Internet Research Ethics: Past, Present, and Future

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Introduction and Background

What would the early visionaries of the Internet, or its earlier manifestations, who saw these virtual networks as a participatory goldmine for research collaboration and conduct, say today about Internet-based research? Would they have imagined such diversity, such potential, such debate, as has emerged around the forms of online datasets, knowledge reuse databases, virtual communities, listservs, blogs, social networking sites, and any of the yet to be determined technologies, tools, or venues? And, would they themselves be surprised with the depth and breadth of ethical conundrums, debates, and conflicts that have emerged from the use of the Internet as a vehicle for, or site of, research activities? Would they explain to the writers of, for instance, The Belmont Report, that the Internet was not conceived as a field of human subjects research? Or, would they suggest that this "thing," the Internet, has the potential to change human subjects research as we have known it for some time, and across locales, embraced, formalized, codified, and regulated it? And, let's ask how the users of these networks imagine themselves in this research debate. As the lines, the boundaries between and among participants, subjects, objects, creators, owners, borrowers, voyeurs, and researchers are disrupted, potentially becoming unrecognizable, (how) are research and research ethics changing? Ultimately, the Internet, broadly conceived, has the potential to fundamentally disturb extant models of human subjects research. Given that ethical guidelines for Internet research have been articulated, and established (e.g., AoIR, 2002; NESH, 2003), there indeed may be a "research ethics" 2.0 emerging. This concept, research ethics 2.0, allows us to think holistically and evolutionarily about the meeting of research methods, ethics, and technologies in general, and Internet, or online, technologies in particular, which will be the focus of this chapter.

In order to get to the current dialogue of Internet research ethics, it is important to contextualize the discussion in the larger framework of research ethics, which, as a strict discipline, has a relatively brief history. The modern traditions of codified, formalized research ethics stem from the Nuremburg Code, released in 1947 as a response to atrocities committed in the name of research during World War Two ([1947] 1949). From the Code, the concept of informed consent of subjects or participants emerged as a basic premise of medical or biomedical research. The World Medical Association's Declaration of Helsinki (first adopted in 1964), which followed the Code, included the concept of informed consent along with broader notions of human dignity and safety. Both the Nuremburg Code and the Declaration of Helsinki were strongly grounded in the medical/biomedical perspectives, while the 1948 United Nations Declaration of Human Rights spoke to a range of basic rights beyond research specificity. Nevertheless, the UN Declaration shares in common with codified research ethics a commitment to basic rights of autonomy, protection, safety, and knowledge.

In the United States, research violations of human rights of dignity and autonomy became well known through the Tuskegee experiments, which began in 1930 and lasted for 42 years. Such ethical issues as deception, respect for persons, and disclosure were raised along research lines. One major debate that emerged specifically out of the Tuskegee experiments is the balance between individual harms and greater scientific knowledge, the latter of which was used as a rationale for the conduct of the research. This debate between the greater good of the individual versus the societal underscores the diverse consequentialist and nonconsequentialist ethical approaches to research ethics. As Israel and Hay (2006) describe them,

consequentialist approaches see the judgement of acts as ethical or not on the basis of the consequences of those acts. Deontological approaches suggest that our evaluation of moral behaviour requires consideration of matters other than the ends produced by people's actions and behaviours . . . Consequentialism exhorts us to promote the good; the latter to exemplify it. (2006, p. 16)

The United States issued formal regulations protecting human subjects in medical and biomedical research in 1974 in the National Research Act; the creation of institutional review boards (IRBs) ensued, and the highly influential National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research was formed. In 1979, *The Belmont Report* was released, and as a policy statement to this day remains the single most important document to use as an ethical base for subject research. It identified three basic ethical principles on which research must be reviewed: respect for persons, beneficence, and justice. Respect for persons is articulated through the informed consent process, and

incorporates at least two ethical convictions: first, that individuals should be treated as autonomous agents, and second, that persons with diminished autonomy are entitled to protection. The principle of respect for persons thus divides into two separate moral requirements: the requirement to acknowledge autonomy and the requirement to protect those with diminished autonomy. (n.p.)

Beneficence entails the concept that

Persons are treated in an ethical manner not only by respecting their decisions and protecting them from harm, but also by making efforts to secure their well-being. Such treatment falls under the principle of beneficence. The term "beneficence" is often understood to cover acts of kindness or charity that go beyond strict obligation. In this document, beneficence is understood in a stronger sense, as an obligation. Two general rules have been formulated as complementary expressions of beneficent actions in this sense: (1) do no harm and (2) maximize possible benefits and minimize possible harms. (n.p.)

Justice, the third basic principle, plays out in research ethics in terms of participation and the fair distribution of risks and benefits. Moreover, using certain selected groups as subjects of research raises questions about justice; specific populations are designated as "vulnerable," and include, for example, children, prisoners, mentally ill or challenged, and pregnant women. Increasingly, students (over the age of 18) are being considered by some boards to fall into this realm as well to avoid higher education researchers tapping into their classes too often and, potentially, inappropriately. Ultimately, as *The Report* asserts,

An injustice occurs when some benefit to which a person is entitled is denied without good reason or when some burden is imposed unduly... There are several widely accepted formulations of just ways to distribute burdens and benefits. Each formulation mentions some relevant property on the basis of which burdens and benefits should be distributed. These formulations are (1) to each person an equal share, (2) to each person according to individual need, (3) to each person according to individual effort, (4) to each person according to societal contribution, and (5) to each person according to merit. (n.p.)

Similar statements, using analogous principles of respect for persons, beneficence, and justice, emerged out of Canada in the late 1970s, policies which since 1994 are embedded under the Tri-Council Policy Statement's Ethical Conduct for Research Involving Humans. Various European Union directives, as well as individual nations' policies, ground human subjects work, including the EU Data Privacy Protection Acts (Directive 95/46/EC, 1995, Directive 2006/24/EC, 2006), the Norwegian research codes (NESH, 2003), and the UK's NHS National Research Ethics Service and the Research Ethics Framework of the Economic and Social Research Council (ESRC) General Guidelines. Since the 1960s, Australian research ethics programs are governed under the National Health and Medical Research Council's Statement on Human Experimentation, with social and behavioral research added to the policy statement in 1986 (NHMRC, 2007). Research ethics committees (RECs) in African countries have a varied existence. In South Africa, for example, RECs date to 1966, at the University of the Witwatersrand (Moodely & Myer, 2007), while other African countries are still working on training and development of formal programs. India adopted its set of medical ethics guidelines in 1980, in its "Indian Council of Medical Research," recently revised and updated in 2000. Also, in 1998, there was a great push for greater ethical awareness and codification of ethics principles for social sciences. In January 2000, the Forum for Ethical Review Committees in Asia and the Western Pacific (FERCAP) was established. While these examples do not constitute a comprehensive review, we can see that formalized research ethics programs range in maturity across the globe.

