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Permalink https://escholarship.org/uc/item/0gw82974

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Publication Date

2024-04-08

DOI

10.1515/9783111142463-005

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CHAPTER 4

ETHICAL ISSUES IN RESEARCH WITH HUMAN SUBJECTS Monica De Roche, Political Science, University of California, Irvine Roxane Cohen Silver, Psychological Science, University of California, Irvine

"All human interaction, including the interaction involved in human research, has ethical dimensions. However, 'ethical conduct' is more than simply doing the right thing. It involves acting in the right spirit, out of an abiding respect and concern for one's fellow creatures."¹

It is often reported in the media that "research finds..." or "research tells us. Accordingly, we often make decisions - from whether to eat meat, smoke, take dietary supplements, who to vote for or whether to vaccinate our children - based on assertions made by research. Many academics conduct some form of research, from education and psychology to social science and medicine. This research seeks to identify some facts or compile information that is reliable in helping us make decisions in important areas. We try to understand what the best course of action is to take, and we routinely rely on research to help us make sense of contradictory recommendations.

It is precisely because research holds such high public regard that consideration of research ethics is so important. But what exactly are the standards that researchers rely on when conducting and publishing research? Are they uniform in nature, or open to interpretation based on circumstance or research question? Many issues abound when discussing research ethics. Furthermore, when research is found to be conducted in an unethical manner, it not only undermines the investigators conducting that research, but also may undermine the legitimacy of science more broadly when news of such breaches reaches the public sphere.

In this chapter, we cover three topics fundamental to research ethics. First, we review historical examples of research misconduct that prompted attention to ethics in human experimentation. These examples provide the framework for assessing the ethical standards that were put in place to protect future research participants and ensure scientific integrity for the research process.

Second, we examine the characteristics that define ethical research standards. Stemming from concerns about the ethics of research, the academic community has developed very clear expectations concerning how research should be conducted. Specifically, we highlight several measures that have established expectations about research with human subjects.

Third, we address research safeguards that are considered when designing research to maintain adherence to research standards. We examine the use of questionable practices, in addition to discussing practical considerations researchers can take to ensure that scientific research is conducted in an ethical manner. We also discuss current issues in research misconduct and consider the moral and practical implications when ethical criteria are not followed.

We conclude by discussing the interconnected roles of investigators and institutional review boards in ensuring the highest ethical standards are met when conducting research, and we contemplate how these measures serve the dual purpose of protecting human subjects while preserving the scientific integrity of research methods.

Historical Examples Prompting Attention to Ethics in Human Experimentation

A focus on ethical research designs is especially important in psychology, cognitive science, or any disciplines that use human subjects. There are several egregious historical examples of misconduct in research where the pursuit of scientific advancement was prioritized over the health and safety of human research subjects. The harm that resulted from these studies brought a great deal of attention to the scientific community and formed the basis of public demands for responsible conduct in research.

Nazi Concentration Camp Experiments

From 1933 to 1945, Hitler created "Concentration Camps" throughout Europe where Jews, gay people, and other individuals determined by the Nazis to possess human deficiencies were removed from society to improve the gene pool. There were a series of experiments conducted by physicians on these individuals that were labeled "medical experiments."² However, many of these experiments were later found to be conducted solely for the sake of experimentation and for no medical benefit whatsoever. Not only were these experiments performed on human beings, but the prisoners of the Concentration Camps were unwilling participants.

