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# Balancing Formal Ethics Requirements and the Practicalities of a Field Study with Vulnerable Populations

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**Abstract**

Most Human-Computer Interaction (HCI) researchers and practitioners are accustomed to the bureaucratic process of having their evaluation or field trial protocol formally vetted for ethical considerations. While this formal process varies by country, the underlying principles are universal. For a large part of HCI research - controlled lab-based usability evaluations of a user interface - the ethics review process is a simple formality. However, for qualitative field research with vulnerable populations, formal ethics requirements can be very difficult to navigate. The dilemma of having to balance practical research concerns with formal ethics review requirements has mostly been foreign to HCI researchers; however, it is a current reality with the increase in qualitative research and field studies, mostly due to new areas of research in HCI, such as that of mobile technologies for developing countries or for marginalized populations. In this paper we present our experiences and challenges in conducting field studies of mobile assistive technologies with marginalized low-literacy adults in a developed country, in the context of following the requirements of the formal ethics process.

## **Keywords**

User studies; ethics; marginalized population, evaluation methodology; assistive technology.

## **ACM Classification Keywords**

H.5.2 [User interfaces]: Evaluation/methodology; K.3.1 [Computer Uses in Education]: Computer-assisted instruction; K.4.1 [Public Policy Issues]: Ethics.

## **General Terms**

Experimentation; Human Factors.

## **Introduction**

For many researchers, validating their experiment or study protocols from an ethics point of view is a routine operation and an essential step in planning the conduct of their research. In most cases, this is part of 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 and government research institutes and are guided by a formal policy created by the three federal funding agencies [1]. In other countries the research ethics guidelines are less centralized (e.g. specific to each university); nonetheless, the principles and implementation share many common aspects across countries and disciplines and are the subject of increased scholarly attention (as illustrated by workshops such as [2].)

For most research the application of such guidelines is straightforward and is part of the planning stages. However in some cases researchers find themselves facing various serious ethical dilemmas when the realities of their field research, experiment, or study do

not match or even contradict the protocol approved or the formal requirements of the REB approval process [3]. This can be in part attributed to the increased bureaucratization of the ethics approval process in its attempt to formalize universally-accepted principles such as ensuring that participants privacy and confidentiality are respected and that they are not harmed or exposed to risks [4].

In the Human-Computer Interaction (HCI) discipline ethics are an integral part of the planning process. In most cases (e.g. controlled lab-based evaluations of a user interface) the ethics review and approval process is straightforward. However, recently we are witnessing an increase in qualitative research, in no small part attributable to a significant increase in efforts dedicated to mobile interactions and the use of information technology (mainly mobile) in developing countries or to provide support (language, medical, education, etc.) to at-risk or marginalized user groups. Such research is bound to run into the same ethics challenges as those faced by other qualitative disciplines – dilemmas (or “moral panics” as termed by [3]) while conducting the fieldwork that could not have been anticipated during the planning and formal approval process.

In this paper we present some of the ethical challenges encountered in our own research on developing and evaluating a mobile support application that provides assistance to low-literacy adults. We focus on the implications of the discrepancies between the formal ethics guidelines and the reality of longitudinal studies of mobile technology with such vulnerable user groups.

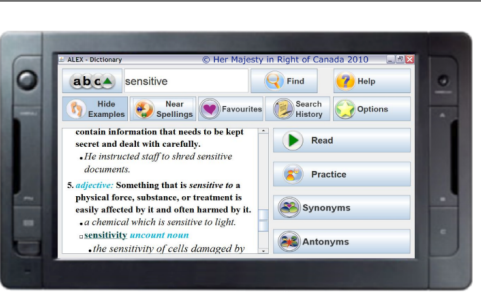


Figure 1: The ALEX© mobile language support application, running on a 7-inch tablet. It was designed following guidelines for inclusive design of mobile tools. ALEX© supports language skills and knowledge acquisition pertaining to real life, by providing intuitive access to various language-based tools (dictionaries, thesauri, pronunciation guide and practice, etc.). A complete description of ALEX© and its evaluation can be found in [5].

**The literacy problem and a solution**

In countries like Canada, low-literacy adults represent a sizeable ratio of the adult population. Unfortunately, due to a variety of economic and socio-demographic reasons, current programs designed to provide learning support and resources to low-literacy adults have difficulty reaching and retaining those that would benefit most from them. For this, we have developed ALEX© in order to help low-literacy adults become increasingly literate and independent.

We have evaluated ALEX© through a six-month exploratory study with 11 participants in two adult literacy classes, part of a program focused on improving general reading and writing abilities. Each participant received one device running ALEX©, to be used both in and outside the classroom. We collected data by frequently observing participants in the classroom environment, and through participants' own verbal accounts of usage outside classroom. The classes are conducted in an informal setting resembling one-on-one tutoring, with several adult learners working independently on their assigned subject but also interacting with each other and with the teacher.

Our study revealed that students perceived the device as helpful for activities essential to the literacy programs, and that such technologies contribute to students' independence with respect to activities requiring the use of literacy skills and increase students' confidence in their own capabilities and motivation to learn.

**Ethical considerations and challenges**

We encountered numerous challenges both in preparing and conducting our research, mainly stemming from the environment in which the study was conducted and the nature of our user group. Most of the

methodological challenges have been extensively described in [6]. Here we elaborate on ethical principles and guidelines that were particularly challenging during our field study.

**Informed consent**

The literacy program is geared toward adults who completed only few years of formal schooling. They are able to carry out some non-complex reading and writing tasks, such as some newspaper reading, writing a very simple letter, etc.

