

WHY AFRICAN AMERICANS SAY “NO”: A STUDY OF PHARMACOGENOMIC RESEARCH PARTICIPATION

Mohammed Nooruddin,BS¹; Courtney Scherr,PhD²; Paula Friedman, PhD¹; Ramesh Subrahmanyam, PhD³; Jeff Banagan,MS³; Diana Moreno,BS⁴; Myurani Sathyanarayanan,MD⁴; Edith Nutescu, PharmD, MS⁴; Tharani Jeyaram,MD⁵; Mary Harris,BS⁵; Honghong Zhang, PhD¹; Adriana Rodriguez,BS¹; Mohammed Shaazuddin,MPH¹; Minoli Perera, PharmD, PhD¹; Matthew Tuck, MD^{3,6}
for the ACCOuNT Investigators

Objective: To identify reasons for nonparticipation by African Americans in cardiovascular pharmacogenomic research.

Design: Prospective, open-ended, qualitative survey.

Setting: Research staff approached patients eligible for the Discovery Project of The African American Cardiovascular pharmacogenomics CONsORTium in the inpatient or outpatient setting at four different institutions during September and October 2018.

Participants: Potential Discovery Project participants self-identified as African American, aged >18 years, were on one of five cardiovascular drugs of interest, and declined enrollment in the Discovery Project.

Methods: After declining participation in the Discovery Project, patients were asked, “What are your reasons for not participating?” We analyzed their responses using a directed content analytic approach. Ultimately, responses were coded into one of nine categories and analyzed using descriptive statistics.

Main Outcome Measures: Reasons for nonparticipation.

Results: Of the 194 people approached for the Discovery Project during an eight-week period, 82 declined participation and provided information for this study. The most common reason for refusal was concern about the amount of blood drawn (19.5%). The next most common reasons for refusal to participate included concerns about genetic testing (14.6%) and mistrust of research (12.2%). Across study sites, significantly more patients enrolled in the

INTRODUCTION

For clinical and translational research to be generalizable to the greater population in the United States, research participants must be racially and ethnically representative. Pharmacogenomic studies, which examine how a person’s genes affect response to medicines, have been conducted nearly exclusively on populations of European descent, thereby impeding the discovery and translation of African

inpatient than outpatient setting ($P < .001$). Significantly more women and younger individuals declined participation due to concerns about genetic testing and too little compensation ($P < .05$).

Conclusions: Collection of blood samples and concerns about genetic testing are obstacles for the recruitment of African Americans to pharmacogenomics studies. Efforts to overcome these barriers to participation are needed to improve representation of minorities in pharmacogenomic research. Enrolling participants from inpatient populations may be a solution to bolster recruitment efforts. *Ethn Dis.* 2020;30(Suppl 1):159-166; doi:10.18865/ed.30.S1.159

Keywords: African Americans; Psychology; Pharmacogenomic Testing; Health Literacy; Health Knowledge; Health Attitudes; Health Practice/Ethnology; Research Participants

American-specific genetic variation into precision medicine.¹ Historically, African Americans have been underrepresented in pharmacogenomic research. This lack of representation has contributed to health disparities in treatment and outcomes across medicine. Disparities in cardiovascular disease provide a well-known example.² Although African Americans are at increased risk for thrombotic diseases compared with Whites, they are underrepresented in cardiovascu-

¹ Department of Pharmacology, Center for Pharmacogenomics, Feinberg School of Medicine, Northwestern University, Chicago, IL

² Department of Communication Studies, Northwestern University, Chicago, IL

³ Washington DC VA Medical Center, Washington, DC

⁴ Department of Pharmacy Systems, Outcomes and Policy and Personalized Medicine Program, University of Illinois, College of Pharmacy, Chicago, IL

⁵ Department of Medicine, Section of Hospital Medicine, University of Chicago, Chicago, IL

