



HCI: ETHICS AND CONSENT

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The trolley problem

Today we will **not** be discussing classical ethics.

Instead we are discussing ethics of study designs and how to conduct research in a way that society considers to be ethical.





The Menlo Report

Ethical Principles Guiding Information and
Communication Technology Research

August 2012



**Homeland
Security**

Science and Technology

A short history lesson on ethics

Tuskegee Syphilis Experiment

- Between 1932 and 1972 the US Public Health Service conducted a study on untreated syphilis
- 600 African American men in Alabama were given free medical care and food for participating
- They were told it was a 6 month study on “bad blood”, but it actually lasted 40 years
- They were never told that they had syphilis, even though the researchers knew that they did
- A cure was found in the 1940's, but Tuskegee patients were prevented from gaining access to it
- 28 participants died of syphilis, 100 died of related complications, 40 wives contracted syphilis, and 19 children were born with congenital syphilis

History of ethics

- 1972 – Tuskegee study ended
- 1974 – US Congress created a commission to study research ethics and write regulations around ethics
- 1978 – Belmont Report officially released detailing a set of guidelines around what “ethical” research on humans looks like
- 1981 – Common Rule went into effect in the US regarding biomedical and behavioral research involving human subjects.
- 2010 – All researchers working on US funded grants must go through ethics training
- 2012 – Menlo Report officially published. Update to the Belmont Report focusing on information communication technology research

The Belmont Report (1974)

- Respect for persons
 - Protecting the autonomy of all people and treating them with courtesy and respect and allowing for informed consent. Researchers must be truthful and conduct no deception
- Beneficence
 - The philosophy of "Do no harm" while maximizing benefits for the research project and minimizing risks to the research subjects
- Justice
 - Ensuring reasonable, non-exploitative, and well-considered procedures are administered fairly — the fair distribution of costs and benefits to *potential* research participants — and equally.

The Menlo Report (2012)

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- Justice
 - Ensuring reasonable, non-exploitative, and well-considered procedures are administered fairly — the fair distribution of costs and benefits to *potential* research participants — and equally.
- Respect for law and public interest
 - Engage in legal due diligence. Be transparent in methods and results. Be accountable for actions.

The Menlo Report (2012)

Principle	Application
Respect for Persons	Participation as a research subject is voluntary, and follows from informed consent; Treat individuals as autonomous agents and respect their right to determine their own best interests; Respect individuals who are not targets of research yet are impacted; Individuals with diminished autonomy, who are incapable of deciding for themselves, are entitled to protection.
Beneficence	Do not harm; Maximize probable benefits and minimize probable harms; Systematically assess both risk of harm and benefit.
Justice	Each person deserves equal consideration in how to be treated, and the benefits of research should be fairly distributed according to individual need, effort, societal contribution, and merit; Selection of subjects should be fair, and burdens should be allocated equitably across impacted subjects.
Respect for Law and Public Interest	<i>Engage in legal due diligence; Be transparent in methods and results; Be accountable for actions.</i>

Respect for persons

- Participation as a research subject is voluntary, and follows from informed consent;
- Treat individuals as autonomous agents and respect their right to determine their own best interests;
- Respect individuals who are not targets of research yet are impacted;
- Individuals with diminished autonomy, who are incapable of deciding for themselves, are entitled to protection. Give them the right to choose and the knowledge they need to make a good decision
- Applications
 - Participants should be fully informed of the costs and benefits of participation (consent)
 - However, implied consent still possible if person choice is respected

Good Example

Research on children in schools. Information sheet created for both adults and parents explaining the study.



Dance-in-Schools Evaluation

Pupil & Parental Information Sheet

What is the Dance-in-Schools Evaluation?

You may be aware that an organisation called YDance is visiting schools across Scotland to introduce children to dance. The school your child attends has been offered the chance to take part and YDance tutors will visit his/her class for 5 weeks during April and May. The aim of the programme is to increase levels of physical activity (which are particularly low amongst young people in Scotland) and improve health/well-being.

Alongside the programme, an evaluation (or study) is also taking place to assess the effects it has on pupils and teachers. Eight local authorities in Scotland are taking part and the focus will be on P6 through to S2.

Who is conducting the study?

