

Five Provocations for Ethical HCI Research

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ABSTRACT

We present five provocations for ethics, and ethical research, in HCI. We discuss, in turn, informed consent, the researcher-participant power differential, presentation of data in publications, the role of ethical review boards, and, lastly, corporate-facilitated projects. By pointing to unintended consequences of regulation and oversimplifications of unresolvable moral conflicts, we propose these provocations *not* as guidelines or recommendations but as instruments for challenging our views on what it means to do ethical research in HCI. We then suggest an alternative grounded in the sensitivities of those being studied and based on everyday practice and judgement, rather than one driven by bureaucratic, legal, or philosophical concerns. In conclusion, we call for a wider and more practical discussion on ethics within the community, and suggest that we should be more supportive of low-risk ethical experimentation to further the field.

Author Keywords

Ethics; Human Trials; Research Practice

ACM Classification Keywords

H.5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous.

INTRODUCTION

In recent years, there has been increased discussion and debate concerning the role of ethics in HCI research. HCI research projects have generated controversy due to their purported unethicity [22]. While much of these discussions take place in informal venues, recent publications by Benford *et al* [7], and Munteanu *et al* [38], have brought ethical issues into the fore. Questions of how HCI research should be conducted, and the common values that underlie our research community, are receiving

renewed scrutiny. In this paper, we similarly engage with the ethical issues in HCI, but our goal is not to summarise or to establish what is ethical and what is not, but rather to question some of the taken for granted foundations of ethics in HCI.

Indeed, we would argue that discussions around ethics frequently suffer from “ethical creep”, where virtuous but impractical positions are advocated, and little attention is paid to how seemingly ethical positions can delay, damage or stop research, with serious implications [48]. In the wake of ethical controversy, the question is asked: “*what is to be done?*”, leading to the planning of further ethical scrutiny and regulation, to the submitting of more research to ethical review, and to the enhancement of existing protections and procedures. Yet, these efforts may not lead to any more ethical research and come at considerable cost [42].

Addressing this concern, our paper is not built around exemplary experiences from specific studies but rather an attempt to engender conversation through five *provocations*. These provocations formulate positions that are controversial, and we expect many might disagree with them. A provocation is the discussion and argument for a position that is used to highlight shortcomings in the consensus in order to encourage new, critical thinking [4]. These provocations are *not* guidelines or rules but tools for critical thinking. The aim is to cast new light on decisions that must be made while conducting our research. These five provocations draw on work on ethics from the Internet Research community and the social sciences more broadly. Our goal in writing them is to open, rather than conclude, discussion and to promote a shift away from positions that, while seemingly axiomatic, we believe could result in damage to the whole field. We encourage critical thinking, pushing against the potential chilling effects [2] on academic discourse of overly strong ethical regulation.

Our first provocation argues that informed **consent** is often unnecessary and can actually mislead by miscommunicating the benefits of participating in research. Second, we argue that research on vulnerable populations should more seriously evaluate who benefits from the research. We turn a sceptical eye onto the important benefits of research to researchers when compared to participants who are left without sustainable benefit after a trial. Third, we question why we preserve anonymity in research, when anonymity may be as much about

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CHI'16, May 07 - 12, 2016, San Jose, CA, USA

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ACM 978-1-4503-3362-7/16/05...\$15.00

DOI: <http://dx.doi.org/10.1145/2858036.2858313>

attempting to imply a generalisability of research findings than a matter of protecting participants. Fourth, we address the *bête noire* of ethical discussions – the institutional review board (IRB). We argue that IRBs can actually damage the ethicality of research, and that we need researcher and institutional responsibility rather than legalistic bureaucracy. Lastly, our fifth provocation goes to the commercial heart of much of HCI research. **If research in HCI is based on data that is not generally available, and so cannot be tested or validated, how is this science? We argue that research that is based on privileged commercial access to data should not be published unless access is provided to all researchers.**

In the discussion, we ask how we might develop new approaches to research ethics that engage with the **interventionist**, design-led research that is characteristic of HCI. The five provocations point to unintended consequences of regulation, oversimplifications of unresolvable moral conflicts, a **bias** in social desirability over what is ethical in effect, and a failure to consider the value of research. Some of the points we make conflict, intentionally, with aspects of current research **consensus**. We believe this can help advance the debate and chart future work. In conclusion, we call for the community to engage in low-risk experimentation with ethics in HCI.

BACKGROUND

We review briefly prior work on ethics within the HCI and Internet research communities. We will, then, consider in more detail two recent controversies that call into question some of the consensus around ethics and ethical practice.

Ethics in HCI

Much has happened since Wendy Mackay in 1995 outlined ethical guidelines for the then relatively new field of HCI [34]. Focusing specifically on the challenges involved when **conducting** research involving video, she argued that these guidelines should go beyond legal requirements. While using video in research was relatively new at the time, we have since then seen a range of new tools for conducting research, new domains of study, and a broad sea change in how knowledge is generated and understood in HCI. While SIGCHI members have notionally signed up to the ACM Code of Ethics [1], these 24 general statements are focused on professionals more than researchers.

