The Handbook of
ETHICAL RESEARCH
With
ETHNOCULTURAL
POPULATIONS & COMMUNITIES

Edited by

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Ethnographic Research on Drugs and HIV/AIDS in Ethnocultural Communities

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The story of my project can join the literature on ethical dilemmas of fieldwork . . . what happens to the women [I interviewed] and my relationship with them as they become transformed into data? My social science training has taught me to keep the "I" out of things (i.e., leave the relationship out altogether), and besides, without data what do I analyze and interpret?

—Alisse Waterston, *Love, Sorrow and Rage*

Don't study the poor and powerless because everything you say about them will be used against them.

—Laura Nader, "Up the Anthropologist"

The American Anthropology Association's Code of Ethics (1998) states that "Anthropological researchers must expect to encounter ethical dilemmas at every stage of their work, and must make good-faith efforts to identify potential ethical claims and conflicts in advance when preparing proposals and as projects proceed." Since the publication of this code, which followed an earlier set of ethical guidelines issued by the Society for Applied Anthropology (1983), standards for assessing good-faith efforts have become more stringent, and the frustrations of communities and researchers over ethical questions and decisions have escalated significantly as well. Indeed, as government and community institutions have implemented ever more demanding review structures and sets of procedures intended to address the ethical issues that arise in studying

humans, social and behavioral research has become increasingly complicated and often quite wearisome. Anthropologists, like their colleagues in other disciplines, have been forced to carefully think through all of the potential risks—however unlikely or improbable—that might be faced by study participants and their communities. Given the particular nature of ethnography as a research methodology, these risks are numerous. Additionally, they have had to confront a set ethical rules (midcourse changes in the research protocol must be approved by a human subject committee; informed consent should be provided by all study participants) that constrain some of the basic strengths of ethnographic research, for example the field discovery and exploration of unexpected findings and the observation of individuals in settings in which informed consent would be impossible to acquire.

THE ETHNOGRAPHER IN ETHNOCULTURAL COMMUNITIES

Based as it is on researcher immersion into the natural social and geographic space of research participants, those engaged in ethnographic research gain access to many arenas of individual and community life and behavior that often are closed to (or even actively hidden from) other kinds of researchers. Moreover, because ethnographers routinely seek to develop an insider's understanding and to comprehend the worldview of study participants, including their deepest feelings (day-to-day as well as most poignant experiences and heart-felt beliefs and ideas), they are pushed to dig ever deeper into the thoughts, sentiments, memories, and relationships of the ethnocultural groups they study. Additionally, as a result of the experience-near nature of their research method (being on hand when

things happen and immediately asking questions about what has happened, why it has happened, and how the participant feels about it), ethnographers are in a position (for protracted periods) of being able to see participants as they carry out their everyday lives, observe unexpected and even undesirable and upsetting events (from the participant's standpoint), and query the participant(s) about the significance of the event. In addition, ethnographers may meet and interact with individuals (encountered by the participant) with whom it may be difficult or impossible to obtain formal consent. For example, during a study in Israel the lead author was on hand when a youthful member of a religious sect that he was studying was caught shoplifting by a merchant. From the standpoint of the boy's community, this was a highly embarrassing occurrence that conflicted sharply with the public image of righteousness and perfection claimed by the group. Knowing that the ethnographer had witnessed the event was quite discomforting for group members. In contrast to their usual openness, they gruffly avoided answering questions for the rest of the day. In short, as discussed below, ethnography allows access to more intimate and private information, including information a group may not wish to be known by outsiders, while at the same time maintaining an informal style that actively weighs against constantly intruding and interrupting the natural flow of events to obtain informed consent.

On another occasion during this same study, while the ethnographer was with group members in one of the apartments they have in a southern Israeli town, a group of police arrived and demanded entrance, which was granted. The police proceeded to ask the ethnographer and members of the group various question (e.g., what was this person—the ethnographer—doing here?)

Although it was not possible to seek informed consent from them, certainly the realization that the police must be keeping very close watch on the group was an important research finding.

Immersion in Participants' Private Lives

Data collection in ethnography is interwoven with the sometimes confidential and quite intimate or highly emotionally charged activities of research subjects, including at times, illegal, unhealthy, and secret behaviors. Because of the extensive access ethnographers often gain to the "backstage" (or completely offstage) areas of participants' private lives, they are in a position to, and commonly do, learn about very guarded information (e.g., love affairs, theft, hidden resentments). Indeed, over time, ethnographers may hear, see, and learn about issues that neither the participant nor the researcher anticipated at the time of formal consent. This kind of access is propelled by the nature of ethnography, which not only exposes the lives of participants but those of ethnographers as well. Once in the field, ethnographers often do not go to work, per se, but rather live on the job, potentially around the clock as events warrant, and thus their personal lives are not (and cannot) be completely separated from those of research participants (Busier, Clark, Esch, Glesne, Pigeon, & Tarule, 1997).

Other behavioral researchers usually can remain snugly in professional roles in their interactions with study participants (e.g., during structured interviews in office settings at research centers) and pretend, at least, that the pathway of knowledge gathering is unidirectional. Ethnographers, however, know that they must open themselves to the gaze of community members and that the nature of their presentation of self will be under close and continued scrutiny. In short, ethnographers know that the success of their project depends in no small measure on how they are judged. This situation is often complicated by the fact that ethnographers initially do not know how to act in ways that will met their host's approval. Often they stumble and sometimes they fall. Bourgois (1995), for example, reports inadvertently embarrassing a major crack dealer by exposing that he could barely read. All ethnographers make similar mistakes, especially early in their fieldwork experience. Ultimately, most ethnographers learn that being open (i.e., reasonably extroverted and chatty), honest (revealing about who you are personally and not giving the impression that you are hiding something), friendly and caring (sharing resources and assistance), and respectful (honoring the dignity of your hosts and their culture) will lead to acceptance in most settings. One consequence of this unique approach to understanding is that ethnographers often develop close personal relationships with at least some study participants (often called "key informants"), friendships that can outlive the period of research and can and sometimes do involve marriage or the establishment of fictive kinship. At the same time, anthropologists can develop enemies or have conflicts with people in the group under study, sometimes by inheriting the enemies of their friends but also because of unintended slights or fears people develop about the ethnographer as an outsider based on fanciful, and perhaps at times not so fanciful, interpretations of the ethnographer's real mission. Moreover, from the participants' perspective, the ethnographer as a distinct person with particular traits and resources often is of far greater interest to the community under study than the ethnographer as a scholarly researcher, a social role that participants may not fully understand or ultimately be much concerned about.

