Constructing an ethical framework to evaluate HCI lab studies involving wearable technology

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Introduction

One category of HCI research often disregarded by IRBs is that of lab studies that evaluate effectiveness of new interaction techniques/systems involving sensing and wearables. In this paper, I study the risks such research poses to the participants and propose a policy to mitigate those risks.

Ethical framework

The lens through which I evaluate participant risk will be based upon two ethical frameworks:

1. McMillan et al. (2013)'s framework for large-scale, mobile HCI trials
2. Frauenberger et al.'s (2017) "In-Action Ethics" framework for "dynamic, unpredictable and participatory" HCI research

Identifiability of data vs. expected collection

McMillan et al. focus on data collection, describing four classifications of ethical responsibility in HCI trials, defined by two key dimensions:

A-1. Users' expectations of data usage
A-2. Level of anonymity afforded by the data logging, storage and transmission processes

Dynamic, participatory design

Frauenberger et al. address ethical dilemmas in modern HCI work that is "dynamic, unpredictable and participatory". They identify a number of ethical challenges, including:

B-1. If the decision-making scope is shared between researchers and participants, ethical responsibility and accountability should also be shared.
B-2. Protecting participants cannot always be fully guaranteed. Informed consent has limitations, especially when the research process and outcomes are partially unknown.
B-3. Involvement is not always voluntary, and withdrawal is not always possible in the middle of participation.
B-4. Data may be collected in unintended ways that deviates from the initial protocol.
B-5. The personal, cultural, socio-historical context (especially of the participants) of the research influences the ethical approach required.

Participant risk factors

Unfair subject selection

B-5 is contextualized in lab studies involving wearable medical devices targeted at vulnerable populations, where risk levels for diseased patients are inherently more substantial than those for healthy populations (Tu & Gao, 2021). Some studies may even aim to intentionally trigger a physiological or psychological condition in participants, such as stress and fatigue experiments.

Insufficient risk assessment

Risks involved in a study are often communicated only at the beginning of the experiment and assumed to be constant throughout the study. In some cases, some known risks are not communicated at all (***B-3***).

Collection of large-scale data

Researchers with limited hardware development resources may choose to use commercially available wearable devices (e.g., Fitbit devices) to collect large-scale data, beyond those required of the study. Since use of the device would be associated with an end-user licensing agreement, this complicates issues surrounding data ownership and usage, especially if the device manufacturer shares tracked data with third parties. This exemplifies ***B-2*** and ***B-4***, highlighting a scenario in which researchers do not have full control over the data.

Poor management of collected data and informed consent

Researchers may employ continuous, real-time transmission of collected data to other devices or cloud storage using wireless communication services. However, if not securely encrypted, the data may be exposed to bad actors in the participants' wireless network.

Additionally, researchers and participants may not be on the same page about the types of data collected as well as the identifiability of the data (mismatch between ***A-1*** and ***A-2***). In cases where participants do not wish to be identified, researchers may promise data anonymization via removal of identifying features, but this has been proven to be ineffective (Hewson, 2016), as other features can be used by researchers to recreate (re-anonymized) profiles of participants.

Policy proposal

I propose the following protocols to determine whether an HCI study satisfactorily protects participants:

Fair and sensible subject selection

Researchers should weigh the potential scientific value against the risk susceptibility for vulnerable groups to determine the appropriate exclusion criteria. If a participant is selected, they should also be individually informed of their risk susceptibility. If they are excluded, they should be informed of the reason.

Transparent and continuous risk assessment

Before commencement, human trials experimenting should clearly identify known risks to participants and outline all possible precautionary and intervention steps to minimize said risks. Suspected but unproven risks should also be communicated to participants.

Researchers should continuously monitor participant risk levels. Should there be internal (e.g., flaw in wearable tracker design) or external (e.g., other research suggesting increased health risk) reasons that the risks involved have changed, these changes should be communicated to the participants immediately. In light of the updates, participants should have full autonomy to end their participation immediately.

Avoiding use of commercial devices

Using commercial wearable devices should be avoided as much as possible. Nevertheless, if this is done, researchers have the responsibility to inform participants of potential secondary usage of data, and provide as much information as available, referencing from the privacy policy documents of the commercial devices.

Additionally, in order to facilitate an environment of shared accountability between researchers and participants (mitigating ***B-1***), researchers should highlight to users:

1. Exactly what measurements are being collected via the device sensors
2. How frequent the measurements are
3. How the measurements are being transmitted to the researchers
4. How to stop the device from taking the measurements

Secure data management

Ideally, if researchers' access to the data is not urgent or required to be synchronous, the wearable device should not have wireless connectivity (Wi-Fi, Bluetooth, etc.). The recorded measurements should be stored on-device, and transmitted directly to the researchers via a wired connection, at whatever frequency is reasonable for the study. If the study strictly requires

synchronous or frequent transmission of data from the device to the researcher, all data should be securely encrypted and transmitted.

Respecting informed consent

If a participant expresses their desire not to be treated anonymously (***A-1***), that decision should be respected, even if the identifying features are not useful for the study. McMillan et al. further proposes that participants should also be offered the opportunity to review (and remove) the data they have generated.

If a participant seeks anonymity, besides removing identifying features, researchers should employ techniques to mitigate the possibility of re-anonymizing the data (***A-2***), such as:

1. Implementing differential privacy by adding noise to the data
2. Decentralizing the collection of data, similar to the DP-3T protocol for COVID-19 contact tracing (Li & Guo, 2020)

Another technique to create more shared accountability (***B-1***) in the management of informed consent is to move away from simplified, one-time user agreements, towards Just-In-Time Click-Through Agreements (Patrick & Kenny, 2003).

References

1. Frauenberger, C., Rauhala, M., & Fitzpatrick, G. (2017). In-action ethics. *Interacting with computers, 29*(2), 220-236.

2. Hewson, C. (2016). Ethics issues in digital methods research. *Digital methods for social science: An interdisciplinary guide to research innovation*, 206-221.

3. Li, J., & Guo, X. (2020). COVID-19 contact-tracing apps: A survey on the global deployment and challenges. *arXiv preprint arXiv:2005.03599*.

4. McMillan, D., Morrison, A., & Chalmers, M. (2013, April). Categorised ethical guidelines for large scale mobile HCI. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems* (pp. 1853-1862).

5. Patrick, A. S., & Kenny, S. (2003). From privacy legislation to interface design: Implementing information privacy in human-computer interactions. In *Privacy Enhancing Technologies: Third International Workshop, PET 2003, Dresden, Germany, March 26-28, 2003. Revised Papers 3* (pp. 107-124). Springer Berlin Heidelberg.

6. Tu, J., & Gao, W. (2021). Ethical considerations of wearable technologies in human research. *Advanced healthcare materials, 10*(17), 2100127.