More recently, Munteanu *et al* [38] draw on their experience in five studies with different populations and interaction structures. From fieldwork with parents of sick children to lab-based studies of interfaces for the blind they highlight the inflexibility of the current ethical review system and suggest **mitigating** action that can be taken while working within the system. These involve, among others, opening a ‘continuous dialog’ with members of the review committee and including a number of possible plans for fieldwork in the request sent for approval to allow the researcher to adjust their ethical practice in the field and follow a more ‘situational ethics’ approach.

In contrast, McMillan *et al* [37] focus specifically on the ethical challenges that have emerged with the possibility of **collecting large data sets using mobile apps**. The authors suggest a framework where the key dimensions are *identifiability*, and *user expectation*, that is, to what extent the data being collected or logged is on par with users’ expectations. When designing applications to be evaluated in a research study, researchers can specifically orient to the amount of relevant data they collect, and whether participants have a reason to expect this particular data to be included. Another relevant point they present, that we will discuss later in relation to issues of anonymity, is that data can easily move beyond control of the study. For instance, users’ content might be combined, through mash-ups and generative production, into other products shared beyond the particular study.

Benford *et al* [7] focus in particular on the peculiarities of studying cultural experiences within HCI and the constraints this places on the standard ethical procedure. They note that the notion of informed **consent** is negotiated with the audience through ticket restraints (age for example), the time, venue, promotional materials, and the artist involved in the performance allow people to use their own judgement without needing full disclosure before hand which may invalidate the performance. They also cover the need to consider the consequences of withdrawal and situations where the artistic integrity and experience can breach traditional ethical concerns such as privacy.

There has also been a series of workshops on ethics at the CHI and CSCW conferences. These have focused on ethics in online social research “in the Facebook era” [11], in large-scale user trials [14], in design research [10], involving co-creation and identity-making, and, most recently, in the study of online socio-technical systems “in a Big Data world” [21]. These workshops illustrate persistent interest in ethical issues as well as continued effort to work on them together as a community, with sensitivity to the shifting social and technological landscape, as well as the multidisciplinary nature of our field.

Ethics in Internet Research

Internet research is a field that shares much with HCI and has, moreover, engaged with ethical issues in depth. In 2002, the ethics committee of the Association of Internet Researchers (AoIR) **advocated** for “a dialogic, case-based, inductive, and process approach to ethics” in a report on ethical decision-making in internet research [20]. An updated report from 2012 [35] continues to highlight the value of addressing and resolving ethical issues as they come up across the many steps in a research process. Ethical concepts should ground inquiry, instead of being taken as “regulatory **hurdles** to be jumped through at the beginning stages of research.” ([35] p. 4)

The AoIR report acknowledges that there may legitimately be several differing views on norms, values, principles, and practices. Even though there is, at times, broad consensus

about whether a particular action was ethical or not, **ambiguity** and uncertainty are more common. Since different, conflicting judgments are possible, AoIR promotes a **deliberative** approach to working through ethical issues. This is reflected in that the report provides a set of questions to support ethical decision-making, rather than a set of practices.

Boellstorff *et al* [8] identify *the principle of care* as the most important guideline in conducting ethnographic research – one without which any set of ethics guidelines will be ineffective. In their view, “taking good care” of **informants encompasses** not only making every effort to avoid doing harm but also working to ensure that informants gain some reward from participation, if possible. This requirement arises from the power asymmetry between researchers and participants, as well as from the common imbalance of benefit between the two parties.

Further debate within the Internet Research community deals with presenting frameworks and supporting discussions around whether, for example, informed **consent** is necessary or not. **When our research data is accessible online, we need to ask if we could use it without the knowledge and consent of the participants.** One such framework is presented by Sveningsson [45] to help make the decision about whether or not data could be used for studies. She argues that it is not enough to only consider whether the data was made public or private, it is also necessary to think about the harm that could be done to the participants, and whether the data contained sensitive or non-sensitive material. Various other approaches recognise the need to adapt such guidelines to the unique, practical circumstances of a study at hand. The casuistic approach to ethics, for which the AoIR advocates, can go so far as to argue that “[e]thics should not be treated as *science*, but rather as a practical *art*” ([36] p. 26).

Recent ethical controversies

Facebook has been involved in two recent controversies in social research. In 2008 the “Tastes, Ties, and Time” study used data from Facebook usage to look at social ties amongst college students [33, 50]. The research group used a corpus of material from university students at a single US university. While the material was collected with the consent of the university and with the acknowledgement of the review board at the university of the researchers, the consent of all those whose data was collected was not obtained. The data was accessed with the collaboration of Facebook, and matched with records provided by the university, to add information about the participants. Even though the researchers took various measures to protect the anonymity of the informants, it did not take long until the university under study was identified. A commentary on the case by Zimmer criticised the research for a misconstrued understanding of the nature of privacy and anonymity on social media [50].