⁶ The George Washington University, Washington, DC

Address correspondence to Matthew Tuck, MD; Washington, DC Veterans Affairs Medical Center; 202.745.8121; Matthew.Tuck@va.gov

lar and pharmacogenomic research.³⁻⁶

Much of what is known about low rates of African American participation in research comes from genetic and biobank studies.⁷ Community-based recruitment is cited by most of these studies as instrumental to facilitating African American enrollment.⁸⁻¹⁰ Successful recruitment has been credited to trust-building and communication strategies with this population.¹¹⁻¹³ In contrast, to the

...while efforts are being made to increase African American and minority enrollment into pharmacogenomic research studies, concerns of low participation rates persist.¹³

best of our knowledge, no literature exists analyzing African American enrollment into pharmacogenomic studies.⁷ Recruitment for pharmacogenomics studies may face additional barriers compared with genetic or biobank studies due to the complexity of describing gene-drug interactions. Furthermore, such studies are often exploring potential race-based differences in pharmacological response. Exploring race-based differences may engender different fears related to eugenics and

race-based mistreatment.¹⁴ Therefore, while efforts are being made to increase African American and minority enrollment into pharmacogenomic research studies, concerns of low participation rates persist.¹³

We established the African American Cardiovascular pharmacogenomics CONsorTium (ACCOuNT) to facilitate the discovery and translation of pharmacogenomic findings with the goal of improving African Americans' cardiovascular health.¹⁵ The CONsorTium is an NIH-funded group of experts consisting of academic institutions, patient organizations, and African American community leaders in Chicago and in the District of Columbia. ACCOuNT consists of several projects, one of which is the Discovery Project. The primary goal of the Discovery Project is to establish an African Ancestry pharmacogenomics research network to facilitate genomic research, and to establish a public pharmacogenomics resource for continued translational research. In addition, the group strives to establish mechanisms to support implementation, diffusion, and continuing evaluation and improvement of precision medicine in African Americans. The purpose of the current exploratory study is to identify the determinants of nonparticipation in cardiovascular pharmacogenomic research, specifically within the Discovery Project, among African Americans.

METHODS

Sample and Procedure

The Northwestern University central institutional review board and the

institutional review boards at University of Illinois at Chicago, the University of Chicago, and Washington, DC Veterans Affairs approved this research. All procedures followed were in accordance with the ethical standards of the IRBs and the Helsinki Declaration of 1975, as revised in 2000.

Potential participants in the Discovery Project were self-identified African Americans on one of five cardiovascular drugs of interest (warfarin, clopidogrel, dabigatran, rivaroxaban, apixaban), screened in the inpatient or outpatient setting at four participating institutions (Northwestern University, University of Illinois at Chicago, University of Chicago, and the Washington, DC Veterans Affairs Medical Center). Study coordinators first asked pre-screening questions including demographic information, history of alcohol or drug abuse within one year prior to enrollment, concomitant anticoagulant use and over-the-counter medications. After pre-screening, patients were asked to participate in the Discovery Project and to provide a one-time draw of 30 mL – 42 mL of blood, depending on the cardiovascular drug the patient was taking. If they declined participation in the Discovery Project, they were asked the open-ended question, “What are your reasons for not participating.” Responses to that question are the focus of this study. Study coordinators recorded participants' responses verbatim in a hand-written note over a period of eight weeks between September and October 2018. Discovery Study recruitment data over the eight-week period also were compiled from the four participating institutions.

Table 1. Demographics of study participants: eligible patients approached during an 8-week period and declined pharmacogenomic study participation at 4 different institutions, N=82

| | | n | % |
|---------------------|--|-----------------|------|
| Approach Setting | Inpatient | 32 ^a | 39.0 |
| | Outpatient | 50 ^a | 61.0 |
| Site | Northwestern University (Outpatient) | 34 | 41.5 |
| | University of Chicago (Inpatient) | 12 | 14.6 |
| | University of Illinois at Chicago (Outpatient & Inpatient) | 23 | 28.0 |
| | Washington, DC Veterans Affairs Medical Center (Inpatient) | 13 | 15.9 |
| Cardiovascular Drug | Warfarin | 38 | 46.3 |
| | DOAC | 30 | 36.6 |
| | Clopidogrel | 14 | 17.1 |
| Sex | Male | 38 | 46.3 |
| | Female | 44 | 53.6 |
| Average age | Mean years [SD] | 61.3 [15.03] | |

a. Denotes significant difference by approach setting ($P < .001$).