Detailed accounts of how these experiments were conducted have been published in the Nuremberg Trial record, in addition to academic journal articles debating the merit of using data from such experiments to further our understanding of current medical issues. These written accounts describe how individuals were submerged in ice water to determine cold tolerance,³ with the justification as seeking to learn how long pilots could exist in icy water. Other prisoners were put into decompression chambers to see how long it would take before they died under high altitude conditions.⁴ These experiments were justified as research about how bodies would respond to extreme conditions. Further experiments were conducted on sterilization.⁵ The Nazis also conducted twin studies, led by the infamous Dr. Mengele, that arbitrarily chose one twin to remain in good condition while the other was subjected to horrible diseases and experiments.⁶ This left tremendous guilt in the twin that was used as the "control" in these studies.⁷

All these horrific experiments were described as research and justified by the fact that they were facilitating the goals of the Nazis. This is a rare example of research misconduct in its most extreme form; however, it is important to recognize that unethical research was not merely limited to activities conducted in Concentration Camps. This did not just happen in Europe, and it was not perpetrated only by Nazis. Unethical research continued through the mid-1900s and was coordinated by respected medical personnel, and in some cases, even facilitated and funded by government researchers, including in the U.S. For example, a more recent study that raised many ethical questions and ultimately contributed to developing more rigorous ethical standards for medical research is the Tuskegee syphilis study.

The Tuskegee Syphilis Study

This study was conducted by respected medical doctors from the U.S. Public Health Service beginning in 1932, around the same time period as the Nazi experiments. The U.S. Public Health program, in collaboration with the Julius Rosenwald Fund (a well-known philanthropic foundation known for helping integrate public schools in the South) characterized the Tuskegee syphilis study as a "*humanitarian effort to benefit the health of rural African Americans*."⁸ The research was intended to examine the natural course of syphilis in African American men to determine if the disease course was the same for white men. In the 1900's syphilis was widespread, and people in public health wanted to understand what syphilis did to people if left untreated.

In Macon County, Alabama, 600 Black men were enrolled in the study; 399 were infected with syphilis, and 201 were not infected with syphilis.⁹ Participants were not told that they had syphilis or that the disease was sexually transmitted, and there is no evidence that they provided consent. At the start of the study, there was no known cure for syphilis; however, in 1943, penicillin was developed to treat syphilis.¹⁰ Even though treatment was available to the infected men, the doctors decided to withhold it from the study participants to raise the consciousness of the public to the problem of syphilis. They wanted to maintain the momentum of public health education in this rural Alabama area. The Tuskegee syphilis study continued for 40 years before finally ending in 1972 when the program was exposed in a local newspaper, leading to public outcry.¹¹

The researchers made a conscious decision that the cost to the participants – who were in a vulnerable group, i.e., poor, rural, and black – was justified by the gains to the wider community. Unfortunately, they continued this work for over 25 years after penicillin was discovered as a treatment for syphilis. Rather than provide penicillin to the infected study participants, the researchers decided to withhold the widely available treatment and to instead track the men until their deaths. This decision not only had catastrophic effects on the study participants themselves, but it also directly and indirectly affected their families, including the exposure and infections of unknowing spouses, children, and others.¹² The negative effects of the Tuskegee study are so far reaching in scope that they cannot fully be quantified. For generations of African Americans, the mistrust in the medical community instilled by it lingers to this day.¹³

Ethical Research Standards

Any discipline that uses human subjects must consider what constitutes responsible conduct in research. The debate between what science *can* accomplish versus what means scientists should employ to achieve it is one that researchers continue to reckon with. Unfortunately, as described above, history is replete with horrendous examples of when the priority for what science *could* accomplish came at a tremendous cost. Many research standards in place today came about after gross misconduct in research that deliberately caused human suffering and death in the name of scientific advancement. The two fundamental standards that established expectations for the responsible conduct of research are the Nuremberg Code and the Belmont Report.

