The essay "Uses and abuses of Tuskegee" drew many responses. An African American reader writes to point out the participation of many African American health workers in the study: "We African Americans must learn from history, but we will only do so if our abuses to ourselves are not hidden. Too often, we have seen the enemy—and it is also us." A physician-researcher expresses concern that researchers' goals may become removed from the population they are trying to help. And two sets of critics of a needle exchange program in Alaska that they likened to the Tuskegee study defend their positions. Also, book author Derek Freeman invites the reader to examine his evidence for the conclusion that Margaret Mead was hoaxed about the sexual practices of Samoan women.

Tuskegee as a Metaphor

The otherwise appropriate and excellent essay "Uses and abuses of Tuskegee" by Amy L. Fairchild and Ronald Bayer (Essays in Science and Society, *Science*'s Compass, 7 May, p. 919) omits important information about the Tuskegee syphilis experiment.

This appropriately vilified experiment would not have been possible without the collaboration of African American physicians, nurses, and community workers at Tuskegee Institute.

This information is well documented in a book to which the authors refer (*1*) and in the excellent television documentary "Susceptible to Kindness: Ms. Evers' Boys and the Tuskegee Syphilis Study" by David Feldshush, produced by the American Conservatory Theater, San Francisco. The omission of the collaboration of African Americans in the Tuskegee experiment is common. At a recent conference at Tuskegee (*2*), the Tuskegee syphilis experiment was repeatedly referred to by the president of Tuskegee University and other speakers. The U.S. Public Health Service and others in the federal government were appropriately castigated, but no one at the conference admitted to the complicity of African Americans. We African Americans must learn from history, but we will only do so if our abuses to ourselves are not hidden. Too often, we have seen the enemy—and it is also us.

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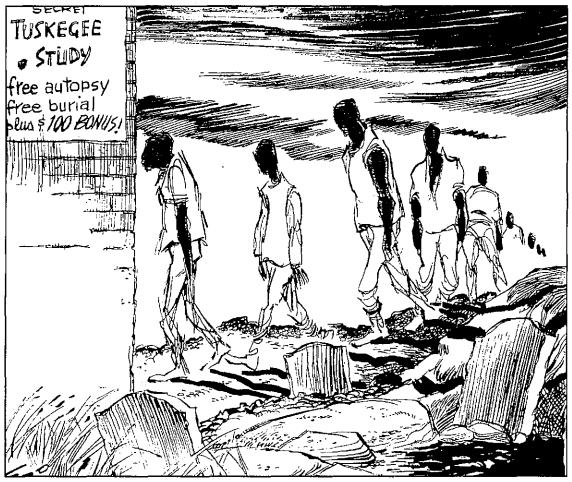
2. *Plain Talk About the Human Genome Project: A Tuskegee University Conference on Its Promise and Perils and Matters of Race*, E. Smith and W. Sapp, Eds. (Tuskegee University, Tuskegee, AL, 1997).

As a physician-researcher working in a public hospital, I have become acutely aware of the strength of the metaphor of the Tuskegee syphilis study in vulnerable populations. A critical point not fully discussed by Fairchild and Bayer is that in both cases of needle exchange, treatment of the underlying medical condition and the social context were not addressed by the intervention, leaving the subjects persistently vulnerable to the possibility of disease. The disconnect between the researchers' agenda and the needs of the community under study parallels the Tuskegee study. In each example cited by the authors, the interventions were focused on the researchers' agenda, not on needs voiced by the community—effective treatment of substance abuse and early treatment and prevention of HIV. In fact, it is unlikely that the investigators solicited the views of the communities. The absence of community assent subsequently led to questions of how the population under study would benefit from the research (*1*).



Cartoon from *The Atlanta Constitution*, 27 July 1997

In addition, the authors prescribe very narrow guidelines for invoking the parallels to Tuskegee. As evidenced in their essay, allegations of "another Tuskegee" come just as often from the lay community as from the scientific. The reality is that knowledge of the Tuskegee study in vulnerable populations and their advocates is widespread, but not always bound by historical accuracy (*2*). Fundamental to each of the examples cited is a population vulnerable because of ethnicity or social class, or both; the perception of withholding therapy; and a controversial disease with the potential to further stigmatize and marginalize that population. These are the criteria used by the lay public to draw parallels to Tuskegee and a combination that historically has led to exploitation. The suggestion of guidelines based only on historical accuracy further emphasizes how removed we have become from the very populations our investigation is intended to help.

