limited to reference lists in the first ten articles. Articles included in this review identify ethical questions such as: How does a researcher determine if the environment is suitable for a subject to take an online survey? How can the researcher know that the data is secure and completely confidential? How will the researcher be sure that a virtual environment is safe for subjects taking an online survey? How does the researcher know that the participant is not a minor? Issues such as finding a truly representative sample, protecting the rights of participants, ensuring that subjects are giving informed-consent, as well as making sure no harm is done to the research participant are important to identify (Whitehead, 2007).

Advantages to Internet Research

The advantage of using web based research methods is having access to populations with whom opportunities to conduct research have never been attempted before (Im & Chee, 2004), but along with these opportunities come ethical problems. Nurse researcher, Ahern (2005), identifies other advantages of using the internet to conduct research. She discusses that internet research is less expensive, less time involvement, more control by the researcher, more accuracy of data collection and analysis, and the ability to provide follow up and or feedback. There are also participant advantages such as anonymity and participation in a personal environment vs. in a laboratory setting (Ahern, 2005). Researchers have used the internet to interview participants, validate instruments and reach vulnerable people as well as conducting virtual focus groups (Ahern, 2005). The organization Mobile Active (2012) discusses three new technologies used for patient or hospital type interactions. These following are startup companies that are reaching out to many areas across the globe. "*MoTech* is a program using mobile phones to connect community health workers and patients in Uganda. *Ubiqu* – a mobile tracking tool for patients with chronic disease, and *InStrat* – a personalized health alert system" (Mobile Active.org, p.1)

Dennissen et al., (2010) identified two positive aspects of performing research on the internet that include ease of data collection and reasonable cost to the investigator. If a research study requires a large sample from many different areas of the world, a researcher can do this with an internet-based survey. The cost is less than traditional studies in that the surveys do not have to be printed, and the researchers spends less time entering data into the computer. Researchers can recruit study participants via the internet vs. costly posters, flyers, or newspaper advertisements (Denissen et al. 2010). A nurse, Heifferty (2011) writes about the use of several other types of computer-mediated communication tools including listservs, blogs, chat rooms, and message

boards. These tools are convenient to use and can facilitate research if there is proper attention paid to the moral issues of observation, intervention and interaction (Heifferty, 2011).

Disadvantages to Internet Research

In an extensive literature review, Ahern (2005) identifies limitations to using the internet for research that include the following, "Lack of control over the test setting; subject recruitment bias; possible equipment problems possible increased time for creation and maintenance of user-friendly, web-based instruments; questionable decreased response rates; possible surveyor error; questionable authenticity of respondents data, limited international scope and competition for attention" (p.62). Research online allows individuals to remain anonymous (Hash & Spencer, 2009); however, how does the investigator know that the person completing the survey is the real person and not a made up persona? Another question posed is how does a researcher know that the environment is suitable for completing a survey or that the person beginning the survey is finishing the survey (Gosling, Vazire, Srivastava & John, 2004)? In order to keep minors from participating, Alessi and Martin (2010) suggest adding an item to the study asking if the participant is 18 years or older. If the participant answers no, the survey would end automatically, with future access to the survey denied (Alessi & Martin, 2010). When conducting an online study, implied consent cannot always be trusted. A suggestion made by Alessi and Martin (2010) is to provide an introductory page explaining the study in detail and then ask participants to click a box saying that they agree or consent to be a part of the study.

Watson, Jones, and Barnes (2007) discuss ethical issues related to a researcher completing a secondary analysis on pre-existing archived information. The participant is not directly involved at the time of data collection but gives permission to review the archived conversations, emails, etc. An example would be an internet support group where discussions take place among those participating from a central subscriber, listserv or email list (Suler, 2000). Although secondary data analysis from archived emails is a valuable method of data collection (Murray & Sixsmith, 2002), Shariff (1999) stresses that it is not always the ethical way to conduct research, as there may be more personal information available in an archived email than the subject would have normally revealed if they had known they were in a research study. Cooke (2008) presents a question "If we can collect vast amounts of data passively without the individual being aware of the data trail they are leaving, does that give researchers the right to use it?" (p. 570). Some researchers would answer 'yes' to this question as they view social networking sites, chatrooms, blogs, and forums as excellent locations to collect data (Nairn, 2009). Teens are especially vulnerable, as they often do not realize that potential employers and or colleges/universities are viewing social networking site information before making decisions on hiring or admission (Narin, 2009). When data is readily available, this does not give researchers the right ethically or legally to use this information without permission (Nairn, 2009). If the researcher collects data in this manner, participants need notification, and the researcher should provide a clear description of the study and the purpose intended before collecting data. The participant should provide informed consent before any data is gathered (Walstrom, 2004).

