Studying the Amateur Artist:
A Perspective on Disguising Data Collected in Human Subjects Research on the Internet

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Abstract

In the mid-1990s, the Internet rapidly changed from a venue used by a small number of scientists to a popular phenomena affecting all aspects of life in industrialized nations. Scholars from diverse disciplines have taken an interest in trying to understand the Internet and Internet users. However, as a variety of researchers have noted, guidelines for ethical research on human subjects written before the Internet's growth can be difficult to extend to research on Internet users (Eysenback & Till, 2001; Frankel & Siang, 1999; Reid, 1996; Thomas, 1996; Waskul & Douglass, 1996). In this paper, I focus on one ethical issue: whether and to what extent to disguise material collected online in published accounts. While some people argue that vulnerable human subjects must always be made anonymous in publications for their own protection, others argue that Internet users deserve credit for their creative and intellectual work. Still others argue that much material available online should be treated as "published." To attempt to resolve these issues, I first review my own experiences of disguising material in research accounts from 1992 to 2002. Some of the thorniest issues emerge at the boundaries between research disciplines. Furthermore, many humanities disciplines have not

historically viewed what they do as human subjects research. Next, I explore what it means to do human subjects research in the humanities. Inspired by issues raised by colleagues in the humanities, I argue that the traditional notion of a "human subject" does not adequately characterize Internet users. A useful alternate mental model is proposed: Internet users are amateur artists. The Internet can be seen as a playground for amateur artists creating semi-published work. I argue that this approach helps make some ethical dilemmas easier to reason about, because it highlights key novel aspects of the situation, particularly with regard to disguising material. Finally, I conclude by proposing a set of practical guidelines regarding disguising material gathered on the Internet in published accounts, on a continuum from no disguise, light disguise, moderate disguise, to heavy disguise.

1.0   What is at Stake

In a graduate class I often teach, "Design of Online Communities," I assign students to study an existing online community. Before they begin, I teach them how to do so ethically, to the best of my understanding of the subject. Their projects are also cleared by Georgia Tech's Institutional Review Board (IRB). In fall 2001, one student, whom I'll call Jane, identified a group she wanted to study, and approached the group's leader to explain her project and ask permission to proceed. It's debatable whether Jane needed to approach the leader or whether she could simply approach group members as individuals asking their participation (Seidman, 1998). I teach my students to err on the side of caution, and approach group leaders first in most situations. The reception Jane received surprised her. Before she could even explain the purpose and scope of what she wanted to do, the leader immediately said, "No, you may not do research here." She

asked if he would please at least listen to details of the study before making a decision, and he again emphatically said no, he would not. Another "researcher" had studied the community six months earlier, and left members feeling like their activities were disrupted and their privacy violated. He asked her to leave immediately and never come back (even as a simple participant), and threatened to start writing letters to university officials if he ever saw her at the site again. Needless to say, Jane picked another site as the subject for her project. If we do not take care to make sure that researchers are respectful and ethical in their conduct, this kind of reception may become more common, endangering our ability to study the Internet as a medium.

Beyond these consequences for our research, if we are too lax in our ethics, we risk violating the rights of individual subjects and disrupting communities we study. For example, Storm King quotes a member of an online support group who writes that he/she is not going to participate actively because of researcher presence in the group. The member writes,

> … when I joined this I thought it would be a *support* group, not a fishbowl for a bunch of guinea pigs. I certainly don't feel at this point that it is a 'safe' environment, as a support group is supposed to be, and I will not open myself up to be dissected by students or scientists. I'm sure I'm not the only person who feels this way. (King, 1996, p. 122).

On the other hand, if we are too strict, we may hamper our ability to understand the medium. The Internet is a large-scale, geographically distributed phenomenon. To construct an extreme example, suppose we treat Internet research as equivalent to medical research. In experimental medical studies, consent is typically obtained through

a face-to-face dialogue between researcher and participant, and documented with signed forms. If we require such a face-to-face dialogue for Internet-based research, than most of the studies conducted about this medium to date would never have taken place. It is simply not possible for researchers to travel to discuss participation in person with all members of an online group who may be located anywhere in the world. Clearly, the lesser risk of Internet research compared to medical research merits less stringent precautions, but how much less stringent?

If regulatory bodies are too strict, then researchers may simply try to avoid their guidance. Any institution accepting federal funds to support research on human subjects in the United States is required to have an Institutional Review Board (IRB) that monitors compliance with human subjects regulations (as expressed in US Federal Code Title 45 regulations[1] ("Protection of Human Subjects," 2001)). Many universities require IRB review for all studies, even if they do not receive such funds. In the ideal case, IRBs serve as valuable partners to researchers, helping them to negotiate the ethical issues that emerge. However, if IRBs are overly strict, then researchers may find ways to avoid their oversight, instead of using them as a resource and source of support. For example, in 2001 the author tried to begin a collaboration with a researcher at another university, whom I'll call Prof. Jones. Jones believes his work is exempt from IRB review, even though he regularly collects data from people on the Internet. Jones might indeed be right, since most of his work concerns unobtrusive observation in public forums. He

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[1] For the purposes of this paper, I will take a perspective centered on law and ethical practices common in United States of America. A US perspective is quite different from a European one or those of other parts of the world; however, an international analysis is beyond the scope of this paper.

chooses not to double-check with his IRB if his studies are exempt, but to simply not send those studies for IRB review, because in his judgement no such review is necessary, and his IRB tends to be extremely cautious. The Georgia Tech IRB approved the collaborative study on the condition that the other institution's IRB did so as well. However, Prof. Jones was unwilling to send this one proposal to his IRB because it went against his principled stance that IRB review is not necessary for the kinds of studies he conducts, and implicitly opens the question of why he has not sent other studies for review. The collaboration never proceeded. This kind of attitude is not uncommon, and, unfortunately in some cases, not entirely unjustified. Board members trained in issues relating to medical research often do not know how to approach work in the social sciences and humanities, and may be uninformed about new technologies. While a great deal of flexibility is written into human subjects regulations, IRBs are often either unaware of the degree of flexibility possible, or too cautious to take advantage of that flexibility. A rational balance between caution and flexibility is possible and is essential to the system functioning as it was intended - that is, with researchers turning to IRBs for assistance in the difficult ethical questions they inevitably will face and receiving judicious and balanced guidance.

