

ETHICS IN RESEARCH

LEARNING OBJECTIVES

1. Describe the design of the Milgram obedience experiments and some of the controversies surrounding its methods and results.
2. Identify three other research projects that helped motivate the establishment of human subjects' protections.
3. Define the *Belmont Report*'s three ethical standards for the protection of human subjects.
4. Explain the role of an institutional review board.
5. List current standards for the protection of human subjects in research.
6. Define *debriefing*, and review the controversy about the Milgram research.



Imagine this: One spring morning as you are drinking coffee and reading the newspaper, you notice a small ad for a psychology experiment at the local university.

We Will Pay You \$45 For One Hour of Your Time

Persons Needed for a Study of Memory

"Earn money and learn about yourself," it continues.

Feeling a bit bored, you call and schedule an evening visit to the lab.

You are about to enter one of the most ethically controversial experiments in the history of social science.

You arrive at the assigned room at the university and are immediately impressed by the elegance of the building and the professional appearance of the personnel. In the waiting room, you see a man dressed in a lab technician's coat talking to another visitor, a middle-aged fellow dressed in casual attire. The man in the lab coat turns, introduces himself, and explains that, as a psychologist, he is interested in whether people learn better when they are punished for making mistakes. He quickly convinces you that this is an important question; he then explains that his experiment on punishment and learning will discover the answer. Then he announces, "I'm going to ask one of you to be the teacher here tonight and the other one to be the learner."

The experimenter (as we'll refer to him from now on) says he will write either *teacher* or *learner* on small identical slips of paper and then asks both of you to draw one. Yours says *teacher*.

The experimenter now says, in a matter-of-fact way, "All right. Now the first thing we'll have to do is to set the learner up so that he can get some type of punishment."

He leads you both behind a curtain, sits the learner in the chair, straps down both of his arms, and attaches an electric wire to his left wrist (Exhibit 3.1). The wire is connected to a console with 30 switches and a large dial, on the other side of the curtain. When you ask what the wire is for, the experimenter demonstrates. He asks you to hold the end of the wire, walks back to the control console, and flips several switches. You hear a clicking noise, see the dial move, and then feel an electric shock in your hand. When the experimenter flips the next switch, the shock increases.

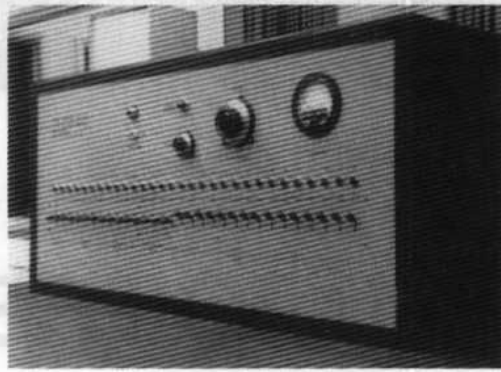
"Ouch!" you say. "So that's the punishment. Couldn't it cause injury?" The experimenter explains that the machine is calibrated so that it will not cause permanent injury but admits that when turned up all the way, it is very, very painful.

Exhibit 3.1 /// Learner Strapped in Chair With Electrodes



Source: From the film *Obedience* © 1968 by Stanley Milgram, © Renewed 1993 by Alexandra Milgram, and distributed by Alexander Street Press.

Exhibit 3.2 /// Milgram's "Shock Generator"



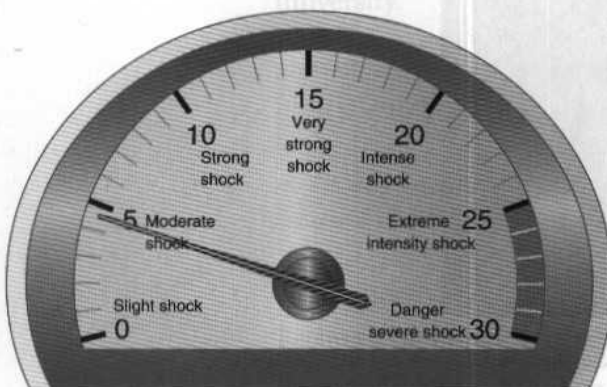
Source: From the film *Obedience* © 1968 by Stanley Milgram, © Renewed 1993 by Alexandra Milgram, and distributed by Alexander Street Press.

Now you walk back to the other side of the room (so that the learner is behind the curtain) and sit before the console (Exhibit 3.2). The experimental procedure has four simple steps:

1. You read aloud a series of word pairs, such as *blue box*, *nice day*, *wild duck*, and so on.
2. You read one of the first words from those pairs and a set of four words, one of which is the original paired word. For example, you might say, "blue: sky-ink-box-lamp."
3. The learner states the word that he thinks was paired with the first word you read (*blue*). If he gives a correct response, you compliment him and move on to the next word. If he makes a mistake, you flip a switch on the console. This causes the learner to feel a shock on his wrist.
4. After each mistake, you are to flip the next switch on the console, progressing from left to right. You note that a label corresponds to every 5th mark on the dial, with the first mark labeled *slight shock*, the 5th mark labeled *moderate shock*, the 10th *strong shock*, and so on through *very strong shock*, *intense shock*, *extreme intensity shock*, and *danger: severe shock*.

You begin. The learner at first gives some correct answers, but then he makes a few errors. Soon you are beyond the 5th mark (moderate shock) and are moving in the direction of more and more severe shocks. As you turn the dial, the learner's reactions increase in intensity: from a grunt at the 10th mark (strong shock) to painful groans at higher levels, to anguished cries of "get me out of here" at the extreme intensity shock levels, to a deathly silence at the highest level. When you protest at administering the stronger shocks, the experimenter tells you, "The experiment requires that you continue." Occasionally he says, "It is absolutely essential that you continue."

Exhibit 3.3 /// Shock Meter



This is a simplified version of the famous Stanley Milgram's **obedience experiments**, begun at Yale University in 1960. Outside the laboratory, Milgram surveyed Yale undergraduates and asked them to indicate at what level they would terminate their "shocks" if they were in the study. Now, please mark on the console in Exhibit 3.3 the most severe shock that you would agree to give the learner.

The average (mean) maximum shock level predicted by the Yale undergraduates was 9.35, corresponding to a strong shock. Only one student predicted that he would provide a stimulus above that level, at the very strong level. Responses were similar from nonstudent groups.

But the actual average level of shock the 40 adults who volunteered for the experiment administered was 24.53—higher than extreme intensity shock and just short of danger: severe shock. Of Milgram's original 40 subjects, 25 complied entirely with the experimenter's demands, going all the way to the top of the scale (labeled simply as XXX). Judging from the subjects' visibly high stress, and from their subsequent reports, they believed that the learner was receiving physically painful shocks. **(In fact, no electric shocks were actually delivered.)**

We introduce the Milgram experiment not to discuss obedience to authority but instead to introduce research ethics. We refer to Milgram's obedience studies throughout this chapter because they ultimately had as profound an influence on scientists' thinking about ethics as on how we understand obedience to authority. Although Milgram died in 1984, the controversy around his work did not. A recent review of the transcripts and interviews with many participants raises additional concerns even about the experiment's scientific validity, as well as its ethics (Perry 2013).

