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Bringing Oversight Review in Line with Online Research

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ABSTRACT

The purpose of an oversight structure or institution is to protect human subjects from research that would pose unacceptable dangers or deny human rights. Review boards provide an independent assessment of research proposals. This additional level of scrutiny is meant to provide an additional level of protection for human subjects. However, oversight of human subject research, as currently carried out in the bureaucratic, rule-based, clinically-biased American system, is too cumbersome with regard to online research. In addition, it is not conducive to the training of ethical Internet researchers. Internet research differs from traditional human subject research in many ways, and the oversight rules governing traditional research do not easily relate to the complexities of conducting research online. Online researchers do not oppose the foundational principles of non-maleficence (avoiding harm) and autonomy, nor do they reject the ideals of informed consent and confidentiality, nevertheless, they face practical dilemmas in attempting to follow these principles and apply these ideals in the various Internet domains. The current oversight system is ill-equipped to assist. A conservative response to this problem of fit might entail adjustments to the oversight system that, in the case of the American system, would entail modifications to the Common Rule and Institutional Review Boards (IRBs). I will argue in this paper, instead, that re-structuring is needed to allow more oversight authority for Internet researchers. I will utilize Consequentialism and Virtue Ethics in making this case.



1. CHALLENGES POSED BY ONLINE RESEARCH

Deborah Johnson (2001), James Moor (1985) and others have noted that the unique features of digital communication – many-to-many communication, anonymity, and reproducibility – create problems for policy makers. This is apparent in regard to copyright infringement, virtual pornography, cyberstalking, etc. This is true for online research, as well, such that ethical quandaries somewhat rare or not to be found at all in traditional research appear in Internet

research. The following set of examples, most of which were reported to The Association of Internet Researchers by members (AoIR, 2001), illustrates this point.

1.1 Many-to-many

Associated with the global reach of online sites is the possibility that online subjects are of different nationalities. To what extent must an Internet researcher attempt to abide by multiple sets of cultural mores and folkways, including privacy norms?

KEYWORDS

Internet Research
Research Ethics
Common Rule
IRB
Virtue Ethics

Online research may fall under multiple national jurisdictions. Should researchers attempt to meet all of the regulatory schemes? Is this even possible given the different rules and procedures across nations?

Admittedly, some clinical and social scientific studies are international, nevertheless, protocols can be anticipated and dealt with more easily than Internet studies in which subjects' citizenry may not be known *a priori*. Furthermore, due to anonymity and pseudonymity (discussed below), subjects' citizenship may remain unknown.

1.2 Anonymity, Pseudonymity

In clinical research it is imperative to establish a subject's identity, with age, gender, medical history, etc., treated as crucial information. Social scientific research is often planned around the disclosure of subject identity or at least the sampling of targeted populations. In contrast, online participants utilize anonymity and the related practice of pseudonymity, thereby making the establishment of subject identity impossible or tenuous at best. (Kling *et al*, 1999) Many web sites caution users not to reveal personal information, and young people are sometimes advised by adults to indicate an older age in their user profile.

One concern is that researchers may be misled about age and minors may participate in studies without parental permission. McKenna and Bargh (2000), on the other hand, note that subjects may be willing to divulge confidences under the "cloak of anonymity" without fully understanding the extent to which they and their messages may be traced back to an IP address and, subsequently, to a workplace, college, etc.

An investigator researching a USENET archive more than likely will be unable to track subjects if they have used pseudonyms. The investigator, therefore, may be hard pressed to contact the subject to

explain the nature of the research and to request voluntary participation (i.e. permission to study the subject's postings). Confidentiality is another matter. Researchers are required to protect the subject by not disclosing the subject's identity. Is it acceptable, however, to disclose a pseudonym? In other words, does confidentiality extend to online identities?

Anonymity can be used by investigators, as well. It is much easier to infiltrate a group when pseudo-identities are easily created and physical cues are absent. Thus, hidden observation is a very practical and tempting approach for Internet researchers. Ethical quandaries abound with this form of research, however, and include participating in immoral activities to pass as a 'native,' taking advantage of marginalized or vulnerable groups, and the conflict between informed consent and deception/non-disclosure.

