CS 498 KA - Experimental Methods for HCI

Research Ethics and HCI

Amy Bruckman

Presented by: Deniz Arsan

What is Research Ethics in HCI?

- May I pay homeless people to answer a survey about how they use their cell phones? Is even a small gift card potentially coercive to people with extremely limited means? Is their financial need so great that their ability to make a rational decision is diminished? (LeDantec & Edwards, 2008).
- If I want to study people's behavior on Facebook, do I have to worry about whether this is allowed by the Facebook Terms of Service? (Gilbert et al., 2008).
- If I am recording data to help make evidence-based decisions in the care of a special-needs child, how do I balance the value of that data with people's fear of surveillance? (Hayes, 2004; Hayes & Abowd, 2006).

What is Research Ethics in HCI?

What is codified in institutional policies and procedures is typically a higher standard than merely legal, and what is ethical is a higher standard than what is allowed by policy or law.

Laws shift at political boundaries, policies shift at institutional boundaries, and ethics shift at cultural boundaries.

What is Research Ethics in HCI?

Researchers create three primary risks:

- First, they risk harming their subjects.
- Second, they risk disturbing the environments they are trying to study (as researchers often do; see Reading and Interpreting Ethnography, this volume). This may also reduce the group's willingness to cooperate with future researchers.
- Third, they create a risk of serious consequences for their institution if ethical violations occur.

The History of Human Subjects Research

Nuremberg War Trials (1949)

Established the basic principles that subjects should provide voluntary consent, and be free to end their participation at any time. Further, the experiment must “yield fruitful results for the benefit of society,” and unnecessary risk should be avoided

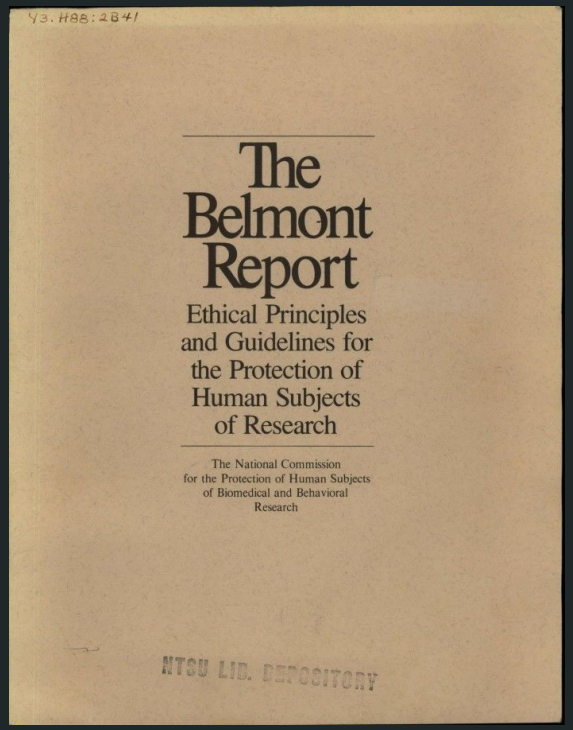
Tuskegee Experiments (1932 - 1972)

400 African-American men with syphilis were monitored for 40 years (1932–1972) without being told of their disease (UNLV, 2012). The study continued for decades after the discovery in 1947 that penicillin cures the disease (CDC, 2011)

The History of Human Subjects Research

Belmont Report (1979)

1. Respect for persons
2. Beneficence
3. Justice



The Belmont Report - Respect for Persons

Treat people as ends in themselves, not means to an end.

“Act in such a way that you treat humanity, whether in your own person or in the person of any other, never merely as a means to an end, but always at the same time as an end” (Kant, 1964)

The Belmont Report - Beneficence

Do not harm and maximize possible benefits and minimize possible harms.

People can be harmed through their participation in ethical studies. The challenge for evaluating the ethics of a proposed study is to weigh possible benefits and harms.

Even when the study has no risks beyond those of participating in everyday life, if it has no potential benefits, it should not be conducted.

The Belmont Report - Justice

Distribute the burdens and benefits equally across society.