I first became interested in this topic as a matter of necessity: I needed to figure out how to conduct my own research ethically. Ideally, a student researcher can rely on their advisors and IRB for guidance in research ethics. However, I quickly found that I was breaking new ground and instead it was necessary for me to devise reasonable solutions to the best of my ability and educate my IRB. I approach this topic as a concerned practitioner, not a trained ethicist.

To situate my remarks, I will begin by telling the story of my own early work in human subjects research on the Internet. It is beyond the scope of this paper to address all the issues that have come up in my work over the last ten years (1992-2002), so I will focus on one issue that I have found problematic: tradeoffs between anonymizing subjects and giving them credit for their work. I'll argue that the idea of giving individuals credit for their creative work pushes us to think not of "human subjects" but of "amateur artists." To explain this concept, I'll briefly review the history of human subjects research in the humanities. I'll try to show how this new perspective makes a few of the many ethical dilemmas of human subjects research on the Internet easier to reason about. Finally, I propose a set of guidelines for helping researchers determine how much to disguise their work in published accounts.

2.0 The Perspective of a Concerned Practitioner

Since 1992, I have done research on educational applications of Internet technology. From the start, I found myself confronted with difficult issues concerning the ethics of human subjects research in this new medium. These comments serve to situate my perspective on this topic. In this narrative, I highlight issues raised and lessons learned. These lessons are my own interpretations; others will certainly have contrasting views. Over the years, I have handled some situations well, others less so. I have simply handled them to the best of my ability, armed only with what I learned in two undergraduate classes in ethical philosophy and thoughtful feedback from colleagues, mentors, and IRB members over the years. I in no way claim to know "the right answers." I simply hope others will find useful the *questions*

that have arisen and be able to improve on my solutions when such issues arise in their own work.

2.1 Summer 1991: Sensitive Information about Internet Users, Obtained Face-to-face

I first began doing human subjects research on the Internet in spring 1991 as a graduate student at MIT in a class on Sociology of Technology, taught by Sherry Turkle. My term paper was entitled "Identity Workshop: Emergent Social and Psychological Phenomena in Text-Based Virtual Reality" (Bruckman, 1992). Over the following summer, I worked as Turkle's research assistant, helping her with fieldwork for what would become her book *Life on the Screen* (Turkle, 1995). As a clinically trained psychodynamic psychologist, Turkle is interested in intimate details of her subjects' lives, and not surprisingly takes a strict view on issues of anonymity in human subjects research. Working in the clinical case study tradition, Turkle omits subjects' names and changes details of life history where these would compromise anonymity. For example, if a subject encountered a significant life hardship that is key to understanding their psyche and their relationship to technology, Turkle might substitutes a different hardship that she believes would reasonably have had a similar psychological effect. To invent a fictional example, a flash flood in real life may become an earthquake in the final account. Key psychological aspects are preserved in the translation: the subject feared for his life, and lost all his possessions. While this introduces unintended nuances and inevitably reduces the accuracy of the portrait, Turkle finds it necessary to protect the subjects' identities.

This disguising also erects barriers to the social practice of science. In an open scientific community, individuals ideally publish results sufficiently detailed for others to attempt to duplicate those results and affirm or question the findings. This idealized model from the physical sciences is always hard to replicate in social sciences, but even harder when the act of protecting subjects adds substantial new barriers to follow-up inquiry by others.

Since Turkle and I eventually (if not initially) met all of our subjects face-to-face, this research was ultimately little different from well-understood modes of human subjects research, and raised few new ethical issues. One new nuance to consider was the way in which communication via the Internet made it easier for subjects in online communities studied to gossip about who was whom in Turkle's written accounts, making it even more necessary than usual to disguise material carefully.

While Turkle generally avoided this problem, exactly this issue arose in response to work by journalist Julian Dibbell. In 1993, Dibbell published an article "A Rape in Cybspace" in *The Village Voice* that got a tremendous amount of both popular and scholarly attention. It relates the story of antisocial behavior Dibbell observed on LambdaMOO, a text-based virtual reality environment (or "MUD"). While Dibbell chose not to disguise subjects in his original *Village Voice* article (Dibbell, 1993), he later chose to do so in the book-length account published a few years later (Dibbell, 1998). He comments on the change in an author's note at the start of the book:

> For the sake of privacy, I made other alterations, the main one being that names were changed from actual to fictitious ones throughout the book. This is common journalistic practice, of course, but here it may seem oddly superfluous considering that the "actual" names I changed were mostly pseudnyms to begin with, used by people whose real-life identities are in many cases still unknown to me. If my approach was unusual, however, so were the circumstances:

LambdaMOO happens to be a world in which, for technical reasons, knowing a person's name is the approximate virtual equivalent of knowing that person's phone number, home address, and social security number as well. And given that that world is also readily accessible to anybody with an Internet account, I thought it best not to offer unavoidable encouragement to any ill-mannered rubberneckers (or worse) who may lurk among my readers.

Additionally, when writing about Lambda residents who could not reasonably be considered "public figures" within the context of the MOO, I sometimes took measures to conceal their identities from other MOOers as well as from visiting outsiders. These measures variously included rewriting the residents' descriptions of their virtual selves and possessions, revising information about their real lives (such as hometown, age, and place of employment), or both. I changed the non-MOO details of some "MOO-famous" figures as well, to keep certain aspects of their real lives private. (Dibbell, 1998, pp. ix-x)

After the book's publication, LambdaMOO members whom Dibbell studied

collaborated to create a chart of who is who, and shared the chart openly with anyone

interested. I have been a member of LambdaMOO since early 1992, and I witnessed the

merriment with which community members played this game. While people generally

understood the disguising was meant for the benefit of community members and

unmasking people was potentially harmful, the detective game was simply too much fun

to resist. While this partially foiled Dibbell's efforts to provide subjects some degree of

privacy for people from the curiosity of insiders in the community, his disguising still

provided protection from outsiders. Furthermore, the more time passes, the more his

disguising is effective. The chart members collaborated to create of who is who in

Dibbell's account was passed around eagerly immediately after the book's publication. It

now still exists, but is difficult to locate.

