

# IIT CARES:

## Creating Access to Remote Electronic Support Ethical Requirements

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### **Background: The Tuskegee Study**

Human history has numerous examples of the unethical treatment of fellows, but perhaps the most infamous example in American history is the Tuskegee Syphilis Study in which 400 adult male African-American men diagnosed with syphilis and 200 without syphilis underwent a study about how the disease progresses when untreated. After ten years of study, twice as many men with syphilis had died. After twenty years, a treatment of syphilis was found—penicillin—but the participants were neither informed nor treated with the antibiotic.

In response to the gross treatment the men who participated in the Tuskegee study underwent, Congress created the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research.

### **Response: The Belmont Report**

In response to the notorious Tuskegee Syphilis study, the newly made National Commission drafted the Belmont report which identified three principles that every research project must adhere to. These three principles are as follows:

1. Respect for Persons
2. Beneficence
3. Justice

The Respect for Persons principle yields the necessity to the right to refuse participation and the right to fully understand the risks and benefits of their participation. From this stems the concept of written consent. Unless the research has extenuating circumstances, the researching team must procure a signed letter stating that the volunteer is aware of all risks, procedures, compensations, and benefits involved with participation. They must also be aware of the rights they have to deny participation at any point without consequence. A letter of written consent has already been drafted and attached as an appendix.

The principle of Beneficence yields to the Institutional Review Board to ensure that all research conducted minimizes risk to individuals and protects their rights as participants. It also sets guidelines for confidentiality and accessing risks to participants.

The final principle of Justice works to ensure that the burden of research is equitably distributed to differing genders, racial backgrounds, income levels, etc. It is very important to note that it is not correct to simply choose easily accessible clients. For the IPRO 345 team, this could be an issue because all percentages of groups need to be equally included in the interviews.

### **Institutional Review Board Requirements**

The I.R.B. board requires two separate procedures to be completed before a single question has been asked. First each interviewer must complete a certification program that takes approximately two hours and is available via <http://phrp.nihtraining.com/users/login.php>. Secondly, an approval application needs to be submitted to the IRB board detailing the interviewing procedures. The process takes approximately thirty days and must be completed before any interviews are completed. This does not include informal meetings with the staff of Mount Sinai Hospital. The form has been included as an attachment. If there are any changes to the research protocol post approval, then the board needs to be notified at [irb@iit.edu](mailto:irb@iit.edu). A re-approval may be required if the changes are substantial.

### **Ethical Interviewing Procedure**

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Prior to interviewing anyone, they must be informed of their rights, risks, and benefits. This may be done by reading the written consent form aloud then having the participant sign stating they are aware of all risks and knowingly agree to participate. All forms of written consent must be stored in a secured location for six years after the conclusion of the experiment.

To avoid confidentiality issues, the identity of the participants should not be revealed to the interviewer. The interviewer must also keep to the pre-approved list of questions. Slight variations may be done, like a wording change, but further questioning needs to be approved by the I.R.B. board. Since the interviews are expected to be voice recorded, the recordings need to be kept in a secured location and destroyed after an appropriate amount of time. No personal information can be presented in any manner without the explicit and written consent of the participant.

### **Conclusion**

It is easy when researching to forget the impact of your questions on the participant; keep their interests at the head of your concerns when doing any interview. It is also advised that they are involved in the research itself. It was suggested that they are invited to the IPRO presentations as a way for them to feel like they are an important part of the research. Anything that could impact the volunteer's comfort needs to be pre-approved by the I.R.B. committee. The Belmont Principles need to be respected, remembered and preserved at all times.