The benefits and costs of an experimental study concerning human subjects usually fall on different individuals. The challenge is to distribute both of them equally.

Examples of Violation:

- People of low economic means being likely to participate in risky studies
- Excluding pregnant women when there are no risks for them or their fetus
- Excluding children to omit extra work for getting consent.

Institutional Review Board (IRB)

- All research involving human subjects must comply with applicable policies for the protection of human subjects.
- An Institutional Review Board (IRB) ensures the ethical and legal conduct of human subject research.
- Universities in the USA that accept federal funding are required to maintain an IRB committee. IRB members must represent diverse disciplines, and must include a non-scientist and a member of the community not affiliated with the university (US §46.107)

Institutional Review Board (IRB)

- Members typically take on a relatively heavy service load, and are required to understand issues in a wide range of disciplines, predominantly outside their own areas of expertise.
- Another function of IRB is to protect their institution from liability and official sanctions.
- Steps for researchers performing studies on human subjects:

  Certification (CITI) ➜ Proposal Submission ➜ IRB Review

Institutional Review Board (IRB)

Three Levels of Review:

- Exempt: Includes research “conducted in established or commonly accepted educational settings, involving normal educational practices,” research on existing public records or where individuals are unidentifiable, and others.
- Expedited: An IRB staff person may quickly approve the protocol without sending it to the full board.
- Full Board: Discussed within (typically) monthly IRB board meetings.

CITI PROGRAM

Completion Date 21-Feb-2018
Expiration Date 20-Feb-2021
Record ID [redacted]

This is to certify that:

Deniz Arsan

Has completed the following CITI Program course:

Course in the Protection of Human Subjects (Curriculum Group)
Social and Behavioral Research (Course Learner Group)
1 - Basic Course (Stage)

Under requirements set by:

University of Illinois at Urbana - Champaign

CITI
Collaborative Institutional Training Initiative

Verify at [redacted]

Human Subjects Research - Protocol Form

Guidelines for completing this research protocol:

- Please submit typed applications via email. Handwritten forms and hard copy forms will not be accepted.
- For items and questions that do not apply to the research, indicate as "not applicable."
- Provide information for all other items clearly and avoid using discipline specific jargon.
- Please only include text in the provided text boxes. The text boxes will expand as they are typed in to accommodate large amounts of text.

Before submitting this application, ensure that the following have been completed.

- IRB Application is complete.
- Relevant CITI modules have been completed for all members of the research team at www.citiprogram.org.
- Informed consent/assent/parental permission document(s) are provided.
- Relevant waivers and appendices are provided.
- Recruitment materials are provided.
- Research materials (e.g. surveys, interview guides, etc.) are provided.
- Any relevant letters of support are provided.

Instructions on the non-exempt review process and guidance to submitting applications, can be found on the OPRS website, https://oprs.research.illinois.edu/. You may also contact OPRS by email at irb@illinois.edu or phone at 217-333-2670.

Submit completed applications via email to: irb@illinois.edu.

Section 1: PRINCIPAL INVESTIGATOR (PI)

The Illinois Campus Administrative Manual allows assistant, associate, and full professors to act as PI. Other individuals may serve as PI after obtaining approval from the necessary party.			
Last Name:	First Name:	Degree(s):	
Dept. or Unit:	Office Address:		
Street Address:	City:	State:	Zip Code:
Phone:	E-mail:		
Urbana-Champaign Campus Status: Non-visiting member of (Mark One) Faculty Academic Professional/Staff (*Student Investigators cannot serve as PI*)			
Training Required CITI Training, Date of Completion (valid within the last 3 years), Additional training, Date of Completion,			

Section 2. RESEARCH TEAM

2A. Are there other investigators engaged in the research? Yes (include a Research Team Form) No
2B. If yes, are any of the researchers not affiliated with Illinois? Yes No

