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- Member of the Interaction Design Lab, broadly working on understanding the role technologies play in people's learning, work, and social activities.
- Current research focus: the design and use of new technologies to support older adults who are socially isolated.
- Principal organizer of the CHI Workshop Series on "Ethical Encounters in HCI"
- Full member on the ACM SIGCHI Ethics Committee.

Contributors

- With contributions from:
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 - John Vines, Newcastle University
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 - Wendy Moncur, University of Dundee
- And based on prior collaborations with:
 - Heather Molyneaux, National Research Council Canada
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 - Susan O'Donnell, University of New Brunswick

The issue

- The need to protect research participants

IN 1971, THE STANFORD UNIVERSITY PSYCHOLOGY DEPARTMENT

Fallout of the Stanford Prison experiment

- Need for stronger ethical principle
 - The initial study design was approved by the university
- Need to consider researchers as participants
 - Prof. Phil Zimbardo's own account:
By the third day I was sleeping in my office. I had become the superintendent of the Stanford county jail. That was who I was: I'm not the researcher at all. Even my posture changes—when I walk through the prison yard, I'm walking with my hands behind my back, which I never in my life do, the way generals walk when they're inspecting troops.
(The Menace Within, R. Ratnesar, Stanford, Aug. 2011)
- Need to deal with unexpected situations occurring during fieldwork

Before ethical guides existed

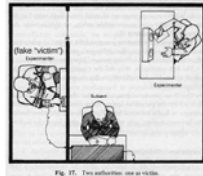
- The Tulane University brain stimulation program



Baumeister, J of History of Neurosciences, 2000, quoting (Heath, 1971)

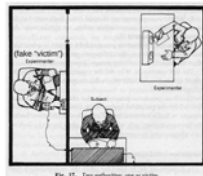
Updating ethical guides

- The Milgram “Electric Shocks” Experiment (1961)



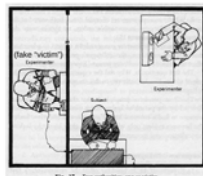
Updating ethical guides

- What was actually wrong with Milgram’s experiment?



Updating ethical guides

- What was actually wrong with Milgram’s experiment?
 - Consent, deceit, (harm)



Updating ethical guides

- Any recent (famous) example from the tech space involving (lack of) consent, deceit, and potential harm?

The principles (today)

- Guidelines and regulations for the ethical conduct of research with human participants governed by institutional Research Ethics Boards (REB, HREC, IRB, etc.)
 - Tri-council Policy Statement on Ethical Conduct for Research Involving Humans (Canada)
 - National Statement on Ethical Conduct in Human Research (Australia)
 - Ethical Guidelines for Good Research Practice by the Association of Social Anthropologists (United Kingdom)
 - Policies implemented independently by each university in the US (under the Common Rule) and other countries
 - Overlap with other regulations, e.g. the EU General Data Protection Regulation (GDPR), or consultative bodies, e.g. the EU Network of Research Ethics Committees (mostly medical)

Universal basic principles

- Scientific value
- Do no harm (*)
- Voluntary participation (*)
- Informed consent (*)
- Right to privacy
- Trust

Respect for persons

- TCPS2:
 - Unacceptable to treat individuals solely as means (mere objects or things) to an end (a research goal)
 - The welfare and integrity of the participant must take priority over all else in human research
- Participants = individuals or groups:
 - Directly involved in research (e.g. users)
 - Indirectly involved in research through the use of their data or biological materials

The participant perspective

- Questions to be asked before starting a study / research / experiment:
 - Is there a power relationship between the researcher and the participants?
 - Are there any cultural norms or practices that need to be factored into the recruitment, consent, or debriefing process?
 - What are the economic circumstances of the prospective participants?
 - Could there be any social repercussions of participation in this project?
 - How can the privacy and confidentiality of participants be protected?

Voluntary participation

- Participation should be **voluntary** (free of undue influence or coercion), **informed**, and **ongoing**
- How to apply:
 - Ensure participants' ability to make voluntary and informed decisions (autonomy)
 - Consider factors that can diminish participant autonomy
 - Consider how to respect the dignity of those lacking autonomy
 - Respect every individual's ability to give or refuse their consent to participate
 - Ensure participants' decision is based on clear information about the foreseeable risks and potential benefits of the study
 - Do not coerce or influence participants

Voluntary participation

- Practical application:
 - Consider participant autonomy in research design
 - Provide enough information about the experiment
 - Ensure complete understanding of the risks and benefits
 - Allay fear of offending researchers in positions of authority
 - Allay worry that their decision will affect their level of care, privileges, or other quality of life issues – most relevant to institutionalized populations
 - Ensure there is no pressure from one's family, friends or community

Concern for welfare

- Research participation can affect the welfare of an individual or group
 - Physical, mental and spiritual health
 - Physical, economic and social circumstances
 - Privacy and the control of personal information
 - The treatment of human biological materials according to the consent of the donor
 - The possible affect of the research on the welfare of participants' friends, family, or other groups

Concern for welfare

- Could participants be exposed to harm:
 - Physical
 - Distress or discomfort
 - Risks:
 - Economical (e.g. losing their job)
 - Social to themselves (e.g. ostracized by their peers)
 - Social to others (e.g. harm to friends, family)
 - Privacy

Concern for welfare

- Informed consent
 - Participants must be able to decide whether the benefits justify the risks in their decision to either consent or refuse to participate in the research
 - Consent materials must give an accurate account of the foreseeable risks and potential benefits
- Research design:
 - Eliminate and/or minimize risks
 - Maximize benefits
 - Provide accurate and accessible information

Any recent examples of problems?

