CHAPTER 3

THE ETHICS OF SOCIAL RESEARCH

THE TUSKEGEE SYPHILIS STUDY

The Tuskegee Syphilis Study was conducted by the United States Public Health Service (USPHS) beginning in 1932. The study examined untreated cases of latent syphilis in human subjects to determine the "natural course" of the disease. Three hundred and ninety nine black males from Tuskegee, Alabama, who already had late-stage syphilis, were recruited for this study along with a matched sample of 201 noninfected males. The subjects were not asked to provide their informed consent in order to participate in this project. Those infected with syphilis in the early 1930s were given the standard treatment at that time, which consisted of administering heavy metals. However, those men participating in the study were, not treated. In fact, the doctor in charge of the study noted "everyone is agreed that the proper procedure is the continuance of the observation of the negro men used in the study with the idea of eventually bringing them to autopsy" (Jones, 1993, p. 132). However, when antibiotics became available in the 1940s and it was evident that this treatment would improve a patient's chances for recovery, antibiotic treatment was withheld from the infected subjects, even though the researchers knew that if left untreated the disease would definitely progress to increased disability and eventually early death. According to some reports, "on several occasions, the USPHS actually sought to prevent treatment" (Heintzelman, 1996, p. 49). The experiment lasted over four decades, and it was not until 1972, in large part prompted by exposure from

the national media, that government officials finally ended the experiment. By that time "74 of the test subjects were still alive; at least 28, but perhaps more than 100 had died directly from advanced syphilis" (p. 49). There was a government investigation of the entire project launched in mid 1972, and a review panel "found the study 'ethically unjustified' and argued that penicillin should have been provided to the men" (p. 49).

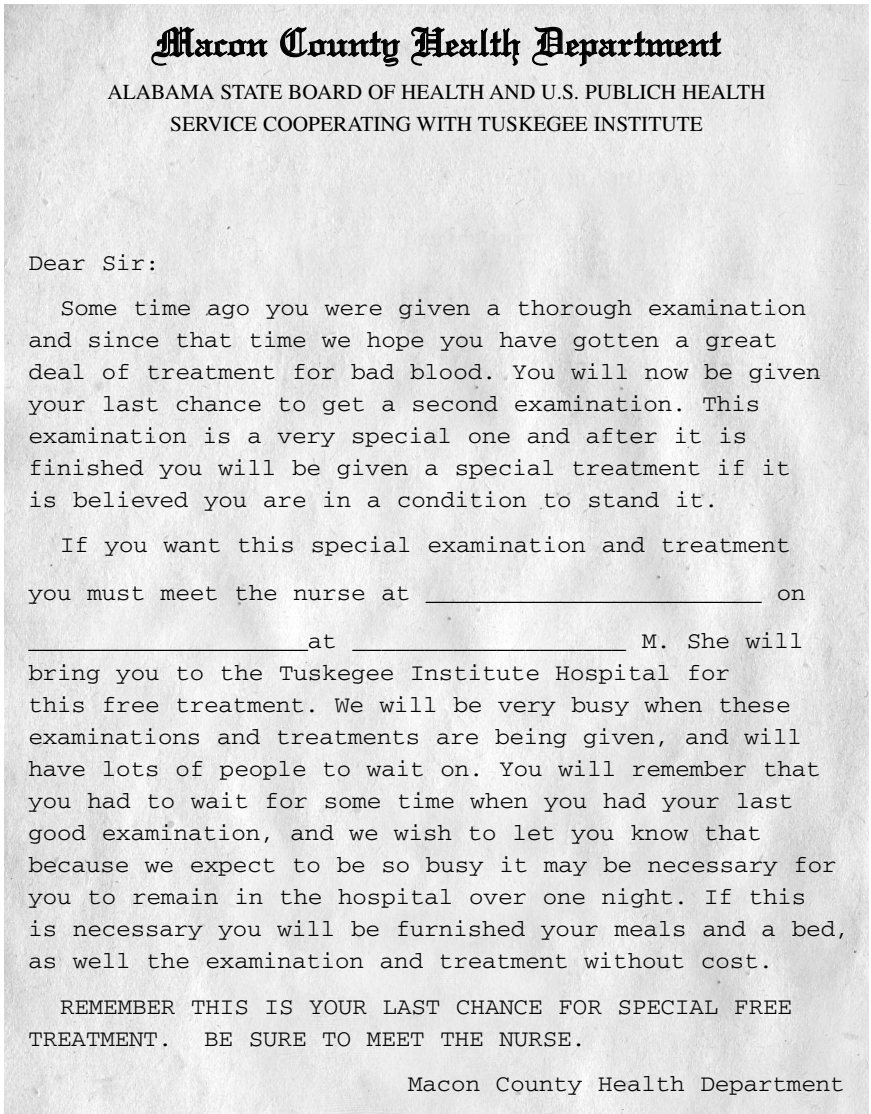
● ETHICAL LESSONS LEARNED FROM THE TUSKEGEE BIOMEDICAL EXPERIMENT: INFORMED CONSENT

At no time in the course of this project were subjects asked to give their consent to participate in the study. They were not told about the particulars of what the study would entail. In fact, those who participated did not volunteer for the project! Instead, they were deceived into thinking that "they were getting free treatment from government doctors for a serious disease. It was never explained that the survey was designed to detect syphilis . . . Subjects were never told they had syphilis, the course of the disease, or the treatment, which consisted of spinal taps" (p. 51). We have reproduced a copy of the original recruitment letter that was first issued in 1933 from the "Macon County Health Department" and the "Alabama State Board of Health and U.S. Public Health Service cooperating with Tuskegee Institute." As you read this letter you will notice that it makes no mention of spinal taps as a standard treatment, but instead claims subjects will receive "special treatment," and even have "people wait on you." You can imagine if you are living in dire poverty and with a serious illness, this letter might seem like a "gift" of life.

In his book *Bad Blood: The Tuskegee Syphilis Experience,* author James Jones notes that the subjects in the Tuskegee experiment had a blind trust in the medical community. As one subject from the experiment notes:

> We trusted them because of what we thought they could do for us, for our physical condition . . . We were just going along with the nurse. I thought [the doctors] was doing me good. (Jones, 1981, as cited in Heintzelman, 1996, p. 50)

There is also a question of whether or not the researchers took advantage of a vulnerable population whom they knew did not have the resources to afford medical treatment or the education to question their medical expertise. In addition, the researchers' stereotypical racist attitudes about black males made it easier to justify their decision to not provide them with treatment:



Macon County Health Department

ALABAMA STATE BOARD OF HEALTH AND U.S. PUBLICH HEALTH SERVICE COOPERATING WITH TUSKEGEE INSTITUTE

Dear Sir:

Some time ago you were given a thorough examination and since that time we hope you have gotten a great deal of treatment for bad blood. You will now be given your last chance to get a second examination. This examination is a very special one and after it is finished you will be given a special treatment if it is believed you are in a condition to stand it.

If you want this special examination and treatment you must meet the nurse at _____ on _____at _____ M. She will bring you to the Tuskegee Institute Hospital for this free treatment. We will be very busy when these examinations and treatments are being given, and will have lots of people to wait on. You will remember that you had to wait for some time when you had your last good examination, and we wish to let you know that because we expect to be so busy it may be necessary for you to remain in the hospital over one night. If this is necessary you will be furnished your meals and a bed, as well the examination and treatment without cost.