> Lesson: Anonymity in published reports may be hampered by subjects
>   themselves
> Members of online communities often enjoy trying to identify disguised subjects
> in written accounts, and may collaborate quite effectively to solve the puzzle of
> who is who and share this information openly with others. Researchers must
> weigh the cost of such disclosures. For low-risk studies, this risk may be deemed

acceptable. For higher risk studies, extra care should be taken in disguising. The researcher may also actively enlist the help of the population, asking them to refrain from guessing who is who.

2.2   Fall 1991—1995: Parental Consent, Obtained Remotely Via Surface Mail and Fax

In fall 1991, I returned from my work with Turkle to the MIT Media Lab, where I was a PhD student in the Epistemology and Learning Group, working with Mitchel Resnick. The focus of my work was then and continues now to be on using online communities to foster constructionist learning (learning by working on personally meaning projects, learning through design and construction activities--(Papert, 1991, p. 1-12)). That fall, I began work on designing a text-based virtual reality environment (or "MUD") intended to be an educational environment for children ages 8-13. This project, MOOSE Crossing (http://www.cc.gatech.edu/elc/moose-crossing/), would become my doctoral dissertation. It opened to the public in October 1995, and I completed my data analysis and writing in summer 1997. I was immediately struck by some significant differences between this research and my work assisting Turkle.

For the purposes of this paper, I will focus solely on issues regarding disguising material collected. (Another key issue raised by this work is how to obtain parental consent and child assent from people you never meet. However, this is beyond the scope of this paper.) In her work, Turkle does not identify the online sites she studies. This significantly aids her in protecting subjects' identities. In the case of my research on MOOSE Crossing, however, it is impossible for me not to identify the site. I can't publish an article about, "an unnamed educational online environment for children"—I'm obviously referring to the one I designed!

Not being able to disguise the name of the site de facto means not being able to protect the confidentiality of some community members. This is especially true of "the regulars." The regulars are the heart of any community (Oldenburg, 1989), and accounts of community life will often refer to them. However, these highly visible community members are often impossible to disguise. For example, in my doctoral dissertation on MOOSE Crossing, one of the regulars was a child who is home schooled. She and her parents have a complicated set of personal reasons for why they chose home schooling. Understanding those reasons helps put her experiences in context. However, her online presence was so prominent and influential that any description of her is easily recognizable. Consequently, sensitive information like her reasons for being home schooled were omitted from the document. While this diminishes the quality of the published results, it was unavoidable.

> Lesson: Disguising subjects in written accounts is not a binary (yes/no) decision, but a continuum. The better you protect your subjects, the more you may reduce the accuracy and replicability of your study.
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> Lesson: The level of risk of the study contributes to a researcher's decision as to how much disguising is appropriate.
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> Lesson: 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.

In fall 1997, I joined the faculty of the College of Computing at the Georgia Institute of Technology, and founded the Electronic Learning Communities (ELC) research group (http://www.cc.gatech.edu/elc). My students and I have engaged in numerous research projects in the design of educational online environments, each of

which raises new ethical issues (Hudson & Bruckman, 2002). One more project is worth discussing in this context: The Turing Game.

2.3   Pseudonyms and Writing About Data in a Searchable Public Archive

In 1998, graduate student Joshua Berman and I began a research project called "The Turing Game" (TG). The Turing Game is a participatory exploration of issues of identity in online environments. To play this online game, a panel of contestants pretend to be members of a particular group—for example, women, Canadians, people over 40 years old, etc. Some of the panelists may really be members of that group; others may not. The audience asks questions designed try to tell who is who, and then votes with sliders on who they think is telling the truth. When the game's moderator decides enough questions have been asked, the panelists reveal their true identity and a discussion ensues about who was fooled and why (Berman & Bruckman, 2001). Game types are user defined. Popular game types concern gender, age (example: who is over 30), and national origin (example: who is Irish) among many others.   Occasionally, users chose to play games concerning sexually explicit topics.

Handling ethical issues with regard to this study took a great deal of thought. We decided to use an online consent process, and received IRB approval for our plan. A password is needed to participate. To obtain a password, users must fill out a web-based form explaining the study. Because of the controversial nature of the subject matter as well as the difficulty of verifying parental consent electronically, we decided to exclude minors. To do so, we simply ask a user's birth year at the start of the online consent process. If they say they are under 18, we politely tell them the site is for adults only.

(Whether this precaution is sufficient is debatable. Reliably excluding minors from studies is challenging, and devising practical and effective solutions to this problem is important to the future of research in this medium.)

Part of the point of TG is to help people reflect on issues of identity in online environments. Towards that end, we decided to publish the game logs on the web. The consent process warns people about the fact that logs are publicly archived.

It has been argued that pseudonyms function like real names, and hence should be treated as real names (Frankel & Siang, 1999). Individuals often use the same pseudonym over time, and care about the reputation of that pseudonym. They may also chose to use a part or all of their real name as their pseudonym, or some other personal detail that is equally identifying. They may also routinely disclose information linking their pseudonym and real name. Pseudonyms are often closely linked with real names and share the function of real names, and hence should be treated in the same way as real names. (In the rest of this paper, I use the terms "name" and "pseudonym" somewhat interchangeably. "Pseudonym" refers to the names people chose to use in computer-mediated communication, not to disguised names in published research accounts about such communication.)

The names published in the web logs are *doubly* pseudonymous: to register for a Turing Game account, you pick a persistent pseudonym. You use this pseudonym in the Turing Game "lobby." From the lobby, anyone can start a new game, choosing the topic and becoming the game's moderator. Starting a new game creates a new room just for that game. To enter a particular game room, you pick a new temporary pseudonym just for the duration of that game. This enables someone who normally goes by "Tim" to

become "Sue" in a game where people are claiming to be women, or "Carlos" in a game where people are claiming to be Latino.

While the decision to make logs public was key to the goals of the project, it raised an unexpected ethical issue. In a journal article about the game (Berman & Bruckman, 2001), we took the log of one game and interviewed each participant on the telephone or in person. The paper explains each person's interpretation of what took place at each step. Even though the names were already doubly pseudonymous, we changed them in the written account yet again.