Qualitative Analysis

We conducted a directed content analysis¹⁶ on participants' responses. Consistent with the goals of a directed approach, we sought to determine whether existing reasons for non-participation in genetics and biobanking studies hold for pharmacogenomics studies, or if unique barriers exist. In keeping with this approach, the Discovery Project team developed three coding categories and definitions a priori based on a review of the literature.^{7,17,18} The initial categories were mistrust of research, concerns about genetic testing, and study requires too much blood. As study coordinators collected responses, they applied the coding categories independently, and then discussed the responses and coding with the rest of the study team on weekly or bi-weekly conference calls. To ensure uniformity and accuracy in coding and to identify new coding categories as they emerged from the data, we used a consensus-based approach to coding.

Statistical Analysis

Response rates, frequencies, and distribution of categorical reasons for refusal were analyzed using descriptive statistics. We examined all associations between categorical variables and outcomes using chi-square analysis. Those with mean values were tested with either ANOVA, two proportion z-test, or t-test. We also examined demographic differences between patients according to groups that were eligible, approached, and missed by research coordinators using chi-square analysis. A P-value of .05 was considered statistically significant.

RESULTS

Table 1 shows the demographics of our participants (N=82), where they were approached, and what cardiovascular drug they were on. During the 8-week study period, there were 466 Discovery Project-eligible

patients. Of those, 194 patients were approached and 272 were missed, cancelled, or were a no-show for their clinic appointment. Of the 194 patients approached, 82 declined participation; 51 asked to take the informed consent form home to review, of whom 17 enrolled at a later date, resulting in a total of 78 participants enrolled within the 8-week period. The majority of patients who declined participation in the Discovery Project (n=82) were approached in an outpatient setting (n=50; 61.0%), female (n=44; 53.7%), and on warfarin (n=38; 46.3%). As in the study pool of those who declined, the majority of eligible patients for the Discovery Project were approached in an outpatient setting (n=117; 60.3%), female (n=106; 54.6%), and on warfarin (n=100; 51.4%). There were no significant differences between eligible and approached patients according to age, sex, and study drug. Furthermore, there were no signifi-

Table 2: Final coding categories and exemplar quotes

| Coding Category | Exemplar Quote |
|---|---|
| Study requires too much blood | “That’s a lot of blood. I have been poked too many times already since I’ve gotten here.” |
| Mistrust of research | “I don’t want my information in a database.” |
| Concerns about genetic testing | “You know the police can get access to your genetic information.” |
| Too little time | “I don’t have time. I’m trying to rush out of here.” |
| No direct health benefit to participant | “How does this help me? There will be others more interested in participating.” |
| Is/has been in too many studies | “I’m already enrolled in a study in North Carolina.” |
| Not enough compensation | “If I’m giving my blood, I should get paid.” |
| No reason given | “I’ve just decided not to [participate].” |
| Other | “I have too much going on already as it is.” |

cant demographic differences between patients who were missed, enrolled, or refused participation.

Table 2 shows the final nine coding categories that resulted from the directed content analysis. The “other” coding category consisted of responses that, by consensus, did not fit into any category.

