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# Meta-Data

## Lesson Goals

* Students will understand the importance and origin of research ethics.
* Students will understand the role that IRB plays in the research process, especially how it safeguards against unethical and unsuccessful research.
* Students will understand the potential conflict of interests in industry-led research.

## Lesson Outcomes

* Students will be able to read an IRB protocol and describe what it stipulates.
* Students will be able to complete an IRB protocol on their own.
* Students will be able to design ethical research for an industry setting.

## Assessments

* Students will complete a written assignment applying the principles of IRB to their own projects.
* Students will reflect on the role of ethics in industry-led research.
* Students will read and report their understanding of an IRB protocol.
* Students will complete CITI training.

## Lesson Plan

* First, students will be introduced to the need for ethics in human subjects research by way of some famous examples of unethical research.
* Then, students will learn about the Institutional Review Board process, from certification to submitting protocols.
* Then, students will learn about the possible conflicts in industry-led research.

# Script

## 3.2.1 Introduction

### 3.2.1.1 Headshot Studio

* [C] David talking
* [A] Clips of the lesson
* [B] Topic; Research Ethics
* Before we start working with real users, there are a few **ethical** considerations we have to make.
* If you’re doing research as part of a university, these are part of the contract with the university to do research on their behalf.
* Even if you’re doing research in industry or independently, these are still ethical obligations to follow.
* These considerations are important not only to preserve the rights of our users, but also to ensure the value of the data we gather.
* [B] Topic; Origin of Research Ethics
* In this lesson, we’ll talk a little about **where** these kinds of ethical needs come from.
* [B] Topic; Basic Ethical Considerations
* Then we’ll talk about some of the **basic** ethical considerations to make.
* [B] Topic; Institutional Review Board: IRB
* We’ll also talk about **Institutional** Review Board, or IRB, the university organization that governs human subjects research.

## 3.2.2 Origin of Institutional Review Board

### 3.2.2.1 Tablet Studio

* [V] Wikipedia headers for various experiments coming up, along with a timeline?
* In the first half of the 20th century, a number of clearly unethical human subjects experiments took place.
* Many of them were conducted by scientists working for the Axis powers during World War II, but famously many were also conducted here in our own backyard.
* Among them: the Tuskegee Syphilis study, where rural African-American men were injected with syphilis to study its progression.
* The Milgram obedience experiment, where participants were tricked into thinking they had administered lethal shocks to other participants to see how obedient they would be.
* The Stanford Prison Experiment, where participants were psychologically abused to test their limits.
* [V] Text of the law?
* In response to this, the National Research Act of 1974 was passed, which led to the creation of Institutional Review Boards to oversee research at universities.
* The Belmont Report further summarizes basic ethical principles that research must follow.
* [V] Highlighted quotes from the law?
* The law dictated that the benefits to society outweigh the risks to the subjects.
* It also dictated that subjects be selected fairly, a direct response to the Tuskegee syphilis study.
* Perhaps most importantly, it demanded rigorous informed consent procedures.
* These efforts all attempt to make sure that the positive results of research outweigh the negatives and that participant rights are always preserved.

## 3.2.3 The Value of Research Ethics

### 3.2.3.1 Headshot Studio

* [C] David talking
* In this lesson, we’re largely focusing on the practical steps we go through to get approval for human subjects research.
* But before we get into that, I want to highlight that this isn’t just a bunch of bureaucratic steps necessary to make sure people are treated ethically at all stages of research.
* IRB’s main task is to make sure the potential benefits of a study are worth the potential risks. So, as part of that, part of their role is to make sure the potential benefits are significant.
* A lot of the steps of the process are there to ensure that the data we gather is useful.
* For example, the IRB is sensitive about the perception of coercion.
* When participants feel coerced to participate in research, the data they actually supply may be skewed by that negative perception, which impacts our data.
* Similarly, we might design studies that have some inherent biases or issues to them. We might demand too much from participants, or ask questions that are known to affect our results.
* Much of the initial training to be certified to perform research is similarly not just about doing ethical research, but also about doing good research.
* By recording who is certified, IRB helps ensure that research personnel all understand the basics of human subjects research.
* IRB is there to monitor for those things as well, and many of the steps of the process ensure that the research we perform is sound and useful.
* After all, if the research we perform is not useful, then even the smallest risks will outweigh the non-existent benefits.