The Nuremberg Code

The Nuremberg Code marked a significant shift that influenced science and how scientific experiments are run today. It set an ethical standard that protects research subjects and adheres to the post-war human rights era.¹⁴ The Nuremberg Code was established after World War II and the defeat of Nazi Germany. The Nuremberg Trials were held to bring war criminals to

justice. Surprisingly, war criminals did not just include generals and military officers but also doctors who committed crimes against humanity during the war. The military tribunals produced 10 standards, collectively known as the Nuremberg Code, that guide physicians' practices when carrying out experiments with human subjects. The Nuremberg Code limits experimentation on humans and mandates that such experiments be conducted in a manner that satisfies *"moral, ethical, and legal concepts."* It includes a mandate for the voluntary consent of research participants and the right of any research participant to terminate their consent at any time, along with safeguards to prevent unnecessary risks on the research participants and to protect against human research for the sake of experimentation alone.¹⁵

The Nuremberg Code was the first official effort to quantify what it was legal to do to people in the name of scientific inquiry and what needed to be done to justify behavior against other human beings for medical and psychological research. Despite this, unethical research continued well into the 20th century, carried out by individual academic researchers and public entities alike. Considering this ongoing dilemma, some scholars argue the Nuremberg Code has not done enough to protect research participants and ensure ethical standards are met.¹⁶

Experiments involving human subjects are nearly always considered *socially sensitive research*, or research that has the potential for social consequences for the participants of that study and/or the larger community. This is especially problematic in studies with the potential for broader inferences to be made about a particular group, or class, of individuals as a result of the study of one subset of that group.¹⁷ These types of socially sensitive research studies are more likely to draw the public's attention to the scientific integrity of the project than other research that is deemed "low risk."

In a cost-benefit analysis, the greater the risk posed to the participants, or participant group, the greater regulation that is expected to ensure the study is conducted ethically.¹⁸ Just as the study of physics can lead to scientific breakthroughs with the potential to better human

existence, it also has the potential to create nuclear weapons. The same can be said for psychological experiments where research that can be used to better understand human behavior can also be used to label and unfairly stereotype or harm certain groups of people. The need for human subjects in many forms of research and the misuse of human research participants indirectly led to the creation of a mandated set of research standards to govern human subjects, starting with the Belmont Report.

Belmont Report

The Belmont Report was commissioned out of the U.S. National Research Act of 1974 to identify the fundamental ethical principles that ought to form the foundation of any research involving human subjects to ensure those subjects are protected and informed.¹⁹ The report considers three basic ethical principles that should be applied to all studies involving human subjects: respect for persons, beneficence, and justice.

Respect for persons means that all research should be conducted in a manner that 1) respects the right of all individuals to personal autonomy and 2) protects individuals with diminished autonomy. The first portion of this mandate dictates that human subjects must enter the research voluntarily and with adequate information about what the study encompasses. This principle of autonomy is often violated in the most egregious examples of research misconduct and is considered a basic, fundamental right to all research participants, forming the basis of the concept of "informed consent."²⁰

Second, respect for persons means that we as researchers must protect people with diminished capacity. This means that it is virtually impossible to conduct experiments on people with diminished mental capacity, and special attention and oversight must be given to research conducted on prisoners, pregnant women (because the fetus cannot grant permission), and children. So, the general notion is that respect for persons must be a primary concern of researchers in theorizing and conducting any study involving human subjects. While most of us

have signed consent forms at the doctor's office before receiving treatment, this principle ensures that people must be able to make the choice to participate and can make this decision themselves.

Beneficence is rooted in the notion that we should do no harm to research participants. Research that is deemed to be without serious purpose or meaning is known as *frivolous* and is considered unethical. An example of this would be putting people into ice water until they pass out. This would be regarded as frivolous, not in the common use of the term, but because it is obvious what will occur. If one is going to engage in experiments on human subjects, the benefits of that research must outweigh the risks to those participants. This principle is seen as an obligation of all researchers when conducting a cost-benefit analysis of a research project and demands that the good of others does not take precedence over the interest of one. Thus, beneficence requires that researchers ensure that subjects are not harmed and that benefits are maximized while possible harms are minimized.

Justice assesses the fair and equitable distribution of both the benefits of research and the burdens of that research. Injustice occurs when a benefit is denied to a subject without good reason or when a burden is inflicted unjustifiably. An example of this principle in action is the aforementioned Tuskegee syphilis study, where one group (the study participants) was denied a benefit (penicillin treatment for syphilis) and as a result, suffered an undue burden (sickness and/or death) for the perceived good of others in contributing to public knowledge about syphilis. In this case, study participants had to bear the burden of the research without receiving any of the purported benefits of that research.