Indeed, the application of strict medical or biomedical principles to social and behavioral research is itself more recent. In their seminal work, Tom Beauchamp and James Childress (1982) provided a thorough discussion of the applicability of medical/biomedical principles in social science research, and, from then on, researchers from disparate non-medical disciplines have done everything from critiquing, lamenting, grudgingly embracing, to outright rejecting such models. For example, Joan Siebert, Stuart Plattner, and Philip Rubin describe the situation as it has played out in the United States:

The biomedical focus of the regulations has always posed problems for social scientists since biomedical (especially clinical) research requires standards that are often inappropriate for social and behavioral research. Although these problems existed in the 1970s through the 1990s, it seems that more flexibility prevailed during these years. IRBs tended to interpret the regulations in ways that were not unduly restrictive of social and behavioral research. (2002, p. 2)

And, moreover, in 2005, in light of ethics reviews of social and behavioral research, some have suggested that ethics boards are suffering from "mission creep," extending reviews into unnecessary terrains:

We recommend focusing on those areas of research that pose the greatest risk, such as biomedical research, while removing or reducing scrutiny of many fields within the social sciences and humanities that pose minimal risk. Some fields, such as journalism and ethnography, and methods, such as oral history, have their own, well-established sets of ethical guidelines and appeal procedures. In addition, they pose virtually no risk to the subjects. (Center for Advanced Study, 2005, n.p.)

Such mission creep became a very public scholarly and policy discussion, as the American Historical Association (AHA) and the Oral History Association (OHA) worked to remove IRB review of oral history research, citing the profession's "long and unhappy experience with the way these policies have been implemented," and concluding "that IRB oversight is in conflict with the essential canons of our practice" (AHA, 2008, n.p). A major issue revolved around the Office for Human Research Protections (OHRP) definition of "human subjects," and the AHA and OHA argued clearly and soundly why oral history as a method *and* practice failed to meet the conditions of OHRP's definition. In consideration of the oral history decision, it is important to recall what an ethics board's functions are. Research ethics are operationalized by their institutional committees, known in various acronyms

as IRBs, ERBs (Ethics Review Boards), or RECs (Research Ethics Committees). Based on their defining guidelines and principles, such review boards are charged with three primary tasks:

- 1 To ensure that adequate informed consent is in place within all research protocols, in order to educate potential subjects about the nature of the proposed research, their rights as research subjects, and the potential risks in order to further respect autonomy and free choice as a research subject.
- 2 To ensure that the risks of research are minimized to the extent possible, and are justified relative to the value of the knowledge to be gained from research. Related to this, the IRB should ensure that the proposed research has scientific merit, so that potential subjects are not exposed to risk for no valuable purpose.
- 3 To ensure that the proposed research is consistent with principles of justice, so that particular segments of the population are not selected to bear the burdens of research while other segments reap the benefits; and conversely, that particular segments of the population are not unjustifiably excluded from participation in research (see, for more discussion, Gallin & Ognibene, 2007).

To those ends, which are indeed appropriate and fair when executed properly, and transnationally, ethics review boards function quite similarly, though their philosophical perspectives will differ. For instance, Buchanan and Ess (2008, p. 276) discuss the differences between Anglo-American-oriented ethics reviews and other EU models:

US (and UK) codes characteristically justify research on the basis of its anticipated outcomes – i.e., as these promise to benefit society at large in some way – thereby requiring researchers only to *minimize, not eliminate, risks to research subjects*... Moreover, the research ethics of countries such as Norway can be accurately characterized as deontological, as they emphasize that the rights of human subjects must never be compromised, no matter the potential benefits (NESH, 2003, 2006). Indeed, this contrast between more utilitarian Anglo-American approaches and more deontological European approaches has been noted by earlier researchers.

While ethics boards worldwide will find common ground within the traditional discourse of research ethics, as articulated in the three aforementioned principles (respect for persons, beneficence, and justice), even in the face of disparate research methods, disciplinary perspectives and norms, and professional codes of ethics, they now face another set of methodological, and thus ethical, challenges: Internet-based research, which at once contests methodologies, ethics, and the application of "rules" to researchers and researched. The concept of ethical pluralism, described below, is emerging as a core framework and philosophical approach from which to conceptualize Internet research ethics. First used as a framework for the Association of Internet Researchers (AoIR) *Ethical Decision Making* document (2002), it stresses the importance of shared ethical norms coexisting alongside distinct cultural (and methodological) difference (see Ess, 2007).

Enter the Internets

Research has been long been conducted on or about early "populations" of Internet users - for example, Usenet studies and early studies of computer-mediated communication - though these were often not considered "human subjects" research. But, there have been a few "notorious" examples of early online research ethics, or violations thereof, which will help us to discuss the field today: first, a telling incident from Carnegie Mellon's infamous Rimm study in the mid-1990s, followed by Dibble's account of "rape in cyberspace" (1993), and Van Gelder's (1985) report of deception of physically handicapped women online and the psychologist who pretended to be one of them. Countless other examples could be included, from the many researchers who were first members of online communities prior to their research role and the subsequent reactions to their presences (eg, Walstrom, 2004; Baker, 2009) to discussions by Stern (2004) and Bober (2004) of online research with minors and the emotional, and methodological, tolls such research can exert, to AOL's mass data dump (Barbaro & Zeller, 2006), to "special" online populations and issues, such as pro-anorexic/pro-eatingdisorder websites, which pose unique ethical quandaries (eg, Dias, 2003; Walstrom, 2004), research on medical conditions (eg, Clark & Sharf, 2007; Dyer, 2001), sexual relationships (eg, Mustanski, 2001; Whitty, Baker, & Inman, 2007), and so on. Ultimately, the field of online research ethics is continually redefined by and defining the ethical challenges researchers experience daily vis-à-vis Internet environments and technologies. Regularly, ethics boards, researchers, and online participants experience highly challenging ethical dilemmas as we see in the following.