The moderator of the game, "Crash" in the paper, told us in interviews that she is a post-operative transgendered person. Issues of gender are particularly salient for Crash, and it greatly enriches the reader's understanding of her participation to know her personal history. She generally prefers not to tell her online friends about her gender transformation.

Here a dilemma ensued: remember that all of the TG logs are on the web. Even though we changed Crash's pseudonym, if one searched for her *exact words*, the log of the game would appear, showing the pseudonyms unchanged. Storm King has noted that accessibility of research data via full-text search is a key problem that Internet researchers must grapple with (King, 1996). Finding the transcript via full-text search would reveal just Crash's temporary pseudonym for this particular game. However, *she was in the habit of often using the same temporary pseudonym*. This is in fact common practice for many Internet users.

Lesson: Pseudonyms often function just like real names.
An individual may use the same pseudonym repeatedly, and may care about the reputation of their pseudonym. People often use part of their real name as a pseudonym, and may also publicly reveal their real name either on purpose or by accident, creating a link from the pseudonym to the real name.

Lesson: For any data accessible via full-text search, it may be difficult to disguise subjects' identities.

Our solution in this instance was to remove the log of this particular game from the public archive. This makes it more difficult to link "Crash" in the paper to the TG user, unless you were a participant in this particular game or can recognize Crash's writing style. This is only possible because we happen to control the online archive in question, and needed to remove only a tiny part of that archive. We are also disregarding the possibility that someone may have saved a private copy of the log downloaded before it was removed. The existence of the public archives made it harder for us to protect the confidentiality of our subjects.

3.0   Human subjects Research in the Humanities

3.1   Two Puzzling Conversations

In 1999, I participated in a workshop organized by AAAS that led to report "Ethical and Legal Aspects of Human Subjects Research on the Internet" (Frankel & Siang, 1999). At the first Association of Internet Researchers (AoIR) conference in Lawrence, Kansas in 2000, I joined with Sanyin Siang from AAAS and Sarina Chen from University of Northern Iowa to propose the formation of an AoIR working group on the topic of the ethics of human subjects research online. The proposal was approved, and I became a member of the newly formed group, chaired by philosopher Charles Ess of

Drury University. In 2001, I was invited to become a part of an American Psychological

Assocation (APA) working group to develop a policy on this topic chaired by Bob Kraut

of Carnegie Mellon University.

At the Second AoIR conference in Minneapolis, MN in 2001, I organized a panel

discussion on the topic, together with Charles Ess, Susan Herring, and Jim Hudson.

Much discussion on ethical issues took place at the conference in many sessions. I was

struck by the fact that two different humanities researchers (who do not know one

another) had essentially the same story to tell. To paraphrase, they both said roughly:

> Over an extended period of time, I recorded a variety of materiel in public online
> chatrooms. When I went to write up my findings, I tried to find the creators of
> that work to ask their consent to use it. However, by that time, most of the people
> were impossible to find online any more. Since I felt that I made a reasonable
> effort, and used material in my final report even where I was unable to locate its
> creator. I used the creators' online pseudonyms unchanged in my account,
> because I felt that they deserve credit for their creative work.

I inquired of the first researcher, did you ask permission as a matter of courtesy or

did you feel that it was necessary? She answered that in her view it was necessary. I

tried to explain that if asking "permission" was simply a matter of courtesy, then she was

within her rights to use the material if that permission was impossible to obtain.

However, if getting "consent" was a required ethical obligation, then if that consent was

not obtained she could not ethically use the material. *There is no concept of "best effort"*

in either human subjects research or copyright law. The researcher reiterated that she

felt that asking "consent" was necessary but using the material anyway was ethical if she

couldn't locate the author/creator. When asked if she changed the names of subjects in

her written account, she replied that she had not. She had not merely deemed it

unnecessary to do so, but in fact found the idea of changing the names ethically problematic, because she saw her subjects as artists entitled to credit for their work.

Clearly the researcher and I were not understanding each other. I was puzzled. We were operating from quite different frameworks, and both failing to translate between them. My puzzlement multiplied later in the conference when I had a nearly identical exchange with a different researcher unaffiliated with the first!

The more I thought about it, the more puzzled I became. Within a traditional framework of human subjects research, their conduct seemed unethical. But on the other hand, it's certainly true that individuals deserve credit for their creative work. Could it be that the framework itself is inadequate to handle the issues at hand?

A host of complicated, difficult, and important issues are raised by these two projects. Is recording activity in a chatroom equivalent to unobtrusive observation in a public space? Is recording chatroom activity without the knowledge or consent of participants ethical? Do participants have copyright over their words? A discussion of all of the thorny questions raised by these projects is beyond the scope of this paper. The rest of this paper will focus on just these two issues:

➢ How do the rules of human subjects research apply to research in the humanities? Is humanities research in any way different from work in other disciplines?

➢ Since my work in this area began with my work assisting Sherry Turkle with highly sensitive subject matter, I tend to err on the side of disguising subjects as carefully as possible. However, these researchers raised the legitimate question that an artist/author also deserves credit for their work. How do you balance the need to protect subjects with the need to give credit where credit is due?

3.2   The Tradition of Human Subjects Research in the Humanities

In trying to address questions of how issues of human subjects research apply to the humanities, I will group a variety of disciplines (literary theory, art history, etc.) together under the label "humanities." This is of course a significant over-simplification. The analysis here will both apply and not apply to different disciplines, institutions, and individuals in complicated ways.

I begin with a simple question: do humanities scholars study human subjects? Until roughly the middle of the 20th century, literary scholars tended to study both the work and the work's creator. In 1954, W. K. Wimsatt and Monroe Beardsley published an influential essay called "The Intentional Fallacy" (Wimsatt & Beardsley, 1954, pp. 3-18). Wimsatt and Beardsley argued that "the design or intention of the author is neither available nor desirable as a standard for judging the success of a work of literary art" (Wimsatt & Beardsley, 1954, p. 3). Roughly two decades later, Roland Barthes would proclaim the "death of the author" (Barthes, 1977, pp. 142-148). Studying the author/artist/creator of a work fell out of intellectual fashion for several decades.