The three principles articulated in the Belmont Report form the foundation of ethical research standards and serve as a basis for the general rules of research that followed. However, this was not a panacea to the issue of regulating ethical research. When the people conducting the research (the researchers) believe that they are doing important, useful work, this belief can

compromise their decision-making. This highlights the need for external monitoring, or oversight, in studies involving human subjects.

Before the 1970s, there were limited guidelines to know if research was ethical. Rather, individual researchers decided it on a case-by-case basis. But no one is totally unbiased about their own work. Researchers want to do the research that they are most interested in and invested in, and this desire inherently informs their motivations and rationalizations to do it. So today, the rules have changed, so now it is not only the researcher who decides what is ethical.

The National Research Act was passed by the U.S. Congress in 1974, which created the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. This Act made it a requirement for Institutional Review Boards (IRBs) to approve studies that involve human subjects and to obtain voluntary informed consent from research participants.²¹ Any research that involves human subjects must go through a review by an IRB, which has strict rules to which both professional and student researchers must adhere. Ethical standards incorporate the idea that subjects should participate voluntarily in a study. They must be able to understand the research and freely decline participation. Researchers must complete a document in which they make the case that their research is not harmful, is useful, and ethical. This document requires a complete research plan to include a detailed account of what participant identifiers will be collected, how this information will be stored, what participant identifiers will be made available in the study (e.g., gender, age), and what risks participants might be exposed to by nature of their participation in the study. The goal of IRBs is to help the researcher decide if experiments are ethical. Perhaps more importantly, IRBs offer a gatekeeping mechanism to ensure scientific integrity both within academia and to those in the community at large.

Today, in the current research climate across the world, there is the expectation that participation in research must be voluntary. However, this is not always the case, and people sometimes do not know they are involved in research. Further, people who take part in the research – called subjects – must be able to understand the nature of the research and have the opportunity to agree or refuse to participate. They should be told how long the research will last. They should be able to opt-out of the project at any time if they wish. These practices, however, are often complicated by competing interests and factors that create "grey areas" regarding how standards are incorporated into each research study design. They require that research safeguards be employed when using questionable research practices.

Questionable Research Practices and Research Safeguards

Questionable research practices are more often found in medical research and psychology compared to other social sciences because the lines between ethical and unethical are often blurry. Consider, for example, the ethics of random assignment to conditions in medical experiments where someone (the control) does not get the potentially life-saving treatment. The control group may instead receive a placebo – an inert comparison or a presumably harmless procedure – but the notion of being assigned randomly to a placebo is ethically challenged. Do the goals of the experimental design justify withholding drugs that might help someone who is sick? One can clearly see the ethical dilemma when employing questionable research practices in a medical setting. But sometimes in psychology experiments, the distinctions are not always as clear, nor the consequences as obvious. Six of these questionable practices will be discussed in greater detail below; they include informed consent, compensation of research participants, deception, debriefing, confederates, and the use of sensitive information in research.

Informed Consent

Informed consent is often complicated in research. For example, subjects are told they *may* or may *not* get the placebo. Moreover, although the experimental procedure is usually presumed to be helpful, it may turn out to be more dangerous than expected. Thus, the notion of informed consent is not only complicated but also ethically ambiguous at times. This is especially true when participants are not fully briefed (and therefore may not fully understand the

implications) on what exactly it is that they are consenting to. The notion of informed consent assumes people are informed about everything to which they will be exposed so they can have full knowledge to agree or decline to participate. In reality, participants may need money or lack access to medical care; or they do not know or cannot fully grasp the reality of what the experiment *can* do to them. All of these issues call into question the ability of the researcher to consistently obtain informed, voluntary consent from research participants.

