PAI 705

Lecture 3

Ethical and Political Issues in Social Research

Research Ethics

- Voluntary Participation.
- No Harm to Participants.

Formalized in the concept of informed consent.

Where this comes from.

Major issues from the medical side of the research world.

Nazi experiments on prisoners of war.

http://www.ushmm.org/wlc/en/article.php?ModuleId=10005168

From the United States Holocaust Memorial Museum.

"The first category consists of experiments aimed at facilitating the survival of Axis military personnel. In Dachau, physicians from the German air force and from the German Experimental Institution for Aviation conducted high-altitude experiments, using a low-pressure chamber, to determine the maximum altitude from which crews of damaged aircraft could parachute to safety. Scientists there carried out so-called freezing experiments using prisoners to find an effective treatment for hypothermia. They also used prisoners to test various methods of making seawater potable.

The second category of experimentation aimed at developing and testing pharmaceuticals and treatment methods for injuries and illnesses which German military and occupation personnel encountered in the field..., prisoners were subjected to phosgene and mustard gas in order to test possible antidotes.

The third category of medical experimentation sought to advance the racial and ideological tenets of the Nazi worldview. The most infamous were the experiments of Josef Mengele at Auschwitz. Mengele conducted medical experiments on twins. He also directed serological experiments on Roma (Gypsies)...in order to

determine how different "races" withstood various contagious diseases. The research of August Hirt at Strasbourg University also intended to establish "Jewish racial inferiority."

Other gruesome experiments meant to further Nazi racial goals were a series of sterilization experiments...."

Question: The experiments were done, and the results were written up. What if there are benefits which could be obtained by using the results of this research?

http://www.nytimes.com/1989/05/21/us/nazi-scientists-and-ethics-oftoday.html?pagewanted=all

A different topic:

Tuskegee syphilis experiments 1932 to 1972. 400 African American men were studied by the US Public Health Service to develop a better understanding of the full progression of the disease.

Subjects were not treated with penicillin even when it became clear that this was an effective treatment of the disease.

There are also ethical issues beyond medical research.

Milgram's study of obedience to authority published in 1963 and 1965.

- An experimenter is the authority in this game and there are two other participants.
 - One participant is the 'teacher' the other is the 'pupil'.
 - $\circ~$ The pupil is taken to a room and strapped to a chair.
 - Electrodes are attached to the pupil's wrist.
 - Teacher sits in front of a control panel with switches, and each switch has a label with a dial for a different number of volts, from 15 to 315.
- The teacher reads a list of word pairs that the pupil has to match up.
 - If a word pair is missed, the teacher administers an electric shock.
 - The experimenter keeps increasing the size of the shock.
 - The pupil is screaming in pain and begging to be released.
 - It proceeds through higher shocks until you no longer hear any sound from the pupil.
 - The experimenter is told no answer deserves the highest shock.
- The pupil was actually in on it and acting, the test is of the willingness to obey by the 'teacher' who is the real object of the experiment.
- 2/3rds of people obeyed up to the end.

1971 Zimbardo's Stanford Prison Experiment.

- Students in a simulation where some are prisoners and some are guards.
- Zimbardo's role was the prison superintendent.
- Some in the prisoner role were suffering psychological damage, and some of the guards became sadistic, which could cause them long term psychological harm.
- The simulation was terminated and participants went through counseling.

Humphreys dissertation study of homosexual acts between strangers meeting in public restrooms in parks, called 'tearooms', leading to the publication in 1970 of the book *Tearoom Trade*.

- Focus on how individuals not living life as homosexuals were participating in the 'tearooms'.
- Typically, three people were involved, the two in the act and a lookout.
- Humphries showed up and played the lookout.
- He then wrote down the license plates numbers of the cars and traced their names and addresses from the police.
- He then disguised himself and visited the people at their homes and interviewed them saying he was doing a survey, not mentioning that he had traced them down from observing them in the park.

A Response.

1974, the National Research Act created the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research.

The Belmont Report. 1979.

http://www.hhs.gov/ohrp/humansubjects/guidance/belmont.html

Basic Ethical Principles

- 1. Respect for Persons. Voluntary participation, and special care for those who lack complete autonomy.
- 2. Beneficence. Do no harm and if possible some good. Contemplate and state risks.
- 3. Justice. Burdens and benefits of research should be shared fairly within society.

