# **Ethical Encounters in Human- Computer Interaction**

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#### Abstract

In the HCI community, there is growing recognition that a reflective and empathetic approach is needed to conduct ethical research in sensitive settings with people who might be considered vulnerable or marginalized. At our CHI 2015 workshop on ethical encounters, researchers shared personal stories of the challenges and tensions they have faced when conducting HCI research in complex settings such as hospitals, with young mental health patients, in schools for children with disabilities, and with homeless people. These research contexts can present significant challenges for HCI researchers who would not typically receive the training that other professionals working in these environments would normally receive. From our discussions with attendees at the CHI 2015 workshop, we identified a number of ethical issues that researchers are grappling with. In this follow-up workshop we aim to build on the lessons learned and to generate pragmatic but sensitive solutions to manage complex ethical issues for HCI researchers working in challenging settings.

### **Author Keywords**

Ethics; sensitive settings; vulnerable participants.

## **ACM Classification Keywords**

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

#### Introduction

For many human-computer interaction researchers "ethics" represents an arduous process that must be followed in order to gain formal approval before we can proceed with our work. There is, however, growing recognition that ethical issues cannot be fully predicted and planned for, and that conducting ethical HCI research may require a more subtle and flexible approach than the strategies advocated by ethics review boards [7].

HCI researchers have begun to openly talk about ethics and to reflect on the particular challenges they have faced when designing and evaluating new technologies. This shift in focus towards ethics as a legitimate topic of discussion in HCI is partly due to HCI's "turn to the wild" [9], as well as a growing tendency for HCI research to be conducted in increasingly complex and sensitive settings. Projects conducted in sensitive and emerging areas can raise new and complex ethical concerns for HCI researchers. In a recent issue of the ACM Transactions on Computer-Human Interaction, Benford and colleagues demonstrated that ethical issues in HCI are not confined to overtly sensitive settings, such as hospitals; ethics are also important to consider when conducting research in public places or when HCI collides with other kinds of work, such as the performing arts [1]. The increasing complexity of HCI research, and the diverse settings in which it takes place, means ethical issues are constantly changing. This requires ongoing reflection and sharing of experiences in order to ensure ethical practice as our discipline evolves.

At CHI 2015 we held the inaugural workshop on "Ethical Encounters in HCI: Research in Sensitive

Settings." This followed other recent CHI workshops that focused on designing for and with vulnerable populations [11] and enabling empathy in design research [10]. In these workshops ethics clearly emerged as a prominent theme in the discussions, suggesting a need for researchers to share experiences and explore these issues further. This motivated our first ethical encounters workshop [12], which provoked lively discussion about the particular challenges attendees had faced when conducting various forms of HCI research in complex and sensitive settings. Following the workshop and a well-received paper on situational ethics presented at CHI [7], we were frequently approached throughout the CHI 2015 conference by other researchers who expressed a need for increased opportunities for researchers to share and discuss challenges related to ethical aspects of HCI research. This led us to organize a follow-up workshop at OzCHI 2015, which attracted much interest from the Australian HCI community [2]. To date, however, these discussions have primarily focused on identifying and reflecting on the challenges faced, with limited discussion of possible solutions or future directions for the HCI community. In the CHI 2016 workshop we aim to push the agenda forward, to provoke discussion that centers not only on identifying common issues, but that also provides lessons, guidelines, and case studies that can be used to inform future good practice in "sensitive HCI" [14].

#### **Summary of CHI 2015 Workshop**

The CHI 2015 workshop on ethical encounters in HCI attracted researchers working in diverse settings who brought a range of perspectives to the discussion. Several common issues and questions emerged, e.g.:

- How do we adopt an empathetic approach and build rapport with our participants, while also maintaining boundaries around the research and maintaining a degree of "professionalism" in our roles as researchers?
- How do we manage group dynamics when using group-based participatory design methods or when designing technologies that aim to provide social connections?
- What policies and practices do we need to ensure that researchers do not experience harm during the research process?
- How do we ensure that the artefacts and technologies we design and introduce have a positive impact? Who is responsible when something goes wrong? How can we make sure that participants do not blame themselves for any difficulty they experience using the technology?
- What are the ethical considerations for "third party" involvement – people who are not research participants but who end up having a role in the study? This can include obvious stakeholders, such as healthcare staff in a hospital setting, or it could include external people, such as those paid to transcribe interviews that include sensitive content.
- How do we design inclusive research practices, while remaining alert to the possibility that participants could experience unexpected harm during the research? How do we adapt our protocols accordingly, and how do we ensure that those who could benefit from the research are still given opportunities to take part?

This workshop will continue the efforts started at CHI 2015 by building on contributions from workshop attendees to generate pragmatic but sensitive solutions

to address complex ethical issues which arise prior to, during the course of, and after research is completed. The ultimate aim of this workshop is to develop a webbased resource and an edited collection of case studies that will provide lessons and strategies to support the ongoing ethical practice of HCI researchers working in sensitive settings.