Setting the stage

Martin Rimm, an undergraduate student, used the "information superhighway" to investigate access to various types of pornographic images, creating a typology of porn and its viewers. At its core, the case was about research ethics as much as pornography, though it became widely known for the latter. Research misconduct was found, while the university's report of the research included the following statements:

The nature of this research has made this inquiry complex. The research pertained to human sexuality, a topic that is emotionally and politically explosive. As a result of the human, social and political implications of the work, it would be given special scrutiny and held to high standards of scientific integrity. At the same time, the *research concerned interactions on computer networks, a relatively new domain where research standards and university policy have not been fully discussed and debated.* (They should be.) Because of this context, and although a few of the problems are easily categorized as "serious" or "not serious," many of the allegations fall into a gray area. (CMU, 1995, emphasis added)

89

Ultimately, this case showed a growing uncertainty around human subjects models and Internet research. According to the Carnegie Mellon report, the research included a database

which showed the log files from 1994 of one BBS [bulletin board system] pornographic service. The fields included name, telephone number, address, driver's license, age, dates and times which pictures had been downloaded . . . In addition to that dataset, Martin Rimm also obtained another set of log files from a different BBS operator, described by Martin Rimm as a friend. This friend obtained further log files of customer-level information from friends who were in the same business. (CMU, 1995)

This one case raises issues of consent, access, privacy, anonymity and identification, researcher integrity, misuse of data by researchers, representation, limits of "public" and "private" data, and ownership of data. Moreover, while this case allows us to think directly about discrete research ethics issues, it forces us to consider the parameters of human subjects research in these emergent, Internetbased realities.

While the Rimm study raised questions of online researcher ethics, we can look to another incident from 1993, the well-known "rape in cyberspace," as Julian Dibble reported it, as a case of online *participant* ethics. The virtual assault, taking place in a MUD (multi-user dungeon), LambdaMoo, resulted in online outrage, but, more than that, it showed how emotion, harms, victimization, and harassment were indeed experienced in and by online communities. Far from being detached, the experiential power of online speech as it impacts participants gave researchers much to think about in terms of methods and ethics; far from being only a representation, this was a reality, with direct human implications, and the effects of the event showed that words and dialogue online could not be separated from real-world harms. As such, this incident was seminal in pushing the boundaries of online experiences into human subjects research: as online/offline realities are diminished as more of our everyday lives exist in some interconnected fashion between or across the two, this case forces us to delve beyond the simplistic dyad of online versus offline and into a more fluid sphere. Within the developed world, at least, the concepts of "being online" and "being offline" are anachronistic as we embrace the ultraconnectivity of our present technological existences, and thus blur research boundaries and binaries. Dibble's subsequent writing on the incident pushed researchers to reconsider the narratives emerging from online research how are identities represented, retold? And, what should researchers do to protect identities in online research? Thus, from the rape incident, the "annihilation" of an online character emphasized to researchers the great importance of online identities, an issue which has continued to garner attention and debate among scholars (see, for example, Lawson, 2004; Reid, 1996; Roberts, Smith, & Pollock, 2004, St Amant, 2004).

Finally, there was Van Gelder's account, originally published in 1985, of Alex/ Joan, a male psychologist who, posing as a woman, befriended handicapped women in a Compuserve BBS. Using a form of deception research, Alex posed as Joan, who shared in the trials and tribulations of an online community. Deep friendships were made, trust built, until the online realities presented by Joan were questioned (p. 534).

Thus it was a huge shock early this year when, through a complicated series of events, Joan was revealed as being not disabled at all. More to the point, in fact, Joan was not a woman. She was really a man we'll call Alex – a prominent New York psychiatrist in his early fifties who was engaged in a bizarre, all-consuming experiment to see what it felt like to be female, and to experience the intimacy of female friendship.

Even those who barely knew Joan felt implicated – and somehow betrayed – by Alex's deception. Many of us online like to believe that we're a utopian community of the future, and Alex's experiment proved to us that technology is no shield against deceit. We lost our innocence, if not our faith.

Joan, like Mr Bungle as described by Dibble, was "outed" by the online community: Van Gelder's account, like Dibble's, raised serious issues of identity, pseudonymity, truth, and rights of participants, as we explore below, while it pushed the normative questions of what researchers *should* do as researchers in online environments, including, and in particular, in forms of deception research. Interestingly, many years later, despite the unique challenges of using deception in online environments, Skitka and Sargis (2006) found that the methodology is actually a common occurrence across psychological research online. (For a fascinating reinterpretation of the Milgram experiment, which brought deception research out very publically, see Slater and colleagues (2006), in which humans interact with onscreen avatars, inflicting "shocks" to examine how the infamous experiment unfolds in light of virtual reality. Among other significant results, this virtual experiment suggested that while the participants certainly comprehended the distinctions of "real" humans versus avatars, there was a significant feeling of ethical sensitivity for the avatars.)

Using these incidents as examples, we can explore how researchers from diverse disciplines think through media and methods, and, as such, think through ethics (or, in the Rimm and Van Gelder cases, *fail* to think through ethics). Historically, then, we can situate the emergence of this sub-discipline of research ethics, Internet research ethics (IRE), in the early 1990s. IRE is defined as the analysis of ethical issues and application of research ethics principles as they pertain to research conducted on and in the Internet. Internet-based research, broadly defined, is research which utilizes the Internet to collect information through an online tool, such as an online survey; studies about how people use the Internet, e.g., through collecting data and/or examining activities in or on any online environments; and/or, uses of online datasets or databases.

