

# The Tuskegee Study of Untreated Syphilis and Public Perceptions of Biomedical Research: A Focus Group Study

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African Americans are less likely than European Americans to participate in biomedical research. Researchers often attribute nonparticipation to the "Tuskegee effect." Using critical qualitative analysis of focus group data, we examined the public's use of the Tuskegee Study of Untreated Syphilis (TSUS) to discuss biomedical research. Our participants articulated three primary themes in relation to TSUS: 1) that TSUS made them suspicious about biomedical research; 2) that other values had to weigh against concerns about TSUS; and 3) that African Americans could take steps to resolve their concerns about TSUS. African Americans were more likely to discuss TSUS than were European Americans. African Americans did not use TSUS to express simple fear. African Americans suggested issues other than TSUS that influence the decision to participate in research. African Americans indicated specific reforms that would increase participation in research. We discuss how a better understanding of African Americans' use of TSUS can enhance research participation and allay concerns about "another Tuskegee."

**Key words:** genetic research ■ African Americans ■ Tuskegee ■ Public Health Service Study of Untreated Syphilis in the Negro Male ■ focus group methodology ■ critical qualitative analysis

*The judgments made in 1973 about the conduct of the Tuskegee Study in 1932 are made with the advantage of hindsight, acutely sharpened over some 40 years concerning an activity in a different age with different social standards. Nevertheless, one fundamental ethical rule is that a person should not be subjected to avoidable risk of death or physical harm unless he freely and intelligently consents.<sup>1</sup> p. 12*

*It is important to be clear about what this study meant for the participants. It meant that for up to 30 months, several hundred people with HIV infection were observed but not treated... Such a study could not have been performed in the United States, where it would be expected that patients with HIV and other sexually transmitted diseases would be treated.<sup>2</sup> p. 967*

When discussions of informed consent and medical ethics take place, a common reference point is the Public Health Service Study of Untreated Syphilis in the Negro Male, more commonly called "The Tuskegee experiment" or the Tuskegee Study of Untreated Syphilis (TSUS). Reactions to TSUS caused a reevaluation of how medical research should be conducted.

The reforms enacted after TSUS did not necessarily change the practice of all biomedical research. The first epigraph comes from the *Final Report* of the advisory panel that suggested these reforms. Although their recommendations have been adopted in the United States, research infected with problems similar to TSUS is still conducted. The second epigraph comes from Angell's *New England Journal of Medicine* editorial<sup>2</sup> discussing a study performed by Quinn and colleagues.<sup>3</sup> In Quinn's study, HIV-positive persons in rural Uganda were observed but not offered treatment. In addition, it is unclear whether these person's sexual partners were informed about their risk. Although institutional review boards approved Quinn's study, Angell indicates that some bioethicists disapproved of the study because it failed to learn the lessons of TSUS. Like Quinn's study, TSUS was not conducted

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in secret. Like Quinn's study, TSUS studied persons of African descent. Like Quinn's study, TSUS did not make treatment available to research "subjects." Like Quinn's study, TSUS denied informed consent by not fully explaining risks and treatment options to these "subjects." And, like Quinn's study, larger institutions approved and funded the study.

TSUS was publicly challenged in 1972. White reports that articles about TSUS were published throughout the life of the experiment, including prominent outlets, such as the *Journal of the American Medical Association*, *Archives of Internal Medicine*, and the *Journal of Chronic Disease*.<sup>4-10</sup> These publications indicated that the biomedical community accepted TSUS. Yet, after Heller's report on the study in *The New York Times*, public reaction was swift and condemnatory.<sup>11</sup> A national review board found that TSUS was unjustified as science.<sup>12</sup> A special commission was appointed, reforms were suggested, and new regulations were enacted.<sup>13-15</sup> Despite these changes, the legacy of TSUS lives on. Tuskegee has become a metaphor for problematic research and serves as a historical marker for discontent with the biomedical community by racial groups chosen as "guinea pigs."<sup>16,17</sup> Moreover, research conducted in the present—research like Quinn's—seems to confirm fears that there could be "another Tuskegee," research that knowingly deprives people of medical care to observe the progression of a disease without the informed consent of the people being studied.

The purpose of this paper is to explore whether members of the public recall TSUS and whether they use the study to interpret current biomedical research. In other words, does this historical marker influence public discussion of biomedicine? The public has dis-

played the ability to recognize TSUS.<sup>18-20</sup> There has not been research into the public's spontaneous use of TSUS in conversations about research. In addition to recognition studies, the public's recall of TSUS, without prompting, should be investigated. Recall memory requires a higher level of cognitive processing than does recognition. Recognition requires the identification of previously learned material only; recall requires a person to integrate contextual cues with old information and to articulate a new statement.<sup>21,22</sup> As such, this study will examine unprompted, spontaneous discussion of TSUS as it emerges in the context of a larger discussion of biomedical research.

The discussions of TSUS examined in this paper come from our research group's larger investigation of the public's understanding of genetics. Although we have reported on specific questions asked to our focus groups elsewhere,<sup>23-25</sup> in this paper, we investigate the use of TSUS as an emergent theme in public discussion. We begin by reviewing previous discussions of TSUS. After noting limitations of this work, we present a focus group study of how members of the public use TSUS as a reference point. We outline differences between African Americans and other ethnic groups in their use of the Tuskegee Study narrative and indicate how TSUS influences public understanding of biomedical research. Finally, we discuss how understanding the ways that TSUS is discussed in public can be used to encourage African Americans' participation in biomedical research.

