

ONLINE SURVEY TOOLS: ETHICAL AND METHODOLOGICAL CONCERNS OF HUMAN RESEARCH ETHICS COMMITTEES

ELIZABETH A. BUCHANAN AND ERIN E. HVIKZAK
University of Wisconsin–Milwaukee

ABSTRACT: A SURVEY OF 750 UNIVERSITY HUMAN Research Ethics Boards (HRECs) in the United States revealed that Internet research protocols involving online or Web surveys are the type most often reviewed (94% of respondents), indicating the growing prevalence of this methodology for academic research. Respondents indicated that the electronic and online nature of these survey data challenges traditional research ethics principles such as consent, risk, privacy, anonymity, confidentiality, and autonomy, and adds new methodological complexities surrounding data storage, security, sampling, and survey design. Interesting discrepancies surfaced among respondents regarding strengths and weaknesses within extant guidelines, which are highlighted throughout the paper. The paper concludes with considerations and suggestions towards consistent protocol review of online surveys to ensure appropriate human subjects protections in the face of emergent electronic tools and methodologies.

KEY WORDS: Web surveys, online surveys, Internet surveys, research ethics, Internet research ethics, Institutional Review Boards

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ONLINE SURVEY PRODUCTS, ALSO KNOWN as Web or Internet surveys, and which include such products as Zoomerang, Survey Monkey, and Questionpro, have emerged over the last few years as highly convenient research tools. These tools enable researchers to create and deliver surveys to subjects/participants in a convenient, expeditious manner, and they produce results in synchronous time, so respondents and researchers can watch data results being compiled instantaneously. They have been embraced by an array of disciplines and professions as a sound way to conduct both formal scientific, survey research as well as informal questionnaires, such as customer or employee satisfaction questionnaires. Survey

research is a widely used methodology across the social sciences; it enables researchers to collect data on an array of issues surrounding the behavior, thoughts, and feelings of people or groups. The purposes of survey research include describing a population, identifying characteristics of a group, describing attributes and characteristics of research interest, explaining a phenomenon, or explaining how variables are related. Survey data can be either quantitative in nature with numeric outcomes, or qualitative with detailed narrative outcomes.

Online survey tools are characteristic of Web 2.0 services (tools and services that give users the tools to interact, edit, contribute, and socialize, such as social networking or micro-blogging) and promote a user-centered model of creation and flow of information; while software programs for data analysis, both quantitative and qualitative, have existed for many years, online survey tools push research methodology toward a very different epistemological and ontological model. Within this new model, a research ethics 2.0 (Buchanan, 2009) emerges, one that is forcing researchers and research regulators to rethink and reevaluate such fundamental research ethics issues as privacy, informed consent, ownership, recruitment, public versus private spaces, and research and scientific integrity itself. Online survey tools are indeed an easy and cost-effective way of conducting many types of survey/questionnaire research projects, as long as the methodological choice is based on sound decisions—not solely convenience and ease. Methodologies are based on assumptions that researchers hold; they are strategies researchers employ, based on the fundamental philosophies and beliefs of the researchers. Certainly, methodological decisions provide the basis of all research; research questions inform and are informed by methodological decisions. Research questions, therefore, drive our methodological choice. And, as Markham (2006) has asserted, methods are ethics—methodological choices are ethical choices. This perspective of method as ethic is important as researchers become more reliant on commercial survey tools, in which methodological, and thus, ethical, choices are embedded by and in the tools' design. This concept of methods and

ethics creates concerns for Human Research Ethics Committees (HRECs).

While we stop short of imposing methodological decisions on researchers, we are involved in decisions around how the ethics of the methods impact human subjects research. The role of the HREC is to ensure respect for persons, beneficence, and justice through such issues as study design, appropriate risks and benefits, and appropriate processes of consent and recruitment. The line between methods and research ethics can therefore blur.

Research Questions and Theoretical Implications

This paper reviews the current state of U.S.-based HRECs and their review processes around online surveys. It draws from a large-scale project underway by Buchanan & Ess (2008), which used an exploratory model to survey 750 HRECs.

The guiding research questions of this paper include:

1. What is the current state of HREC review of online research?
2. What specific ethical considerations arise in the use of online survey tools?
3. What best practices exist, or should exist, for researchers and HRECs in the use and review of online survey tools?

We propose that a more comprehensive discussion around the changing nature of research and changing ethical concerns as new types of methods are introduced will improve the ways in which we, as researchers and as research reviewers, reflect on and promote human subjects protections. Specifically, we hope this paper enlightens and informs our readers about the concerns shared among the HREC community around online survey tools and what issues should be highlighted in this type of research. Thus, the theoretical and practical implications of this research revolves around integrated research and education by first advancing an understanding of both the significant ethical issues raised in Internet research, with an emphasis on online survey tools, *and* how far HRECs, as the primary ethical gatekeepers of research in the United States, understand and seek to resolve these issues as they emerge in research proposals from across the disciplines. Further, our work around current HREC policies and procedures allows us to highlight potential deficits and thereby identify the greatest needs regarding resources necessary for ethically informed and responsible reflection, advice, and decision.

