
Ethical Encounters in HCI: Implications for Research in Sensitive Settings

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Abstract

This workshop builds on the success of prior workshops that brought together HCI researchers to share stories about ethical challenges faced when conducting research in sensitive settings. There is growing recognition that reflective and empathetic approaches are needed to conduct ethical research in settings involving people who might be considered vulnerable or marginalized. At our previous workshops, researchers discussed personal experiences and described the complex challenges they have faced in research as diverse as designing information systems for families of children in palliative care [6] to analyzing social media posts about mental health [1]. In this follow-up workshop we aim to extend opportunities for knowledge-sharing, build on the lessons learned, and generate a range of resources to help HCI researchers manage complex ethical issues when working in sensitive settings.

ACM Classification Keywords

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

Introduction

“Research ethics” is often tolerated as an arduous process that researchers must follow in order to gain formal approval before research can begin. In this series of workshops, we take a broad view of what

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counts as “research ethics”. Doing ethical research is not *just* about adhering to institutional review processes; nor is it *just* about ensuring we obtain informed consent from our participants, or that the data we report are sufficiently anonymized. Rather, doing ethical research means being aware of, and responding to, numerous small details in the research process that cannot always be predicted and that can sometimes disrupt and derail studies, even causing harm to participants and/or researchers [9][13].

Issues that fall under the umbrella of research ethics can overlap considerably with other research concerns [24]. These include methodological issues and pragmatic details, such as ensuring researchers are sufficiently trained to do the research they are undertaking. In this workshop, we recognize that these issues are entwined. We do not aim to disentangle ethics from other research concerns because ultimately methodological and pragmatic concerns can result in ethical challenges – for example, when a researcher is insufficiently trained or supported to conduct research with sick children, there is increased risk of harm for both participants and researchers [12].

Ethics in HCI research has become a topic of much discussion and debate in recent years (e.g., [3] [4] [7] [13] [15]). For instance, at CHI 2016 Brown et al. presented a series of provocations about the ethical challenges faced by our community [3]. This was followed by a lively town hall meeting about the new ACM code of ethics. Amy Bruckman’s chapter in the book *Ways of Knowing in HCI* provides a useful overview of why ethics matters in human-computer interaction [4]. As she states, ethics is growing in importance in HCI, partly due to the growing scope of HCI research: ‘As HCI expands its domain to every

corner of the human experience, issues of research ethics keep getting more complicated’.

Our own work about ethics has focused on HCI research conducted in sensitive settings, with participants who might be considered vulnerable or marginalized. For instance, we have worked with: socially isolated older adults [25][27], people with chronic and complex conditions [20], people with low levels of literacy [14], refugee communities [16], and women experiencing significant mental health issues [18], among others. Projects conducted with participant groups such as these can raise new and complex ethical concerns for HCI researchers. Other disciplines, such as sociology and anthropology, have long recognized the challenges of working in such settings. In HCI, however, we have the added complexity of often designing with our participants or introducing new technologies into their lives. This can create a need to carefully manage vulnerable participants’ misunderstandings or inflated expectations about technology, as well as ensuring participants are well supported when the technology does not work as expected [20][25][27]. The *Ethical Encounters in HCI* workshops (see side box summaries) are motivated by our experiences conducting research in these sensitive settings. The challenges we have identified and discussed during the workshops, however, and the associated implications, are relevant for ensuring good HCI research practices more generally.

In the CHI 2017 workshop we aim to push the agenda forward, to provoke discussion that centers not only on identifying common issues, but also collecting examples of good practice that can be used to inform future approaches in “sensitive HCI” [28]. While we will

Summary of previous workshops on ethical encounters in HCI

At CHI 2015 we held the inaugural workshop on “Ethical Encounters in HCI: Research in Sensitive Settings” [25]. This followed other recent workshops that focused on designing for and with vulnerable populations [21], enabling empathy in design research [17], and ethics in participatory design, held at CSCW 2015 [2].

We conducted a second “ethical encounters” workshop at OzCHI 2015 [5] and another at CHI 2016 [26].

These workshops have attracted both novice and experienced researchers working in diverse settings to share experiences and critically reflect on ethical issues encountered in their work. For more information: www.ethicalencountershci.com

continue to collect case studies of ethical dilemmas faced by HCI researchers, we will also examine how existing ethics policies and guidelines support our research activities. Through this we hope to establish a critical sensitivity to ethical issues within the field of HCI, while also developing and collecting resources to support good practice going forward.

Workshop Themes

The 2017 workshop will continue to build conversations around the themes of preceding workshops. In addition, we will extend our focus on formal guidelines and policies to examine their relevance and value as resources for good practice in ethical HCI research.

