Several years ago, the University of Minnesota hosted a lecture by Alan Milstein, a Philadelphia attorney specializing in clinical trial litigation. Milstein, who does not mince words, insisted on calling research studies “experiments.” “Don’t call it a study,” Milstein said. “Don’t call it a clinical trial. Call it what it is. It’s an experiment.”

Milstein’s comments made me wonder: when was the last time I heard an ongoing research study described as a “human experiment”? The phrase is now almost always associated with abuses. Ask people what they think of when they hear the phrase “human experimentation” and chances are they will reply, “Nazis.” James Jones gave his book Bad Blood the subtitle The Tuskegee Syphilis Experiment. Philip Zimbardo’s controversial study on the psychology of imprisonment is commonly referred to as “The Stanford Prison Experiment.” New Zealand’s most notorious research scandal, on women with cervical carcinoma in situ at Auckland Women’s Hospital, is known colloquially as “The Unfortunate Experiment.” Asking a prospective subject to sign up for a medical experiment would probably get roughly the same response as asking him or her to sign up for a police interrogation.

It wasn’t always this way. In the early days of American bioethics, scholars used the word “experimentation” in the same neutral way that they later began to use “research study” and “clinical trial.” Hans Jonas titled his famous 1969 Daedalus article “Philosophical Reflections on Experimenting with Human Subjects.” In the 1966 essay “Ethics and Clinical Research,” Henry Beecher made frequent use of phrases such as “experimental subjects,” “human experimentation,” and “experimentation in man.” Richard McCormick and Paul Ramsey often used the phrase “experimentation” in their debate in the mid-1970s about research on children. This usage reflected the vocabulary of medicine itself, in which the word “experiment” had not yet acquired a menacing undertone. For instance, Ancel Keys did not hesitate to use “experiment” in describing his work on the physiological effects of semistarvation at the University of Minnesota in the 1940s. In the two-volume book that resulted in 1950, The Biology of Human Starvation, Keys and his colleagues even titled one chapter “The Minnesota Experiment.”

By the time I began working in bioethics in the early 1990s, however, “experiment” was being phased out. Today, when anyone involved in health care uses “experiment,” it is usually in reference to scandals from the past. Over the past ten years, for instance, PubMed lists only thirty-four articles with the phrase “human experimentation” in their titles, and thirty of those concern either historical research abuses or ethically controversial research.

Experimentation has also disappeared from codes of ethics. When the Nuremberg Code was published in 1948, it referred to “experiments,” “experimental subjects,” and “experimental physicians.” It made no mention whatsoever of “research.” The first version of the Declaration of Helsinki, issued in 1964, employed a combination of phrases: sometimes “experimentation,” sometimes “research study.” That mixed language stayed relatively consistent through the next six revisions of the Declaration. But in 2008, when the Declaration was revised in Seoul, “experiment” was almost completely purged from the document. The word is used only once in the current version, and then only in reference to the need for “animal experimentation.”

What is the reason for such a dramatic shift? A charitable answer is that it simply reflects greater attention to lin-
guistic accuracy and precision. Not all research studies are experiments. Nor are they all clinical trials. Chart reviews, surveys, ethnographies, epidemiological studies, and many other kinds of medical research could hardly be described as “experiments,” insofar as “experiments” suggests scientific testing conducted under controlled conditions. In addition, as the authors of The Belmont Report pointed out, not all experimental procedures count as research. A radical new procedure may be untested and thus experimental but not part of a formal research study. Maybe the phrase “research study” is simply intended to be broader and more inclusive.

But today, even the most obviously experimental research studies are described in language that seems intended to hide that fact. Take, for instance, the disastrous trial of TGN1412 at Northwick Park Hospital in 2006. This was a phase I study of a monoclonal antibody that, within minutes after it was administered, sent six subjects on the way to multisystem organ failure. If any drug could qualify as experimental, it was TGN1412, a novel immune-modulatory compound that had never before been administered to humans. Yet in the consent form that the research subjects were asked to sign, the words “experiment” and “experimental” never appear.

It’s not hard to understand why. In 1995 the Advisory Committee on Human Radiation Experiments surveyed patients to compare their perceptions of the terms “clinical trial,” “clinical investigation,” “medical study,” “medical research,” and “medical experiment.” Patients ranked the phrase “medical study” as by far the most benign-sounding term. A “study” means looking at records, said one patient. “It is mostly paperwork, documents, or the books and things.” Patients thought the phrase “medical experiment” suggested a riskier, scarier undertaking. One said, “I envision all kinds of weird things done to the body, and I assume that’s not true, but also I envision a medical experiment maybe . . . done in a laboratory sealed up somewhere where no one even knows what [is] going on.” Some people said they would not consider taking part in an “experiment” unless they were terminally ill.

These responses point to a more plausible explanation for the shift away from “experiment.” Once the word became associated in the public mind with abuse and exploitation, calling something an “experiment” started to sound like an ethical condemnation. Today the choice whether to refer to the testing of a new drug in humans as an “experiment” or a “research study” seems like an ideological decision, like whether to call waterboarding “torture” or “enhanced interrogation” or whether to use the term “alien” instead of “immigrant.” Many writers and organizations, attempting to remain neutral, simply choose the language sanctioned by the authorities.

In this case, it is clear what the authorities prefer. The research establishment has a vested interest in using language that portrays its work as safe, carefully regulated, and socially beneficial. And of course, if the language itself does not comply, it can be pushed. In 2008, for instance, in order to combat unfavorable public opinion about medical research, Eli Lilly funded a public relations campaign called “Medical Heroes in Everyday Places.” Developed by the public relations firm Ogilvy and Mather and organized through the Center for Information and Study on Clinical Research, the purpose of the campaign was “transforming public perception of the clinical trial participant from ‘guinea pig’ to ‘medical hero.’” An updated campaign in 2015, titled the “Rethink Research Competition,” produced slogans such as “Heroes aren’t hard to come by,” “Remedi THIS,” and “Going study.”

