

ETHICAL ASPECTS IN
RESEARCH INVOLVING HUMAN
PARTICIPANTS: QUESTIONS TO
LIVE WITH AND AN ONGOING
MINDSET



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(mostly based on material by Sergio Sayago)



Have you ever thought about...

- How would **you** like the (people you care for)'s dignity, privacy, freedom, health...to be handled in a research study?
- Whether the **outcome** of the research study will have a **use** that could pose a threat to the human participants' security, privacy, dignity...?



Three parts

- **PART A: Ethics, research involving humans**
 - Concepts and definitions
 - Professional ethics, research ethics, tools & process
 - Introduction to some dilemmas
- **PART B: “Questions to live with”**
 - Examples of ethics in research involving humans
 - Ethical concerns matter, but resist final answers; you need to wrestle with the questions and find your own answers
- **PART C: An ongoing mindset**
 - There is no recipe: online & f2f, vulnerable and mainstream users, established and emerging technologies...
 - Doing ethical research is
 - a process full of dilemmas &
 - rests on your commitment to fulfill ethical obligations &
 - part of quantitative and qualitative research (and a combination of both)



Concepts and definitions

- **What does “research involving human participants” mean?**
 - There is an intervention or interaction with another person for the purpose of gathering information, OR
 - Information is recorded by the researcher in such a way that a person can be identified directly or indirectly with it
- **Note:** Spontaneous conversations, if gathered in a publicly accessible venue, is not (regarded as) human *subjects* research



Dilemma: public/private use

- First ethical dilemma:
Spontaneous conversations, if gathered in a publicly accessible venue, is not human subjects research
- **BUT WHAT IF...**
 - you reveal – for some reason - personal information about the people? Technology might come to our rescue: encryption...
 - We take for granted the public/private aspect of Internet?
 - **Internet is a public domain:** you are a lurker, and the participants read in a magazine that information they posted on an Online Social Network (OSN) has been published...
 - **Internet is a private domain:** you, as a researcher, think that an OSN is public, but it is not (you did not read the Terms & Conditions)...



Concepts and definitions

- **Ethics** are widely defined defined as the standards of proper conduct
- You might come across different types of ethics
 - Personal ethics: your own principles of right and wrong behavior
 - Corporate ethics: obligations promulgated by the organizations that employ a researcher
 - **Professional ethics**: set of standards of conduct adopted by professionals (written under the label “**code of ethics**”)
 - **Research ethics**: forms of behavior that have normative expectations for researchers
- This seminar focuses on professional and research ethics

Barakat, N., 2011. Engineering Ethics : A Critical Dimension of The Profession. In *IEEE Global Engineering Education Conference*. Amman, Jordan, pp. 159–164.



Professional ethics

- **ACM Code of Ethics and Professional Conduct**
 - <http://www.acm.org/about/code-of-ethics>
- **British Computer Society Code of Conduct**
 - <http://www.bcs.org/category/6030>
- **Code of Ethics and Conduct British Psychology Society**
 - http://www.bps.org.uk/system/files/documents/code_of_ethics_and_conduct.pdf
- **Code of ethics of the American Anthropological Association**
<http://ethics.aaanet.org/ethics-statement-0-preamble/>
- **Codi Deontològic del Col·legi oficial d'Enginyeria en Informàtica de Catalunya**
 - <http://www.enginyeriainformatica.cat/wp-content/uploads/2009/07/codi-deontologic-coeinf-12-cat.pdf>



... professional ethics

- **What do they say?**
- (Let us ignore the membership element)
- **ACM:** Avoid harm to others, Be honest and trustworthy...
- **BPS:** Respect, Competence, Responsibility...
- **AAA:** Obtain informed consent and necessary permissions, Make your results accessible...
- **Note:** How do you see yourself meeting these standards of conduct? Should be worry about them in our research?



