

PERCEPTIONS OF PARTICIPATION IN AN OBSERVATIONAL EPIDEMIOLOGIC STUDY OF CANCER AMONG AFRICAN AMERICANS

Purpose: Recruitment and retention of African Americans in cancer research studies has become increasingly important. However, little is known about factors bearing on recruitment and retention in etiologic observational studies of cancer. We assessed perceptions and attitudes of African Americans towards participation in an observational epidemiologic study of cancer, and attitudes toward the data collection process.

Methods: Five focus groups, each lasting approximately 2 hours, were conducted. Participants were comprised of men and women between 41–65 years of age. A total of 35 adults from three rural and two urban counties in North Carolina participated. Data were analyzed using NVivo software.

Results: Four key themes emerged on the perception of participation and retention in an epidemiologic study of cancer: 1) fear of cancer prognosis; 2) conflicts between mistrust and trust in researchers; 3) comprehension of prospective study purpose, structure, and participation strategies; and 4) the necessity for and obligation to provide feedback.

Conclusion: Results indicate that African Americans would be willing to participate in epidemiologic studies to identify etiologic risk factors for cancer. However, culturally appropriate efforts to thoroughly inform them of study process and progress are deemed essential for successful recruitment and retention. (*Ethn Dis.* 2005;15:68–75)

Key Words: African Americans, Cancer, Epidemiologic Studies, Focus Groups, Recruitment Methodology

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INTRODUCTION

Morbidity and mortality of colon and prostate cancer, as well as breast cancer mortality, are greater among African Americans than European Americans.^{1–3} Higher rates are particularly pronounced among residents of the southeastern United States.² Despite their disproportionate burden, little is known about the risk factors of these cancers among African Americans.^{1,4} Understanding factors that contribute to cancer development among African Americans may identify effective cancer prevention measures. To identify risk factors in this population, appropriate observational epidemiologic studies, including population-based prospective studies, must be undertaken.

Adequate participation and retention is a critical methodologic issue in observational epidemiology.³ Recruiting African Americans to participate in cancer studies can be challenging^{1,5} because of mistrust,^{6–8} poor communication,² and barriers such as time and socioeconomic constraints.⁹ Most studies of recruitment and participation among African Americans have been done in the context of interventional clinical trials (eg, a random allocation process or some invasive procedure).^{4–8,10,11} Some intervention studies have reported the influence of perceived risk of cancer toward participation.^{2–4,12} Although these types of studies provide useful information on participation of African Americans in health research, they are relatively short in duration, involve some type of intervention, and primarily focus on the participant's role rather

than the researcher's responsibilities. Little is understood about perceptions and attitudes of African Americans on participation and retention in observational studies conducted to identify etiologic risk factors for cancer.⁶ This type of information is best gathered from qualitative inquiry. In 2003, Hoyo et al report on the perceptions of participation in cohort studies among African-American men; they found poor knowledge of cancer-site specific heterogeneity to be a barrier to participation.⁷ Perceptions and attitudes of African Americans toward modes of recruitment typical in large prospective studies, such as mailed questionnaires, are also not known. The purpose of this research was to evaluate African Americans' perceived importance of participating in an observational cancer study and their attitudes toward the data collection process.

METHODS

Study Population

A non-probability sample of urban and rural counties in North Carolina, with large populations of African Americans, was selected as target areas for recruitment. Participants were selected from three rural counties and two urban counties. In each county, an African-American key contact was identified to help with recruitment. A snowball approach was used to identify other African Americans in the community who would participate: key contacts contacted African-American acquaintances in the community who may be interested in participating, the acquaintances con-

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tacted other potential participants, and so on. Participants included African Americans 40 to 65 years of age. This age group was selected because it precedes the age with the highest incidence of colon, prostate, and breast cancers¹³ and is most likely to be targeted in an epidemiologic observational study designed to identify risk factors for cancer. At the conclusion of the focus group session, participants received a modest stipend for their participation.

Focus Group Sessions

Five focus groups were conducted. Each focus group was held at a centralized location within each county (eg, town hall, church, YMCA). At the beginning of each session, the facilitator reiterated the purpose and explained the

procedures, which included tape recording the session for accuracy. Written informed consent was obtained from each participant. Afterward, participants completed a short demographic sheet. Researchers served as note takers, capturing general concepts and nonverbal information important to analysis, such as facial expressions, moods, and interpersonal exchanges.¹⁴ Focus group questions were based on previous literature regarding recruitment and participation in clinical trials.^{1-6,11} An experienced focus group leader asked participants questions (Table 1) regarding their perceptions of cancer; strategies for recruitment of African Americans for a long-term, observational study; and their attitudes toward a draft questionnaire, designed to be mailed to African Americans in North Carolina. Each session lasted approximately two hours. Refreshments were provided. A description of the focus group participants is provided in Table 2.

