Ethical Issues in Research

What is Research Ethics?

- Research Ethics is the ***application of moral rules and professional codes*** of conduct to the collection, analysis, reporting, and publication of information about research subjects, in particular active acceptance of subjects' right to privacy, confidentiality, and informed consent.
- Incorporates **ethical principles** into research practice.
- May involve a balance between and within principles and practices.
- Research Ethics covers **all stages of research, from beginning** of research through **to completion and publication of results and beyond.**

Need for Research Ethics

- Came about due to historical experiments such as :
  1. Little Albert (1920)
  2. Tuskeegee syphilis study (1932-1972).
  3. Milgram's (1963) obedience study.
  4. Stanford Prison Experiment (1971).
- The Nuremberg code (1947) – Principles of informed consent, absence of coercion, properly formulated experimentation, beneficence to participants.

Ethical Issues that should be considered in Research

1. **Confidentiality**- Assurance that any identifying information will not be made available to anyone who is not directly involved in the study without permission.
   - Confidentiality means that the researcher agrees ***not to reveal the identity of the participant*** to anyone other than the researcher and his or her staff.

2. **Anonymity** means that the ***identity of the participant is not know by anyone, including the researcher.***
   - An example of this would be where a researcher had a large group of people fill out a survey instrument but NOT include their names on the instruments. In this way, the researcher will have the data but no names.

3. **Informed Consent**- this means that prospective research ***participants must be fully informed*** about the procedures and risks involved in research and ***must give their consent to participate.***
4. **Voluntary Participation** requires that ***people not be coerced into participating in research.***
5. **Right to Withdraw**-Withdrawal rights means that ***participants*** must be told they ***have the right to participate or withdraw from a study at any time*** and ***for any reason*** during the research ***if they wish to.***

Informed Consent Special Circumstances- ***requires the guardian's approval***

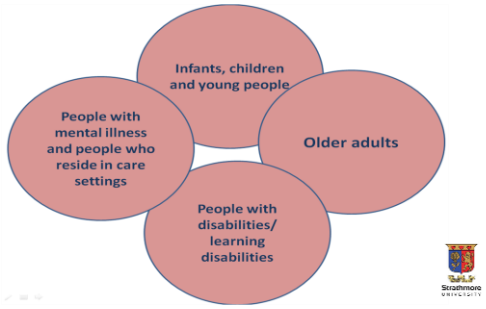


TABLE 4.1 Information to Include in a Consent Form

Purpose of the research along with a description of the procedures to be followed and the length of time it will take the participant to complete the study
A description of any physical or psychological risks or discomforts the participant may encounter
A description of any benefits the participant or others may expect from the research
A description of any alternative procedure or treatment that might be advantageous to the participant
A statement of the extent to which the results will be kept confidential
Names of people the participant may contact with questions about the study or the research participant's rights
A statement indicating that participation is voluntary and the participant can withdraw and refuse to participate at any time with no penalty
A statement of the amount and schedule of payment if participants are to be paid for participation
The information should be written at an eighth-grade reading level; in cases targeting specific populations, a sixth-grade reading level might be appropriate

For additional tips on preparation of the consent form, go to http://ohrp.osophs.dhhs.gov/humansubjects/guidance/ictips.htm.

EXAMPLE OF A RESEARCH CONSENT FORM

Tufts University Institute for Global Leadership
96 Packard Avenue
Medford, MA 02155
USA

CONSENT TO PARTICIPATE IN RESEARCH STUDY
Short Form WrittenConsent (to be used with oral consent form)

STUDY TITLE: Rural Education in Balan, Haiti

INVESTIGATOR: Valerie Schenkman

Short-Form Written Consent

I confirm that the researcher has explained the elements of informed consent to the participant.

The subject knows that their participation is voluntary, and that they do not need to answer all questions. The purpose of the research as well as the risks and benefits have been explained. The procedures as well as the time commitment have been outlined. The participant understands issues of confidentiality.

Witness Name _____

Witness Signature _____

Participant Name _____

Participant Signature _____

Tufts University Institute for Global Leadership
96 Packard Avenue
Medford, MA 02155
USA

WITHDRAWAL OF PARTICIPATION: Should you decide at any time during theinterview or discussion that you no longer wish to participate, you may withdraw your consent without prejudice.