The timing is significant: right around the time Wimsatt and Beardsley were writing, the first human subjects guidelines were being written, in response to Nazi atrocities. The Nuremberg Code was first published in 1947, and ideas expressed there were further refined in the Helsinki Declaration of 1964 (Belmont Report, 1979). Thus, during the era when some disciplines such as medicine and the social sciences were developing traditions of human subjects research, literary studies and other fields in the humanities were moving away from studying living people. Studying the life and works

of an author who is dead is not human subjects research (Pritchard, 2001). Studying just the works of a living author is also not human subjects research, unless you actually interact with the person in the course of your research. Through the formative period in the field of the ethics of human subjects research, most humanities scholars did no work with human subjects.

Studying real live people returned to prominence in some parts of the humanities with the rise of cultural studies as a critical approach. One famous early work in the field is Dick Hebdige's "SubCulture, the Meaning of Style" (Hebdige, 1979). Hebdige chose to study pop culture rather than high culture, as practiced by ordinary teens rather than professional authors or artists. Hebdige wrote about cultural trends through general observations, with no clear data collection method described. The transition to true human subjects research becomes clearer in later cultural studies work such as Janice Radway's *Reading the Romance*, a book in which she explicitly borrows research methods from anthropology (Radway, 1984). Published in 1984, Radway had the novel idea to study not the text as written, but the text as read. Her subjects were avid readers of romance novels, and she began to ask questions about the practice of reading and what it meant in her subjects' lives. In her research, Radway did detailed interviews with romance *readers*. This is clearly human subjects research.

While the rise of cultural studies as a critical approach helped to reintroduce human subjects research into literary studies, an even stronger force was the rise of the Internet. On the Internet, millions of non-professionals are engaged in both consuming and creating cultural artifacts in sometimes dramatically new ways. This unprecedented

development is clearly worthy of study. However, the researchers coming to this new topic often come from disciplines without strong traditions of human subjects research.

3.3   Studying the Famous: an Idealized Scenario

Literary scholars and art historians who study famous creative professionals typically do not view what they do as human subjects research, even if they study living authors and artists, collecting data from them directly. What would it mean if they did view this activity as human subjects research, within traditional established guidelines?

The closest literary studies in the pre-war, pre-structuralist era came to studying human subjects was in the study of famous creative professionals and their work. What does it mean to study a famous artist, author, or musician? "Fame" plays no role in regulations for human subjects research in the United States. Human subjects regulations do not apply to "elected or appointed public officials or candidates for public office" (US Title 45 section 46.101.b.3.i); there are, however, no legal exemptions for other kinds of "public figures." The notion of a "public figure" is most clearly expressed in journalistic ethics. The Society for Professional Journalists (SPJ) Code of Ethics states that to minimize harm, journalists should:

> Recognize that private people have a greater right to control information about themselves than do public officials and others who seek power, influence or attention. Only an overriding public need can justify intrusion into anyone's privacy. (*SPJ Code of Ethics*, 1996)

Journalists recognize that famous individuals have a reduced right to privacy compared to ordinary citizens. Note, however, that the concept of a "public figure" is not mentioned in either The Belmont Report (*The Belmont Report*, 1979) or the United States Title 45 regulations that govern the conduct of human subjects research supported by federal funding ("Protection of Human Subjects," 2001).

Let's suppose that I wish to do a study of a famous living composer, funded by a grant from the National Endowment for the Humanities. I'll call this fictional composer, "Joe Musica." Is this human subjects research? Let's review the definitions of a "research" and "human subject". US title 45 section 46.102 contains the following definitions:

> d) *Research* means a systematic investigation, including research development, testing and evaluation, designed to develop or contribute to generalizable knowledge. […]
> (f) *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.

By these definitions, if I solely analyze Musica's compositions and popular press and scholarly accounts of his work, this is not human subjects research. However, as soon as I interview Musica or perhaps follow him around observing a day in his life as he composes, the project becomes human subjects research.

Should Musica be anonymized in a study for which he is a subject? To answer the question, we need to know what kind of study it is. Were he to happen to volunteer for a blood pressure study with 1000 participants, he would, of course, be anonymized, like any other participant in the study. Were he to volunteer for a study of the effects of fame on blood pressure together with a small sample of other people often in the limelight, he would still likely be anonymized. However, if the study is about the reason for which he is famous, his music, it is impractical to try to do so, and also may defeat the purpose of the study. Typically, a core objective of studying a prominent cultural figure is to enhance our understanding of that specific individual, not just the creative process in the abstract. Furthermore, a researcher working on an anonymized subject works alone,

and it can be difficult for other scholars to either critique that work or build on it.

Sensibly enough, the law does not require that all human subjects be treated as

anonymous. Section 46.111 states that in order for a study to be approved by an IRB:

> (7) When appropriate, there are adequate provisions to protect the privacy of
> subjects and to maintain the confidentiality of data.

We can construe it as <u>not</u> appropriate to protect the privacy of a "public figure"

under some circumstances. Nonetheless, since the biography our hypothetical scholar is

writing is human subjects research, the requirements for informed consent apply.

Presumably the consent form presented to Musica for consideration before the

interviewing and observations began would note the fact that he would not be

anonymized in written accounts, and caution him that those written accounts may not be

uniformly flattering, so he should conduct himself accordingly while being observed.

One factor the IRB would ideally weigh in such a situation is the degree to which

the subject can be viewed as a public figure. We accept a higher degree of risk for public

figures than for private citizens. The distinction between public figure and private citizen

is, of course, not binary but a continuum. It is also not fixed for an individual but

changes over time and by context. For example, someone who is famous among linguists

is likely not famous in the broader sense (unless they are Noam Chomsky). Someone

experiencing Warhol's promised '15 minutes of fame' is a public figure for a very limited

time in a very limited context.