If Rimm was infamous for ignoring the ethical issues raised in and by research conducted online, Dibble's *Rape in Cyberspace*, Turkle's *Life on the Screen* (1995) and Markham's *Life Online* (1998), showed the potential for deeper engagement

with the realities of conducting – and participating in – Internet-based research, as they brought the "human" aspect, and more specifically, the reality of human harm, to the fore of online realities, including, and especially in, research activities. The "virtual field" was exposed, and its inhabitants became "subjects." There was much to explore, and many methodological ways of doing so. This was confirmed in 1996, in a watershed issue of *The Information Society*, when a range of international and cross-disciplinary scholars addressed directly the meeting of ethics and online research, calling into question the applicability and appropriateness of extant ethical guidelines, notably, human subjects protections models as articulated in the US in particular, for emerging forms of online research. Scholarly interest was piqued, and subsequent work followed in the landmark meeting and report of the American Association for the Advancement of Science (AAAS); Frankel and Siang asserted in 1999 in order to "both protect human subjects and promote innovative and scientifically sound research, it is important to consider the ethical, legal, and technical issues associated with this burgeoning area of research" (p. 2). Frankel and Siang based their approach on traditional research ethics principles of respect for persons, beneficence, and justice. Following Frankel and Siang, in 2000, the AoIR formed an Ethics Working Group, which put together a foundational set of ethical guidelines for online research (AoIR, 2002). Theirs was the first international and interdisciplinary framework to emerge, and articulated disparate ethical traditions and the ways such traditions inform researchers. It built on the aforementioned long-standing human subjects models, while considering a host of disciplines and new media that challenge any direct application of such models to online environments; the rationale behind the guidelines is stated:

The Internet has opened up a wide range of new ways to examine human inter/ actions in new contexts, and from a variety of disciplinary and interdisciplinary approaches. As in its offline counterpart, online research also raises critical issues of risk and safety to the human subject. Hence, online researchers may encounter conflicts between the requirements of research and its possible benefits, on the one hand, and human subjects' rights to and *expectations* of autonomy, privacy, informed consent, etc. (AoIR, 2002)

Importantly, the AoIR document stresses the plurality of ways in which ethical decisions can be made, depending on the approaches or traditions used to frame and analyze an issue, and, it emphasizes cultural difference in human subjects models and approaches to how research ethics are to be regulated (if at all).

Following in 2003 and 2004, three major books (Buchanan, 2004; Johns, Chen, & Hall 2004; Thorseth, 2003) were published on Internet research ethics, and each delved deeper into the array of ethical issues outlined by Frankel and Siang, and AoIR, and built on the development of IRE as a discrete field, with its own evolving research base. While those texts were inter- and cross-disciplinary perspectives on IRE, the discipline-specific guidelines of the American Psychological

Association's report from the Board of Scientific Affairs' Advisory Group on the Conduct of Research on the Internet were also released in 2004. Kraut et al. argued that while Internet research is not inherently more risky than traditional forms of research, the risks and safeguards will be different for psychological research. Then, two Internet-research specific journals appeared: 2006 saw the first publication of the *International Journal of Internet Science*, which emphasizes "empirical findings, methodology, and theory of social and behavioral science concerning the Internet and its implications for individuals, social groups, organizations, and society" (*International Journal of Internet Research Ethics* was released, dedicated to exploring "cross-disciplinary, cross-cultural research on Internet Research Ethics. All disciplinary perspectives, from those in the arts and humanities, to the social, behavioral, and biomedical sciences, are reflected" (*International Journal of Internet Research Ethics*, 2008).

Thus, scholarly interest in the Internet has become clearly evident, with the research base around "Internet studies" bridging disciplines and locales. Methodological diversity - and with it, ethical pluralism, what AoIR (2002) and Ess (2006) describe as an acceptance of more than one judgment regarding the interpretation and application of a shared ethical norm - abounds in Internet studies. A continuum of online research is emerging, where on one extreme, the "human" in the human subjects aspect of the research, is not at any risk, and the research is, perhaps, not human subjects based at all, as is the case in discourse or content analyses of Internet materials, to authentic human subjects work, where lives can be affected, risks and benefits must be calculated, and individual identities must be strongly protected. Specific research methods range widely along a continuum. At one extreme we have analyses of datasets, aggregated and decontextualized, merely representing some facet of experience, devoid of connection with individual people (though the 2008 Facebook dataset release and subsequent identification reveals that researchers must exercise great caution when making datasets and code books publically available; see, for example, Zimmer, 2008a). Further along the continuum there is the use of online surveys, in which a range of ethical issues can be found, sometimes to the surprise of the researcher and researched, for instance, where individuals may or may not be readily identifiable, and where data may or may not be in the full control of the researcher, depending on the tool (see Buchanan & Hvizdak, 2009). Toward the other end of the continuum we have participant observations of lists and the people who inhabit them, and complex, in-depth ethnographies of people and their communities online, with the potential to harm individuals if their real-life (or onscreen-life) identities were exposed (see Baker, 2009; Walstrom, 2004).

Researchers from all disciplines may find themselves along this continuum: Methodological choices inform and are informed by ethical issues, as Annette Markham (1998, 2006) has long argued convincingly, while the topics of research themselves vary from non-sensitive (entertainment, for example) to highly sensitive (eating disorders, health), thereby adding another dimension to the ethical complexity of research online. Thus, we must consider the ethics of the methodological choices as well as the ethics of research questions and/or problems in determining how we evaluate and respond to the myriad ethical issues in online research. These issues abound, ranging from questions around privacy, consent, representation, attribution, authorship, plagiarism, redefinitions of personal and public, to legal issues, including copyright, libel, defamation, and harms. All of these have been explored extensively across the literature in descriptive ways, and normative discussions have emerged across disciplines (see, for example, the IRE bibliographies at the Internet Research Ethics Clearinghouse, 2008).

Academic disciplines from arts and humanities, to social sciences, to medical and health-related disciplines are all represented in the IRE literature, though Buchanan and Ess (2008) have found that in the US, ethics boards review online research primarily from the social sciences, followed by medical/health. Moreover, bibliometric counts of scholarly articles reveal increasing numbers of articles addressing Internet ethics issues across all disciplines (Buchanan & Hvizdak, in progress), while IRBs in the United States are reporting increasing interest and/or concern around Internet-based research protocols in general (Buchanan & Ess, 2008). To some extent, varying disciplines, in their own methodological fashion, engage with these and other potential ethical issues on their own unique disciplinary terms; with methods guiding ethics, these disparate issues are often challenging to define in absolute terms. In short, when dealing with Internet research ethics debates, definitive "answers" are often elusive. Ethics boards in particular must make *judgments* around research ethics issues, and there is a large degree of subjectivity involved when the issue or problem in question is not well "codified." Bringing the ethics review process to a highly transparent level holds potential for much richer dialogues around ethical issues, and removes a great deal of the confusions which emerge around research review. Especially because Internet research changes amazingly quickly, codification of general principles and their application to specific issues is quite difficult. This means that judgment concerning a given set of issues or contexts - specifically as ethical pluralism enables such judgments to vary in ways appropriate to local contexts and specific details - becomes an especially crucial component of our approach to IRE.