REMEMBER THIS IS YOUR LAST CHANCE FOR SPECIAL FREE TREATMENT. BE SURE TO MEET THE NURSE.

Macon County Health Department

This letter is reproduced from an educational website at the University of Illinois's Poynter Center for the Study of Ethics and American Institutions (http://poynter.indiana.edu/sas/lb/facts.html.)

> The rationale was that the conditions existed "naturally" and that the men would not have been treated anyway, according to the premise that shaped the study—that African Americans, being promiscuous and lustful, would not seek or continue treatment. (Brandt, as quoted in Heintzelman, p. 49)

Poor decisions on the part of the researchers, influenced by bigotry, allowed this to happen. But this kind of research is simply unacceptable. It demonstrates how racism can lead to inhuman treatment of human subjects. It is argued that the effects of this experiment have to some extent created a long-lasting impact on the black American community, casting a "long shadow on the contemporary relationship between African Americans and the biomedical community" (Gamble, 1997, p. 1773).

● THE CENTRALITY OF ETHICS IN THE RESEARCH PROCESS

Ethical discussions usually remain detached or marginalized from discussions of research projects. In fact, some researchers consider this aspect of research an afterthought. Yet, the *moral integrity* of the researcher is a critically important aspect of insuring that the research process and a researcher's findings are "trustworthy" and valid.

The term *ethics* derives from the Greek word *ethos* which means *character*. To engage with the ethical dimension of your research requires asking yourself several important questions:

- What moral principles guide your research?
- How do ethical issues enter into your selection of a research problem?
- How do ethical issues affect how you conduct your research—the design of your study, your sampling procedure, etc.?
- What responsibility do you have toward your research subjects? For example, do you have their informed consent to participate in your project? What ethical issues/dilemmas might come into play in deciding what research findings you publish? Will your research directly benefit those who participated in the study?

A consideration of ethics needs to be a critical part of the substructure of the research process from the initial conception of your problem to the interpretation and publishing of the research findings. Yet this aspect of the research process does not often appear in the diagrams of the models of research we discussed in Chapter 2. A brief history of the ethical aspects of research will better help us understand why this still remains the case.

● A BRIEF HISTORY OF RESEARCH ETHICS

Formal consideration of the rights of research subjects grew out of the revelations of the terrible atrocities that were performed in the guise of scientific

research on Jews and other racial and ethnic minority groups in Nazi concentration camps during World War II. One result of the revelations of these appalling medical experiments perpetrated *in the name of science* resulted in the creation, in 1949, of the *Nuremberg Code,* a code of ethics, which starts off with the stipulation that all research participation must be voluntary. Other codes of ethics soon followed, including the *Declaration of Helsinki* (1964). This code was specifically developed "in part as an alternative to the Nuremberg Code, which dealt exclusively with nontherapeutic [research promising no direct benefit to the subject] research" (Alvino, 2003, p. 896). This code protects research subjects in both therapeutic and nontherapeutic contexts. The Declaration of Helsinki notes several central procedures that should be applied in biomedical research:

> Every biomedical research project involving human subjects should be preceded by careful assessment of predictable risks in comparison with foreseeable benefits to the subject or to others . . . The right of the research subject to safeguard his or her integrity must always be respected. Every precaution should be taken to respect the privacy of the subject and to minimize the impact of the study on the subject's physical and mental integrity and on the personality of the subject. (p. 896–897)

The Council for International Organization of Medical Sciences (CIOMS) was also created for those researching in developing nations (Beyer & Kass, 2002). Throughout the history of scientific research, ethical issues have captured the attention of scientists and the media alike. While extreme cases of unethical behavior are the exception not the rule in the scientific community, an accounting of these projects can provide important lessons for understanding what can happen when the ethical dimension of research is not considered holistically within the research process.

GUIDELINES AND LAWS GOVERNING THE RESEARCH PROCESS ●

Unfortunately, when the Tuskegee experiment began, there was no institutional review board (IRB) to oversee the goals of the project. It was not until the mid 1960s that the federal government began the process of developing a set of "official rules" governing the treatment of research, partly in response to such medical abuses as the Tuskegee experiment and others (see Beecher, 1966; Jones, 1981), which ultimately led to the passage by Congress in 1974 of the National Research Act. This act set up an Office for the Protection of

Research Risks (OPRR) and was housed in the National Institutes of Health (NIH). The act called for the establishment of a "Commission on Protection of Human Subjects of Biomedical and Behavioral Research" (Alvino, 2003, p. 897). These ethical principles were released by the Commission in 1978 in a report known as the "Belmont Report," which was later revised to incorporate additional protections for young children who participate in the research process (p. 898). In 1991, these revised guidelines, known as the Common Rule, received widespread adoption by federal agencies (p. 898). The Common Rule mandated, among other things, that any institution receiving federal funds for research must establish an institutional review committee. These committees, known as *Institutional Review Boards* (IRBs), have the job of watching over all research proposals that involve working with human subjects and animals. Universities and colleges, for example, that receive federal funding for research on human subjects are required by federal law to have review boards or forfeit their federal funding. IRBs are responsible for carrying out U.S. government regulations for human research. They must determine whether the benefits of a study outweigh its risks; that consent procedures have been carefully carried out and that no one group of individuals has been unfairly treated or left out of the potential positive outcomes of a given study (Beyer & Kass, 2002). This is, of course, important in a hierarchically structured society where we can't simply assume racism, sexism, homophobia, and classism won't make their way into research. Certain types of research, for example, educational research dealing with "instructional strategies," may have an "exempt status" and a full review by an IRB may not be required (DHHS, 1989).

It is noteworthy that, over the course of more than four decades, even after the USPHS had finally set up a Code of Research Ethics for the treatment of research subjects, the Tuskegee experiment was still allowed to continue (Heintzelman, 1996, p. 52). This raises questions about how effective and accountable research projects are to IRBs as well as about the effectiveness of the range of professional ethics codes that are part of most professional associations and currently serve as guidelines for conducting research (see for example the American Sociological Association, 1992; the American Psychological Association, 1981, see the APA website, http://www.apa.org/ethics/homepage.html).

● HOW WELL ARE RESEARCH SUBJECTS PROTECTED TODAY?

It has been over thirty years since the government issued its regulations for protecting human subjects in research studies receiving federal funding, yet

there continue to be cases involving human subjects that have resulted in harm and death. As one researcher notes: "The history of research involving human subjects has been described by ethicists as one of 'progress propelled by scandal'" (Alvino, 2003, p. 895). Concerning the current scandals in the field of biomedical research, Alvino says:

> . . . the highly publicized death of Jesse Gelsinger, a research subject who died as a result of his participation in a gene therapy trial at the University of Pennsylvania, aroused significant media attention and public concern regarding the safety of clinical trials. His story is far from unique . . . Medical research suffered another blow . . . when it was discovered that researchers and pharmaceutical companies involved in research at Cornell and Tufts had failed to notify the National Institutes of Health that six gene therapy research subjects had died during experiments over a nineteen-month period. (p. 902)

At the center of many of the debates regarding the protection of human subjects is the question of whether informed consent procedures are *sufficient* to protect human subjects, and the ability of IRBs to *oversee the research process* in their home institutions. Why didn't the IRBs report the deaths of research subjects to the federal agencies involved in funding these projects? Were the research subjects given proper information regarding the side effects of the study? In the case of Jesse Gelsinger, he was an 18-year-old college student at the time he participated in the University of Pennsylvania study in 1999. An investigation of his death showed that (1) he in fact was not a good candidate for the study in the first place, and (2) he was not provided with adequate information concerning the extreme adverse side effects that other participants in the study had experienced (p. 908). Jesse's father notes: "[I]t looked safe. It was presented as being safe . . . I was misled" (*Chicago Sunday Times*, Feb 3, 2000, p. 23). This has too often been the case.

