Situational Ethics: Re-thinking Approaches to Formal Ethics Requirements for Human-Computer Interaction

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ABSTRACT
Most Human-Computer Interaction (HCI) researchers are accustomed to the process of formal ethics review for their evaluation or field trial protocol. Although this process varies by country, the underlying principles are universal. While this process is often a formality, for field research or lab-based studies with vulnerable users, formal ethics requirements can be challenging to navigate – a common occurrence in the social sciences; yet, in many cases, foreign to HCI researchers. Nevertheless, with the increase in new areas of research such as mobile technologies for marginalized populations or assistive technologies, this is a current reality. In this paper we present our experiences and challenges in conducting several studies that evaluate interactive systems in difficult settings, from the perspective of the ethics process. Based on these, we draft recommendations for mitigating the effect of such challenges to the ethical conduct of research. We then issue a call for interaction researchers, together with policy makers, to refine existing ethics guidelines and protocols in order to more accurately capture the particularities of such field-based evaluations, qualitative studies, challenging lab-based evaluations, and ethnographic observations.

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H.5.2 [User interfaces]: Evaluation/methodology; K.4.1 [Public Policy Issues]: Ethics.

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Ethics; Research protocol; Field studies; Situational ethics; Vulnerable populations.

INTRODUCTION
Recently we are seeing a wider and changing range of studies, from traditional usability evaluations to ethnographic research and to user-centered or participatory design. Our user populations have also changed; they now often include vulnerable groups – participants who may benefit the most from our research but potentially suffer from researcher engagement. HCI as a discipline has always been dedicated to studying and designing for such user groups which often entails work outside the traditional confines of laboratories. While ethics has long been an essential part of designing research in HCI [21], these practice-based methods can more *dynamically* affect all aspects of ethically conducting the research: privacy, confidentiality, consent, harm and risks, trust and authority.

In most cases, preparing for a study or evaluation involves a formal process of receiving approval from an administrative body responsible for ensuring all research follows sound ethical principles. In Canada, these bodies (Research Ethics Boards – REBs) are present in all universities as well as the National Research Council, and are guided by the formal Tri-Council Policy Statement on Ethical Conduct for Research Involving Humans [31]. In the United Kingdom, research involving human subjects is carried out under the governance of various bodies (professional organizations, universities, the National Health Service - NHS) and their policy statements (Ethical Guidelines for Good Research Practice by the Association of Social Anthropologists of the UK and the Commonwealth). In countries such as the US the ethics guidelines are less centralized (e.g. specific to each university); nonetheless, the principles and implementation are shared across countries and disciplines and the subject of increased scholarly attention (as illustrated by workshops such as [8]).

For most research, the application of such guidelines is straightforward. However in some cases researchers find themselves facing various serious ethical dilemmas when the realities of their field research do not match or even contradict the formal requirements of the ethical approval process [14]. This can be partly due to the bureaucratization of the ethics approval process in its attempt to formalize universally accepted principles (privacy, confidentiality, avoiding risks or harms [13]). However, we are currently witnessing an increase in studies conducted outside traditional contexts (e.g. mobile interfaces providing health or educational support for at-risk user groups [20] or studies using non-traditional sources such as online internet research, requiring a push for interdisciplinary global internet research ethics [3], [6]). Such work is bound to run into ethical challenges similar to those faced by disciplines where fieldwork has long been the norm, resulting in dilemmas (or "moral panics" [14]) not anticipated during the planning and formal approval process, such as changing from covert to overt researcher due to personal ethical qualms [18], resulting in fact in significantly less data being collected, or having ethical and moral concerns related to how difficult it is for a medical anthropologist to "disengage and disentangle … from fieldwork" [16].

In this paper we present some of the ethical challenges encountered in our own research. These examples, while covering a wide range of evaluation methodologies and settings, illustrate a common thesis: that contemporary HCI research often does not fit "traditional" or *static* ethical templates. To a certain extent, the HCI community is adapting to the ethical challenges prompted by the changing nature of the evaluations and field studies: [4], arguing for the consideration of new practices and reconsideration of old research norms to face ethical challenges posed by evaluations with large user groups; [2], bringing attention to ethical issues such as consent related to online social research (or [7], to authorship); [5], calling for further research into how to account for new ethical challenges when designing interactive technology and its evaluations; [19], making the case for greater flexibility of ethics and interpretation of data collected when conducting research that require membership in a community at risk of privacy exposures; or [9], proposing a more ethically-minded approach to technology design. However, in many other cases of both field and laboratory research, the realities of conducting the study can unexpectedly differ from what the researchers have planned for. It is thus time to introspectively look at the ethical implications raised by the ever-changing demands of HCI research that cannot always be anticipated as exemplified by the case studies presented in this paper.

Formal processes and policies have been essential in ensuring that research with human participants is carried out in an ethical manner. In this paper, we focus on the implications of the discrepancies between the formal ethics guidelines and the reality of conducting HCI studies with marginalized populations or in challenging environments. Our rationale is to draw the attention of interaction researchers and policy makers to the *situational* ethics which can be unpredictable and at times called for when conducting fieldwork, especially in novel areas. The rest of this paper is structured around four cases studies. For each of these we present the ethical challenges we encountered during the conduct of the study. Drawing from our experiences illustrated by these case studies, we conclude with a set of recommendations for addressing the ethical challenges posed by the newer real-life contexts and diversity of research method we are now encountering.

