Ethical Encounters in HCI: Research in Sensitive Settings

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Abstract

With HCI researchers conducting studies in increasingly
sensitive and difficult settings, ethics is emerging as a
key concern for the HCI community. New technologies
are now being designed and evaluated in settings that
involve vulnerable or marginalized participants and that
can be emotionally challenging for researchers. Research
in these settings can produce complex ethical dilemmas
that are often emergent, diverse, and highly
contextualized. In addition, there may be discrepancies
between the realities of HCI fieldwork and the formal and
often rigid processes of obtaining ethics approval in
research institutions. Given these issues, it is important
for researchers to communally reflect on ethical
encounters in HCI research. This workshop will provide a
forum for researchers to share experiences about ethical
challenges they have faced. These discussions will be
used to develop a handbook of practical lessons
representing the breadth and depth of ethical issues
emerging in HCI research in sensitive settings.

Author Keywords

Ethics; Sensitive settings; Vulnerable participants.

ACM Classification Keywords

H.5.m. Information interfaces and presentation (e.g.,
HCI): Miscellaneous.

Introduction

The field of human-computer interaction (HCI) has seen a noticeable shift in focus in recent years, with more research now conducted outside the workplace or home and in increasingly sensitive settings. Researchers are designing and evaluating technologies for activities as diverse as end of life care [7], bereavement support [6], and social support for the elderly, the very young, and people with complex mental health issues (e.g., [10], [13], [15]). Furthermore, HCI research often aims to not only understand participants and the worlds they live in, but to also intervene in those worlds through the design, implementation, and evaluation of new technologies [14].

For any research involving human participants it is crucial to consider and plan for ethical issues. Many projects conducted in sensitive and emerging areas, however, can raise new and complex ethical concerns for HCI researchers. These issues often cannot be fully predicted and planned for at the outset of the research or are not covered in formal ethical approval documents and processes (e.g. IRB in the US, IRAS in the UK). They are emergent, diverse, and embedded in the context in which the research takes place [4]. Thus, there is a need to consider and reflect on the ethical issues that emerge during the course of each research project. HCI researchers are beginning to recognize and respond to concerns about ethics (e.g., [6], [7], [14]). The topic of ethics emerged as a central issue in two recent CHI workshops that focused on designing for and with vulnerable populations [12] and enabling empathy in design research [11]. In addition, a CSCW workshop [1] and forthcoming special issue for the journal *Interacting with Computers* suggests that ethics has become an important component of theoretical discussions about co-creation in HCI. Building on these initial reflections,

this workshop will provide a forum for researchers to share practical knowledge about ethical challenges in HCI research. We recognize that some of these issues are well-known to social scientists and we want to foster interdisciplinary dialogue about these experiences. The ultimate aim of this workshop is to develop a handbook that will draw on practical experiences and interdisciplinary learnings to provide a toolkit of lessons and strategies to inform future ethical practice for HCI research in sensitive settings.

Workshop Themes

Procedural ethics vs ethics in practice

There are institutional governance procedures in place to ensure that all research projects involving human participants are designed to adhere to core ethical principles. These are known as "procedural ethics" [4] and can be contrasted with the unanticipated "ethics in practice" issues that emerge during the course of the research. This workshop aims to explore the tensions between procedural ethics and ethics in practice. The workshop will focus on identifying and unpacking "ethics in practice," but we also invite contributions from researchers who were challenged by having to adhere to procedural ethics requirements. Understanding how people have dealt with these challenges will form an integral component of the handbook that we aim to develop. In addition, we will examine current practices in related social sciences, such as anthropology and visual sociology (e.g. [2]), for lessons that can inform researchers, administrators, and policy-makers in their continuous efforts to make ethics processes more flexible and relevant.

Researcher wellbeing and role conflict
Issues discussed in the HCI literature include concerns about how to protect researchers' emotional wellbeing when designing technologies in sensitive settings such as with the bereaved or with very sick children [8]. In addition, researchers may experience conflict regarding the role they play in these settings. In one case, a researcher working with the bereaved encountered ethical difficulties when participants misinterpreted his role and mistook the purpose of the focus group discussion for a bereavement support group [6]. In complex situations like this, researchers can experience dilemmas about how to respond appropriately. Coming face-to-face with participants' vulnerability in these settings can be confronting [15]. In this workshop, we invite participants to describe similar dilemmas, discuss how they responded, and reflect on how they cope with emotionally challenging situations.

Setting or blurring boundaries
A common and related challenge when working closely with vulnerable or marginalized participants is maintaining boundaries around the researcher's role and the setting of the research. Researchers need to decide how much to intervene when, for example, describing the purposes of the project (without coercing participants to take part), ensuring participants are supported in the research process, and providing comfort when a participant shows signs of distress. It is especially difficult to maintain boundaries and non-bias when research is conducted "in the wild" of real-world settings, involves spending considerable time with participants, or engages participants in collaborative design and digital content creation [3]. Munteanu and colleagues experienced difficulties when evaluating a mobile learning tool with adult learners in a small

community: they often encountered participants outside the research setting and had to decide whether to use the data collected during these serendipitous encounters [9]. This workshop will explore similar challenges that researchers have faced, and discuss lessons that can be learned from disciplines outside HCI, such as cultural anthropology (e.g. [3]).

Consent and participation
An important component of ethical research is gaining participants' informed and voluntary consent to take part. When working with some vulnerable populations it can be difficult to ensure that participants are fully aware of the consequences of their participation. Low literacy, for example, presents interesting ethical challenges. Institutional ethics boards usually require researchers to use "plain language statements" to communicate the purposes of the research, but these often include mandatory statements that are difficult to adjust for participants who can read only basic text [9]. Furthermore, the use of content published on social media is becoming increasingly common in HCI research, but researchers are only beginning to grapple with the ethical issues that these new forms of data collection can provoke. Information published on social media is usually written for a particular audience, and researchers need to consider the ethics of appropriating this material for academic purposes, especially when this is done without the authors' consent [5].

Workshop Aims and Outcomes
This workshop invites contributions from researchers working in diverse settings and using a range of methodologies. The workshop aims to:

- Provide a forum for researchers to share experiences of ethical encounters in HCI research.

- Identify common issues researchers have faced, both within HCI and in related social science fields, and explore how these have been addressed.

- Identify the unresolved challenges that researchers continue to grapple with and explore options for responding to these challenges.

- Discuss how ethical encounters will grow and change as emerging (and disruptive) technologies continue to be introduced into sensitive settings.

- Produce a practical handbook that reflects the breadth and depth of ethical issues emerging in HCI research in difficult and sensitive settings.

The workshop will provide opportunities for researchers to learn from each other and from related disciplines to develop practical strategies to respond to ethical issues in HCI research. These strategies will be communicated to the HCI community through a handbook of good practice for ethical HCI research in sensitive settings.

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