1.3 Reproducibility: Public-Private Space

In the physical domain it is often clear to researchers what constitutes a public space, and it is generally held in research ethics that researchers may observe behavior in public settings without seeking and receiving informed consent. However, the private/public nature of cyber sites is so much more complicated, with sites having varying degrees of accessibility and different sets of norms and practices. Participants' expectations vary, as well, and it may be impossible to know if subjects cannot be contacted. A message posted online, although most likely written by a user with the intent to participate in a discussion, can be 'reproduced' by others for other purposes. Should a researcher assume that a subject has understood the domain to be a public one – that a message could be reproduced by outsiders, such as researchers?

Alternatively, should the researcher assume that subjects, perhaps naïvely, expect privacy in their postings? Moreover, online privacy can be thought to encompass a space free of intrusions from unwanted messages and, ironically, this would mitigate against researchers inquiring about the subject's expectations.

Should a researcher remain 'hidden' so as to not disrupt a chat room or MUD, for

instance, or is it more appropriate to respect subjects' self-determination and receive permission for observation/participation?

1.4 Other Concerns

In contrasting the standard psychology lab design with its Internet counterpart, Nosek, Banaji and Greenwald (2002) point out the following concerns with online research: 1) security of the data transmitted, 2) safety of stored data on files connected through a server, 3) premature disconnection with subject and he/she missing an opportunity to be debriefed, 4) absence of a researcher to deal with problems that subjects may encounter during an online experiment, and 5) under-representation of populations falling along the socio-economic fault line of the digital divide.

1.5 Contingent Nature of Online Research Ethics

The response by AoIR to the many questions regarding online research and ethics is instructive. AoIR made no attempt to establish a formal set of rules to be applied universally. General ethical principles (e.g., the duty to protect human dignity) and more specific research ethics (e.g., confidentiality) were affirmed, nevertheless, the specific *application* of such principles was not dictated. Disagreements among committee members are candidly reported, but more importantly, it is asserted that "the *context* of research (e.g., more public-like vs. more private-like spaces) and the *types of questions* asked (e.g., with regard to form of conversation vs. content of conversations) may strongly shape specific ethical responses." (AoIR, 2001 original emphases)

In its final report, AoIR asserts that guidelines are needed, but not recipes (Ess and AoIR, 2002). Unfortunately, this recommendation is at odds with the rule-based system imposed by the American oversight structure.

2. THE AMERICAN OVERSIGHT STRUCTURE

Like the American health care system, the regulatory structure for human subject

research is a patchwork. Research conducted on human subjects for the purpose of creating 'generalizable knowledge' falls under one scheme whereas research for commercial purposes falls under another.

In regard to the former, a consortium of over sixteen Federal departments and agencies adhere to a set of rules/procedures referred to as the Common Rule (Title 45 Code of Federal Regulations Part 46 (45 CFR 46)). Universities, colleges, hospitals,

Like the American health care system, the regulatory structure for human subject research is a patchwork.

private research facilities, etc., are required to have their researchers abide by the Common Rule if the research is to be supported by grants bestowed by any member of the consortium. In practice, most research institutions require all human subject research, including those not funded by the consortium, to follow the Common Rule.

The other key feature of the American oversight system is the Institutional Review Board (IRB). These boards review research proposals to determine if the requirements of the Common Rule are being followed, and the boards decide the fate of the proposed research projects – approve, modify, or disapprove. Most IRBs are 'in-house,' meaning that organizations establish and operate IRB(s) with their own personnel.

2.1 Criticisms from Inside

The National Bioethics Advisory Commission was charged by executive order in 1995 to provide recommendations to Federal agencies regarding the oversight of research. Its final report entitled, "Ethical and Policy Issues in Research Involving Human Subjects," characterized the system of protections as a "patchwork arrangement" "no longer sufficient," "too narrow in scope," and "unnecessarily bureaucratic." (2001, Prologue, I) The Commission identified online research as

one of many new forms of research (others included industry-sponsored, multi-site, and community research) for which the system is ill-suited.

Of relevance to this discussion is the Commission's critique of IRBs. It was acknowledged that IRBs are too rigid and cumbersome. More specifically, they 1) are

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overburdened by case loads, dominated by a medical-clinical approach to review, and often have poorly trained members, and 2) have limited flexibility in matching the risk level of proposed studies with an appropriate level of independent review. The Common Rule, and in particular the rules regarding waivers for informed consent, was criticized as well. The Commission recognized that the restrictions under which informed consent may be waived (primarily written with clinical studies in mind) are too rigid and prohibitive of certain types of social scientific research.