Throughout this book, we discuss ethical problems common to various research methods; in this particular chapter, we present in more detail some of the general ethical principles that professional social scientists use in monitoring their work.

HISTORICAL BACKGROUND

Formal procedures for the protection of participants in research grew out of some widely publicized abuses. A defining event occurred in 1946, when the Nuremberg war crime trials exposed horrific medical experiments conducted during World War II by Nazi doctors in the name of "science." During the 1950s and 1960s, American military personnel and Pacific Islanders were sometimes unknowingly exposed to radiation during atomic bomb tests. And in the 1970s, Americans were shocked to learn that researchers funded by the U.S. Public Health Service had, for decades, studied 399 low-income African American men diagnosed with syphilis in the 1930s to follow the "natural" course of the illness (Exhibit 3.4). In the

Obedience experiments (Milgram's):

A series of famous experiments conducted during the 1960s by Stanley Milgram, a psychologist from Yale University, testing subjects' willingness to cause pain to another person if instructed to do so.

Nuremberg war crime trials:

Trials held in Nuremberg, Germany, in the years following World War II, in which the former leaders of Nazi Germany were charged with war crimes and crimes against humanity; frequently considered the first trials for people accused of genocide.

Exhibit 3.4 /// Tuskegee Syphilis Experiment



Source: Tuskegee Syphilis Study Administrative Records. Records of the Centers for Disease Control and Prevention. National Archives—Southeast Region (Atlanta).

Tuskegee syphilis study:

Research study conducted by a branch of the U.S. government, lasting for roughly 50 years (ending in the 1970s), in which a sample of African American men diagnosed with syphilis were deliberately left untreated, without their knowledge, so that researchers could learn about the lifetime course of the disease.

Belmont Report:

Report in 1979 of the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research stipulating three basic ethical principles for the protection of human subjects: respect for persons, beneficence, and justice.

Respect for persons:

In human subjects ethics discussions, treating persons as autonomous agents and protecting those with diminished autonomy.

Beneficence:

Minimizing possible harms and maximizing benefits.

Tuskegee syphilis study, many participants were not informed of their illness and were denied treatment until 1972, even though a cure (penicillin) was developed in the 1950s (Jones 1993).

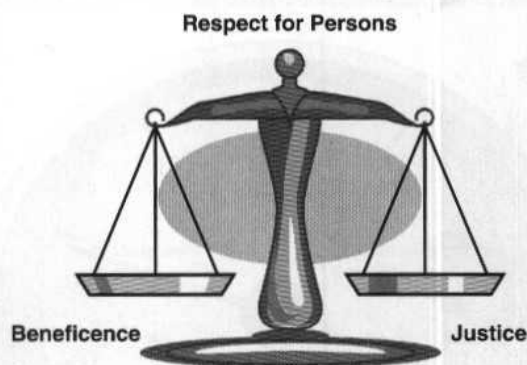
Such egregious violations of human rights resulted, in the United States, in the creation of the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. The commission's 1979 *Belmont Report* (U.S. Department of Health, Education, and Welfare 1979) established three basic ethical principles for the protection of human subjects (Exhibit 3.5):

1. **Respect for persons**—treating persons as autonomous agents and protecting those with diminished autonomy
2. **Beneficence**—minimizing possible harms and maximizing benefits
3. **Justice**—distributing benefits and risks of research fairly

The Department of Health and Human Services and the Food and Drug Administration then translated these principles into specific regulations, which were adopted in 1991 as the **Federal Policy for the Protection of Human Subjects**, sometimes known as the "Common Rule." This policy, revised in January 2018, has shaped the course of social science research ever since, and you will have to consider it as you design your own research investigations. Some professional associations—such as the American Psychological Association, the American Political Science Association, the American Sociological Association, university review boards, and ethics committees in other organizations—set standards for the treatment of human subjects by their members, employees, and students; these standards are designed to comply with the federal policy.

Federal regulations require that every institution that seeks federal funding for biomedical or behavioral research on human subjects have an **institutional review board (IRB)** that reviews research proposals. If you do research for a class assignment, you may need to prepare a brief IRB proposal, so board members can be sure that your project meets all ethical standards. IRBs at universities and other agencies apply ethics standards that are set by federal regulations (Sieber 1992: 5, 10). To promote adequate review of ethical issues, the regulations require that IRBs include members with diverse backgrounds, from on and off campus. The 2018 revisions generally made social science research less tightly regulated by simplifying consent forms, reducing ongoing reviews, and expanding the range of exempted activities.

Exhibit 3.5 /// *Belmont Report Principles*



Source: U.S. Department of Health, Education, and Welfare 1979.

ETHICAL PRINCIPLES

The American Sociological Association (ASA), like other professional social science organizations, has adopted, for practicing sociologists, ethical guidelines that are more specific than the federal regulations. Professional organizations may also review complaints of unethical practices when asked.

The *Code of Ethics* of the ASA (2018) is summarized at the ASA website (www.asanet.org); the complete text of the code is also available at this site.

Mostly, ethical issues in research are covered by four guidelines:

1. To protect research subjects
2. To maintain honesty and openness
3. To achieve valid results
4. To encourage appropriate application

Each of these guidelines became a focus of the debate about Milgram's experiments, to which we will refer frequently. Did Milgram respect the spirit expressed in these principles? You will find that there is no simple answer to the question of what is (or isn't) ethical research practice.

Protecting Research Subjects

This guideline, the most important, can itself be divided into four specific rules:

1. Avoid harming research participants.
2. Obtain informed consent.
3. Avoid deception in research, except in limited circumstances.
4. Maintain privacy and confidentiality.

Avoid Harming Research Participants

This standard may seem straightforward, but it can be difficult to interpret in specific cases. Does it mean that subjects should not be harmed even mentally or emotionally? That they should feel no anxiety or distress?

The most serious charge leveled against the ethics of Milgram's study was that he had harmed his subjects. A verbatim transcript of one session will give you an idea of what participants experienced as the "shock generator," which made it appear they were delivering increasingly severe shocks to the learner (Milgram 1965: 67):

- | | |
|----------------------|---|
| 150 volts delivered. | You want me to keep going? |
| 165 volts delivered. | That guy is hollering in there. . . . He's liable to have a heart condition. You want me to go on? |
| 180 volts delivered. | He can't stand it! I'm not going to kill that man in there! You hear him hollering? He's hollering. He can't stand it. . . . I mean who is going to take responsibility if anything happens to that gentleman? [<i>The experimenter accepts responsibility.</i>] All right. |
| 195 volts delivered. | You see he's hollering. Hear that. Gee, I don't know. [<i>The experimenter says: "The experiment requires that you go on."</i>] I know it does, sir, but I mean—phew—he don't know what he's in for. He's up to 195 volts. |

Justice:

As used in human research ethics discussions, distributing benefits and risks of research fairly.