Analysis

The tape recordings of the focus group sessions were professionally transcribed and analyzed. Three focus group experts independently reviewed the tapes, transcripts, and researcher notes for themes and trends and compared them to assess level of agreement. The analysts

Table 2. Participant characteristics (N = 35)

Urbanicity	
Rural	80.0%
Urban	20.0%
Age (yrs) (N = 34)	
Mean (SD)	51 (±6.6)
Range	41-65
Gender	
Male	20.0%
Female	80.0%
Marital status (N = 34)	
Married	38.2%
Divorced	20.6%
Widowed	8.8%
Single	32.4%
Occupation (%) (N = 34)	
Retired	32.4%
Education	11.8%
Technical	5.9%
Manual	17.6%
Clerical	5.9%
Other	26.4%
Annual household income (N = 28)	
Mean (SD)	\$39,390 (±23,609)
Range	\$1,500-\$90,000
Family history of cancer (N = 33)	
Yes	45.5%
No	54.5%
Education	
Less than high school diploma	8.6%
High school diploma	25.7%
Vocational school	2.9%
Some college	31.4%
College degree	17.1%
Masters degree	14.3%

Table 1. Focus group questions

Perceptions of Cancer

- What comes to mind when you hear the word HEALTH?
- What comes to mind when you hear the word CANCER?
- What do you think causes cancer?
- Do you feel that African Americans are more at risk for developing cancer?
- Do you feel that studies on cancer are more of a help or more of a burden to African Americans?

Strategies for Recruitment of African Americans

- Would you be willing to participate in a study like this?
- Would you be willing to continue to answer questions every two years or so?
- How can we convince others to participate in a study like this?

Views about Questionnaire

- Is the questionnaire easy to understand and fill out?
- Would you fill out the questionnaire if it came to your house?
- What would make you want to fill it out?
- How is the length—too long, too short?

agreed on thematic labels. Data were then coded and grouped with NVivo software (NVivo qualitative data analysis program; Melbourne, Australia; QSR International Pty Ltd. Version 1.2, 2000). Themes for each specific aim of the study were categorized across sessions.

RESULTS

A total of 35 adults participated; the actual attendance at each focus group was 10, 9, 9, 4, and 3. The mean age of the sample was 51 years (Table 2).

Table 3. Emerging focus group themes by qualitative code category

Specific Aim	Code Category	Emerging Themes
Perceived importance of participating in observational study of cancer	Perceptions of cancer and the necessity of longitudinal studies of cancer among African Americans	<ul style="list-style-type: none"> ● Fear of cancer prognosis ● Conflict between mistrust and trust of researchers
Attitudes toward data collection	Data collection procedures in African-American communities Strategies for sustaining participation	<ul style="list-style-type: none"> ● Comprehension of study structure, purpose, and participation strategies ● Feedback

Participants were predominantly female (80%) and had some college education. Nearly 40% were married, about one third were single, and another third were widowed or divorced. Although occupation varied, approximately one third were retired. The mean and median annual household income were nearly \$40,000 and \$38,000, respectively. Over 54% reported a family history of cancer. The majority of the participants were from rural counties (80%).

Focus group discussions centered around four main areas: perceptions of cancer, perceived necessity and burden of epidemiologic studies of cancer among African Americans, data collection procedures most appropriate in African-American communities, and strategies to maximize recruitment and retention in longitudinal studies (Table 3). The four emerging themes were: 1) fear of cancer prognosis; 2) conflict be-

tween mistrust and trust in researchers; 3) comprehension of prospective study purpose, structure, and participation strategies; and 4) the necessity for and obligation to provide feedback. Support of these themes is provided below.

Fear of Cancer Prognosis

Apparent willingness to participate in long-term studies on the causes of cancer was associated with fear of death, long-term illness, and deforming treatment side effects that “change the body image.” The fear appeared to be deep-rooted, and some participants expressed the fear of even saying the word “cancer.” Some of these perceptions were based on experiences with family members or friends who battled later stages of diagnosis with cancer. However, most exhibited lack of knowledge about cancer pathogenesis, prevention, and treatment. This, coupled with fear of cancer,

gave rise to fatalism and poor perceived locus of control (Table 4).