Literature Review

Discussions of ethical and methodological issues of the use of online surveys in empirical research are relatively sparse, focusing on a few key issues and not at all on the specific concerns of HRECs. Cho & LaRose (1999), Nancarrow, Bruce, & Pallister (2001), and Evans & Mathur (2005) discuss ethical and most notably privacy issues in their examinations of Web survey methodology. Cho & LaRose list physical, informational, psychological, and interactional as the types of privacy invasion that Web survey invitation recipients and respondents are most likely to feel, while Nancarrow, Bruce, & Pallister note seven “sins” researchers can commit online: excess, exposure, omission, privacy, off-loading costs, negligence, and complacency. They encourage the World Association of Opinion and Marketing Research Professionals (ESOMAR) to take these into account when considering a code of ethics on Internet research (this code has since been updated to include such provisions), and to provide technical tips and education to researchers on checking the security level of sites. Evans & Mathur (2005) state that CASRO, ESRA, and the Marketing Research Organization have in fact all updated their codes of ethics to include privacy and security issues specific to online surveys.

Some of the literature involving online surveys speaks of ethical issues only in terms of improving response rates, not necessarily protecting human subjects from risk or harm. Scriven & Smith-Ferrier (2003) briefly mention privacy, confidentiality, and anonymity concerns of respondents, the perception of survey invitations as spam or containing viruses, and the level of data security as all having a possible impact on data quality and response rates; further, measures should be taken to protect data, such as encryption. Simsek & Veiga (2001) also note that to increase both response rates and quality of data (such as responses to sensitive questions), researchers must establish trust with the respondents, provide an explanation of the purpose of the study, how a respondent is selected, how data will be used, and who will have access to it, which the authors argue should all be done in the introduction to the survey. This is in keeping with HREC protocols that include an informed consent document or information sheet. Kaye & Johnson (1999) assert that “[r]esponse rates . . . might be influenced by a general mistrust of online surveys and a reluctance to share opinions and preferences in a nontraditional environment” (p. 334), and that invitations might be perceived as spam. In addition to technical barriers and a lack of “electronic equivalents to response-stimulating efforts” (Couper, 2000, p. 474),

Couper cites privacy and confidentiality concerns as reasons for low response rates of Web surveys, especially when the survey topic is of a sensitive nature.

Other areas in the literature examining privacy, confidentiality, informed consent, and security center around the suggested steps researchers should take in carrying out online surveys. Evans & Mathur (2005) state that “clear, visible, respondent-friendly privacy policies are imperative” (p. 211) in the use of online surveys and that security concerns may be lessened by having respondents “visit secure websites rather than e-mailing surveys as attachments” (p. 211). Eysenbach & Wyatt (2002) provide respondent, survey, and investigator features that are suitable and unsuitable for Web surveys, citing respondents’ desire to avoid spam, best practices for obtaining informed consent, and the creation of a privacy statement that discloses the use of cookies and storage of data in an archive (including respondent quotations) as imperative to ethical online survey research. Gunn (2002) notes security and privacy as a concern of Web survey respondents, suggesting that the researcher provide alternate methods of returning responses (e-mail, postal mail) if there is concern. In a survey of international students at Arizona State University, Sills & Song (2002) distributed unique randomly assigned passwords to aid in achieving anonymity and security.

Noting the distinction between confidential and anonymous data is a major concern for HRECs and research regulators, though it was not explicitly mentioned in-depth in the literature. Researchers should understand clearly the possibilities for subject identification in online survey work, and be cautious when collecting any sort of sensitive data on such sites. Pro-ana (eating disorder) websites have been a major area of concern for researchers and boards; for example, Dias (2003) notes: “Because many on-line sites are openly accessible to the public, obtaining informed consent is often not done. However, care needs to be taken to exercise that the ‘fair use’ of contributions to public forums respects participants’ privacy and protects them from harm” (p. 33). Sveningsson’s (2003) recommendations for researchers concerning the continuum of public-private sites, and sensitive-nonsensitive data can assist researchers and HRECs in understanding the level of risk to subjects and participants. For example, data from medical listservs or sexually explicit data would fall in the private, sensitive quadrant, while entertainment or hobby-based data on a public newsgroup would typically fall into the public, non-sensitive quadrant. Nevertheless, this is a continuum and specific considerations must be given to each type of proposed research.

Both researchers and HRECs can use the growing literature as a guide when considering the use of and reviewing protocols involving online surveys for empirical human subjects research. Our survey of HRECs, however, indicates that education and guidance in this area is still lacking. The easy or convenient nature of these online tools brings to the fore emerging questions of electronic data security storage on third party servers, proper informed consent protocols in an anonymous or pseudonymous environment, the connections between autonomy, voluntariness, and survey design (being unable to skip questions, for example), appropriate subject verification (ensuring respondents are over 18), and guaranteeing informed consent through the use of click-box agreements on online surveys, among an array of other issues.