What this situation highlights is also a contextual concern, a need to consider in what context users shared information. **In this case there was unauthorised secondary use – when information posted on Facebook for social networking purposes was repurposed for research without authorization from the informants.** Or as Zimmer puts it, the research team failed “to recognize that users might maintain strong expectations that information shared on Facebook is meant to stay on Facebook.” Finally, and critically for the discussion in this paper, it should be noted that the study set-up was approved by an IRB. **According to Zimmer, this shows how review boards despite being experts on ethics do not always have the right expertise to review research protocols for internet research.**

A more recent controversy within, and beyond, the HCI community followed the publication of a large-scale experimental study of emotional **contagion** on Facebook [31]. This study caused **controversy** over the participation of Facebook users (who had their mood influenced through experimental manipulation of their timeline) without their consent. Jeff Hancock, one of the authors, reflected on the controversy during a keynote talk at CSCW 2015 [26]. Here, he argued that novel, large-scale methods and collaborations between academia and industry raise new ethical questions. He reported the ethical decisions made during the Facebook Emotion study and the reasons why the study attracted such massive attention and criticism. Hancock concluded with thoughts on how the criticisms might act as a gift for the research community, opening opportunities to move the discussion, and practice, forward. The impact of these controversies often takes the form of appeals to broaden the role and scope of institutional review boards [30]. Keegan [ibid.] argues that these appeals are a ill-conceived policy recommendations, emerging from moral panics [48]. Instead of increased oversight, he calls for avoiding “ethics creep” [25] by developing alternative ethical frameworks that reflect enduring moral commitments and apply them to the contemporary circumstances of HCI research.

One workshop at CSCW 2015 set out to document guiding principles for scholars doing research online in a “post-Snowden” world, where “many Internet users are suddenly more aware of who might be watching their digital footprints” ([21] p. 290). This effort is timely and important, since as Zimmer has pointed out, “[c]oncerns over consent, privacy and anonymity do not disappear simply because subjects participate in online social networks; rather, they become even more important.” ([50] p. 324). Indeed, if we do not settle these ethical questions ourselves they may be settled for us – by government, the mass media, or the corporations that fund our research. The “chilling effects” of these decisions could inhibit or outlaw research. We are faced with the possibility of researchers being prosecuted, with some suggesting even criminal responsibility [40].

FIVE PROVOCATIONS

Let us move on to our provocations. A provocation is the discussion and argument for a (possibly extreme) position which is used to highlight shortcomings in the consensus, and to encourage rethinking established positions. While the different authors have different positions on each provocation, we believe that each one works to provoke reflection on accepted positions that, although taken for granted, may be wrongheaded or damaging. These provocations are clearly not guidelines, advice or recommendations — they should not be understood or cited as established points but as controversial, conversation enabling, conjectures. As Cavell puts it, “appealing to ordinary language turns to the reader not to convince him without proof but to get him to prove something, test something, against himself” ([13], p76). Through these conjectures we hope to encourage critical thinking in new ways, to present challenges to our ethical reflexes and norms, and to raise discussion on the ways in which we approach our research.

In each of the areas our provocations touch upon, there has been considerable debate about how we should conduct research ethically: How might different ethical models apply to HCI? What might that mean for our research practice? In challenging current shared understandings, our provocations may read as unorthodox. Yet, we hope that considering alternative perspectives can help to sharpen our responses and provide insight into edge cases.

The first provocation takes on informed consent, connecting to questions and debates from medical research about whether informed consent is a realistic and necessary goal. Second, we explore the ethical requirements of working with vulnerable populations and the definition of a ‘vulnerable’ participant in the eyes of IRBs and researchers. Third, we engage with issues arising from conflicts in the goals and expectations of researchers and participants. Here, in particular, we consider the sharing and co-creation of data in the course of research. Fourth, we challenge the role of IRBs. As has been discussed at length before [42], one issue with IRBs is their overriding concern with bureaucratic and legal functions over their ethical role. We might ask, then, to what extent might these concerns cause IRB boards to harm research (and, as a result, societies) by either delaying or banning inquiry. Lastly, we discuss some of the issues related to the involvement of commercial organisations in HCI and how this can conflict with research practice. This issue is complicated by the availability of large datasets internally to organisations from their related corporate functions, and the problems of privileged access.

Provocation 1: Written informed consent does little to protect participants.

Since Nuremburg [3], the concept of informed consent has become central to medical practice, medical research practice, and, more recently, social science research. It works as a double cure: against researchers misleading or

deceiving research participants, but, also, against harm being done to participants without their knowledge. It has, then, both an informational and a duty of care function. It is in medical settings that informed consent has become most broadly institutionalised. Yet it is in medicine where informed consent has also been extensively critiqued. As Katz writes in two articles:

“The phrase “informed consent” evokes [...] magic expectations. Its protagonists often convey that once kissed by the doctrine, frog-patients will become autonomous princes.” [28]

“[I]nformed consent in today's world, is largely a charade which misleads patients into thinking that they are making decisions when indeed they are not.” [27]

Indeed, studies of consent practices throw light on the ways in which consent is almost always achieved through ritualistic procedures, through the use of professional authority, and where after consent is given patients have little recollection of what they consented to. In 1980, Cassileth *et al* [12] asked patients to recall the contents of consent forms they had completed the day before: “Only 60 per cent understood the purpose and nature of the procedure, and only 55 per cent correctly listed even one major risk or complication. We found that three factors were related to inadequate recall: education, medical status, and the care with which patients thought they had read their consent forms before signing. Only 40 per cent of the patients had read the form “carefully.” Most believed that consent forms were meant to “protect the physician's rights.” [12]

In turn, ethnographic studies [23] in medicine have illustrated how consent is something that is gained from patients, while conducting medical treatment, with doctors passing quickly through the consent procedure, and implicitly making use of their own position of power with respect to patients to obtain the consent they desired. Even in cases where written consent is obtained, this can be achieved in the form of a request by a doctor to “just sign this bit of paperwork”, instead of through the careful reflection of patient and practitioner. Looking at this practice in a positive light, we can understand that there are, necessarily, differing levels of expertise between doctor and patient – or researcher and participant – on the topic of the study being conducted. The point of *informing* the participant should not be seen as giving them the same understanding of the study as the researcher has. After all, to what extent can we expect participants to be ‘informed’ about a research lifeworld to which they might have little or no access (or interest)? How much of participants’ time can we demand before the costs of the research outweigh the benefits, or simply that many enough participants drop out to render the research meaningless?