## 3.2.4 Getting Started: CITI Training

### 3.2.4.1 Tablet Studio

* [T] IRB web site
* If you’re going to be doing research as part of a university project or class, you’ll need IRB approval.
* Different universities have different processes and policies for getting started with IRB.
* We’re going to describe the Georgia Tech policy since that’s where this class is based, but you should check with your university to make sure you’re following the right policies for your school.
* <click Required Training>
* At Georgia Tech, you are required to complete the Collaborative Institutional Training Initiative Program, or CITI Program.
* To do so, you’ll click here.
* Then, log in with your Georgia Tech account.
* Then, complete Group 2 Social / Behaviorial Research.
* After completing this, you’ll receive your completion report.
* Once you’ve completed this, you’re ready to get started with IRB.

## 3.2.5 Getting Started: IRB

### 3.2.5.1 Tablet Studio

* [T] Go to gtapps.gatech.edu/irb/
* After you’ve completed any necessary training, you can access the IRB application for your own university.
* We’re doing this in terms of Georgia Tech, so here’s the tool we use.
* Here, you’ll see your protocols under My Protocols.
* A protocol is a description of a particular research project.
* It outlines the procedures that IRB has approved regarding consent, recruitment, experimentation, and more.
* After a protocol is approved, any changes must be submitted to IRB as an amendment to be accepted separately.

## 3.2.6 IRB Protocols: Basics

### 3.2.6.1 Tablet Studio

* [T] IRBwise
* Generally speaking, you may not ever be asked to complete a protocol yourself: you might instead just be added to an existing protocol.
* Still, you should make sure to understand the procedures outlined by any protocol to which you’re added.
* We’ll run through the process of creating a protocol, but this will also cover the details to know about any protocol to which you are added.
* [T] The following examples will be illustrated by an exemplary IRB protocol being edited, to be written.
* Every protocol starts with a title of the project, and the addition of certified personnel.
* <click Add/Modify Certified Personnel>
* Here, the certified personnel for a protocol are added.
* The Primary Investigator must always be added first, and must be a faculty member.
* In the event that someone’s certification isn’t already entered into the system, the completion report should be attached on this screen.
* <close Add/Modify Certified Personnel window>
* The Protocol Description covers at a high level the research to be done. This should briefly touch on what will be done, what the goal of the research is, and what subjects will be asked to do.
* <scroll down to II. The Protocol: Research Design and Methodology>
* Under The Protocol: Research Design and Methodology, we describe our research.
* First, we describe the research design and methodology.
* With human subjects research, this focuses on what users will experience and in what order.
* It also covers some experimental details, like how subjects might be assigned to different experimental conditions.
* Then, we describe the duration of human subjects’ participation, to make sure subjects aren’t being asked to do too much.
* Depending on what we’re doing, we may then need to provide data collection methods. This includes things like surveys, pre-tests and post-tests, interview scripts, etc.: anything pre-prepared to elicit data from the participant.
* Then, we need to describe the benefits and risks of the study. Benefits may not be to the individual participants, but rather to the greater community as a whole.
* Then, we describe the statistical analysis planned if any; qualitative research may not have a statistical analysis plan.
* Finally, we describe the start and end dates of the research. Often, this will break the research into a data collection phase and a data analysis phase.
* We won’t generally need to worry about the remaining options because we are not doing clinical studies and we generally will not have external funding unless you’re working on a professor’s research project.
* So, now we can move on to Subject details.

## 3.2.7 IRB Protocols: Human Subject Interaction

### 3.2.7.1 Tablet Studio

* [T] Protocol
* Because we’re interested in human-computer interaction, we almost certainly will have human subject interaction.
* So, click yes here, and then click here.
* <click ‘Click Here’ next to ‘Yes’ in III.A>
* This will ask us a number of questions regarding our interaction with subjects.
* First, how many subjects do we anticipate having, and of what genders?
* Second, are we specifically targeting any vulnerable populations?
* Third, what is the rationale behind our answer to the first question? If we’re doing statistical tests, this may be the number of participants necessary to find a certain effect size.
* If we’re doing qualitative research, this would be the number of participants necessary to get a variety of views.
* Alternatively, we might have external limits on our number of subjects: for example, if you’re doing classroom research, your maximum number of subjects is the class size.
* Next, we state the inclusion criteria. Who are we specifically including?
* Next, we state the exclusion criteria. Who are we specifically excluding? Oftentimes, these will be inverses of one another, but there may be times they are more specific. For example, if we were doing research on undergraduate computer science education, our inclusion criteria might be undergraduate students, but our exclusion criteria would be undergraduate students that have already taken a computer science class.
* We can continue to ignore prompts regarding clinical research.
* If we’re including any vulnerable populations, we note here how we protect their rights; for example, for children, we obtain both their consent and their parents’ consent.
* Finally, we describe how we will recruit participants.
* First, we note what we’ll say and how we’ll communicate it to them.
* If we’re using the Georgia Tech subject pool, we’ll indicate so here.
* Second, we’ll note what compensation we provide to participants, if any.