Method

The groundwork for the current paper, Buchanan & Ess’s National Science Foundation grant-funded study of 750 HRECs (2008), was approved by the University of Wisconsin–Milwaukee HREC under protocol approval 0702201. A waiver to document informed consent was obtained for the study. Surveys focusing on HREC review practices surrounding Internet research ethics were sent by U.S. mail to 750 U.S.-based HRECs, stratified across Carnegie classification types. Data were collected during a seven-month period from November 2007 to May 2008. Internet research was defined as research that: (a) uses the Internet to collect information, e.g., through online surveys; (b) studies how people use the Internet, e.g., through collecting and examining activities on listservs, Web sites, blogs, or other online environments; and/or (c) gathers and analyzes datasets available online. Two hundred and thirty-four responses were obtained and used as the basis of this analysis, a response rate of 31.2%. Responses were analyzed both quantitatively and qualitatively. There were also follow-up interviews with selected respondents, which served as a form of triangulation for the survey results.

In addition to the numeric data reported, three open-ended, qualitative data-generating questions were used as the basis of the current paper. Two of these questions were:

- Based on your experiences reviewing Internet research protocols, please identify common *weaknesses* you may see in proposals using Internet research methods (for instance, misunderstanding of technologies, misunderstanding of online communities, misunderstanding of federal HREC regulations).

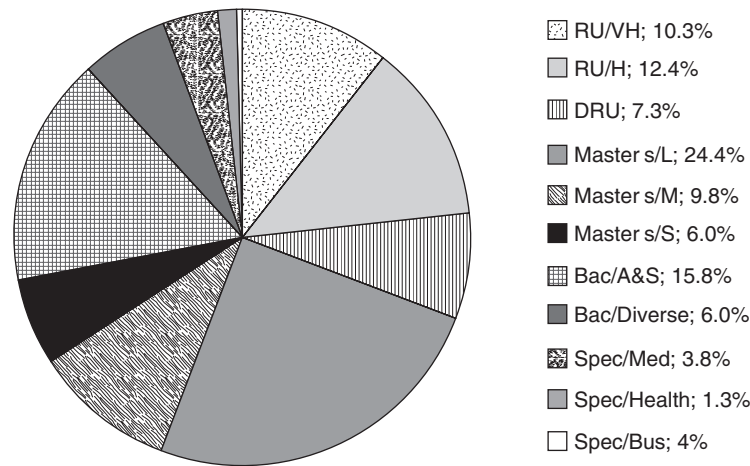


FIG. 1. Breakdown of Respondents' Institutional Carnegie Classification.

- What would you, as an HREC member or administrator, ideally like to see in a set of guidelines about Internet research ethics?

We found these questions to be most relevant in helping us to determine the ethical issues that most concerned HREC reviewers regarding online survey methodology. However, what many respondents found to be weaknesses, others found to be strengths in using this methodology. For this reason, survey-specific responses to the following question will also add to the discussion, demonstrating a wide range of perspectives and interpretation around Internet research in general, and online surveys in particular (see Tables 1–3).

- Based on your experiences reviewing Internet research protocols, please identify common *strengths* you may see in proposals using Internet research methods (for instance, attention to privacy issues, attention to security issues, attention to informed consent issues).

Results and Discussion

The majority of respondents came from Carnegie-classified Master's degree-granting institutions and Baccalaureate arts and sciences institutions, with smaller percentages coming from Doctoral research universities and research universities (Very High and High research activity), and small representation from tribal colleges and special colleges (such as business and medical institutions) (Figure 1).

The overwhelming majority (94%) of respondents to the survey stated that online survey research was the

type of Internet research reviewed most often. Respondents indicated they were typically reviewing 0–5 Internet-related research protocols per month. Of the online surveys reviewed, nearly all fell into the exempt category of review, indicating that the nature of the data was not overly sensitive nor were vulnerable populations being surveyed. One respondent elaborated on an online survey project that involved health-related data and fell under a full board review, in which not only were the standard HREC protocols taken into account, but the Health Information Protection and Portability Act (HIPPA) was a consideration. This particular institution had previously developed its own survey tool and did not rely on a commercial product, which is not the norm (Figure 2).

Still, slightly more than one-third (34.6%) of those respondents did not regard the privacy and security policies of commercial tools as part of their protocol

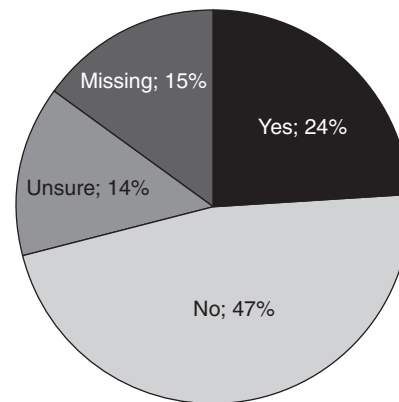


FIG. 2. Institution Has a Specific Tool to Use for Online Surveys.