Applications of these Principles

- Informed Consent
 - Information needs to be provided to participants
 - Comprehension needs to be verified
 - Voluntariness much characterize the decision to participate
- Assessment of Risks and Benefits.
 - The nature and scope of risks and benefits must be clearly stated.
 - A systematic (non-arbitrary) assessment of the risks and benefits must be conducted
- Selection of subjects
 - Special care of institutionalized, minors, minorities.
 - Concept of justice in the distribution of benefits and the burden of risk should be followed.

Anonymity. A given response cannot be linked to a given respondent even by the researcher.

Confidentiality. A researcher can identify the individual associated with a response, but promises not to do so publicly. Data can be released after scrubbing it of individually identifiable information. Household code. But again, where does the removal get to the point where it can't be figured out? Names of children, but ages, gender, and number?

Make sure to not promise anonymity when you really mean confidentiality.

Court case: At issue was a survey that was conducted following the Exxon Valdez spill.

- Trying to record in a confidential survey the multidimensional impacts of the oil spill.
- Exxon took the survey firm to court and got the court to order the researchers to turn over the surveys with the individual identifying information.
- Intention was to cross-examine them on survey responses.
- The overall Valdez case ended before a decision was reached on whether survey respondents could be forced to testify.

2002 "Certificate of Confidentiality" by USDHHS.

"Persons authorized by the NIH to protect the privacy of research subjects may not be compelled in any Federal, State, or local civil, criminal, administrative, legislative, or other proceedings to identify them by name or other identifying characteristics" How do we deal with the ethics of deception?

Deception of your identity or objectives is unethical but may be allowed if the case is seen as compelling by a review board.

It may be due to concerns like the Hawthorne effect we talked about earlier, deception is critical to making an experiment work.

One way to potentially resolve the ethics here is allow deception going in, but debriefing with full disclosure – including the reason for the deception- after the results are collected.

- You might end up with annoyed participants
- You might end up causing them harm when they view how they performed for what they thought was expected of them compared to the real objective of the research.

Analysis and Reporting

There is an ethical obligation to report limitations and flaws in your methods, since you know better than anybody else what the issues may be.

You have an obligation to report what you found, even (especially) if it is not what you hoped you would find.

You can't publish the same paper in two places. You can't make up your data. You can't present other people's work as your work.

http://retractionwatch.com/

USAID guidelines on human subjects. <u>http://www.usaid.gov/sites/default/files/documents/1864/200mbe.pdf</u> Here at Syracuse University:

Syracuse University Office of Research Integrity and Protection

Syracuse University Forms for Human Research <u>Office of</u> <u>Research.http://orip.syr.edu/human-research/forms-list/forms.html</u>

To be allowed to do Human Subject research you need to take a training class at the Collaborative Institutional Training Initiative of the University of Miami

https://www.citiprogram.org/

Things to think of when considering IRB and Research Ethics in an International Context.

Increasingly, we find we are being asked to train enumerators in Research Ethics.

- Takes a while you are not trying to get them to compare ways of getting answers out of unwilling participants.
- Case of the shopkeeper relative and credit question.

While you can take away the sheet, what was said to the enumerator is in the head of the enumerator and there is no way to take it out (well, not ethically!). They generally remain in that same community.

Issues of working with research institutes in other countries that may not have official IRB.

Issues of working with multiple universities coordinating work in a given study site. Which University IRB is to be followed?

Issues of consulting on projects that have a research component. A consulting firm runs the IRB review through a given university and researchers at other universities work on the data.

Are perceptions of tolerable risks and the balance of benefits and costs universal or might the answer be context and cultural situated?

Are research ethics global, or are there context specific aspects that make there be a different answer to the question depending on where it is asked?

What are we to make of an IRB in Syracuse making decisions about what is ethical and allowable in my research in rural Senegal?

Given corruption, poor governance, and a lack of transparency, do we want to place control over allowable research with each country where research is conducted?

Statements of financial interest, conflict of interest forms have become much more stringent.

Political Aspects of Social Research.

Issues center on the substance (what did you look at and what did you find) and use (who will use this in what political debate) of research findings.

A key principle we strive for in Social Research is that the researcher's normative / political orientation should not influence, or play as small a role as possible, in determining the research findings.

- Avoid re-running the model if you don't like the sign and significance of a variable you want to be the other sign.
- But what about the choice of topic?
 - Will this not be somewhat guided by what the person is interested in?
 - Impact of a minimum wage?
 - Gender differences in earnings?
 - Race and university admissions?

One level of critique is to ask whether it is feasible to keep the values held by the researcher out of the research process.

Another level of critique is to ask whether it is desirable to keep values held by the researcher out of the research process – for example Marxist, Feminist, and Race based analysis is often conducted within a given set of normative values about power and class relationships.