## Background

The Tuskegee Study is a landmark in the history of medical ethics. The study is more than a testament to the ability of some people to dehumanize other people

**Table 1. Summary of Demographic Characteristics of Focus Group Participants**

| <b>N</b>                    | <b>African-American<br/>118</b> | <b>European-American<br/>71</b> | <b>Hispanic<br/>15</b> | <b>Multiracial<br/>11</b> | <b>Total*<br/>216</b> |
|-----------------------------|---------------------------------|---------------------------------|------------------------|---------------------------|-----------------------|
| Fall 2001 Moderator Guide   | 60                              | 46                              | 8                      | 0                         | 115                   |
| Spring 2002 Moderator Guide | 58                              | 25                              | 7                      | 11                        | 101                   |
| Urban area                  | 61                              | 19                              | 0                      | 1                         | 61                    |
| University town             | 42                              | 19                              | 1                      | 10                        | 82                    |
| Regional hub                | 82                              | 33                              | 14                     | 0                         | 72                    |
| Male**                      | 75                              | 38                              | 8                      | 6                         | 127                   |
| Female                      | 41                              | 33                              | 7                      | 5                         | 86                    |
| Mean age                    | 34.36                           | 30.93                           | 34.60                  | 25.45                     | 32.7                  |
| Median Income               | \$50,000                        | \$55,000                        | \$39,500               | \$50,000                  | \$50,000              |
| Median educational level    | Some college                    | College degree                  | College degree         | Some college              | Some college          |

\* One participant declined to self-identify racially on the demographic forms.  
\*\* Two participants declined to self-identify a sex on the demographic forms.

or of the fascination with science over other human values. TSUS has become a metaphor for concerns that members of the public have about biomedical research. The medical literature emphasizes TSUS's exploitation of vulnerable populations.<sup>17,26-31</sup> Although there has been much attention paid to the fact that the subjects in TSUS were all African-American, this population was also exploited because of its low socioeconomic status and because of the lack of formal education received by these subjects. TSUS also symbolizes the arrogance of the government and of physicians in deciding which patients "deserve" proper medical treatment and which patients do not.<sup>17,28,30</sup>

The combination of exploitation and arrogance may have led the Public Health Service to feel that they owned not only the research findings but the very bodies of the men participating in the study. Roy<sup>32</sup> has concluded that the use of these 600 men's bodies for profit at the expense of the men's humanity amounted to a new form of slavery. In addition to exploitation of "subjects," TSUS has also become a metaphor for medical malpractice in research.<sup>17,20,33-34</sup> The decision to withhold initial treatments of heavy metals (the best available therapy for syphilis in the 1930s) and of penicillin (following its discovery in the 1940s) so that untreated syphilis could be observed across the lifespan has come under much scrutiny.<sup>20,26-28,35-36</sup> Although TSUS was defended in 1972<sup>37</sup> and has defenders in the present,<sup>4</sup> the withholding of therapy has been compared to genocide—the systematic killing of a racial or cultural group—because race was used to select those who would go untreated.<sup>30,33,38</sup>

Given the associations made by medical ethicists and historians among TSUS, genocide, and slavery, it is unsurprising that African Americans are more aware of TSUS than are European Americans.<sup>30,33,39</sup> Additionally, African Americans are more likely to distrust the biomedical system than are European Americans.<sup>40</sup> This distrust, it is often asserted, is because of TSUS. For example, Cox,<sup>41</sup> p. 2 claims that TSUS is fundamental to the "lore of prejudice and persecution children learn in many black communities." TSUS is assigned blame for low African-American participation in clinical trials, blood donation, vaccination, and other medical research and intervention.<sup>19,20,26,38,42-45</sup> TSUS has also been identified as the root for African-American cultural myths. For instance, beliefs that HIV/AIDS was designed by the government to exterminate African Americans have been laid at TSUS's door.<sup>16,17,29-30,33,34</sup> Likewise, TSUS is faulted for myths that crack cocaine and Agent Orange are products of the Central Intelligence Agency aimed at African Americans.<sup>20,45</sup> Because of the prevalence of these beliefs, there have been calls for greater cultural sensitivity in biomedical research and for the redress of larger

discrimination in society to rebuild trust.<sup>16,17</sup>

These calls, some believe, have gone unanswered by biomedical researchers and by the U.S. federal government. Because of the complexity of the "Tuskegee effect" and the difficulty of addressing public concerns about biomedical research, public health authorities may tend to ignore the "Tuskegee effect" when attempting to recruit participants of color for research studies.<sup>16,20</sup> Moreover, the failure to address concerns linked to TSUS may lessen the credibility of public health authorities for persons of color because rumors about biomedical research are unaddressed. Other scholars indicate that there may not be a "Tuskegee effect," as mistrust of biomedical research predates TSUS.<sup>17</sup> The "Tuskegee effect" may be minimal, as people are more likely to cite time constraints, familial obligations, or a fear of having blood drawn as reasons for not participating than they are to cite concerns about TSUS.<sup>41</sup>

The ability to address these concerns is also constrained by false understandings of TSUS. That is, because people do not know what "really" happened in TSUS, the public may need to be educated about historical facts and the protections for human subjects that have since been enacted. According to a 1999 poll by the Kaiser Family Foundation, only 38% of the public claims to have heard of TSUS.<sup>46</sup> A greater percentage of African Americans (59%) claims to have heard of TSUS. Among all groups, the foundation found that a substantial portion of those who have heard of the study reported that TSUS was the training of the Tuskegee Airmen, a heart disease study, or did not know. Public understanding of TSUS is not necessarily bound by historical accuracy, as some of those who know that TSUS was about syphilis believe that the government deliberately infected the participants.<sup>27,28</sup> Although many people claim to be familiar with TSUS, they often misstate the nature of the study, its extent, and its duration.<sup>20</sup>

As such, some researchers believe that concerns linked to TSUS are a problem of education. These researchers maintain that once the public receives accurate information, their concerns will evaporate. Indeed, White<sup>4</sup> goes so far as to defend TSUS. He claims that TSUS was nonracist, that it followed the best-known norms of treatment regarding penicillin, and that nontreatment of syphilis was a standard practice. Few researchers go as far as White. They do indicate, however, that describing substantive changes between TSUS and current research will reduce potential participants' concerns about enrolling in biomedical research.<sup>47-48</sup>

## Research Question

Despite debate over the "meaning" of TSUS, explorations of the public's use of TSUS in reacting

to biomedical research have been rare. Most studies that outline public concerns linked to TSUS are historical reviews or ethics commentaries designed to promote better research norms. Freimuth and colleagues<sup>20</sup> showed HBO's *Miss Evers' Boys* and asked focus groups for reactions. Although references to fiction are not unproblematic because of their free use of "artistic license," films like *Miss Evers' Boys* can provide a dramatic presentation of ethical issues and serve as a starting point for discussion.<sup>49-50</sup> A few studies have used survey techniques to evaluate the public's self-reported knowledge of TSUS and its ethical implications.<sup>18-19,46</sup>