Section 3. PROTOCOL TITLE

Section 4. FUNDING INFORMATION

4A. Is the research funded? Research is **not funded** and is **not pending** a funding decision (Proceed to Part 5). Research is **funded** (funding decision has been made). Funding decision is **pending**. Funding proposal submission date:
4B. Indicate the source of the funding. University of Illinois Department, College or Campus, *please specify*: Federal, *please specify*: Commercial Sponsorship & Industry, *please specify*: State of Illinois Department or Agency, *please specify*: Other, *please specify*:
4C. Sponsor-assigned grant number, if known:
4C. A complete copy of the funding proposal or contract is attached. Attached, *please specify title*:
4D. Funding Agency Official To Be Notified of IRB Approval (if Applicable) **Name:** **Agency:** **E-mail:** **Phone:**

Section 5. CONFLICTS OF INTEREST

Please indicate below whether any investigators or members of their immediate families have any of the following. If the answer to any of the following items is yes, please submit the University of Illinois approved conflict management plan. If you have any questions about conflicts of interest, contact coi@illinois.edu.
5A. Financial interest or fiduciary relationship with the research sponsor (e.g. investigator is a consultant for the research sponsor). Yes No
5B. Financial interest or fiduciary relationship that is related to the research (e.g. investigator owns a startup company, and the intellectual property developed in this protocol may be useful to the company). Yes No
5C. Two or more members of the same family are acting as research team members on this protocol. Yes No

Section 6. RESEARCH SUMMARY

6A. In lay language, summarize the objective and significance of the research.
6B. Indicate if your research includes any of the following: Secondary data (use of data collected for purposes other than the current research project) Data collected internationally (include International Research Form) Translated documents (include Certificate of Translation Form and translated documents) Research activities will take place at Carle
6C. Letters of support from outside institutions or entities that are allowing recruitment, research, or record access at their site(s) are attached. Yes Not Applicable

Section 7. PERFORMANCE SITE

7A. List all research sites for the protocol. For non-University of Illinois at Urbana-Champaign sites, describe their status of approval and provide contact information for the site. If the site has an IRB, note whether the IRB has approved the research or plans to defer review to the University of Illinois at Urbana-Champaign.
Performances Sites
#1
#2
#3
If there are additional performance sites, include them on an attachment and check here:
7B. Is this a multi-center study in which the Illinois investigator is the lead investigator, or the University of Illinois at Urbana-Champaign is the lead site? Yes No **If yes, answer 7C and 7D. If no, move to Section 8.**
7C. Who is the prime recipient of funding, if funded?
7D. What is the management and communication plan for information that might be relevant to the protection of research subjects (e.g. unanticipated problems involving risks to subjects, interim results, and protocol modifications)?

Section 8. PARTICIPANTS

8A. For each performance site, indicate the estimated total number of participants.			
Performance Site	**# Male**	**# Female**	**Total**
#1			
#2			
#3			
TOTALS			
If additional performance sites are included on an attachment, check here:			

8B. Select all participant populations that will be recruited.

Age:

Adults (18+ years old)
Minors (≤17 years old)
Specific age range, *please specify*:

Gender:

No targeted gender (both men and women will be recruited/included)
Targeted gender, *please indicate*: Men/boys Women/girls Other, *please specify*:

Race:

No targeted race (all races will be recruited/included)
Targeted race, *please specify*:

College Students:

No targeted college population
UIUC general student body
Targeted UIUC student population, *provide the instructor or course information, name of the departmental subject pool, or other specific characteristics*:
Students at institution(s) other than UIUC, *please specify*:

Other:

Inpatients
Outpatients
People who are illiterate or educationally disadvantaged
People who are low-income or economically disadvantaged
People with mental or cognitive disabilities or otherwise impaired decision-making capacities
Adults with legal guardians
People who are non-English speaking
People with physical disabilities
Pregnant or lactating women, human fetuses, and/or neonates
Prisoners or people with otherwise limited civil freedoms
Other, *please specify*:

8C. Describe additional safeguards included in the protocol to protect the rights and welfare of the populations selected above.

Section 9. RECRUITMENT

9A. Select all recruitment procedures that will be used.