EXAMPLE: FIELD STUDY OF A MOBILE LANGUAGE SUPPORT APP FOR LOW-LITERACY ADULT LEARNERS

Context

In Canada, close to 50% of adults are considered to have literacy levels below the minimum functional requirements for today's society [1], and programs designed to provide learning support and resources to low-literacy adults have difficulty reaching and retaining those that would benefit. We[1] developed a mobile language assistant (ALEX) for use both in the classroom and in daily life, in order to help low-literacy adults become increasingly literate and independent. We evaluated ALEX through a six-month exploratory study with 11 adults enrolled in a literacy program. Each participant received one tablet running our app, to be used both in and outside the classroom. We collected data through frequent classroom observations and through participants' own verbal accounts of usage elsewhere. Our study [25] revealed that the app was helpful for activities essential to the literacy program and increased students' independence with respect to the use of literacy skills and their confidence and motivation to learn.

We encountered numerous challenges both in preparing and conducting our research. Most of the methodological issues are described in [26]. Here we elaborate on ethical principles and guidelines that were particularly challenging during our field study. After several iterations during which we have received very useful suggestions[2] from the REB, the approved study protocol covered a longitudinal study to be conducted in-situ with low-literacy adults, and with instruments (e.g. questionnaires, consent forms) adapted to the particularities of our user group. However, as shown here, it was impossible to anticipate and formally capture the challenges encountered during the study proceedings.

Informed consent

The literacy program is geared toward adults who completed only a few years of formal schooling, typically up to middle school. They are able to carry out some non-

[1]This work was conducted while the first author was affiliated with the National Research Council Canada.

[2]Such as allowing participants to take the consent forms home for two weeks and review them with a trusted person.

complex reading and writing tasks, such as some newspaper reading and writing a very simple letter.

Each potential participant received one mobile device running our literacy application, and was instructed on the use of the device and of the application through a one hour long one-on-one session with the researcher. Researchers also explained the details and objectives of the study, informed them of the information described on the consent forms, and encouraged them to review the forms with the teacher (who often acted as a proxy between researchers and participants), a family member, or friend. After a review period of up to two weeks, participants decided if they wanted to continue with the study.

We found that the adult learners struggled to understand the forms, and most signed without reading them. Only one participant read the consent form. One participant jokingly drew the comparison with signing the contract for a new cell phone plan. Despite our efforts to phrase the consent form in accessible, plain language, our final version was still worded in a relatively formal way, to satisfy the requirements of the ethics review process. We found ourselves explaining this form to participants, only to be cut short by them signing it to get the formalities over.

A similar departure from established ethical requirements occurred with the device review process. Normally participants have a few minutes to familiarize themselves with the application before signing the consent form. Our approved protocol allocated a week for this phase, during which we visited the classes daily for technical support. While we were not supposed to be collecting study data at that time, most participants started to offer their feedback, suggestions for improvement, and examples of usage, although they were not officially enrolled in the study. We faced a procedural ethical dilemma of whether we should collect such valuable data, before the consent forms were signed.

Privacy and confidentiality

It is a routine ethical expectation that participant privacy and confidentiality are guaranteed, particularly for research involving vulnerable user groups. Our approved protocol was to collect data through confidential interviews. In practice however, the study details and participants' use of the application were openly discussed in the classroom among participants, and also with non-participant students. While we conducted interviews as privately as possible and no audio was recorded, the daily observations were often a mix of tech support, participants' feedback, and personal stories on using the app, all shared in the classroom.

While ethics guidelines exist for consent forms for studies that are conducted with group interactions in which participants are explicitly informed that their group interactions are not entirely private, our protocol was not designed for this situation. We chose not to revisit the already-signed forms after noticing these group interactions, since signing the consent form was already a tedious task for participants, and since many non-participants were also included in these group interactions. Despite the departure from the privacy protocol outlined in our original REB application we decided to continue collecting data in this manner since privacy risks were minimal – the adult learners were already sharing many personal details in the classroom.

Reflections on research

Voluntary participation

The Policy Statements [31] for human-subject experiments require voluntary enrollment. Not all learners in the classroom enrolled in the study: some simply did not want the burden of having to take care of a device that was not theirs, while others were in the literacy program only for short periods of time. Yet almost all of these non-participants used our application, as most participants willingly lent them their devices while in the classroom. While no one was pressured to enroll in our study, the non-participants who used the borrowed devices became, in a way, involuntary subjects. Their interactions with classmates were described to researchers by the study participants, and on occasion, directly to researchers by these non-participants. This raises the ethical (and moral) question of whether data collected from non-participants should be included in researchers' analysis.

Exposure to risks and harms

Informing participants of any risks to which they are exposed is an essential ethics component of any study. Typically in HCI research, such risks are not greater than those from using everyday technology; such statements still must be disclosed to participants before they enroll in the study. However, such a disclosure is significantly limited when the system to be evaluated is being used by non-participants, a very common occurrence in our field study.