#### **Workshop Themes**

The workshop will collect and discuss case studies that are relevant to foundational themes in the ethical conduct of HCI research. We will continue to explore key themes that formed the focus of last year's workshop, and introduce new themes that emerged during previous workshop discussions and through our ongoing reflections with colleagues in the CHI community (as seen, for example, in [14]).

#### Researcher wellbeing

A prominent issue that emerged in the CHI 2015 workshop discussion is that HCI research sometimes takes place in institutional environments where there are insufficient practices and policies that aim to protect researchers during fieldwork in difficult settings [5]. Some of our discussions revolved around the issue of gender and the challenges that gender relations can create during fieldwork with particular groups. We identified a need for further work to establish key strategies for ensuring researchers do not experience harm, or for providing researchers with support when they find the research process difficult.

#### Building rapport and blurring boundaries

A related challenge is the need to build rapport with participants, which can lead to a blurring of boundaries around the researchers' role and the setting of the research. One of the most significant ethical (and moral) challenges that is often encountered by researchers in longitudinal evaluation of technologies is the familiarity between researchers and participants that can develop naturally over such a long period of time [7]. This can have positive consequences in the participants' unreserved feedback, but also lead to expectations of researchers becoming intimately involved in the social lives of participants. In addition, introducing new technologies into participants' lives provides an extra layer of complexity that can make it difficult to know how much researchers should intervene [13]. The case studies collected during the CHI 2015 workshop further illustrate a need to continue our analysis of the ethical implications of such situations and how practitioners can (and when they should) maintain boundaries around the research.

#### Consent and participation

An important component of all ethical research is gaining participants' informed and voluntary consent to take part. However, when working with some vulnerable populations it can be difficult to ensure that participants fully understand what is required of them. Additionally, the notion of free will does not always apply. In some professional settings, for example, people might be required to participate as part of their employment (e.g. evaluations of interactive technologies with military or law enforcement partners [7]). With particular demographic groups, such as young children, proxies may be required to provide consent. Parents, teachers, or carers may assist in recruiting participants, which then raises questions of whether participants have been coerced. This is a further blurring of the difficult distinction between ethics and morality when conducting human-subjects

research. The workshop discussions will consider the particular features of HCI research that can make informed consent and participation challenging, including the challenge of conducting research about technology use in online environments.

Exposure to risk and harms through new technology Typically in HCI research, potential risks for participants are no greater than the risks encountered when using everyday technology; such statements still must be disclosed to participants before they enrol in the study. However, such a disclosure is significantly limited when the system to be evaluated is being used by nonparticipants, a common situation when evaluating interactive technologies "in the wild" [6,7,8]. In addition, we can never fully predict how a new technology will be used, or what might go wrong with the technology. In the previous workshop, McNaney and Vines [4] described the anxiety their participants experienced when the technology they were evaluating did not work as expected. In another example, older adults using an iPad app to share messages found that it sometimes exacerbated, rather than ameliorated, their loneliness when people did not immediately respond to their messages [13].

#### Financial compensation and coercion

In field trials of interactive applications we are generally accustomed to compensating our participants for their efforts. However, increasing such compensations can be perceived as a form of coercion with respect to participation. On the other hand, as illustrated in a case study of blind participants testing a Braille text input app on smartphones [7], participants could perhaps benefit more from receiving a free copy of the app (in perpetuity) than from being handed a typically-meagre

one-time financial compensation. Such "ethical dilemmas" faced often by HCI researcher deserve further consideration.

Tools and methods for ethics awareness
HCI researchers rarely receive any formal training in
dealing with ethical issues. This calls for further
investigation into the methods that are effective in
making designers and researchers more aware of
ethical issues (besides mandatory training sessions that
are often ineffective in dealing with ethical dilemmas
that emerge unexpectedly during fieldwork). Recent
research has looked at developing tools for engaging
design and development teams with the topic of ethics
early on in their research [3]. This workshop will
consider whether such approaches can be expanded to
develop additional text and web-based resources.

#### **Workshop Aims and Outcomes**

The workshop aims to: (i) provide a forum for researchers to share experiences of ethical encounters in HCI research, (ii) build a body of case studies that illustrate common ethical challenges in HCI, and (iii) identify how those challenges have been, or can be, addressed. The workshop will provide opportunities for researchers to learn from each other and develop practical strategies to respond to ethical issues in HCI research. These strategies will be communicated to the HCI community through a website and handbook describing experience-based understandings of ethical good practice for HCI research in sensitive settings.

#### **About the Organizers**

Jenny Waycott (main contact) 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. Until 2014 he was a Research Officer with the National Research Council of Canada. Cosmin's multidisciplinary work includes speech and natural language interaction for mobile devices, mixed reality systems, learning technologies for marginalized users, assistive technologies for older adults, and ethics in human-computer interaction research.