Studies showing films or utilizing survey techniques rely on the principle of recognition to explore public understandings of TSUS. Recognition—an awareness that something perceived has been perceived before—requires that the participant have associations when a person mentions TSUS.<sup>21,22</sup> In recognition, a stimulus is presented to which a person reacts. The awareness that emerges from recognition may be incomplete or incorrect. These studies do not address recall. Recall—the remembrance of what has been previously learned or experienced—requires response that draws on more complete understandings of the term or concept.<sup>21,22</sup> Recall goes beyond simple awareness in that it assigns both denotative and connotative values to the person, place, or thing recalled. Recall is also more spontaneous. Recall also allows free association, the expression of new ideas, and the integration of new knowledge with old knowledge. Even when a person is not specifically asked about a topic, they may think of that topic in a larger discussion. The questions in survey research are less able to take advantage of recall because surveys must be consistent and are highly structured. As such, they generally rely on recognition.<sup>51</sup> Because recognition and recall operate through different cognitive pathways, different kinds of research may be needed to access recall than are used to access recognition.<sup>52-53</sup> Qualitative methodologies tend to have a more free-flowing nature than do quantitative methodologies. In addition, qualitative methods open space for participants to build on the ideas presented by other participants in addition to questions posed by the researcher. Qualitative methods allow the research participant to indicate the topics and concepts that he or she believes are important, rather than those that the researcher has predetermined are important. As such, qualitative methods are more useful for study of how concepts are recalled than are quantitative methods.<sup>54</sup>

The central research question in the public understanding of TSUS and its implications for biomedical research should go beyond recognition. The central research question, when one is interested in how public decision-making is influenced by TSUS,

should be centered on recall. As such, our central research question is: In discussions of biomedical research, do members of the public use Tuskegee as a touchstone for articulating concerns about such research? That is, do members of the public spontaneously recall TSUS in these discussions? In addition, we should explore whether the public draws on TSUS to formulate arguments. If there is a substantial "Tuskegee effect," members of the public should articulate TSUS as a concern without the urging of the investigators.

## Participants and Procedures

To explore if members of the public draw on TSUS to express their understanding of biomedical research, a focus group methodology was employed. As part of a larger project that is investigating the public's understanding of medical genetics, our study group conducted 24 focus groups with 215 total participants from August 2001 through March 2002 in the southeastern United States. Twelve groups had persons self-identifying as "black" or "African-American," seven groups had persons self-identifying as "white" or "European-American," and two groups had approximately equal numbers of African and European Americans. One group had persons self-identifying as multiracial, and two groups had persons self-identifying as Hispanic or Latino. Moderators were matched by self-identified race, with one integrated focus group being moderated by an African-American female and the other moderated by a European-American female. Moderators were of the same race as focus group participants in an effort to elicit honest and open dialogue about genetics, race, and human genetics research. Sessions lasted about two hours.

Participants were recruited by nomination from a community advisory board in three areas: a large urban area, a regional hub that was primarily agricultural but is now in transition, and a university town. Community advisory boards were first asked to discuss what constituted their community. Then they were asked to nominate individuals not on the board who would represent the perspectives in their community. Those individuals were then telephoned by research team members and invited to participate if they did not self-identify as "experts" in genetics. These individuals were considered to have "lay knowledge" of genetics because they did not have in-depth academic or practical experience with genetic science that would qualify them as "experts." Participants were told by whom they were nominated and offered \$50 in compensation.

As indicated in Table 1, participants were 118 African Americans, 71 European Americans, 15 Hispanics, and 11 self-identified multiracial persons, and

one person declined to answer; 86 were female, 127 were male, and two declined to answer. All participants provided written informed consent, and appropriate institutional review boards approved the study. People with a lay understanding of genetics were recruited from urban (61), suburban (82), and rural (72) communities in the southeastern United States. Participants ranged from 18–64 years of age ( $M=32.7$ ). Family income ranged from \$7,500 to \$700,000 with a median of \$50,000 (median income for the state is \$36,372). Educational levels ranged from less than high school (3%) to a terminal degree (1%). Most participants had either a high school diploma (20%), some college education (31%), or had completed a bachelor's degree (31%). The remainder had some graduate (9.5%) or doctoral (5.2%) education.

Standard qualitative focus group procedures were followed. Moderators employed a series of questions, which had been developed by the research team and then reviewed and revised by the three community advisory boards. Groups that met from August to December, 2001 were asked common questions from a 21-question moderator guide, while groups that met from January to March 2002 were asked common questions from a 29-question moderator guide. Both moderator guides are available upon request to the authors. Moderators included follow-up probes and revised wordings in questions to seek full exploration of the issues by as many participants as possible. Audiotapes of the sessions were transcribed. These transcripts were then compared to the videotape and corrected as necessary. Transcripts were not corrected for grammar or for formality in order to capture the oral nature of the discussion.

Specific questions asked by the moderators have been reported on elsewhere. These questions included, among others, what participants thought the phrase “a gene for heart disease” meant (Fall 2001 groups),<sup>23</sup> what concerns participants had about consuming race-based pharmacogenomics medications (Spring 2002 groups),<sup>24</sup> and the roles that inherited genes, social factors, personal behaviors, and ecological environments played in the development of human attributes, such as height, weight, mental abilities, and risk of genetic disease (all groups).<sup>25</sup> In our research group's previous studies, we performed our analyses primarily to answer questions that our research team posed. In the current study, we drew on the standards of critical qualitative research to investigate one of the significant topics articulated by our participants that were not posed by our moderator guides.

In this study, a critical qualitative analysis of talk turns related to Tuskegee was performed. Critical qualitative focus group research differs substantially from market-based methods of focus group research.<sup>55</sup> Rather than beginning with traditional norms of

logico-deductive research wherein a question is asked and the responses are coded for trends in response to that question and reduced to a numerical categorization, critical qualitative research begins with anomalous data that does not fit preconceived questions and expected types of answers. After conducting previous studies, members of our research team noted several references to TSUS that cut across questions and did not fit into the expected answers to our questions. Having noticed this anomalous data, two members of our research team (the authors) collected TSUS-related terms such as “Tuskegee,” “syphilis,” and “Macon County, AL.” These terms were then used to identify all talk turns where TSUS was discussed. Because thematic analysis is contextual, we (the authors) also examined the discourse surrounding these mentions. Sections where participants used TSUS to discuss their understanding of biomedical research were isolated for closer analysis. The purpose of this analysis was not to reduce the comment made to fit into previous questions but to allow the data to generate ideas that could be further investigated in later studies. Critical qualitative investigations are designed to, a) allow participants a voice in shaping the research that emerges from focus group sessions, b) make sense of anomalous human behavior that does not fit preconceived questions, and c) provide data points that can be investigated in later research for further generalizability. As such, we (the authors) do not claim that all TSUS-related phenomena can be explained through a single theory, such as the fear-based paradigm articulated in the literature review, but instead seek to open space for a greater diversity of views about TSUS that are articulated in reference to biomedical research. We report examples from this use of TSUS below.