The issue of writing things that are less than flattering about an identifiable

human subject is thorny. *Human subjects regulations do not prohibit us from doing harm*

to subjects. The relevant section on harm is in this section of the Federal code:

46.111 Criteria for IRB approval of research.

In order to approve research covered by this policy the IRB shall determine that all of the following requirements are satisfied:

(1) Risks to subjects are minimized: (i) by using procedures which are consistent with sound research design and which do not unnecessarily expose subjects to risk, and (ii) whenever appropriate, by using procedures already being performed on the subjects for diagnostic or treatment purposes.
(2) Risks to subjects are reasonable in relation to anticipated benefits, if any, to subjects, and the importance of the knowledge that may reasonably be expected to result. In evaluating risks and benefits, the IRB should consider only those risks and benefits that may result from the research (as distinguished from risks and benefits of therapies subjects would receive even if not participating in the research). The IRB should not consider possible long-range effects of applying knowledge gained in the research (for example, the possible effects of the research on public policy) as among those research risks that fall within the purview of its responsibility. ("Protection of Human Subjects," 2001)

What, then, does the researcher do when she discovers something potentially embarrassing about Musica in the course of normal research? For example, what if the researcher discovers that Musica often composes while under the influence of illegal drugs? Certainly this sheds significant light on the creative process. But is publishing this information appropriate? Is revealing this fact "reasonable"? As Susan Herring notes, not all research methods or results need please subjects (Herring, 1996). Ideally, the scholar would carefully weigh the public benefit of making the revelation, and balance this against the potential harm to the subject. There might be substantial public benefit to better understanding the life of this important cultural figure. In an idealized world, she would consult her IRB for guidance, and they would help her to sort through the uncomfortable situation she finds herself in. And continuing our ideal picture, the IRB would not automatically say "no, don't reveal it," but might give serious

consideration to the idea that the revelation might be justified, even if it does substantial

real harm to the subject.

3.4   Studying the Artist: Common Practice

Having worked through a hypothetical case of how this should be handled in

theory, I was curious how it is typically handled in practice. To investigate, I emailed

officials at the National Endowment for the Humanities (NEH) the following question:

> How do you decide whether an NEH project constitutes 'human subjects
> research'? Do you deal with this a lot? If someone is doing a study of a living
> artist, would this usually go to an IRB for approval?

Multiple mid- and senior-level NEH officers I emailed and spoke with all said the

same thing: the NEH has always interpreted the human subjects regulations as not

applying to them. (All asked not to be named or directly quoted.) To make the point,

one official sent me a web page listing members of a government sub-committee on

human subjects research. A dozen different government agencies are represented on the

committee—including groups as diverse as the Department of Agriculture, the CIA, and

the Consumer Product Safety Commission—but not the NEH or NEA

(http://ohrp.osophs.dhhs.gov/references/humansubcomrost.htm).

The regulations give a great deal of discretion to the director of a government

agency, so it's legally allowable for the NEH's director to simply state that the rules don't

apply:

> (i) Unless otherwise required by law, Department or Agency heads may waive the
> applicability of some or all of the provisions of this policy to specific research
> activities or classes or research activities otherwise covered by this policy. Except
> when otherwise required by statute or Executive Order, the Department or
> Agencyhead shall forward advance notices of these actions to the Office for

Protection from Research Risks, National Institutes of Health, Department of Health and Human Services (DHHS), and shall also publish them in the **Federal Register** or in such other manner as provided in Department or Agency procedures. (Title 45, section 46.101)

Most work historically supported by the NEH does not constitute human subjects research. As we have seen, according to Federal Codes, it only becomes human subjects research when you deal with a living person, and actually interact with that person (and not just their work or secondary sources on their work). Since human subjects research has not traditionally been a part of work in the humanities, researchers are often not trained in this area.

Has this state of affairs led to harm being done to subjects? Attention from scholars is typically appreciated by public figures like artists and politicians. Public figures may often resent intrusions into their lives by journalists; however, intrusive behavior by scholars is much less common. A journalist may be willing to "burn bridges" by publishing an unflattering exposé, which often serves the public good but damages the journalist's ability to work with that individual in the future. On the other hand, a scholar studying a famous artist or author is less likely to be willing to damage their relationship with their subject of study. The subjects usually understand the scholar's goals and methods, and grant or deny access to personal information accordingly. The system currently works fairly well without IRB involvement.

However, two trends are changing this landscape: the growth of interdisciplinary work, and the rise of the Internet as both subject and medium for research. Each trend increases the complexity of the issues and creates new risks for human subjects.

3.5   Studying the Amateur Artist Online

> Cyberspace is not Disneyland. It's not a polished, perfect place built by
> professional designers for the public to obediently wait on line to passively
> experience. It's more like a finger-painting party. Everyone is making things,
> there's paint everywhere, and most work only a parent would love. Here and
> there, works emerge that most people would agree are achievements of note. The
> rich variety of work reflects the diversity of participants. And everyone would
> agree, the creative process and the ability for self expression matter more than the
> product (Bruckman, 1995).

On the Internet, everyone can be an author, everyone can be an artist.   I will try
to make the case that viewing the Internet as a playground for amateur artists is useful in
reasoning about one subset of ethical issues in human subjects research, issues
concerning disguising people in published accounts. Different perspectives are suitable
for different situations, and this metaphor is a lens that is useful in reasoning about some
situations.

Amateur artistry is of course not a new phenomenon. In most cultures, children
typically have their amateur artwork displayed in their home. Scholars in the field of folk
art study amateur work by adults. Neither amateur art nor its ubiquity are new.
However, what is new with the advent of the Internet is the wide distribution of that art.
While once upon a time only immediate family and friends saw a child's crayon
drawings, now many parents post them on the World Wide Web. Art students post their
portfolios. I post my poetry and photography. They're not very good, and I typically
send the link only to close friends, and only when I'm feeling brave. But I enjoy writing
poems and taking pictures, and for some irrational reason I enjoy posting them even

when I don't widely disseminate the link. This is typical behavior for a modern amateur artist.

Figure 1:   A photograph by the author, posted in her home and on her web pages. (Bryce Canyon, Utah, 1999).

One of my photographs hangs in the hall of my house (see Figure 1). My husband had a print framed as a surprise birthday gift. Were you to choose to study amateur photography before the Internet age and wished to comment on this photo, you would clearly need my permission to do so. You could not gain access to my house

without my permission, and in the process we would naturally negotiate the terms of that access. Whether the researcher construes this as human subjects research or not, a negotiation would take place and I could hopefully make a choice about how much access to grant to either my work or discussion of personal details relating to its creation. Were I to submit the work to a gallery, however, it's clear that a critic from the local paper could comment on the work without my knowledge or consent. The professional public display of the work changes the rules.