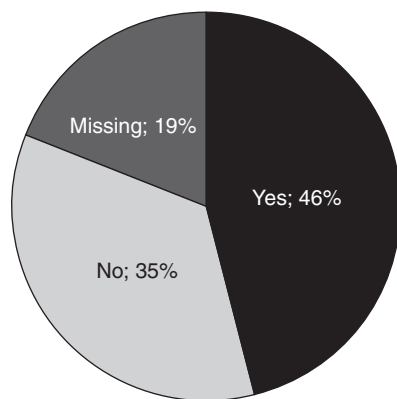


FIG. 3. Regulatory Documents Are Used in the Review of Internet Research (i.e., CFR, OHRP Decision Charts).

review process. Further, 73.9% of responding RECs did not have a designated review person to examine Internet research-based protocols. Only 4.7% of responding RECs required ethics training specific to Internet-based research for researchers, while only 19.2% required HREC members to engage in training specific to Internet research ethics. While Internet research is a concern to their RECs, (as cited by 44.4% of participants), 42.3% of respondents indicated that the regulatory documents did help in reviewing Internet research, while a significant portion did not respond to this question (20.9%) (Figure 3).

The Collaborative Institution Training Initiative (CITI, 2009) provides a module related to Internet research, and as local institutions can require CITI compliance, researchers and board members are getting exposure to the ethics of Internet research through that avenue.

In addition to these data, the qualitative data collected provided great insights to the mind-sets of responding RECs concerning online surveys. What some respondents found to be weaknesses in both Internet research-based protocols and in the use of online survey tools specifically, others found to be strengths. The relevant responses pertaining to the strengths and weakness of online survey tools were thematically coded into the following areas: Security/Storage, Anonymity/Confidentiality, Sampling, Consent, Design, HREC Regulations, Spam. With the notable exception of HREC regulations, these areas correspond to the major issues described in the literature review. Many of the long-standing principles and language that HRECs encourage their researchers to use, such as “We will store your data in a locked cabinet in an undisclosed

location for a period of ten years,” becomes less certain in the face of online storage. For some, it is a mixed blessing—data that never disappears (permanence and longevity of paper data) versus online data loss due to changing technologies and obsolescence. The ideas of privacy and identification are also diffused, with online identities and tracking now a common occurrence. One participant commented specifically on the emergence of Google and its powerful searching capabilities. A text search within Google can often point to a source, and thus a person.

Table 1 provides examples of responses indicating the mixed HREC perspectives around strengths and weaknesses in online surveys. Given the interdisciplinary nature of Internet research *and* given the local interpretations found among HRECs, there is bound to be disagreement. These disagreements are not unique to Internet research, of course, as any HREC member will acknowledge sometimes heated debates over protocol review. Nevertheless, this research demonstrated that despite starting with the common decision-making models and from the basic principles of research ethics, there is certainly subjectivity in HREC interpretation and review of online research, which is not a pejorative statement. Such interpretation is grounded in disciplinary, institutional, and historical differences in RECs and their interworkings at the local level. For instance, one board discussed a time in their recent history when rules were so strictly applied that the HREC was regarded as the “enemies on campus.” When a new administrator took over and made strides to reach out to the campus research community, the HREC was seen in a new light. As a result, this HREC operates in full compliance but evaluates itself as somewhat permissive as opposed to strict or somewhat strict in their protocol reviews. Thus, its local historical past influences its current review model.

While some respondents clearly sought specific guidelines, others found no explicit need for “rules” or guidelines beyond those that currently exist (Table 3). These comments reflect a feeling that Internet research, or online surveys in particular, are not qualitatively different from traditional forms of research. One respondent indicated that asking if the ethics of online surveys are different from traditional research ethics is not the appropriate question to ask. Instead, he/she suggested that was like comparing “apples and oranges.” Instead, this respondent encouraged us to consider how best to translate ethics from one environment to another. Notably, the Association of Internet Researchers Ethics Guidelines seek to do just that (Ess & AoIR Ethics Working Committee, 2002).

TABLE 1. Comparative Responses to Questions, Demonstrating Discrepancies in Review.

Responses presented are those *specifically* referencing online surveys.

1. Based on your experiences reviewing Internet research protocols, please identify common weaknesses you may see in proposals using Internet research methods (for instance, misunderstanding of technologies, misunderstanding of online communities, misunderstanding of federal HREC regulations).
2. Based on your experiences reviewing Internet research protocols, please identify common strengths you may see in proposals using Internet research methods (for instance, attention to privacy issues, attention to security issues, attention to informed consent issues).