Despite the fatalistic perceptions, including those of an inevitable poor quality of life, the same participants later expressed a need for long-term research studies to achieve a better understanding of the disease, for the larger good of African Americans. They felt that research would give them knowledge of cancer etiology and prevention that they desired. They expressed desire to participate in studies by nodding their heads “yes” when asked the question, “Would you participate in studies like these [observational research study on cancer]?”

Conflict Between Mistrust and Trust in Researchers

Participants exhibited conflict between the perceived need and motivation to participate in observational research studies of cancer versus their per-

Table 4. Emerging theme 1 (fear of cancer prognosis) and related quotes

Theme	Quotes
Fear of cancer prognosis	
<ul style="list-style-type: none"> ● Fear 	<p>‘... cousins have died from cancer ... but nobody’s talking. So there’s a fear just talking about it, period.’</p> <p>‘... [cancer is] scary ...’</p> <p>‘... that word [cancer] is devastating to me.’</p>
<ul style="list-style-type: none"> ● Change in body image 	<p>‘... I guess the thought of just being disfigured ... I wouldn’t want to have that stigma ...’</p> <p>‘... I think another thing that particularly women think about when they think of breast cancer is body image changing ... now, body image is big thing for women ... that means so much to them.’</p>
<ul style="list-style-type: none"> ● Fatalism 	<p>‘... simply death ... I think of death when I think of cancer. Long suffering and death.’</p> <p>‘... the first thing I think of is, you know, time is short for the person that has it.’</p> <p>‘... [Cancer means] life with a death sentence.’</p> <p>‘... [cancer means] I would be not enjoying my life because I would be sitting around worrying about how much more time I would have to be up or what I can do ... in other words I would be worrying more or less how much time I have left to live instead of enjoying my life itself.’</p>
<ul style="list-style-type: none"> ● Perceived locus of control 	<p>‘... but as far as a way [that you] can predict cancer ... in the end, I feel like, whatever is meant for you, you are gonna have ... but prevent it ... I don’t believe that ...’</p> <p>‘... I think some things we’re gonna get, regardless ... some fellas get this ... some get that ... something to do with your background ...’</p>

Table 5. Emerging theme 2 (conflict between mistrust and trust of researchers) and related quotes

Theme	Quotes
Conflict between mistrust and trust of researchers	
<ul style="list-style-type: none"> Perceived need of epidemiologic (risk factor) information 	<p>'... I think that [research] is a help ... particularly cancer because it takes the lives of so many people ... the more you know about it, the more you can change your lifestyles and do the things that you can to prevent it or catch it at a stage that it can be treated ...'</p> <p>'More knowledge you have of it, you know, you can kind of see how you could prevent it. You know, either, on that order.'</p> <p>'A lot of times when I watch the news and hear about studies, I often wonder how many, are they using African Americans in a lot of these studies ... are they just focusing on the White community when they are doing the studies? ... [researchers need to be] inclusive in that.'</p>
<ul style="list-style-type: none"> Lack of trust of medical establishment 	<p>'... you can't trust the results because so much comes out that is conflicting ... a lot of the studies, its like I was saying about medication. Why is the study being done? You know, unless you know the real reason, because you can skew any study to come out to ... your ... hypotheses ... we need to become more truthful in this country.'</p> <p>'... there's enough history to suggest that the medical profession just don't give a hoot. And even if they did do these studies ... will anything really good come of any of this? Cause there's no evidence to suggest that anything good has come of much of anything else in the past?'</p> <p>'... sometimes when I'm alone and reflecting, I get kind of angry. Angry that there is no cure. Have we pursued it ... as we should have? ... because cancer just didn't happen the other day. Cancer's been around for a while. And why aren't there cures for cancer?'</p>
<ul style="list-style-type: none"> Anger, confusion, frustration 	<p>'[Research studies] ... are more of a confusion ... because so much is conflicting ... one minute this [causes cancer] and then the next minute something else causes it ...'</p> <p>'... so many studies [have been] done, and so many different people involved ... and [one study] will say this is happening this way, and another will say its doing just the opposite. So, at times it's confusing ...'</p> <p>'... they telling' me all these years, they found out that eating, like, maybe, say bacon, will give me cancer ... and later on ... they'll come back and say, 'no, it won't give you cancer'. And I'm like well, what do I do? Do I just continue to do my thing? But, they don't really know. So they make me just say, forget it.'</p>

ceptions of the research community. As in prior studies,⁶⁻⁸ participants felt that researchers in general could not be trusted, as a result of historic and perceived exploitation of African Americans. Additionally, participants were confused about the benefits of research studies (Table 5).