Research ethics: impacts

- Research ethics scandals
 - **The Little Albert experiment, US, 1920:** human conditioning, 11-month-old infant to fear rats by associating them with loud noise. The research was conducted without the knowledge or consent of Albert's parents
 - **January 28, 1986:** the **Challenger spaceship** exploded just over a minute into its flight. Seven astronauts were killed while being watched over global media by millions of viewers. The failure was blamed mostly on engineering technical errors which involved ethical considerations
- Ethical misconduct by researchers will, most likely, inflict harm and cause physical damages to multiple human lives, property, or both



Research ethics: human rights

- **Human *subjects* have rights**
- **Charter of fundamental (human) rights of the European Union: Dignity, Freedoms, Equality, Solidarity, Justice**
 - Article 3.1. Everyone has the right to respect for his or her physical and mental integrity
 - Article 8.1. Everyone has the right to the protection of personal data concerning him or her
 - Article 8.2. Such data must be processed fairly for specified purposes and on the basis of the consent of the person concerned or some other legitimate basis laid down by law



Research ethics: laws

- **It is regulated (often) by law**
- **International Compilation of Human Research Standards**
 - Over 1,000 laws, regulations, and guidelines that govern human subjects research in over 100 countries, as well as the standards from a number of international and regional organizations ([DOC](#)), <http://www.hhs.gov/ohrp/international/index.html>
- **In Spain**
 - 1. Oviedo Convention on Human Rights and Biomedicine (1999): http://www.coe.int/t/dg3/healthbioethic/texts_and_documents/ETS164Spanish.pdf
 - 2. Law 14/2007 on Biomedical Research: <http://www.catedraderechoygenomahumano.es/images/novedades/SpanishLawonBiomedicalResearchEnglish.pdf>



... laws

- 3. Royal Decree 223/2004: Regulation of Medication Clinical Trials:
www.cerc-europe.org/documents/Royal_decree_223.2004.pdf
- 4. Royal Decree 1015/2009: Drug Availability for Special Purposes (Spanish):
<http://www.boe.es/boe/dias/2009/07/20/pdfs/BOE-A-2009-12002.pdf>
- 5. Organic Law 15/1999 of December 13 on the Protection of Personal Data:
https://www.agpd.es/upload/Ley%20Org%E1nica%2015-99_ingles.pdf
- 6. Law 14/2007 on Biomedical Research, Title I, Article 5:
<http://www.catedraderechoygenomahumano.es/images/novedades/SpanishLawonBiomedicalResearchEnglish.pdf>
- ...
- **Note:** Organizations might have their own local regulations



Ethics vs. laws

- Laws and ethics; sometimes they are a happy couple, other times...
- **It is ethical, but legal?**
 - Let's suppose you're studying how a community of drug dealers use ICTs. You're asked by the police to reveal information. Yet, you have an ethical agreement with the drug dealers; they allowed you to conduct your research study. What do you do?
- **It is legal, but ethical?**
 - Let's say you are in the middle of your study, which looks at how the driving experience is (keeping fingers crossed) improved by the Google glasses – we assume drivers can wear them while driving. Your participants are over 18 and able-bodied people. But you see that one of them gets very tense and is about to have a car accident. What do you do?



Key points

- Ethics in research involving humans (in ICT) **should be UNAVOIDABLE**
 - **Note:** A willingness to risk one's self-interest for ethical obligations/commitment to your participants
- Ethics in research involving humans is PERVASIVE
 - From writing up the project, conducting the research to publication
- Fulfilling ethical obligations in your research is not only GOOD ethics but also GOOD science



Pivotal tools: informed consent

- “All international declarations stipulate that, prior to consent, **each participant in a research project should be clearly informed** of its goals, its possible adverse events, and the possibility to refuse to enter or to retract at any time with no consequences” (Ethics for Researchers, FP7-EU, 2007)
- **Informed consent documents** generally ask the subject to attest that he or she has been informed about:
 - the nature of the study, his or her participation in it, the potential risks or lack thereof,
 - that s/he is free to discontinue participation at any time with no penalty,
 - and other standard warnings as apply in the respective instance



... informed consent

- **Who should consent?**
 - Imagine your participants have some type of cognitive impairment. In this case, researchers seek consent from their relatives, doctors...
- **How to inform?**
 - Oftentimes, face-to-face is not possible (online, for example)
 - You might think: ok, I will write up the “Terms & Conditions” page, which will be the first page to appear in your online survey. Do you think (or know) that people read these T&C?
- **What and how to write it?**
 - The wording becomes very important: “use the information you provide me within this study for my research” – what information? What does research mean – this study, another, papers, presentations...?