Issue	Weaknesses Seen in Internet Protocols	Strengths Seen in Internet Protocols
Security/Storage	<p>"No understanding of third-party survey sites."</p> <p>"The most common weaknesses in Web-based survey research are researchers not encrypting data transfer, not understanding issues around identifiers such as IP addresses that some survey host services collect, and not explaining the data collection process in terms of where data are stored (by survey hosting service), etc."</p> <p>"Student- and faculty-written surveys need better security and privacy assurances."</p> <p>"Mostly, lack of attention to the above two points in #16 [The primary things I often see in a strong, well-written Internet research protocol include: (1) RE: Security-If the researcher sends each respondent in Internet research survey a unique link for the survey, do they have all the necessary protections in place? That is, identify: where is the server housed? Who has access to this data? How will the data be stored? How long before the data is destroyed? (2) If the researcher collects e-mail or other personally identifiable data in the Internet survey and promises confidentiality, does he or she understand that the identifiable data collection point should ideally be on a separate server? i.e., at the end of the survey when they collect data for a drawing or other incentive and must collect personal data to notify the respondent.]"</p>	<p>"Use of survey engines effectively deals with security."</p> <p>"Administrative surveys (faculty and students) have increased regarding security and privacy issues."</p> <p>"A statement about the online survey tools' security/privacy measures. Also statements from the university IT verifying that their efforts are safe and reasonable."</p> <p>"Each of the cases I have seen use some form of secure site to which participants log in and that site gives a code or they designate one that does not reveal personal names or e-mail addresses. One researcher had students use a designated computer at their convenience to log in to the survey."</p>
Questions/Survey Design	<p>"Survey Monkey and other technologies allow people to construct surveys that may not have valid question that results in statistically significant results."</p> <p>"Not allowing a participant to skip a question to move on to the next."</p> <p>"Failure to allow participants to skip questions or end participation without data being saved."</p> <p>"Lack of attention to detail when entering survey questions regarding accuracy of the question wording, punctuation, logical order. Also, a lack of understanding how to select options such as only one response possible in a Likert scale."</p> <p>"Clarity in protocol-specifically how the data is input by the ."</p> <p>respondent</p> <p>"The issues I see have to do with study design but not vis. ethics."</p>	<p>"Doing Internet surveys removes any variation due to interviewer."</p> <p>"Ease of administering surveys."</p> <p>"Easy recruitment, instant results for those who conduct the survey, nothing lost in the mail."</p> <p>"Many trees and much fuel are saved by conducting survey research this way (even as compared to a mailed survey)."</p>
Anonymity/Confidentiality Issues	<p>"Students conducting surveys and students monitoring chat rooms misunderstand that the technology prevents true anonymity of responses (misunderstanding of technologies)."</p> <p>"Further they do not understand that merely eliminating identifiers may not be sufficient to control risks. For example, we had a study proposed once for a survey to be conducted via the Internet in which medical students from our institution would indicate whether and how often they used over-the-counter or illegal stimulants or sleep aids to manage the stress of being in medical school. They indicated to us that they thought the study qualified for minimal risk review because the students were not required to give their</p>	<p>"Attention to confidentiality of responses (anonymity)-Use of Zoomerang to assure anonymity."</p> <p>"Protocols that seem least problematic use Survey Monkey with already established panels that can be offered chance to participate; which maintain anonymity, not just confidentiality; and that have an established method of compensation."</p>

(Continued)

TABLE 1. (Continued)

Issue	Weaknesses Seen in Internet Protocols	Strengths Seen in Internet Protocols
	<p>identification. They did not understand that as minor a breach of confidentiality as the release to the public that any of our medical students had answered yes to any of the questions could be compromising to us and our med. students as a class."</p>	<p>"The primary things I often see in a strong, well-written Internet research protocol include: . . . (2) If the researcher collects e-mail or other personally identifiable data in the Internet survey and promises confidentiality, does he or she understand that the identifiable data collection point should ideally be on a separate server, i.e., at the end of the survey when they collect data for a drawing or other incentive and must collect personal data to notify the respondent."</p>
	<p>"I wonder how representative a sample is obtained in anonymous surveys solicited by e-mail."</p>	<p>"Awareness of confidentiality by minimizing identifiers or sensitive data to be collected or by heaving a method to print and mail completed survey."</p>
	<p>"Anonymity, particularly when subjects must respond through e-mail (as opposed to using programs such as Survey Monkey) has become a debatable issue."</p>	<p>"All surveys have been completed anonymously."</p>
		<p>"Studies are generally anonymous or use engines that delete identifying information (Survey Monkey)."</p>
		<p>"A strength of Internet research may be related to the use of survey providers such as Survey Monkey in that they act within the role of honest broker, providing the raw data stripped of all identifiers."</p>
		<p>"The use of good survey providers can help promote anonymity."</p>
		<p>"Lots of advantages to researchers, e.g., low cost, ability to survey over broader geographical and demographic areas."</p>
Sampling/ Participants	<p>"Underage participants may complete surveys meant for adults."</p>	<p>"The only common strength is that the Internet allows the recruitment of larger numbers of subjects from any part of the country or world."</p>
Informed Consent	<p>"In proposals review, the greatest weaknesses are the following: Students conducting surveys abbreviate and oversimplify the online explanation of informed consent (trivializing federal regulations that they know well)." "We do find that naïve investigators, particularly students, are not aware of most of the above issues. There still seems to be a widespread misconception in the research community that does survey research that there is such a thing as implied consent or passive consent (that is, if you fill the survey out, you are consenting to doing it, much as your own consent implies. I am assuming that your HREC gave you a waiver of documentation of consent for this study, but that they did NOT give you permission to use 'passive' consent)."</p>	<p>"We don't have many, but . . . Informed consent (must acknowledge reading before survey appears)."</p>
HREC Regulations	<p>"Some researchers do not understand how their 'simple surveys' fall under HREC regs."</p>	<p>"Consent is similar to mail surveys."</p>
Surveys Viewed as Spam	<p>"Potential for bad 'PR' for institution, i.e., surveys viewed as spam."</p>	