To this end, we will discuss discrete research ethics issues as they exist across Internet venues. This range of venues is expansive. In 2002, Ess and AoIR identified such venues as homepages, blogs, search engine searches, email (personal email exchanges), listservs (exchanges and archives), Usenet newsgroups, ICQ/IM (text-based), iChat, CUSeeMe and other audio-video exchanges, chat rooms including Internet relay chat (IRC), multiple-user domains (MUDs) and object-oriented MUDs (MOOs), gaming, images and other forms of multimedia presentation (webcams, etc.), and (some forms of) computer-supported cooperative work systems. Since the AoIR *Ethical Decision Making* document, Web 2.0 has produced more interactive forums, such as social networking sites and hyper-blogging, which are producing their own emergent normative zones of research ethics. This chapter will conclude with a discussion around those issues.

Ethical Considerations

Public/private

Traditionally, the IRE literature has been highly concerned with privacy issues, as it is a prominent concern for ethics boards, and, as our examples earlier revealed, the relationship between public and private online plays out in complex ways. Sveningsson (2004) provides some clarity, by suggesting that

if the medium is public and the information shared is not sensitive, we might conclude that it is acceptable to make exceptions as for ethical requirements. If, on the other hand, the medium is public and the information is sensitive, we might have to be more careful when making our decisions. (p. 55)

Thus, how researchers protect the privacy of their subjects or participants dictates the extent of interactions with them. And if the venue has a specific notice to researchers, stating its site policy about expectations, researchers should first review those. In this way, the "rules" surrounding what is public and what is private come from the participants or "gatekeepers" of a site, and a researcher should convey this information to an ethics board for consideration. For instance, there may be a statement notifying users that the site is public, and open to/for researchers, or, it may have an explanation of expectations of privacy in specific areas or domains. There may be a statement affiliated with the venue indicating whether discussion, postings, etc., are ephemeral, logged for a specific time, and/or archived in a private and/or publicly accessible location such as a website. For example, the AoIR list states:

air-l is a public forum and . . . your words will be available to everyone subscribed to the list and placed in a public archive. Messages sent via email can easily be reproduced and circulated beyond their originally intended audience, and neither the list manager, the association's officers, nor the server's host are responsible for consequences arising from list messages being re-distributed.

Moreover, researchers can look to see if there are mechanisms that participants or users may choose to employ to indicate that their exchanges should be regarded as private, for instance, "moving" to a private chat room, using specific encryption software, or conversing through a dedicated email or instant message account. Ethics boards may suggest that researchers inform participants that online communications are not necessarily secure, and that electronic communication is subject to tracking, permanence and thus long-term use beyond the scope of the intended research, and other online abuses. The prevailing interest in databanks or shared data hubs, and the emerging policies from ethics boards on banking hold potential for ethical debate as well. Informing the participants of these risks allows them to assess the extent of possible harms from engaging in an online research project. An interesting example of potential risk involves research on illegal activities online. Consider an ethics board in the US which received a protocol from a researcher who was interested in studying sexual minorities (homosexuality) in India through chat rooms. In India, homosexuality itself is not "illegal," but the act of, or the solicitation of, same-sex relations are grouped under illegal sexual activity. Thus, if a chat room participant solicits same-sex relations in a chat room, it would be construed under Indian law as illegal activity. Risk to subjects becomes much higher in this instance, and, thus, increased informed-consent processes are critical.

As we are seeing, misuses of online activities in the forms of pre-interview screening on social networking sites by potential employers, irresponsible representations by military recruiters, privacy violations by insurance industries, among others (see, for example, Elefant, 2008; Olsen, 2006; Gallagher, 2008), raise concerns for researchers who do intend to protect against risk of privacy violations. We hope that researchers are not seen as yet another entity trolling for information, and that ethics boards can play a proactive role in facilitating research, not inhibiting the kinds of online research taking place, by working to understand and mediate the complexities of Internet research ethics. And, moreover, researchers and boards which begin from a point of protecting basic participant rights from the outset will avoid such reputational and/or professional damage to the research enterprise. With this, "research creep," the use of research data to inappropriate and/or unethical ends, can hopefully be avoided.

Determining the extent of public and private is also meshed within methodological choice. For instance, Dias (2003, p. 33) describes her own methodological, and thus ethical, choices in her research of pro-anorexia (pro-ana) websites:

Because many on-line sites are openly accessible to the public, the obtaining of informed consent is often not done . . . However, care needs to be taken to exercise the "fair use" of contributions to public forums that respects participants' privacy and protects them from harm. My ongoing research is a feminist poststructuralist discourse analysis of the data I have collected from various pro-ana websites since September 2001 . . . In order to guarantee participants' confidentiality, I have removed all names and pseudonyms from the narratives I present. I have only accessed publicly available information from pro-ana websites; that is, I have not accessed any forums or chat rooms that required a password, pseudonym or my participation. I have not asked participants any direct questions, nor have I directly interacted with them in any way. Though most of the links to the websites I am referencing are no longer active . . . I have chosen not to provide any links in referencing my sources in order to further protect the women's privacy. Instead, I have referenced them as "Anonymous."

Notably, a common assumption holds that the greater the acknowledged publicity of the venue, the less obligation there may be to protect individual privacy, confidentiality, and rights to informed consent. Dias, despite using "public" sites, chose to maximize privacy concerns, due to the sensitive nature of her research. Ess (2007), among others, has called this "good Samaritan ethics," the response to go above and beyond the letter of the law and push towards "harmony and resonance" (p. 3).