Perhaps it should not be surprising that bioethicists have changed their language as well. Today’s bioethicists are employed by hospitals and medical schools, publish in medical journals, and apply for NIH research grants. Some consult for pharmaceutical companies and contract research organizations. In this world, medical language serves as a kind of code for insiders. The choice to use a particular word or phrase indicates where the user is situated in relation to the invisible lines between researchers and subjects, clinicians and patients, advisors and critics. As long as bioethicists worship in the same church as the scientists and the clinicians, it will feel natural for them to sing the same hymns.

The choice to abandon the word “experiment” is emblematic of a larger movement beginning in the 1990s, in which many bioethics scholars moved from being critics of the research enterprise to being its champions. Probably the most striking example is the argument now made by a number of prominent bioethicists that every citizen has a moral duty to enroll in research studies. “There is a prima facie obligation to participate in biomedical research,” a group from the Department of Bioethics at the National Institutes of Health has written—an obligation that includes even research sponsored and designed by the pharmaceutical industry. “Whether a study is publicly or privately financed,” the group insists, “has little bearing on the obligation to participate in that study.”

Their is still a minority view. But a much larger and more influential shift can be seen in the way many bioethicists have come to champion the social benefits of research, especially to particular “communities.” In the 1990s, for instance, feminist writers began to argue successfully that excluding women from clinical trials meant excluding them from the social benefits of medical research—namely, knowledge about how illnesses affect women and what drugs and procedures might be best used to treat them. Conceptualized in this way, research guidelines did not simply protect subjects from harm; they denied communities access to health care. Once research was described anew as a social benefit, it could be used as a justification for recruiting subjects from some of the very populations that had been victimized in the past. Only twenty-five years after the Tuskegee syphilis experiment, for example, the authors of Beyond Consent would suggest that “overprotection” of racial minorities may result in a failure to address their health needs.
Along with the reconfiguration of research as a social benefit have come efforts to replace the term “research subject” with the softer, friendlier “research participant.” In a 2001 report, the National Bioethics Advisory Commission laid out its rationale for the change. The word “subject,” the commission said, “connotes society’s worst fears about research participation, rather than its aspirations.” One way to dispel such fears is to use the phrase “participant” in order to emphasize that “individuals should be active, not passive, in the decision to enroll in research studies.”

This particular change was driven at least partly by patient advocates. During the early days of HIV-AIDS activism, many advocates resented being seen as mere test subjects and wanted to play a more active role in planning a research agenda. To many, the phrase “research participant” felt empowering. Whether subjects were actually empowered is another matter. This change to the language may make subjects sound more like collaborators in the research enterprise, but it does not change the fact that the subjects are the ones taking the experimental drugs—rather than the ones designing the protocol, administering the medication, analyzing the data, or authoring the publications. A handful of activists understood this power relationship more clearly. In the mid-1990s, when Bob Helms began publishing Guinea Pig Zero, his zine for research subjects, Helms and his fellow operatives used phrases such as “lab rat,” “guinea pig,” “brain slut,” and “medical meat puppet” in order to highlight their relative lack of power.

Because no agency tracks deaths and injuries in medical research, it is hard to know whether research has become safer or more dangerous in recent decades. But research scandals are not hard to find. The most notorious recent scandal, of course, is the death of Jesse Gelsinger at the University of Pennsylvania in 1999. But there have been many others. There were the deaths of healthy volunteers such as Nicole Wan at the University of Rochester, Ellen Roche at Johns Hopkins, and Traci Johnson at Eli Lilly Laboratories. There was Protocol 126 at the Fred Hutchinson Cancer Center, in which at least twenty subjects died; Pfizer’s notorious Trojan trial, in which eleven Nigerian children died; and the “bacteria-in-brain” episode at the University of California, Davis, in which three neurosurgical patients died. My own institution, the University of Minnesota, has been involved in a series of psychiatric research scandals dating back to the 1990s—most notoriously, the suicide of Dan Markinson in an industry-funded antipsychotic study in 2004. The poor and disenfranchised have been hit especially hard—for instance, in the SPBCF International episode in Miami, in which researchers paid undocumented immigrants to test the safety of unapproved drugs in a converted motel, or by the ongoing recruitment of mentally ill subjects from homeless shelters in Philadelphia.

It is entirely understandable that careful, conscientious medical researchers would want to distance their work from the exploitation and injustice of the past. And if the word “experiment” conjures up past scandals, it is natural that they would prefer to avoid it. But is that strategy intellectually honest? As early as 1996, George Annas argued that it was not. “[F]or many potential research subjects, deception or self-deception is inherent in our current research endeavors,” Annas wrote, comparing the language of clinical research to the political sloganeering of Orwell’s 1984. “Even a cursory examination of modern human experimentation demonstrates,” he said, “the pervasiveness of three double-speak concepts: experimentation is treatment, researchers are physicians, and subjects are patients.”

It is hard to disagree with Annas. Yet it is even harder to fight against the linguistic current. The shifts that Annas warned about in 1996 are now so fully entrenched that they strike no one as unusual, much less controversial. Even Annas himself occasionally used the phrase “medical research,” rather than “experimentation,” in his critique. I have done the same here, of course. Doing otherwise would strike many readers as an unnecessary provocation. To the extent that this is true, the fight has already been lost.

Alan Milstein says that when he is deposing clinical investigators, he often asks them why they don’t use the word “experiment” when they talk to subjects. Inevitably, they say that the word carries too much baggage. To which Milstein replies, “That is what is so wonderful about language. Words carry meaning and history.”