Federal Policy for the Protection of Human Subjects (also known as the Common Rule):

Federal regulations codifying basic principles for conducting research on human subjects; used as the basis for professional organizations' guidelines. Newly revised in January 2018.

Institutional review board (IRB):

A group of organizational and community representatives required by federal law to review the ethical issues in all proposed research that is federally funded, involves human subjects, or has any potential for harm to subjects.

210 volts delivered.

225 volts delivered.

240 volts delivered.

The experimental manipulation generated “extraordinary tension” (Milgram 1963: 377):

Subjects were observed to sweat, tremble, stutter, bite their lips, groan and dig their fingernails into their flesh. . . . Full-blown, uncontrollable seizures were observed for 3 subjects. One . . . seizure [was] so violently convulsive that it was necessary to call a halt to the experiment [for that individual]. (p. 375)

An observer (behind a one-way mirror) reported, “I observed a mature and initially poised businessman enter the laboratory smiling and confident. Within 20 minutes he was reduced to a twitching, stuttering wreck, who was rapidly approaching a point of nervous collapse” (Milgram 1963: 377).

Milgram’s “Behavioral Study of Obedience” was published in 1963 in the *Journal of Abnormal and Social Psychology*. The next year, the *American Psychologist* published a critique of the experiment’s ethics by psychologist Diana Baumrind (1964: 421). From Baumrind’s perspective, the emotional disturbance in subjects was “potentially harmful because it could easily effect an alteration in the subject’s self-image or ability to trust adult authorities in the future” (p. 422). Milgram (1964) quickly countered,

Momentary excitement is not the same as harm. As the experiment progressed there was no indication of injurious effects in the subjects; and as the subjects themselves strongly endorsed the experiment, the judgment I made was to continue the experiment. (p. 849)

Milgram (1963) also attempted to minimize harm to subjects with postexperiment procedures “to assure that the subject would leave the laboratory in a state of well being” (p. 374). A friendly reconciliation was arranged between the subject and the victim, and an effort was made to reduce any tensions that arose as a result of the experiment.

Debriefing:

A researcher’s informing subjects after an experiment about the experiment’s purposes and methods and evaluating subjects’ personal reactions to the experiment.

In some cases, the “dehoaxing”—or **debriefing**—discussion was extensive, and all subjects were promised (and later received) a comprehensive report (Milgram 1964: 849). But Baumrind (1964) was unconvinced: “It would be interesting to know what sort of procedures could dissipate the type of emotional disturbance just described” (p. 422).

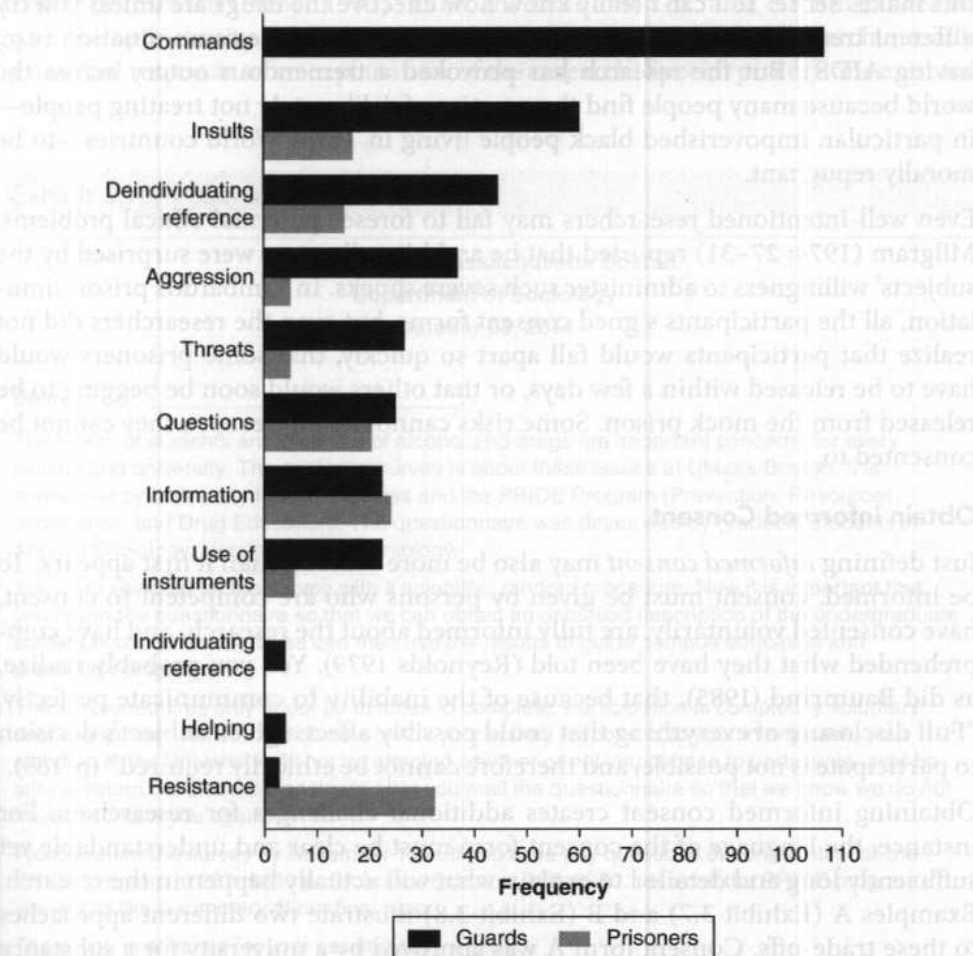
When Milgram (1964: 849) surveyed subjects in a follow-up, 83.7% endorsed the statement that they were “very glad” or “glad” “to have been in the experiment,” 15.1% were “neither sorry nor glad,” and just 1.3% were “sorry” or “very sorry” to have participated. Interviews by a psychiatrist a year later found no evidence “of any traumatic reactions” (Milgram 1974: 197). Subsequently, Milgram argued, “The central moral justification for allowing my experiment is that it was judged acceptable by those who took part in it” (Milgram as cited in Cave and Holm 2003: 32).

In a later article, Baumrind (1985: 168) dismissed the value of the self-reported “lack of harm” of subjects who had been willing to participate in the experiment and noted that 16% did *not* endorse the statement that they were “glad” they had participated in the experiment. Many social scientists, ethicists, and others concluded that Milgram’s procedures had not harmed subjects and so were justified by the knowledge they produced; others sided with Baumrind’s criticisms (Miller 1986: 88–138).

