Ethics Responsibilities Across the Risk Spectrum in HCI Research

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ABSTRACT
This position paper draws on our experience of a range of projects on the ethics risk spectrum in Human-Computer Interaction (HCI) research to reinforce the central role that the ethics approval process must play in this research. Near one end of the spectrum we consider studies of clinical interaction with patients in tertiary-level hospital settings. At the other end we consider low risk (Expedited levels 1 and 2) interview-based research about Fair Trade supply chain information flows that may touch on cultural and economic issues.

We present these studies from the point of view of the ethics responsibilities that fall on HCI researchers when unexpected circumstances arise, potentially confronting situations are presented and awkward or difficult decisions need to be made. At the higher-risk end, as shown by our hospital studies, the HCI researchers' ethics responsibilities may be clearly defined and may have a focus on both the participants in the research and on the well-being of the researchers themselves.

At the lower-risk end, as in our interview-based Fair Trade studies, HCI researchers may have responsibility for decisions that maintain ethical standards in the face of the unexpected events that can happen in these less structured research settings. We give three examples to illustrate our experience that, regardless of the level of risk involved in the project, the ethical responsibilities that our HREC approval gives us as HCI researchers need to remain at the forefront of our attention during the project.

Author Keywords
Human Research Ethics, Ethics in HCI research, Risk in HCI research

ACM Classification Keywords
H5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous.

INTRODUCTION

In our discussion of the role of Human Research Ethics Committees (HREC) in Human-Computer Interaction (HCI) research we draw on examples from both ends of the spectrum of risk assessment. At the high-risk end of the spectrum we have studies concerning the introduction of advanced Information and Communications Technologies (ICT) into the environment of actual clinical treatment of patients in tertiary-care hospitals. At the low-risk end we have an interview-based project studying the information flows along the supply chains of Fair Trade commerce and the possible implications of deploying ICT solutions to enhance feedback loops to producers.

The lead time for a high-risk HCI project may be months or years, with plenty of time to iterate over HREC applications compared to a possible lead-time of weeks for a low-risk project. A high-risk project may involve research partners with specific application skills so that during the active phase of the data gathering the HCI researchers may play only a minor role with little or no decision-making. A low-risk HCI project may fully involve the HCI researchers in the project's conduct and decision-making. A high-risk project may involve possibly more than one HREC iterating over the research proposal until a clear and stable plan for the research is approved. A low-risk project, such as our interview-based Fair Trade study, may involve only one HREC. It may also involve exploring unknown territory where unexpected circumstances arise that require the HCI researchers to be responsible for decisions on process that need rapid variation support from the HREC.

We will use examples from different positions on the risk spectrum in this paper to illustrate our position that the ethical responsibilities that the HREC approval confers on us as HCI researchers deserve a prominent place in both the planning and the conduct of the research, regardless of the risk level associated with that research. Our three examples are:

1. Designing, building and installing a broadband telehealth system at the Royal Children's Hospital in Melbourne and then conducting post-operative outpatient consultations for four weeks in September 2007.

2. Observing and reporting on a range of types of surgery at The Canberra Hospital from 2012 to early 2014.
3. Conducting interviews with consumers, importers and producers of Fair Trade handicrafts from April to September 2015.

In the first example the surgeons were responsible for the patients' treatment but the HCI researchers had contact with the patients/parents before (confirming the informed consent) and afterwards (conducting the exit interviews). In the second example the surgeons again were responsible for the patients' treatment but the HCI researchers had no contact with the patients. In the third example the HCI researchers were responsible for the entire interaction with the interviewees.

OUR THREE EXAMPLE PROJECTS

Broadband Telehealth for Post-operative Paediatric Outpatient Consultations

The telehealth system for this project was developed and trialled by staff at the Commonwealth Scientific and Industrial Research Organisation (CSIRO) at the request of the Department of Surgery at the Royal Children's Hospital in Melbourne, Australia (Figures 1, 2 and 3). Its purpose was to test the concept of using broadband telehealth to conduct routine outpatient consultations for child patients who had recently had surgery at this hospital. This hospital has a large catchment and the motivation for the project was to reduce the burden of travel that falls on families whose children have these classes of complex surgery (Stevenson, Hutchins, and Smith 2010).

The trial involved conducting the same pattern of weekly outpatient clinics over a four-week period in September 2007. A telehealth suite comprising a "surgeon's room" and a "patient's room" was set up in two meeting rooms, the patients/parents reported to a nearby waiting room and the researchers brought them in turn to the telehealth suite where the consultation was conducted. The telehealth consultation followed very closely the pattern of normal face-to-face consultations, but with an assistant located with the patient to perform examinations and other tasks as directed by the surgeon. This was followed by a face-to-face meeting of surgeon and patient/parents in the "patient's room". The patients/parents then completed an exit interview before being escorted back to the waiting room.