2.2 Criticisms from Outside

Following meetings in 1999 and 2000 with representatives from professional societies in anthropology, sociology, political science, and history, the American Association of University Professors (AAUP) issued a critical report on the American oversight system (2000). It was noted that IRBs and the Common Rule were established in response to unethical biomedical research. Approximately 75% of proposals reviewed by IRBs are from biomedicine, and the majority of board members are from biomedicine. As with the Commission's report, the AAUP found a medical-clinical bias in the system, and this was singled-out as being the most serious obstacle to social scientific investigations.

For example, IRBs accustomed to clinical

research with risks-benefits of a physical nature have some difficulty evaluating the social risks-benefits described in social science proposals.

Because interventions in clinical research are invasive and usually entail health risks, the ethical obligation to obtain informed consent is readily apparent. Accordingly, the Common Rule has very strict rules regarding informed consent, including full disclosure of the research protocol, providing a statement of risks and benefits, and obtaining signatures. However, full disclosure could undermine some social scientific investigations that require spontaneity or natural behavior of subjects, and obtaining signatures may be impractical or potentially dangerous to subjects (for example, anonymity is preferable in cases where illegal behavior is divulged). Researchers are permitted to request a waiver from these strict rules, but the allowances are strictly regulated as well, and IRBs, accustomed to straightforward informed consent plans from clinical research, often respond with caution.

As discussed before, online research presents equally, if not more challenging, sets of issues. The common use of anonymity and pseudonymity and the expectation of privacy present formidable obstacles to obtaining signatures. Informed consent to examine postings in message board archives may be impossible to secure.

Citing these and other issues, AoIR (2001) noted that the specific rules established for traditional human subject research are too inflexible for Internet research.

3. POLICY CHOICES

The oversight system was built to protect the interests of human subjects. They are the primary stakeholders. Obviously, researchers have a stake in the system as well. Other stakeholders, such as academic disciplines, service providers, and the general public, benefit from worthwhile research going forward. The merits of the current regulatory structure include: 1) the normative expectation that research be structured in such a way as to minimize harm and to honor the dignity of the human subject and 2) the establishment of independent review to see these ideals

through. If done well, subjects are protected, researchers benefit from an 'outside' review, and valuable research continues.

None of the critics of the American oversight system mentioned above contest this and all support a normative scheme and independent review.

The current system fails to the extent that promising research is stymied or, more seriously, having lost faith in the fairness or effectiveness of the Common Rule and IRBs, researchers circumvent independent review. In the latter scenario, subjects do not have the benefit of an important advocate and researchers place themselves in a precarious legal and moral position. Moreover, findings may be tainted by scandal, and the public's trust in research may be diminished.

Thus, the policy choice is not between keeping or doing away with oversight, rather it concerns how the oversight system is to be amended or redrawn to become more accessible and inclusive. A conservative strategy would 1) retain the Common Rule, albeit add more exemptions and waivers, and 2) modify existing IRBs. I suggest, instead, the development of field-specific guidelines and IRBs. This approach, I feel, will better serve online researchers and subjects.

3.1 Conservative Strategy

The Common Rule provides uniformity in terms of standards and routines in the review process. In theory, this allows for a measure of across-the-board quality control. However, as has been discussed, the set of rules are more applicable to some types of research (clinical) than others. Waivers may be added, but in order to prevent the opening of gaping loopholes, waivers are often written with strict exclusionary language. This is evident in the rules for obtaining a waiver of informed consent. To assist researchers in working through the rules regarding waivers, the Office for Protection from Research Risks (OPPR) issued in 1998 a decision-tree chart, which is reproduced in Figure 1.

For the online researcher grappling with nuances of subject identity, private/public domains, and trying to figure out what investigative role to play (hidden vs. announced, passive vs. participant), these

seemingly straightforward rules can be maddening. For example, what are the rights of a subject who goes by a pseudonym and participates in a virtual community that is visible to all? Does the subject have a right to privacy, and does this extend to their entire public record of postings and actions? In regard to research in sequestered spaces, does the potential risk of inadvertent disclosure of a subject's information, and subsequent loss of standing in a virtual community, warrant the categorization of the research as "greater than minimal risk?" Devised to exclude, these rules provide little help in *informing* ethical practice, and more than anything else it is guidance, not restrictions, that online researchers need.