COSTS BENEFITS TO YOU: There are no direct costs involved with participation, although you may miss an hour of work and possibly pay for that time. There are also no direct benefits to you. However, your participation will contribute to a greater awareness of Haiti and greater awareness of its successes and challenges as you and your community view them, as well as the opportunity to bring those challenges home to Tufts University and make an effort to address them. My final report will be presented at various conferences and your participation will help to bring greater attention to the issues facing Balan and greater Haiti.

REQUEST FOR MORE INFORMATION: You may ask more questions about the study at any time. Please contact Valerie Schenkman at valerie.schenkman@tufts.edu or at _____ while I am in Haiti. You may also contact Sherman Teichman at the Institute for Global Leadership in the US by calling + 1(617) 627-3415. This study has been approved by the Institutional Review Board at Tufts University, so you may contact the IRB Administrator, Lara Bisbode, by calling + 1(617) 627-3417.

SIGNATURE: I confirm that the purpose of the research, the study procedures, the possible risks and discomforts as well as benefits have been explained to the participant.All questions have been answered. The participant has agreed to participate in the study.

_____ _____
Signature of Person Obtaining Consent Date

The participant agrees to be audio-taped YES NO Initial _____
The participant agrees to be photographed YES NO Initial _____
The participant agrees to be videotaped YES NO Initial _____
The participant would like his/her name to be used YES NO Initial _____

_____ _____
Witness Signature Date

_____
Witness Name Printed

6. **Protection of participants from harm-** Researchers have a primary responsibility to ***protect participants from physical and mental harm*** during the research. Normally, the risk of harm must be no greater than in ordinary life, i.e. participants should not be exposed to risks greater than or additional to those encountered in their normal lifestyles.

7. **Deception** in research may sometimes occur if it is necessary to conduct a study ***without fully informing participants about the true purpose and nature of the study because it may affect the accuracy of the results***.

- The researcher is ethically obligated not to use any more deception that is needed to conduct a valid study.
- ***If extensive deception is used debriefing must be used.***
- The researcher ***must ensure the participants do not suffer any stress as a result of the procedure***, and ensure participants are fully debriefed at the end of the study.

8. **Debriefing-** The process of ***informing participants after the session of the experiment's true purpose*** to increase their understanding and remove possible harmful effects of deception. The researcher should also provide information on services available to help treat any stress resulting from the study.

9. Data Protection: Data protection is an ethical issue. It involves respect for individuals and their rights regarding privacy and **the use of information about them**. The following issues are particularly important:

a.) Definition of personal data	Personal data is any information about a living individual who can be identified either directly from the data or by combining your data with other available information.
b.) Transparency	As a minimum, you should ensure that research data subjects receive the following information: • what information you hold about them; • how you will use that information; • whether you disclose the information to other organisations (and which ones); • whether you combine that information with other data; If you cannot provide this to research data subjects, you must justify this in your ethics proposal and explain what other measures you have taken, such as publishing a statement covering this information.
c.) Physical and IT security	You should take physical and IT security measures appropriate to the risk level of the personal data. Personal data on mobile devices should be encrypted.
d.) Written procedures	You should have written procedures setting out how the personal data is to be handled, stored and accessed.
e.) Passing data to third parties	You should only pass personal data to third parties if you have a written agreement in place governing the use and security of the information and procedures to ensure the transfer is secure.
f.) Receiving data from third parties	If you are using data from another organisation or harvested from the Internet, you must confirm that the use in your research is compatible with what the data subjects were told would happen to the data. For example, Twitter users are told that their public tweets will be used for research; Facebook users are told that their posts will not be collected using automated means.

Little Albert Experiment

- In the study, Watson and graduate student Rosalie Rayner exposed the 9-month-old tot, whom they dubbed "Albert B," to *a white rat and other furry objects*, which the baby enjoyed playing with.
- *Later*, as Albert played with the white rat, Watson would make a *loud sound behind the baby's head*. After a number of conditioning trials, Watson and Rayner reintroduced the animals and furry items without the scary noise.
- Through the conditioning, the animals and objects that were once a *source of joy and curiosity had become a trigger of fear*.

Ethical Issues in "Little Albert" experiment

- The experiment was designed to condition an emotional response of fear in the participant. It could therefore reasonable by assumed that the participant would be emotionally traumatised by the experiment, and that **he may have suffered lasting psychological harm as a result.**
- Watson failed to seek permission from Albert's mother' therefore, **no informed consent was obtained** and **withdrawal rights were not explained**.
- Watson did not **debrief** either Albert or his mother, to extinguish the conditioned fear response, and though no one is sure what became of Little Albert, he was probably left with an irrational fear of anything white and fluffy.
- Watson failed to follow the ethical principles of **confidentiality**. He published results of his experiment without ensuring that Little Albert would remain anonymous.