Or, consider the possible harm to subjects in the famous prison simulation study at Stanford University (Haney, Banks, and Zimbardo 1973). Philip Zimbardo’s prison simulation study was designed to investigate the impact of being either a guard or a prisoner in a prison, a “total institution.” The researchers selected apparently stable and mature young male volunteers and asked them to sign a contract to work for 2 weeks as a guard or a prisoner in a simulated prison. Within the first 2 days after the prisoners were incarcerated in a makeshift basement prison, the prisoners began to be passive and disorganized, and the guards became “sadistic”—verbally and physically aggressive (Exhibit 3.6). Five “prisoners” were

Prison simulation study (Zimbardo’s): Famous study from the early 1970s, organized by Stanford psychologist Philip Zimbardo, demonstrating the willingness of average college students quickly to become harsh disciplinarians when put in the role of (simulated) prison guards over other students; usually interpreted as demonstrating an easy human readiness to become cruel.

Exhibit 3.6 /// Chart of Guard and Prisoner Behavior



Source: From *The Lucifer Effect* by Philip G. Zimbardo. Copyright 2007 by Philip G. Zimbardo, Inc. Used by permission of Random House, an imprint and division of Random House LLC, and Random House Group Ltd. All rights reserved.

soon released for depression, uncontrollable crying, fits of rage, and, in one case, a psychosomatic rash. Instead of letting things continue for 2 weeks as planned, Zimbardo and his colleagues terminated the experiment after 6 days to avoid harming subjects.

Participants playing the prisoner role certainly felt some stress, but postexperiment discussion sessions seemed to relieve this; follow-up during the next year indicated no lasting negative effects on the participants and some benefits in the form of greater insight. And besides, Zimbardo and his colleagues had no way of predicting the bad outcome; indeed, they were surprised (Haney et al. 1973).

Withholding beneficial treatment can be another way of causing harm to subjects. Sometimes, in an ethically debatable practice, researchers will withhold treatments from some subjects, knowing that those treatments would probably help the people, to accurately measure *how much* they helped. For example, in some recent studies of AIDS drugs conducted in Africa, researchers provided different levels of AIDS-combating drugs to different groups of patients with the disease. Some patients received no drug therapy at all, even though all indications were that the drug treatments would help them. From the point of view of pure science, this makes sense: You can't really know how effective the drugs are unless you try different treatments on different people who start from the same situation (e.g., having AIDS). But the research has provoked a tremendous outcry across the world because many people find the practice of deliberately not treating people—in particular, impoverished black people living in Third World countries—to be morally repugnant.

Even well-intentioned researchers may fail to foresee potential ethical problems. Milgram (1974: 27–31) reported that he and his colleagues were surprised by the subjects' willingness to administer such severe shocks. In Zimbardo's prison simulation, all the participants signed consent forms, but even the researchers did not realize that participants would fall apart so quickly, that some prisoners would have to be released within a few days, or that others would soon be begging to be released from the mock prison. Some risks cannot be foreseen, so they cannot be consented to.

Obtain Informed Consent

Just defining *informed consent* may also be more difficult than it first appears. To be informed, consent must be given by persons who are competent to consent, have consented voluntarily, are fully informed about the research, and have comprehended what they have been told (Reynolds 1979). Yet, you probably realize, as did Baumrind (1985), that because of the inability to communicate perfectly, "Full disclosure of everything that could possibly affect a given subject's decision to participate is not possible, and therefore cannot be ethically required" (p. 165).

Obtaining informed consent creates additional challenges for researchers. For instance, the language of the consent form must be clear and understandable yet sufficiently long and detailed to explain what will actually happen in the research. Examples A (Exhibit 3.7) and B (Exhibit 3.8) illustrate two different approaches to these trade-offs. Consent form A was approved by a university for a substance abuse survey with undergraduate students. It is brief and to the point but leaves quite a bit to the imagination of the prospective participants. Consent form B reflects the requirements of an academic hospital's IRB. Because the hospital is

used to reviewing research proposals involving drugs and other treatment interventions with hospital patients, it requires a very detailed and lengthy explanation of procedures and related issues, even for a simple survey. Requiring prospective participants to sign such lengthy forms can reduce their willingness to participate in research and perhaps influence their responses if they do agree to participate (Larson 1993: 114).

When an experimental design requires subject deception, researchers may withhold information before the experiment but then debrief subjects after the experiment ends (Milgram did this). In the debriefing, the researcher explains what really happened in the experiment, and why, and responds to subjects' questions. A carefully designed debriefing procedure can often help research participants deal with their anger or embarrassment at having been deceived (Sieber 1992: 39–41), thus substituting for fully informed consent before the experiment.

Finally, some participants can't truly give informed consent. College students, for instance, may feel unable to refuse if their professor asks them to be in an experiment. Legally speaking, children cannot give consent to participate in research; a child's legal guardian must give written informed consent to have the child participate in research (Sieber 1992). Then, the child must in most circumstances be given the opportunity to give or withhold *assent* to participate in research, usually by a verbal response to an explanation of the research. Special protections exist for

Exhibit 3.7 /// Consent Form A

University of Massachusetts Boston

Department of Sociology

October 28, 2014

Dear _____:

The health of students and their use of alcohol and drugs are important concerns for every college and university. The enclosed survey is about these issues at UMass/Boston. It is sponsored by University Health Services and the PRIDE Program (Prevention, Resources, Information, and Drug Education). The questionnaire was developed by graduate students in Applied Sociology, Nursing, and Gerontology.

You were selected for the survey with a scientific, random procedure. Now it is important that you return the questionnaire so that we can obtain an unbiased description of the undergraduate student body. Health Services can then use the results to guide campus education and prevention programs.

The survey requires only about 20 minutes to complete. Participation is completely voluntary and anonymous. No one will be able to link your survey responses to you. In any case, your standing at the University will not be affected whether or not you choose to participate. Just be sure to return the enclosed postcard after you mail the questionnaire so that we know we do not have to contact you again.

Please return the survey by November 15th. If you have any questions or comments, call the PRIDE program at 287-5680 or Professor Schutt at 287-6250. Also call the PRIDE program if you would like a summary of our final report.

Thank you in advance for your assistance.

Russell K. Schutt, PhD
Professor and Chair

Research Consent Form for Social and Behavioral Research

Dana-Farber/Harvard Cancer Center

BIDMC/BWH/CH/DFCI/MGH/Partners Network Affiliates

OPRS 11-05

Protocol Title: ASSESSING COMMUNITY HEALTH WORKERS' ATTITUDES AND KNOWLEDGE ABOUT EDUCATING COMMUNITIES ABOUT CANCER CLINICAL TRIALS

DF/HCC Principal Research Investigator / Institution: Dr. Russell Schutt, PhD/Beth Israel Deaconess Medical Center and Univ. of Massachusetts, Boston

DF/HCC Site-Responsible Research Investigator(s) / Institution(s): Lidia Schapira, MD/Massachusetts General Hospital

Interview Consent Form**A. INTRODUCTION**

We are inviting you to take part in a research study. Research is a way of gaining new knowledge. A person who participates in a research study is called a "subject." This research study is evaluating whether community health workers might be willing and able to educate communities about the pros and cons of participating in research studies.