Pivotal tools: review process



- **Ethical application:** Written *before* the project/research study. You need to know *what* you are going to do – during and after the study - *how*, with *whom* and *where*, and how you will address ethical issues
- **Institutional Review Board:** approval of and oversee research protocols. The review takes time.
- Yes, projects / research studies *might* be *rejected* if ethical issues are not satisfactorily addressed (according to the IRB)



To sum up PART A

- **Definitions / terminology:** research involving human participants, ethics and different types of ethics
- **Code of conduct of (several) professions**
- **Research ethics:** their relevance, human rights and laws, informed consent and basic review process
- **Introduction to some dilemmas**



QUESTIONS TO LIVE WITH



Walking a tightrope: ethical challenges in participant observation

- Sensitive research topic: **female gambling culture**
 - Non-mainstream group & vulnerability of research participants
- 40 field trips to the three largest casinos in southeast Ontario, regularly taking shuttle buses with casino-goers
- “By assuming a **covert research role**, I was able to observe natural occurrences in gambling settings, but unable to make peace with **disturbing feelings of my research concealment**”
- Talking on the shuttle buses...
 - Women **volunteered their information before knowing who I was**
 - With my research role shifting from concealment to disclosure, their attitudes towards me accordingly changed **from sharing to silence**



Walking a tightrope: ethical challenges in participant observation

- “By **uncovering my research identity**, I was able to fulfill ethical obligations as a researcher, but **unable to get the female gamblers to speak their minds**”
 - “I don’t want to talk to you about gambling because you work for the government.”
- **So? A detached insider**
 - “Instead of actively engaging personal interactions or substantial conversations with female gamblers, I mainly recorded the gambling activities I observed and the spontaneous conversations”
 - Plus interviews (people recruited through fliers)



Walking a tightrope: ethical challenges in participant observation

- Question to Live With
 - “Everyday social realities are fluid, unpredictable. Doing ethnography in sensitive research topics is like walking a tightrope”
 - *How do you address this in an ethical application **before** you are in the field?*
 - “Mindful consideration of the well-being of marginalized individuals and communities being studied because as researchers, not only should we aim to uncover and interpret the voices, but also to understand the silence”
 - *If you’re not ready or prepared to do so, should you do ethnography/ participant observation?*



Human research subjects on the internet

- Assignment to graduate students: study an existing online community
- “Before she could even explain the purpose and scope of what she wanted to do, the leader immediately said, “**No, you may not do research here.**” She asked if he would please at least listen to details of the study before making a decision, and he again emphatically said no, he would not. Another “researcher” had studied the community six months earlier, and **left members feeling like their activities were disrupted and their privacy violated**”
- **Note:** Do you remember “do no harm”?

Bruckman, A., 2002. Studying the amateur artist : A perspective on disguising data collected in human subjects research on the Internet. *Ethics and Information Technology*, **4**, pp.217–231.



Human research subjects on the internet

- “if we are **too lax in our ethics**, we risk violating the rights of individual subjects and disrupting communities we study”; BUT “if we are **too strict**, we may hamper our ability to understand the medium”
 - **Face-to-face in Internet-based research??**
 - “Board members trained in issues relating to medical research often do not know how to approach work in the social sciences and humanities”
- **Note:** IRB are key, if they fail...it is *always* our fault?

Bruckman, A., 2002. Studying the amateur artist : A perspective on disguising data collected in human subjects research on the Internet. *Ethics and Information Technology*, **4**, pp.217–231.



Human research subjects on the internet

- Anonymizing participants in online communities: changing names and details of life history where these would compromise anonymity
- “This disguising also erects barriers to the social practice of science. In an open scientific community, individuals ideally publish results **sufficiently detailed for others to attempt to duplicate** those results and affirm or question the findings. This idealized **model from the physical sciences is always hard to replicate in social sciences**, but even harder when the act of protecting subjects adds substantial new barriers to follow-up inquiry by others”

Bruckman, A., 2002. Studying the amateur artist : A perspective on disguising data collected in human subjects research on the Internet. *Ethics and Information Technology*, **4**, pp.217–231.