Data collection

Our formal ethics application to the REB allowed for small changes such as the phrasing of a question[3]. However, during the field study we still found ourselves in situations where we needed to improvise, e.g. during data collection. The participants' literacy levels made it difficult to conduct rigorous, structured data collection. Verbally-administered questionnaires, even rephrased with the help of teachers, at appropriate literacy levels, did not elicit meaningful answers. Instead, we conducted semi-structured interviews, adapting the questions for individual participants, or having to set them in the context of a personal story.

Another example of such departure from protocol was the "unplanned" data collection that occurred outside the classroom. Being located in a small city, we encountered

[3]Any significant changes in research instruments were to be submitted to the REB for review.

participants in various public spaces or stores. Participants took advantage of such encounters to ask various technical questions but also to relate their app use experiences. Again as researchers we faced the dilemma of whether to ignore this data. In fact, we suggest it would be impossible and perhaps even unethical to ignore such valuable data.

Participant-researcher rapport

One of the most significant ethical (and moral) challenges was the familiarity between researchers and participants that developed naturally during six months of daily visits. A positive consequence was the participants' unreserved feedback, but also their expectation of researchers becoming intimately involved in the class activities and beyond (e.g. answer questions, share personal details, attend the holiday party, ask for a ride after class, even extending the loan of a device to a participant whose school-aged child started using our app for homework.). While all efforts were made to ensure unbiased data collection [25], it was difficult to maintain a social distance – an increasing occurrence in HCI research as ethnographies become more common (e.g. [32]).

Discussion

A longitudinal, ethnographic evaluation where researchers are immersed in the observed environment for extended periods of time can represent a significant challenge from an ethical perspective for researchers unfamiliar with these methods (as well as for ethics review committees that review only science and engineering research). Informed consent, privacy, confidentiality, or harm are principles that must be evaluated in the particular context of the study, as they can be widely different than the usual template of usability evaluations familiar to HCI researchers.

EXAMPLE: FIELDWORK WITH PARENTS OF SICK NEWBORN INFANTS

Context

This project[4] involved fieldwork with parents of sick newborn infants who were cared for in a Neonatal Unit (NNU) in a large Primary Care hospital in the UK. We [23] designed, developed and evaluated a prototype software tool that mediated the communication of health updates and support needs across the social network on behalf of the parents [22]. A user-centred, Grounded Theory approach was taken [12].

We used focus groups to establish what information parents were willing to share with network members. Full details of the study are available in [22]. Before carrying out fieldwork with parents in the sensitive context of the NNU, we conducted a pilot focus group at a parenting conference with seven mothers, whose children who had been cared for in the NNU but had subsequently been discharged. Participants were asked what information they would want to be sent on their behalf to their friends and relatives about their baby while (s)he was in NNU. The researcher-facilitated focus group lasted one hour.

Following on from the pilot focus group, we intended to run focus groups with parents of babies currently in NNU. Here, we planned to ask participants what information they would want to be sent to their friends and relatives about their baby while (s)he was in NNU. Recruitment criteria to participate were strict: for example, parents would be excluded if it was the first week after admission, if the baby was the subject of a care order (parents legally denied access), or if the parent had a learning disability or mental or terminal illness, was unable to consent for themselves for any reason, or was a Prisoner/ Young Offender.

Formal ethical approval

For the pilot focus group, our university's Ethics Committee carried out the review. For the studies with parents who currently had babies in NNU, ethical approval was obtained from the NHS Local Research Ethics Committee (LREC), and reviewed by university administrators for indemnification. LREC requirements are extensive, with approval required for any research with: *"... patients and users of the NHS. This includes all potential research participants recruited by virtue of the patient or user's past or present treatment by, or use of, the NHS. It includes NHS patients treated under contracts with private sector institutions. Individuals identified as potential research participants because of their status as relatives or carers of patients and users of the NHS, as defined above."* [28]

One of the LREC's main concerns was that we would avoid placing parents under yet more stress: these parents were already under considerable stress because they had a very sick baby. Clearly, ethical approval is essential in carrying out research with sick people (and with parents of sick babies and their supporters). It is not acceptable for participants to be asked questions that might make them even more depressed or worried about their condition, however useful these questions are from the perspective of satisfying research questions. This is an important constraint on working with patients and their carers. In contrast, the sort of knowledge acquisition activities which are carried out with medical staff do not usually have an emotional impact on them – although of course it is not ethically acceptable to make medical staff depressed or stressed either [23].

Advance planning was needed, as the hospital-based research had to be signed off by the LREC. The ethical approval process called for a highly detailed submission, which included a description of the research, the staff involved and their backgrounds, contact points for complaints, participant information and consent forms. The process was time-consuming: it can take up to 60 days to

[4]This research was supported by the UK Engineering and Physical Sciences Research Council, under grant EP/D049520/1 and a doctoral training award.

establish whether initial ethical approval for research will be granted, and a review of substantial amendments to research plans can take up to 35 days. The approval process included attendance at an LREC meeting, where the researcher answered questions about the research from the large committee (approximately 14 people), made up of health professionals and lay members. Advance planning was somewhat at odds with our Grounded Theory approach, which calls for the development of research plans that can flex depending on findings from each incremental study.