Other interesting venues from which to consider the public/private debate are blogs. Technorati's "State of the Blogosphere 2008" reveals there is variation in the actual numbers of blogs but reports on data suggesting that there were 94.1 million US blog readers in 2007 (50 percent of Internet users), 22.6 million US bloggers in 2007 (12 percent), 84 million worldwide have started a blog, with 26.4 million in the US, and 346 million worldwide read blogs, with 60.3 million in the US. Of course, the range of topics is exhaustive, and online researchers have found fertile ground in blogs. From a research ethics perspective, in the US, research conducted using a blog as a data source would not be reviewable by an IRB. For instance, if a researcher used only text from a blog, as part of an analysis, and did not interact with the blog author through, e.g., interviews or surveys, no IRB review or approval would be needed, as it is not considered "human subjects" under the federal definition (45cfr46.102f): "Human subject means a living individual about whom an investigator (whether professional or student) conducting research obtains (1) Data through intervention or interaction with the individual, or (2) Identifiable private information." "Identifiable private information" is "information about behavior that occurs in a context in which an individual can reasonably expect that no observation or recording is taking place, and information which has been provided for specific purposes by an individual and which the individual can reasonably expect will not be made public (for example, a medical record)." Therefore, if a researcher is getting data from a blog that is public, then it would not meet the criteria for review as set forth in the US regulatory documents. Still, using a blog as a data source in research raises significant ethical issues. These issues revolve around identities and consent, and ownership.

Identities and consent

Dias's choice to anonymize the sites in her research speaks directly to the issue of identification, anonymization, and pseudonymization across online research. Roberts, Smith, and Pollock (2004) suggest a range of considerations for researchers using pseudonyms in their reports, as online pseudonyms are often identifiable. Indeed, online posturing and reputation must be considered, and in order to address this, Bruckman (2002, n.p.) found "Disguising subjects in written accounts is not a binary (yes/no) decision, but a continuum," while Sixsmith and Murray (2001) recommended removing all references to pseudonyms, names of sites, and so on. This, of course, raises methodological concerns, as ethnographers, for instance, rely on such details to weave the realities of their narratives. Bruckman also suggested that "the better you protect your subjects, the more you may reduce the accuracy and replicability of your study," and "if it is not possible to fully disguise your subjects, you may need to omit sensitive information from published results, even if this diminishes the quality of the research" (2002, n.p.). We can see how

decisions researchers make around participant contextualization and identification simultaneously raise ethical and methodological complexities.

And, the issue of identification is ultimately interrelated with the process of consent. Lawson (2004) provided a well-crafted array of options for consenting to research and its products. Notably, Lawson calls informed consent a "negotiation," which allows researchers to think of it in less rigid, static ways than the traditional research ethics models suggest. Consent is a process, from which participants can select a range of options:

1. consent to having their nickname and communicative text used for data analysis only (no publication of name or text);

2. consent to having either their nickname or text published in an academic work, but never together (i.e., no identifiers);

3. consent to having either their nickname or text published in an academic work, but never together (i.e., no identifiers) and providing they get to see the "write up" prior to publication;

4. consent to having both their nickname and text published in academic work, thereby being credited as the authors of their own words; or

5. consent to having both their nickname and text published in academic work, thereby being credited as the authors of their own words, providing they get to see the "write up" prior to publication. (Lawson, 2004, p. 93)

Lawson's suggestions push us as online researchers to embrace a more fluid interaction with participants, but, beyond that, she calls into question the concept of ownership of words and data in online research, an issue that becomes more complex in online research.

The issue of consent is confounded greatly in the use of databanks and data repositories. As more funding bodies and institutions require, or highly encourage, some form of "data deposit" from researchers, including such products as field notes, code books, instruments, and results, how consent applies must be considered. Consent typically covers strict parameters of participation. A research subject understands the context in which his or her participation will take place: she understands, in theory, how the data will be used. Once a reuse database or databank removes the original context, questions of risk, intentionality, and ownership immediately rise. A participant - and a researcher - may lose the control and ownership once assumed with one's data. An interplay of complex methodological and ethical integrity, disciplinary difference, and disagreements around "data" face an array of stakeholders. Growing interest in the construction of databanks and reuse repositories stems from a sense of data as a public good, that research data can increase in value for society (a utilitarian model) when multiple researchers have access to them. Hesitation on the part of researchers to deposit such data stems from multiple points: a long-standing model of the ownership of one's data; certain disciplinary beliefs around revealing one's method or "trade secrets:" lack of incentive and lack of support to do the "work" to actually deposit the data sources; and ethical review models which restrict or delimit the terms of research data. The ethics of reuse databanks has been confronted by medical boards, who typically require participants/subjects to consent to banking of data for a future use. Social science boards will indeed now need to consider the implications of banking of such artifacts as video, audio, and text, as each media raises unique ethical quandaries (see Carusi & Jirotka, 2008). The relationship among researchers, researched, ethics boards, and funders in light of data repositories promises to be fascinating, and should be the subject of future considerations.

Ownership

The concept of ownership of data in traditional research is fairly straightforward. The researcher and his/her institution typically own the data that is collected participants consent to that implicitly. Researchers have the paper copies of surveys, the audio recordings, the field notes. In the US, these documents or recordings are protected under copyright law, while international treaties such as the World Intellectual Property Organization (WIPO) Copyright Treaty, as well as individual data laws worldwide protect such expressions (for detailed discussions of information law, see Lipinski, 2008; Burk, Allen, & Ess, 2008). Online research activities, whether in the form of an online survey (to be described hereafter), or list activities, or blog postings, for example, experience different forms of ownership, and it is less clear who is the sole, or shared, owner. Venues may express specifically what the terms of ownership may be. Recently, Hvizdak (2008) found in her analysis of 138 blogs authored by women that 38 percent of the blogs expressed some type of copyright-protected status, indicating that creators in the digital realm seek to contribute to cultural production while at the same time retaining authorial credit. This was made especially evident through a high rate of requests for attribution in future uses of the bloggers' works. Thus, a researcher may not need an ethics board review to use a blog, but the blog author him or herself may dictate the terms of use, ownership, and attribution, perhaps through Creative Commons licenses or other self-designated attribution models. Participant-observation as a methodology can contribute to a very fuzzy notion of ownership, as a researcher is at once contributing and taking, in a dyadic or dialogical relationship. The onus falls on the researcher and the community/venue to assure his/her parameters around the ownership of the data, and how s/he portrays these data is notably, and intricately, connected with identity and representation. A researcher can easily alienate the community being studied by wrongfully representing their words, images, and ideologies, and claiming them as his/her own "research data." International boundaries - or lack thereof - confound ownership, as databanks, datasets, servers, find their homes across borders. Transborder data flow became a well-known issue in light of Refworks, an online research management tool. Its servers were housed in the US, and data stored there were therefore subject to release under the auspices of the Patriot Act (CBC News, 2006). Finally, researchers' misuse or misappropriation of online data raises other legal issues, such as harm and negligence, which Lipinski (2008) has

recently detailed. Lipinski's focus on the legal issues of researchers using listserv, discussion board, blog, chat room and other sorts of web or Internet-based postings uses a legal framework for considering risks and benefits in researcher activity and subsequent reporting. His work does not include a discussion of online survey tools, to which we now turn, as another major venue for online research.