TABLE 2. Responses *Specifically Referencing Online Surveys* to the Question: What would you, as an HREC member or administrator, ideally like to see in a set of guidelines about Internet research ethics?

Issue	Responses
Security/ Storage	<p>"Guidelines re: online recruitment, and re: security of 'anonymous' online survey tools."</p> <p>"There is no oversight on the use of sites such as Survey Monkey and we have not been able to determine how secure the information is on such a site. What liability does the investigator and/or institution have when such sites are used?"</p>
Questions/Survey Design	<p>"How controversial can survey questions be?"</p> <p>"How questions may need to be framed differently."</p> <p>"What is acceptable/what is not acceptable in terms of survey structure and survey; usage. I would like to see exemplars of acceptable and unacceptable surveys."</p> <p>"Guidelines on how to handle issues such as software that requires respondents to answer all items before the survey can be submitted (thus violating the participants' right to skip answering some questions)."</p>
Anonymity/ Confidentiality	<p>"Key concern is anonymity—how to construct surveys that cannot be traced."</p> <p>"Confidentiality issues concerning data collection websites, such as Survey Monkey."</p> <p>"Example policies, guidance on whether or not use of controls to remove the IP address on commercial survey instruments (i.e., the investigator does not receive identifying information) should be considered anonymous."</p>
Sampling/Participants	<p>"Guidelines for procuring e-mail addresses."</p> <p>"Verification of authenticity."</p> <p>"Verification of each responder to complete survey only once (e.g., not stuffing the ballot box!)."</p> <p>"What pitfalls to be aware of if surveying people using online survey systems."</p>
HREC Approval	<p>"Yes—are institutional approvals recommended to survey employees, students, alumnae, etc. via Internet?"</p> <p>"Is the use of engines such as Survey Monkey acceptable, especially since these sites do not make sure that the individual posting the survey has the necessary HREC approvals before accepting the survey?"</p>
General Requests for Guidance	<p>"Guidelines for . . . commercial survey companies and HREC review, investigator training."</p> <p>"A list of commonly use survey tools such as Survey Monkey or Flashlight that have been 'vetted' and approved for security and confidentiality."</p> <p>"Info about the various online survey options—students are generally more savvy than faculty and feel quite comfortable using online tools."</p> <p>"Judgments about the reliability and safety of websites and other online services and tools."</p> <p>"Listing of specific software/Internet survey tools that are acceptable with respect to guidelines."</p> <p>"Probably obvious—how do these ethics differ from, say, surveys that are handed out in a classroom or to patients in a clinic? We have reviewed two protocols to survey faculty members at chiropractic colleges about proper terminology to be used intra-professionally. Are these unique ethics issues for that situation?"</p> <p>"Highlighting any special issues involved in online research, especially surveys."</p> <p>"Discussion about Internet surveys security (Survey Monkey, etc.)."</p>

Best Practices

Research data collected with online survey tools runs the gamut on the public-private, non-sensitive-sensitive spectrum. As such, and as with any other protocol review, the "case-by-case" model works for the HREC process. Nevertheless, HRECs have worked for many years with the general best practices models designed for non-online surveys. Buchanan & Ess's ongoing data collection indicates that suggested starting points would be useful for those reviewing online survey-based research protocols.

We recommend that HRECs follow their typical review models, and include the following areas for consideration. Many of these are already basic areas to

be addressed in a research protocol, but the questions should now be extended to reflect the policies of the survey tool itself as they impact human subject protections:

1. Is the type of data considered sensitive (e.g., health, medical, sexual, political)?
2. Does the survey tool privacy policy contradict local HREC policy? If so, how will the contradictions be resolved?
3. What measures are in place to safeguard data at the site of data collection?
4. Does the survey tool company store the data on its own servers?
 - a. Where are the servers housed, e.g., are they under the purview of U.S. law and regulations?