Formal approaches to ethics and their relevance to HCI
In many countries, research with human participants is governed by various formal policies. Often this takes the form of carefully-crafted documents that assist institutions to implement their own procedures. In some countries such formal policies are national in coverage, both providing guidance to researchers and acting as the “letter of the law” – for example in Canada all research with human participants that is conducted at publicly-funded institutions must follow the Tri-Council Policy Statement (TCPS2) [19]. Such frameworks have successfully guided ethically-difficult fieldwork in many disciplines; yet HCI researchers often indicate their unsuitability for interpreting the ethical challenges encountered especially during fieldwork with novel interactive technologies. The CHI 2017 workshop will include discussion of these policies and an interrogation of the applicability of existing guidelines to the ethical dilemmas participants have experienced. This will enable us to identify the gaps in existing guidelines, to inform resources that will be developed as an outcome of this workshop.

Researcher wellbeing and training

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 [12]. Coming face-to-face with participants’ vulnerability in these settings can be confronting. This issue can be complicated in HCI because of the inherently interdisciplinary nature of our work. It is not uncommon for HCI researchers to work in areas where they lack domain expertise (e.g., aged care). As more research is being conducted in sensitive settings where the researchers themselves may have little or no prior experiences, it becomes important to discuss the need for appropriate training to ensure good ethical research practices are followed, and to ensure strategies are in place to protect researchers’ emotional wellbeing. One way in which this can be (and is being) achieved is through collaboration with domain experts; that is, ensuring that we recognise, build on, and work with, expertise in other relevant disciplines (e.g., social gerontology when working in aged care settings). In this workshop, we will discuss how to explicitly include strategies for coping with emotionally challenging situations, and how to make use of domain expertise, in the planning and conduct of the research.

Caring for participants and compliance

Furthermore, we will invite reflections on the often tacit nature and role of ‘caring for participants’ in research. Especially in studies that involve what we describe as vulnerable participants, care does play, and should play, a key role in knowledge production. Caring for participants is often claimed to be ethically valuable; caring enables researchers to respond to the persons’ needs or demands [6]. In design research, we find

Outcomes from previous workshops

Outcomes from our prior workshops include:

- Published articles from attendees and organizers [20][23][28]
- A special issue in *Interacting with Computers* [15]. This grew out of the CSCW workshop on participatory design and ethics [2].
- A collection of case studies and examples, in the form of position papers available on the workshop website.

We continue to be approached by other researchers and practitioners working in difficult research design contexts, who seek advice on challenges related to ethical aspects of HCI research and practice. This suggests a need for these discussions to continue to grow and evolve; hence, the need for regular workshops on this topic.

proposals that explicitly consider the wellbeing of the participant when involved in research activities [11]. Care for, and consideration of, the participants can mitigate potential discomfort and aid the formation of a closer relationship that enables a more nuanced understanding of the person. Giraud and Hollin [6], however, highlight how caring for participants by creating more comfortable research conditions for them also presents a way to 'manufacture compliance'; to prevent for instance participants choosing to end their research involvement. As researchers we need keep challenging our motivations as to why and how we make certain decisions that we perhaps perceive as 'caring for participants'. Are these truly in the interest of the person or rather self-serving to the research and associated aims? This challenge is even more acute in contexts where research participants cannot advocate for themselves, are more susceptible to being influenced by others, or experience distortions in their own relationships with other people. How can we make sure that we are not coercing or abusing participants?

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 [23]. Much of the research that has been discussed at our workshops to date involved extended periods of time working with participants in field studies. When engaging in this "embedded" design and evaluation work, ethical issues can arise in the way participants come to understand the role of the researcher. Through their extended involvement with participants, the researcher may become perceived as carers, friends, or advocates. This unwittingly extends the researcher's professional role

and can raise ethical challenges around issues of coercion/consent and deciding when, or how much, to intervene when a participant shows signs of distress. This workshop will continue to explore challenges that researchers have faced in fieldwork, and discuss lessons that can be learned from disciplines outside HCI, such as cultural anthropology (e.g. [6]).

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 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 [14]. 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 an academic audience, especially when this is done without the authors' consent [10].

Additionally, the notion of free will does not always apply, for example in some professional settings (e.g. evaluations of interactive technologies with military or law enforcement partners [13]), or in care settings where participants are clients recruited through a care provider [25]. In other cases, participants might be compelled to participate because of perceptions about

benefits an intervention may have on their lives [20] or because they receive free goods as in-kind compensation for participation [13]. Furthermore, disclosure is significantly limited when systems under evaluation come to be used by nonparticipants, a common situation when evaluating technologies “in the wild”. Such “ethical dilemmas” faced often by HCI researcher deserve further consideration [13].