CASE STUDY

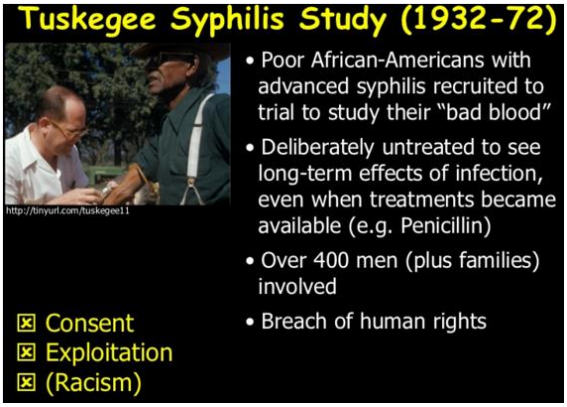
- Piliavn et al (1969) investigated the behaviour of bystanders in an emergency situation to see how quickly they would offer help to someone (a confederate of the study) who had collapsed on a New York underground train. The confederate acted either as if he were drunk (when he carried a bottle in a brown paper bag) or as if he were disabled (when he carried a black cane). Observers recorded how long it took for anyone to offer help. There was no opportunity to debrief participants.

Ethical Issues

- Participants were unaware that they were taking part in an experiment, therefore they could not **consent** to take part and it was also not possible to **withdraw** from the study or be **debriefed**.
- Furthermore, seeing a victim collapse may have been stressful for the participants, they also may have felt guilty if they didn't help, therefore leading to **psychological harm.**

TUSKEGEE SYPHILIS STUDY(1932)

- In the fall of 1932, the fliers began appearing around Macon County, Ala., promising "colored people" special treatment for "bad blood."
- "Free Blood Test; Free Treatment, By County Health Department and Government Doctors," the black and white signs said. "YOU MAY FEEL WELL AND STILL HAVE BAD BLOOD. COME AND BRING ALL YOUR FAMILY."
- Hundreds of men — all black and many of them poor — signed up.
- The study recruited 600 black men, of which 399 were diagnosed with syphilis and 201 were a control group without the disease.
- The researchers **never obtained informed consent** from the men and never told the men with syphilis that they were not being treated but were simply being watched until they died and their bodies examined for ravages of the disease.



Example Question

- Every year, all 15 year-old school students across the country complete a 2-week *Work Experience Programme* towards the end of the school year. Each student spends two weeks working for an employer who has volunteered to offer internship. The programme is intended to help the students make career and study choices and to prepare them for the world of work. However, the government is concerned that the programme is not achieving its aims. Recent news stories have highlighted complaints from the students and their parents about the range and quality of placements, and from employers about the support provided for them and for the students.
- The government has commissioned your research company to find out how the Work Experience Programme could be made more effective in achieving the above objectives. This research will involve ***gathering information from the students and employers along with parents and school staff.***
- Before commencing with a national programme of research, your research company intends to conduct **A PILOT STUDY** at six schools in different regions of the country, using both qualitative and quantitative research. It hopes that information gathered during this initial study will help inform the national study. The schools involved have agreed to participate in the research.

b) Your company has decided to conduct the qualitative phase of the research first. It intends to hold qualitative interviews and questionnaires with groups of **students** and **groups of staff** at each school, and to conduct telephone depth interviews with a number of **parents** and **employers** in each of the selected areas. Identify ***the ethical issues you need to consider*** when recruiting each of the groups in the sample.

GROUP	ETHICAL ISSUES TO CONSIDER
STUDENTS	• The requirements for conducting research with under 18s, in particular ***the need for informed consent from parents*** as well as students. • The ***data protection issues*** relating to the use of school databases for access to personal information; therefore ask School to send letter to parents asking for permission and response.
SCHOOL STAFF	• ***Data protection issues:*** Current staff school email addresses can be used – but not personal ones. The company can email staff using staff email or put a notice in staff room?
PARENTS	• ***Data protection issues: (Passing Information to third parties)*** Since company cannot access the school database for the parents contacts, the Invitation letter should come from school.
EMPLOYERS	• ***Data protection issues: (Receiving Information from third parties)*** Since the company cannot access the school database for the employers contacts, then the research company needs to get an Invitation directly from school asking for permission to contact the employers.

Sequence of Events in a Research Study

- Informed consent,
- Data collection,
- Debriefing