Despite these attitudes, participants expressed desire for and described the importance of long-term cancer studies in African Americans. Their motivation and desire to participate were evident and implied a level of trust in researchers. However, these attitudes, coupled with conflicting concerns about potential exploitation of African Americans, led to feelings of anger, confusion, and frustration toward researchers and the health messages they may deliver. Focus group participants expressed the need for caution when contemplating participation in research studies, including those on cancer.

Comprehension of Study Structure, Purpose, and Participation Strategies

In discussions on strategies for recruiting African Americans to participate in a long-term cancer research study, the facilitator initially described the structure of a prospective study by explaining the differences between an observational study and an intervention (eg, clinical trial, behavioral intervention). This explanation was followed by questions on the willingness to participate in an observational, long-term (or prospective) study on cancer among African Americans. Participants seemed to have a general comprehension of the basic differences between these study designs. Participants appeared to be more apprehensive toward participating in studies involving administration of medications (eg, randomized clinical trials comparing active drug to placebo)

than studies that observed existing behaviors over time (Table 6).

To further explore their willingness to participate in an observational study, focus group participants were each given a 32-page sample draft questionnaire for review, similar to what would be used in a prospective, observational, epidemiologic study of cancer. Since mailed questionnaires are often the most cost-effective data collection strategy for large-scale epidemiologic studies of cancer,¹³ it was important to identify attitudes toward and factors related to completing them, particularly given potentially high attrition rates among African Americans. When asked to share their first reactions, length was the prevailing concern.

Interestingly, despite the immediate negative reaction to the questionnaire's length, all participants said they would complete the questionnaire, although not immediately after receiving it in the

Table 6. Emerging theme 3 (comprehension of study structure, purpose, and participation strategies) and related quotes

Theme	Quotes
Comprehension of study structure, purpose, and participation strategies	
• Type of study (observational vs clinical trial)	'... I definitely wouldn't want to take any medicines ... and then too, I know in studies, they give people a lot of placebos too, and I want to know what I'm taking.' '... [I'll participate] as long as no medication is involved.'
• Perceptions of questionnaire	'... letting people know that it would be mainly just ... answering a questionnaire, it would not be like taking any medicines ... because that scares people.' '... it's way too long ... 300 some ... oh god ... I don't have time for this ... a lot of people are going to throw it out ...' 'Well, it's easy to understand. It's just long.' 'Cut it down girl, cut it down ...' 'My first reaction is this is too long ... but if I got this, I'd look at this and put it aside till I felt like I had enough time to deal with it, which would probably be no time soon. This is, I mean, it's a good thing, and I admit that, but my goodness ...' '... isn't there a way like ... kind of break it down into two parts, like send one part, and then after they send that back in, say well, you know, like two months later, we want to send you another one ...'
• Explanation of purpose	'... I probably would not [participate] ... unless anyone could stress the importance, you know, maybe [through] a spokesperson from the church or something' 'I think definitely letting people know up front, and the first thing you're gonna tell them is the purpose, and then basically what it will entail ... letting people know in the very beginning that it does not entail any [experimenting] ...'
• Benefit to African Americans	'... [I would continue to answer questions every two years] if it might help somebody. ...' '... Because we want to know if it's anything that we are doing as a race to cause, you know, to let ourselves down, in the future I'm willing [to participate].' '... tell them who you were, what you're doing ... And then ask them would they be willing to do a survey or whatever, and tell them how it's gonna help.'
• Site of administration and recruitment	'I think our biggest stronghold in our community is in our church. And we have ... professionals in the churches, and with them putting the emphasis on the importance of it, I think your response is gonna be very good ...' 'I think you might could get greater feedback somewhere like [a clinic] ... and if you have it so that they could do it right then.' '... the African-American culture's a very sociable culture. And they like coming together. You will get more out of them when you bring them all together.' '... it would be a good idea to ... get into a contract with the company ... and distribute this among the employees in the company, you know, to figure out some kind of way to get them to fill it out there ... Because when you're on the job, no matter what job you're doing, if you got 15 minutes away from that job, doing something like this, you would want to do it ...' 'Don't call my house!' (in response to telephone interviews) 'I'd say sorry ... I'm not interested. I'd hang up the phone.' (in response to telephone interviews)
• Human resources	'... [champion endorsers] would not work ...' 'For me, it would depend on if they [a spokesman] had been in this situation. If they were not a cancer survivor, they don't need to be talking to me about it' 'The only way that that would make a difference is if it was somebody that was a cancer survivor. Otherwise ... what they say wouldn't be valid.' '... if they survived because they made some changes [in] these things you are finding as causes ... we are a religious group ... and if [the spokesman] says I survived, then you'll say I'll survive too ... I can survive ... God's gonna take care of me too ...'