Community Description and Assessment: Contemporary Ethnographic Minefields

Finally, a completed ethnographic account stands as a public description and assessment of aspects of the group in question. Although anthropologists often attempt to hide the name or the location of the group through the use of pseudonyms, sometimes this is not possible, and some members of the group under study may learn about and be offended by how they feel their group is portrayed to the world. For example, a group of Latino undergraduate students in a New York university were assigned by the second author of this chapter to read an article by Singer (1996) on the biosocial entwinement of substance abuse, violence, and AIDS in the inner city and had unexpectedly negative reactions to what they read. One student commented, "My problem with this is that it says if you're Latina and a drug user, you're apt to get AIDS or be a victim of violence." This statement expressed a general unease among class members with seeing these three epidemics linked together as descriptive features of their community and, the students concluded, inherent community characteristics in the mind of the article's author. The students interpreted the author's argument as deterministic. They felt that Singer implied that being Latino/a, HIV positive, using injection drugs, and being victimized by violence were, in effect, inescapable attributes of people of color living in poor, urban neighborhoods.

In the article in question, Singer introduced the term *syndemic* to conceptualize the intimate relationship between multiple mutually reinforcing diseases and a set of social structural factors that increase the likelihood of there being numerous coterminous threats to health among the poor; however, calling focused attention to the critical importance of discrimination, racism, structural violence, and economic disadvantage in shaping abundantly documented indicators of comparatively poor health status among inner city populations did not lessen the students' indignation at what they perceived as an unfounded generalization, a stereotype of poor people, and a slight against Puerto Rican women imposed by an outsider. The second author attempted to clarify the utility of the concept of syndemics (Singer & Clair, 2003): It discourages the traditional public health focus on only one major health problem at a time and the biomedical tendency to look at health separate from the wider social relations that promote unhealthy conditions among the poor, which did help to move class discussion to an agreement that the term has some value. Still they asked, "How can you bring attention to health disparities without reinforcing them? How can you also point out community strengths and resiliency and not always emphasize a negative image?"

On another occasion, Singer and a colleague reported on the findings of a study of continued AIDS risk in Hartford to a community advisory group comprised primarily of members of ethnocultural and sociocultural minorities from around the state. In reporting the findings, Singer noted that a goal of the research was to identify practical changes that could be readily implemented without enormous cost. Thus, he commented, although eliminating poverty would help to fight the spread of AIDS in a city like Hartford where most people with AIDS are indeed poor, this was not a goal that could be achieved easily or rapidly. A member of the audience objected to this stance, not because it delayed the elimination of poverty but because to him it implied that only the poor get AIDS. Others in the room agreed with this interpretation, suggesting the keen sensitivity that exists about AIDS-related issues in ethnocultural communities.

Ethnographic Study of Illicit Drug Use and AIDS Risk

As these examples suggest, a further ethical complication is the fact that some arenas of ethnographic research are especially fraught with moral challenges and almost unavoidable ethical dilemmas, whatever the intentions of the ethnographer. Ethnographic study of illicit drug use and AIDS risk is one such arena because its focuses on behaviors that are at once illicit and stigmatized and because the behaviors of concern to such researchers have the potential for raising issues of community representation and public portrayal.

The cases cited in this chapter are based on research carried out through the Hispanic Health Council in Hartford, Connecticut, a community-based research, direct service, health education, and advocacy organization. As a research institution, the Hispanic Health Council has had an established Human Subject Committee to review all of its grant proposals for many years. Because most of our research grants have been submitted to the National Institutes of Health or the Centers for Disease Control and Prevention, all of our research proposals include a section on research with human subjects that discusses ethical issues that pertain to the study in question. Although this section of proposals broadly addresses the main types of ethical questions that are relevant to our research (getting subject consent, potential risks and how they will be handled, protecting confidentiality), the field of naturalistic human research is always unpredictable, changing, and filled with potential for both social and ethical dilemmas. We have been keenly aware of these issues in that since the late 1980s, a large body of our research has focused on illicit drug users, the majority of whom come from minority ethnocultural communities, who daily are engaged in activities that put them and others at high risk for disease, injury, and arrest.

Issues of concern in our research on drug use include ethical predicaments generated by existing drug prohibition laws (Buchanan, Khoshnood, Stopka, Santelices, & Singer, 2002), the need for guidelines to steer publicly funded research on illicit behaviors like drug use (Singer et al., 1999), the physical and ethical dangers inherent in the study of street violence as a factor in drug use behavior (Marshall et al., 2001; Singer, Scott, Wilson, Easton, & Weeks, 2001a), and the ethical challenges of research videography with active drug users. In this chapter, we review how the Hispanic Health Council has responded to some of these ethical challenges to research in light of its goals as a community-based health research, advocacy, and service organization.

DRUG LAWS AND ETHICAL RESEARCH

The starting point for any examination of ethical dilemmas encountered by researchers trying to study and understand mood-altering drug use is the criminalization of some (but not all) kinds of these drugs. A number of different types of ethical challenges for researchers are created by the existence of laws prohibiting drug possession and sales, including researcher actions that increase the potential for the arrest of research participants, disruptions of access to drug supply because of participation in research, risk of arrest for the research staff, threats to the confidentiality of the participants, and issues involving informed consent in working with people suffering from a criminalized addiction (Buchanan et al., 2002). Each of these will be discussed in turn.

Risk of Arrest

For illicit drug users, it is possible that participating in a research project may

increase their risk of arrest. One way this can happen is through an increase in their visibility to police. Although addiction and the frequent need to acquire illicit drugs and paraphernalia often force drug users to be more visible than they would like, they commonly engage in strategies intended to hide from the criminal justice system both their actions (e.g., by using drugs in hidden places, by not carrying syringes or drugs on them for long periods, by avoiding locations with heightened police activity) and their identities (e.g., by avoiding the stereotypic appearance of a rundown, street drug user). Although it is not uncommon for the police to be aware of many of the regular, street-active drug users in a given locale, others may successfully hide their illicit drug use for long periods of time; however, when drug users enroll in a drug use study, some of these defenses may be inadvertently lowered. In light of the AIDS epidemic, this is doubly problematic, as incarceration might be perceived as a form of AIDS risk, given prison bans on access to condoms and sterile syringes, despite frequent illicit sex and injection drug use in prisons (Kane & Mason, 2001).