What about the display of the photograph on my web page? Is it more like the photo hanging a public gallery or one in my private home? William Mitchell suggests that if you are searching for a metaphor from architecture, the front porch of a home might be more suitable in many situations. Front porches are in-between public and private, with carefully evolved social rituals for how one behaves in this liminal space (Mitchell, 2001). What is the status of the web page photo? We could quibble about nuances regarding whether the page is linked to other pages and advertised or not, but generally speaking this is more similar to the photo in the gallery than the one on my wall.

Note that relying on our intuitive notions of "public" and "private" here is potentially misleading (Eysenback & Till, 2001). Dennis Waskul and Mark Douglass observe that "the labels of 'public' and 'private' are metaphors applied to the context of cyberspace" (Waskul & Douglass, 1996, p. 131). They continue that "the blurring of public and private experience is particularly characteristic of on-line research. What is 'public' and 'private' is not always clear in conception, experience, label, or substance" (Waskul & Douglass, 1996, p. 131). The web page is ultimately neither a public place

like an art gallery nor a private place like the hallway in my home—it is a web page.

Thinking of a photo on a web page as existing in a place comparable to a physical place

is an analogy. Deborah Johnson notes that while reasoning by analogy can be a powerful

way to understand ethical dilemmas relating to computers, it also has dangers. She writes

that "the danger is that we may be so taken by the similarities of the cases that we fail to

recognize important differences" (Johnson, 2001, p. 23).

Similarly, I argue that we can no longer view "published" and "unpublished" as a

binary distinction. Instead, it is now a continuum. Most work on the Internet is "semi-

published." When my photograph of Bryce Canyon is featured on the front page of

cnn.com, it is published in the traditional sense. However, when it is posted on a private

web page not linked to any public web page as it is now, it is somewhere in between the

traditional categories of published and unpublished. Similarly, the humanities

researchers discussed earlier were recording activity in chatrooms that would otherwise

be ephemeral. Those words can also be construed as "semi-published," in between

traditional categories of published and unpublished.

In the US, work posted on the Web is implicitly copyrighted (Litman, 2001).

While you could discuss my photograph without permission, you would need permission

to make a copy of it (except in cases where the copy constitutes "fair use"). While you

could discuss my photograph without permission, as soon as you decide to interview me

about it (whether the interview is in person or via phone, the Internet, etc.), this arguably

becomes a case of human subjects research. In that case, the study would need to go

through review by an IRB, and a consent form would likely be required. In many cases

where research is low risk, the requirement for documentation of consent can be either waived or electronic consent can be accepted.

It shouldn't surprise you, however, that this is not what currently typically happens. In many cases, scholars study large amounts of information available online without taking the time to speak with the people who created it. When researchers do chose to talk with creators of work, they often ignore the requirement to go through a human subjects review process. They also often reprint the work without permission, even though this may constitute a copyright violation (if the copies go beyond "fair use").

As we have seen, studying professional artists and other prominent public figures is technically a case of human subjects research, but in practice is often not treated as such. Since those trying to publicly promote their work are generally aware of the risks and benefits involved, this leads to few problems. However, amateur artists are often less aware of those issues, and hence more inherently vulnerable as a group. Before the advent of the Internet, this caused few problems, because amateurs did not have their work published, and access to it had to be negotiated. With amateur art now widely available without negotiation of access, new problems arise.

3.6   Pseudonyms of Amateur Artists

I have argued that it often does not make sense to anonymize the work of a famous artist, even if he/she is treated as a human subject. But what about amateur artists? Should they be treated as vulnerable human subjects whose privacy needs to be protected by hiding their online pseudonyms and real names? Or would that rob them of a legitimate claim to credit for their creative work? To answer the question, we need to understand the purpose and methods of the specific study.

If the study is low risk, it seems appropriate to give amateurs credit for their work if they desire it. Researchers need to ask, "do you want me to list your real name, your pseudonym, both, or neither?"

If the study is higher risk, then listing either names or pseudonyms is probably not appropriate. As always, the degree of risk must be balanced against the benefits of the study. The subjects' degree of being a 'public figure' may also be taken into account, as we have seen. Before the research is conducted, the researcher needs to explain the risks of the study and the fact that their work will not be credited. The subject can take this into account in deciding whether to participate in the study.

Note that making this decision based on whether the study is, in the researcher's judgement and the judgement of their IRB, high risk is not the same thing as whether the subjects *request* to be named or anonymized. In Elizabeth Reid's study of an online site for survivors of abuse, some informants agreed to speak to her only on the condition that they be named. She acceded to their wishes, but now feels that she should not have. Reid writes:

> The often commented upon disinhibiting effect of computer-mediated communication could conceivably lead people to agreeing to or even insisting on a kind of public exposure by which they may eventually be harmed. The allure of self-revelation can be strong in any circumstances. The popularity of confessional talk shows and literature testifies to both the exhibitionistic and voyeuristic streaks that lie in many psyches. In online environments where consequences to actual lives of participants can be hidden behind the illusion of a virtual/actual dichotomy, this tendency towards uninhibited behavior can make the social researcher's job seemingly easier and thereby place an added burden of responsibility on his or her shoulders. (Reid, 1996, p. 172)

Neither choice, to list names or hide them, is without problems in practice. If you hide names, you deny people credit for their creative work. If you list names, you may

have to omit potentially harmful statements from your written accounts. This can have a negative impact on the quality of your published work—if you can only say nice things, you sometimes can't tell key parts of the story. Even if you name the online group you are studying but change names, you may still have to omit some details.

What then determines whether a study is "low" or "minimal" risk? "Minimal risk" is defined by Title 45 (section 46.102) as:

> (i) *Minimal risk* means that the probability and magnitude of harm or discomfort anticipated in the research are not greater in and of themselves than those ordinarily encountered in daily life or during the performance of routine physical or psychological examinations or tests. ("Protection of Human Subjects," 2001)

Some groups are inherently vulnerable. Any study of work by members of a support group for people with a serious disease probably can <u>not</u> be construed as minimal risk. However, risk is a function as much of the goals of the study as of the population being studied. Even if you are studying something as innocuous as people's web-based abstract art, the study is *not* low risk if you wish to comment on how some people spend an obsessive amount of time in this pursuit to the detriment of their personal relationships and job performance. The conclusion I draw, then, is that whether to change names must be decided on a case by case basis, depending on the subject, goals and methods of the particular study.