Student subject pool, *please specify*:
Email distribution
MTurk, Qualtrics Panel, or similar online population, *please specify*:
US Mail
Flyers/brochures
Website ad, online announcement (e.g. eWeek), or other online recruitment, *please specify*:

Newspaper ad
Verbal announcement
Other, *please specify*:
Not applicable (secondary data only)

9B. Drafts or final copies of all recruitment materials (including verbal scripts) are attached.

Yes Not Applicable

9C. For each group of participants, describe the details of the recruitment process.

Section 10. WITHHELD INFORMATION

10A. Do you propose to withhold information from subjects prior to or during their participation? Yes No If yes, complete the rest of Section 10 and also submit the Alteration of Informed Consent Form. If no, move to Section 11.
10B. What information will be withheld?
10C. Why does this information need to be withheld for the purposes of the research?
10D. How will participants be debriefed?
10E. A draft or final copy of a written debriefing that will be provided to participants is attached. Yes Not Applicable

Section 11. SCHOOL-BASED RESEARCH

If subjects will be recruited from Illinois public or private elementary or secondary schools, additional deadlines and procedures may apply. Criminal background clearances might be required. Special consideration must be given to the exclusion of protected populations. Please contact the School University Research Relations (researchplacements@education.illinois.edu) for more information. Mark one:

Illinois schools **will** be used Illinois schools **will not** be used

Section 12. INCLUSION AND EXCLUSION CRITERIA

12A. List specific criteria for inclusion and exclusion of subjects in the study, including treatment and control groups.

12B. Explain how the inclusion/exclusion criteria will be assessed and by whom. If special expertise is required to evaluate screening responses or data, list who will make this evaluation and describe their training and experience.

12C. Drafts or final copies of all screening materials are attached. Yes Not Applicable

12D. Describe procedures to assure equitable selection of subjects. Justify the use of the groups marked in Section 8B. Selection criteria that target one sex, race, or ethnic group require a clear scientific rationale.

Section 13. DEVICES & EQUIPMENTS

Indicate if your research includes any of the following.

Equipment [Researchers collecting physiological data, not testing the device]
(*include Appendix A, the Research Equipment Form*)

Devices [Researchers planning to test devices on human subjects]
(*include Appendix B, the Device Form*)

Materials of Human Origin
(*include Appendix C, the Biological Materials Form*)

Drugs and Biologics
(*include Appendix D, the Drug and Chemical Usage Form*)

MRI AT BIC To use the Beckman Institute Biomedical Imaging Center (BIC) in human subject's research, you must obtain prior approval from the BIC (217.244.0446; ryambert@illinois.edu) and use BIC-approved screening and consent forms. Attach:

BIC approval BIC screening form BIC consent form

Section 14. RESEARCH PROCEDURES

14A. Select all research methods and/or data sources that apply.

Surveys or questionnaires, *select all that apply*: Paper Telephone Online
Interviews
Focus groups
Field work or ethnography
Standardized written, oral, or visual tests
Taste or smell testing
Intervention or experimental manipulation
Exercise and muscular strength testing
Noninvasive procedures to collect biological specimens (e.g., hair and nail clippings, saliva, etc.)
Noninvasive procedures to collect physiological data (e.g., physical sensors, electrocardiography, etc.)
Procedures involving radiation
Recording audio and/or video and/or taking photographs
Recording other imaging
Materials that have already been collected or already exist, *specify source of data*:
HIPAA-protected data
FERPA-protected data
Other, *please specify*:

14B. List all testing instruments, surveys, interview guides, etc. that will be used in this research.

Drafts or final copies of all research materials are attached. Yes

14C. List approximate study dates.

14D. What is the duration of participants' involvement?

14E. How many times will participants be asked to engage in research activities?

14F. Describe the research procedures in the order in which they will be conducted.

Section 15. SUBJECT REMUNERATION

Refer to the University Business and Financial Policies and Procedures for further guidance on the compensation process and reporting requirements.

15A. Will subjects receive inducements or rewards before, during, or after participation?
Yes No
If yes, complete the rest of Section 15. If no, move to Section 16.