Professional associations such as the American Educational Research Association (AERA), the American Sociological Association (ASA), and the American Psychological Association (APA) also outline general ethical guidelines for their members. Each of these associations has a website that discusses a range of specific ethical concerns in each of these professions. The American Psychological Association's website (http::://www.apaorg/ethics/code2002.html) for example, outlines specific ethical categories of conduct, from general principles of professional conduct that deal with issues such as integrity and justice to more practice-specific concerns such as privacy and confidentiality of patients and research subjects. There are also ethical guidelines on record keeping and fees as well as ethical guidance on issues that

may come up in a therapeutic situation, such as those especially pertaining to sexual intimacy with clients and therapy with former sexual partners. There are also guidelines for resolving ethical issues, such as how to handle complaints and discrimination.

Thus far we have been focusing on biomedical research. To what extent do the ethical issues in the sciences carry over into the *behavioral* and *social* sciences? Researchers conducting biomedical studies often present a "protocol" that outlines the specific steps they will follow in conducting research on human subjects. Qualitative research is, by its very nature, open to discovery and change in research goals. It may be nearly impossible for the qualitative researcher to account for all of the happenings in the research setting, and it may be hard to go back and forth to a Human Subjects Committee (like an IRB) for approval each time a project takes an unexpected turn. Adler and Adler (2002) argue that obtaining informed consent hits those researchers practicing participant observation the hardest:

> Participant observation has a fuzziness about what is research and what is not, as ethnographers are observers of everyday life and may be generating insights and gathering data from people in all kinds of situations (a waitress at a restaurant, a fellow passenger on an airplane, a person whose child is the same age as one's own). They may not know in advance what information will drift their way and that may prove explicitly useful, either currently or in the future. (p. 40)

In addition, there is often a very personal engagement with research subjects that is often not found to the same extent in biomedical research, raising even more prominently the possibility of undue power, influence, and authority being wielded in the research process.

There are some "classic" examples of extreme violations of ethics in the annals of behavioral and social scientific research as well. Perhaps one of the most egregious comes from a 1963 research project on "obedience to authority," conducted by psychologist Stanley Milgram. Milgram wanted to understand the conditions under which individuals obey authority figures. His research protocol called for deceiving volunteer subjects into thinking they were involved in an experiment on the impact of punishment on memory. Volunteers first read a series of word associations to the individuals (confederates) under a variety of experimental conditions: (1) where they could not see or hear the confederate; (2) they could hear the confederate protest but not see the confederate; (3) they could hear and see the confederate; (4) same conditions as (3) except the subject was required to place the confederate's hand on a shock plate. If confederates were unable to repeat the

words, volunteers were asked to administer an "electric shock" to them, increasing the voltage for each wrong answer in order to enhance learning. Subjects had a fake voltage meter in front of them with readings "from slight to severe shock," with a sign warning of the danger in using the equipment posted next to the meter. Some subjects protested upon hearing confederates complain about pain and other medical problems. Even though some volunteers wanted to quit the experiment, the researcher in charge insisted that they continue, saying that he (the researcher) would take responsibility. Some subjects, however, did not protest and even went on to administer what they considered the "highest," most lethal, shock to a confederate, even when they had received no feedback that the person was even alive (Milgram, 1963).

Stanley Milgram's experiment deceived his volunteer subjects and failed to obtain their informed consent. The protocol of this experiment did not allow subjects to quit even when some protested and asked that it be stopped. In addition, some subjects experienced psychological distress knowing they actually could administer what would be considered a lethal shock to another human being.

THE ETHICAL DILEMMA OF COVERT RESEARCH ●

Some researchers argue that their research must be conducted in a "covert" manner in order to obtain the information they need to understand certain social phenomena. For example, researchers have gone undercover to study such underground cultures as the drug culture (see Williams, 1996) and used deception in order to find out about the inner workings of the social life of drug dealers and drug takers, often observing individuals engaging in illegal activities and sometimes finding themselves asked to engage in these same activities. There would be no point in asking for the informed consent of the members of this closed society, since they would most likely not want their organization studied. Williams, who did participant observation on a subculture of cocaine users and dealers in the after-hours clubs in an inner city, notes the following concerning his undercover activities:

> I was in a Brooklyn club where I was already conspicuous as a nonuser of cocaine. It seems that I was also overzealous. In the sense that I was staring too much and asking too many questions. One of the club's owners came over to me and said "Listen, my man, if you're undercover, I got people that'll take care of that." I was not sure whether he meant force or bribery, but in any case I stopped going to that club . . . As a researcher,

> I knew what data I needed: information on cocaine users and the associated nightlife, street myths about use . . . But as most researchers know there is a quid pro quo in every research situation . . . I was asked to do a variety of favors, such as lending money and finding social workers . . . On many occasions I was asked to engage in illegal acts. . . . This and similar requests put me in an awkward position. (Williams, p. 30)

- Is it ethical to go undercover?
- Is it ethical to engage in illegal activities under the guise of research?

One can imagine those social scientists studying deviant behaviors, such as life in the underground drug trafficking world, and how difficult it might be to obtain the informed consent of everyone involved in order to study the inner workings of the illicit drug trade.

- What does the researcher do when he or she confronts information or situations where individuals are observed to engage in major violations of the law?
- Is the researcher ethically obligated to report such activity?
- What about the risks the researcher is taking in terms of his or her own life if they do so?

Deception in research doesn't have to occur by going "undercover" in carrying out research projects. The Milgram experiment was a study in deception. From the start, Milgram did not truthfully explain the nature of the experiment, and he deceived subjects into thinking they were in fact applying electrical shocks to another human being. Some qualitative social science research methods, like fieldwork, also require some type of deception between the researcher and the researched. Sociologist Herbert Gans, conducting fieldwork in Park Forest, a suburb near Chicago, in Boston's West End, and in Levittown, a New Jersey suburb, relates his personal reflections on the anxiety he experienced in what he finds is "the deception inherent in participant observation":

> Once the fieldworker has gained entry, people tend to forget he is there and let down their guard, but he does not; however much he seems to participate, he is really there to observe and even to watch what happens when people let down their guard. He is involved in personal situations in which he is, emotionally speaking, always taking and never giving, for he is there to learn and, thus, to take from the people he studies, whereas they are always giving information, and are rarely being given anything. Of course they derive some satisfaction from being studied, but when they ask the participant observer to give—for example, help or advice—he

> must usually refuse in order to maintain his neutrality. Moreover, even though he seems to give of himself when he participates, he is not really doing so and, thus, deceives the people he studies. He pretends to participate emotionally when he does not; he observes even when he does not appear to be doing so and like the formal interviewer, he asks questions with covert purposes of which his respondents are likely to be unaware. In short, psychologically, the participant observer is acting dishonestly; he is deceiving people about his feelings and in observing when they do not know it, he *is* spying on them. (Gans, 1982, p. 59)

Herbert Gans represents a particular point of view on the role of the researcher as participant in the fieldwork experience. The idea that the researcher should remain neutral and "detached" from the research subject tells us that he or she aspires to the goal of "objectivity" in the research process. This objectivity then is enhanced by deception. Yet, as we have seen, this frame on the research process is one of many *paradigms* one can bring to the fieldwork experience. There are those who believe the researcher does not need to maintain distance between the researcher and the researched. Ann Oakley (1981), in fact, critiques this model of neutrality and instead argues for bridging this divide through empathy and affinity. Other ethnographers feel that this form of closeness between researcher and researched also has its problems and that one can become too close to respondents. This in turn can create a series of conflicts and deceptions. Ethnographer Judith Stacey comments:

> . . . the irony I now perceive is that the ethnographic method exposes subjects to far greater danger and exploitation than do more positivist, abstract, and "masculinist" research methods. And the greater the intimacy—the greater the apparent mutuality of the researcher/researched relationship—the greater is the danger. (1991, p. 114)

Stacey notes that the further involved she became with her respondents the further exposed she became to situations within the field that left her open to the possibility of manipulating and betraying her respondents (p. 113). So we can see that issues of disclosure and trust are actually very complex.