Studies explicitly of amateur art self-published online may at first seem like an unusual topic affecting a small minority of academic researchers and small numbers of artists. However, in many ways, *all user-created content on the Internet can be viewed as various forms of amateur art and authorship*. For example, consider simple discussions in bulletin-board-like systems. There is a rich tradition of the letters of

famous people being collected, published, and treated as important documents of both historical and literary merit. Bulletin board discussions may be viewed as amateur work in the genre of the art of letters. Some real-time chat is done by professional artists as a form of performance art. Ordinary chat and instant message can be viewed as amateur performance art. Of course this amateur "art" has varying degrees of artistic merit—but so does professional art! The degree of variation in quality is simply higher for amateur work.

Viewing Internet users as amateur artists does not replace a more traditional human subjects perspective, but complements it. The two metaphors emphasize different facets.

4.0 Practical Recommendations

Viewing Internet users as amateur artists highlights certain key features of the ethical situation:

- The need to balance

➢ the right of Internet users to receive credit for their creative and intellectual work, and
➢ the need to protect vulnerable human subjects in research studies.
- The "semi-published" nature of much Internet-based communication, making

  traditional notions of "published" and "unpublished" inadequate for analysis.

Based on this perspective, I propose the following practical guidelines. These ideas emerged from a combination of personal experience (section 2) and theoretical reflections (section 3). These are not meant to be hard and fast rules, but "rules of thumb" to guide both researchers and IRBs in their decision making.

Proposed Guidelines for
Treatment of Names and Online Pseudonyms
in Published Accounts

Before the start of a study involving Internet-based research, the researchers and their IRB must decide whether subjects' identities will be disguised, and if so to what degree. These guidelines assume we begin with material gathered via ethical means. (Ethics of data collection is beyond the scope of this discussion.)

Online Pseudonyms:

- Note that online pseudonyms function similarly to real names, and should be treated in the same way one treats real names, because:
  ➢ They are often de facto traceable to real names.
  ➢ People care about the reputation of their pseudonyms.
  ➢ In other words, they function for most purposes just like real names, and should be treated the same way.

Levels of disguising:

There is a continuum of possibilities from no disguise to heavy disguise. Where is selected along this continuum affects not just whether names and other identifying details are changed, but also the content of what may be published. Four spots along the continuum are characterized:

I.   No disguise
The Internet is rather like a playground for amateur artists. In many cases, people deserve credit for their creative work. In such situations:

- Pseudonyms and real names may be used with permission of the individual.
- The individual's claim to copyright over the work is respected.
- The real author of the work is verified. (Some work may be copied or highly derivative, meaning credit belongs to the original author.)
- The researcher should omit details that would be harmful to the subject if revealed. Example: Suppose you are studying artwork posted online, and discover that one of the most prolific artists rarely leaves his house and has few friends, devoting all his time to online art. You probably should omit that from the written account, even if it significantly contributes to your readers' understanding of the work being studied.

II.   Light disguise
- The group is named.

- Names, pseudonyms and some other identifying details (place names, organizational and institutional names, etc.) are changed.
- Verbatim quotes may be used, even if they could be used to identify an individual.
- Group members themselves may be able to guess who is being discussed.
- An outsider could probably figure out who is who with a little investigation.
- Details that are harmful to individuals should be omitted.

Example: the author used light disguise in her study of MOOSE Crossing, the educational online environment for kids she created. While sensitive details (for example a particular child's difficulties in school) would have enriched the written accounts of learning on the site, they were omitted.

III.   Moderate disguise
- A compromise position is chosen, incorporating some features of light disguise and some of heavy disguise, as appropriate to the situation.
- Details of the specific compromise are reviewed by the researcher's IRB (as they are in all levels).

IV.   Heavy disguise
- The group is not named.
- Names, pseudonyms and other identifying details are changed.
- Verbatim quotes are not used if a search mechanism could link those quotes to the person in question.
- Some false details may be deliberately introduced.
  - ➢ For example, if you are studying a support site for a chronic disease, you might change the disease in published accounts.
- No one would likely recognize the subject (except perhaps the subject him/herself).
- Someone deliberately seeking to find a subject's identity would likely be unable to do so.
- Details that would be harmful to the subject if disclosed *may* be revealed, because the subject has been carefully anonymized.

▪▪

Conclusion

The Internet blurs traditional categories like "professional" versus "amateur," "published" versus "unpublished," and "public" versus "private." Existing rules for the ethical conduct of human subjects research that rely on these categories are thus difficult to extend to this new medium. In this analysis, I have, first, reviewed how issues regarding disguising subject matter have emerged in my own work. Second, I have

discussed what it means to do human subjects research in the humanities; and, finally, I have proposed a set of guidelines for disguising (or not disguising) material collected online. This is just one of a host of complex ethical issues this new medium raises for researchers and IRBs. Data of course needs to be ethically collected before it can be ethically published. That issue and many others have not been addressed in this analysis.

What "seems reasonable" depends to a great extent on the metaphors and analogies we use to understand the phenomena at hand. We don't have intuitions for what is ethical in this new medium per se, so we instead compare it to other media and settings that are better understood. Which metaphors and analogies we chose greatly influence the conclusions we reach. We may come to very different final results if we say that "an Internet chatroom is like a public square" than if we say that "an Internet chatroom is like my front porch" or "an Internet chatrooms is like a telephone party line." In this paper, I have argued that the metaphor that the Internet is like a playground for amateur artists is useful in reasoning about some ethical dilemmas, because it highlights key features of the environment. However, it's worth noting that ultimately the Internet is neither a public square, porch, telephone line, or playground—it is the Internet. Over time the research community will need to develop intuitions for what is allowed there, equitably balancing the rights of Internet users and the value to society of research on this new medium.

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