## Results

There were apparent ethnic differences in the use of Tuskegee. Out of the 24 focus groups, only those groups with African-American participants mentioned TSUS. No group composed solely of European Americans, Hispanics, or multiracial persons referenced TSUS. The only mention of TSUS by any European-American participants in our study was after an African-American male mentioned TSUS as a reason for being suspicious of genetic engineering. In this integrated group, two European-American female participants agreed with him.

*2i-111: As an African-American, I'd be suspicious. I want to say that, basing it on history. I think about things like the Tuskegee experiment and things like that. So as an African-American, I'd be aware of what's going on. You know? Yeah, because of history, what happened.*

2i-202: *Right. I would be suspicious too. People use things improperly all the time. People do manipulate society.*

2i-206: *Yeah, manipulate society with the data.*

2i-202: *Manipulate things for their own needs all the time. So if there was any kind of reference like that, I would be suspicious.*

This conversation was the only discussion of TSUS by non-African-American participants. After TSUS was mentioned by an African-American participant, some European-American participants validated his concern. Their concerns, however, were not as potent or specific as those of African Americans. The European-American participants appeared to be more concerned with the propensity for manipulating data than they were with the methodological and racial implications of TSUS. Although participant 2i-111 did not clarify his concerns about TSUS, the statements made by other African Americans (as described below) indicated that TSUS is a potent marker for African Americans.

The relative absence of mentions of discussion of TSUS by European Americans, Hispanics, and multiracial persons, as compared with African Americans, may indicate that TSUS has greater salience for the African-American community than it has for members of other ethnic communities. This finding, in itself, is not surprising. Because African Americans were the “subjects” in TSUS, there is more likelihood of identification between contemporary African Americans and the TSUS subjects than there is for other ethnic groups. When contemporary experiences with discrimination in medicine are taken into consideration, the indication that TSUS is a touchstone for African Americans and not for others should be expected.

### Suspicious Based in TSUS

Indeed, TSUS was a marker for distrust of biomedical research for African Americans. African-American participants in our focus groups indicated that the experience of TSUS made them less likely to trust medical research. TSUS was not raised as an issue by the moderators. Rather, the participants in our African-American groups used the discussion of biomedical research to raise the issue of TSUS themselves. This conversation between an African-American female and an African-American male is indicative:

4-108: *Um, this is just a general question. Do people still have concerns about being tested? I mean, I know that a lot of people of our race don't believe in being part of research studies or being tested, and*

*when you're talking about genetics, I mean, they may, you know, conjure up some negative connotations...*

4-101: *They have reason to.*

4-108: *They may still have problems with the Tuskegee experiment.*

4-101: *Exactly.*

4-108: *[They use it] as a tool for why they may not trust their healthcare provider or feel like they can open up enough to talk to their healthcare provider related to this, because they don't want any testing to be done on them. I mean, I still see it as a problem.*

4-101: *It is a problem.*

In the conversation, the mention of a concern about being tested was linked to TSUS. The implications of TSUS for the African-American community were clearly explained. Some African Americans may believe that participating in the biomedical system will expose them to further dangers. TSUS does not force African Americans to distrust medicine. Instead, the way that African Americans use their understanding of TSUS may be what undermines trust in healthcare.

TSUS does not influence all African-American understandings of the biomedical system. Instead, some African Americans may generally be suspicious of the system and raise questions about it. When the issue of TSUS is inserted into the debate, however, mention of TSUS can alter the direction of the conversation. For example, in the middle of a discussion about possible race-based pharmacogenomics,<sup>24,60</sup> participant 12-108, an African-American female, indicated that she was influenced by earlier discussions of TSUS. She said,

*When he mentioned the Tuskegee experiment, I'm like, Oh, gad! This is... That's scary. I would have run the other way. I would. Simply for, I mean, our government's history in this country, I would seriously have to question, "What are they trying to do to us now?" I really would. "And what is the drug?" Is it going to kill more of us before we're 55? I mean, what's going on and historically—I mean, before he mentioned the Tuskegee issue, I was thinking like, "Well, maybe." [LAUGHS] And then we said that, I said, "Oh yeah, they're lying." So I couldn't—I don't know if I could trust something like that.*

This participant indicated that when the issue of TSUS was incorporated into the debate, it enhanced her concerns about race-based pharmacogenomics.

The acceptability of race-based pharmacogenomics was not fixed when this participant first considered it. The “maybe,” though, was converted into a firm “no” when the specter of TSUS arose. Because the salience of TSUS was strong for this participant, race-based pharmacogenomics became something that could not be trusted and was, in all probability, based on lies.

### **TSUS and the Intersection with Other Issues**

Previous discussions of how TSUS influences perceptions of biomedical research have largely assumed that most African Americans adopt views similar to those of participant 12-108. Although TSUS is a strong and salient marker for many African Americans, consideration of TSUS does not exist in a vacuum. Instead, African Americans may also weigh concerns about TSUS with and against other issues relevant to biomedical research.

Some African-American participants indicated that concerns about TSUS needed to be balanced against the need for sufficient African-American representation in biomedical research. That is, even if TSUS raised concerns about exploitation, for a medication to be considered safe and effective for African Americans, enough African Americans had to be included in the medication’s evaluation. This need is illustrated in a conversation in one of our groups:

*9-104: You know, there’s a great amount of people out there who don’t know to think about beyond just what they’re saying. And think more about, “Well, who did they test and actually who are these people?” Thinking beyond exactly what they’re saying. And saying, “Well, okay. I’m black so this is going to be great for me” and then go out and get it and it’s not the whole story.*

*9-101: But you wouldn’t think they would just test blacks? You got the Tuskegee incident. That was when they just tested the black guys for Syphilis. I’m sure they would just test black people, I mean.*

*9-114: But I’m saying not all black people are alike.*

*9-101: No, heck no.*

*9-114: But I’m saying, who’s to say that they’re testing what’s extensive enough to cover all the bases?*

*9-101: That’s true. You never know. I mean, what might work for you, might not work for other black women.*

As this conversation developed, the need for representative research was made more important than concerns about TSUS. As such, medications that

work for European Americans could not be assumed to be equally safe or efficacious for African Americans. The participants in our groups had enough understanding of the scientific method to realize that a small sample does not reflect the whole population. Moreover, the inclusion of just a few African Americans would be insufficient as well. As such, for these participants, the issues of TSUS and of representative research needed to be balanced.