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We invoked the Tuskegee study analogy in the perinatal AZT trials because (i) both were prospective studies in which participants were denied known effective treatments; (ii) both were conducted or funded by the U.S. Public Health Service; (iii) both involved people of color; (iv) both included violations of informed consent (*1*); (v) both were justified by claiming that this was the only appropriate study design; (vi) both were defended by positing differences between previous and present study populations; (vii) both were justified by asserting that study participants would not have been treated anyway; and (viii) both were terminated only after exposure in the lay press.

The Alaska needle exchange study meets criteria (i), (ii), (iv), (v), and (vii) (*2*). Unlike all other needle exchanges, to our knowledge, drug injectors not enrolled in the study cannot use the needle exchange. Drug injectors in the study are provided identification cards and randomized to use the needle exchange or to receive a bus map of Anchorage with phar-

macies identified; they are also instructed how to talk and dress in order to convince a pharmacist to sell them a syringe, a violation of local Anchorage law (*3*). (Fairchild and Bayer note only that pharmacy sales are legal in the state of Alaska.) When a study participant presents himself or herself at the needle exchange, a card reader produces the person's image on a computer screen and instructs the staff person whether to admit the drug user. If someone randomly assigned to not use the needle exchange attempts to do so, he or she is turned away from the needle exchange and provided the map.

Certainly there are differences between these unethical studies and Tuskegee. But the dictionary defines an analogy as "a likeness in one or more ways between things otherwise unlike" (*4*). Tragically, these studies are similar to Tuskegee in more than enough ways to justify the analogy.

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Fairchild and Bayer are correct to advocate caution in the use of analogies between disputes about contemporary events in research ethics involving human subjects and the Tuskegee study. Having written extensively about the need for care in drawing analogies, we can only applaud their interest in drawing attention to this issue. However, they are wrong when they take us to task for inappropriately drawing a key ethical lesson from the Tuskegee study in our own critical comments concerning a test of needle exchange in which the subjects were not told the truth about all of their options. The design actively prevented the subjects from obtaining access to interventions that would have put them at less risk and used the incidence of the subject's acquisition of hepatitis B as a marker of efficacy in the trial.

The clinical trial at issue was constructed so as to leave subjects open to preventable infection by a serious disease by limiting their knowledge and their options. The ethical argument invoked in defense of this morally repugnant design was that the knowledge to be gained could not be gained by any other methods and was of such value as to justify the design. This, of course, is precisely the justification some defenders of the Tuskegee trial argued at the time the study was being challenged as unethical.

Analogies must be generated with caution. Sloppy analogies to historical events

such as Tuskegee abound. Caution and accuracy are crucial so as not to demean or deprecate the horrific moral abuses to which human beings were subjected in the past in the name of medical progress. But the argument we made concerning the Alaska needle exchange study met the criteria for appropriate use of analogy that has appeared both in our own writings and in the essay by Fairchild and Bayer. Our invocation of the argument that Tuskegee provided a crucial ethical lesson—that the value of research does not permit denying a known, efficacious cure and full disclosure to any human subject—was and remains valid with respect to the proposed Alaska needle exchange study.

It appears that Fairchild and Bayer would restrict the use of analogies only to circumstances that are identical to past abuses. But analogies and metaphors can appropriately focus our attention on aspects of current problems, even if not entirely identical to what happened in the past.

The past deserves respect, but it also must be examined for the lessons it can teach. Tuskegee teaches much richer lessons than Fairchild and Bayer say we can draw.

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Response

The concerns raised by Lurie, Wolfe, Caplan, and Annas center on the question of whether it was ethical to conduct a trial comparing needle exchange to pharmacy access to sterile injection equipment. Clearly, they believe that the available evidence on the efficacy of needle exchange precluded such a study on ethical grounds and that such a trial paralleled the abuses of Tuskegee.

It is instructive to note that on both ethical and empirical grounds, the special National Institutes of Health committee impaneled to review the Anchorage study reached a different conclusion (*1*). It emphasized that the challenged trial was not a comparison of needle exchange against no intervention—that would have been unethical. The study, rather, involved an examination of two approaches to the provision of sterile injection equipment [it was such an equivalency trial that Lurie and Wolfe demanded in their critique of the placebo-control trails of the antiviral drug AZT to prevent maternal-fetal human immunodeficiency virus (HIV) transmission in Third World countries]. The committee noted that those in the pharmacy arm would receive a continually updated list of Anchorage pharmacies that would sell needles to people not known to have a medical condition warranting the use of

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President Clinton and Vice President Gore apologizing to a victim of the Tuskegee syphilis study, 16 May 1997

injection equipment. Reports from project participants about their experience in obtaining injection equipment would aid study staff in updating the list.