- Frame this in relation to Milgram's experiment, but within HCI
 - E.g. ensuring consent when deceit is used



Justice

- Treat all people (direct or indirect participants) fairly and equitably. Ensure fairness and equity.
- Fairness
 - Treat all people with equal respect and concern for their welfare – it does not necessarily mean treating everyone the same
- Equity
 - Distribute the benefits and burdens of research participation. No segment of the population should be unfairly burdened with the harms of research. Nor should any individuals or groups be neglected or discriminated against in the opportunity to benefit from knowledge generated by research.

Justice

- How to apply
 - Who are the participants? Why this group and not others? (exclusion/inclusion must be scientifically valid)
 - Are any participant groups over- or under-represented because of their vulnerable circumstances? (vulnerability can be relative)
 - Are there measures in place to treat people in vulnerable circumstances justly in the context of the research?
 - Is there an imbalance of power between participants and researchers?

Additional note: privacy principles

- Right to privacy
 - Everything from questionnaire answers to video recordings
 - Ability to withdraw consent to use data
- Confidentiality
 - Researchers' duty to protect any identifiable data
 - This extends to voice recordings, sensor data, etc.
- Anonymity
 - Right of participants to stay fully anonymous (not have to reveal anything)
 - This is the preferred "default" unless scientifically justified otherwise

Case study setup

- STEP 2 of 3
 - Briefly discuss the selected two or three case studies with the group (from an ethics perspective)
 - We will get into more in-depth analysis later

And the “ethics” panic



Ethical dilemmas

- Increased strictness of institutional ethics approvals
- Unexpected situations during field studies
 - Leading to “moral panics” (van den Hoonaard, 2001)
- Common to fields such as Anthropology
 - But made increasingly difficult to anticipate with unexpected use of interactive technologies “in the wild”
 - “Known unknowns” replaced by “unknown unknowns”
- We are largely unprepared for this in techno-centric disciplines

What's at stake?

- Increased fieldwork with vulnerable populations
 - Often involving technology and its **unpredictable** uses
- Increased ethical concerns when researchers **have less control** over the setting of a study
 - Privacy
 - Confidentiality
 - Consent
 - Harm and risks
 - Trust and authority

What can you do about it?

- We need to increase our understanding of the ethical challenges we face in Human-Computer Interaction fieldwork (and related disciplines)
 - Four case studies of unexpected ethical encounters that **dynamically** affected the ethical conduct of our research
- We need to be aware of and contribute to guidelines and best practices

A mobile language support for low-literacy adults

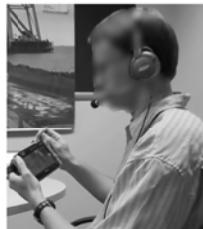
- ALEX – a mobile app for everyday tasks & classroom use, supporting reading and vocabulary acquisition
- Ethnographic evaluation
 - 12 adult learners
 - 6 months
 - Researchers fully immersed in daily literacy classes



(Munteanu et al., J. PUC 2013)

Ethical challenges

- Ignoring (verbal) consent forms
- Open sharing of private data amongst participants and non-participants
- Non-participants' use of technology:
 - (In)voluntary participation
- Unplanned data collection outside the established protocol
- Participant-researcher rapport
- Unexpected device loss



A communication tool supporting parents of sick newborns

- Mediation of health updates and support needs for parents of kids in neo-natal care
- A Grounded Theory approach to evaluation
 - Pilot ran off-site at a conference of caregivers and parents
 - (Planned) Implemented through in-hospital focus groups
- Detailed and rigorous ethics application



(Moncur et al, CHI 2013)

Ethical challenges

- Grounded Theory at odds with rigid ethics protocol approval
- Sensitive setting – parents unwilling to participate in a hospital-based focus group
 - But were willing to attend in-person, off-site interviews
- Participation was affected by care events
- Emotionally-charged setting
 - Even for parents whose experiences were a decade old
 - Researcher as (passive) participant
- Privacy was not a concern, but emotional support was



An immersive, interactive infantry training simulator

- Game-based interaction through voice, gesture, and tangibles for infantry and law enforcement training
 - Developed based on field-based requirement gatherings
- Fully-immersed evaluations
 - Observations of routine tasks
 - Five subject-matter experts
 - Three-day sessions, repeated twice (6 months apart)



(Murteanu et al, CHI 2012)