Some might argue that a certain amount of "strategic" deception is needed when researchers are especially interested in "studying up" (see Korn, 1997). The study of elites is not a common practice within the social sciences (for exceptions, see Hertz & Imber, 1995, and Odendahl & Shaw, 2002). The elite and semi-elite population hold key positions within society, yet their

activities and power remain invisible to the average citizen. Elites often protect their privacy through a myriad of self-imposed barriers, ranging from unlisted phones and email accounts to the hiring of staff to screen their calls and contacts and security personnel to prevent unwanted contact with those outside their elite culture. Adler and Adler (2002) note that current IRB and professional associations who fear lawsuits have developed codes of ethics that now ban all aspects of covert research, using the argument that it is almost impossible to obtain informed consent. In addition, these boards cannot protect the researcher from revealing the identity of their respondents if they are asked to do so by officials investigating their research findings. Adler and Adler (2002) note:

> Clearly, if we are being told that we cannot protect our own subjects from official investigation short of our or their going to jail, which not everyone is willing to do, some changes are necessary. Is the new system the best way? If you fundamentally shut down research there is no risk to subjects because researchers will not know anything. (Adler and Adler, 2002, p. 42)

Johnson and Altheide (2002) reflect on professional ethics, given their 65 years of combined experience as university scholars. They note the lack of legal protection of social scientists regarding the confidentiality of their sources as a "political" and not a moral issue:

> In the United States, the first amendment of the constitution protects journalists by guaranteeing free speech and a free press. Social scientists lack such protection regarding confidentiality of sources, however, and we surmise that this is best seen as a political, rather than a moral one. If social scientists had such protection, we speculate that we might be addressing a different set of ethical issues—perhaps ones such as how social scientists abuse their constitutional protection. (p. 69)

Adler and Adler (2002) argue that ethics boards have overstepped their function, which has resulted in the unanticipated outcome of favoring the dominant classes over the weaker: "Powerful, elite groups can now better hide their mechanisms of control, while weak and powerless groups have lost the ability to tell their stories from their own perspective" (p. 40). These researchers lament the fact that covert research, such as that done by Erving Goffman in his classic work, *Asylums,* which provides readers with a bird's eye view of the treatment of the mentally ill by those who care for them, and that carried out by Gary Marx (Marx, 1988) on the activities of control

agencies such as the police, will no longer be possible under the new ethics guidelines.

Haggerty (2004) has identified what he terms an "ethics creep" that has taken over social science research "in the name of ethics." He defines this term as follows: "This is characterized by a dual process whereby the regulatory system is expanding outward to incorporate a host of new activities and institutions, while at the same time intensifying the regulation of activities deemed to fall within its gambit" (p. 391).

RESEARCHER FOR SALE?: CONFLICTS OF INTEREST IN THE RESEARCH PROCESS

Academics are under financial pressures from their universities to obtain grants for research. More and more of these grants are coming from commercial institutions such as drug companies:

> The sharp increase in privately funded (i.e., industry sponsored) research has created an atmosphere that breeds conflicts arising from compelling financial incentives. These conflicts may arise from researchers' financial relationships with companies whose products they are studying, whether the research is sponsored by the government or by the company itself. (Alvino, 2003, p. 906)

In some cases, universities are becoming enmeshed with industrial research interests. Angell (2000) points out the problem of academic medicine being "for sale." She notes:

> Academic medical institutions are . . . increasingly beholden to industry . . . Some academic institutions have entered into partnerships with drug companies to set up research centers and teaching programs in which students and faculty members essentially carry out industry research. Both sides see great benefit in this arrangement. For financially struggling medical centers, it means cash. For the companies that make the drugs and devices, it means access to research talent, as well as affiliation with a prestigious brand. (p. 1516)

It is possible that in some cases members of a university's own IRB boards can have a vested interest in the very studies they have oversight on. Alvino notes:

> Although IRB members are supposedly foreclosed from participating in review of any project or study in which they have a conflicting interest . . . there is no way to ensure that the research facility or individual researchers are not operating under such conflicts. (2003, p. 902)

An article in the *L.A. Times* cited a Yale University study which remarked that "one quarter of the biomedical researchers at universities had commercial ties serious enough to raise questions of financial conflict" (Hotz, 2003, p. 14, as cited in Alvino, 2003, p. 902).

- What are the ethical implications of accepting funding for research?
- How can academics and IRBs work together most effectively?
- How can funding sources, such as the National Science Foundation (NSF) or The National Institute of Mental Health (NIMH), help alleviate the tensions between funding research and ethics?

● ETHICAL DILEMMA: DIVIDED LOYALTIES

Bell and Nutt (2002) talk about their "divided loyalties" in terms of how their professional and occupational commitments pull them in many different directions, creating ethical dilemmas arising from the multiple roles they bring to a research setting. Linda Nutt describes how her professional role as a social work practitioner who is "bound by general social work codes of practice" (p. 79) conflicted with her role as researcher:

> As she was leaving the home of a new carer following the research interview Linda Nutt noticed an unambiguously sexually explicit picture in the hallway. For most researchers this would not be an issue; art is a matter of personal taste. But Linda Nutt wasn't just a researcher she was also a practitioner. Frequently when children are placed in foster homes little is know about their life experiences so new carers are instructed to assume that all children have been sexually abused unless specifically told otherwise . . . There is a statutory responsibility to disregard confidentiality where children are at risk. Nonetheless, because she wanted to keep the roles clear and separate—to act as a researcher (and be in receipt of information) and not as an employee . . . (who could give then information), Linda Nutt chose not to tackle this issue with these new careers but spent several days considering this ethical dilemma. In the end the social worker practitioner identity overcame that of the researcher identity and Linda Nutt informed the local authority of her unease regarding the picture and its potential impact upon the foster children. (p. 79)

Some researchers employ research techniques that raise ethical issues regarding how human subjects are treated. Homan notes what he calls the "softening up" techniques to get at more personal information from respondents who may be unwilling to talk:

> The insidiousness of softening-up techniques is demonstrated by some impertinent questions reserved for the latter and more compliant stages of the interviews and questionnaires: having scrupulously sought and obtained a general consent from respondents and their parents. (1992, p. 328)