mail. Suggestions were made to sequentially mail sections of the questionnaire over time to reduce the burden of complexity. Participants felt that appropriately addressing this methodologic concern could help maximize participation and promote long-term commitment to the study.

Participants also believed that knowing the ultimate purpose of the study, particularly as it benefits African Americans, and the general reasons for asking the large volume of questions would promote and sustain participation. There was also a general consensus on the need and obligation to educate or

“prime” potential participants for their long-term involvement in a prospective study by keeping them well-informed of the process. When asked for the best ways to prime potential participants, using champion endorsers or a famous spokesperson was not an appealing strategy. However, inspirational messages

Table 7. Emerging theme 4 (feedback) and related quotes

Theme	Quotes
Feedback	
<ul style="list-style-type: none"> • Incentives 	<p>'... monetary gratification? Absolutely! But the real reason would be to help others, right? Do the survey so that others would benefit from what you ... have experienced. And although that's the real reason, it would help to have monetary compensation.'</p> <p>'... now that I think about it, I don't know whether [giving participants compensation] is a wise idea. It may weigh, or change the results. They could be doing it just for that, rather than sitting down and being honest with themselves ... those who volunteer are gonna do it because they deem it as being important [and] are gonna do it anyway.'</p> <p>'[money is] a motivating factor, but I always worry when people get compensation for doing something, whether their answers are truthful. Or whether they're just doing it because they're gonna get paid. You have no way of checking.'</p>
<ul style="list-style-type: none"> • Importance of feedback 	<p>'Let them know that you're gonna give them some feedback. I mean on the results. Cause we want to know the answers ...'</p> <p>'Newsletters would be good for follow-up ... don't feel like you sent something and that's the end of it. You get a reply saying this is what we've done with the information that you've sent us ... you know [it can say] this is where we are with this study. And you feel like, well, at least somebody's giving me some feedback. You know, and you feel like I'm not just out there doing it for nothing ...'</p>

from cancer survivors were considered a motivator for sustained participation.

The site of questionnaire administration was also deemed important to promote participation. Although mailed questionnaires were preferred over telephone, participants preferred group completion at places where African-American adults congregate, such as work and churches. However, regardless of the venue, participants felt that being well-informed about the study and process from a lay perspective was critical to sustained participation.

The Necessity for Feedback

Participants considered providing feedback to be one of the most important strategies to increase long-term study retention. This included behavioral feedback, such as incentives or compensation, and most significantly, informative feedback (Table 7).

... researchers must be proactive in designing and implementing culturally appropriate studies.

Most participants expressed that incentives or compensation would be a motivating factor for participating in a long-term study, but they would not be the primary reason for doing so. The importance of incentives seemed to vary by urbanicity. Some urban participants believed that monetary compensations could lead to reporting bias. They were more inclined to be motivated by the receipt of information about cancer and how to prevent it. Thus, new knowledge about cancer, whether for themselves, a family member, a friend, or for African Americans in general, was deemed essential for retention.

Informative feedback was the most consistently reported strategy for maximizing retention in a prospective cancer study. Participants longed for information. Thorough and appropriate information about the etiology of cervical, prostate, and colon cancer, including methods of prevention, would allow the participants to make informed choices about their health or the health of loved ones. Additionally, the notion of periodic feedback on the study's progress appeared to give the participants a sense of ownership of the study, which would be a key motivational factor. Newsletters were considered the most convenient medium for providing feedback for a

prospective study using mailed questionnaires.

DISCUSSION

Our results suggest that African Americans would be willing to participate in observational epidemiologic studies to identify risk factors for cancer, including a prospective study. However, researchers must be proactive in designing and implementing culturally appropriate studies. Thoroughly informing participants of the process is essential for successful recruitment and retention. These results are not limited to participation in studies of breast, colon, and prostate. They are applicable to cancers of all types. However, fears about cancer prognosis, distrust of researchers, and information and feedback from the study are critical elements that may affect their motivation to participate.