Ethical challenges

- Ethics board judgement – no approval required
- (In)voluntary participation
 - Subjects were ordered to participate by their superiors
- Researcher-participant rapport
- Researchers became participants (almost involuntarily) and exposed to harm
- Trust and authority
 - Researchers followed soldiers' commands
 - But could still expose them to superior officers (our partners)



A touchscreen typing app for blind mobile users

- BrailleTouch – a software keyboard for accessible text entry on mobile phones based on braille typing
- Lab-based evaluation with 11 blind participants
 - 90 minute sessions of various typing tasks
 - “Typical” data collection: demographic info, interviews, device interaction logs, video/audio recordings



(Romero et al, MobileHCI 2011)

Ethical challenges

- Desire to evaluate the technology
 - Formal process was a burden
 - Most participants used the voice consent as an intro to the tech
 - Trust in researchers – nobody asked for a sighted observer
- Privacy
 - No concerns about recordings
- Direct long-term benefits from the study



Designing a photo-based digital storytelling app for seniors

- PhotoFlow – a tablet-based interactive photo browsing app to help seniors engage in storytelling / reminiscing
- Used a contextual inquiry to expose mental models of how seniors tell stories around (paper) pictures
 - Ethnographic-like observational method
 - Follows a master-apprentice approach (researcher is the apprentice)
 - Required immersed / engaged / participatory observations



(Benett Axtell, U of T / TAGlab)

Ethical challenges

- Conducting ethnographic field work with older adults
 - Visits to participants' homes – safety considerations
- Blurry of boundaries between researcher and participant
 - “Forced-fed” homemade cookies, lemonade, etc.
 - Asked to help with home decorations, online shopping, fashion advice
- Privacy / ethical decisions needed to be taken by the researcher “on the spot”
 - Request from participants to be placed in follow-up focus groups together with “eligible bachelors”

Case study activity – solving ethical dilemmas

- Summary of activity:
 - Work in pairs or small groups
 - 10-15 minutes discussing a dilemma before moving to the next of your chosen set of 2 or 3
 - Brainstorm responses to the questions and write responses on paper
 - Each group/pair will add to those answers when they get to that dilemma

Case study activity – solving ethical dilemmas

- Scenario 1: Transcribing sensitive information
- Scenario 2: Managing group dynamics
- Scenario 3: Researcher safety
- Scenario 4: Managing communications with participants
- Scenario 5: Blurring of boundaries
- Scenario 6: The role of the researcher

Go to: <http://hci-ethics.ca/CHI2019>

Case studies are posted under the “Handouts” section

HCI research in non-traditional environments

- Disconnect between approved protocols and the realities in the field
- Increasing vulnerable participants' exposure to “ethical risks”
- There's interest for understanding HCI-specific ethical issues
 - (Bos, 2009), (Detweiler, 2011), (Ess, 2007), (Friedman, 2006), (Mackay, 1995), (Lingel, 2012)
- Also well explored in other fields
 - **But interactive tech is an ethics disruptor in HCI fieldwork**

HCI research in non-traditional environments

- Key disruptors:
 - Lack of path dependency
 - Multi-disciplinarity / collaborations
 - Uncontrolled / unpredictable variables
 - Background in CS-related disciplines
 - Lack of active research in ethics within HCI (in Canada)

(Sadownik, Munteanu, Zhu, 2016)

So what can we do?

- Look for “Ethical triggers”
 - Vulnerable populations
 - Ability to give consent changes during deployment (e.g. dementia, personal life events)
 - What are the power dynamics?
 - Sensitive settings
 - Some may be “hidden”, e.g. unexpected exposure to painful memories
 - In-the-wild deployments of technology
 - End-users as participants or researchers as participants
- Not all of these may trigger the elevated “Risk” box on your REB application!

So what can we do?

- Special note on “Researchers as participants”
 - Jurisdictional intersection between Ethics and Health&Safety
 - Not well covered by TCPS2
 - Delicate balance between familiarity and professional distance
 - May compromise the data collection
 - Too friendly => biased data; too distant => shallow data
 - May expose researchers to legal risks
 - Too involved in participants' private life
 - But difficult to ignore requests for help (e.g. can you hug your participants?)

So what can we do?

- Follow a **situational approach** to ethics
 - Design protocols that can be revised under unexpected conditions
 - Learn from existing case studies and available resources
 - CHI Workshop on Ethical Encounters in HCI, 2015, 2016, 2017
 - CHI'15 paper for examples:
 - Helping participants with rides, school homework, social events
 - Being involved in personal tragedies / health crises / etc.
 - SSHRC Knowledge Synthesis Report on Ethics in Techno-centric fieldwork (2016)
 - Canadian Tri-Council Policy
 - ACM SIGCHI Ethics Committee

So what can we do?

- Continuous approach to ethics
 - Maintain dialogue with your Research Ethics Board
 - Engage multidisciplinary expertise
 - Study the relevant national or university policies
 - Be involved in research on ethics (incl. REB volunteering)
 - Integrate ethics in your grad curriculum, esp. on techno-centric fieldwork



Thank you!

<http://hci-ethics.ca/CHI2019>