It is expected that about 10 people will take part in this research study.

An institution that is supporting a research study either by giving money or supplying something that is important for the research is called the "sponsor." The sponsor of this protocol is National Cancer Institute and is providing money for the research study.

This research consent form explains why this research study is being done, what is involved in participating in the research study, the possible risks and benefits of the research study, alternatives to participation, and your rights as a research subject. The decision to participate is yours. If you decide to participate, please sign and date at the end of the form. We will give you a copy so that you can refer to it while you are involved in this research study.

If you decide to participate in this research study, certain questions will be asked of you to see if you are eligible to be in the research study. The research study has certain requirements that must be met. If the questions show that you can be in the research study, you will be able to answer the interview questions.

If the questions show that you cannot be in the research study, you will not be able to participate in this research study.

DFCI Protocol Number: <u>06-085</u>	Date DFCI IRB Approved this Consent Form: <u>January 16, 2007</u>
Date Posted for Use: <u>January 16, 2007</u>	Date DFCI IRB Approval Expires: <u>August 13, 2007</u>

Research Consent Form for Social and Behavioral Research

Dana-Farber/Harvard Cancer Center

BIDMC/BWH/CH/DFCI/MGH/Partners Network Affiliates

OPRS 11-05

We encourage you to take some time to think this over and to discuss it with other people and to ask questions now and at any time in the future.

B. WHY IS THIS RESEARCH STUDY BEING DONE?

Deaths from cancer in general and for some specific cancers are higher for black people compared to white people, for poor persons compared to nonpoor persons, and for rural residents compared to non-rural residents. There are many reasons for higher death rates between different subpopulations. One important area for changing this is to have more persons from minority groups participate in research about cancer. The process of enrolling minority populations into clinical trials is difficult and does not generally address the needs of their communities. One potential way to increase participation in research is to use community health workers to help educate communities about research and about how to make sure that researchers are ethical. We want to know whether community health workers think this is a good strategy and how to best carry it out.

C. WHAT OTHER OPTIONS ARE THERE?

Taking part in this research study is voluntary. Instead of being in this research study, you have the following option:

- Decide not to participate in this research study.

D. WHAT IS INVOLVED IN THE RESEARCH STUDY?

Before the research starts (screening): After signing this consent form, you will be asked to answer some questions about where you work and the type of community health work you do to find out if you can be in the research study.

If the answers show that you are eligible to participate in the research study, you will be eligible to participate in the research study. If you do not meet the eligibility criteria, you will not be able to participate in this research study.

After the screening procedures confirm that you are eligible to participate in the research study: You will participate in an interview by answering questions from a questionnaire. The interview will take about 90 minutes. If there are questions you prefer not to answer we can skip those questions. The questions are about the type of work you do and your opinions about participating in research. If you agree, the interview will be taped and then transcribed. Your name and no other information about you will be associated with the tape or the transcript. Only the research team will be able to listen to the tapes. Immediately following the interview, you will have the opportunity to have the tape erased if you wish to withdraw your consent to taping or participation in this study. You will receive \$30.00 for completing this interview.

DFCI Protocol Number: <u>06-085</u>	Date DFCI IRB Approved this Consent Form: <u>January 16, 2007</u>
Date Posted for Use: <u>January 16, 2007</u>	Date DFCI IRB Approval Expires: <u>August 13, 2007</u>

(Continued)

Research Consent Form for Social and Behavioral Research

Dana-Farber/Harvard Cancer Center

BIDMC/BWH/CH/DFCI/MGH/Partners Network Affiliates

OPRS 11-05

After the interview is completed: Once you finish the interview there are no additional interventions.

N. DOCUMENTATION OF CONSENT

My signature below indicates my willingness to participate in this research study and my understanding that I can withdraw at any time.

Signature of Subject
or Legally Authorized Representative

Date

Person obtaining consent

Date

To be completed by person obtaining consent:

The consent discussion was initiated on _____ (date) at _____ (time.)

☐ A copy of this signed consent form was given to the subject or legally authorized representative.

For Adult Subjects

☐ The subject is an adult and provided consent, to participate.

☐ The subject is an adult who lacks capacity to provide consent and his/her legally authorized representative:

☐ gave permission for the adult subject to participate

☐ did not give permission for the adult subject to participate

DFCI Protocol Number:
06-085

Date DFCI IRB Approved this Consent Form: January 16, 2007

Date Posted for Use:
January 16, 2007

Date DFCI IRB Approval Expires: August 13, 2007

other vulnerable populations—prisoners, pregnant women, mentally disabled persons, and educationally or economically disadvantaged persons. And in a sense, anyone deliberately deceived in an experiment cannot be said to really have given “informed” consent, since the person wasn’t honestly told what would happen.

Social media and digital technologies have in recent years opened the doors to new kinds of ethical problems in research, by blurring the lines between public and private behavior. If you have a Facebook page with 1,500 “friends,” is that your private page or a public document? In Chapter 8, we’ll see how social researchers are eagerly mining such data for information on people’s social networks. “Employers are looking at people’s online postings and Googling information about them, and I think researchers are right behind them,” said Professor Nicholas Christakis (as cited in Rosenbloom 2007: 2), a Harvard sociologist, in a *New York Times* article in 2007. But the federal guidelines under which IRBs are set up didn’t anticipate the Internet. “The [human subject] rules were made for a different world, a pre-Facebook world,” said Samuel D. Gosling, a psychology professor at the University of Texas who uses Facebook as a data source. “There is a rule that you are allowed to observe public behavior, but it’s not clear if online behavior is public or not” (as cited in Rosenbloom 2007: 2). And it’s probably no surprise to you that social media companies are using your personal information both to conduct their own experiments and as a product they sell to other businesses!

In truth, though, the public versus private debate is a long-standing issue in social science. Laud Humphreys (1970) decided that truly informed consent would be impossible to obtain for his study of the men who have sex with other men—strangers—in public facilities. Humphreys himself served as a lookout—a “watch queen”—for men who were entering a public bathroom in a city park with the intention of having sex. In a number of cases, he then left the bathroom and copied the license plate numbers of the cars driven by the men, and learned who they were. One year later, disguising himself so that they wouldn’t recognize him, Humphreys visited the homes of the men and interviewed them, telling them he was conducting research on a broad range of social issues. In his book *Tearoom Trade*, Humphreys concluded that the men who engaged in what were then widely viewed as deviant acts were, for the most part, married, suburban, apparently straight men whose families were unaware of their secret sexual practices. But debate has continued ever since about Humphreys’s failure to tell the men what he was really doing in the bathroom or why he had come to their homes for the interview. He was criticized by many, including some faculty members at Washington University in St. Louis, who urged that his doctoral degree be rescinded. However, many other professors and members of the gay community praised Humphreys for helping normalize conceptions of homosexuality (Miller 1986: 135).