Reflections on research

Recruitment and participation

Recruitment for the pilot focus group was successful. The women who attended showed little interest in the 'small print' of the information sheet and consent form. They were enthusiastic about taking part and wanted to get started rather than spend time on paperwork. An eighth participant did not fit the inclusion criteria – she was a childless midwife who had worked in NNU, and was interested to hear women's experiences. Participants were asked if it was acceptable for her to stay, and agreed. The researcher thus asked that she observe but did not contribute actively.

In contrast to the pilot focus group run at the parenting conference, NNU parents were uniformly unwilling to join a group discussion in the hospital. However some were willing to be interviewed by the researcher, either individually or with their partner (n=6: 4 female, 2 male). While it was necessary to adjust the research design to cater for the (much) smaller group size, we used the same discussion stimuli as the focus group, and remained faithful to the ethical approval granted.

Even when parents satisfied ethical criteria and agreed to participate in the hospital study, their attendance was not guaranteed. Attrition prior to participation could occur through lack of availability (e.g. - a mother might be feeding her baby, speaking to medical staff, have friends and family visiting, the baby being discharged early), reorientation of the baby's care from active to compassionate (palliative) care, or parents simply having a bad day and no longer wanting to participate. Amongst those parents who agreed to be interviewed, some interruptions occurred when nursing staff called parents away to attend to their babies or speak to doctors, but the parents returned to complete the interviews.

Involvement

The pilot focus group was highly emotionally charged. Despite the participants' experiences of NNU being up to 11 years ago, all participants ended up crying as they shared vivid memories of their experiences. The focus group was planned to last for 60 minutes, but ran for 90 minutes, until the room was booked for use by another activity. Participants volunteered that the focus group had given them an "invaluable" opportunity to discuss not only the types of information that they gave out when their baby was in hospital, but also their shared experiences of having a very sick baby in NNU, and their frustrations. All of the participants wept freely during the focus group, as they shared their experiences.

The midwife who had joined the group served a valuable role in comforting women who were distressed. As she had experience both in NNU and in caring for new mothers, she was well-placed to take this role. Her tactful intervention also allowed the researcher to keep discussion going in the focus group, and to draw attention away from distressed participants.

Discussion

For the pilot focus group, ethical approval was granted on the basis that participants would provide fully informed consent, fit the inclusion criteria, and participate in a discussion lasting an hour, facilitated by a researcher. What actually happened deviated from this substantially. For the researcher, guiding the focus group to satisfy the research questions in such emotionally charged circumstances was a challenge both professionally and personally (previously highlighted in [24]). Despite this deviation, rich discussion and insight into the experiences of parents were generated. This was valued by the participants, who made clear that they appreciated the opportunity to talk through their experiences of NNU together, as well as by the researcher.

In contrast, participants whose babies were currently being cared for in NNU were not enthusiastic about talking through their experiences in a group. Their intense and traumatic experience of having a very sick baby was immediate, not softened by time, and they were living through a period of uncertainty and worry. Whilst we adhered carefully to the questions we intended to explore in a focus group, and to the ethical approval granted, it was necessary to adjust our methodology by reorienting it to individuals or pairs. This called for a situational interpretation of the granted ethical approval. To have re-applied for ethical approval with such unexpected but minor changes would have led to significant delays and a need to recruit afresh.

The depth of insights delivered by working with parents who had authentic experience of NNU outweighed the disadvantages of (justifiably) strict ethics procedures. Their experiences were quite different to those of parents of well babies, and could be difficult for others to understand [23]. This illustrates the need for a flexible approach when planning the ethical aspects of such research – for example, by providing the option for focus groups *and* interviews in the research design and ethical approval process.

EXAMPLE: A LAB-BASED EVALUATION OF AN INFANTRY TRAINING SIMULATOR

Context

Interaction with serious games systems, such as mixed-reality training simulators, is a cost-effective alternative to field-based courses for military or law enforcement training. A realistic rendering of scenarios and conditions allows trainees to transition from course-based (classroom) instruction to applying their knowledge, skills, and judgment to solving real-life situations.

In partnership with the Canadian Forces, we[5] have developed a flexible mixed-reality infantry training simulator (presented in detail in [11]). Built as a research platform, it supports multimodal interaction between trainees and an immersive serious gaming environment projected onto multiple walls, allowing the re-creation of real-world environments and interactions with life-size characters. The game was developed according to requirements drafted in collaboration with subject-matter experts (e.g. infantry instructors). The customizable simulator supports tangible interactions such as simulated stun grenades and laser rifles for engaging in realistic combat with the game avatars. The system allows trainees to interact and engage in dialogue with virtual characters under different scenarios, by way of automatic speech recognition. The scenarios can be modified on the fly by instructors through a control interface that runs on a tablet.

Study protocol

Building such a complex system required significant user involvement. Beside collecting requirements and receiving feedback from subject-matter experts, extensive user testing was needed to iteratively develop and refine the system. This occurred through several technology demonstrations to our partners, but also through two 3-day testing sessions with a team of five soldiers, carried one year apart. While these two sessions were crucial in the development of the simulator, they have raised several ethical challenges during both the planning and execution phases.