Responsibility for recruiting the patients and for conducting the consultations fell completely with the surgeons. The role of the HCI researchers during the consultations was as observers, keeping mental and written notes and managing the video recordings [tripod-mounted video cameras recorded the events in each of the two rooms]. Before and after the consultations the HCI researchers had contact with the patients/parents, confirming the informed consent before the consultation and conducting the exit interview.

Figure 1: The Surgeon's Room. Photo courtesy of the Royal Children's Hospital, Melbourne

Figure 2: The Patient's Room - right-hand side. Photo taken by the paper's first author

Figure 3: The Patient's Room – left-hand side. Photo courtesy of the Royal Children's Hospital, Melbourne

The HREC's concerns, which were addressed in the ethics approval application, were 1) confidentiality of the patients' personal information and of the video recordings, 2) recruitment of patients for whom this type of consultation would be appropriate, 3) the provision of a follow-up face-to-face meeting between surgeon and patient/family and 4) provision for patients to withdraw from the trial at any stage and not lose their outpatient appointment. Hospital policy required appropriate security vetting of the HCI research staff.

A responsibility that fell on the HCI researchers concerned separating the roles of the clinicians and the

HCI researchers in the eyes of the patients/parents. We were in a large teaching hospital where there were many different people involved in caring for the patients and it became important for the HCI researchers to make it clear to the patients that we were not clinical staff. Even though we were dressed in formal "suits and ties" and wore hospital ID badges like the clinicians, it was important that conversational interactions before and after the consultation were not interpreted as clinical advice.

The HCI researchers' responsibilities also included how they should handle unexpected variations in the overall trial protocol and, in particular, on how they should report these in their results. Examples include withdrawal of consent during the consultation and discovering at the start of the consultation that the patient was outside the approved guidelines for recruitment to the project. This project also highlighted the importance of the personal relationships between the surgeons and the patients/parents in the overall consultation process and the strengths and tensions that could arise. The HCI researchers needed to be careful how they reported on such observations.

Observing surgery at The Canberra Hospital

These observations were part of a project investigating the possible role of gesture-based control of the display of patients' image data during surgery [in order to keep the surgeons' hands sterile]. It was led by the HCI researcher and involved both observations of surgery and interviews/discussions with the five surgeons who were the research partners. Its purpose was to re-visit evidence from the surgeons and from the operating theatre related to this gesture-control concept. The observations covered a range of surgical procedures (neurosurgery, vascular surgery, general surgery and catheter-based vascular procedures) and they involved the HCI researcher's presence in the actual operating theatre. The operations were scheduled some weeks in advance and the surgeons notified the HCI researcher when an appropriate surgical case was available for observation. A journal paper reporting on this study is in the process of being submitted.

The Australian Capital Territory Health Department has its own HREC. Because the surgeons were responsible for the presence of the HCI researcher in their operating theatre and because the observation process did not influence the patient's treatment the HREC's main concern was that the patients give informed consent to their surgery being observed. The surgeons had copies of the information sheet and consent form and arranged for formal consent prior to the operation.

The responsibility for the patient's pathway through the hospital system was entirely with the surgeon and there was no contact between patient and HCI researcher. During the operations the surgeon directed the HCI researcher on where to stand in the operating theatre and sometimes the senior nurse in charge of the theatre gave more specific instructions but otherwise the HCI researcher's duties were to stay out of the way, speak only when spoken to and observe.

An unspoken assumption was that it was the HCI researchers' responsibility to look after their own well-being. This included physical wellbeing (it is cold in an operating theatre and standing still for several hours is difficult) and mental wellbeing (explicit open surgery procedures can be very confronting). Guidance was occasionally offered – one surgeon was keen to explain the complexities of the operation to first author and to the medical student. Another time, the first author was invited to come over to the operating table to stand next to the anaesthetics trolley. The anaesthetist took him firmly and guided him up to the edge of the table, saying "stand up tall and close, so that when you faint you will fall backwards [rather than forwards onto the patient]". The primary decision for the HCI researcher at any stage of the operation was whether to stay or leave the operating theatre.

A premise of this project was that gesture-based control of image displays might be available to assist the surgeon when something unexpected happened. We did, indeed, observe one such event and we were not properly prepared for it. After 15 minutes of struggling with a particular surgical issue the surgeon led an assistant into the adjacent observation room and directed him to open his [the surgeon's] laptop and manipulate the pre-loaded 3D scans of the patient. The tension was such that the assistant was unable to follow the quite simple trackpad-based instructions.