Compensation of Research Participants

There are ethical dilemmas involved not only with compensating research participants but also with determining how much compensation those research participants should receive. Sometimes people are offered so much money or so many benefits to do the research that their ability to opt-out of the research becomes only theoretical. This may be especially true when substantial sums and/or free medical care are offered to vulnerable populations, thereby calling into question whether the compensation is coercive and interferes with their ability to consent to the research freely.

To give just one example, consider an adolescent who has asthma. Emma was offered the opportunity to take part in an experiment with a new experimental drug. She was told she would be given either a placebo or a new medication. Emma was asked to fill out a diary for several months after she took the drug/placebo. Emma was offered \$850 to take part in this experiment. Emma's mother thought this was coercive precisely because of the generosity of the researchers: for a 15-year-old girl, \$850 is a lot of money. When Emma's parents asked why the compensation was so high, they were told that teenagers would not participate unless they got substantial compensation. So, there are concerns with what we could call "coercive compensation." Compensation should not be so high that it inhibits participants from opting out, even if they have qualms later. In this case, Emma decided to participate in the study. Her parents, well-educated and sensitive to the possible problems involved in the research, nonetheless allowed it because

the potential benefits of the experimental drug exceeded their concerns. However, after only a week on the new drug, it became apparent to both Emma and her parents that she was in the control group. Emma's health was not improving, but because she had committed to continue with the research until the end, Emma ended up going four months without getting any additional treatment. It is quite critical that people be allowed to withdraw from experiments, but, as this illustration suggests, there are many reasons why people may not withdraw when, perhaps rationally and objectively, they have good reasons to do so.

Researchers sometimes withhold full compensation until the end of the experimental trial, both to encourage participation and minimize attrition (that is, dropout). Researchers are expected to report any dropout from the experimental and control groups when they seek to publish their study findings; there are also many implications to changes in the number of study participants over the course of a study that may negatively impact the results. So, researchers have a strong incentive to keep participants invested in the experiment for the duration of the study, and monetary compensation is a strong motivator for most people. Thus, some experimenters try to balance this by giving compensation over time; if a participant drops out before the end of the study, it is felt that they should still get some compensation for their efforts, but not all of it. In other words, participants are not penalized for withdrawing from the study, thereby ensuring the voluntary nature of the research, while also still providing an incentive for them to remain in the study for its entire duration.

Deception

There is a class of experiments conducted in the real world where people do not know they are in an experiment. An example of one of these field experiments would be a study that explores circumstances that promote helping behavior, for example, when such behavior is modeled by others out in the street or a subway station. In those situations, it is deemed more ethical *not* to tell people they are in an experiment as it is expected that they will change their

behavior if they are made aware that they are being watched, which defeats the purpose of examining how people behave when they think no one is watching.²²

Sometimes subjects are told the experiment is about Topic A when it is really about Topic B. This is often the case when researchers feel that if participants knew the real purpose of the study, that knowledge would likely influence their behavior. For example, in studies of eating behavior, people are often told that they are in an experiment on taste perception. Is the food tasty? Sweet? etc. Findings have revealed that sometimes people eat more when they are unobserved.²³ But to get them to engage in eating in a laboratory, they are often told a "cover story" that is not true. Essentially, their "informed" consent is deceptive.

Researchers do this because the knowledge of the true purpose of an experiment would likely lead them not to behave naturally. For example, the Milgram study, where participants were induced by an authority figure to give an electric shock to another study participant (a confederate of the researcher) was said to be on learning, not on authority.²⁴ In fact, there is no way to do studies on many topics *without* deceiving people. Deception experiments are less popular than they were decades ago but remain quite common. Nonetheless, ethical standards still need to be met when deception is employed. The usual way this is achieved is by asking: What are the risks and what are the benefits of this proposed study, and are the benefits greater than the risks? In many cases, a deception experiment can thus be judged ethical.