Formal Ethical Approval

The guidelines of the Canadian Tri-Council Policy [31] on conducting ethical research suggests that a formal ethics approval is not needed if participants perform tasks that are part of their routine workplace activities. Soldiers often participate in the evaluation of various simulators as part of their on-the-base training, and engaging in activities that simulate battlefield conditions is also a regular activity. However, carrying out such tasks in our lab for the purpose of fine-tuning an interactive system may not fall as clearly under the definition of "routine work duties". We have described this situation to our Research Ethics Board, who thoroughly analyzed the circumstances and took a proactive role in helping us properly frame the ethical dimensions of our experiment. In the end, the REB judgment was that a formal ethics application was not required for this study. Nevertheless, an uninformed impromptu visitor to our lab could have easily labeled the setup and activities as a rather typical HCI human-subject evaluation.

Reflections on research

Voluntary Participation

Free will is fundamental to conducting ethical research, and experimenters must ensure that participants are voluntarily enrolling. In our simulator's evaluations, the two teams that took part in the trials were not explicitly given such choice. Instead, their superiors (our military collaborators) tasked them with taking part in the trials. One can argue that free will is not typically associated with military duties. Moreover, all of the participants enjoyed themselves during the study, and even took over our lab to take advantage of the opportunity to train using a new simulator, and in a sense welcomed having a break from their usual routine on the base[6]. Nevertheless, we were faced with having study participants being present in our lab[7] not by their own will – an example of the difficult distinction between ethics and morality when conducting human-subjects research.

Researcher-Participant Rapport

Often the relationship between researchers and participants is not symmetrical. In fact, various elements of the formal ethics guidelines (informed consent, no harm, voluntary participation, confidentiality, no-consequence withdrawal) are intended to prevent situations where researchers are in a position of authority over the participants. Yet in our study, we found that this relationship was often challenged with respect to authority (and trust), and left us wondering who is "in control". Soldiers became comfortable with the simulator, the researchers, and the lab – by the end of the second day the soldiers "took over" the lab and the experiment [27]. This entailed using the simulator to draft new training routines, which signified an unconditional technology acceptance, but also left us with very little control over how the evaluation was carried out. Some of the developers and researchers from our team also ended up half-willingly as "living props" in these new training routines, which included various degrees of physical strain. On the other hand, researchers were still in an asymmetrical position of trust, as the identity of soldiers was not anonymous and actions could have been reported to their superiors. Overall the general atmosphere was friendly and resembling the typical military camaraderie, having lunch together, or researchers being challenged to a friendly (virtual) shooting competition. However, the unfolding of the evaluations, mainly the contrast between soldiers taking control of aspects of the evaluation and the researchers'

[5]This work was conducted while the first author was affiliated with the National Research Council Canada.

[6]In a way, one can draw a parallel to the unwitting participation of end users in product improvements or marketing analyses.

[7]The lab is part of a civilian-funded institute, not affiliated with the Department of Defence.

technical collaboration with their superiors, raises the question of who was in a position of authority and trust.

Discussion

The lab-based user evaluation described here seemingly occupied a "gray area" of formal ethics. While approval was deemed unnecessary, the study proceedings raised several questions about what constitutes voluntary participation, and how the relationship between researchers and participants should be managed. Users were never exposed to any harm or privacy violation[8], yet the study could, at best, be described as "unconventional". This raises the questions of how well formal ethics procedures account for such unconventional cases, and also highlights the importance of having, such as in our case, a proactive and well-informed REB that became a partner in deciding how best to approach this study from an ethical perspective.

EXAMPLE: LABORATORY STUDY OF MOBILE TOUCHSCREEN TYPING WITH BLIND PARTICIPANTS

Context

Mobile texting is a ubiquitous form of communication. Yet, mobile text entry is often difficult due to size constraints. Phones have too many buttons, physical or virtual, that are too small. This problem is particularly limiting for the visually impaired, especially on touchscreens. For this, we designed BrailleTouch [29], a software keyboard for touchscreen mobile phones based on braille typing, supporting accessible text entry for the visually impaired on commodity smartphones. We evaluated our app during a laboratory study with 11 visually impaired participants ([30]), through 90-minute text-entry sessions repeated on different days, comparing our app to various text entry alternatives. We collected non-identifiable demographic data, surveys, interviews, typing speed and accuracy, and we recorded participants' voice and video of their hands interacting with the device.

Informed consent procedure

Together with our Institute Review Board (IRB), we designed an informed consent procedure to closely take into account our participants' visual impairment. We carefully crafted a script informing participants of the research questions of the study and their rights. During the design of the study, we had different options of allowing the participants to read the script. They could read it on a braille printout or listen to it with a screen reader. We decided to read the script to them and make it as natural as possible. As a result, we were able to ascertain that the participants had heard and understood the consent form. Furthermore, we recorded the delivery of the script and the acceptance from the participant saying "I consent". While the reading of the consent required more time than it would have taken the participants to read it in braille or with a screen reader, we considered it a courtesy and a crucial step in building trust, especially given that the participant would spend several hours over several days in our study. Participants appreciated our approach.