Eynon, Schroeder, and Fry (2009) identified two areas where internet research use is growing rapidly but is also creating ethical dilemmas. The first area is that of experimentation with collecting data in a virtual environment. An example of this is *Second Life*.

Second Life is a company formed in San Francisco, CA by Linden Labs in 2003. *Second Life* is a virtual world online. In this environment, users (residents) create their individual avatar (virtual self) and can interact with other avatars in a simulated 3-D environment (Beard, Wilson, Morra & Keelan, 2009). Nurses could potentially use *Second Life* when educating adolescent patients about risky sexual behaviors. An avatar (virtual teen) could be placed in a risky sexual situation that requires communication. Providing real time examples that teens are facing today during educational sessions may be more appealing to the younger, tech savvy generation than traditional education methods. The CDC has used *Second Life* as a way to collect passive research data and surveillance on health issues (Beard et al., 2009). Moreover, the CDC has a site called *CDC Island on Second Life* that has been conducting focus groups with avatars (Cassanova, 2009). It is important when doing this type of research that Institutional Review Board guidelines are closely followed; however, as Narin (2009) points out, many times it is difficult to respect the virtual respondents rights when the respondent has no idea they are in a study (Nairn, 2009).

The other area is participant observation as part of an ethnographic method of online research. In this type of data collection, there is ease of access to information, and there is an opportunity for observing an individual unobtrusively. In a virtual world there can be multiple environments providing endless possibilities for social or psychological research (Schroeder, 2006). Maher (2008) provides an ethnographic research example of immersion in a classroom environment that is using interactive online communication in the classroom. As a researcher, who has permission to access conversations with students, investigating cyberbullying or other forms of violence may lead to discovery of interventions for problems faced in schools related to this type of technology (Maher, 2008).

The question remains according to Eynon et al. (2009); can the researcher transfer virtual environments to face-to-face situations? Individuals exposed to 3-D graphical space interactions with avatars online may communicate as they would with a real individual in a traditional environment, but individuals may also take on a completely different persona depending on the circumstances surrounding their reasons for being online in this manner (Blascovich, 2002). In virtual ethnographic studies, the researcher does not have the ability to assess the mental state of the participant, and some virtual environments can be dangerous emotionally to a participant, such as an avatar witnessing a crime online. Enyon et al. (2009) stressed that "people should not be put into a position where by they treat virtual others as beyond ethical boundaries, even when the research participant will be aware that an avatar is not the same as a physical person" (p.191).   How does a researcher know that the avatar (virtual participant) of the study can mentally adapt to a difficult situation presented in a virtual environment? What if the participant is home alone and may be facing serious mental health concerns? The researcher is disadvantaged because of the physical distance from the participant. This distance makes it difficult to determine if something is amiss as opposed to a traditional environment; the investigator would be present to offer assistance at a time of distress (Eynon et al., 2009). The issue of follow up and intervention when problems arise should be a clear part of an online protocol. Researchers should be aware that causing distress to research participants has been deemed against ethical conduct (Eynon et al., 2009)

The researcher conducting participant observation must be aware that not all information in the online world is open to use in the study. For example, privacy and freedom values may vary from country to country, therefore the values on different cultures and individuals must be investigated (Fry, 2006). The researcher should treat online information in a similar manner in regards to privacy of the traditional environment. Those subjects that participate in online research studies need to be aware that researchers are monitoring their actions and personal information could ultimately end up being discussed in a public forum once the study is completed (Eynon et al., 2009). One further concern with research on the internet is that it is possible for an outside individual to trace back data collected in a research study to the person who is behind the voice or written word. At this point, the researcher is at risk for breach of confidentiality. For example, if part of an online discussion is included in a presentation of the finished research product (poster presentation or podium presentation), this could cause serious privacy violations (Eynon et al., 2009). It is important for the researcher to not only gain informed consent but to ensure that individual knows what he/she is consenting to and to also ensure that the individual is competent to give consent (Varnhagen, Gushta, Daniels, Peters, Parma, Law….. Johnson, 2005).