In addition, those in the pharmacy arm, like those in the needle exchange arm, would receive counseling, educational interventions, and assistance in gaining access to hepatitis B immunization.

It was on the basis of these facts that the committee concluded (*1*), "Given current knowledge that clean needles can reduce the spread of various infections among injecting drug users, it is appropriate to conduct a randomized study to compare the effectiveness of two methods of providing access to clean needles—a needle exchange program and an enhanced pharmacy sales program. To characterize this research as comparing treatment with no treatment is a serious misrepresentation. Both groups will receive interventions that need to be compared for their relative effectiveness, and the results of this study will inform public policy. This trial meets the ethical justification standard of prior uncertainty about which treatment is superior."

Those who participated in the committee's work were not naïve about the demands of research ethics or about the complexities of evaluating the relative efficacy of approaches to harm reduction among intravenous drug users. The review panel was headed by Yale physician and expert on research ethics Robert Levine and included James Childress and Ezekiel Emanuel, senior figures in the field of medical ethics, and David Vlahov, an internationally known expert on needle exchange, drug use, and HIV infection.

Given both the consideration and conclusions of the review panel, we find it difficult to understand how the allegation that the Anchorage study involved a "morally repugnant design" that bore even the remotest resemblance to Tuskegee can be given credence.

One way to avoid the "sloppy analogies to historical events such as Tuskegee" that Caplan and Annas deride is to carefully enumerate the criteria of evaluation characterizing the fundamental nature of abuses that make a study like Tuskegee a critical, enduring point of reference. But enumeration does not preclude sloppy analogy. Thus, of the eight criteria Lurie and Wolfe list, four [numbers (ii), (iii), (v), and (vi)] might apply to any ethical, well-designed, publicly funded study involving people of color.

Corbie-Smith underscores a point we sought to make in our essay. Tuskegee helps to explain the profound distrust felt by many African Americans for the research establishment. But what she does not acknowledge is the difference between the illuminating role of Tuskegee as a metaphor and the demands imposed by the uses of analogy.

Finally, Bowman opens up an issue that, while beyond the scope of our essay, warrants serious discussion—the way in which those who should be allies of the socially vulnerable may find themselves serving the interests of unethical researchers. It is the prospect of such an unholy alliance that makes the existence of searching external review—in which the careful uses of historical analogy can serve a critical function—so imperative.

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Margaret Mead in Samoa

I found Martin Orans's review (*Science*'s Compass, 12 Mar., p. 1649) of my book *The Fateful Hoaxing of Margaret Mead: A Historical Analysis of Her Samoan Research* (Westview, Boulder, CO, 1998) partisan in the extreme.

In her letter of 15 February 1926 to her supervisor, Franz Boas, Margaret Mead stated that for the first time in her brief stay in Manu'a she planned to conduct, during April 1926, a "special investigation" of the sexual behavior of her sample of adolescent girls.

On 19 March 1926, after having told Boas that her "problem" was "practically completed," Mead wrote to Boas announcing that she had decided to cut short her fieldwork by more than a month. She then left Manu'a for the south of France without carrying out, during April 1926, her planned "special investigation" of the sexual behavior of her adolescent girls.

Margaret Mead (center) and friends in Manu'a, American Samoa, in 1926

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These historical facts seem inconsistent with the view that Mead engaged in deliberate falsification. If she had indeed been involved in deliberate falsification, she would never have made her Samoan papers available for public scrutiny in the Library of Congress.

In marked contrast, the historical facts confirm the sworn testimony of Mead's traveling companion Fa'apua'a Fa'amu that on 13 March 1926, on the island of Ofu, Mead was hoaxed by Fa'apua'a and her friend Fofoa about the sexual mores of the Samoans. Of this Mead appears to have been totally oblivious, as is anyone who has been successfully hoaxed. Thus, Orans's statement that I claim that Mead committed "a crime of misrepresentation" is incorrect.

That Mead was hoaxed makes fully credible her revealing letter to Boas of 14 March 1926, as well as her words, "I am leaving here with a very clear conscience," uttered before she sailed from Manu'a on 16 April 1926. A Boasian ideologue she may have been; a deliberate cheat about major anthropological issues she was not.

The detailed evidence for this (based on primary sources) is contained in my book *The Fateful Hoaxing of Margaret Mead,* and I invite readers to consider for themselves the historical evidence contained in that book and come to their own conclusions.

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