If you served on your university’s IRB, would you allow research such as Humphreys’s to be conducted?

Avoid Deception in Research, Except in Limited Circumstances

Deception occurs when subjects are misled about research procedures. Frequently, this is done to simulate real-world conditions in the lab. The goal is to get subjects “to accept as true what is false or to give a false impression” (Korn 1997: 4). In Milgram’s (1964) experiment, for example, deception seemed necessary because actually giving electric shocks to the “stooge” would be cruel. Yet, to test obedience, the task had to be troubling for the subjects. Milgram (1974: 187–188)

Tearoom Trade:

Book by Laud Humphreys investigating the social background of men who engage in homosexual behavior in public facilities; controversially, he did not obtain informed consent from his subjects.

insisted that the deception was absolutely essential. Many other psychological and social psychological experiments would be worthless if subjects understood what was really happening to them while the experiment was in progress. But is this sufficient justification to allow the use of deception?

Some important topics have been cleverly studied using deception. Gary Marshall and Philip Zimbardo (of prison study fame), in a 1979 study, told the student volunteers that they were being injected with a vitamin supplement to test its effect on visual acuity (Korn 1997: 2–3). But to determine the physiological basis of emotion, they actually injected them with adrenaline, so that their heart rate and sweating would increase, and then placed them in a room with a student stooge who acted silly. Jane Allyn Piliavin and Irving Piliavin, in a 1972 study, staged fake seizures on subway trains to study helpfulness (Korn 1997: 3–4). George Schreer, Sandra Smith, and Kirsten Thomas (2009) investigated racial profiling by sending “customers” to browse in high-end retail stores and then observing the behaviors of salespersons. Would you allow such deceptive practices if you were a member of your university’s IRB? Giving people stimulating drugs, apart from the physical dangers, is using their very bodies for research without their knowledge. Faking an emergency may lessen one’s willingness to help in the future or may, in effect, punish the research subjects—through embarrassment—for their reaction to what is really “just an experiment.” Is it right to expose the biases of unwitting salespeople?

The development of virtual reality environments may provide a way of lessening these dilemmas. For example, Mel Slater, Angus Antley, and a team of European researchers (2006) repeated the Milgram obedience experiment procedures with virtual reality techniques. According to participants’ statements, behaviors, and physiological responses, they seemed to experience the immersive virtual environment as if it was real, even though they clearly understood that the “Learner” they observed was only virtual. The participants also responded to the “Experimenter’s” requests in ways similar to what occurred in Milgram’s “real” experiment.

The new federal regulations relax concerns about deception of the type that is often used in laboratory experiments in social psychology. Specifically, the regulations authorize deception in research “where the subject is informed that he or she will be unaware of or misled regarding the nature or purposes of the research” (Chadwick 2017: 4).

Maintain Privacy and Confidentiality

Maintaining privacy and confidentiality after a study is completed is another way to protect subjects, and the researcher’s commitment to that standard should be included in the informed consent agreement (Sieber 1992). Procedures to protect each subject’s privacy, such as locking records and creating special identifying codes, must be created to minimize the risk of access by unauthorized persons. For the protection of health care data, the **Health Insurance Portability and Accountability Act (HIPAA)**, passed by Congress in 1996, created much more stringent regulations. As implemented by the U.S. Department of Health and Human Services in 2000 (and revised in 2002), the HIPAA Final Privacy Rule applies to oral, written, and electronic information that “relates to the past, present, or future physical or mental health or condition of an individual” (Legal Information Institute 2006, § 1320d[6][B]). The HIPAA rule requires that researchers have valid authorization for any use or disclosure of “protected health information” from a health care provider. Waivers of authorization can be granted in special circumstances (Cava, Cushman, and Goodman 2007).

Health Insurance Portability and Accountability Act (HIPAA):

A U.S. federal law passed in 1996 that guarantees, among other things, specified privacy rights for medical patients, in particular those in research settings.

However, statements about confidentiality should be realistic. In 1993, sociologist Rik Scarce was jailed for 5 months for contempt of court after refusing to testify to a grand jury about so-called ecoterrorists. Scarce, a PhD candidate at Washington State University at the time, was researching radical environmentalists and may have had information about a 1991 "liberation" raid on an animal research lab at Washington State. Scarce was eventually released from jail, but he never violated the confidentiality he claimed to have promised his informants (Scarce 2005). Laws allow research records to be subpoenaed and may require reporting child abuse. A researcher also may feel compelled to release information if a health- or life-threatening situation arises and participants need to be alerted.

The National Institutes of Health can issue a **Certificate of Confidentiality** to protect researchers from being legally required to disclose confidential information. Researchers who focus on high-risk populations or behaviors or sensitive topics, such as crime, substance abuse, sexual activity, or genetic information, can request such a certificate. Suspicions of child abuse or neglect must still be reported, and in some states, researchers may still be required to report such crimes as elder abuse (Arwood and Panicker 2007).

Confidentiality:

Provided by research in which identifying information that could be used to link respondents to their responses is available only to designated research personnel for specific research needs.

Certificate of Confidentiality:

Document issued by the National Institutes of Health to protect researchers from being legally required to disclose confidential information.



Research That Matters

You are driving on the highway at about 3 p.m. on a Friday when you see a police officer standing by his squad car, lights flashing. The officer motions you to pull off the road and stop in an area marked off with traffic cones. You are both relieved and surprised when someone in plain clothes working with the police officer then walks over to your car and asks if you would consent to be in a survey. You then notice two large signs that say NATIONAL ROADSIDE SURVEY and VOLUNTARY SURVEY. You are offered \$10 to provide an oral fluid sample and answer a few additional questions on drug use.

This is what happened to 10,909 U.S. motorists between July 20 and December 1, 2007, at sites across the United States. Those who agreed to the oral fluid collection were also offered an additional \$5 to complete a short alcohol and drug-use disorder questionnaire. Before they drove off, participants were also offered a \$50 incentive for providing a blood sample. Drivers who were found to be too impaired to be able to drive safely (blood alcohol level above .05) were given

a range of options, including switching with an unimpaired passenger, getting a free ride home, or spending a night in a local motel (at no expense to them). None were arrested or given citations, and no crashes occurred in relation to the study. Those younger than 21 years and those who were pregnant were given informational brochures because of the special risk they face if they consume alcohol.