A conservative change to IRBs would be to improve the quality of extant boards. The Commission, for example, proposed the accreditation of boards and the required training of IRB members. These are sound suggestions, but fail to address the concern raised by the AAUP panel that current boards, dominated by professionals from biomedicine, may not have sufficient experience or background to appreciate the complexities of social science research practice and ethics. The training recommended by the Commission is geared to the proper application of the Common Rule, however, the training deemed crucial by the AAUP is obtained through practice in the respective discipline.

In putting forward a set of guidelines for Internet researchers, AoIR emphasized the *interdisciplinary* character of online research. (Ess and AoIR, 2002) It has been suggested in this paper that the unique set of online research practices and ethical concerns may allow one to see online research as a field of study in which Internet researchers should train. It is practical training in Internet research/ethics, and not formal training in the Common Rule, that is proposed below.

3.2 Alternative Strategy

Whereas the Common Rule and IRB structure presuppose the universality of research ethics and research practices, an alternative approach would accept the importance of principles while allowing for the contingent nature of research practices. If the latter

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graph TD
    Q1[I. Will the research in its entirety involve greater than 'minimal risk' (Section 46.102(i))?]
    Q2[2. Is it practicable to conduct the research without the waiver/alteration?]
    Q3[3. Will waiving/altering informed consent adversely affect subjects' rights and welfare?]
    Q4[4. Will pertinent information be provided to subjects later, if appropriate?]
    End1[Waiver or alteration possible, if IRB documents these four findings and approves the waiver or alteration.]
    End2[No waiver or alteration.]