Given the close ties among members of the visually impaired community, the news of our app spread quickly among potential participants who simply wanted to try the app. In fact, a number of individuals requested that we distribute our app through the app store as soon as possible. To many of them, participation in the study was an opportunity to get early hands on experience with the technology. In fact, we discovered that many visually impaired and blind individuals are actually very early technology adopters. While they wanted to use the technology, they did not necessarily want to go through the long hours of typing the study entailed. For those who signed up for the study, they seemed eager to get on with using the technology and the consent form was simply a formality to get over quickly. They mostly paid attention to the consent form to know more about the details of the study than to ensure we were protecting their privacy. They were not concerned about the consent form. Most significant, they did not express uneasiness about the proposed recording of their interaction. No one asked, for example, for a trusted sighted individual to be present while we recorded to verify that we followed the protocol of not recording participants' faces. This is in stark contrast[9] with the typical ethical approach for conducting research with at-risk users, which in this case proved to unnecessarily exceptionalize our blind participants (a concern often encountered in anthropological research [17]).

Privacy and confidentiality

We recorded video of the participants consenting, in lieu of signatures on paper. We recorded sound and video of their hands interacting with the devices. We informed the participants that we would not use any identifiable data in our publications. We informed participants that the IRB might review our records to audit our adherence to the protocol, including not recording their faces during the typing tests. None of the participants expressed concern over the recordings, even though they could not verify its contents. They simply did not pay any attention to it.

Reflections on research

Recruitment and exposure to harm

Recruiting participants was challenging. Our study demanded around seven hours of participation over five days. We included only legally blind adults proficient in

[8]One can argue that even the anonymized reporting, through publications such as the one here, of participants' activities, amounts to exposing them to breaches of confidentiality with respect to their superiors in the workplace.

[9]In fact, this is also in contrast with the situation encountered in the evaluation of the infantry training simulator, where ethical approval was deemed unnecessary, yet several concerns about participants' vulnerabilities emerged later in the evaluation, as described in the previous section.

braille typing. However, braille literacy is the greatest predictor of employment among blind adults, thus making it difficult to recruit among employed adults (despite a financial incentive being offered). Additionally, while we provided courtesy transportation from the participants' location to our laboratory and back to reduce participants' anxiety, this created significant logistical challenges and exposure to risks and harms not anticipated initially.

In retrospect, we learned several valuable lessons about preparing a protocol for this population that could have been included in the ethics review process. For example, we could have conducted the study at participants' locations. The loss of experimental control over environmental variables such as noise and potential interruptions, may have overcome part of the difficulties of recruitment. Furthermore, realizing that our target population consisted of working adults, we could have limited the time participants stayed in the study by, for example, designing a mixed within- and between-subject protocol. Again, we could have traded off individual independent variable evaluation for greater participation, which is what most of the individuals in our target population wanted.

Ownership and involvement

Our users wanted to participate, get their hands on the prototype, tell their friends, and have an opportunity to provide constructive feedback to make a potential product better. They made our goals their own. We could have provided greater and more diverse opportunities for the community to be a part of the study, balancing study control with participant inclusion. In fact, after the release of the results from this study, a major news outlet ran a story on our app and we received over 700 unsolicited emails worldwide for releasing the app on the App store [10]. Currently, we are working towards our most profound goal, to have lasting positive impact in the community of our study, the community of our volunteers, through the release of our app in the App store. Greater participation could have significantly cut the time to release by providing us with greater opportunity to interact with the community.

Discussion

Conducting technology evaluations with people with disabilities can be challenging from an ethical perspective. Clearly, a significant impairment such as blindness needs to be factored in the research protocol to ensure protection of participants' safety, privacy, and dignity. While we took such steps in our study design, we were also confronted with unexpected challenges during the study (e.g. travel) that were difficult to address after the study has started. Several of the ethical principles that we went to great lengths to implement (informed consent, privacy while recording) were of less concern for the participants themselves. This may be due to the study being perceived as less of an experiment and more of a trivial "app testing", but also due to our participants' desire to contribute to what they perceived as important for their community. While this in no way diminishes the importance of a rigorous ethics review, it highlights the need to consider participants as equal research partners instead of human subjects.

SUMMARY

The four cases discussed highlight how disconnections can occur between the protocols approved by research ethics boards and the realities of conducting HCI research in non-traditional environments. In one case where the researchers were able to work through research challenges with the research ethics board, a satisfactory solution was developed. This example highlights the need for researchers to see research ethics boards as partners in the research process. Also, some of the research contexts discussed might be new to HCI researchers accustomed to controlled evaluations of technology, but familiar to many social sciences researchers, suggesting that collaborating with researchers from other disciplines would be fruitful. At the same time there could be challenges involved in presenting protocols that use social science approaches for review by an ethics board comprised solely of members with expertise in computer science and engineering. Taking a long-term view, it is clear that HCI research in non-traditional contexts requiring ethics approval is expanding. Given this situation, it makes sense for HCI researchers to become involved in higher-level activities of developing research ethics policies that are inclusive of these new contexts.