TABLE 3. Responses to Question Indicating that HRECs Do Not See a Need for Specific Internet Research Guidelines: What would you, as an HREC member or administrator, ideally like to see in a set of guidelines about Internet research ethics?

"Biased question: phrasing assumes guides are needed. Leave it up to the individual HRECs. No guides are needed."

"I'm not certain separate guidelines are needed—especially at a small undergraduate institution."

"Existing OHSP guidelines are sufficient."

"Truly, nothing more specific than we apply to conventional studies. We assume colleagues will understand the differences between legitimate and other sites."

"Not really. Existing protocol should suffice."

"I would think such a document totally unnecessary and likely to lead to even more HREC 'Mission Creep.'"

"Not necessarily—the interpretation of federal guidelines is sufficient at the moment."

"APA seems reasonable in issues of confidentiality."

"I am not aware of the specific Internet guidelines or the need for them. I have always felt that the regulations were broad enough for all research review."

"Nothing—I honestly feel that all evaluations can be done using the guidelines currently available."

"No—this hasn't been an issue and if we did get Internet research proposals, they would be subjected to the SAE guidelines/standards we have."

"For some of the projects that can be considered 'Internet research,' it is simply a change of methods (i.e., online surveys, etc.), or sources (online database), so is not as difficult to review. However, guidelines for research that 'observes' or participates in things like online chat rooms, etc., or games would be beneficial."

"Personally, I'm not sure there needs to be a specific set of guidelines. There already exist guidelines for waiver of written documentation of consent (signed consent forms), data security and confidentiality, etc. I don't see Internet research as different from any other research with respect to federal and institutional policy (with the caveat, of course, that Internet research is usually questionnaire based, so it's obviously different from pharmaceutical, medical, etc. research)."

"I think our policy is adequate at this point. I've given up on expecting guidelines on this from the feds so we've made up our own."

"I don't see a need for special guidelines."

"Existing guidelines are adequate."

"I don't see any need for specific guidelines, especially if they come from OHRP that takes on way too much weight. This is not 'rocket science'—common sense usually works best."

- b. How long will the data be stored on the servers, and does this contradict the time frame indicated by the researcher or institutional policies?
- c. What happens to the data after the researcher completes his/her work on the survey tool? How are the data destroyed?
- d. How will cross-border data be handled if IP addresses are considered by one country to fall under privacy regulations?
- 5. Must participants/subjects furnish personally identifiable data to the survey company in order to complete the instrument for research? If so, researchers should make it clear how such data will be used, if at all.
- 6. Is the survey tool agent sending spam requests for participants or is the researcher responsible for sending requests for participation?
- 7. Does the survey company assume responsibility if data are lost or exposed during a security breach? What mechanisms are in place from the survey company to alert researchers and participants in the event of data loss or intrusion?
- 8. Does the survey tool company sell its data to third parties, and if so, how are data protected? How will

- ongoing consent be assured, if new participants are added and contacted by the survey tool agent?
- 9. Encourage researchers to work with local institutional IT departments on value-sensitive design survey tools (J. Watt, personal communication, April 3, 2009).

In addition to these considerations, some HRECs find the following directives useful for other forms of Internet research:

- 1. State whether the Internet site is considered public or private space. State whether you have obtained permission from the list owner or administrator to recruit subjects from, or post messages on the site. Researchers shall also obtain permission to use archived data from a list or site. (Permission may be verified by an e-mail from the list owner or administrator, and a copy should be included in your protocol.)
- 2. Inform the subjects that there is no completely secure interaction online. The following statement must be inserted into the informed consent document, as it relates to keeping collected data confidential and the risk/benefit of participation in the study: "As an

- online participant in this research, there is always the risk of intrusion by outside agents, i.e., hacking, and therefore the possibility of being identified.”
3. The protocol will describe how subjects will be identified in written reports, whether by use of their screen names or pseudonyms.
 4. The researcher should ensure that the data and identifiers shall be kept on different servers.
 5. Researchers shall provide a forum for participants to ask questions online before consenting to participate in a research project.
 6. Ensure that the commercial online survey agent does not send “spam” requests for participation.

Research Agenda

With the myriad forms of online research and the continuing changes poised in and through technologies and research, online research ethics will only continue to present future research and practice opportunities. Specifically, in the realm of online surveys, we suggest a more value-conscious design. For instance, James Watt, Director of the Rensselaer Polytechnic Institute’s Social and Behavioral Research Laboratory, recommends an “open-source model for an Internet survey research tool that would remove the reliance on commercial tools with their inherent dangers and would also give academic researchers a full set of questionnaire design tools that would allow them to create ways of eliciting information from research participants that go beyond the very elementary current norm. There are ways to explicitly deal with issues of data security, identity, and permission that could be made nearly invisible to the researcher (or at least a whole lot easier than they now are)” (J. Watt, personal communication, April 3, 2009).