Practical Suggestions

Longo (2010) discusses that nurses have been conducting research studies using the internet for at least the last ten years. In a study by Im and Chee (2002), they identify the dramatic increase in using the internet to conduct research. These two nurse researchers conducted studies exploring cancer pain experiences in different genders and ethnic groups. Social workers, Alessi and Martin (2010) discuss that software designed for data collection is easy for even a novice researcher. Examples of software include Survey Monkey (www.surveymonkey.com), Zoomerang (www.zomerang.com), and Zarca (www.zarca.com). Using these methods, the

researcher can download data onto a spreadsheet format and easily convert it into a statistical program for analysis. However, it is important that when designing surveys for internet research, that the surveys are "participant friendly" and that there is a smooth functional process when completing the survey (Crawford, McCabe & Pope, 2010). As easy as it might be to use software products to collect data, this process does not come without ethical problems.

Some populations may be harder to reach due to social isolation or discrimination. An example of a group would be the gay, lesbian, bisexual and transgender individuals (GLBT) (Sullivan & Losberg, 2003). These internet populations (such as the GLBT group) are convenience samples and may contain selection bias. Kraut (2004) discusses that the problem of a biased sample with a longitudinal study. People change email addresses more often than they change cell phone numbers or street addresses, so dropout rates and nonresponse bias may be more difficult to control. Researchers should be willing to switch modes of contacting participants if this does occur (Kraut, 2004).   Therefore, the results are not generalizable to the populations that completed the surveys (Eysenbach, 2004). All researchers should consider how the population will be sampled before beginning a study and acknowledge the character of the sample thus providing information on possible bias (Sullivan & Losberg, 2003).

Longo (2010) recognizes the importance of maintaining validity and reliability when conducting internet research. Thoroughly evaluating surveys for past use is wise before moving to the online environment (Ritter, Lorig, Laurent & Matthes, 2004). One question of importance related to the ease of data collection is the variations in measurement and the reliability of the subjects completing the survey. Gosling et al. (2004) investigated common preconceptions about internet data including one preconception that internet samples are not geographically and demographically diverse. These researchers found that "using internet methods are at least as diverse as many of the samples already used in psychological research" (Gosling et al. 2004, p. 102). Furthermore, Gosling et al. (2004) study shows that using the internet is as good quality as that of paper and pencil surveys and that many preconceived conceptions are now proven to be invalid.

Strategies to address ethical issues of internet research

Im and Chee (2002) discuss three documents that need consideration when designing an internet research study. The 1978 National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research (later named the Belmont report) serves as a guide for conducting research (National Institutes of Health 2011). The International Council of Nurses Code of Ethics published in 2000 is also important to incorporate. Finally, the Health Insurance Portability and Accountability Act (HIPPA) that was developed by the Department of Health and Human Services needs to be carefully considered. Even with these documents, Im and Chee (2002) posit that there are few guidelines to protect individuals participating in internet research. Im and Chee (2002) further state that when conducting internet research, there are five specific aspects to incorporate, "They include a) anonymity or confidentiality, b) security, c) self-determination and authenticity, d) full disclosure and e) fair treatment" (p. 267). Looking back at the Belmont report as a model provides the nurse researcher and the Institutional Review Board direction in protecting participants of internet research.

Children are increasingly on the internet as seen in a study by the Pew Internet and American life project. The study showed that "66% of married–with-children households have a high–speed broad band internet connection at home" (Wellman, 2008, p.1). National and international guidelines explain that children may be enrolled in research but only if their parents or legal guardians give permission (Council for International Organizations of Medical Sciences, 2011). How can an internet researcher ensure that the parents have given consent? Including children as research subjects is something needed, but legally and ethically, it is important to know of the *Children's Online Privacy Act (COPPA)*. As of 1998, this law provides that websites cannot collect information from children under the age of 13 (O'Keefe, Clark & Pearson, 2011). Preadolescents are increasingly more apt to falsify age; for this reason, it is important for parents to be aware of this common practice and monitor sites visited while online (O'Keefe et al., 2011).