By its very nature, qualitative research often requires emotional engagement with those with whom we build knowledge. Jean Duncombe and Julie Jessop (2002) discuss how some researchers can lack sympathy for their respondents and "fake" their interest and concern for those they research. Jean Duncombe describes how she wound up treating some of her respondents in a research project she was conducting:

> . . . we found it more difficult to achieve rapport where we did not spontaneously feel empathy with our interviewees. For example in an early study of Youth Training Schemes (YTS), Jean felt she established a "genuine," if shallow rapport with the YTS trainees and with the more conscientious employers who took training seriously, because she was "on their side." But with the more exploitative employers and trainers (who provided neither jobs nor training), she knew she was faking rapport to "betray" them into revealing their double standards, and sometimes whilst smiling at them she almost smiled to herself, thinking: "What a revealing quote" . . . Julie felt uncomfortable and personally compromised when she found that, in order to obtain a "good" interview, it seemed necessary to smile, nod and appear to collude with views she strongly opposed. (Duncombe & Jessop, 2002, p. 115)

Researchers are human just like everyone else. Accordingly, we all bring our own likes, dislikes, emotions, values, and motivations to our research projects. It is unrealistic to expect that you will always like those you research, or that you will always naturally feel 100% engaged. This being said, bear in mind that it is you, the researcher, who has initiated this process and involved others (your subjects). Consider this carefully as you contemplate your ethical obligations to your research participants, but as you think through these issues, do so with your own "humanness" in mind—be realistic and fair to all involved.

● IS INFORMED CONSENT THE SOLUTION FOR ETHICAL ABUSES IN RESEARCH?

A major principle underlying many of the ethical policies which have historically grown up around the issue of how to treat research subjects has been the use of "informed consent," the right of subjects to decide anonymously whether they will be involved in a research endeavor (Faden & Beauchamp, 1986). Some ethicists question the extent to which informed consent has lived up to the promise of anonymity for research subjects (Cassileth, Zupkis, Sutton-Smith, & March, 1980). Research has pointed out that subjects do not always understand the medical aspects of the clinical project they are participating in, and some do not even know that they may in fact be participating in a research trial (Lynoe, Sandlund, Dahlqvist, & Jacobsson, 1991; see also Appelbaum, Roth, Lidz, Benson, & Winslade, 1987). As we have seen earlier in this chapter, there are many instances in which there is failure to fully disclose to research subjects the full extent of the risks and benefits of participating in a study, and this has led to some disastrous research outcomes for some of those who participated in clinical trials and biomedical research. There is, then, a *practice* and a *reality* to providing informed consent. There exists a wide variation in how well researchers carry out the policy of informed consent in their ongoing research projects. For example, we present two types of letters on informed consent a researcher might write to parents regarding their child's participation in a research project on body image. Wee observe that "Letter A" contains a much more detailed account of the research problem, including several research goals and an explanation of how the research will be carried out.

Letter "A"

Dear Parents:

My name is _____ and I am a Sociologist and teacher at _____College. I have previously conducted several studies on self-esteem in young girls. Currently, I am conducting a study on body image and self-esteem among African American and white pre-teen and adolescent girls. I firmly believe that it is essential to include a sample of African American girls. It has been my experience that the attitudes and beliefs of this important group have been all too often left out. They need a voice and this is why I am writing to you today, to ask for your help and permission to interview your daughter. I would also like to take a moment to tell you a little more about the study.

I plan on having the girls meet at the Health Center for pizza and soda after school in groups of three or four to chat about self-esteem and body image. If your daughter chooses to participate, with your permission, the interview will take no more than 45 minutes and her participation will be completely voluntary.

This research project will study pre-teen and adolescent attitudes about body image and self-esteem. Some of the questions that we will explore are:

1. From whom and where do pre-teens learn perceptions of body image and self-esteem? For example, what role do peers and the mass media play in influencing pre-teens' and adolescents' attitudes about their weight and body image?

2. What factors (if any) appear to "protect" pre-teen and adolescent girls against feelings of low self-esteem, and what factors (if any) contribute to a depressed sense of body esteem?

I envision this study as a unique opportunity. As I said earlier, we need to give young black women and the black community a stronger voice. I believe that my project can accomplish that. Yet even more importantly, I believe that providing an opportunity for the girls to get together to chat with friends and peers about issues of black identity and self-esteem will serve as a mechanism for black female empowerment.

Attached you will find a consent form which, upon agreement, is to be signed by your daughter and yourself and brought to the Health Center the day of the interview.

If you have any questions or concerns, please feel free to call me at home: _____ or work: _____.

Thank you for your time and I look forward to hearing from you soon.

Sincerely,

_____ Ph. D.
Chair, Department of Sociology
Professor

* * * * *

CONSENT FORM

I, _____ , understand that I will be a participant in Dr. _____research project on body image and self-esteem among white and African American pre-teens and adolescents.

I also understand that my participation is completely voluntary and that if I feel it necessary, that I may discontinue the interview at any time.

Taking into account all that has been said above, I, _____ , agree to give you, _____, my interview, trusting that all information shall be kept strictly confidential.

* * * * *

If the maker of the above agreement is under the age of 18, this consent form must also be signed by their parent/legal guardian.

I, _____ , understand that my daughter, _____ , has in the above lines, agreed to participate in Dr. _____ research project on body image and self-esteem among white and African American pre-teens and adolescents.

I also understand that her participation is completely voluntary and that, if my daughter or I feel that she should discontinue the interview, she may do so at any time.

Taking into account all that has been said above I, _____ , give you Dr. _____, permission to interview my daughter, trusting that all information shall be kept strictly confidential.

"Letter B" is much shorter and provides few details concerning the research goals, and, from it, it would be difficult to ascertain very much about the substance of the research project goals.

Letter "B"

Dear Parents:

My name is _____ and I am a Sociologist and teacher at _____ College. I am conducting a study on body image and self-esteem among African American and white pre-teen and adolescent girls.

I plan on having the girls meet at the Health Center for pizza and soda after school in groups of three or four to chat about self-esteem and body image. If your daughter chooses to participate, with your permission, the interview will take no more than 45 minutes and her participation will be completely voluntary.

Attached you will find a consent form which, upon agreement, is to be signed by your daughter and yourself, and brought to the Health Center the day of the interview.

I appreciate the opportunity to interview your daughter. If you have any questions or concerns, please feel free to call me at home: _____ or work: _____.

Thank you for your time and I look forward to hearing from you soon.

Sincerely,

* * * * *

CONSENT FORM

I, _____, understand that I will be a participant in Dr. _____ research project on body image and self-esteem among white and African American pre-teens and adolescents.

I also understand that my participation is completely voluntary and that, if I feel it necessary, I may discontinue the interview at any time.

Taking into account all that has been said above, I, _____ , agree to give you, _____, my interview, trusting that all information shall be kept strictly confidential.

* * * * *

If the maker of the above agreement is under the age of 18, this consent form must also be signed by their parent/legal guardian.

I, _____, understand that my daughter, _____, has, in the above lines, agreed to participate in Dr. _____ research project on body image and self-esteem among white and African American pre-teens and adolescents.

I also understand that her participation is completely voluntary and that if my daughter or I feel that she should discontinue the interview, she may do so at any time.

Taking into account all that has been said above I, _____, give you, Dr. _____, permission to interview my daughter, trusting that all information shall be kept strictly confidential.