Hilary Davis is a Research Fellow in the Department of Computing and Information Systems at the University of Melbourne. She conducts research in complex and sensitive settings, including healthcare settings and the family home. She has worked with a variety of participant groups including pregnant women with type 1 diabetes, young cancer patients, and distributed intergenerational family groups.

Anja Thieme is a Postdoctoral Researcher in the Human Experience & Design (HXD) group at Microsoft Research, Cambridge. Her research focuses on sensitive and empathic approaches to the design and evaluation of digital technology for vulnerable populations including people suffering from significant mental health problems, or children with visual impairments.

Wendy Moncur is a Reader in Socio-Digital Interaction at the University of Dundee. She is also a Visiting Scholar at the University of Technology Sydney in Australia, and Associate Director of the Social Dimensions of Health Institute in Scotland. 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 digital health researcher at Open Lab - Newcastle University. Her research interests focus around 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 and has experience working in both clinical and HCI research environments.

John Vines is a Lecturer at Newcastle University. His research focuses on engaging a wide range of groups in design processes during the early stages of technological development. He has expertise of working with vulnerable user groups, specifically in the context of envisioning future social care, financial management and health-related technologies and services.

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.

#### **Workshop Website**

http://ethicalencountershci.wordpress.com/

#### **Pre-Workshop Plans**

We will promote the workshop via appropriate professional mailing lists and through contacts established during our CHI and OzCHI 2015 workshops. Social network groups (e.g., LinkedIn, Twitter) will be created to encourage discussion. A WordPress site has been established and participants will be invited to add moderated comments to contribute to pre-workshop discussions about key themes. 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 settings and using a range of methodologies in HCI research.

#### **Workshop Structure**

The workshop will be interactive, involving a mix of focused small-group discussions and whole-group brainstorming. In the introductory session, participants will be asked to provide a statement about their research background and current work and describe an ethical dilemma they have encountered in their research. The workshop will include two breakout sessions with parallel small group discussions. In the first session, participants will be divided into preestablished reading groups and engage in an interactive peer review about each position paper. Following this breakout session the whole group will discuss the key themes that emerged from the paper reviews; these themes will form the basis of a web-based resource that will be developed during the afternoon activities. In the second breakout session, small groups will

workshop practical lessons and guidelines in response to the key themes.

#### Timetable

09:00-09:30 Welcome

09:30-10:30 Participant introductions

10:30-10:45 Coffee break

10:45-12:00 Breakout session: Position paper reviews 12:00-12:30 Whole group discussion: Key themes from

breakout session

12:30-14:00 Lunch

14:00-15:30 Breakout session: Brainstorming

responses to key themes

15:30-16:00 Whole group discussion

16:00-16:15 Coffee break

16:15-17:00 Final group discussion: Lessons to share

with other HCI researchers

17:00-17:30 Workshop close: Planning next steps

19:00 Workshop dinner and drinks (optional)

#### **Post-Workshop Plans**

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. In addition to publishing key lessons and guidelines on the workshop website, the organizers aim to publish an edited book that will include chapters from workshop attendees and feature lessons about HCI-specific ethical research experiences.

# Call for participation: CHI 2016 Workshop on Ethical Encounters in HCI

This one-day workshop will be held as part of the CHI 2016 annual ACM SIGCHI Conference on Human

Factors in Computing Systems, held in San Jose, USA, between 7 and 12 May 2015.

#### Important Dates:

Early submission deadline: 14<sup>th</sup> December 2015

Early notification: 21<sup>st</sup> December 2015

Final submission deadline: 8<sup>th</sup> January 2016

• Final notification: 15<sup>th</sup> January 2016

• Workshop day: 7<sup>th</sup> or 8<sup>th</sup> May 2016

HCI research is moving into increasingly sensitive and challenging settings. New technologies are now being designed and evaluated with vulnerable or marginalized participants in contexts that can be emotionally challenging for researchers. Research conducted in these sensitive and emerging areas can produce complex ethical dilemmas. This workshop aims to provide a forum for researchers to share experiences and learn from ethical challenges encountered in HCI research conducted in sensitive settings. From this workshop we aim to develop a handbook of practical strategies to inform good practice for future HCI research. Attendees will be invited to develop their workshop paper into a chapter for the book.

We invite researchers working in sensitive settings to submit 4-6 page case studies (in ACM Extended Abstract format) that describe ethical challenges they have experienced in their research and illustrate how they addressed or responded to those challenges.

Submissions should be sent in .pdf format to ethicalencountershci@cs.toronto.edu. Position papers will be reviewed by a committee of experts and selected on the basis of relevance to the workshop

themes, quality of presentation, and potential to stimulate discussion.

At least one author of each accepted submission must register for the workshop and at least one day of the main conference. For more information, please visit: http://ethicalencountershci.wordpress.com/

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