Informing participants enough for them to validly consent is a negotiation, and in this negotiation the level of trust a

participant has in the researcher or clinician is a factor in how much information they need to decide whether to participate or withdraw. Having the participants trust that the researcher is not out to intentionally harm them, and that the risks involved are as described, should not be seen as an abuse of power but as fundamental to the trust relationship between participant and researcher. The standard IRB stance that all subjects are ‘manipulable victims’ [42] infantilizes them. The resulting legalization of the relationship between participant and researcher with a document that casts the researcher as an untrustworthy individual engaged in a dangerous practice and the participant as a victim without agency causes more harm than it prevents. This harm stems from undermining the participants’ sense of agency, and, as a result, lessening their sense of altruism, and exposing them to the negative emotional state of feeling that they must be on guard against being somehow *duped* by the researcher who attempts to gain their trust.

In medicine, patients usually describe consent as a way for the doctors to protect themselves legally, rather than as a procedure that protects the patient. [9] There is also the case of research with children, where the parents need to give consent and the children have no legal say in being studied [15]. Another recent HCI example of the asymmetry in power relations is the case of research with animals, where animals cannot give consent to participate in studies and design experiments [47]. We argue that the legalizing of consent obscures the ethical responsibilities in these cases.

We might consider consent in HCI studies to be of a higher quality. Yet, with Mechanical Turk studies and studies that make use of software deployed through app stores, or social media, is this really the case? In these settings, informed consent may be no more than the “click-through” set up around legal agreements which actively force users to lie that they have “read and understood” a long multi-page document in complex legalistic language (cf. [37]).

In many situations, there is no deceit and the possibility of harm to the participants is so slight as to be negligible. In such cases, the act of asking consent in a meaningful way may do more harm to participants (in terms of wasting their time) than the study itself. In interventionist HCI studies of this type, where the deployment of an application, service, or device and the access to it is the compensation for participation, the act of using the system could be interpreted as consent. Indeed, in much of research, participants benefit morally, socially, and personally from participation. Moreover, often research takes place using the passive monitoring of participants (e.g., logging, archival, and public/online observation). The personal benefits, in HCI, are not only of access to novel systems or services, or even the occasional payment for participation. Altruistic acts bring with them a personal benefit, in the form of a positive emotional change [42], and also a social benefit in being seen to be benefiting the wider community.

The right to sacrifice oneself for the benefit of others should be respected by researchers.

Our critique of informed consent should not be taken as an argument that it is not an important tool for ethical research, but rather that it should not be considered the ‘gold standard’ that research must always conform to. Also, gaining informed consent does not absolve the research itself of potential harm. We are arguing that the legal requirements should be separated from the ethical. In other words, not harming or burdening participants is more important than teaching them the intricacies of academic studies, and that given the multifaceted benefits of research, there is a level of harm and effort below which participation can be assumed as the default.

Provocation 2: Interventions with vulnerable populations must result in greater benefit for them than for the researchers.

One longstanding procedure with research is that special procedures need be administered when participants are members of vulnerable populations, such as the young, prisoners, or individuals with mental health issues. Most IRBs’ definition of participant implies vulnerability to the influence and power of the researcher. Yet, a member of a vulnerable population is seen to be at a greater risk of this influence. When the power differential, in socio-economic status or political leverage, between the researcher and participant is seen to be unduly strong, or when the risks of revealing membership of a population could harm the participants in some way, the population is seen as vulnerable.

The usual procedure for working with vulnerable populations is thus that special restrictions are placed on the research, extra procedures are implemented, and the research undergoes more extensive review. Certain sorts of research that are possible with non-vulnerable populations, especially those involving forms of deception or social interaction between participants, are often prohibited.

Dealing with these problems can be such a burden on research that researchers are reluctant to take on projects of this nature. For instance, research on patient-centred care is skewed towards excluding the patient, because the process of getting access to the relevant materials is complicated. Another example is research on children, where ethical standards call for informed consent from parents, in a way that makes consent procedures troublesome to the point where such studies are avoided. Even when, for example, children may be keen to be part of a study (and suffer from not being able to participate if their peers do), if their parents withheld consent (or simply do not attend to the request), the children are not allowed to participate.

This is not to say these are not distinctive ethical issues that need to be addressed. Outside HCI, in the development and social policy literature, there has been considerable critique of studies where little benefit comes to the community

itself. Some communities are heavily researched, such as poor or migrant populations in cities with strong research communities. This can result in a somewhat jaundiced view on research [16]. We might similarly ask whether some groups such as ‘turkers’ or ‘wikipedians’ have been researched out of all magnitude to their number.