    Q1 -- No --> Q2
    Q1 -- Yes --> End2
    Q2 -- No --> Q3
    Q2 -- Yes --> End2
    Q3 -- No --> Q4
    Q3 -- Yes --> End2
    Q4 -- Yes --> End1
    Q4 -- No --> End2
  
```

I. Will the research in its entirety involve greater than 'minimal risk' (Section 46.102(i))?

No

Yes

No waiver or alteration

2. Is it practicable to conduct the research without the waiver/alteration?

No

Yes

No waiver or alteration

3. Will waiving/altering informed consent adversely affect subjects' rights and welfare?

No

Yes

No waiver or alteration

4. Will pertinent information be provided to subjects later, if appropriate

Yes

No

No waiver or alteration

Waiver or alteration possible, if IRB documents these four findings and approves the waiver or alteration.

An even more difficult task for an online

Having an interdisciplinary Internet research organization develop IRBs would not violate any existing practices or rules. For example, there are IRBs sponsored by hospitals. Even though most IRBs are 'in-house' and handle cases from researchers within their respective institution, there are

exceptions. For example, some for-profit IRBs are national and even international in scope, and will review proposals from anywhere for a fee. Online research IRBs should not be for-profit, but otherwise could operate in a similar manner. Board members need not meet face-to-face to review cases and, with their experience in digital communication, members should feel quite comfortable communicating online.

The composition of online research IRBs should follow existing recommendations, which suggest a mix between specialists and non-specialists. The specialists should be drawn from the various disciplines engaged in online research, thereby reflecting the interdisciplinary character of Internet research. The non-specialists could be drawn from the online population, the best candidates being those familiar with the various domains. Diversity of members in regard to race, gender, and cultural backgrounds should be sought.

4. ETHICAL ANALYSIS

Besides these pragmatic concerns of construction and constitution, it is important to consider whether a change to the current system is worth it. In this last section of the paper, I utilize Consequentialism and Virtue Ethics to make this case. My intent here is simply to illustrate some advantages of the alternative strategy—by no means is this meant to be an exhaustive analysis as it is limited to only two ethical theories and no attempt is made to point out the differences between the theories.

4.1 Consequences

As with any untried policy, it is difficult to anticipate all of the positive and negative consequences, nevertheless I would expect there to be a net gain from implementing the more radical strategy described above. The number of instances in which online researchers decide not to submit proposals to IRBs, effectively bypassing independent review, should decrease for the following reasons: 1) online researchers would feel more confident in the relevance of guidelines developed within the field, 2) they would feel more confident in IRBs whose members are familiar with the nuances of

online research, and 3) they may be more willing or feel obliged to support a review system that they or their colleagues have developed. If more proposals went through IRB review under a field-based system, more subjects would be protected with the additional level of scrutiny. Also, researchers would avoid the moral and legal jeopardy of bypassing independent review.

It is difficult to know how many studies by graduate and undergraduate students never go forward due to a reluctance to face a bureaucratic and potentially hostile review. Unfortunately, the conservative strategy would continue down the road of rules and more rules and the IRBs would remain as alien as ever. In contrast, it would be in the best interest of a field-based overview organization to develop an efficient and relevant system that encourages the research of their graduate and undergraduate students.

As stated above, online research currently may fall under multiple national jurisdictions and this presents a problem for researchers, as it is very difficult for them to negotiate the different sets of rules and procedures across countries. A uniform system would eliminate this hurdle.

One could argue that if a permissive set of guidelines emerged that favored researchers at the expense of protecting subjects' rights, the primary stakeholders would lose out. But, for this to happen there would have to be a double failure—on the part of the field-based oversight organization and the inter-

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The American oversight system was developed not with the virtuous researcher in mind but with the specter of unethical scientists

national accrediting body. There is no reason to believe, however, that both groups would lose sight of ethical principles and their charge to protect human subjects.

4.2 Virtue Ethics

The American oversight system, although encouraging the adherence to ethical prin-

ciples, was developed not with the virtuous researcher in mind but with the specter of unethical scientists (e.g. Nazi experimenters, Tuskegee researchers). It was built to be a regulatory system, and it is rule-based. In other words, the researcher is motivated to follow the rules in order to be allowed to conduct research. Once again, the potential weakness of this approach is that rules may be too inflexible or difficult to apply.

Virtue ethicists suggest another path for ethical conduct, and that is through developing strong character and sound judgment. Winograd (1995:33) notes that it is “good judgment” and “helpful intuitions,” not rules, which will allow the individual to make the best decision in difficult situations. Charles Ess and AoIR emphasize the central role of judgment in ethical decision-making and assert that “such judgment cannot be reduced to a simple deduction from general rules to particular claims.” (2002: 4) Virtue is developed through the formation of good habits which, in turn, are acquired through practice and learning within a field or profession. Thus, it is best to perceive the virtuous person not as a heroic individual, but as a participant in a virtuous community or way of life.

Virtue ethicists have called for the teaching of computer ethics throughout the educational system in the hope that students will become aware of ethics and ethical issues in computing (Grodzinsky, 2001). In the most ambitious programs, students are provided the opportunity to conduct ethical analyses and to make ethical decisions.

This approach rests on the assumption that the more students are involved in applying ethics (initially under the tutelage of mentors), the more they will be prepared for ethical conduct in their careers. Although the emphasis is on the student and his or her maturation, this assumption can be extended to all: involvement is necessary for the development of strong char-

acter and sound judgment.

Unfortunately, online researchers play a very limited role in the current regulatory structure. For the most part they remain outside the decision-making process, in the sense that they have had little say in regulatory matters and tend to have poor representation on IRBs. If this were to change, as proposed in this paper, and the responsibility for oversight went to the research practitioners and online participants, a new training ground for ethical practice would become available.

Imagine a scenario in which online researchers – those already engaged in reflection and discussion of research ethics and oversight – help formulate the first guidelines. IRBs become a place for members to train in the practice of making sound judgments regarding research ethics. Other researchers, including graduate and undergraduate students, gain experience in formulating ethical research designs as they submit proposals for independent review. As described, this suggests a higher level of involvement than is apparent today and it suggests a structure or system that provides training/socialization for novices – a framework for a robust community of ethical researchers.

5. CONCLUSION

Tinkering with the current oversight system would do little to alter its structure of authority. Rules would continue to be fashioned by government agencies and decisions regarding research proposals most likely would continue to be made by IRB members not involved in online research.

However, if we wish guidelines to be more sensitive to the nuances of Internet research, online researchers must be allowed authority to draft them. Furthermore, if we expect more from the oversight system and envision it as a training ground for virtuous research conduct, online researchers must be provided the authority to run the review process.

I believe that online researchers, with the help of others, are capable of assuming these responsibilities. Also, I believe that for a regulatory system increasingly criticized for being unwieldy, overburdened,

and exclusive, delegating authority would bring about positive change.

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