The Dance-in-Schools Initiative (DISI) and evaluation are funded by the Scottish Executive Health Department. Dr Candace Currie, Jo Inchley and Janine Muldoon at the Child & Adolescent Health Research Unit (Edinburgh University) are carrying out the research. Should you require any further information, please contact Janine on 0131 651 6561 or by writing to the following address:

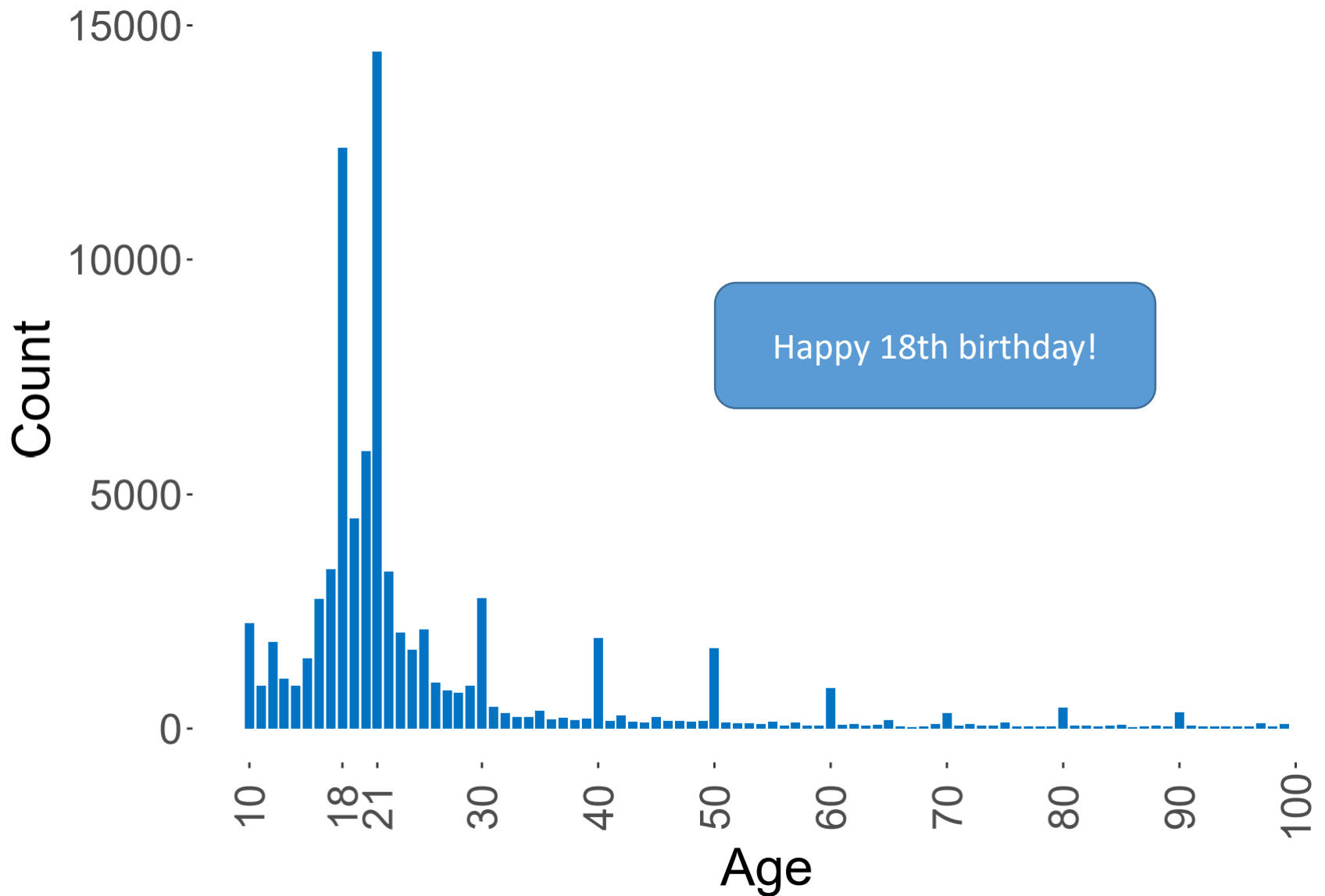
Poor Example

Purposely
selected
vulnerable
population and
did not provide
data

Tuskegee Syphilis Experiment

- Vulnerable population specifically selected with low education and access to resources
- They were told it was a 6 month study on “bad blood”, but it actually lasted 40 years
- They were never told that they had syphilis, even though the researchers knew that they did
- A cure was found in the 1940’s, but Tuskegee patients were prevented from gaining access to it

Twitter study of age disclosure



Beneficence

- Maximize the possible benefits and minimize the possible harms
- Will this research make society better? What risks will the participants experience?
- Applications
 - Systematic analysis of the risks and benefits of the research to both the individual and to society at large
 - Risks can happen much faster in ICT research

Good Example

Deception study where participants were asked to log into their actual bank accounts on a computer which had been “hacked” by the researchers but the security indicators were still actuate

Research question: will users enter their password if all the security indicators are missing?