Rather than focus on harm we might, instead, ask who benefits: Is it just the researchers? For example, in cases where technology is deployed to vulnerable communities, it is often taken away at the end of the study. The practical realities of research funding make this understandable, yet this is an area where the constraints placed on medical research have not reached HCI – and where they maybe should. With participants in pharmaceutical trials there are considerable post-trial treatment obligations – even if a particular drug does not reach the market [17]. Yet farmers in sub-Saharan Africa are not guaranteed the right to continue using a learning platform or a crop rotation calculator after a research project has dissolved. Instead of focusing on the possibility of participants being pressured into taking part in the study, perhaps the focus should be on reflecting on and engineering lasting benefit to the community being studied. Leaving broken technology, or removing devices at the end of a study can break with the duty of ongoing care that conducting ethical research requires.

The problem of pressure to participate also becomes less worrisome when participants are made to feel that they are actively collaborating in the study of or intervention into their community. While the relationship between participant and researcher is often much closer and more personal than what is expected by IRB rules and regulations [42], formalising this and recognising it as part of ethical practice could put HCI at the forefront of ethical research with vulnerable communities.

Provocation 3: Anonymisation should be an option presented alongside co-creation of research with participants, not a default.

A key premise in how we conduct ethical research is to protect the privacy and integrity of participants. This commitment is often attended to by anonymising data so that participants cannot be identified. There are two assumptions underlying this idea. The first is that it is possible for researchers to effectively anonymise their participants in publication or presentation. The second is that participants want and benefit from anonymity.

There is a relationship between the amount of information in any message and its anonymity [46]. The more information a message entails, be it with a quote, picture, or video, the more there is that can be used for re-identification with the help of other data sources. This means that in order to make a case in a paper or presentation, the researcher has to decide the level of anonymity to afford the participant in balance with the extra information that adds credibility to their claims, and

transparency to their justification. Moreover, this means that there is no such thing as an anonymous piece of data from a participant that also supports an argument. Family and friends can still identify an image with a blurred face. A textual snippet as short as a Tweet can be de-anonymised by comparing it statistically against online text posted to IMDB [39]. When we say that we will anonymise our participants, effectively what we mean is that we will not openly point to their identity and that we will not subject them to embarrassment or ridicule them by linking them to compromising data. If we, or the participants, truly wish to hide their act of participation altogether, then effectively no data can be directly shared from a participant.

Anonymity as a default is based on the idea that participants *want* to be anonymous. In the first provocation, we touched on the social benefits of participation. It can be hampered by anonymity. It also goes against some of the driving mechanisms of social media practices, of being seen and recognised for contributions, receiving likes and comments, and reposts in the form of e.g. retweets and regrams. Increasingly, it is being recognised that those who publish material online should be seen as authors or artists who should be referenced and acknowledged. For example, Bruckman argues for “[t]he 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”. ([11] p. 229).

In one of our own studies of Instagram use [49], it turned out that our study participants did not want anonymity. Rather, they were happy that their social media productions might gain a bigger audience through publication in research outlets. Therefore, we chose not to change the user names when presenting the material. This shows how traditional ideas about privacy and participants’ anonymity are no longer valid in certain communities and contexts. However, this is not to say that social media users do not have a strong sense of privacy and what it involves (cf. [9]). In fact, as boyd has argued, it is hard for users to understand the boundaries of the information they share online, since “[t]he dynamics of mediated social interactions – including invisible audiences, collapsed contexts, and persistent content, complicate things” ([ibid] p. 61). Publishing the data from our study lead to some discussion with the publisher who first wanted us to exclude all user names in the paper. Later, it was agreed upon that the images included should be considered artwork and we, therefore, needed copyright forms to be signed for each Instagram image being published. In this case, protecting the anonymity of the participants in the study, while seemingly the straightforward thing to do, would have led to going against the morals of the community under study. Similar issues also come up in ethnographic work. In Duneier’s book *Sidewalk* [19], he reports his participants’ pleasure in being named in “a book” – their struggles being acknowledged and their lives taken seriously. In another case [5], the decision to change user names to protect the

participants' anonymity was considered problematic, as discussed by the authors, since the group under study was marginalised. Disguising the name of an online community for young lesbian women, the authors argue, was in a way unethical because of the political repercussions: the anonymisation of names could be seen as giving into the assumption that homosexuality is something to be ashamed of and could risk further marginalising the group. As the authors put it: *"Overly protective research ethics risks diminishing the cultural capital of those engaging in cultural production through Internet technologies, and inadvertently contributing to their further marginalization."* ([5] p. 244).

In all research, it is important to recognise the asymmetry between those doing the research and those under study. As HCI researchers, we have an added responsibility because we often deal with system development in some form. This means that we have the power to control and administer the system being used. When publishing material based on studies of systems designed or developed by the researcher, it becomes harder to keep identities hidden. As Bruckman [11] points out, disguising the name of the online community she studied was impossible because she was involved in designing the platform they used. As HCI researchers, we have a different perspective here than social scientists, who are generally not directly involved in system development, but study existing platforms and technologies.