To avoid police harassment, field researchers conducting drug studies commonly introduce themselves and their research mission to police personnel, especially to those who walk the beat and are likely to see the researchers in certain places known for their role in the drug trade. Therefore, as a result, individuals seen spending time with researchers may be assumed by the police to be engaged in illicit drug use. Even if the police do not know the ethnographer, they are well aware that Whites who live in suburban areas travel to the inner city to buy drugs. From the police perspective, any ethnic minority person observed to be hanging out with a White person in certain neighborhoods is probably assumed to be buying drugs for them. As a result, if the ethnographer is White, the police may begin to pay greater attention to the activities of minority individuals seen with the ethnographer.

Additionally, the police may confiscate potentially incriminating research materials from drug users. For example, in one study, we enrolled drug users in a diary-keeping activity and asked them to record all instances of syringe acquisition, use, and discard for 1 week (Stopka, Springer, Khoshnood, Shaw, & Singer, 2004). The purpose of this method was to learn about the context of HIV risk as close to the actual event as possible. What do drug injectors actually do when a needle breaks in the middle of the night and they are forced to find another syringe in order to avoid the pains of withdrawal? Is this a moment when they are most likely to engage in risk? Despite instructions to avoid incriminating details, some participants included the places where drugs were acquired and the names of friends and acquaintances with whom they used drugs. On one known occasion, a participant was taken into custody by the police while in possession of his diary, which contained entries on drug use from several previous days. When booked at a local jail, the participant's diary was found by the arresting officer who began to flip through it. Throughout, the officer maintained a jocular conversation with the participant, implying that information in the diary might be used against him. In the end, the participant was released and not charged with a crime (he had only been loitering in front of the Hispanic Health Council building while awaiting an appointment to turn in his diary), and the diary was returned to him. Although we had dodged a bullet in this instance, the risks of this research method became abundantly clear. Subsequently, participants were given more explicit instructions to avoid including names, places, or other incriminating information and were required to turn in their diary every few days.

Risks From Drug Network Research

Another risk of research participation for drug users is that their drug supplier may notice that they are spending time with research staff, individuals who may not look like they are from the neighborhood. In the above-mentioned study, participants sometimes expressed concern that drug dealers might conclude that they were collaborating with the police and refuse to sell them drugs. For someone with a drug addiction, this is a frightening prospect. If their usual drug supplier refuses to sell to them, participants are forced to buy from other sellers, perhaps in other parts of the city. Searching for a new dealer, in turn, makes the participant visible to the police or might result in them being "burned" (sold highly adulterated "empty" drugs by an unfamiliar drug seller).

Risks to Research Staff

Risks associated with drug criminalization also extend to research staff. Drug scenes are the sites of heightened rates of violence of several sorts, including conflicts among dealers over selling areas ("turf"); attempts by drug users to "rip off" drug dealers for their drugs or money; retaliation by higher-level drug dealers for drug theft; short-tempered attitudes among addicted, drug-craving users; conflicts over fair distribution among individuals who pool their limited resources to buy drugs; and police harassment. The crack cocaine scene has been particularly violent, for example, because the trade is predicated on a low-profit-per-unit/high-volume business that puts a high premium on the best selling locations, which tend to be fought over by rival dealing organizations. It is possible for researchers to be unwittingly caught in any of the various types of violence that can break out suddenly in street drug scenes (Williams, Dunlap, Johnson, & Hamid, 1992).

Although such incidents involving injury to researchers are not common, researchers have, on occasion, been the targets of violence during the research process. Bourgois (1995), for example, was mugged along with others because of being in the wrong place at the wrong time, although he was not targeted because he was a researcher. Jacobs (1998), in contrast, was robbed at gunpoint by one of his key informants (Luther, a 17-year-old crack dealer) and later harassed by him with repeated baiting telephone calls (5–10 times a day for 6 weeks) precisely because he was a researcher. In this instance, after 40 interviews, the informant was offended and angered because Jacobs had moved on to interview other crack dealers (facilitated by Luther) and was no longer relying on him as his primary source of information about the crack scene. From a research standpoint, developing new research relationships and sources of information to broaden the scope of understanding was completely justified and scientifically appropriate. From the informant's point of view, however, it was a breach of personal relationship, a slap in the face to someone who had generously given a tremendous amount of information about crack dealing and provided contacts with other dealers and now felt used and taken for granted. From the informant's perspective, it was the relationship and not the research that was of primary importance, a lesson Jacobs learned the hard way at the point of a long-barrel .45 caliber pistol.

Risks to Confidentiality

Following federal guidelines and other precedents, our research team adheres to strict protocols for storing and retrieving all data and information collected from participants in order to protect their confidentiality. These procedures include the following:

- Informed and signed consent in the language of choice of participants prior to enrollment in a research project
- Voluntary participation, including the right of subjects to refuse to answer any questions, without risk of losing services offered by the Hispanic Health Council
- Use of arbitrarily constructed participant identification codes called unique identifiers on all questionnaires and interviews
- Storage of raw data in locked filing cabinets and password-protected computers
- Exclusion of any individually identifiable information from computerized data files and avoidance of participants' names in group discussions
- Storage of master identification lists in separate and locked facilities controlled by the project director
- Use of collected information for research purposes only

Although we believe that these procedures effectively protect study participants under most conditions, there are reasons to question whether this protection is universal.

We conduct interviews with drug users in various public buildings, like the Hispanic Health Council, a community health center, and a community center that houses other programs, as well as on the street or in "shooting galleries" and similar locations. Most of these settings have a normal flow of public traffic. As participants enter and exit these sites, it is always possible that they might run into or be seen by someone they know, including staff from other projects, and asked to explain, or rather more likely lie about, their reasons for being there. For many addicts, this is not an issue because everyone who is important to them already knows about their drug habit; however, for others, their addiction may remain a guarded secret or only be discussed with a few confidants. Because they participate in illegal behaviors, loss of confidentiality could mean a loss of a job, guardianship of children, insurance, or housing.