Online surveys

Few can argue that online survey products, such as Zoomerang, SurveyMonkey, and QuestionPro have emerged over the last few years as the most convenient online research tools available. They have been embraced by an array of disciplines and professions, as *the* way to conduct both formal scientific research as well as informal surveys, such as customer or employee satisfaction. We will consider these tools now, given their predominance in Internet-based research, and because the literature surrounding the use of online survey tools points to a number of ethical areas for consideration.

Convenience is often cited as the reason for adopting any of the many free, or inexpensive, tools available, as users can generate surveys, send a link to their respondents, and have their data automatically compiled and analyzed without the wear and tear of mailings, data entry, and subsequent data analysis. Recent data collected by Buchanan and Ess (2008) reveal that in the US, the most frequently reviewed type of online research by IRBs is the online survey. But, only roughly half of responding IRBs review the privacy policies or user agreements that go along with these commercial tools, while even fewer (one third) of those have their own institutional tools to assist researchers in developing survey tools which are built around ethical or value-sensitive design considerations.

Yet, if a researcher uses a tool such as QuestionPro or SurveyMonkey, issues of privacy, ownership, and data security emerge that do not necessarily arise with traditional paper-based surveys. Tracking IP addresses, third-party access, auto-fill-ins, public Internet terminals, and ownership of the data contribute to a situation where research subject/participants can be identified. In traditional research settings, the researcher assumes responsibility for protecting the participants' identities, but in online research, he or she may not be solely responsible. The risks increase when certain types of sensitive data are being collected, such as medical information, and thus participants deserve greater protections (Svengingsson, 2004). Recent debates in the EU have shed light on the differences in opinion around personal privacy and IP addresses. While, for instance, Google's Gmail strips IP addresses from users' mail on the view that even dynamic IP addresses can be used to determine a sender's identity, the EU data privacy provisions specifically consider IPs as personal information and thus subject to regulation.

The literature around online surveys is growing, as researchers are considering the methodological *and* ethical components of online survey tools. Cho and LaRose (1999) and Nancarrow, Bruce, and Pallister (2001) discuss ethical and most notably

privacy issues in their examinations of web survey methodology. Cho and LaRose list physical, informational, psychological, and interactional as those types of privacy that invitation recipients and respondents are most likely to feel are being invaded. As computers become extensions of ourselves and are used outside of the home, an unsolicited invitation to participate might be seen as an invasion of physical privacy. The authors, however, name the most serious privacy violations as psychological and informational. Psychological privacy violations include a concern that researchers have observed certain emotional states while trolling chat rooms for participants, less perceived control over information online and so less trust in the researchers, the demarcated boundary between researcher and respondent. Informational privacy violations involve questions of how a researcher collects data, what he or she collects, and how it is used and disposed of; matching responses with data obtained while trolling; false identity of the researcher; cookies, IP addresses, and linking personal data to web use.

In their discussion of the use of web and specifically email surveys for health research, Scriven and Smith-Ferrier (2003) mention privacy, confidentiality, and anonymity concerns of respondents, the perception of survey invitations as spam or as containing a virus, and the level of data security as all having a possible impact on data quality and response rates. The authors note that such measures as encryption should be taken to protect data. Simsek and Veiga (2001) also note that in order to increase both response rates and quality of data (such as responses to sensitive questions), researchers must establish trust with the respondents and 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. The authors argue that this should all be done in the introduction to the survey. These recommendations are in keeping with traditional components of an informational document and informed-consent process in research protocols. Moreover, Cho and LaRose (2001) assert that a respondent's concerns about informational privacy leads to decreased response rates. Im, Chee, Tsai, Bender, and Lim (2007) have examined the feasibility of contacting members of Internet communities for participation in survey research. Interestingly, while this method raises serious, and obvious, privacy concerns such as trolling and unannounced chat room observation as a means of collecting participant data, this paper did not discuss these issues. Spam and trust building were addressed, but only as related to increasing response rate, and informed consent was obtained by having respondents click an "I agree to participate" button. Participants were assured that data was confidential "unless a participant appeared at risk for harm." Kaye and Johnson (1999) retrieved email addresses from newsgroups, chat rooms, and listservs in their use of a survey to examine the use of the web for political information, stating that "Response rates also 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 also that invitations might be perceived as spam. The authors used IP addresses in their study to crosscheck against a list of emails for duplication, which raises questions about IP addresses and privacy.

Some of the literature around online surveys centers on discussions of privacy (including privacy policies), confidentiality, informed consent, and security, with a focus on the suggested steps one should take in carrying out online surveys. Evan's (2005) overview of the strengths and weaknesses of online surveys states that "clear, visible, respondent-friendly privacy policies are imperative;" further, security concerns can be lessened by having respondents "visit secure websites rather than e-mailing surveys as attachments" (p. 211). Eysenbach and Wyatt (2002, p. e13) give respondent, survey, and investigator features that are suitable and unsuitable for web surveys, stating "under no circumstances should a researcher blindly spam" to attain survey respondents. "Informed consent may also play a role when researchers report aggregate (collated and hence anonymous) data on usage patterns . . . crucial here is an appropriate privacy statement," stating how and why cookies will be used, and asking communities and individuals if they agree to be quoted in a retrievable archive. Further, informed consent can be obtained by stating the study's purpose, who is involved, that privacy will be assured, how data will be reported, and who it will be shared with "before participants complete the questionnaire (p. e13)." Gunn (2002) notes security and privacy as a concern of web survey respondents, but also interestingly points out that data collected without the respondents' knowledge - time of survey, browser used, IP address - can be a "double-edged sword" (n.p.). Respondent data can be beneficial to the researcher in discovering statistics related to the respondents, and can also be used to demonstrate that respondents act differently when taking web surveys. It is suggested that researchers be concerned about data privacy and security and allow for an alternate mode of response (mail, phone) if the respondents have these concerns.