## 3.2.8 IRB Protocols: Consent Procedures

### 3.2.8.1 Tablet Studio

* [T] Protocol
* One of the most important elements of IRB approval is consent.
* So, you would click here to complete your protocol’s consent procedures.
* <click to add consent procedures>
* First, we need to indicate what kind of consent we’ll receive.
* Most commonly, this will be Written Consent Required.
* In this case, participants will sign or digitally sign a consent form to start the study.
* In some cases, a waiver may be obtained.
* First, a Waiver of Consent can be obtained under certain circumstances.
* This means we do not have to receive subjects’ consent at all.
* This generally applies when subjects will not be directly affected by the research.
* For example, if we wanted to study educational or health data that has already been obtained and is anonymous, we might receive a waiver of consent.
* Similarly, if we were to go sit in a coffeehouse and take notes on the order-taking process in a way that did not identify anyone, we might receive a waiver of consent.
* We might also receive a Waiver of Documentation of Consent.
* This occurs for low-risk research where the written consent itself would be the only record of the participant’s identity.
* This applies a lot to survey research or unrecorded interviews, where participants can be informed of their rights at the start, and continued participation constitutes implicit consent.
* After selecting an option, we give a justification for our waiver selection if necessary.
* We then describe our plan for obtaining informed consent: generally this will be to provide the consent form to participants at the start of the study.
* If we are involving children, non-English speakers, or other at-risk populations in our study, there are some additional boxes to complete.
* It is also important for us to assess whether participants are continuing to consent to the study.
* Finally, it is possible to have protocols where deception or concealment are involved.
* In HCI, we might want to tell participants that an interface is functioning even if someone behind the scenes is making it look functional.
* For example, if we were testing a new version of something like Siri, we might tell participants it is functioning, when in reality someone is scripting her responses to test different approaches.
* If we’re using deception or concealment like that, we’ll indicate so here.
* Finally, we need to upload consent forms.
* <tab over to ORIA>
* At Georgia Tech, ORIA provides a consent form template that we can tweak to meet the needs of our study.
* The template provides in-depth directions on what to supply. Generally, this is where we disclose to participants the details of the rest of the protocol: what we’re researching, why, how, and why they’re invited to participate.

## 3.2.9 IRB Protocols: Wrapping Up

### 3.2.9.1 Tablet Studio

* [T] Protocol
* Of the remaining fields, the only one we’re likely interested in is data management questions.
* The others are generally related to healthcare studies or other types of studies that we will not generally be doing, although you should look at the titles to make sure they do not apply to you.
* <click Data Management>
* Under data management, we want to describe how we’ll keep participants’ data safe.
* This includes descriptions of how we’ll keep any identifying information about participants and how we’ll safeguard the data itself.
* <close Data management>
* Finally, there are some questions related to certain types of studies we should answer: generally, the answer to these will be ‘no’ for us.
* Finally, when we’re done, we want to click Save and Continue Application.
* On the next page, we can preview everything on one flat screen, then check off that we have no conflicts of interest (or report them if we do).
* Finally, we submit this to the principal investigator to pass along to the IRB office itself.
* After submission, we will generally hear back from IRB in about three weeks about whether the study was accepted and what changes need to be made if it was not.

## 3.2.10 Research Ethics and Industry

### 3.2.10.1 Tablet Studio

* [V] University logos on one side, industry logos on the other
* Institutional Review Boards govern any research institutions that receive support from the federal government.
* But what about research that doesn’t receive any federal support?
* Very often, companies will do research on their users.
* This is especially pertinent in HCI: lots of companies are doing very interesting research on their users, including lots of rapid A/B testing.
* There’s a lot of potential knowledge there.
* But at the same time, much of what they do likely would not pass IRB if it were university research.
* [T] [This paper](http://www.pnas.org/content/111/24/8788.full.pdf)
* This came up recently with Facebook.
* Facebook wanted to see if they could predict what would make users happy or sad, and as a result, tweaked the newsfeed for some users to test out their ideas.
* In other words, they tried to manipulate their users’ mood.
* [V] Highlight “was consistent with Facebook’s Data Use Policy, to which all users agree prior to creating an account on Facebook, constituting informed consent for this research.”
* Facebook argues that this was consistent with their own Data Use Policy, which permits them to perform experiments like this.
* Social scientists, however, would argue that this does not constitute informed consent: informed consent is specific to a certain experiment, temporary for a known period of time, and given without coercion.
* Some would argue that “if you don’t agree, you can’t use Facebook” is coercion.
* These are some difficult issues, and if you end up working in HCI in industry, you’ll likely find yourself wrestling with them.