For example, at one site we have used for interviewing participants, the security guard is well known in the community. He is familiar with many of the drug addicts from the local neighborhood, greeting most by name. Under such circumstances, the possibility exists that unbeknownst to the guard, one of his children or some other relative, friend, or acquaintance who is addicted could show up at the site for an interview. Similarly, we have had cases in past studies in which we have interviewed both partners in a romantic relationship but one or both was unaware of the other's drug use. Conversely, on one occasion a relative of one of our outreach workers spotted him in the field talking with drug users and subsequently spread rumors about the individual, a recovering addict, having had a drug relapse.

As these examples suggest, the opportunities for loss of confidentiality are numerous and hard to completely avoid. Over time, research organizations like the Hispanic Health Council tend to learn from their own errors and those of others about the many ways confidentiality can be broken and implement measures to avoid known dangers (e.g., ensure that all staff, including non-researchers like receptionists, bookkeepers, janitors, and security guards understand confidentiality and their responsibilities to maintain it).

PAYMENT TO DRUG USERS

It has become standard practice to pay drug users for their time to participate in research. Some have questioned the paying of research incentives to drug users because it is assumed that they will use the payment to buy more drugs (and potentially be put at HIV or other risk during drug consumption). Although far fewer drug users would participate in research if no monetary incentives were offered, there would be no fewer drug users

nor any drop in drug use. Research is not the engine fueling drug use. Readily available addictive drugs combined with social misery, humdrum jobs, and thrill seeking are more likely causes of drug use; however, research does have the potential to lower risk and provide a link to a hard-to-reach population, a link that may serve eventually as a bridge to drug treatment.

Benefits of Research Stipends

Additionally, although it makes only limited impact in the larger scheme of things, it is likely that stipends paid to drug-using research participants may actually reduce crime, as the participants will not have to carry out their usual income-generating "hustle," which for some involves "boosting" (shop lifting), breaking and entering, opportunistic theft, or mugging, to raise the money needed to buy drugs that day. By asking drug users about their daily involvement in such crimes, it would be possible in any research project to roughly calculate the crime reduction benefits of participant incentives. Still the question can be raised: Are researchers complicit in assisting drug users in their self destruction?

Referrals. Almost all drug researchers would answer no to the question above because they are aware of the full set of interactions that constitute researcher/drug-user professional relationships. Although the risks noted above are both real and significant, it is also true that participation in research offers drug users a number of potential benefits. Participants are provided with HIV risk reduction information and materials, and their questions about risk are answered by trained staff. Staff are also trained to provide information about the drug treatment system (available providers, lengths of stay, admissions criteria, disqualifications, costs, etc.) and are expected to offer requested referral assistance. If a participant wants to go into drug detoxification or treatment, our research staff make the necessary phone calls, collect needed information that providers will require, and even provide transportation and follow-up as needed. Additionally, for known participants who need a letter indicating that they have been using opiates (e.g., heroin) for a required period to qualify for methadone treatment, our staff provide certification. The Hispanic Health Council also operates a small emergency food bank and has an emergency fund to meet an immediate participant expense, for example, to pay money owed to the methadone clinic so that the participant will be able to enter drug treatment. As a general ethical rule of operation, the pressing health needs of study participants always take precedence over the needs of research.

Support systems. Moreover, because the decision to stop drug use does not come easily, the relationships that develop with project staff may play a role in the decision to seek help to enter into drug treatment. It is not unusual for an individual to start as participants in research, be assisted by research staff to enter into drug treatment, complete treatment, and subsequently be hired as a project outreach worker, a position that may be the first legal employment. Moreover, study participants regularly express appreciation concerning their involvement because of the attention they receive and the opportunity research participation provides for self-reflection—including realization that drug use exposes them to many risks and takes a heavy toll on their lives—suggesting that participation in research expands the opportunities for health-promoting change among drug users. The therapeutic benefits of research participation, at least for some study participants, is an aspect of research that is often overlooked, especially in critiques of research characterizing it as a system that

takes away from, but does not give back to, the community being studied. Research that is fully based in a community by being implemented through, or in conjunction with, community agencies and driven by an authentic commitment to community service has the potential to reverse the usual direction of resource flow from the community to research (Singer 1993).

Justice. One additional factor contributes to researcher assertions that payment to drug-using research participants is ethical. Researchers assert that drug users over the age of 18 years are legal adults and should not automatically forfeit their right to be paid for their work and knowledge because they are addicted to drugs. To decide that drug users cannot be paid because of their disability, whereas non-drug-using participants in similar social science research can, would be both an insulting form of infantilization and discrimination against the disabled (National Institute on Drug Abuse defines drug addiction as a brain disease).

STUDYING ILLICIT BEHAVIORS WITH PUBLIC FUNDING

The ethical issues confronted in the study of illicit drug users are further complicated by the fact that most of this research is federally funded and supported by public monies. This source of funding raises issues of legality, responsibilities to employers (including protecting their access to future funding), responsibilities to colleagues, and responsibilities to the researcher's discipline (including protecting access to future funding). It also increase the possibility for public, governmental, and mass-media scrutiny because of the use of public funding. Although it is generally accepted that researchers' most fundamental ethical responsibility is to the

people who volunteer as participants in their research projects, we also have a strong responsibility to protect our sponsors from inappropriate condemnation, although it is recognized that our research findings may result in appropriate condemnation of our sponsors because of their failure to meet their own social obligations. Specific issues include the following:

- *Responsibility that arises when the researcher is aware of illegal behavior by subjects.* Is a federally funded researcher obligated to report this information to criminal justice authorities (Carey, 1972; Soloway & Walters, 1977)? Although there are those who might support this as reasonable researcher responsibility, such reporting would make illicit drug research impossible, as researchers would, in effect, become "snitches" and drug users would no longer talk to them.

- *Responsibility that arises when the researcher is aware of dangerous or unhealthy behavior by subjects (e.g., sharing syringes, sexual contact without condoms).* If, for example, a federally funded researcher knows the positive HIV status of one partner in a drug using dyad, is the researcher obligated to tell the other partner so that they can take actions to prevent infection?

- *Special responsibilities that arise from working with subjects like illegal immigrants, whose very presence is punishable by the government.* Are federally funded researchers obligated to report undocumented individuals who appear to be in the country illegally and, further, engaged in illicit drug use?

- *Special responsibilities that arise from working with highly vulnerable populations, including ethnocultural and sexual minorities and traditionally oppressed populations, as well as with individuals whose behavior*

makes them subject to social opprobrium. What extra responsibilities do researchers have in working with these populations, including responsibility to address risks that present, but not as a result of participation in research?