John H. Lacey and others from the Pacific Institute for Research and Evaluation, C. Debra Furr-Holden from Johns Hopkins University, and Amy Berning from the National Highway Traffic Safety Administration (NHTSA, which funded the study) reported the procedures for this survey in a 2011 article in the *Evaluation Review*. The survey explained that all data collected were maintained as anonymous, so no research participants could be linked to their survey.

The 2007 National Roadside Survey identified 10.5% of the drivers as using illegal drugs and 3% as having taken medications.

Source: Adapted from Lacey, John H., Tara Kelley-Baker, Robert B. Voas, Eduardo Romano, C. Debra Furr-Holden, Pedro Torres, and Amy Berning. 2011. Alcohol- and drug-involved driving in the United States: Methodology for the 2007 National Roadside Survey. *Evaluation Review* 35: 319–353.

The details in Milgram's 1963 article and 1974 book on the obedience experiments make a compelling case for his commitment to achieving valid results—to learning how obedience influences behavior. In Milgram's (1963) own words,

It has been reliably established that from 1933–45 millions of innocent persons were systematically slaughtered on command. . . . Obedience is the psychological mechanism that links individual action to political purpose. It is the dispositional cement that binds men to systems of authority. . . . For many persons obedience may be a deeply ingrained behavior tendency. . . . Obedience may [also] be ennobling and educative and refer to acts of charity and kindness, as well as to destruction. (p. 371)

Milgram (1963) then explains how he devised experiments to study the process of obedience in a way that would seem realistic to the subjects and still allow “important variables to be manipulated at several points in the experiment” (p. 372). Every step in the experiment was carefully designed to ensure that subjects received identical stimuli and that their responses were measured carefully.

Milgram's (1963) attention to validity is also apparent in his reflections on “the particular conditions” of his experiment, for, he notes, “Understanding of the phenomenon of obedience must rest on an analysis of [these conditions]” (p. 377). These particular conditions included the setting for the experiment at Yale University, its purported “worthy purpose” to advance knowledge about learning and memory, and the voluntary participation of the subject as well as of the learner—as far as the subject knew. The importance of some of these “particular conditions” (such as the location at Yale) was then tested in subsequent replications of the basic experiment (Milgram 1965).

However, not all psychologists agreed that Milgram's approach could achieve valid results. Baumrind's (1964) critique begins with a rejection of the external validity—the generalizability—of the experiment. “The laboratory is unfamiliar as a setting and the rules of behavior ambiguous. . . . Therefore, the laboratory is not the place to study degree of obedience or suggestibility, as a function of a particular experimental condition” (p. 423). And so, “the parallel between authority-subordinate relationships in Hitler's Germany and in Milgram's laboratory is unclear” (p. 423).

Milgram (1964) quickly published a rejoinder in which he disagreed with (among other things) the notion that it is inappropriate to study obedience in a laboratory setting: “A subject's obedience is no less problematical because it occurs within a social institution called the psychological experiment” (p. 850).

Milgram (1974: 169–178) also pointed out that his experiment had been replicated in other places and settings with the same results, that there was considerable evidence that subjects had believed that they actually were administering shocks and that the “essence” of his experimental manipulation—the request that subjects comply with a legitimate authority—was shared with the dilemma faced by people in Nazi Germany and soldiers at the My Lai massacre in Vietnam (Miller 1986: 182–183).

But Baumrind (1985) was still not convinced. In a follow-up article in the *American Psychologist*, she argued that “far from illuminating real life, as he claimed, Milgram in fact appeared to have constructed a set of conditions so internally inconsistent that they could not occur in real life” (p. 171).

Milgram assumed that obedience could fruitfully be studied in the laboratory; Baumrind disagreed. Both, however, buttressed their ethical arguments with assertions about the external validity (or invalidity) of the experimental results. They agreed, in other words, that a research study is partly justified by its valid findings—the knowledge to be gained. If the findings aren't valid, they can't justify the research at all. It is hard to justify any risk for human subjects, or even any expenditure of time and resources, if our findings tell us nothing about human behavior.

Encouraging Appropriate Application

Finally, scientists must consider the uses to which their research is put. Although many scientists believe that personal values should be left outside the laboratory, some feel that it is proper—even necessary—for scientists to concern themselves with the way their research is used.



Careers and Research

Manan Nayak, Senior Project Director



After Manan Nayak graduated from the accelerated BA/MA program in applied sociology at the University of Massachusetts Boston, she began her career as a quality assurance analyst for a university-affiliated medical center. Initially, she used her quantitative skills to manage data from multiple clinical trials. In this role, she submitted regular reports to various committees, including the data safety and monitoring committee that ensures each study is scientific and ethically appropriate based on federal regulations. However, it was not until she became a clinical researcher that she appreciated the importance of human subjects boards. As she approached eligible patients

for studies, she learned that many patients wanted to participate in the hopes that the data collected could help someone else—despite already dealing with the effects of treatment and multiple demands on their time. The patients' selflessness motivated Nayak to develop her research career and learn more about ethical and regulatory issues and how to ensure that research teams adhere to strict guidelines. She worked alongside investigators to write applications that clearly state the process the research team will follow, including how participants are identified, what they will be asked to consent to and for how long, as well as how their data will be collected, stored, and distributed. The procedures outlined and approved by the regulatory boards are followed strictly, and any major or minor deviations are reported to the IRB immediately, along with a resolution indicating how infractions can be avoided in the future. Bringing to fruition a research study and making a small contribution in understanding how a treatment affects a group of patients and the challenges they face during treatment are the rewards of doing such research. Nayak's advice is to realize, in the excitement of doing social research, the many opportunities available to apply skills you learn in research courses.

Milgram made it clear that he was concerned about the phenomenon of obedience precisely because of its implications for people's welfare. As you have already learned, his first article (1963) highlighted the atrocities committed under the Nazis by citizens and soldiers who were "just following orders." In his more comprehensive book on the obedience experiments (1974), he also used his findings to shed light on the atrocities committed in the Vietnam War at My Lai, slavery, the destruction of the American Indian population, and the internment of Japanese Americans during World War II. Milgram makes no explicit attempt to "tell us what to do" about this problem. In fact, as a dispassionate psychological researcher, Milgram (1974) tells us, "What the present study [did was] to give the dilemma [of obedience to authority] contemporary format by treating it as subject matter for experimental inquiry, and with the aim of understanding rather than judging it from a moral standpoint" (p. xi).

Yet it is impossible to ignore the very practical implications of Milgram's investigations. His research highlighted the extent of obedience to authority and identified multiple factors that could be manipulated to lessen blind obedience (such as encouraging dissent by just one group member, removing the subject from direct contact with the authority figure, and increasing the contact between the subject and the victim).