Workshop Aims and Outcomes

As evident from our workshop last year **Error! Reference source not found.** and from our paper on Situational Ethics [13], HCI researchers rarely receive any formal training in dealing with ethical issues. Grounded in the above themes, this workshop will create resources to support future HCI research and practice. The intended outcomes include:

- The creation of an online repository of “HCI ethics stories” which is open to all researchers and which will act as a community-based, grassroots portal enabling other researchers to continue benefitting from shared (and sharing) experiences.
- The development of resources that provide learning materials, examples, and strategies of good practice in ethical HCI research. These will be available online and will be communicated to the HCI community through courses run at relevant HCI conferences.
- Concrete steps towards developing a framework that captures the particularities of the ethical conduct of HCI research with human participants. This framework will be disseminated in the HCI community through a published article following the workshop.

Workshop proceedings

All accepted workshop papers and documentation will be published on the workshop series website:
<http://ethicalencountershci.com>

Before the Workshop

We will promote the workshop via professional mailing lists and through contacts established during our previous workshops. Social networking (e.g., LinkedIn, Facebook) will be used to share the call and encourage discussion. Fitting with the workshop's goal of developing a case book of ethical encounters in HCI, submissions will be solicited in the form of case studies (4-6 pages long). All accepted papers will be pre-published on the workshop website. Small reading groups will be created and participants will be asked to prepare for the workshop by reading each other's case study. We aim to bring together a group of 15-25 researchers working in diverse and sensitive settings and using a range of methodologies in HCI research.

During the Workshop

Following introductions, participants will be divided into pre-established reading groups and engage in a “Q&A” discussion about each position paper (60 minutes). In a second breakout session, small groups will examine existing resources and guidelines to identify gaps (60 minutes). Following each breakout session, the whole group will discuss the key themes that emerged from the sessions; these will form the basis of a report about the workshop proceedings. The workshop will conclude with a plenary discussion focused on efforts to develop a framework of ethical issues specific to HCI research and to establish a more systematic study of the issues.

After the Workshop

The rich discussions in this workshop will be used to develop a toolkit of practical examples and lessons reflecting the breadth and depth of ethical issues emerging in HCI research in sensitive settings. A final report of workshop proceedings will be published on the

workshop website and the organizers will propose a discussion piece for *Interactions* magazine. The organizers aim to publish an edited book that will include chapters from workshop attendees and feature lessons about HCI-specific ethical research experiences.

About the Organizers

Jenny Waycott is a Lecturer in the Department of Computing and Information Systems at the University of Melbourne. Her current work focuses on the design and use of new technologies to support older adults who are socially isolated.

Cosmin Munteanu is Assistant Professor at the Institute for Communication, Culture, Information, and Technology (University of Toronto at Mississauga), and Associate Director of the Technologies for Ageing Gracefully lab. Cosmin's multidisciplinary work includes speech and language interaction for mobile devices, mixed reality systems, learning technologies for marginalized users, assistive technologies for older adults, and ethics in human-computer interaction.

Hilary Davis is a senior Research Fellow in the Living with Disability Research Centre (LIDS), La Trobe University and Swinburne Social Innovation Institute, Swinburne University, in Melbourne, Australia. She conducts research in complex and sensitive settings. Her current research focuses on digital participation for diverse and marginalised communities, including people with intellectual disabilities, housebound people and those disadvantaged due to place.

Anja Thieme is a Postdoctoral Researcher in the Human Experience & Design (HXD) group at Microsoft Research, Cambridge. Her research includes sensitive, empathic and innovative approaches to the design and

evaluation of digital technology for a range of use groups including people suffering from mental health problems, or persons with vision impairments.

Stacy Branham is a Postdoctoral Researcher in Information Systems at the University of Maryland Baltimore County. She studies communication in intimate couple relationships in which mental disorders and physical disabilities complicate the day-to-day challenge of staying connected

Wendy Moncur is an Interdisciplinary Professor with a joint appointment across Duncan of Jordanstone College of Art and Design and the School of Nursing and Health Sciences at the University of Dundee. Her work focuses on the design of technology to support being human in a Digital Age, grounded in HCI and informed by knowledge from other disciplines including anthropology, sociology, psychology and design. It addresses sensitive contexts including end of life, bereavement, serious illness and relationship breakdown which stir up challenging ethical questions.

Roisin McNaney is a Lecturer in Digital Healthcare Technologies at Lancaster University. Her research focuses on the role that digital technologies might play in supporting self-monitoring and management practices in people with Parkinson's specifically and chronic health conditions more generally. She comes from a clinical background originally and has experience working in both clinical and HCI research environments.

John Vines is a Professor in the School of Design at Northumbria University. His research focuses on involving diverse communities and citizens in design processes during the early stages of technology development. He has expertise working with vulnerable user groups, specifically in the context of envisioning

future social care, financial management and health-related technologies and services.

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