- *Special responsibilities that arise from research awareness of highly intimate and confidential information about subjects, including information that, if disclosed, could cause harm to subjects or put them at risk (Wright, Klee, & Reid, 1998).* For example, researchers may learn that a drug-using participant has stolen money from a drug dealer and, as a result, has put at risk his or her own life or the lives of others, like family members. What is the responsibility of the researcher in possession of this information?

- *Need for standards for responding to participant requests and demands for involvement in problematic (including illegal) behavior by the researcher, as well as pressure to redirect research project resources in ways not intended in the study design.* Given that drug users may provide hours of interview or observation data to researchers, what are the boundaries of reciprocity vis-à-vis participants (as noted in the case of Jacobs above)?

Ethnographers studying drug users must confront all or most of these (sometimes burdensome) issues in terms of the well-established ethical standards of beneficence, respect, and justice, while simultaneously never losing sight of their responsibilities to their various constituencies (subjects, sponsors, employers, colleagues, the wider community). As these lists make clear, ethical issues place significant burdens and potentially contradictory demands on drug researchers, and, as noted below, this weight is magnified by ethnographic methods of knowledge generation.

Ethical Challenges of Ethnographic Immersion

Additionally, given the nature of drug use and the sociocultural survival and coping patterns that have emerged among drug users over the last 90 years when drugs like heroin and cocaine were first outlawed in the United States and elsewhere, a number of specific problematic behaviors and ethical dilemmas in federally funded research with drug users emerge (Singer et al., 1999), including the following examples of researcher participation:

- Sharing drugs with subjects, a not unknown nor unreported practice (Myerhoff, 1976) in ethnographic studies, especially outside of the United States or with specific ethnocultural populations (e.g., Native Americans)
- Procuring (through buying, trading, etc.) drugs for research participants, which a researcher might be tempted to do if a key research participant was badly "dope sick" (in drug withdrawal) or otherwise incapacitated
- Holding or transporting drugs for participants, which a researcher might be persuaded to do to protect a key research participant from arrest
- Transporting participants to acquire drugs, to assist them to avoid the police, or to help dope sick participants to "score" drugs more quickly
- Allowing participants to use drugs in a researcher's car, home, or other property, or on property belonging to the researcher's employer because the participant could not easily and quickly find another safe location to avoid police detection
- Giving/loaning subjects money to buy drugs in return for all the information the participant has provided to the researcher
- Helping prevent HIV or other blood-born infection by acquiring sterile syringes to give to subjects in a city without legal syringe exchange or legal over-the-counter purchase of syringes from pharmacies

- Holding syringes or other drug paraphernalia for participants, again to help them avoid detection or arrest by the police
- Assisting participants to avoid arrest for illegal activities, for example by serving as a lookout during illegal activities like drug purchase or use
- Having sex with participants (another behavior that is not unknown in other types of ethnographic research) (Bolton, 1992; Wolcott, 2002)

NIDA/Hispanic Health Council Workshop

In response to concerns about the lack of ethical standards in federally funded ethnographic research with drug users, in 1998 representatives of the National Institute on Drug Abuse (NIDA) requested that community-based researchers at the Hispanic Health Council convene a workshop to review the issues noted above and to formulate a set of guidelines. Drug researchers from several research projects around the country were invited to participate in the workshop. Using a methodology for confronting and resolving ethical issues in research developed by Patricia Marshall, the workshop was able to resolve a variety of issues and to propose a set of standards for ethical drug user research. These standards were subsequently published by NIDA (Singer et al., 1999). Although recognizing the social pressures that could lead ethnographers to engage in any of the bulleted items listed above, workshop participants found that all of these behaviors were problematic and ethically unacceptable (except for legally acquiring sterile syringes to replace broken or potentially infected syringes). In each case, the behaviors in question (buying drugs for participants, sharing drug with participants, etc.) placed the study participant, the researcher, the research sponsor, the employer of the researcher, fellow researchers, science, or the community at large at risk in some fashion.

Workshop participants placed special importance on the *principle of good reputation*. This principle is described in the American Anthropological Association's *Principles of Professional Responsibility* as follows: "Anthropologists bear responsibility for the good reputation of the discipline and its practitioners. . . . They must not behave in ways that jeopardize either their own or other's future research or professional employment." For example, the sharing of drugs with study participants, it could be argued, could lead to a rapid loss of good reputation for the ethnography of drug use in the eyes of federal and other funders, as well as in the view of Congress, which provides the budgets for federal research institutions. Workshop members recognized that there may be occasions to challenge federal actions with regard to drug users, for example imprisonment of individuals for drug use in spite of NIDA's definition of addiction as a brain illness and ethical issues raised by judicial sentencing mandates for specific *forms* of drugs, like the significantly higher sentencing mandates for *crack* cocaine vs. *powder* cocaine, which has contributed to significantly greater numbers of individuals from minority ethnocultural communities being in prison. These issues, however, did not apply in the case of most of the bulleted items above.

Additional Aspects of Violence and Ethics in the Study of Drug Use

Although some like the New York students described earlier feel that social researchers overemphasize drug use and violence descriptions of inner city ethnocultural communities and ignore community resiliency, vitality, and creativity, the narratives of street drug users are replete with incidents of hostility, aggression, and even brutality (Duke, Teng, Simmons, & Singer, 2003). But they also hold acts of kindness and generosity (Singer, Scott,

Wilson, Easton, & Weeks, 2001). In fact, the ethnographic research on drug use did not until relatively recently focus particularly on violence. The inadequate attention given to violence as a factor in drug use and drug-involved sexual activities, including rape, is a notable shortcoming of qualitative drug use and AIDS risk research. Our research, however, and the work of various other researchers indicates that violence is a regular and frequent component of the lives of street drug users, commonly beginning during childhood and continuing throughout their drug careers (El Bassel, Gilbert, Wu, Go, & Hill, 2005; Romero-Daza, Weeks, & Singer, 2003). Although violence must be understood to fully understand drug use and HIV risk among drug users, it is also critical to the understanding of several ethical issues in drug research.

Payment for Peer Recruitment

Understanding the role of violence in the lives of drug users is important to understanding the issue of research incentives discussed above. One type of incentive drug researchers often use, one that is critical to a sample construction stratification commonly used in drug research (i.e., peer-driven sampling), is payment to drug users for the recruitment of friends and associates into the research sample. This approach allows drug researchers to reach layers of the drug-using population not effectively tapped by other methods, providing, as a result, a more accurate and complete picture of the complex and partially hidden world of drug use (Heckathorn, Broadhead, Grund, & Stern, 1995); however, this approach also opens up the possibility of coercion, for example when stronger or otherwise more socially powerful individuals force others to come in to be interviewed and then take some or all of the incentive that is paid, in addition to their "head hunter" fee.