RECOMMENDATIONS

The examples presented in this paper cover a relatively wide range of HCI research. However, an underlying theme can be seen emerging: contemporary HCI research, especially that involving vulnerable or at-risk participants, has its own unique ethical challenges that do not fit the ethical templates which we are accustomed to. Our four case studies provide examples of unanticipated situations, how they relate to the formalities and rigorousness of the ethical process, and how under-prepared researchers can find themselves dealing with such unexpected ethical challenges once their studies are underway.

As a community we need to take an active role in managing such challenges. We presented our case studies as (simple yet telling) examples that may start a longer-term discussion on how we approach HCI research from an ethical perspective. We hope our contribution will lead to the future development of a "situational ethics" framework that will assist HCI researchers as they navigate the challenges of fieldwork. As a first step, and based on the lessons learned from our shared experiences, we propose several recommendations[10] for HCI researchers to address

[10]We believe that any solutions to these ethical challenges will require thorough scrutiny, evaluation, and refinement from the HCI community. As such, we can only suggest recommendations based on our own experiences – we wanted to avoid passing the exact "ethical edicts" (overly rigid and often not applicable to all

the ethical issues posed by the dynamic nature of studies in novel areas:

- Look for "ethical triggers" in their research protocol – elements that indicate potential challenges during the field study: participants that could belong to vulnerable populations, sensitive settings, in-the-wild deployments of technology, and possibility of blurred lines between being a research participant or an end-user. Most researchers, as was the case in our own examples, are trained to detect such triggers. However, a deeper level of scrutiny is often required – as shown, for example, by the evaluation of the infantry training simulator, where the blurring of participant / research line was not anticipated.
- Incorporate into research design the ability to assess ethical risks and adjust protocols responsibly in the field in response to participant needs, particularly in emotionally charged settings or when evaluating technologies as readily available apps "in the wild" (including handling indirect participation or unexpected requests from participants). While researchers often see ethics as a compliance issue [15], a "situational ethics" approach to planning and conducting fieldwork may allow researchers to better adapt to particular unexpected conditions that arise after the design of the research and ethics protocol. To be successful, such an approach may require an improved rapport between researchers and their institutional Ethics Boards, as detailed in our next recommendation.
- Maintain a continuous dialogue with the Ethics Board when navigating the protocol design challenges and during the study. Board members may have encountered similar situations in other disciplines, and can provide guidance on the ethical issues that may arise. The dialogue may be difficult at times but many of the challenges can be addressed head-on by researchers increasing their sharing of experiences and best practices, and by volunteering for such boards. Our own experience is that being pro-active leads to better understandings of the research challenges, as illustrated in this paper and also as witnessed recently by three of the co-authors after having taken on more responsibilities with their respective ethics boards.
- For researchers, assembling multidisciplinary research teams, even when the study goals are relatively set within one area. This is particularly relevant when the participants are vulnerable or at-risk – common cases in social sciences.
- For institutions that have review boards consisting of committees dedicated to separate disciplines, ensuring that members of such committees have a multidisciplinary background – as many research studies are crossing the boundaries of what constitutes a well-defined research area.
- Become involved in the process of revising ethical guidelines. By participating in stakeholder consultations that continually update ethical policies, HCI researchers have an opportunity to take ownership of decisions that affect their research and raise the awareness of the dynamically-changing contexts of HCI research.

forms of research) that we provided evidence against.

CONCLUSION

The formal requirements of the ethics approval process are often at odds with the realities of conducting qualitative field research. With the recent increase in qualitative research being carried out in HCI, particularly on mobile technologies with marginalized or at-risk populations, ethical challenges that are well known in many disciplines will also become an issue in HCI research. As illustrated by recent publications, such challenges are already acknowledged as an essential factor in designing research protocols by the HCI community; however, our own work highlights the discrepancies, from an ethical perspective, between the planning stages of field research in HCI and the realities of fieldwork.

In this paper we presented our own such challenges in conducting various HCI-related field studies. We showed that some of the established ethical guidelines used to develop the study protocols did not provide proper guidance in dealing with specific situations encountered during our study, and left it up to researchers to make decisions based on personal moral principles rather than on meaningful guidelines. Based on our shared experiences, we proposed recommendations for a *situational* approach to such ethical issues in both the planning and execution stages of the research. We hope that, by illustrating these examples, the HCI community will become more aware of the dynamic nature of the ethical challenges of field research, lab-based evaluations, or qualitative research, especially with at-risk or vulnerable users, and will join the inter-disciplinary efforts of creating ethical guidelines and formal review processes that are flexible and reflective of the diversity of research methods and real-life cases that we encounter.

REFERENCES

[1] ABC Canada. Who Wants to Learn? ABC Canada Literacy Foundation Report. 2001

[2] Bos, N. et al.. Research ethics in the Facebook era: privacy, anonymity, and oversight. ACM *CHI 2009.*

[3] Buchanan, E.A. and Ess, C. Internet Research Ethics and the Institutional Review Board: Current Practices and Issues. *SIGCAS Computers and Society* (39:3), 2008

[4] Chalmers, M. Ethics, logs and videotape: ethics in large scale user trials and user generated content. *CHI 2011.*

[5] Detweiler, C. et al. Values in Design - Building Bridges between RE, HCI and Ethics. *INTERACT 2011*

[6] Ess, C. and Jones, S. Ethical Decision-Making and Internet Research: Recommendations from the AoIR Ethics Working Committee. In *Buchanan, E.A. (Ed.), Readings in Virtual Research*. 2004.