"Letter B" contains the minimum information that can be given to respondents. Both letters insure respondent *confidentiality,* that is, their names cannot be used in any written material concerning the research or in discussions of the research project, and interview materials will also be stored in a safe place free from disclosure. This means the researcher and others working on the project will not know the identity of the respondent, for example, a respondent will returns a survey questionnaire with no name on it.

These letters, however, point up some of the *political dimensions* involved in creating an informed consent letter.

- Why do researchers differ in how much they reveal of research project goals?

It may not always be in the interest of the researcher to be forthcoming regarding full disclosure. Some researchers may even go out of their way to

explain the research project as a "*cover story*," and this may be built into the original design of the research project:

> The selection or invention of details to constitute the cover story and convince intended respondents is an element in the design of a research project. That requires skills of persuasion. Investigators develop a sense of what details allay fears and what prompt suspicions. As in other types of negotiation, such as bargaining over salaries, the initiating party uses a gambit declaring a position which it may concede and which supposes an opposition of interests between the negotiating parties. The investigator will reveal further information if required but in many cases subjects will not be briefed to ask pertinent questions and the project will move on quickly from negotiation to interview. (Homan, 1992, p. 324)

If respondents initially refuse to participate in a research project, rather than accepting the right of the researched to act autonomously, this is often viewed as a failure on the part of the researcher, and there is a tendency of the researcher to break down "the defenses of respondents" through a variety of means, from group pressure to exploitation of friendships. To this issue, Homan says:

> In various ways research projects trade upon a relationship with agencies in power or authority. Sutherland was able to research the secretive and exclusive Rom community, which was normally hostile to representatives of the world outside it by exploiting her role as teacher of its children. (p. 325)

There are even times when following ethical guidelines may not always be in the best interests of your research respondents. Baez points out the ethical conundrum he experienced in maintaining the *confidentiality* of his respondents. Baez interviewed 16 minority faculty members regarding their personal experiences with the tenure and promotion process at one private university. He notes that maintaining confidentially can be a double-edged sword. Keeping the interviews confidential, especially for untenured faculty, allowed him to obtain candid data regarding racism and sexism within this university. On the other hand, confidentiality prevented him from reporting " . . . serious contradictions within an institution that, through institutional documents and public comments by key administrators, purported to be supportive of racial and cultural diversity . . . I could not do so without feeling that I would be identifying my respondents to others in the institution" (2002, p. 39). Bear in mind that you often don't know what your research will

teach you, and it can be very difficult not to try and effect social change in some situations.

Patton (2002) notes that respondents are now maintaining their right to "tell their stories" (p. 411) without hiding their identities, especially when they see the project as an opportunity to gain empowerment through telling their stories and perhaps becoming a catalyst for social change. Patton suggests a number of important ethical dilemmas that flow from this new viewpoint on confidentiality:

- Should the researcher "impose confidentiality against the wishes of those involved?"
- Are human subjects committees "patronizing and disempowering" if they turn down those respondents who wish to reveal their identities?
- Does the research subject make the choice independent of others in their social context? What about the privacy of significant others in their lives, such as children, spouse, and extended family members? (p. 411)

Beyond all of these considerations, some researchers are very cognizant of ethics in practice, attempt to use informed consent, and still experience challenges. Sarah Maddison is a feminist sociologist at the University of New South Wales in Australia where she focuses on gender and social policy. Maddison encountered several problems when trying to use informed consent in her ethnographic work with a feminist student group. Let's join Maddison behind the scenes.

Behind-the-Scenes With Sarah Maddison

A couple of years ago I was engaged in project researching a group of young student feminists drawn from various university campuses in New South Wales. The Cross Campus Women's Network (CCWN) was a loose coalition of women who met on a fortnightly basis. At each meeting there would be between five and 10 women and, with the exception of the convenor, these could often be a different group of women each fortnight. It was this changing roll call at each meeting that created a major obstacle for the ethical conduct of this research: although I had carefully explained the purpose of my research and sought permission to attend and participate the first time I went along, there were women at subsequent meetings who missed out on my spiel and became very suspicious of my presence and my intentions.

(Continued)

(Continued)

So they kicked me out! The convenor emailed me and asked me not to attend any more meetings until they had resolved this issue between themselves (apparently there were differing views about the merits of my research within the group). I was allowed to send an email to the group explaining myself again and then I just had to sit and wait. Time to reflect on power (shared), clarity (and confusion) and consent (given—and taken away again).

I have to say I felt pretty foolish—but in actual fact it was my fear of *appearing* foolish that had put me in this situation to begin with. As a researcher wanting to begin the "participant" part of the participant observation process I was reluctant to continually draw attention to my researcher status by outlining my project every time I saw a new face. I really wanted to blend into the group and participate in meetings like I was "one of them" not an outsider. More than anything I wanted them to forget what I was doing there so that I could somehow observe, participate and consume what "really" went on in their meetings. I rushed in there with the arrogant assumption that the merits and importance of my research were obvious to all and the belief that no one would *not* want to participate.

So stupid—and so wrong. They were right to kick me out because I was behaving very badly, and totally unethically. I had forgotten for a moment that the presence of a researcher always and inevitably changes the dynamics and practices of a group and that my very presence made the group a *different* group to the one that had existed before I strutted through the door. More importantly, I had deluded myself that, as a participant observer, I could somehow, sometimes take off my researcher hat and be "one of them." Of course I knew all these things before I began, but in my enthusiasm to get the project started I had left my ethical practice at the door as I barged on through.

My delusions of invisibility made me forget the first and most golden rule of any sort of research—*consent*. How could my research have any integrity if even one member of the group did not realise I was a researcher? How dishonest of me! How misleading! I could really only be grateful that these young women were feisty and confident enough to boot me out while they considered their choice to participate in the project. There would be many other groups of potential research subjects who would not have the confidence to ask a researcher to leave their group. This awareness made me reflect anew on the significance of power in research relationships and the role that consent must play in clarifying these power relationships.

After a few weeks I was informed that they had decided to let me come back, and I returned gratefully and with my tail between my legs. I had learnt my lesson. Even though I had thought I had been completely open and transparent about my project, I had been careless about ensuring that *every* member of the group had a good understanding of who I was, why I was there and what the research might achieve—an essential step for ethical research in which informed consent is crucial to the legitimacy of the entire project. This is not a lesson I will forget in a hurry and I am thankful for these young women's patience in helping me learn it again.

There is a great deal we can learn from this example. Specifically, Maddison shows how ethical practice is an ongoing consideration. Moreover, ethical issues and informed consent provide the researcher with an opportunity to learn about themselves and develop as researchers—ethics are a doorway to reflexivity.

