

IRB:Taming the Wild?

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Abstract: Dealing with the Institutional Research Board (IRB) has become an important part of doing human subjects research, but not without encountering criticism and controversy about applying a biomedical ethics model to doing research in the social sciences. Open discussion about how the IRB shapes our research has been largely absent from the HCI community, yet this issue could well be the deciding factor on whether or not we are able to carry out our plans to perform research in non-traditional environments.

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The IRB (institutional research board) has become an integral part of doing human subjects research in the United States. Inspired by such horrors such as the experiments done by the Nazis and the Tuskegee experiments where participants did not give informed consent to participate in the trials, the protocol serves to ensure that research is done ethically and vulnerable subjects are protected. However, the scope of the IRB has extended to include many fields such as anthropology, oral history and journalism which has caused increasing controversy as scholars argue that the biomedical model of the IRB does not apply to them. For example, historians object to the frequent requirements imposed on them to anonymize their participants or destroy recordings, journalists argue that IRB interference violates their first amendment right to freedom of the press and ethnographers stress that the requirements of stipulating interview questions in advance goes against the normal practice of conducting field interviews which build on new information gained during the course of a conversation.[1] So how does the IRB impact the practice of user-centered design and usability in the wild? I argue that it has a dampening effect on education and discourages the involvement of the user in design which seems to contradict the spirit in which the IRB was started.

I was first introduced to the IRB my first semester as a master's student. My project team, composed of 3 other new graduate students thought it would be fun to create educational tools for children for a museum exhibit. We obtained the cooperation of a local science museum and had the project well under way when we belatedly found out that projects involving minors were not eligible for expedited

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review by the IRB and that we would it would probably take months to get approval, which would not allow us to finish the project before the semester was over. We were allowed to implement our kiosks in the museum but were not allowed to talk to the kids playing with the project or even leave survey cards for them to fill out so the evaluation phase consisted of us staring at the kids from a distance of about 3 feet. Needless to say, the project grade suffered, and chalking it up to experience, I warned incoming students to avoid projects with kids unless they were working with a faculty member who had a pre-approved IRB protocol.

My most recent encounter with the impact of IRBs on research was on a project dealing with a mobile social networking software to aid in therapy sessions. In the scenario described, the patient would be encouraged to turn to their device to find one of their fellow patients to help them through the panic attacks. As someone who had suffered from panic attacks firsthand as a teenager, I found this scenario naïve and possibly dangerous on several levels, not the least of which would be potential dependence on a device and the increased panic when inevitably people with busy lives of their own were not available to help the person in need. However, the researcher in charge of this aspect of the project admitted the IRB rules did not allow them to consult with people who suffered from panic attacks about what the implications would be in designing a system so they consulted exclusively with clinical psychologists who would ostensibly be deploying these systems on their patients. Ironically in raising my concerns, I felt that I put myself at risk in front of my advisor and his colleagues who were now primed to my experience on the other side of the psychologist's couch.

Now the IRB is well within its reason to consider children and mental health patients as protected populations who merit special ethical consideration. But the point with these two examples is that the systems were still to be deployed to these groups—the intervention with the IRB was limited to the use of direct evaluation and input into the design and experience of the product. We were not prevented from letting kids use the kiosk--what was deemed potentially harmful was allowing us to talk to them to get even basic feedback. For the second example, trials would be conducted by experienced psychologists to get feedback from the patients, but the fact that the patients weren't involved from the beginning of the design process meant that they were being denied a voice which could potentially create a dangerous situation at the time of implementation and might have prevented the design of a more suitable product that met their needs.

The first example was a clear case of inexperienced researchers matched with a first-time instructor that approved a project that had little chance of being approved by the IRB. It is not a coincidence that the best class research I did during grad school was with a faculty member who was savvy enough in her dealings with the IRB to do a group protocol for our research projects so we could spend more time actually doing the research rather than spending a good part of the semester revising and re-submitting protocol. For the experienced researcher with the time and patience to invest the months involved in getting a protocol approved, this might not even be

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an issue. But for students hoping to finish a class, get experience and graduate within a fixed amount of time, this is sometimes not an option. Anecdotes abound of students deciding to go with “safe” topics, deliberately restricting sampling to people from their university or in the case of some top graduate students deciding against continuing in academia because of the frustration and limitations involved with getting research approved by the IRB. After taking a qualitative methods class where we couldn’t do any interviews or interaction with participants aside from observations so we could qualify for expedited review, I was left to wonder whether or not it was ethical to prevent students from learning how to practice first-hand ethnographic research under supervision and instead release them without having had that prior experience into the “real world” where there are no IRBs. Much as grade school teachers are forced to “teach to the test” it seems that university instructors are being forced to “assign to the IRB”, letting potential restrictions get in the way of education and making the focus on rounds of administrative paperwork rather on the ethical research that the IRB is supposed to stand for.

The second example is a little trickier to navigate. After all, it would be ludicrous to ask anxiety patients to evaluate the development of a potential medication before going to clinical trials since they are not experts on pharmacological reactions. But I feel like this analogy fails when it comes to user-centered design. Part of the justification for involving the user from the beginning is to create products that work for them instead of waiting until the end of the design cycle to evaluate usability, when there is not much opportunity to change and when we are limited to recording their reactions. Explicitly denying the potential user to have a say at a stage in which the potential harm is at its least and when they have the most opportunity to make an impact is demeaning and evokes the feelings of patient powerlessness that motivated the need for an IRB in the first place.

A recent white paper[2] which addressed the mission creep of the IRB and made recommendations for change proposed that information be collected on both good and bad IRB practices since we can not rely exclusively on rumors and anecdotes to advocate for changes that need to be made. With a few notable exceptions [3], we seldom hear about the impact of IRB on determining how we carry out our research and if it does in fact promote more ethical research or ends up preventing research from being done at all. Given the wide interdisciplinarity of the HCI community, how would we even decide on potential changes? Should we band together with other social science scholars to press for removing our research from IRB review? Would we be able to come together as a field to decide on a code of ethics as with the case of journalism? Should students band together to press for less stringent policies for class projects or should instructors be pressured to do work in advance to insure that their student’s projects can be approved within a reasonable amount of time? Should we focus our time on educating the IRB about how user-centered design and usability research works so that our studies get approved more readily? Will it be up to advocacy groups and researchers coming from “protected” populations to ensure that their voices are represented fairly and not merely gagged? These are some of the questions that I think would be worth discussing in this workshop.

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