In one such incident, a participant in one of our studies brought in a young woman whom he introduced as a member of his social network. The young woman, however, appeared to be reluctant to be interviewed and kept glancing nervously at the man who recruited her for the study. An appointment was made for an interview for her, but the woman missed the appointment and a subsequent appointment made for her through her alleged network member. Finally, on the third try, the woman and her recruiter came in. Taken to a one-on-one interview room, the woman admitted that she was afraid of the man who brought her in and did not want to participate in the interview (and, hence, did not participate) (Singer, Simmons, Duke, & Broomhall, 2001). The damage, however, was done. Because of the study, she had been coerced into doing something she did not want to do. The recruiter, in turn, was no longer allowed to bring in individuals for interviewing.

Reporting Lifetime Experiences: Effects on Participants and Investigators

As researchers have begun to explore the role of violence in both drug use and drug-related AIDS risk, they have started asking drug users about their lifetime experiences with violence. By raising this issue in a much more direct and detailed fashion than previously, the potential has been created for provoking, or at least exacerbating, emotional problems for participants. For example, during interviews on violence, especially violence experienced as a child, participants on occasion complain of painful memories or become emotionally upset and tearful. Even while providing an opportunity for informants to unburden themselves by talking (possibly for the first time) with an interested and concerned listener about painful experiences, interviews about violence have the

potential to produce considerable emotional upset and distress for study participants.

Researchers who are not explicitly trained and experienced in addressing such upset in a supportive professional manner may be uncertain about how to handle the torment expressed by participants, leading to strong feelings of inadequacy for the researcher and frustration and confusion for the informant. For this reason, implementing prior arrangements for providing study participants with professional intervention is a critical component of study designs focused on negative experiences among participants. In interviewing on violence, clear and specific discussion of the topics to be covered and the potential for upset become especially important during the consent process.

Secondary trauma, emotional damage experienced by someone who is exposed to another's particularly intense description of traumatic events, is an additional potential outcome of ethnographic research on violence (Simmons & Koester, 2003). Interviewing a series of drug users and hearing about the level of violence in their lives, including the wrenching cruelties that they have suffered at the hands of partners, dealers, other drug users, the police, and sometimes street gang members, can become a significant emotional burden for interview staff. At times, we have implemented coworker support groups to address job-related stress issues while maintaining a contract with a mental health provider should staff need professional intervention. See Chapter 11 by Ana Mari Cauce and Richard H. Nobles for an account of a study in which both participant intervention and coworker support groups were used.

ETHICAL ISSUES IN VIDEOGRAPHY WITH DRUG USERS

One of the goals of street ethnographic research with drug users is the development of a detailed understanding of the precise technical processes and varied equipment used in drug consumption, with the intent of gaining insights about how these behaviors and implements create or prevent health risks for participants. Another goal of this research is the assessment of the role of particular kinds of social relationships in the acquisition, preparation, and use of drugs. Because of the conditions under which drug use often occurs, achieving these goals can strain the capacities of the single ethnographic researcher. Critical events may take place in concealed locations, occur rapidly, involve multiple actors and a shifting cast of participants, and contain complex and overlapping activities. Trying to merely watch what is happening and use these observations to develop a fine-grained and carefully contextualized description, a traditional task of ethnographic research, may prove to be a frustrating experience for the street ethnographer.

For example, while observing drug consumption by a group of injectors in which several syringes and "cookers" (containers used to mix drugs and water) are being passed back and forth, it may be impossible to accurately track the pathways of equipment transfer. As the ethnographer closely focuses on one part of a drug use scene, he or she may miss other behaviors that are of equal or even greater importance. In order to overcome some of these difficulties, a number of street ethnographers have videotaped drug use scenes (e.g., Finlinson, Colon, Robles, & Deren, 1998), thereby providing a permanent record of events that can be reobserved to identify previously unrecognized acts, social interactions, relevant features of the physical setting, and participant statements and conversations.

Appeals and Challenges of Video

The appeals of video are considerable. Better than any other approach, filming

allows viewers to experience the feeling of what it was actually like in the field setting (Rosenberg, 1980, p. 5). Additionally, the introduction in recent years of low-cost, lightweight, and easy-to-operate equipment has made ethnovideography a practical research strategy. Indeed, videotaping has become a ubiquitous feature of modern life generally, one that can, as the Rodney King case suggests, have important impacts on society; however, as the debates that ensued from the King case indicate, there are an abundance of ethical questions that arise in the cinema verité filming of social events. From the anthropological standpoint, some of these issues involve the use of ethnographic films as educational tools (Piccini, 1996). Gonzalez (1975), for example, asserts that often ethnographic films only serve to confirm rather than debunk social stereotypes about those he called the "exotic other," whereas Williams, Steenveld, and Tomaselli (1986), conversely, point out the potential dangers of cinematic romanticism. Other issues stem from the act of producing a potentially accessible and enduring visual record. In the case of the ethnovideography of street drug use, this entails capturing images of illegal, socially condemned, and often risky behaviors.

The decision to videotape drug injection and crack cocaine smoking by our Hispanic Health Council research team grew out of our efforts to understand the actual processes and patterns of drug consumption, the social networks of drug users, and the social settings in which drug use and AIDS risk frequently occur. Videotaping offered our team an approach for the following:

- Identifying previously unknown pathways of HIV transmission through specific activities and the use of particular drug consumption equipment
- Closely examining the exact stages of the drug-using process and the AIDS and other health risks associated with each stage

(e.g., for assessing whether, before or after injection, drug injectors retain bleach in their syringes for a sufficient time to deactivate HIV)

- Determining the ways in which the social context of illicit drug consumption fosters particular patterns of use and associated risk

During 1998, we videotaped four drug use scenes: (a) a single drug injector injecting heroin in an abandoned building; (b) five drug injectors "shooting up" together in a city park; (c) a cocaine user smoking crack in the kitchen of his rented apartment; and (d) a cocaine user converting crack back into an injectable form by mixing it with vinegar on the hood of his car. These recordings have proven to be very useful in achieving our research objectives; for example, they have helped us to "see" the common and potentially important role of cigarette smoking during both illicit drug injection and drug smoking episodes. But in the course of making and showing these brief videos, our team encountered a number of difficult ethical challenges.