Debriefing

Sometimes, but not always, the participants are debriefed after an experiment, i.e., the true nature of the experiment is disclosed to them. If people know they are in an experiment and the researchers use cover stories that are not true, it is considered unethical *not* to debrief participants. An example of this is a research study in which participants are given performance feedback after an assigned task. The true purpose of the study is to measure how negative

feedback affects self-esteem, but participants are told that the study is measuring their cognitive performance abilities.²⁵

In such a study, those participants assigned to the experimental condition complete an arbitrary task on the computer and are given negative performance feedback and told that this is *"a statistically reliable predictor of cognitive ability and future decision-making capacity."* Participants in the control condition are told that the performance feedback is *"generated at random and therefore invalid."* Afterwards, participants in both groups complete a measure of self-esteem. In a study that used this procedure, results indicated that as predicted, participants in the experimental condition reported lower evaluations of their self-esteem.²⁵ Other studies have taken this a step further to then have participants perform additional tasks to measure how feedback impacts future performance.²⁶

In these cases, *not* debriefing the subjects could lead to long-lasting negative effects on their self-esteem, and thus the potential benefits of the study would not outweigh the risks to the participants. Debriefing focuses on the responsibility of the researcher to do no harm to research participants. But these issues need to be carefully weighed on a case-by-case basis.

Confederates

Another questionable research practice is the use of confederates. In many introductory social psychology courses, one of the things that is done is to have students conduct their own studies around campus. Some of these rudimentary psychology studies (based on the classic Asch conformity experiments) illustrate that if you have everybody walk into an elevator and turn backwards, others will do the same thing.²⁷ The people facing the back of the elevator are accomplices, or confederates, of the researcher; sometimes called stooges. These individuals act out a prescribed role as a research participant, or as in the case of the elevator study, they may pretend to not be a part of an experiment at all in order to induce natural behavior from the actual study participants.

One experiment that used confederates was conducted on personal space, which built on the notion that people feel uncomfortable if their personal space is invaded. Previous research on personal space was anecdotal so researchers wanted to understand the physiological consequences of having one's personal space invaded. They argued that it was an uncomfortable experience, and this emotional arousal should have physiological consequences. The study was done in a U.S university in men's urinals. The researchers examined urination responses as a measure of personal space physiology.²⁸ Researchers would assign subjects to one of three situations.

The first was a close invasion of personal space. There was a confederate standing at the urinal in the middle, so the subject had to use the urinal next to the confederate beside them. The second was a moderate invasion of personal space. A confederate was stationed in the restroom, but the subject was not forced to use the urinal directly adjacent to them. In the third (control) condition, there was no one in the restroom when the subject entered. The researchers had an experimenter in a stall with a periscope and two stop watches to measure the onset of urination of the subject and how long it lasted as they used the urinal. This was to measure delay of onset of urination and speed of completion. They found that the closer someone was next to you, the more time it took to start urination and the longer it took to finish.²⁸

In this experiment, there was no informed consent. People were just going into the lavatory. Yet they were being examined using a urinal. Should people be informed in advance? Doing so would affect the experiment, so someone must decide if the risk exceeds the cost from a violation of privacy. Ask yourself how you would feel in this situation. Would it be better for you to be told there was someone in a stall, measuring the start and end of your urination time with a stopwatch? Or are you better off not knowing you are being observed? In the urinal study, there was no way to remove the embarrassment of being observed, so the researcher would not debrief because they could not take away the shame of being observed by a confederate.

The urinal study is one in which the question of ethics is overwhelming (and it is important to note that in today's research environment, it is unlikely that this kind of research would be allowed to occur), however there are many other examples in which the answer to these questions is not as black and white. It is in these myriad grey areas that researchers must be especially sensitive to the potential ethical dilemmas involved when utilizing questionable research practices.