Moreover, often the anonymisation of data is not something that can be done without degrading the amount of information in the dataset [46]. This is an important consideration in terms of the replicability of research, especially given that the re-purposing of datasets by other researchers and in other disciplines is becoming an expected part of the lifecycle of datasets. Indeed, it could be argued that we are ethically bound to use the participation of each participant to the fullest possible benefit for society. We, therefore, ask what the reasonable limits to anonymity are and whether in the future it will be possible to promise participants that their identities are protected.

This becomes particularly challenging, as pointed out by McMillan *et al* [37], when identification techniques are gradually progressing, meaning that what is anonymous at one point in time might not be so in the future. As we saw with the university-based "Tastes, Ties, and Time" Facebook study, even though the researchers in this case thought they had taken "extreme measures" to keep their participants' identities protected, it only took a few days before the different pieces of information were put together and participants' identities revealed [50]. Whenever we promise participants that their data will be 'anonymous', what we are, in fact, promising is a best effort to stop the data being transferred to those with ill intent (already a legal requirement for anyone collecting other people's data in the EU), and a best effort attempt to make tracing an individual piece of data back to a single person a non-trivial

task. By using the word 'anonymous', we raise expectations, not only for ourselves as researchers, but also for the participants.

Provocation 4: Institutional review boards delay and damage research out of proportion to any harm they prevent. We should replace them.

Van den Hoonaard's ethnographic work on ethical review boards [48] presents a critical view of how much they understand of the research they are regulating and how much benefit (ethical or otherwise) they bring. Indeed, he goes on to argue that IRBs have resulted in a narrowing of methods, with researchers abandoning covert and action research, IRBs acting to "cut across the grain of social research". Schneider draws on this work, but goes further arguing in "The Censor's Hand" [42] that "imperial IRBs" have led to a widespread mis-regulation of research, with IRBs acting to censor research. According to Schneider, IRBs are propagated by "moral entrepreneurs", drawing on Becker's [6] description of "the crusading reformer who is profoundly disturbed by some evil and who feels that nothing can be right in the world until rules are made to correct it". Schneider goes on to outline ways in which research could be regulated without IRBs, such as drawing more heavily on researchers' own involvement and insights.

It is worth reflecting on the cost of IRBs. Due to the nature of the regulations that guide and bind IRBs, they are charged only to protect the participants from harm – not to weigh the costs in money or time, nor in terms of balancing the potential good the research could cause against the harm it risks doing. Ethical review processes are an extension of organisations and their practices, meaning that some boards will conduct well-balanced reviews, while others will not. At times, review boards will approve unethical research. However, due to their mandate, it is more likely that boards will over-react and reject, or delay, valuable studies.

Dingwall [18] documents the case of a study on hygiene practices in the British National Health Service. This social science study was to understand the practice of reuse of single-use equipment responsible for an estimated seven deaths per year. Yet, Dingwall depicts how this study was delayed and made less effective by the ethical review process he was institutionally forced to undergo. The review board asked for separate approval and review from each hospital. While this might seem like a reasonable request it "potentially generated [the requirement of] 1600 signatures and 9000 pages of documentation" [18]. Moreover, Dingwall argues that through slowing down the research, and the recommendations which helped cut infection rates, the IRB review resulted in a number of deaths. Delaying research can harm studies, slow down research, and delay any positive impacts that might result.

A more pernicious issue concerns the nature of IRB approval. Usually boards use review forms to elicit from researchers the ethical procedures of their research. Yet, much of the ethical work of studies is decided in the field,

on a moment-to-moment basis. For qualitative interview work, for example, in discussion with participants the study will be frequently re-described with adjustment to the participants' interaction. Study goals might be simplified or practical outcomes emphasised over academic ones. The nature of research also means that it can change radically post-ethical review. While most ethical procedures request re-review, the real-time nature of research is that it is often responsive to results as they happen. The pre-planned nature of research in HCI is exaggerated beyond credibility by the IRB process, and often research can change radically between design and implementation. This is the case especially where applications or services are being designed and built with the participants' input.

The IRB process comes at a monetary cost as well. Each form must be filled out by a, usually relatively highly paid, researcher, and each of these forms must be reviewed by a number of, usually more highly paid, reviewers. Each delay results in the time of the researchers who could be conducting research to be spent on other things. Moreover, the vast majority of funding for research that is subject to IRBs is funded by public money [42]. Another issue with IRBs is that as a small research field HCI protocols and experiments are reviewed by researchers from other disciplines. Ethical review boards rely heavily on the experience of their participants, their own judgments about ethics and their own knowledge from their own fields of expertise. This can result in nonsensical requirements put onto HCI research.

One way to ameliorate most of the issues this provocation brings up would be to conduct ethical review through peer-review. By placing review in the hands of practitioners on two levels – once during trial planning, and again before publication – the ethical sensitivity to participants that IRBs foster in researchers is kept, but extended through the research with a pre-publication check, allowing them to explain their ethical responsiveness. By publishing these ethical statements and their relationship to the research conducted alongside the results, ethical practice will not only be transparent – it will be something to be discussed and learned from. It would also provide a proof of ethical practice to help protect our field from external regulation and to inform others on our practices. Here, the relatively small size of HCI can be turned to an advantage.

Provocation 5: Publication of research performed with, or within, a commercial entity should be blocked until the complete dataset is made available to others – both during review and for future replicability of analysis.