Human research subjects on the internet

- Question to Live With
 - When you are in the field (online / offline), you want to gather lots of data. Yet, this should not be at the expense of spoiling the field. There might be other researchers who want to do their research there.
 - *How can you do both?*
 - “Qualitative researchers find research ethical boards' insistence on knowing the exact questions being put to interviewees impossible to fulfill”*
 - *Qualitative and quantitative worlds...how to set up an effective IRB?*

*Van den Hoonaard, W. ed., 2001. *Walking the Tightrope. Ethical issues for qualitative researchers*, Toronto, Ontario, Canada: University of Toronto Press.

- “Whilst it is standard to ensure that the wellbeing of participants is taken into account in research design and the ethical approval process, **it is much less common for the researcher's own emotional wellbeing to be considered explicitly**”
- Emotional distress: researching the End of Life from a digital perspective...
- Question to Live With
 - Is it a **take-it or leave-it** approach?



Future generations of researchers

- “The public grants engineers (researchers) the rights to self regulate and practice their profession in exchange for the great benefits they bring to society while safeguarding and protecting the health and welfare of that society”
- “Governmental funding agencies, like the National Science Foundation (NSF) of the USA, are now strictly requesting ethics training of personnel operating on project funded by the agency” (and to get funding, too)



Future generations of researchers

- Questions to Live With
 - Given that research ethics are (so) important, it seems to make sense to teach research ethics, but...*can we? Is it not something you learn while doing? Or both?*
 - *Is there (or should be) room for research ethics in the curriculum of undergraduate and graduate students?*

C. Harris, M. Pritchard, and M. Rabins, *Engineering Ethics, Concepts and Cases*, 4th edition, 2009, Wadsworth Cengage Learning, Belmont, Ca.



To sum up PART B

- **Examples of ethics in research involving human participants in ICTs**
 - Walking a tightrope while doing ethnography
 - Issues in doing and publishing research with people in the Internet
 - Human participants and human researchers
 - Considering research ethics in the next generation of researchers
- A number of **Questions to Live With**



AN ETHICAL *MINDSET*



Wrapping up...a *mindset*

- Ethics in research involving human participants is **important**:
 - because of our profession,
 - due to human rights,
 - because we are committed to good science
 - probably, more relevant than laws, which should be considered too 😊
 - No matter the methodology of research (qualitative, quantitative, or a combination of both)



Wrapping up...a *mindset*

- There are tools, procedures, guidelines and laws, but **there is not any magical recipe:**
 - Different types of research: ethnography, experiments, both...
 - Different types of human participants: children, people with disabilities...
 - Different (and emerging) technologies: online & f2f,
 - Different topics: sensitive,...



Wrapping up...a *mindset*

- Doing ethics in research involving human participants is
- **a process full of dilemmas &**
- **rests on the researcher's commitment to fulfill ethical obligations**
- **time-persistent...**

Wrapping up...a *mindset*



Last January many protesters in Kiev's Maidan Square received a menacing text message that read: "Dear subscriber, you are registered as a participant in this mass disturbance."

- **The Era of Big Data**
- 10 years ago...but now...
- The sensor-infused world
- Once collected, data can be stored indefinitely
- Where is your data stored? How has access to it?
- **And “tomorrow”?**



Some further readings...

- *The Human Use of Human Beings. Cybernetics and Society*, by Norbert Wiener, Free Association Books, London, 1989.
 - Although he did not use the term ‘computer ethics’ (which came into common use more than two decades later), he laid down a comprehensive foundation for computer ethics research and analysis
- *The Cambridge Handbook of Information and Computer Ethics*, edited by Luciano Floridi. Cambridge University Press, 2010.
 - The Cambridge Handbook of Information and Computer Ethics provides an ambitious and authoritative introduction to the field, with discussions of a range of topics including privacy, ownership, freedom of speech, responsibility, technological determinism, the digital divide, cyber warfare and online pornography



Some further readings...

- Mclean, A., 2011. Ethical frontiers of ICT and older users: cultural, pragmatic and ethical issues. *Ethics and Information Technology*, p. 1-14
 - E-inclusion for a growing ageing society brings ethical obligations with it. Ethics for whom?
- Walther, J.B., 2002. Research ethics in Internet-enabled research : Human subjects issues and methodological myopia. *Ethics and Information Technology*, 1(4), pp.205–216.
 - A (very) provocative critique to a traditional (medical) view of research involving humans in the Internet
- ACM, IEEE, Ethics and Information Technology journal...