15B. Select all forms of remuneration that apply.
Cash, *please specify amount:*
Check, *please specify amount:*
Gift Certificate, *please specify amount:*
Lottery, *please specify amount:* *and odds:*
Course Credit, *please specify amount:* *and specify equivalent alternative activity:*
Other, *please specify*:

15C. Will payment be prorated before, during, or after participation?
Yes, *please specify how:*
No

15D. For each group of participants, describe the details of the remuneration plan, including how, when and by whom they will be notified.

15E. The information listed above is provided on the relevant consent forms.
Yes

Section 16. SUBJECT OUTLAY

Will subjects incur costs for research-related procedures (e.g. longer hospitalization, extra tests, use of equipment, lost compensation, transportation over 50 miles, etc.)?
No Yes, *please explain:*

Section 17. CONFIDENTIALITY AND PRIVACY

17A. How is participant data, records, or specimens identified when received or collected by researchers? Identifiers include, but are not limited to, name, date of birth, email address, street address, phone number, audio or video recordings, and SSN.
No identifiers are collected
Direct identifiers are collected
Indirect identifiers (e.g. a code or pseudonym used to track participants);
Does the research team have access to the identity key? Yes No

17B. Select all methods used to safeguard research records during storage:
Written consent, assent, or parental permission forms are stored separately from the data
Data is collected or given to research team without identifiers
Data is recorded by research team without identifiers
Direct identifiers are removed from collected data as soon as possible
Direct identifiers are deleted and no identity key exists as soon as possible
Participant codes or pseudonyms are used on all data and the existing identity key is stored separately from the data
Electronic data is stored in a secure, UIUC-approved location, *please specify*
Hard-copy data is stored in a secure location on UIUC's campus, *please specify*
Other, *please specify*:

17C. How long will identifiable data be kept?

17D. Describe provisions to protect the privacy interests of subjects.

17E. Describe the training and experience of all persons who will collect or have access to the data.

Section 18. INFORMED CONSENT PROCESS

18A. Indicate all that apply for the consent/assent/parental permission process.

Written informed consent (assent) with a document signed by
adult subjects parent(s) or guardian(s) adolescents aged 8-17 years

Waiver of Documentation (signature) of Informed Consent *(include the relevant Waiver Form)*
adult subjects parent(s) or guardian(s) adolescents aged 8-17 years

Waiver of Informed Consent *(include the relevant Waiver Form)*
adult subjects parent(s) or guardian(s) adolescents aged 8-17 years

Alteration of Informed Consent *(include the relevant Alteration Form)*
adult subjects parent(s) or guardian(s) adolescents aged 8-17 years

18B. List all researchers who will obtain consent/assent/parental permission from participants.

18C. Describe the method for obtaining consent/assent/parental permission.

18D. Describe when consent/assent/parental permission will be obtained.

18E. Will participants receive a copy for their records? Yes No, *if no, explain*:

18F. Indicate factors that may interfere or influence the collection of voluntary informed consent/assent/parental permission.

No known factors

Research will involve students enrolled in a course or program taught by a member of the research team

Research will involve employees whose supervisor(s) is/are recruiting participants

Participants have a close relationship to the research team

Other, *specify any relationship that exists between the research team and participants*:

If applicable, describe the procedures to mitigate the above factors.

Section 19. DISSEMINATION OF RESULTS

19A. List proposed forms of dissemination (e.g. journal articles, thesis, academic paper, conference presentation, sharing within industry, etc.).
19B. Will any identifiers be published, shared, or otherwise disseminated? Yes No **If yes, does the consent form explicitly ask consent for such dissemination, or otherwise inform participants that it is required in order to participate in the study?** Yes
19C. Do you intend to put de-identified data in a data repository? Yes No **If yes, explain how data will be de-identified.**

Section 20. RISKS & BENEFITS

20A. Describe all known risks to the participants for the activities proposed, such as risks to the participants' physical well-being, privacy, dignity, self-respect, psyche, emotions, reputation, employability, and criminal and legal status. Risks must be described on consent forms.
20B. Describe the steps that will be taken to minimize the risks listed above.
20C. Indicate the risk level. **No more than minimal risk** (The probability and magnitude of harm or discomfort anticipated for participation in the proposed research are not greater in and of themselves than those ordinarily encountered in daily life or during the performance of routine physical or psychological examinations or tests). **More than minimal risk** (answer 20D)
20D. If you checked that the research is more than minimal risk, describe the provisions for monitoring the data to ensure the safety of subjects, such as who will monitor data and how often, what criteria will be used to stop the research, etc.
20E. Describe the expected benefits of the research to the subjects and/or to society.
20F. Weigh the risks with regard to the benefits. Provide evidence that benefits outweigh risks.