Of relevance to this discussion of online surveys is transaction log analysis, which is typically not considered reviewable research by ethics boards, as it is not human subjects research. Transaction log analysis, as a form of research, has been used since the 1960s, and is a systematic analysis of searches, or user queries, and outputs. While once contained within closed (non-networked) systems, transaction logs of Internet searching are widely used by researchers. While in the United States IP addresses typically fall outside of the definition of "personal information," and thus some deny the identifiable connection between an IP address and a "person," others have raised privacy and identity concerns. As we have seen above, EU data laws define IPs as personal information - 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" (2008, p. D01). In the US specifically, public awareness of transaction log methodology hit home in 2006 when AOL released a huge dataset of some 650,000 users' searches, under the presumption that the data were anonymous. This was quickly proven untrue, as individuals could indeed be identified, when the New York Times crosschecked this "anonymous" data with other publicly available data (Barbaro & Zeller, 2006). A similar incident occurred the following year with NetFlix, when two Texas-based researchers de-anonymized some of the Netflix data by comparing rankings and timestamps with public information in the Internet Movie Database (IMDb) (Narayanan & Shmatikov, 2005; see also, Schneier, 2007).

As online survey use continues, ethics boards and researchers must consider the implications of their use – as we have accepted throughout, methodological choices are indeed ethical choices (Markham, 2006), and, as such, the choice of an online survey should be made with reason and attention to integrity and responsibility, not only with an eye to convenience and possible research outcomes, including possible benefits of such research for both the researcher and others.

Future Directions and Future Research: Research Ethics 2.0?

The emergence, or acceptance, of Web 2.0 allows us to think through research ethics and methods in a dyadic or dialogical fashion. It is strongly likely that 2.0 technologies *and* ideologies will amplify the process of community decision-making, precisely as it blurs the boundaries that are essential to more dichotomous models of research ethics. For instance, Michael Zimmer (2008b, n.p.) has recently suggested that

Web 2.0 represents a blurring of the boundaries between Web users and producers, consumption and participation, authority and amateurism, play and work, data and the network, reality and virtuality. The rhetoric surrounding Web 2.0 infrastructures presents certain cultural claims about media, identity, and technology. It suggests that everyone can and should use new Internet technologies to organize and share information, to interact within communities, and to express oneself. It promises to empower creativity, to democratize media production, and to celebrate the individual while also relishing the power of collaboration and social networks.

For instance, Web 2.0 could seem to reinforce the importance of procedural (Habermasian/feminist/communitarian) approaches that emphasize the importance of fostering the ethical as it emerges "from the ground up," that is, from within the communities in question, rather than from the top down, as ethics boards typically function as enforcers of law or policy. The technologies of Web 2.0 themselves dictate authorship and the types of content created, thus imposing a predetermined structure (or anti-structure) which makes determining authorship, the role of subject and object, researcher and researched, more complicated. User guidelines and agreements set the parameters of what a user can do and say, thus there is a set of rules that override what an ethics board may actually consider. And beyond that, normative zones are also self- and community-generated. Thus, ethical norms are being imposed from hierarchical powers (i.e., user guidelines/terms of agreements), the users themselves (who can, for example, determine the levels of access they individually allow to others), *and* research ethics

boards who then determine how a researcher can interact in this process. As social networking, hyper-blogging, folksonomies, Wikis, etc., continue to change social interaction, research itself and thus research ethics must change. E-research is growing, across disciplines, and with it research ethics boundaries are morphing. Ess (2003) and Berry (2004) used the concept of "open-source ethics" to describe a vision of participatory ethical models. This vision holds great promise for the future relationship between and among researchers, policymakers and enforcers, and the "researched." This "open-source" or participatory model is not unique to, or owned by Web 2.0, of course. As noted, the AoIR guidelines grew out of this framework, and transcend Web 1.0, 2.0, and beyond, as they provide the essential pluralistic judgment described earlier. Moreover, as a framework or foundation from which to make decisions and assert judgment, this model can be found in Aristotle's work and his emphasis on praxis as the domain against which theory must always be tested and out of which theory will be revised (Ess, 2008). Ultimately, through this particular moment in research, Web 2.0 holds the potential, as a ubiquitous medium that encourages the collapse of binary models, to push stakeholders in the research process to creatively – and productively – disrupt research itself. The concept of transformative research is at stake - and research itself cannot be transformative if the models that govern it remain static. Research ethics itself must be transformative.

The Internet and its various technologies, tools, platforms, and venues have provided novel research grounds for decades, and there is no sign of stopping. What has changed is the dynamic raised between researchers and researched. Feenberg, Bakardjieva, and Goldie (2004) asked directly, "what do the subjects get out of it anyway?" and this question continues to give us pause, as the boundaries between subjects and objects lessen more and more. Ethics boards across the world have specific and distinctive legal and ethical responsibilities, and since their inception, their approach has been a top-down, regulatory design, for practical, institutional reasons. Their philosophical approaches may favor rights or duties over consequences; they may operate as rule-based over relationship-based, given their cultural specificity; they may be less "strict" with social sciences over medical reviews; they may exempt oral histories. But, fundamentally, they have been static, while research around them changes. Institutions benefit, economically, socially, ideologically, politically, from certain models and modes of research. Yet, they stand to learn from the community-based, emergent forms of ethics that are coming from such guidelines as AoIR's, and from the many self-generated models and modes of ethical decision-making abounding on the Internet. Researchers should not turn away from their ethics boards; instead, they should work in tandem to forge the next generation of research ethics, one that still embraces core principles while creating new opportunities for important research endeavors. A time of intercultural research ethics (borrowing from Capurro's 2008 concept of intercultural information ethics) is upon us, in the guise of Internet research ethics. It is in all of our interests, as researchers across disciplines and across cultural boundaries, to embrace the potential of Internet research ethics 2.0 and beyond.

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