- Notified participants that their actions would be recorded
- System did not record passcodes or other private data
- Care was taken with the technical design to make sure the participant’s bank credentials remained safe
- Participant was debriefed after the study
- Participant was told how to protect themselves in the future

Poor Example

Researchers knew before the study that being in the study might negatively impact the survival of a baby

Research question: how much oxygen do premature babies need to prevent death or blindness?

- Randomized assignment to high or low oxygen conditions
- Current best practice is to assign oxygen based on doctors opinion
- Existing research says that high oxygen levels can lead to blindness
- Primary outcome variable was if the babies developed sever eye disease or die

Justice

- Who should bear the burdens of research and who should receive the benefits?
 - To each person an equal share
 - To each person according to individual need
 - To each person according to individual effort
 - To each person according to societal contribution
 - To each person according to merit
- Application
 - Selection of research participants

Good Example

Truly random sample of all students in the US that received a PhD degree. If you don't "voluntarily" fill out this survey they will keep emailing you and sometimes send someone to your door to have you take it in person.



SDR Study Information

You have been randomly selected to represent the population of doctorate holders trained in science, engineering, and health fields at U.S. academic institutions for the 2017 Survey of Doctorate Recipients (SDR). The SDR is not an employer-based survey and seeks to represent doctorate-degree holders whether they are working, retired, seeking work, or in some other situation.

Your survey participation helps make the SDR data series more complete, accurate, and reliable. While we hope that you will agree to fully participate in the SDR, it is a voluntary survey for which you are not required to answer any questions.

The SDR is sponsored by the National Science Foundation (NSF) and the National Institutes of Health (NIH). The NSF and NIH are independent agencies of the U.S. government dedicated to promoting the progress of science. The 2017 SDR data collection activities are contracted to NORC at the University of Chicago.

NORC at the University of Chicago is a not-for-profit social science research organization serving the public interest and promoting informed decision making.

More information about NORC can be found at:

www.NORC.org/Research/Projects/Pages/Survey-of-Doctorate-Recipients.aspx

If you have questions about your rights as a study participant, you may call the NORC Institutional Review Board Administrator, toll-free within the U.S., at 1-866-309-0542.

All information you provide will be kept strictly confidential and safeguarded in accordance with the Privacy Act of 1974 and the Confidential Information Protection and Statistical Efficiency Act of 2002. Your responses are used for research purposes only.

Per the Federal Cybersecurity Enhancement Act of 2015, your data are protected from cybersecurity risks through screening of the Federal systems that transmit your data.

Information that personally identifies you is separated from your survey responses. Published reports show only summary information.

You are uniquely qualified to contribute to this study and cannot be replaced by anyone else – please participate in the 2017 SDR.

Poor Example

Artificial Intelligence systems are trained on available data, which can be biased.

Microsoft Kinect Can't Identify African-Americans?



By Usman

Nov 5, 2010

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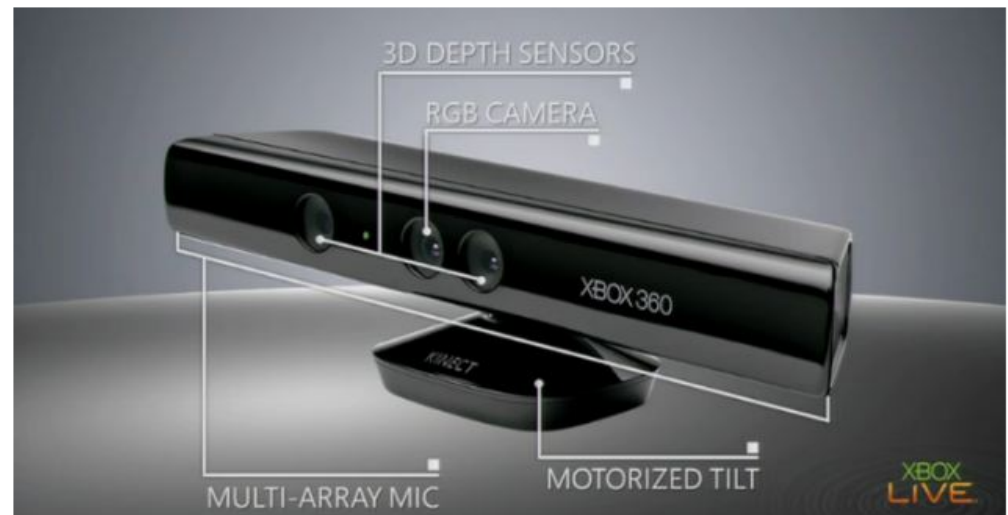
SHARES

f SHARE

t TWEET

SUBMIT

Houston... we have racism. Microsoft's recently launched Kinect device, while undergoing testing at GameSpot, had trouble identifying two dark skinned employees. Apparently, the employees in question had trouble getting the facial recognition features to work.