Sensitive Information

Mitigating potential harmful effects of research continues even after a study has concluded. In many cases it is important to ensure that the research participant's identity is protected. This is especially true regarding sensitive data where the individual could be harmed or face negative social consequences if their identity were compromised. So, for example, a study will often not reveal exactly where it occurred. If research is not conducted anonymously and the researchers retain data that they have promised to keep confidential, it is the researcher's responsibility to keep that information confidential. We researchers must ensure the data are not stolen. When interviewing subjects, researchers are compelled to disclose what the researcher will and will not do with this information, in addition to informing the participant how this disclosure may potentially affect them. For example, if conducting research with individuals who have been exposed to a disaster, it is important to consider how re-exposing them to that trauma may psychologically affect them and provide appropriate coping resources.²⁹ We need to ensure our work is useful, in addition to ethical, to do the most good and the least harm.

Current Issues in Research Misconduct

We have all heard stories in the press in which a researcher is discovered to have conducted research in a blatantly unethical manner. These incidents range from reporting erroneous data and withholding findings to falsifying data and fabricating experiments.³⁰ While these incidents may not carry the obvious gravitas of experiments such as those conducted in the Nazi Concentration Camps or the Tuskegee syphilis study, "lower cost" examples of research misconduct still cause damage in terms of the erosion of public trust in academics and the institution of scientific research more broadly. This leads one to question why research misconduct continues and what can be done to stop it.

There is an age-old mantra within academia concerning the "publish or perish" prerogative and the pressures that academics face in meeting publishing mandates; mandates which have partly been blamed for some researchers conducting and/or reporting unethical research. An analysis of all 788 English language academic papers retracted over a ten-year period found, however, that 53% of fraudulent papers were written by a 'repeat offender' compared to 18% of erroneous papers. Interestingly, the study revealed that significantly more papers were retracted for fraud versus errors in research in the U.S. *than in any other country*.³¹

These findings seem to infer that in the instances where data are falsified or fabricated, the intent was fraud rather than misguided error, which further validates the need for regulatory oversight in research practices. While we can all agree that falsifying or fabricating data is unethical, there is a lack of consensus within academia as to the severity of other ethical dilemmas.³² Many of these involve questionable research practices, or grey areas; some of which were described in the preceding sections, where research guidelines are often open to interpretation and competing interests.

Conclusion

For a long time, discussing ethical dilemmas in research was not common practice within the academic community. The publicity surrounding some of the more egregious examples of research misconduct noted in the prior section made it clear that regulations were needed, but for many years the focus of these regulations were more pragmatic in nature, such as obtaining informed consent and ensuring the confidentiality of research participants' identities. However, in recent years there has been a gradual shift towards greater transparency regarding the ethical implications as it applies to *all* aspects of research – from planning and piloting to publishing and authorship. In that vein, the American Psychological Association's Ethics Code now provides recommendations for navigating ethical issues by encouraging researchers to actively discuss ethics and work closely with their institution's IRB to maintain systems of accountability *throughout* the research process.³³

In closing, it is important to note that ethical dilemmas are very rarely black and white. As this chapter has attempted to illustrate, multiple decisions are made at every step of the research process, and at every one of those steps, there are important decisions to be made about how to proceed in an ethical manner. And all of this is not without controversy. Some scholars question whether IRBs have transitioned from their intended role of protecting human subjects to protecting the researchers and institutions that fund them.³⁴ Furthermore, the regulations are sometimes seen as unduly burdensome to researchers, especially student researchers conducting studies with minimal likelihood of risk to human subjects.³⁵

Thus, discussing ethics in research must be an ever-evolving, ongoing dialogue between both researchers and the public alike. Acknowledging the constraints in providing proper regulation and oversight of research are critical to ensuring accountability within the scientific community. Previous egregious examples of ethical misconduct have resulted in catastrophic consequences to individuals and groups, in addition to undermining the legitimacy of researchers and scientific research more broadly. As researchers, we must accept accountability for how ethical dilemmas in research have threatened to undermine the work that we do. This is not only key to individuals who depend on research to help them make important decisions, but also in maintaining public trust in the scientific integrity of research.

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