[7] Ess, C. Internet Research Ethics. In *Joinson, A. (Ed.), Oxford Handbook of Internet Psychology*. 2007

[8] Ethics Rupture: An Invitational Summit about Alternatives to Research-Ethics Review. St. Thomas University & University of New Brunswick, 2012.

[9] Friedman, B. et al. Value Sensitive Design and Information Systems. *Human-Computer Interaction and Management Information Systems*, 2006.

[10] https://itunes.apple.com/app/brailletouch/id579725651 accessed on 2015/01/07.

[11] Fournier H. et al. A Multidisciplinary Approach to Enhancing Infantry Training through Immersive Technologies. *I/ITSEC 2011*.

[12] Glaser, B.G. and Strauss, A.L. *The Discovery of Grounded Theory*. Weidenfeld and Nicolson, 1968.

[13] Guta, A. et al. Resisting the seduction of "ethics creep": Using Foucault to surface complexity and contradiction in research ethics review. *Journal Social Science & Medicine,* 2012.

[14] van den Hoonaard, W. Is Research-Ethics Review a Moral Panic? *Canadian Review of Sociology (38),* 2001.

[15] Kahn, J.P. and Mastroianni A.C. Moving From Compliance to Conscience: Why We Can and Should Improve on the Ethics of Clinical Research. In *Arch Intern Med.* 161(7) 2001.

[16] Killshaw, S. Ethics in studying contested illness. In *McClancy, J. (Ed). Ethics in the Field*. 2013

[17] Kim, S.N. Whose voice is it anyway? Rethinking the oral history method in accounting research on race, ethnicity and gender. In *Critical Perspectives on Accounting*, 19(8), 2008

[18] Li, J. Ethical Challenges in Participant Observation: A Reflection on Ethnographic Fieldwork. *The Qualitative Report (*13:1), 2008.

[19] Lingel, J. Ethics and dilemmas of online ethnography. *CHI 2012*.

[20] Marsden, G. and Jones, M. Inspiring Mobile Interaction Design. ACM *CHI 2011 Course.*

[21] Mackay, W. Ethics, lies and videotape. ACM *CHI 1995*.

[22] Moncur, W., Masthoff, J., Reiter, E., Freer, Y., and Nguyen, H. Providing Adaptive Health Updates across the Personal Social Network. Human–Computer Interaction 29, 3 (2014), 256–309

[23] Moncur, W., Mahamood, S., Reiter, E., and Freer, Y. Involving healthcare consumers in knowledge acquisition for virtual healthcare. AAAI Fall Symposium Series, AAAI Press (2009), 43–51.

[24] Moncur, W. The Emotional Wellbeing of Researchers: Considerations for Practice. In *Proceedings of the ACM SIGCHI Conference on Human Factors in Computing Systems (CHI)*, 2013.

[25] Munteanu, C., Molyneaux, H., Maitland, J., McDonald, D., Leung, R., Fournier, H., and Lumsden, J. Hidden in plain sight: Low literacy adults in a developed country overcoming social and educational challenges through mobile learning support tools. In the *Journal of Personal and Ubiquitous Computing*, Springer-Verlag, November 2013

[26] Munteanu, C., Molyneaux, H., Maitland, J., McDonald, D., Leung, R., Lumsden, J., and Fournier, H. A Tale of Two Studies: Challenges in Field Research with Low-literacy Adult Learners in a Developed Country. In *Proceedings of the ACM SIGCHI Conference on Human Factors in Computing Systems (CHI)*. 2012.

[27] Munteanu C., Fournier, H., Lapointe, J.F., Emond, B., and Kondratova, I. We'll Take it from Here: Letting the Users Take Charge of the Evaluation and Why that Turned Out Well. In *Proceedings of the ACM SIGCHI Conference on Human Factors in Computing Systems (CHI).* 2013.

[28] National Research Ethics Service. *NRES guidance on information sheets and consent forms*. 2007.

[29] Romero, M., Frey, B., Southern, C., and Abowd, G.D. BrailleTouch: designing a mobile eyes-free soft keyboard. In Proceedings of the *ACM International Conference on Human Computer Interaction with Mobile Devices and Services (MobileHCI)* 2011.

[30] Southern, C., Clawson, J., Frey, B., Abowd, G.D., and Romero, M. An evaluation of BrailleTouch: mobile touchscreen text entry for the visually impaired. In Proceedings of the *ACM International Conference on Human Computer Interaction with Mobile Devices and Services (MobileHCI)* 2012.

[31] Tri-Council Policy Statement: Ethical Conduct of Research Involving Humans, 2nd edition, 2010.

[32] Williams, A. et al. Anchored mobilities: mobile technology and transnational migration. *ACM DIS* 2008