Case 1: Videotaping Bystanders

The first of these problems, and perhaps the one that has been the least difficult to handle, occurred during the filming of the lone heroin injector in a local abandoned building. Located not far from our organizational offices, this neglected and rapidly deteriorating (now leveled) building stood very near to a high-traffic "drug-copping" (drug-buying) area of the city. Access to the building through a doorless back entryway was somewhat hidden from passing cars and pedestrians on the adjacent busy street. These two factors, the ready availability of drugs and concealed entree, made this a popular "get off" site for local drug users. On the day of the filming, two project ethnographers visited the site, as they had on several

previous occasions. The building was empty, save for the enormous accumulation of general garbage and injection-related litter scattered on the floor (discarded syringes, water bottles, bleach bottles, AIDS prevention literature, cigarette butts, soda cans, and crumpled tissues). The latter served as ample reminder of the frequent use of this site for illicit drug consumption. As arranged, the study participant (who had already signed an informed consent concerning the filming) joined the ethnographers after he had acquired a $10 bag of heroin. He quickly took a seat on a milk crate in a somewhat lighted corner of the main room and removed his newly acquired bag of heroin, injection equipment, and syringe cleaning supplies from his bag and set these on a small box. He was now ready to shoot up.

Over the next half hour, this project participant was filmed answering questions posed by the lead author of this chapter, mixing and shooting up heroin, and bleaching and rinsing his injection equipment. This process continued without interruption; but as the filming was coming to a close, two additional individuals arrived at the site intent on consuming drugs. These individuals were not known to the ethnographers. They did seem to recognize the project participant. An uneasy moment passed until these individuals reached the conclusion that we were not narcotics officers or some other threat to them. Although we did not know them personally, they were apparently quite aware of our research program on street drug use. Consequently, instead of running away (the most typical response) or resorting to violence (a less likely but not unimaginable response under certain conditions), these individuals pulled their jackets over their faces and laughingly implored us not to film them (which we had no intentions of doing anyhow). As the researchers left the building, the individuals went to a favorite corner to inject their drugs.

The incident described above was very brief and ended without negative consequences, but it did reveal the potential problems that could ensue from filming in a readily accessible and widely used drug site. However common, cameras are an understandable threat to street drug users, who are aware that the police use video cameras for surveillance. Although it is difficult for many of them to long protect their identities from the police, some report that they have never been arrested. Indeed accounts exist in the literature of drug users who go to considerable lengths to keep their activities a secret (e.g., Kane & Mason, 1992). Cameras have the potential to breach the walls around this hidden information. Further, using them in settings where drug users gather creates the possibility that some individuals may form incorrect impressions about the purpose and identities of the researchers. We sought to minimize these dangers by visiting the site beforehand to make sure that no one was present. In street ethnography, however, once the action begins, the researcher does not control the research setting. Although the presence of a stranger is unsettling for those engaged in illicit activities, a stranger with a camera is all the more cause for alarm. This incident alerted us to the need for considerable caution to minimize the potential for misunderstanding associated with videotaping in natural settings.

Case 2: Videotaping Minors in Illicit and Health-Endangering Behavior

Our next attempt at videotaping was with a group of drug injectors who told us that they shoot up together every day at a secluded location in a local park. As we got to know members of this network, which was self-named "the Super Seven," we inquired about the potential for videotaping its daily drug use ritual. The leader of this group, an enterprising individual who

was always seeking ways to participate in our various research initiatives (and be paid for his participation), seemed open to this idea. When he learned that we were starting a new project focused on understanding the pathways of adolescent drug abuse, he told us that a 19-year-old was about to be initiated into his drug use network by being voluntarily injected with heroin for the first time. We were invited by the network leader to videotape the event.

Although this offer would allow us to view a previously unobserved occurrence, an individual's first injection of an illicit drug, and to videotape a network of drug users, it raised significant ethical questions as well. The individual to be inducted into the group was a minor. Moreover, based on interviews with participants, we knew that at least two members of the network were infected with HIV. If syringes were shared during the injection process, he could be exposed to HIV or other diseases, for example hepatitis.

After fully discussing this situation, research team members reached the conclusion that it would be unethical to be present at or film an adolescent's initiation into drug injection and possible exposure to HIV without trying to dissuade him from pursuing this risky course of action. This put team members in an awkward position because we could be in violation of the wishes of the Super Seven drug network and be seen by them as interfering with their group activities, something that we promised we would not do. As is common during ethnographic fieldwork with street drug users, we were forced to choose between two ethically flawed options.

Beneficence. The basis for our dilemma is found in the wording of the *National Commission for Protection of Human Subjects of Biomedical and Behavioral Research* (1978), specifically in the report's discussion of the enshrined ethical principle of beneficence. The report reads: "Persons are treated in an ethical manner not only by respecting their decisions and protecting them from harm, but also by making efforts to secure their well-being" (p. 6). In this instance, respecting the decisions of group members could block us from making efforts to secure the well-being of the initiate member. Our decision to attempt to persuade the group that the initiation of a minor was wrong was based on our conclusion that in this instance, and with the information we had at hand (health risks of injection drug use and injection equipment sharing), the well-being of a minor superseded our commitment to nonjudgemental, nonintrusive interaction with study participants.

Limitations of ethical codes. Prioritization of potentially conflicting ethical standards is an unavoidable aspect of complex research contexts, a label that well fits the study of street injection drug use. The Belmont Report (p. 1) reads as follows with reference to various codes of proper conduct in research:

> The codes consist of rules, some general, other specific, that guide the investigators or the reviewers of research in their work. Such rules often are inadequate to cover complex situations; at times they come into conflict, and they are frequently difficult to interpret or apply.

In the end, we were rescued from this dilemma when it turned out that the initiation ritual was a ruse dreamed up by the drug network's leader to peak our interest in the group. Our interest, however, was already peaked because of the leader's assertion that group members gathered together each day at the same time to share drugs. If this was true, it constituted a behavior that we had not seen in various other loosely bounded networks of drug users that we were tracking in several of our street ethnographic studies. Consequently, we arranged to have the

leader take us to this communal event for videotaping.