Babbie also notes Participatory research, which we will get to later, has as a goal not only research, but also transformation.

Issues of conducting research within a political context.

Babbie develops the idea around Social Research and Race.

Going back to the late 1880s, Sumner, who was skeptical of the ability of the Government's ability to change social attitudes was part of the context of 1896's "Separate but equal" Supreme Court decision.

Myrdal (1944) study of race illustrated ways in which the position of African Americans in society did not match US values of social and political equality.

Moynihan (1965) and his study of the African American family located problems in the family and legacy of slavery.

Coleman (1966) finds little difference in academic outcome can be attributed to school integration when other factors are held constant.

Jensen (1969) compared racial differences on IQ tests, and concluded there was a racial component. As you can guess, that did not go over so well!

Murray and Herrnstein (1994) The Bell Curve revisited this topic and was also controversial.

What is interesting to note and understand is that the critiques of these kinds of studies generally take place in the realm of a critique of the methods. We criticize the methodology, we question the data gathering, we run the same data with a different model specification and get a different result.

At one level this can be somewhat suspect, as if I don't like your result I will use different methods to get the result I prefer given my political values.

At another level, this might be OK since I have to declare my logic and justification for my preferred methodology, and then others can critique what I did and what I found.

Politics can arise to block federal research funding.

Jesse Helms, 1989 opposing the Laumann study on contemporary sexual practices to inform the response to the AIDS epidemic.

Effectively blocked the NIH path, and Laumann and team eventually had to find a private sector sponsor of the research.

Note there are limits to blocking the research, this is about blocking the use of federal funds for research.

In a similar case, we can consider Congressional opposition for CDC research on the risks of firearms as a public health issue since 1996.

In my USAID funded projects, I have a list of things I can and can't do with the USAID funds, a sample is pasted next to give you a sense of this.

C.9 USAID ELIGIBILITY RULES FOR GOODS AND SERVICES (April 1998)

a. Ineligible and Restricted Goods and Services: USAID's policy on ineligible and restricted goods and services is contained in ADS Chapter 312.

(1) Ineligible Goods and Services. Under no circumstances shall the recipient procure any of the following under this award:

- (i) Military equipment,
- (ii) Surveillance equipment,
- (iii) Commodities and services for support of police or other law enforcement activities,
- (iv) Abortion equipment and services,
- (v) Luxury goods and gambling equipment, or
- (vi) Weather modification equipment.

(2) Ineligible Suppliers. Funds provided under this award shall not be used to procure any goods or services furnished by any firms or individuals whose name appears on the "Lists of Parties Excluded from Federal Procurement and Nonprocurement Programs." USAID will provide the recipient with a copy of these lists upon request.

(3) Restricted Goods. The recipient shall not procure any of the following goods and services without the prior approval of the Agreement Officer:

(i) Agricultural commodities,
(ii) Motor vehicles,
(iii) Pharmaceuticals,
(iv) Pesticides,
(v) Used equipment,
(vi) U.S. Government-owned excess property, or
(vii) Fertilizer.

Prior approval will be deemed to have been met when:

(i) the item is of U.S. source/origin;

(ii) the item has been identified and incorporated in the program description or schedule of the award (initial or revisions), or amendments to the award; and

(iii) the costs related to the item are incorporated in the approved budget of the award. Where the item has not been incorporated into the award as described above, a separate written authorization from the Agreement Officer must be provided before the item is procured.

Note trying to buy motos rather than rent them.

Note buying poker chips for IBLI extension game.

Politics of a census.

Who are we are how many are we?

Where are we?

Redistricting and changing number of representatives based on census outcomes?

Potentially undercounting of urban poor becomes a politically contested issue.

Asking citizenship status can lead to a systematic impact.

Methodologically, moving from a full enumeration of the population to a sample based methodology is also politically contested. Big picture overview of this topic in summary.

- 1) Science and research do not exist in a world distinct from the political domain.
 - a. The researcher has values and these will have some influence on the topics researched and conclusions drawn.
 - b. The findings fit into somebody's political agenda and are opposed by somebody else with an agenda.
- 2) We can still do good social science in this context.
 - a. There is something like consensus about theory and methods in social science research – note the point that the disputes about findings in studies focusing on race have mostly revolved around disputes over methods.
 - b. Keep this in mind if you are looking at the GMO case.
- 3) We need to be aware of the implications of our research in the context of competing political ideologies and other researchers out there doing work.
- 4) We can try to keep our work as scientific and free from bias as possible, but still have political opinions and values.
 - a. We should as researchers be participants in public debate, and expressing both our personal values and our research findings.