According to the website, the system recognized one person's face "inconsistently", and when it came to the second staff member, the device was "never able to properly identify the other despite repeated calibration attempts."

What's confounding is the fact that at the same time, the Kinect had no problems identifying a third dark-skinned employee, right after a single calibration. Lighter-skinned employees not of African-American lineage were all easily identified on the first try.

Fortunately, the problem seems to only be with facial recognition, and not with skeletal tracking as that worked fine for all three dark-skinned employees. Since skeletal tracking is the primary manner to play games with Kinect, it's somewhat reassuring that at least this feature works.

Respect for Law and Public Interest

- Compliance
 - Make sure you know what the laws are and don't break them
 - When breaking laws must be done, engage in due process
- Transparency and Accountability
 - Make the contents of research clear, including how data will be handled and used
 - Clearly communicate risks
 - Document the contents of your study and make that documentation public

Good Example

Asking relevant governing bodies for support in advance of conducting potentially problematic work.

Crypto guru Matt Green asks courts for DMCA force field so he can safely write a textbook

Next move in EFF's plans to regain the right to tinker

By [Iain Thomson](#) in [San Francisco](#) 30 Sep 2016 at 22:31

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“Researchers should be encouraged to educate the public and the next generation of computer scientists. Instead, they are threatened by an unconstitutional law that has come unmoored from its original purpose of addressing copyright infringement. We’re going to court to protect everyone whose speech is squelched by this law, starting with Dr Green and his book.”

as ATM machines, smart cars, and medical devices. But this could lead

Confusing Example

Password data breaches are not legal. But when they are made public should we use them for the good of the public?

RockYou settles FTC charges related to 2009 breach

Online gaming firm will pay \$250,000, submit to independent audits for 20 years after exposing data on 30 million users



By Jaikumar Vijayan

Computerworld | MAR 27, 2012 5:06 PM PT

RockYou will submit to third-party security audits for the next 20 years as part of a settlement of charges filed by the U.S. Federal Trade Commission in connection with a [Dec. 2009 data breach](#) that exposed email addresses and passwords of more than 30 million people.

As part of the settlement announced Tuesday, the online social gaming company will also pay a \$250,000 civil penalty to settle charges that it violated the Children's Online Privacy Protection Act (COPPA) by knowingly collecting email information from about 180,000 underage children without first getting parental consent.

The proposed settlement also requires RockYou to maintain a formal data security program and prohibits it from making 'deceptive claims' about its privacy and security practices.

[Further reading: [What is blockchain? The most disruptive tech in decades](#)]

In a statement, RockYou CEO Lisa Marino called the settlement a "fair" one.

"We appreciate the work the FTC has done in this process as they have been fair, reasonable and timely throughout," she said. "The events that led to this

— CURRENT JOB LISTINGS —

Consent

An advertisement should:

- Be short and easy to read or decide to ignore
- Explain the main content of what participants will be asked to do
- Explain what the costs, benefits, and risks of participating are
- State who to contact about the research in case of concern
- State if the research has been through ethical review

A consent form should:

- Who you are
- What the study involves, what they will be asked to do
- What kind of data will be collected and how it will be used
- What rights the participant has
- Compensation, if any
- Risks, if any beyond normal computer usage

We are students in the Human-Computer Interaction course at the University of Edinburgh. For our first coursework we are studying how students at the University of Edinburgh use calendaring systems such as paper calendars, Google Calendar, and Office 365 Calendar.

In this survey we are investigating how people use their online calendars so that we can better understand their calendar-related needs and choices. We will ask you for some information about yourself, about the way in which you use computers and the internet, about the tools you use to manage your timetable and other events.

Completing the survey will take about 10 minutes. You can interrupt the survey at any time and return to finish it later. All the data that you provide will be stored on SurveyMonkey and user-level access will be restricted to our group. Questions marked with a red star are mandatory - you will need to answer them in order to complete the survey. Data you provide will be deleted two months after the last day of this school term.

This project has undergone ethical screening in accordance with the University of Edinburgh School of Informatics ethics process (RT1432).

Do you agree to take part in this study, and do you agree that I can use your data for my HCI student project?