Another law is the *Child Internet Protection Act (CIPA)* implemented in 2001. This law addresses content viewed over the internet in school libraries and on school computers. Under this law, the school must block any offensive content that is obscene, shows child pornography or could be harmful to minors (Federal Communication Commission, 2001). *CIPA law* requires schools to have a policy and intervention plan to address the safety and security of minors while using electronic communication at school (Kowalski, et al. 2008). If a researcher is utilizing a school computer to collect data, he/she must have approval from the school administration and be aware of this law and the importance of blocking anything that would be harmful (Kowalski et al, 2008).

Eynon et al. (2009) suggests the use of the "human subject model" when conducting online research (p. 197). In this model, the three concepts are informed consent, anonymity, and confidentiality. It is important to recognize that not all study participants may view these rights the same way (Reidenberg, 2000). For example, adolescents who routinely put their location on facebook or twitter or discussing very personal situations online, thus are putting themselves in danger of predators that may be lurking on social network sites (O'Keeffe & Clarke, 2011). Many researchers use the human subjects' model for online research however; some researchers suggest that this model may not be the best for an online environment in regards to ethical concerns (Basset & O'Riordan, 2002). Heilferty (2011) discusses that "care must be taken with internet expression, since unique questions arise about data collection regarding ownership, copyright and selection of representative material" (p. 948). When a researcher faces an ethical problem in regards to internet research, Eynon et al. (2009) notes that he/she should look to the legal system in the jurisdiction where he/she is conducting the study. The problem with this is that if the research is global, each country may have individual protection policies that the researcher must follow.

There is an *Association of Internet Research (AOIR)* that has ethical guidelines for online research developed by members (AOIR, 2002). These guidelines are constantly changing as new technologies develop (Eynon, et al. 2009). Another organization that influences ethical guidelines for internet research is the *Economic and Social Research Council (ESRC)*. Contacting these two agencies to confirm the appropriateness of an online research study would prove beneficial (Basset & O'Riordan, 2002). Data collected online is also stored online on a larger server. Ethically it is important to notify participants that the information they

have given in an online survey will be secure, but is this foolproof? There are methods of saving data on devices such as *Iron Key* (Iron Protector.com) that is a storage device for data. This device will protect data downloaded from viewers with encrypted coding, but what about those researchers that do not use these special devices? Denissen et al. (2010) suggests that when a researcher obtains consent, the researcher should make the participant aware and provide them a way to be able to correct any personal information that may identify them.

The cost of doing a research study may be less in materials, but the researcher must be knowledgeable in internet security issues. It is possible that hackers could interfere and manipulate the data causing ethical and legal concerns (Denissen et al, 2010). Kaslow, Patterson & Gottlieb (2011) discuss that psychologists must use careful judgment when seeking information online since there are currently no ethical codes or laws to define the ability to use this information. An example of such consideration is an online study involving gay, lesbian, bisexual and transgender populations conducted by Alessi and Martin (2010). One of their concerns was the possibility of the study participants getting upset after answering questions involving sexually sensitive subjects. Even though the Institutional Review Board did not require the researchers to provide mental health support, the researchers still provided information that could lead participants to support services if the need arose.

Watson et al. (2007) has proposed a strategy to follow when conducting research on the internet particularly when using archived emails or other archived discussions. These researchers stress that it is important to consider all factors that could be relevant to ethical health research. The following show the steps for a researcher to use as a guideline in this particular type of internet research.

[Click here to See/Download Appendix for Figure 1: Decision Tree in pdf format](#)

"**Step 1 – Assess whether users consider the virtual community to be a public or**

private space. Look for an acceptable use policy, insure the policy states it is a public site, and open to those with genuine interest.

Step two – Assess membership access (to support groups). Is membership open or restricted? Does membership require a simple email request or a submission of a biography or reasons for joining?

Step three – Assess the level of intrusion. Is there intention to publish direct quotes? To what extent will the researcher interact with the group?

Step four – Assess the vulnerability of the group. What is the purpose of the group? What the nature of the discussion and is the group seeking privacy?

Step five – Assess the potential risk of harm to the participants. Minimize harm to any participants.