The last provocation we engage with concerns the interactions between commercial interest and research ethics. This provocation is not only about the replicability of studies performed on corporate data, it also puts attention on HCI research carried out on commercial applications or services where one of the goals is to improve it. By forcing the data to be opened to academics and competitors alike, companies that wish to take advantage of the expertise in

the field will have to fund foundational research, the results of which they and others can apply, rather than pushing research into a narrow, blinded, alleyway.

Much HCI research is either funded directly by commercial entities, or is even conducted within those commercial entities. In most cases, there is little conflict or issue – research usually is sufficiently foundational that there is some distance between commercial products and the research. At other times, the research is focused on the invention of new potential products or services, or the identification of user 'needs'. The practical application of computer science is such that its outputs are frequently directed in this direction, and the funding or location of the research is less important.

As others have noted, however, there is at least the potential for problems here [41]. To take an analogous example, research into gambling has long suffered from problems in that funding for the majority of research comes from companies that profit from gambling [43]. To be free to consider whether the products we are designing are harmful in some cases, funding from those who profit from selling them might constitute a conflict of interest. Issues that are damaging to the industry overall, or that question the role of technology itself, may be neglected.

The popular game Candy Crush Saga, for example, is estimated to earn the majority of its money from less than 5% of its users, so called 'whales' [44]. While the publishers may be willing to fund research on the compelling nature of their game for these players, who may spend hundreds of dollars a day on the game, research on the harm caused or the nature of addiction to digital games may find it difficult to get access to the same data. After all, it would be somewhat unreasonable to expect a commercial entity to fund research that would undermine its product. An advantage of the technology field, especially in HCI, is that there is such diversity in organisation and product, that even the largest actors are not monopolistic in the research space. However, while this has not presented itself as a problem so far, it could as the field matures.

As researchers, we present ourselves as being scientifically motivated, when it can be argued that the ultimate purpose of our work in HCI is to make money for the corporations funding the research by informing them in how to build better products. However, there are times when making money might conflict with making a product better. For example, Quicken has conducted considerable user-led research into tax preparation. At first appearances, this would seem to have a noble goal: making financial software easier to use. When the topic was explored at a recent workshop at CHI [29], it was noted that the best tax return may be no tax return, but this is something Quicken has politically lobbied against while funding research on making tax return software easy to use.

To be clear, we are not arguing against corporate funding of research, or even that research with a commercial aim is ethically problematic. Rather, it is that such funding creates blind spots and that it is important to both acknowledge and engage with these issues as topics of research in their own right. As a community, we must face the problem head on and discuss inserting into our everyday research practice the safeguards, checks, and balances that will engender confidence in and respectability of HCI research.

DISCUSSION

Our five provocations put forward problems with current ethical practice within HCI and a series of quite radical and wide-ranging solutions to them. These solutions should not be seen as a manifesto or statement of intent. They are meant as tools to allow us to better discuss the current state of our ethical obligations and practices in light of alternatives that broaden the room for thought. We should emphasise that we are not abating anyone to ignore their current organisational or legal regulation – in nearly all cases research needs to be lawful (see [40] for a rare exception). Yet we are encouraging debate about those regulations and laws.

We are also not arguing for the abolition of IRBs overnight, or against consent and anonymity in all cases, or that corporations could never fund valid research. In some senses the provocations are extremes to counter prevailing wisdoms and to help us consider alternatives. Our provocations work, then, as ways of encouraging new thinking that does not follow the “review and ban” ethical stereotype. The alternative that we argue for here is one that considers ethics more as a situational aspect of our interactions with research participants and communities.

A key notion that underlies our provocations, and ethical discussions and guidelines in HCI and other fields, is the definition of *harm* to participants and beyond. The definition of harm by ethicists and IRB boards is something that goes beyond that defined in law. Here, Schneider [42], notes that in law, at least in the USA, “*because society’s ‘rough edges’ need ‘a good deal of filing down,’ people are ‘expected and required to be hardened to a certain amount of rough language’ and ‘inconsiderate and unkind’ acts*” ([42], quoting from the American Law Institute *Restatement of Torts*, 1965). Yet, the harm envisaged by IRBs across North America and Europe, as well as by professional bodies regulating medical and psychological research, does not take into account the interactions that participants *must* have in everyday life to make them valid participants in the first place. Making someone mildly uncomfortable, slightly irritated, or momentarily inconvenienced, should not constitute a barrier for research. Yet, it does. This is not in itself a provocation as, in our opinion, any call to change the current definition is not a provocative statement.

How the ethics of researchers come into play in the research encounter, and how research ethics and purposes may come into conflict with the concerns and ethics of those who we

study is of interest. It is not just that ethical guidelines need to be “applied” but rather that they are artfully manipulated to make research possible while acting ethically towards participants and the wider community [24]. While existing ethical guidelines can provide some information, in this paper, we have explored the gap between rules, regulations and ethical bureaucratic instructions, and the practice of ethical research and judgements in HCI research. We want to open the discussion by bringing out some points that are of particular relevance for HCI.

The distinctive character of ethics in HCI

HCI’s ethical challenges are, of course, strongly related to broader ethical discussions in the online social science research communities. As with social science ethics, researchers must grapple with issues such as how to present themselves as researchers, who gets to benefit from research, how is participant anonymity to be handled, and so on. Yet, there are distinctive challenges, even from the growing ethics of HCI research field [7, 14, 37, 47].