Two issues are relevant here. The first relates to the importance of the HCI researchers not getting involved in the work at hand. In the abstract it is easy to understand that we are not clinicians and we have neither the role nor the responsibility to do anything. In practice it felt like the "open the laptop" instruction was directed at the small group of people crowded into the observation room and it was very difficult to fight that automatic response to do something "helpful" in a situation where there was clearly a problem. It took us a moment to catch our instinctive reactions and step back. Perhaps this cautious behaviour should be drilled into anyone undertaking observations in critical working environments like these.

Secondly, we had an important data point for our study but we needed to think carefully about how to present this data ethically. We were not well prepared for what we should do should such an event actually happen. Three issues are immediately apparent: a. We needed an exit plan so that we could get out of the way promptly, b. We needed a way to report what we had seen in a correct and meaningful manner and c. We needed a plan to deal with our own mental wellbeing in the event of a bad clinical outcome from the procedure.

Interview-based study of Fair Trade supply chains

This project involved a domain exploration of information flows from overseas producers to Australian consumers in fair trade handicraft supply chains. The study focussed on determining whether producers' information needs about their customers and target market were being met and on the potential for new ICT interventions to improve these reverse feedback loops (Taylor et al. 2015). The primary researcher was a final

year undergraduate IT student with a strong personal involvement in fair trade advocacy, operating under the supervision of two academic staff in the field of HCI. The university's HREC approved an Expedited Level 1 (E1) application to interview Australian fair trade consumers and importers, while a separate Expedited Level 2 (E2) application was required for producer interviews by telephone/Skype given the sensitivities associated with collecting data from "overseas". Consumer and importer contacts were recruited through the primary researcher's personal networks, while producers were recruited via recommendations from importers who had participated in the study.

Ethical considerations related firstly to the commercial sensitivities associated with interviewing importers and producers, both forming links in the same supply chain. Our processes required us to communicate directly with producers during the recruitment process and exclude importers and producers from mutually participating in the same interview to ensure that participants could speak freely, without creating tensions with commercial implications. This approach required importers to provide the researchers with email addresses of producers to whom we were an unfamiliar party, so importers had to work through their own organisation's procedures to identify amenable producer participants and release their details to us in an ethical manner. Secondly, we drew on the expertise of the importers, and our own research into the producers' cultural contexts to frame our interactions and questions in sensitive ways, while maintaining an awareness of our own position with respect to our participants. We conducted the interviews in a time efficient manner as we were mindful of the fact that participants were volunteering time away from their work or businesses to speak with us.

Before commencing an interview, we required consumers and importers to complete a written consent form adapted from the HREC template, and we talked through an oral consent script with producers. The consent forms requested participants to specify whether they would prefer attribution according to three closed options: participant category, pseudonym, or non-attribution. While the HREC procedures focussed on concealing participant identities, these forms were silent on whether and how to capture a participant's preference to instead be identified by their real names in the research outputs. Since transparency is an important principle of fair trade (FTAO 2013), some importer and producer participants stated that they were happy to be identified in association with their interview data as this was consistent with their values of openness and honesty in their communications. The researchers found it challenging at times to reconcile Australian HREC processes and expectations with these alternative attribution desires expressed by participants.

The purpose of this study was to explore an area that was not well documented and unexpected issues were encountered during both the recruitment of participants and conduct of the interviews. This required the researchers to maintain a detailed mental picture of their ethics protocol to enable them to identify cases requiring deviation from the approved processes in real time, and apply for protocol variations addressing these cases within tight timeframes. In the producer interviews with non-native English speakers unfamiliar with academic research, explaining the concepts of an ethics committee, risk, and consent demanded considerable skill from the researchers. Sound judgement was also required in gauging the producers' understanding of the project and implications of their participation, along with an awareness that the final research outputs may be broadly distributed.

DISCUSSION

Three important aspects bridge the examples in this paper. Firstly, it is important for HCI researchers to maintain an awareness of their ethics responsibilities at the forefront of their mind during their research activities. It can be easy to think only of the explicit ethics committee requirements (examples include the classical information-sheet→consent-form→interview-questions→close) and to forget that the participants may interpret the researchers' activities as part of a wider context.

Secondly, it is important for HCI researchers to plan for ethics-based contingencies. HCI field work can be inherently unpredictable. A professional approach to this work involves careful planning and ethics-based responsibilities and contingencies should be part of that plan.

Finally, HCI field work takes the researchers into other people's lives and can expose them to information that unexpectedly sensitive. It is the researchers' responsibility to treat this information with appropriate respect for the context in which it was acquired.

ACKNOWLEDGMENTS

The authors acknowledge the participants and our research partners in each of the three studies mentioned in this paper, and also acknowledge the support that we received from the various HRECs associated with these projects.

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