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# Rethinking Informed Consent

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**Abstract**

Informed consent has become the baseline for ethical practice in research with human subjects. While such practice can be a good safeguard against researchers taking advantage of participants, the side-effects – ethical complacency, colouring the relationship between researcher and participant, training participants to consent with little reflection – are often ignored. We argue that informed consent may, in some cases, be doing more harm than good due to these issues.

**Author Keywords**

Ethics, Informed Consent, Harm

**Introduction**

This paper highlights one of the five *provocations* we present in our CHI 2016 paper [4] that aims to broaden the conversation on ethics in HCI. As we write in the paper: “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 [1]. 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.”

In a previous workshop at CHI [6] and a subsequent paper [9], we have focused specifically on the ethical challenges that have emerged with the possibility of collecting large data sets using mobile apps. There, we proposed 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. This dimension of expectation is, we have come to realise, a key measure of the amount of information that needs to be imparted to a participant for the informed consent model to work. 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 in the study procedure. If participants would expect an application to collect certain types of data, then the researcher's burden to inform is different than in cases where they want to collect data that are seemingly unrelated to the apparent functioning of an application.

In our work on improving disclosure regarding logged information as a way to improve consent practice for mobile applications [10], we saw that in cases where research consent and legal consent are combined the information absorbed by the participant is less than ideal. The 'trained to accept' [2] nature of the consent here was checked by displaying the participants' data back to them (GPS locations of use in this case) in different forms and assessing with an in-app questionnaire their resultant understanding of what data they were sharing.

The concept of informed consent is central to medical practice, medical research practice, and social science research. It works to guard against researchers misleading or deceiving research participants, and against harm being done to participants without their knowledge. It serves both an informational and a duty of care function. But all too often, consent is thought of

in terms of a legal duty. This can obscure or obfuscate the goals of getting consent.

### **When Informed Consent Causes Harm**

It is in medicine that informed consent has become most institutionalised, and where the practice of informed consent has been most extensively critiqued. Studies of consent practices show how consent is almost always achieved through ritualistic procedures and the use of professional authority. In these situations, after consent is given patients have little recollection of what they consented to. In 1980, Cassileth *et al* [5] asked patients about 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.'"*

Ethnographic studies in medicine [8] have also illustrated how consent is something ritualistic and inherently reliant on the authority of the medical professional. It is gained from patients while the doctor is conducting medical treatments, with doctors passing quickly through the consent procedure implicitly making use of their own position of power to obtain the consent they desire – or in their view *need* – to serve the best interest of the patient. In cases where written consent is obtained, this sometimes comes in the form of a request by a doctor to "just sign this bit of paperwork", instead of through careful, joint reflection of patient

and practitioner. The equivalent of this approach to informed consent in digital settings is treating consent as a click-through-agreement.

Looking at the practice of gaining consent 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. It is fair to ask to what extent we can (or should) expect participants to be 'informed' about a research life world 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 lead to many enough participants dropping out to render the research meaningless?

#### *Informed consent and vulnerable populations*

We argue that the standard IRB stance that all subjects are 'manipulable victims' [11] infantilizes them. It reduces participants' agency and overstates the power differential in most participant-researcher relationships. While in some cases, for example when it comes to work with vulnerable populations, such safeguards to consent may be necessary, they should be brought about through negotiation and collaboration. Otherwise, the 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 risks causing more harm than it prevents. This not only undermines the participants' sense of agency, it also results in a lessening of 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.

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 [7]. 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 [12]. We argue that the legalizing of consent obscures the ethical responsibilities in these cases.

If framed as a conversation, a negotiation where a mutual trust and understanding needs to be achieved with the participants rather than the signing of a legal document then children and other vulnerable populations are much more easily empowered with the agency and respect they deserve.

The benefits of participation (beyond remuneration or access to technology or systems) should also be taken into account. Altruistic acts can bring with them a personal benefit, in the form of a positive emotional change [11], and also a social benefit in being seen to be benefiting the wider community. Participants' right to sacrifice oneself for the benefit of others should be respected by researchers.

#### *Why bother the participant with consent?*

Where there is no deceit and the possibility of harm to the participants is so slight as to be negligible, why ask for consent? 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.

Indeed, as boyd [3] points out, as website users we are continually being experimented on through A/B tests as a fundamental part of our use of the web. Algorithms such as the Facebook timeline *depend* upon emotional manipulation and testing for their success. The outcry around the emotional contagion study may have been less about testing and consent, as such, but about users' relationship with and understanding of Facebook as an organisation and service.

One could argue that in interventionist HCI studies 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. This would depend, of course, on the design of the system and participants' reasonable expectations with regards to the data being collected for analysis [9]. As touched upon earlier, participants can benefit morally, socially, and personally from participation in research. When research takes place using the passive monitoring of participants (e.g., logging, archival, and public/online observation), it could be argued that the default stance of a responsible citizen (paying for this research already through their tax contribution) should be one of participation.

### **Conclusion**

We don't want to argue here for an end to informed consent, or 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 and that somehow magically resolves ethical issues. It must be understood, by researchers and participants alike, that 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, and that there is a level of harm below which participation should be assumed.

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