The desire to have effective medication was not a theoretical issue for our participants. For example, when an African-American male tried to raise TSUS as a reason for not participating in research, an African-American female responded with a thorough explanation for why she set concerns about TSUS aside and chose to participate in an NIH-sponsored research study. In this group, the following conversation took place:

*6-105: A lot of people don’t trust the federal government.*

*6-108: They’re just testing.*

*6-105: A lot of people don’t trust things. Like somebody mentioned the Tuskegee thing. I ain’t going to go....*

*6-108: I did some of those studies just to get money off of [them]. And I didn’t see nothing wrong with some of them. But it was a sleep study. They wanted to monitor me and see how I sleep. You know see how my mind is thinking, you know, how far it carries on and stuff like that. So I thought that was a good study for me to get on and everything and stuff. So when this person had, like, a sleeping disorder and everything, and they was like judging me with them and stuff. I thought that was good for the fact I was helping another person out. But you know, a lot of people don’t be interested in studies like that that help other people out.*

Participant 6-108 transformed participant 6-105’s TSUS-based concerns into a weak excuse. For 6-108, the need to help sick people was a more important value than concerns about TSUS. Because of her personal experience with this sleep study, 6-108 indicated that the central variables under study compared a person with an illness to a person without that illness. The issue of race—and, thus, the reference to TSUS—was not valid when considering the utility of this study. By changing the ground rules and placing a different system of judgment on biomedical studies, concerns about TSUS could be suppressed in favor of an ethic that cares for the needs of others.

Reconsidering the weight of TSUS did not always require that a second participant provide alternative values to place against concerns linked to TSUS. In fact, our participants carefully weighed TSUS

against the potential advantages of biomedical research. This complexity is reflected well in participant 12-103's attempt to decide whether his concerns about TSUS should outweigh his desire to take advantage of genetic engineering. He said:

*After the Tuskegee experiment, I just about run another way. ... I just don't trust people that have that kind of genetic knowledge and all that. I just, you know—I mean—I'm conflicted because ... it's just one of those things that you want to give your child every advantage in this society, getting more and more competitive. I don't think I'd do anything like looks-wise, you know, but I would do something, you know, to insure that she was disease-free, or, you know, something, you know, to just try to give her an edge over ... disease or things that might hurt her in life or something like that. Kind of, you know, vaccinate her, if you will, against all that kind of stuff. But this right here, you know, I don't know. I'd stay away from medicines because I'm just convinced that, you know, when it comes down to AIDS and stuff like that, you know, I'm convinced that it was meant to, you know, for some reason. It's an old rumor and it never really substantiated, you know, conspiracy theory. But I just feel like, you know, this government and this world don't really mean black people no good.*

This statement points to many of the issues identified in previous research. 12-103 indicated that TSUS has made him suspicious of the biomedical community. He also related these concerns to what he explicitly identifies as conspiracy theories about AIDS. These concerns, however, are placed into balance with the desire to “vaccinate” his daughter through genetic engineering against disease. Thus, rather than concluding that TSUS is a sufficient reason to not participate in the biomedical system, 12-103 indicated that it is an important issue that must, nonetheless, be considered among others. Although 12-103 ultimately concluded that he did not want to participate in genetic engineering, his complex decision-making indicates that TSUS does not cause African Americans to act irrationally because TSUS took place.

The question of rational objection versus irrational objection to biomedical research because of TSUS was raised by our participants. Our participants indicated that TSUS was a good reason to object to biomedical research but also held that education about how medical studies are performed and the availability of opportunities for participation would allow these concerns to be addressed and overcome. The need for rational, informed decision-making about participation was outlined by our participants in conversations similar to the following. Participant 10-110, an African-American female, said:

*I agree with P112 on the education aspect of what she is saying, but I also—I don't just think it came from the Tuskegee catastrophe. We have been, as a race, have been shoved aside—it's not like we don't—we're not capable of getting the education, it is that they make it that much harder for us to get the education, and you know, they got all the resources. So it's like we, you know, like we don't want to learn, or want to a, know about these studies, but every time, it seems like when you try to get involved in something they either want to talk over your head, and see I'm one of them people, I don't mind, if I don't know something, I will ask. I don't care if I'm hanging with the President. If he say a word that I don't understand, I'll stand up in front of anybody and say, “excuse me, that word you just used, you need to define that for me, cause I want to know what you're talking about.” There's nothing wrong with not knowing—you know, and I will ask you, so you know I just think that we have a lack of distrust, but it's not misplaced. We kinda get the short end of the stick all the time, and it's time for that to turn around some.*

Distrust because of TSUS was only one reason that African Americans do not participate in biomedical research studies. Other reasons create a more complex picture. According to participants like 10-110, a lack of education on the part of many African Americans was a leading cause of nonparticipation. Blame was assigned primarily to a racist educational system that does not provide equal opportunities for African Americans. To remedy this problem, 10-110 suggested that African Americans need to insist that things that they do not understand be clearly explained. Thus, 10-110 claimed that when African Americans are recruited for participation in biomedical research studies, they need to ask questions about the study to see what is involved and to make an informed decision about participation.

### Solutions to the “Tuskegee Effect”

Requesting additional information was only one of the solutions to the “Tuskegee effect” proposed by our participants. Because they recognized advantages to African Americans from participation in biomedical research, our participants indicated that African Americans should participate more often. Encouraging participation, however, required more than additional education. Two additional components were suggested. Both suggestions require the active involvement of African Americans in the biomedical system.

The first addendum provided by our participants was the need for greater involvement by African-American physicians in conducting biomedical research. Participant 6-110, an African-American



female, suggested that African Americans would be more likely to trust African-American physicians than they would be to trust European-American physicians. She said,

*I think people seem to remember like the Tuskegee incident, a lot of people that are really afraid to be involved in that kind of stuff anyway. I mean, that's why I said, dealing with a black doctor person. Because I know that his motives might be a little better when I talk to an African-American person than a white doctor.*

This higher level of trust accorded to a physician of the same ethnic background than to one of a different ethnic background is not unique. African Americans have repeatedly expressed greater trust in, and higher preference for, African-American healthcare providers than in European-American healthcare providers.<sup>40</sup> This preference does not correspond to objective measures of patient care quality. Indeed, there is no significant difference in the objective quality of care provided to African-American patients by African-American physicians than that provided by European-American physicians.<sup>61</sup> Instead, this preference may be because African-American patients may believe that African-American providers are more likely to share similar cultural values, beliefs, and experiences that affect healthcare provision than are European-American providers.<sup>62</sup> As such, if African-American providers become more involved in the recruitment of African-American participants in biomedical research and in the conduct of studies, it is possible that African Americans will be more likely to participate.