## 3.2.11 Exercise: Research Ethics and Industry

### 3.2.11.1 Tablet Studio

* [T] [This paper](http://www.pnas.org/content/111/24/8788.full.pdf)
* People are still discussing whether or not Facebook’s study on its impact on users’ moods was ethical.
* Facebook maintains that the study was consistent with its own Data Use Policy, which constitutes informed consent.
* Opponents argue that it doesn’t.
* What do you think?
* If you think that this was ethical, why?
* If you think that it was unethical, what could have made it ethical?

### 3.2.11.2 Exercise

* [E] “Was Facebook’s experiment ethical?”
* [E] “Yes”, with a box to elaborate
* [E] “No”, with a box to elaborate

### 3.2.11.3 Tablet Studio

* [V] Exercise text?
* If you said yes, there are several reasons you might have stated.
* You might agree that the terms of service for the site constitute fair use.
* You might also have read the paper or some articles about it and noted that they did have IRB approval for the study, or that Facebook also has its own internal IRB.
* If you said no, there were some things you might have believed Facebook could have done differently.
* Maybe they could have separated out consenting to the research studies from the rest of the tool.
* Maybe they could have specifically requested that individual users opt-in, and alert them when the study was done.
* Even if the original study was ethical, there were likely things that could have reduced the backlash.
* At the same time, those things might have affected the results.
* These are the trade-offs we deal with.

## 3.2.12 Paper Spotlight: “Evolving the IRB: Building Robust Review for Industry Research”

### 3.2.12.1 Tablet Studio

* [T] Visual of [the paper](http://scholarlycommons.law.wlu.edu/cgi/viewcontent.cgi?article=1042&context=wlulr-online)
* In a recent paper in the Washington & Lee Law Review, Molly Jackman and Lauri Kanerva, two Facebook employees, explore exactly this issue.
* <scroll to abstract>
* [A] Highlight ‘existing ethical guidelines for research do not always robustly address the considerations’.
* Jackman and Kanerva specifically note that the ethical guidelines developed in the context of academia do not always address some of the considerations of industry.
* [A] Highlight ‘companies should develop principles and practices around research that are appropriate to the environments in which they operate’.
* In response, the authors directly advocate for setting up a set of principles and practices for industry environments.
* In other words, rather than just ignoring the parts that aren’t relevant for industry, the authors advise creating a new set of standards specifically for industry.
* <scroll to IV. Designing a Process>
* To do so, Facebook designed its own internal review process.
* In this case, Facebook’s process is heavily reliant on deferring to a research area expert.
* I don’t say ‘defer’ in a bad way. A key part of IRB is that experiments are reviewed by people with no incentive to permit the study if it isn’t ethical.
* Facebook tries to replicate this by referring studies to an expert reviewer, who in turn decides whether an additional review or even external IRB is necessary.
* The other thing that is important to note, though, is that Facebook isn’t under any strong obligation to do this.
* Universities that receive federal funding are governed by the Belmont Report, but companies are not yet governed by any similar law.
* So, we rely on companies to govern themselves. In Facebook’s case it seems to be going well, but you might find yourself at a company that doesn’t have such a program, and you’ll have to apply these standards yourself.

## 3.2.13 Design Challenge: Ethics and MOOC Recording

### 3.2.13.1 Headshot Studio (Behind Camera)

* [C] David talking
* <<to be scripted>>

## 3.2.14 Conclusion

### 3.2.14.1 Headshot Studio

* [C] David talking
* [A] Clips of the lesson
* [B] Topic; Research ethics
* In this lesson, we’ve talked about research ethics.
* Research ethics guide the human subjects research we do to make sure we’re respecting the rights of our participants, as well as making sure that the data we’re gathering is good and useful.
* At every stage of our design life cycle, we want to keep respect for our participants at the forefront of our thought.
* That means being wary of experimenting in ways that might negatively affect users.
* That means only asking users to dedicate their time to evaluating interfaces that are well-thought out.
* And that means respecting users’ viewpoints and position in the design process.