Step six – Assess the members. Is it a small intimate group? Is the membership stable?

Is the membership open or restricted?

Step seven – Obtain the list or support group owner's permission to use the site.

Before conducting any research, make sure that the list owner has endorsed the study.

Step eight – Consider the researchers ethical stance.

The researcher must weigh the risks /benefit ratio to participate"

(Watson et al., 2007, p.400-402).

Current and future issues in Internet Research

Watson, Jones, and Burns (2007) discuss that research via the internet is still in the early stages therefore new ethical concerns will continue to emerge. Researchers should consider ethical frameworks as the one Watson describes and continue high ethical standards as they move into this new territory of research (Thomas, 2004). If research on the internet is to continue, it is important to conduct data collection and dissemination ethically in order to have the same quality and outcomes as the traditional method of data collection and analysis. Ethical standards will help research participants to maintain trust in the integrity of each method of study (Berry, 2004). Ethical issues such as privacy in a public environment need clear guidelines. When collecting data and disseminating the results, the researcher is obligated to conduct these processes according to ethical guidelines. In addition, when working with cultures across the globe, legal and social situations need accommodation (Eynon et al. 2009).

A journal entitled *International Journal of Research Ethics* began in 2008. This journal's readership is growing rapidly as more researchers are choosing to utilize online surveys to collect data. In this journal, there is extensive discussion about the ethics of using a "bot" (automated data collection tool) and other topics such as confidentiality, privacy, and anonymity (Carlin, 2008). If a researcher is planning to conduct his/her study on the internet, it is wise to subscribe to this free open access journal as it will help the researcher to be up to date on new ideas, legal issues, technologies, and ethical problems encountered during studies done in this fashion.

Longo (2010) suggests that future studies might compare traditional pen and paper instruments to an online format to see what issues arise in subject response rates and the equivalence of the instrument format. The ethical concern of anonymity of participants has come up in the past and will continue in the future (Alessi & Martin, 2010). When a user of a particular web site enters personal information, "cookies" are formed which track this information. There are ways to disable these cookies to help ensure anonymity (Hash & Spencer, 2009). Dennisen et al. (2010) discuss that because internet based research is so popular as well as cost and time effective, it will continue in the future as technology continues to improve. If Institutional Review Boards in university settings do not establish and publish clear guidelines related to this type of research, internet research could easily be discredited (Denissen et al., 2010). There is also a need for researchers to develop theoretical models that are for internet research specifically (Denissen et al., 2010).

Heilferty (2011) found several articles that provided guidance on internet research, but there was no comprehensive conceptual model to provide direction as the technology is ever changing and does not appear to be slowing down. Two books published in the last year that address internet research are now available. Hoerger & Currell (2012) wrote Ethical Issues in Internet Research, a chapter in the *APA Handbook of Ethics in Psychology*. Fisher & Vacanti-Shova (2011) published *The Responsible Conduct of Psychological Research: An overview of ethical principles, APA ethics code standard and federal regulations*.

In summary, this article has provided information about current internet research and ethical issues related to such studies. Positive and negative aspects internet research have been addressed as well as strategies to address these specific ethical concerns such as privacy of subjects, internet research with children, working in virtual environments and online support groups, or archived emails. The author has introduced an association *(AOIR)* to assist with ethical guidelines in conducting research, and Watson, Jones, and Burns (2007) have recommended strategies for internet research. The author has discussed the future of internet research and the important ethical considerations to investigate before moving forward with this type of data collection, analysis, and dissemination to the public. These areas will continue to be in need of attention and close monitoring so that internet research has the same credibility as traditional methods.

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Author Bio:

Susan G. Williams

Susan is a Nursing PhD student at the University of Alabama in Birmingham. She is studying cyberbullying from a biobehavioral perspective and the effect this behavior has on an adolescent's mental health. She is planning to use an internet survey in a school setting to conduct her research with adolescents who have been cyberbullied. Susan is also an instructor at the University of South Alabama College of Nursing in Mobile, AL. Her PhD work is partially sponsored by the Leadership Education in Child-Health Nursing (LECHN)- Maternal Child Health Bureau – T80MC09653. Faculty advisors are Anne Turner-Henson, DSN, RN, FAAN and Marti Rice PhD, RN FAAN

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