THE PRACTICE OF ETHICS IN SOCIAL RESEARCH ●

Ethics exist within a social context. The ethical dilemmas we discussed in this chapter serve to remind us of the importance of including an ethical perspective in the very foundation of our research project. Ethical rules cannot possibly apply to all events that can happen in a given project. Rubin and Rubin (1995) note that ethical guidelines do not begin to cover all of the ethical dilemmas you may face in the practice of social research:

> You cannot achieve ethical research by following a set of preestablished procedures that will always be correct. Yet, the requirement to behave ethically is just as strong in qualitative interviewing as in other types of research on humans—maybe even stronger. You must build ethical routines into your work. You should carefully study codes of ethics and cases of unethical behavior to sensitize yourself to situations in which ethical commitments become particularly salient. Throughout your research, keep thinking and judging what are your ethical obligations. (Rubin & Rubin, 1995, p. 96 as quoted in Patton, 2002, p. 411)

A useful distinction we might keep in mind here is the difference between what Homan (1992) terms *ethical codes* and *ethical values.* Agreeing to comply with ethical codes as outlined in an informed consent proposal does not absolve the researcher from adhering to the underlying ethical values contained in these codes, yet very often "they invite observance in the letter rather than in the principle" (p. 325). Homan (1992) reminds us that the danger is that many researchers think their moral obligation begins and ends with the signing of the letter of consent. In some cases an informed consent letter is seen as one protecting the researcher more than the researched. One anthropologist notes:

> I fear that informed consent, when mechanically applied using a form or some verbal formula, becomes more of a protection for the researcher than the researched. Informed consent obtained in this way is unilateral rather than bilateral and protects the researcher against charges from participants that they did not understand fully the intent or outcome of the research. (Fluehr-Lobban, 1998, p. 199)

Ethics does not exist in a vacuum. As King, Henderson, and Stein (1999) note:

> . . . the ethics of human subjects research may be universal but is at the same time deeply particularized, so that what autonomy or informed consent or confidentiality or even benefit and harm *means* depends on the circumstances. The circumstances do not determine whether any of these "Western" moral concepts applies, but *how*. (p. 213)

● EMERGENT ISSUES IN ETHICS RESEARCH: ARE WE MOVING TO A NEW "ETHICS" PARADIGM?

King, Henderson, and Stein's (1999) observations on ethical behavior point to a shift in thinking about how ethics is incorporated into the research process. They discuss a paradigmatic shift in thinking of ethics as a based on moral principles (principalist paradigm) largely independent of specific circumstances, to one based on a view of ethics embedded in contextual relationships (relationship paradigm). A principalist might be concerned about the inherent "relativistic" point of view contained within a relational ethics perspective, while a relationalist might charge a principalist with "moral imperalism, paternalism and absolutism (see King, Henderson, & Stein, 1999, p. 217).

Ethics viewed through each of these paradigmatic lenses asks different types of questions, and it weighs in differently on what priorities should be stressed in a discussion of the ethics of human subjects research. Up to now, a principalist paradigm has guided the development of the ethics guidelines for IRBs and professional associations. What is needed to move the discussion of ethics forward is a more concerted dialogue between these two perspectives, and perhaps, some say, even a synthesis. King, Henderson, and Stein (1999) suggest some important questions that might be fruitful to address in such a dialogue:

> To whom do we turn for moral argument? How shall we constitute the community, or communities, to examine these things together? The language of the question is significant. It means, "With whom are we in a moral relationship of equals?" Not "who will adjudicate this for us? Who will tell us the rules?" But, "With whom can we talk? With whom can we work toward an answer?" (King Henderson, and Stein, 1999, p. 224)

CONCLUSION ●

Integrating ethics into the research process, starting with the selection of the research problem, to carrying out research goals, to the interpretation and reporting of research findings, is critical to ensuring that the research process is guided by ethical principles beyond informed consent. This chapter challenges us as researchers to become aware of the range of ethical dilemmas researchers confront in the carrying out of the day-to-day tasks of any research project. An important step beyond securing informed consent lies in the researcher engaging in self-reflexivity, by asking:

- What is my "ethical standpoint" on the research process?

You may find the following checklist of questions useful in uncovering your own ethical perspective on the research process:

- What type of ethical principles guide your work and life beyond the professional code of ethics you are bound by through a given discipline or professional association?
- Where do your ethical obligations to the researched start and end?

Knowing your own ethical standpoint as a researcher is an important internal guide as to how to proceed in your research. Michael Patton (2002) provides an "ethics checklist" (p. 409) to take into account as you proceed with your research project. We have adapted Patton's list to include a range of research inquiries.

PATTON'S CHECKLIST OF QUESTIONS FOR CONDUCTING AN ETHICAL RESEARCH PROJECT ●

- How will you explain the purpose of the inquiry and methods to be used in ways that are accurate and understandable to those you are researching?
- Why should the researched participate in your project?
- In what ways, if any, will conducting this research put people at risk (psychological, legal, political, becoming ostracized by others)?
- What are reasonable promises of confidentiality that can be fully honored?

- What kind of informed consent, if any, is necessary for mutual protection?
- Who will have access to the data? For what purposes?
- How will you and your respondent(s) likely be affected by conducting this research?
- Who will be the researcher's confidant and counselor on matters of ethics during a study?
- How hard will you push for data?
- What ethical framework and philosophy informs your work and ensures respect and sensitivity for those you study, beyond whatever may be required by law? (Adapted from Patton, 2002, p. 408)

A good example of ethical reflection within the research process comes from a study conducted by Huber and Clandinin (2002). They interviewed inner-city elementary school children and relate the ethical "give and take" they engaged in to the process of understanding the lives of inner city youth. They cite the importance of creating an "ethic of relational narrative inquiry" that goes beyond the requirements of signing a consent form.

> From a nonrelational research ethics perspective, we had met the ethical requirements, but this was not sufficient . . . When we felt disease around who we were as researchers in relation with Azim [a respondent the researchers' study] we realized we needed a different way of understanding what it means to live out ethical research with children as coresearchers in relational narrative inquiry. (p. 794)

They found that a "relational model" of inquiry requires a great deal of "reflexivity" on the part of the researcher (especially when studying a vulnerable population). Putting their reflexive experience into the research process enables them to engage in a dialogue with their own ethical standpoint and to ultimately confront their own personal biases as researchers as well as teachers of elementary school children. In the end, they became more attentive to the complexities of co-creating meaning and the necessity of living within the tensions they experienced as co-researchers:

> As we entered into coresearcher relationships with children, we began to be very thoughtful about what plotlines were shaping us as teacher researchers, as researcher teachers, as researchers. Attending to the maintenance of relationships with children, now and in the future, became, for us, a first consideration . . . we need to reframe ethical concerns into

> concerns of relational responsibility. We realized that our attentiveness to relationship could conflict with dominant stories of what "good" teachers and "good" researchers do. Plotlines for good researchers do not often attend to the aftermath for children's lives as their first concern. As relational narrative inquirers engaged with children as researcher, we realized that it was here that we needed to attend. (p. 800)

It is our hope that this chapter provides you with an awareness of the importance of the ethical dimension in the research process. We have also tried to offer some of the tools you'll need to enhance your awareness of your own ethical standpoint and its application in your ongoing research endeavors. The various components of ethical practice continue to come up throughout the following chapters, including a discussion of emergent ethical concerns linked to computer-driven research (see Chapter 10).

GLOSSARY ●

Confidentiality: This means that research subjects are protected by remaining unidentifiable. That is, their names may not be used in any written material concerning the research or in discussions of the research project. Any interview materials must be stored in a safe place.

Cover Story: Researchers who choose to use deception may even go out of their way to explain the research project as a cover story (this may be built into the original design of the research project).

Deception: Researchers may be dishonest about who they are or what they are doing and thus use deception in order to conduct their research.

Disclosure: A researcher may or may not reveal, or disclose, his or her identity and the purpose of their research. In accord with ethical considerations, we advocate full disclosure whenever possible.

Ethical Codes: These are codes of conduct set in place to protect the research subjects and their setting—neither of which should be harmed by the research process. By agreeing to comply with ethical codes, as outlined in an informed consent proposal, the researcher is absolved from adhering to the underlying ethical values contained in these codes, yet very often "they invite observance in the letter rather than in the principle" (Homan, 1992, p. 325).