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-on-one session with the researcher, lasting typically one hour. Researchers also explained the details and objectives of the study and informed them of the details described on the consent forms, and encouraged them to review the forms with the teacher, 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 had difficulties understanding the consent forms. Most signed them without reading it. Only one participant read the consent form, although researchers' suspected the participant treated it more as a reading challenge than as getting informed on the study protocol and details. 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 formal and fairly rigid way to satisfy the requirements of the ethics review process. We found ourselves trying to

explain the details of this form to participants, only to be cut short in our explanations by the participants, who signed it to get the formalities over with quickly.

A similar departure from established ethical requirements occurred with the device review process. Under normal circumstances participants have a chance to review and familiarize themselves with the application, usually for a few minutes before signing the consent form. In our study, the protocol approved by the REB outlined that we were to give participants a week. This was justified due to participants' need for a longer period of time in reviewing the forms, but also to avoid overwhelming participants by demanding they sign the forms right away. During this week we visited the classes daily with the stated intention of assisting participants strictly with technical troubleshooting. However during this review process when we were not supposed to be collecting study data most participants started to offer their feedback and suggestions for improvement and informed us on how they were using the application although they were not officially enrolled in the study. We faced a procedural ethical dilemma of whether or not we should collect and use such data before having consent forms signed. It was clear that the information forthcoming from participants during this week was valuable and would not likely be available after that initial familiarization week was over.

### ***Privacy and confidentiality***

During qualitative field studies, and particularly for those involving vulnerable user groups, the privacy and confidentiality of participant-researcher interactions are paramount. However, we found that it was difficult to conduct our study while fully ensuring confidentiality. The approved protocol was for the researchers to

collect data from individuals 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. This occurred both when researchers were present and at other times. While we conducted interviews as privately as possible and no audio was recorded, the daily observation sessions were often a mix of technical support for application troubleshooting, feedback from participants, and personal stories on using the application, all shared publicly 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 that then occurred in practice. 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. We decided to continue collecting data in this manner (despite the departure from the privacy protocol outlined in our original REB application) since privacy risks were minimal – the adult learners were already sharing many personal details in the classroom.

### ***Voluntary participation***

Human-subject experiments require participants to enroll voluntarily and without coercion. Not all the learners in the classroom enrolled in the study: some simply did not want the burden of having to take care of a device that wasn't theirs, while others were in the literacy program only for short periods of time. Yet

almost all of these non-participants fully used our application, as most participants willingly lent them their devices (while in the classroom). While no participant 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 encountered by using computing devices in everyday life; such statements still must be disclosed to participants before they enroll in the study. However, such a formal disclosure is significantly limited in cases where the application or device to be evaluated is being used by non-participants, a very common occurrence in our field study.

#### ***Study protocol***

Our approved formal ethics application to the REB had allowances for minor variations in the research protocol. However, during the field study we still found ourselves in situations where we needed to improvise. One such example is the administration of questionnaires. The participants' literacy levels made it difficult for researchers to conduct rigorous, structured data collection. Even questionnaires phrased, with the help of teachers, at appropriate literacy levels, did not elicit meaningful answers (questions were not answered

at all or participants provided answers from which no useful information could be extracted). As such, the final questionnaire was administered in the form of a semi-structured interview, with the researchers adapting the questions to the literacy level of individual participants. Moreover, we had to rephrase questions and often set them in the context of a personal story or example in order to elicit an answer from the participant.

Another example of such departure from protocol was the "unplanned" data collection that occurred in places outside the classroom, which was the location specified in the protocol where data collection was to occur. Our study was conducted in a relatively small city, and during the six months we encountered participants in various public spaces (e.g. grocery or general stores – some of them working in such places, or simply while shopping). Participants took advantage of such encounters to ask various technical support questions but also to relate their experiences while using the application. 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 for researchers to ignore valuable data when conducting their analysis.

#### ***Participant-researcher rapport***

One of the most significant challenges, both from an ethical but also from a moral perspective, was the familiarity between researchers and participants that developed naturally during six months of daily visits. A positive consequence was that participants were unreservedly providing feedback to researchers, but also that they expected researchers to become more intimately involved in the class proceedings (e.g.

answer questions, share personal details, attend the holiday party). Participants regarded researchers as members of the community formed around the classrooms, exemplified by a request made by a participant for a ride to a medical appointment after class. While all efforts were made to ensure unbiased data collection (as discussed in [6]), it was difficult to maintain a social distance between researchers and participants – for example, the loan of the mobile device to one participant was extended beyond the data collection period as her school-aged child started using the device (and our application) for homework.

### **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 in developing countries or with marginalized populations, it is expected that the ethical challenges that are well known in many disciplines will become an issue in HCI research as well.

In this paper we presented our own such challenges in conducting field studies with low-literacy adults using a mobile language support application. We showed that some of the established ethical guidelines used to develop the study protocol 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. We hope that, by illustrating these examples, the HCI community will become more aware of the ethical challenges of conducting qualitative research, especially with

vulnerable populations, and will join the interdisciplinary efforts of creating ethical guidelines and formal review processes that are flexible and reflective of the diversity of research methods and real-life cases we encounter.

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### **Authors' biographies**

**Dr. Cosmin Munteanu** is a Research Officer with the National Research Council Canada (NRC). His area of expertise is at the intersection of Automatic Speech Recognition, Natural Language Processing, and Human-Computer Interaction, having conducted research aimed at improving humans' access to and interaction with information-rich media and technologies through natural language. Presently, Cosmin leads several academic and industrial research projects that explore speech and natural language interaction for mobile devices, assistive technologies, and mixed reality systems, while also serving as an internal reviewer for applications to the NRC Research Ethics Board.

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