Section 21. INVESTIGATOR ASSURANCES

- I certify that the information provided in this application is complete and correct.
- I certify that I will follow my IRB Approved Protocol.
- I accept ultimate responsibility for the conduct of this study, the ethical performance of the project, and the protection of the rights and welfare of the human subjects who are directly or indirectly involved in this project.
- I will comply with all applicable federal, state and local laws regarding the protection of human subjects in research.
- I will ensure that the personnel performing this study are qualified and adhere to the provisions of this IRB-certified protocol.

The original signature of the PI is required before this application may be processed (electronic signature are acceptable).

_____

Principal Investigator Date

Section 22. DEPARTMENTAL ASSURANCE (OPTIONAL)

If the PI is not eligible to serve as PI under the Campus Administrative Manual, the applicable academic dean, institute director, or campus administrative officer indicates their approval of the researcher to act as Principal Investigator. Please note that departmental assurance only needs to be provided in the initial application.

_____

Applicable Authorizing Officer Date

Human Subjects in HCI Research

- Normally, human subjects research presumes subjects who are lay people with no special knowledge of the research domain.
- In HCI research, it is common that subjects are knowledgeable about the domain of inquiry.
- As a result, it is important to credit them correctly if their contribution is significant. It would be harmful otherwise. (Beneficence)

“In some cases, people we interview are proud of things they have done online (for example creative projects) and would like to have their real name listed in our published reports. If you would like to request that we use your real name if possible, please sign below. We will not be able to use your real name if we feel there is anything that might embarrass you in our report. For most people, using a fake name (that we invent) is the right choice, so you do not need to sign here but you may if you wish.”

Ethical Challenges in Internet Research

- Determining if the nature of research involves human subjects
  - Using publicly available, online resources (public comments, posts) are not classified as working with human subjects
  - It's considered working with human subjects If one interacts with the author of the content
  - This unfortunately creates a disincentive to conduct high-quality research

- Online postings may be findable with a search engine
  - Not a problem if the subjects wish to be identified by name
  - For situations which bring risks to the participants, not quoting any online postings is a solution
  - Can also "disguise" subjects

Terms of Service (ToS)

- May set conditions for when research is allowed, or may prohibit research altogether.

- Abiding by the ToS is always a safe choice. However, some researchers argue that it is not always necessary or appropriate. E.g. ToS includes clauses that are not legally valid or reasonable

Recruiting Subjects Online

- Internet-based recruiting introduces the additional challenge that the researcher may disturb the research environment through the process of soliciting participants.
- Researcher presence and request for study participation is more likely to be perceived as disruptive if the researchers are seen as not belonging on the site.
- Crowdsourcing with services like Amazon Mechanical Turk is in conflict with Belmont's first principle (Respect for persons) since workers are seemingly invisible.

Recording Interactions

- Relevant ethical issues:
  - Is it ethical to record activity in a chat room or a virtual world without consent?
  - Does this constitute activity of unidentified individuals in a public place?
- One solution suggests that traces of online interaction may not be recorded without permission; however, a participant observer may take field notes on his/her own experiences without permission.
  - As soon as observer asks questions for research, consent is required
- Requesting consent might be disruptive for the environment under study

Summary

Belmont Report

- Respect for Persons
- Beneficence
- Justice

IRB Process

- Duties of IRB
- IRB Review Types: Exempt, Expedited, Full Board
- Application Process

Ethical Issues

- Human Subjects
- Online Recruiting
- Terms of Service
- Online Recording