The idea of research for the public good, or the democratization of research, should be our goal. Watt’s open-source model is one example of research transparency, and works towards this democratization of research. Transparent research methods and methodologies are antithetical to proprietary methods embedded in current online survey tools and methods, as more researchers and ethicists express concern around commercial data collection and storage or what Buchanan (in press) has called “the outsourcing of research.”

In addition, as more cross-cultural, trans-border research is conducted online, differences in data security and privacy must be addressed. For instance, if a researcher is conducting an online survey in the U.S. and in Europe, E.U. data protection laws consider IP addresses as personally identifiable data, while the U.S.

has not embraced this perspective. In the United States, IP addresses typically fall outside of the definition of “personal information.” Notably, Peter Scharr, Germany’s data protection commissioner, caused strong reaction among such search engines as Google and Yahoo with his statement in early 2008 that an IP address “*has* to be regarded as personal data” (quoted in White [2008], emphasis added; see also Buchanan, in press). IP addresses were cited as an issue of concern throughout Buchanan and Ess’s research, as researchers disagree on the potential risk of identification through IP addresses. Such research as transaction log analysis is rarely, if ever, considered human subjects research, but researchers and HREC members are growing in awareness of the use of such data if the information connected to the IP addresses is of a sensitive nature. Encryption of such data is highly recommended for researchers, especially those collecting or using sensitive private information.

Until each tool is vetted and its privacy policies and data security policies understood, we cannot be 100% certain how security, consent, and privacy are instantiated within the individual tools. We can use best practices and local standards to ascertain the level of potential risks and benefits, and therefore offer the best protections possible within a given protocol.

Educational Implications

Not only do HRECs need continuing education to keep up with the emergent technologies and the nuanced ethical issues presented by and through them, but also the next generation of researchers must consider and practice a transformative research ethics, in which we explore and embrace room for difference in extant models of research ethics and review. Transformative research, and by extension transformative research ethics, crosses boundaries of discipline, locale, and ideology, and creates new opportunities and new perspectives on the research enterprise. As online research assumes more prominence, we suggest that an understanding and appreciation of online research ethics in research methods courses be prioritized. This crosses disciplinary boundaries. The Internet research ethics literature provides basic starting points for methodological and ethical considerations:

[Y]ou should collect data for one specific and legitimate purpose and . . . [it] should be guarded against any form of misuse, loss, disclosure, unauthorized access, and similar risks. People should know about which personal data are stored and used and should

have access to them. . . . Anonymity of the participants should be guaranteed and maintained during the research and in using the material. People should know that a researcher records their chats. This also means that simply lurking (reading and copying chatroom exchanges) is not legitimate. There are several forms of “netiquettes” for the different areas of Internet research, and researchers should know them and act according to them. (Flick, 2009, p. 279)

Knowing the etiquette of a specific Internet locale and the norms and philosophies of the specific Internet community, along with the requisite human subjects principles, moves researchers and HRECs to what Ess (2007), among others, has called “good Samaritan ethics,” or the response to go above and beyond the letter of the law, representing a push towards “harmony and resonance” (p. 3).

We thus conclude with this concept of harmony and resonance. HREC review is not an easy task. HREC members work in the intersections of researchers, federal regulation, local institutional policy, and a continually shifting research landscape, so the topic of this paper, online surveys, is but one realm of complexity. HRECs will continue to face emergent ethical and methodological decisions. We hope our research provides a common ground, a starting point for future discussions, and that we can continue these discussions with collegiality and collaboration.

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Author Note

Address correspondence to: Elizabeth A. Buchanan, Center for Information Policy Research, University of Wisconsin–Milwaukee, P.O. Box 413, Milwaukee, Wisconsin, USA 53202. Phone: 414-229-3973; Fax: 414-229-6699; E-MAIL: eliz1679@uwm.edu.

Authors' Biographical Sketches

Elizabeth A. Buchanan is Director of the Center for Information Policy Research, and Associate Professor in the School of Information Studies at University of Wisconsin–Milwaukee. She was a Visiting Fellow at the Oxford e-Research Center, 2008–2009, and is Chair of the Association of Internet Researchers Ethics Working Group and Co-Director of the International Society for Ethics and Information Technology. She teaches in the areas of information ethics, intellectual freedom, and research methods, and serves on an Institutional Review Board at the Medical College of Wisconsin.

Erin E. Hvizdak is a Master of Library and Information Science candidate at University of Wisconsin–Milwaukee and a graduate research assistant at the Center for Information Policy Research (CIPR). She presented on the topic of online survey research at the Association of Internet Researchers annual conference in Copenhagen, Denmark, and is currently a fellow in the International Society of Ethics and Information Technology (INSEIT), through which she is researching human research ethics in the computer sciences.

Author Contributions. Each author contributed equally to this paper.

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