A widely publicized experiment on the police response to domestic violence, mentioned earlier, provides an interesting cautionary tale about the uses of science. Lawrence Sherman and Richard Berk (1984) arranged with the Minneapolis police department for the random assignment of persons accused of domestic violence to be either arrested or simply given a warning. The results of this field experiment indicated that those who were arrested were less likely subsequently to commit violent acts against their partners. Sherman (1993) explicitly cautioned police departments not to adopt mandatory arrest policies based solely on the results of the Minneapolis experiment, but the results were publicized in the mass media and encouraged many jurisdictions to change their policies (Binder and Meeker 1993; Lempert 1989). Although we now know that the original finding of a deterrent effect of arrest did not hold up in many other cities where the experiment was repeated, Sherman (1992: 150–153) suggested that implementing mandatory arrest policies might have prevented some subsequent cases of spouse abuse. In particular, in a follow-up study in Omaha, arrest warrants reduced repeat offenses among spouse abusers who had already left the scene when police arrived. However, this Omaha finding was not publicized, so it could not be used to improve police policies. So how much publicity is warranted, and at what point in the research should it occur?

What can researchers do if others misinterpret their findings, or use them in misleading ways? For example, during the 1980s, Murray Straus, a prominent researcher of family violence (wife battering, child abuse, corporal punishment, and the like), found in his research that in physical altercations between husband and wife, the wife was just as likely as the husband to throw the first punch. This is a startling finding when taken by itself. But Straus also learned that regardless of who actually hit first, the wife nearly always wound up being physically injured far more severely than the man. Whoever started the fight, she lost it (Straus and Gelles 1988). In this respect (as well as in certain others), Straus's finding that "women hit first as often as men" is misleading when taken by itself. When Straus published his findings, a host of social scientists and feminists protested loudly on

the grounds that his research was likely to be misused by those who believe that wife battering is not, in fact, a serious problem. It seemed to suggest that, really, men are no worse in their use of violence than are women. Do researchers have an obligation to try to correct what seem to be misinterpretations of their findings?

CONCLUSION

One famous recent research project stirred a huge controversy within sociology and, indeed, made waves nationwide, raising a host of ethical issues. Alice Goffman was a young, white, undergraduate at the University of Pennsylvania when she began studying the African American women she worked alongside in the college cafeteria. Her project started out as a paper for a sociology course. Soon she was meeting the women's families and friends; then she moved into their (mostly black, working-class) neighborhood, where eventually she lived for 6 years, writing her PhD thesis and a book, *On the Run: Fugitive Life in an American City* (2014), about what she learned. *On the Run* became a nationwide bestseller, compellingly presenting the stories of young men and women living on the streets, continually dodging police and parole officers, engaging in a range of mostly minor crimes and deviant activities. Goffman herself lived with the men and women she studied, was (and remains) friends with many of them, and was even a marginal participant in their illegal acts. A grounding theme of her book was the oppressiveness of constant police presence in the lives of her subjects; the book was important in raising national awareness of the phenomenon and effects of mass incarceration. Early reviewers raved about the depth and originality of the research, as well as the power of the stories told, and sales skyrocketed.

But criticism quickly followed, charging Goffman with everything from shoddy research to exploitation and even aiding in attempted murder. Some critics said that as a white woman from a privileged background, Goffman was just using her African American subjects for her own purposes, that she made money from their suffering, that she was making her career at the cost of black people. Others charged that the stories seemed too dramatic to be true and that Goffman might be making up, or at least embellishing, the events that she reported and that a survey she ran seemed unrealistically detailed, with (for instance) more respondents than the neighborhood could actually produce. Others charged that the precision of her reports could identify her subjects to police, or at least reveal their methods to law enforcement, exposing them to still more harassment. Still others charged her with promoting and abetting unlawful activity, such as driving a young man around who claimed to be looking for another man he wanted to kill. Finally, some critics suggest that her name gave her unjustified status: She is the biological daughter of Erving Goffman, one of the best-known sociologists of the 20th century, who died while his daughter was an infant. The range and personal virulence of the attacks were notable. Even within the ranks of professional sociologists, there remain today angry divisions over the validity and ethical status of her work, although widely respected figures are on both sides of the debate.

Ethnographic fieldwork such as Goffman's can produce a host of ethical challenges. By comparison, most survey research creates few if any serious ethical challenges and can even be enjoyable for participants. In fact, researchers from Michigan's Institute for Survey Research interviewed a representative national sample of adults and found that 68% of those who had participated in a survey

were somewhat or very interested in participating in another; the more times respondents had been interviewed, the more willing they were to participate again (Reynolds 1979: 56–57). Conversely, some experimental studies in the social sciences that have put people in uncomfortable or embarrassing situations have generated vociferous complaints and years of debate about ethics (Reynolds 1979; Sjöberg 1967).

Research ethics should be based on a realistic assessment of the overall potential for harm and benefit to research subjects. In this chapter, we have presented some basic guidelines, and examples in other chapters suggest applications, but answers aren't always obvious. For example, full disclosure of "what is really going on" in an experimental study is unnecessary if subjects are unlikely to be harmed. In one student observation study on cafeteria workers, for instance, the IRB didn't require consent forms to be signed. The legalistic forms and signatures, they felt, would be more intrusive or upsetting to workers than the very benign and confidential research itself. The committee put the feelings of subjects above the strict requirement for consent.

Ultimately, then, these decisions about ethical procedures are not just up to you, as a researcher, to make. Your university's IRB sets the human subjects protection standards for your institution and will require that researchers—even, in most cases, students—submit their research proposal to the IRB for review. So an institutional committee, following professional codes and guidelines, will guard the ethical propriety of your research; but still, that is an uncertain substitute for your own conscience.

/// KEY TERMS

<i>Belmont Report</i> 48	Federal Policy for the Protection of Human Subjects 49	Obedience experiments (Milgram's) 47
Beneficence 48	Health Insurance Portability and Accountability Act (HIPAA) 58	Prison simulation study (Zimbardo's) 51
Certificate of Confidentiality 59	Institutional review board (IRB) 49	Respect for persons 48
Confidentiality 59	Justice 49	<i>Tearoom Trade</i> 57
Debriefing 50	Nuremberg war crime trials 47	Tuskegee syphilis study 48

/// HIGHLIGHTS

- Milgram's obedience experiments led to intensive debate about the extent to which deception could be tolerated in psychological research and how harm to subjects should be evaluated.
- Egregious violations of human rights by researchers, including scientists in Nazi Germany and researchers in the Tuskegee syphilis study, led to the adoption of federal ethical standards for research on human subjects.
- The 1979 *Belmont Report*, developed by a national commission, established three basic ethical standards for the protection of human subjects: (1) respect for persons, (2) beneficence, and (3) justice.
- The Department of Health and Human Services adopted the Federal Policy for the Protection of Human Subjects in 1991. The policy requires that every institution seeking federal funding for biomedical or behavioral research