First, in HCI we are frequently involved in the creation or design and implementation of particular social environments. HCI researchers are frequently involved in actually building the very environments that they study. This already sets up an interesting position for researchers – they are automatically in a privileged position vis-à-vis the participants. Second, in many cases, the outputs of HCI research are not only constrained to understanding and representing those being researched, but have an orientation towards change in terms of design. Researchers attempt to design systems using and drawing on the studies undertaken. This gives participants a conversely privileged position – they can influence the future shape of the tool they are using. This is not a unique position. For example, in the social sciences, researchers might participate in what they study and policy orientated research can run into similar issues. However, it is a particular challenge for those who might recruit participants with reference to the company that they are researching for, or for what the results could potentially be used for.

Situated, Ordinary Ethics

We suggest a distinctive approach to ethics, one that is grounded not in the bureaucratic or legal concerns but rather in the sensitivities of those being studied and the practice of being ethical. As an contrasting example, in Goffman’s view interaction’s obligations are more ‘etiquette’ than ‘ethics’ proper, and we strain to preserve a semblance of propriety in ‘ceremonial’ fashion, irrespective of whatever ‘substantive’ moral sentiments may – or may not – drive them [32]. In the same way we hope to find HCI ethics grounded in everyday practice and judgements, rather than in reflection on philosophical abstracts. Notions such as busyness, getting things done, minimising harm, altruism, and showing respect by understanding that the participants are also striving to behave ethically, need to be

adopted to make ethical research become practical and achievable.

To take this approach we suggest three practical measures that could be taken in future work:

1. *Differentiate between ethics as practice versus ethics as law.* As discussed in this paper, and as several of the studies we have referred to have highlighted, it is important to recognize that IRBs do not solve ethical issues, they only transform them. Review boards deal with the legal implications of studies, whereas researchers have to consider a range of different moral and ethical restrictions. Researchers are often doing more than what is asked of them legally, or in fact sometimes promise more than they legally can promise. This does not mean that we should not have review boards, but it means that we need to put emphasis on ethics as practice. One of the practical implications of this could be to focus on learning among peers and providing opportunities for junior researchers to learn from those with more experience, and in doing so keep an open debate on ethical considerations in research practice. As Guillemin and Gillam [24] suggest, ethically important moments in practice should be reflected upon. To keep up this ongoing debate is particularly important in our domain, where we constantly encounter new configurations of users and technology, and where laws, regulations and guidelines are not updated with the same speed.

2. *Support low-risk experiments around ethics.* The idea of experimenting with ethics may seem like a dangerous (even unethical) position. Yet if we take the perspective that ethics is a situated practice then we can argue that we need to discover and explore how different ethical positions might fit different scenarios. There is no set of primary ethics that can be followed in every situation, and in different situations we might need to be inventive to understand how research might be conducted without damaging others. One way of finding out what the particular ethical and moral rules of a particular community are, and how best adapt to them, is simply to start conducting the research and learning from the participants.

3. *Start a conversation on the definition of harm in ethics.* It is almost without question that the broad and sensitive definition of harm used in ethics is, in itself, harmful. Where there are disagreements on the best course of ethical action there will be disagreements on what constitutes harm to a participant. We need to move beyond the current definition which is often taken to mean ‘any negative effect; emotional, physical, social, or monetary’ and begin to balance harm against not only the good that the research may do in the future but also the good participation can do for the participant and their community.

There is no right to not be offended, but the legal definition of emotional tort may be a step too far. We would not want research to routinely cause the friction and inconvenience that other problematic encounters do in day-to-day life. The

political or religious zealot haranguing pedestrians may be something that people must live with, but is not a model for ethical research. However acknowledging the fact that some inconvenience can be caused, and that the benefits can make up for that inconvenience is a step toward a consistent and coherent definition of harm for ethics in HCI.

CONCLUSION

In conclusion, we call for a wider and more practical discussion on ethics within the HCI community. These provocations should be taken *not* as guidelines or recommendations but rather as a starting point for conversations around how, and if, we act ethically in our research. Our goal has been to expand on the assumptions that are embedded within much of the current discussion on ethics in HCI, and in drawing on literature from outwith HCI to show that the taken-for-granted positions may not be as assured as one might think.

In particular, we think that there is an increasingly important role for ethical experimentation to inform our ethical practice. We, as a community, must explore how participants themselves *do ethics* – and in so doing, recognise that ethical practice does not lie solely in the domain of the researcher. As some of the work cited here shows, there is often a divide between participants’ views of ethics, and those of researchers, and yet another divide between those and the mandates of institutional review boards. The opportunity presents itself to exploit these gaps in order to find out more – not only about how we strive to behave ethically in our research, but also in how we research the ethics of HCI as a topic in itself.

ACKNOWLEDGMENTS

The research was made possible by LETStudio, University of Gothenburg, and a grant from the Swedish Governmental Agency for Innovation Systems (VINNOVA) to the Mobile Life VINN Excellence Centre. We thank Erin Brady and Pedro Ferreria for a discussion on challenges in ICTD research that led to this paper’s second provocation.

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