Case 3: Participant Identity

On the day this was to be carried out, two members of the network were arrested for shoplifting and were not present. The other five gathered together in a park in the seclusion of a clump of trees and proceeded, with little encouragement from two project ethnographers, to tell us about their drug-using patterns, AIDS risk prevention strategies, income generating efforts, group dynamics, and related matters. As they talked, they injected drugs into their arms, each individual in his/her own manner. We filmed the event without incident, although the presence of several police cars driving through the park gave us reason for discomfort in that we had in our possession the videotape showing each of the participants injecting drugs and signed consent forms agreeing to allow us to videotape drug injection. Our anxiety peaked when one of the police cars parked just down the hill from where the group was gathered; however, the police remained oblivious to the activities of the injecting group.

Is deidentification possible? To minimize the risk for the participants, a strong effort was made to avoid showing participants' faces; however, because of their movement during the filming process, this proved to be impossible and brief glimpses of several faces were recorded by the video camera.

When we subsequently showed part of the footage (in which no participant faces were exposed) as part of a university presentation about street ethnography, several members of our larger research team who had not yet seen it but who had contact with some of the participants expressed concern that the identities of participants could be detected, for example from an arm tattoo. Another individual who reviewed the video worried that the police might be able to determine the gathering site of the group and lay in wait to arrest them.

Natural or video-motivated behavior. Also expressed was the view that, given the initiation ruse, the whole gathering had been staged to gain the small cash incentives that we offered for allowing us to interview participants and videotape their activities. Other issues were aired as well, but these were not specifically about ethical issues per se (e.g., that the participants were probably much more careful to avoid AIDS risk during injection than they would have been were the camera not present and that they would not have been inclined to inject one at a time, which was not requested by the researchers but did facilitate filming each individual's injection behavior).

One-on-one interviews that we conducted with individuals who participated in the network videotaping affirmed to us that the group had not just been constituted for the purposes of making the videotape; however, these interviews suggested that the strength of group ties was not as great as suggested by comments made by the leader during the videotaping. This point was confirmed when the Super Seven subsequently disbanded. One of its pivotal members, the leader's wife whose earnings in commercial sex appeared to have supplied a disproportionate share of the drugs used by the group, was injured in a car accident.

Risk of video seizure. These issues aside, we were still left feeling uncertain as to whether we had put the participants at special risk by making the video. Compared with field notes, in which participants' names can be disguised and their identities kept confidential, a film record has a higher potential for the breach of confidentiality. Although our research records have never been subpoenaed,

state child welfare officials once attempted (unsuccessfully) to force a staff member to testify as part of an effort to end the parental rights of one of our project participants. Consequently, our projects have sought and been awarded federal protection from the seizure of our research data, which would include our video recordings; however, any showing of the video does create some potential that a member of the viewing audience will recognize an individual. Although it is our intention to minimize this risk by having even partial glimpses of participants' faces digitally scrambled, in such research it is impossible to completely eliminate all risks.

Case 4: When Participants Must Deceive Others

The final example involves videotaping crack use. A participant in one of our studies who was a regular crack user agreed to being videotaped smoking several rocks of crack in his possession. The participant approved the videotaping in his apartment. When the ethnographers arrived at the apartment, the participant proposed filming in the kitchen; the camera was set up quickly and filming commenced. In the middle of the filming, however, two other individuals who lived in the apartment arrived and were clearly quite surprised to find their roommate being filmed using crack. As recorded by the video camera microphone, one of these individuals questioned whether the ethnographers were police; however, the participant, thinking quickly if dishonestly, responded that the ethnographers were from a drug treatment clinic and the filming was needed to verify drug use prior to treatment. The filming concluded without further incident, but from an ethics perspective the incident was regrettable.

As a result of his involvement in our study, the participant had been put into a situation in which he found dishonesty to be the only credible answer that came to mind

(because he wanted to hide from his roommates the fact that he was being paid for his involvement in the video). Had his roommates chosen to question his innovative if unusual answer, friction could have developed and gotten out of hand.

As these examples suggest, videotaping drug users, however appealing as a research strategy, cannot be entered into without considerable planning and a full consideration of the ethical traps inherent in this undertaking. Both the act of filming and the existence of a visual record generate their own ethical questions that require acceptable answers, for example deleting faces, ensuring that permission to film is clear, and devising concrete plans for how to use the video.

CONCLUSIONS

Addiction, overdose, disease, street violence, vulnerability to injury, and exposure to the elements constitute a set of grave threats to the lives and well-being of drug users and, in fact, are the cause of many drug user deaths each year (Singer, 2005). Additionally, and contrary to what some appear to believe, drug users are not an isolated population and can be a source of infection for other sectors of society. For all of these reasons, the study of drug use is a critical public health activity (Power, 2001). Since the beginning of the AIDS epidemic in particular, research focus on drug use has expanded considerably. As a result, the number and kinds of ethical issues raised in such research also has expanded. Although research and public focus on ethical issues in research have taken enormous leaps in recent years, illness, stigma, and illegality make the study of illicit drug use an especially important issue in the ethical-research discourse.

Given the many ethical challenges faced in studying active, not-in-treatment, illicit drug users, some might conclude that this line of research is too fraught with human-subject

issues to be warranted. Additionally, in some cases, especially when multiple review panels are involved (e.g., in collaborative projects involving several research institutions), researchers have been pushed to the limit to address potential human-subject questions and quandaries; however, the critical need for research on drug use, which is an ever changing behavior and hence in continual need of restudy, demands that a fair balance be achieved between protecting human subjects and conducting critically important research. Although in the increasingly distant past the balance was tipped in the favor of anything-goes research, today social scientists—researchers who are not engaged in medical clinical trials or otherwise testing potentially harmful interventions—sometimes feel as if an inordinate amount of time is spent addressing minute human-subject issues like changing a word here and there on consent forms, explaining fairly straight forward procedures in microscopic detail, and resolving conflicting views across multiple initial review boards, rather than conducting vital public health research.

Ethnographers have been especially concerned about the application of human-subject protocols developed in biomedicine (in response to significant ethical violations) to the kinds of research procedures they employ (Fluehr-Lobban, 2003; Marshall, 1992; Marshall & Koenig, 1996). Currently, there is little in the social sciences in the way of human-subject protocol evaluation to determine if various decisions, requirements, procedures, and standards do, in fact, protect research subjects from harm or injury. Perhaps such evaluation is the new frontier in the field of research ethics.

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