Focus group members expressed that participation could be increased by providing participants with better information about the study and its importance, including benefits to the community. Moreover, recruitment is likely to be enhanced by insuring that potential respondents clearly understand what is required to participate in an obser-

vational longitudinal study versus a clinical trial. For example, clinical trial participation is hampered by the socioeconomic and time constraints inherent in periodic clinic visits,^{9,15,16} coupled with the time it takes to complete a questionnaire. Studies investigating barriers to recruiting African Americans into clinical trials suggest both men and women can be recruited if trust was increased.^{15,17,18} Clear, thorough explanations of what observational studies are and level of commitment required may increase their knowledge base, which may be the first step toward improving motivation to participate. Additionally, most agreed that keeping the participants involved using feedback and updates about the study's progress may increase trust. Focus group participants indicated that feedback is key to retaining African Americans in observational research.

Most focus group participants said that they would be willing to participate in an observational study, because of the perceived importance. At the same time, participants were concerned about the possible exploitation of African Americans. These perceptions can only be counteracted if researchers address fears of African Americans in a rational, incremental way. Investigators must understand participants' fears so that they can be acknowledged and addressed, in part to increase participation and retention, which may require professionals experienced in these areas (eg, consultants). Finally, researchers must realize that the structure of the study must be designed in such a way that is feasible for potential participants to complete. Thus, community members should be involved in the process and the dialogue in developing these research studies to ensure their appropriateness.^{15,19} Participants in our research would complete a mailed questionnaire, but they suggested using one shorter than the 32-page instrument used in the focus groups or dividing and mailing the instrument in successive waves.

Men and women included in these focus groups were self-selected, educated, and perhaps service-oriented. More than 65% had some college education, and some women admitted above-average interest in health. In addition, focus group data tend to be consensus-based; hence applying these findings to the whole state or other southern states may be difficult. However, participants, who were recruited from rural and urban areas of the state, and by virtue of their self-selection, may represent community gate-keepers. Thus, their perceptions may reflect those of the community they represent. Barriers such as fear of being an experimental victim and general mistrust of the medical establishment have been corroborated in previous clinical trials.^{4,5,9,15} Therefore, these findings can help plan observational studies of cancer etiology. We also did not inquire whether the participants had a history of cancer screening; this may suggest health-seeking behavior or perception of greater risk. This group may have different perceptions regarding participation in research than someone with low health-seeking behaviors or lesser perception of risk.

One limitation of the study is that participants were never asked whether fear of cancer prognosis has any influence on their willingness to participate in a longitudinal study of cancer. However, the same people who expressed fear of cancer later expressed the need and desire to participate in research studies. Fatalism and fear of cancer have been described by other articles.²⁰⁻²³

Participants also expressed their unwillingness to participate in studies if they have to take drugs or have specimens taken. Many longitudinal epidemiologic studies require biologic specimens to be collected which may hinder participation. Participants said that they would be willing to participate in a longitudinal research study on cancer; however, how long participants would be willing to be followed is unclear.

Many previous qualitative studies,^{4,9}

as well as quantitative studies,²⁴ have investigated the recruitment of African Americans in research studies, but these studies focused on characteristics of the participants that may influence their decision to participate. Wyatt et al developed a model of research participation that examines what researchers can do to provide an environment that promotes participation.²⁵ The present study offers additional study structure and design suggestions. Although several other studies have identified mistrust as a factor affecting participation,^{4,9,17,18,24} our study provides new information regarding the importance of feedback. A few studies have described feedback as important; however, participants wanted feedback on biological samples (if collected) to ensure proper usage⁷; feedback in the form of study results were also deemed important.¹⁹ The use of cancer survivors, not necessarily famous, as spokespersons was also suggested. Our study notes the importance of providing informative health messages. In practice, observational epidemiologic study results may not yield clear prevention messages. In providing feedback, researchers should therefore be careful with the presentation of results, since they may be misinterpreted.

Focus group research is a necessary precursor to etiologic studies and may reveal previously unidentified strategies highly effective in recruitment and retention of African Americans. Our study was able to observe initial reactions to a long survey and receive feedback on how to improve the questionnaire and the process. Implementing such strategies may improve recruitment and retention, ultimately improving the quality of longitudinal research.

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