In addition to African-American healthcare providers becoming more involved, our participants suggested that African Americans also need to demand opportunities for participation in biomedical research while protecting their rights as “human subjects.” Responsibility could not be devolved to healthcare providers. Even if healthcare providers intended to include more African Americans in research, our participants indicated that actual change would occur if, and only if, change was demanded by African Americans. This conversation is indicative:

*10-118: It's going to come from within us to turn anything around, so we need to look within ourselves to make the change, because they're not going to do it—it's going to be like that. I know we're going.*

*10-110: But they have the control, we can change, but.*

*10-101: We can change but we don't have the control.*

*10-110: Right, we can change, and we can progress, but we can't force them to progress, and, and accept us as equals, do you know what I'm saying—we gotta step up to the plate.*

*10-101: They already think we are equal already, and we're not.*

*10-110: And that is what they are basically so threatened by.*

The “they” to whom they are referring in this conversation is unclear. “They” might be the biomedical research community. Alternatively, “they” might be a larger system of white privilege that pervades the United States. Whoever “they” are, they are outside of the African-American community. “They” are not all-powerful, though. These participants indicated that, to have systemic change in the conduct of biomedical research, African Americans need to demand such change. Changes could include treating African-American participants in research studies as active and involved participants, rather than as objectified “subjects,” or putting greater emphasis on conditions that affect African Americans disproportionately. These changes could threaten established biomedical interests, a concern of which our participants were aware. Nevertheless, our participants indicated that, for African Americans to trust biomedical research, they needed to voice demands for change.

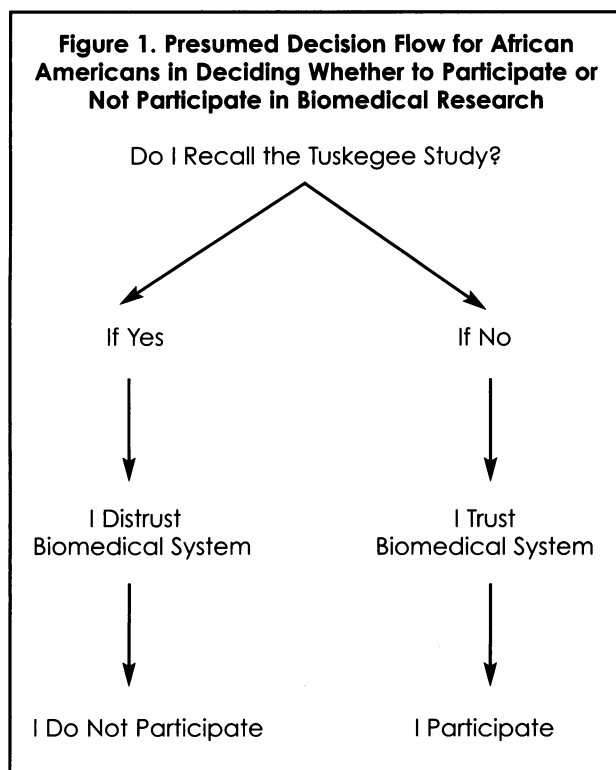
## DISCUSSION

Our results indicate that TSUS is a touchstone for some people's understandings of biomedical research. TSUS is used differently by different communities. The way that TSUS is used by the public—particularly the African-American public—is also more complex than suggested by previous research. Rather than serving as a base of fear, our findings suggest a multifaceted situation. Yes, TSUS makes some people decline participation in biomedical research. Yet, TSUS is placed into a decision-making matrix in which multiple values are weighed against one another to decide whether TSUS is a sufficient reason to refuse to participate. Finally, the response to TSUS is not the simple rejection of participation but is, instead, the articulation of demands for change in the way that biomedical research is conducted.

TSUS is a touchstone for some communities in coming to understand biomedical research.<sup>16,17,20,28,30,33,34,39</sup> African Americans are the ethnic group most likely to use TSUS as a way of interpreting biomedical research. European Americans, Hispanics, and multiracial persons did not raise the question of TSUS in their groups. As indicated by the single European-American discus-

sion of TSUS, a discussion in response to an African-American statement, these ethnic groups may *recognize* TSUS but are not likely to *recall* it on their own. Because recall requires that the concept under discussion be used to interpret new data or ideas on a spontaneous basis, it is possible that European Americans, Hispanics, and multiracial persons do not place TSUS at a high level in their cultural reservoirs for immediate interpretation. As indicated by previous research, African Americans are more likely to have thoughts of TSUS “at their fingertips” in public discussions. This cultural touchstone may be less relevant to non-African Americans. As outlined above, African Americans are more likely to perceive consubstantiality with the participants in TSUS than are members of other ethnic groups. As such, African Americans should be more likely to recall TSUS spontaneously than members of other ethnic groups. In this area, our findings agree with those of previous researchers.

Our research also suggests that the African-American public’s use of TSUS to understand biomedical research may be much more complex than previous researchers have suggested.<sup>18-20,47-48</sup> This simple model of African Americans’ decision-making in contexts of biomedical research is illustrated in Figure 1. Previous researchers have implied that African Americans recall TSUS and then refuse to participate in biomedical research. These assertions take two facts—that TSUS took place and that African Americans have lower participation in biomedical research than do European Americans—and assert a causal link



between these facts. Although fewer African Americans participate in biomedical research than is desirable for representative and reliable research,<sup>63-64</sup> recall of TSUS is not an absolute barrier to participation. Nevertheless, many researchers assert that, because TSUS happened, it caused African Americans to not participate. This sort of reasoning represents the *post hoc ergo propter hoc* fallacy in that it assumes a causal relationship between a chronologically prior fact and a chronologically subsequent fact. Of course, there sometimes is a relationship, but chronological subsequence does not necessitate logical consequence. In addition, African Americans have never withdrawn entirely from biomedical research. Although African Americans may be critical of or cynical about participation, a substantial number of African Americans participate nonetheless. If TSUS led directly to nonparticipation, then no African Americans would participate in biomedical research.