Ethical Values: See Ethical Codes.

Informed Consent: Informed consent is a critical component in ethical research which uses human participants. Informed consent means that participants fully understand what the study is about, how the results will be used, that their participation is voluntary and can be stopped at any time, and that their identity will be protected.

IRB: Institutional review boards (IRBs) ensure that studies using living subjects are ethical and will not cause harm.

Moral Integrity: The moral integrity of the researcher is a critically important aspect of insuring that the research process and a researcher's findings are "trustworthy" and valid.

Nuremberg Code: A code of ethics, which starts off with the stipulation that all research participation must be voluntary.

● DISCUSSION QUESTIONS

1. What is the "ethical substructure" of the research process and why must ethics be attended to holistically?

2. Although informed consent is a critical component of ensuring the ethical dimension of your research project, there have been instances in which there was a failure to fully disclose to research subjects the full extent of the risks or benefits of participating in a study. Therefore, who do you believe is responsible for any unintended consequences?

3. The questions brought up in this chapter include: Where do your ethical obligations to the researched start and end? What responsibility does the researcher have to the participant after the research process has "ended"? Does the researcher still have a responsibility for any emotional and psychological problems that ensue in part because of the research project? What do you think about these issues?

4. IRBs were created to oversee the research process and ensure that "no one group of individuals has been unfairly treated or left out of the potential positive outcomes of a given study." However, as discussed, IRBs have proved ineffective in certain cases where members of IRBs have a vested interest in the very studies they oversee. Therefore, do you believe IRBs to be an effective resource in ensuring ethical centrality in research processes? If not, what is your suggestion for improving the assurance of the ethical dimension of the research process? To your mind, what would be the most effective means of ensuring "ethical consideration/safety" in research projects conducted in universities?

5. As noted in this chapter, informed consent does not absolve the researcher from all ethical issues. Why is this? What are some ethical considerations one must keep in mind when conducting "covert research" or "participant observation"? What are some other ways of making sure that the ethical dimension is given its proper place in your research project?

6. Do you believe it is the responsibility of the researcher to reveal information concerning the research participant if he or she feels it benefits the subject? Why or why not?

7. If a researcher imposes confidentiality in the research process, do you see this as a way of disempowering research participants who want to reveal their identities? Do you believe it is the sole responsibility of the researcher to determine whether information should be kept confidential? Should the issue of confidentiality be a collaborative effort? To what extent should it be collaborative?

8. If a sociologist is interested in studying underage teenagers' drinking and driving behaviors—what are some of the ethical considerations the researcher would have to keep in mind? Discuss some of the ethical dilemmas you would encounter. How would you structure your research project (bearing in mind the centrality of ethics in the structuring of your research process)?

SUGGESTED WEBSITES ●

National Science Foundation

http://www.nsf.gov/bfa/dias/policy/docs/45cfr690.pdf

This link is to the current law regarding informed consent/IRBs/human subjects: "The Common Rule for the Protection of Human Subjects for Behavioral and Social Science Research."

http://www.nsf.gov/bfa/dias/policy/hsfaqs.htm

This is a list of "frequently asked questions" concerning the above legislation.

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

This is a link to: "The Belmont Report: Ethical Principles and Guidelines for the Protection of Human Subjects of Research."

http://www.nsf.gov/bfa/dias/policy/guidance.htm

This site has a section entitled "Human Subjects" with information concerning the basic principles of human subject protection as well as information about IRBs.

Online Ethics

http://onlineethics.org/

This is a link to the "Online Ethics Center for Engineering and Science." They claim that their mission is "to provide engineers, scientists, and science and engineering students with resources for understanding and addressing ethically significant problems that arise in their work, and to serve those who are promoting learning and advancing the understanding of responsible research and practice in science and engineering."

If you click on "Contents of the Online Ethics Center (OEC)" and then "Research Ethics":

http://onlineethics.org/reseth/index.html

This page contains cases, discussions, guidelines, and regulations that place responsibility on the researcher and how she or he conducts research (including information about both issues of research integrity and the treatment of research subjects). It also includes useful links to reference materials concerning research ethics (with a list of websites and governmental sites devoted to this topic).

National Institutes of Health

http://obsr.od.nih.gov/

This is a link to the Office of Human Subjects Research, which provides information about the existing legislation concerning the use of human subjects and research (as well as the ethical dilemmas involved). It also provides links to other governmental websites dealing with the issue.

http://www.nih.gov/sigs/bioethics/IRB.html

This link is entitled "Human Subjects Research and IRBs." It contains links to policies and regulations, guidance for investigators, IRB resources, short courses on bioethical issues in human studies, research resources, and human subjects research tutorials.

http://www.nlm.nih.gov/pubs/cbm/hum_exp.html

This is a link to a very extensive list of references, all dealing with ethical issues in research involving human participants. The table of contents (you have to scroll down the page a little to get this) breaks down the page into different categories, making it easier to find your specific topic. The bibliography contains information regarding reference materials, including journals, books, government documents, etc.

U.S. Department of Education

http://www.ed.gov/about/offices/list/ocfo/humansub.html

This is a link to the "Protection of Human Subjects in Research" page. This page includes links to general information concerning human subjects in research and the regulations and legalities surrounding using human subjects in research. It also contains information about "Guidance and Educational Materials" (with links to "The Belmont Report" and the "Institutional Review Board Guidebook").

American Sociological Association

http://www.asanet.org/memberfs/ecostand2.html.

This is a link to the ASA's *Code of Ethics*. The *Code of Ethic*s is available on the site, and there is also a downloadable PDF version.

American Psychological Association

http://www.apa.org/ethics/homepage.html

This link discusses the APA's new Ethics Code. It has three downloadable versions of the code as well as links to ethics in the news and ethics resources/reference materials.

American Association for the Advancement of Science

http://www.aaas.org/spp/sfrl/projects/intres/main.htm

This is a link to the "Ethical and Legal Aspects of Human Subjects Research in Cyberspace," which contains a link to the report prepared

by the AAAS staff (which was created after a workshop was convened in collaboration with the NIH concerning Internet research involving human subjects).

Indiana University's Poynter Center for the Study of Ethics and American Institutions

http://poynter.indiana.edu/links.shtml

This site contains links to ethics centers, publications, research ethics, research policy, and general information about ethics. As stated on the website, the Center's Mission is "dedicated to studying a broad range of ethical issues in American public life. Interdisciplinary in aim, the Center uses the full resources of Indiana University to initiate research and teaching across traditional academic boundaries." The site contains very useful resources for teaching research ethics. Of particular interest is their on-line interactive teaching module titled "The Least of My Brothers," that explores the ethical issues surrounding the Tuskegee Syphilis Experiment. There is a detailed Instructor's Manual that accompanies this module. See their sub-link: http://poynter.indiana.edu/sas/lb/

International Sociological Association

http://www.ucm.es/info/isa/about/isa_code_of_ethics.htm

This page contains the American Sociological Association's Code of Ethics. This code consists of a preamble as well as four sets of specific ethical standards.

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American Sociological Associations' Ethical Standards: http://www.asanet.org/memberfs/ecostand2.html. This list consists of topics such as informed consent, use of

deception as a research practice, etc. *See also:* Guidelines For The Conduct Of Research Involving Human Subjects At The National Institutes Of Health: http://www.helix.nih.gov.8001/ohsr/guidelines.html

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