Rather than assigning a simple cause-effect relation between TSUS and low rates of African-American participation, our participants indicated that their understandings of TSUS did not lead to a simple refusal to participate. Our participants articulated three primary themes in relation to TSUS: 1) that TSUS made them suspicious about biomedical research; 2) that other values had to weigh against concerns about TSUS; and 3) that African Americans could take steps to resolve their concerns about TSUS. Previous research accounts well for the first only.<sup>19,20,26,38,40-45</sup> Our findings agree with previous researchers who claim that TSUS has made African Americans suspicious of participating in biomedical research. Our findings differ from previous research in that we do not claim that this suspicion leads to nonparticipation directly.

Suspicion may not stop participation in and of itself. The possibility of participation despite suspicion may be because humans are likely to include multiple factors in their decision-making. Previous research suggests that TSUS is a frightening concept that overwhelms all other components of decision-making.<sup>16,17,20,29,30,33,34,38,45</sup> Our findings suggest that other values may be weighed against TSUS. As illustrated in Figure 2, we suggest that African Americans may engage in a complex process of decision-making when deciding whether or not to participate in new biomedical research. African Americans are not likely to recall TSUS and withdraw from participation. Instead, our participants suggested that the desire for safe and effective medications, the imperative to help themselves and others, and the need for informed decision-making must be considered alongside concerns linked to TSUS. The desire for safe medication may require African Americans to participate in biomedical research despite concerns about TSUS, as the

cost-benefit ratio may balance best in favor of participation. The imperative to help others—a Samaritan ethic—may require that service to others be placed above one's personal concerns or desires. The need for education may indicate that making decisions out of fear, rather than informed choice, is a blameworthy, not praiseworthy, process. Regardless of the ethic chosen, our participants indicated that fear-based decision-making was less desirable than a more complex way of thinking through decision-making.

When memories of TSUS are faulted for the lower rates of African-American participation in the biomedical system, the current biomedical system is absolved of responsibility because the indirect victims of TSUS—African Americans today—are accused of transferring fears improperly to a new medical environment. The Institute of Medicine (IOM)'s report, *Unequal Treatment*, however, indicates that patient beliefs are only one variable in a larger set of causal factors for healthcare and research disparities.<sup>40</sup> African-American interpretations of disparity in medical research and treatment, and their likelihood of requesting and receiving treatment, are influenced by conscious and unconscious stereotyping and prejudice by both patients and providers, by disparities in the social, legal, and economic environments, and by actual differences in physical examinations performed and diagnostic test results reported. When these factors are combined, the IOM indicates that patient input is only one part, and a small part, of differences between African Americans and others in choosing to take part in medical research and treatment. TSUS may be a “representative anecdote” about biomedical research, not an absolute barrier to participation. TSUS chose its subjects not just because they were African-American, but also because they were poorer, less educated, of lower status, and seen as less-deserving than European Americans by physician and governmental agents.<sup>17,26-31</sup> As such, TSUS may reflect more than the problems of a single study. TSUS may also reflect social, economic, cultural, legal, and ethical forces that have traditionally disadvantaged and may continue to disadvantage African Americans and serve as a representative anecdote that articulates these themes. This anecdote, however, is countered by other stories and discussions that tell the advantages of research participation. As such, we question the simple link between concerns about TSUS and nonparticipation. Instead, it is probable that the decision not to participate in biomedical research is a multifaceted decision, not a simplistic fear-based reaction.

Finally, our participants suggested possible solutions to the “Tuskegee effect.” Although the “Tuskegee effect” is probably much weaker and much less causal than commonly assumed in previous research,<sup>26-28,32,35,36</sup>

the “Tuskegee effect” should be addressed for that small part of the population that reacts out of fear. Our participants provided valuable ways to address concerns about TSUS. Each of these ways of addressing TSUS may also influence choices in the decision flow, illustrated in Figure 2, that enhance the likelihood that African Americans will participate. Our African-American participants called for more community education so that African Americans would better understand what biomedical research was, why it was being conducted, and why they should participate. This community education might help to allay concerns linked to TSUS and might allow the considerations of other values that weigh against TSUS. Our participants also called for more African-American physicians to be involved in biomedical research. Just as the recognition of ethnic consubstantiality with the participants in TSUS may raise concerns about research, our participants suggested that the recognition of ethnic consubstantiality with researchers could allay these concerns. Lastly, our participants suggested that African Americans become more involved in framing research concerns. As part of a larger platform advocating ethnic equality, our participants indicated that biomedical research could be one plank in that advocacy. Altogether, these suggestions were not fear-based reactions. Instead, they were responsive discussions of how the “Tuskegee effect” could be countered. If these suggestions were adopted, it is possible that African Americans would be more likely to participate in biomedical research.

## CONCLUSION

When our findings are taken together, they indicate that TSUS *is* an issue that emerges in the African-American public's understanding of biomedical research. Our findings expand the discussion of TSUS beyond a paradigm of fear and suspicion. The African-American public may engage TSUS more critically than previous researchers have suggested. Although TSUS is articulated as a reason to be suspicious of the biomedical community, discussion does not stop at that point. Instead, the African-American public may weigh the issues encapsulated in the Tuskegee metaphor against other needs for the African-American community.

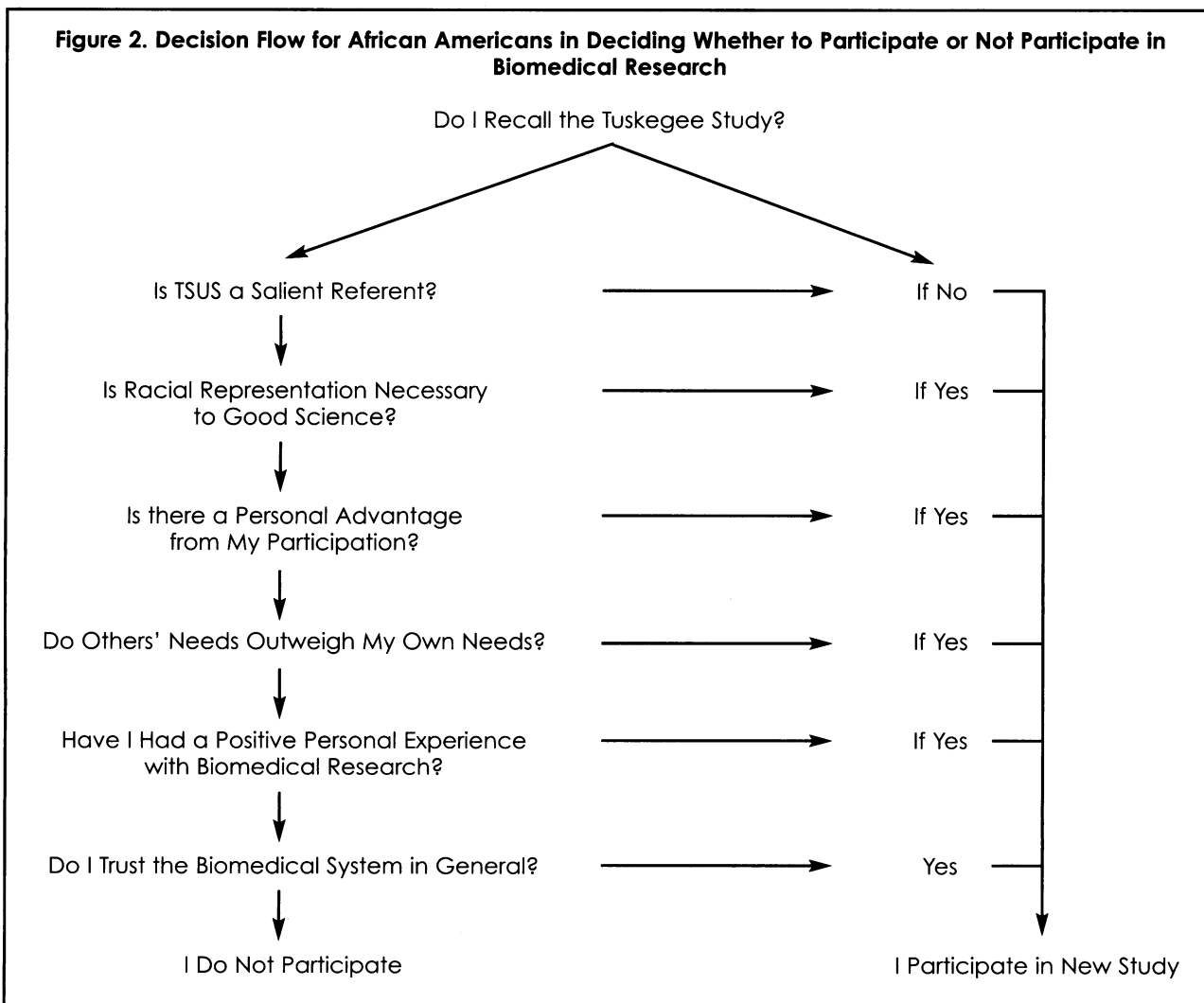
The African-American public does not want “another Tuskegee.” Reforms in biomedical research may not have been enough to fully allay suspicions of “another Tuskegee.” Nevertheless, the African-American public may recognize the benefits of African-American participation in biomedical research. African Americans may recognize that their participation may be necessary for the development of safe and effective medications. African-American participation in biomedical research studies, however, is

lower than European-American participation. If these benefits were better emphasized when recruiting African-American participants, African-American participation might rise. Additionally, if further reforms suggested by our participants were enacted, African-American participation might rise.

The reforms suggested by our participants are not impossible. In fact, one of the reforms suggested by our participants is easily adopted. Biomedical research teams can and should include more African-American researchers and physicians. Greater participation by African-American investigators would be beneficial not just from an “affirmative action” standpoint. Greater participation by African-American investigators may make African Americans more likely to participate in studies. A second reform— broader community education—is somewhat more difficult. Members of the public are unlikely to read scientific journals and may not always recognize the links between biomedical research and medical practice. Biomedical researchers may want to make this connection clearer in their reporting and may wish to pres-

ent their findings in more public forums, such as the newspaper and television news. Physicians may want to explain how their practice is informed by research and indicate how the public’s participation in research has made these practices possible. By taking these steps, researchers and physicians may display a better face of biomedical research and raise the general awareness of the need for participation. Given the larger disconnect between research and medicine for African Americans than for European Americans, these explanations may need to be directed towards African-American patients in the medical office and the so-called “black media.” The final reform—and the most difficult—is the claim that African Americans need to be more proactive in representing their concerns to the biomedical community. If such concerns are expressed to the biomedical community, it is the role of researchers to take these concerns seriously and adapt research programs.

When evaluating these concerns, it is important to consider the communities that articulate these concerns. The concerns articulated by our participants



about TSUS are representative of the participants in these groups. Although the majority of research indicates that African Americans are likely to share views of the biomedical system regardless of socioeconomic status, educational level, geographical location, age, sex, or other factors,<sup>40,46</sup> alternative concerns linked to TSUS may be named by participants from different social locations than were named by the participants in our focus groups. When attempting to involve more African Americans in biomedical research, specific communities should be asked what their particular concerns are and what recommendations these communities offer for making participation more amenable. The African Americans who made recommendations in our study were from a slightly higher socioeconomic group than are many African Americans. African Americans from a lower socioeconomic group may offer different concerns linked to TSUS and recommendations for overcoming them. In addition, many of our participants knew community leaders, making it possible that our participants were more likely to be politically and culturally active. Although community leader contact is one of the most effective strategies for recruiting participants of color and participants who are economically disadvantaged,<sup>65</sup> participants who are more disconnected from community leaders may view biomedical research beyond their ability to change and may be less likely to offer recommendations. Finally, our participants were all residents of the southeastern United States. It is possible that African Americans from Macon County, AL, the site of TSUS, would express more reluctance to participate in biomedical research, whereas African Americans from Chicago would express less reluctance because of geographic removal from the site of TSUS. Geography may also matter to the kind of recommendations that African Americans make for having more racially inclusive biomedical research, if such recommendations are made at all. Additional study that will offer additional avenues for representative and reliable research is needed.

In investigating reasons for the relative lack of participation by African Americans in biomedical research, we also need to be careful about the assumptions that we make. These assumptions are not just about African Americans as a population, but our assumptions of what African Americans believe. If we assume that TSUS is a prohibitive barrier to African-American participation, then the ability to recruit greater numbers of African-American participants is already lost. If we take a deeper look at how the African-American public uses TSUS to understand biomedical research, however, opportunities for adapting to concerns exemplified by TSUS become available. The African-American public is not just a

population infected with fear of participation. The African-American public is a well of ideas for making research more representative and for enhancing African-American participation in research studies. By investigating their concerns as well as considering their suggestions, research can become more reflective of the needs of the whole population.

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