Table 3 shows the distribution of reasons for refusal by demographics and category. Of those who refused to participate in the study, 94% (n=71) were willing to state a reason for refusal. The most common reasons potential participants declined enrollment (n=82) were “study requires too much blood” (n=16, 19.5%), “concerns about genetic testing” (n=12,

14.6%), “mistrust of research” (n=10, 12.2%), and “not enough compensation” (n=9, 11.0%). The least common reasons for refusal to participate were “no direct health benefit to participant” (n=5, 6.1%) and “no reason given” (n=5, 6.1%). “Other” reasons given for declining participation included concerns about insurance coverage, feeling ill, and needing more time to contemplate the research (n=11, 13.4%). There were significant differences by age for reason given for declining participation. Patients who reported “concerns about genetic testing,” “no direct health benefit” or “not enough compensation” were significantly younger (P<.05). Significantly more men

responded that they had “concerns about genetic testing” and “have been in too many studies” (P<.05), and significantly more women responded that there was “not enough compensation” and “other” (P<.05).

By study site, enrollment rates were higher in the inpatient setting (n=40; 37%) than in the outpatient setting (n=38; 11%; P<.001). Significantly more patients (n= 242; 89%) were missed by research coordinators in the outpatient setting than inpatient setting (P<.05). More outpatients (n=39; 33.3%) asked to take the consent form home to review than inpatients (n=12, 15.6%). Those who took consent home were slightly older than other groups

Table 3. Reasons patients gave for declining participation by category

| Reason | Mean age in years [SD] | % Male | n (%) |
|---|---------------------------|-------------------|-----------|
| Study requires too much blood | 67.06 [13.1] | 43.8 | 16 (19.5) |
| Mistrust of research | 66.2 [16.3] | 60 | 10 (12.2) |
| Concerns about genetic testing | 54.6 [16.9] ^a | 83.3 ⁺ | 12 (14.6) |
| Too little time | 60.33 [14.1] | 50 | 8 (9.8) |
| No direct health benefit | 44.0 [23.8] ^a | 60 | 5 (6.1) |
| Participant is/has been in too many studies | 66.0 [9.2] | 83.3 ^b | 6 (7.3) |
| Not enough compensation | 55.56 [13.9] ^a | 33.3 ^b | 9 (11.0) |
| No reason given | 67.40 [11.9] | 20 | 5 (6.1) |
| Other | 68.36 [14.4] | 27.3 ^b | 11 (13.4) |
| Total | | | 82 (100) |

a. Denotes significant difference by age (P<.05).

b. Denotes significant difference by sex (P<.05).

(mean=aged 66.1years), though the difference was not statistically significant. Men were more likely to enroll in the study (n=15; 65%) than women (n=2; 7%) after taking the consent home (P<.0001).

DISCUSSION

This study demonstrates that concerns about genetic testing is an ongoing issue for African Americans; our findings support results from prior studies. Research in this area has shown minority status and concerns about how genetic specimens will be used are predictive of low participation rates in genetic research.¹⁹⁻²² Consistent with findings from biobank studies,²³ more than 26% of respondents in our study who declined participation cited mistrust of research and concerns about genetic testing. To our knowledge, no research exists that looks at reasons for nonparticipation among African Americans in pharmacogenomic studies. Racial health disparities are already present in pharmacogenomics, making this research gap particularly alarming.²⁴ Disparities will continue to worsen with underrepresentation of African Americans. Therefore, research in this area should be a continuing priority.

A recent review exploring barriers to participation in genetic and biobanking studies found mistrust to be the most frequently cited barrier to participation.⁷ In contrast, the most common reason for declining participation in the Discovery Project was the amount of blood required. Study coordinators informed eligible participants during the consent pro-

cess of the need for up to 42 mL of blood, using a layman’s description of 3 tablespoons. Historically, the public has been reluctant to give blood for genetic testing and storage.²⁵ This reluctance, however, has been shown to be more prevalent in the African American population.¹⁹ Although not possible for our project, other researchers have successfully circumvented this issue by using less invasive strategies, such as collecting DNA via buccal swabs or saliva.^{13,19,26}

This study also examined reasons patients declined by age, sex, and medication type. Interestingly, there were significant differences in reasons for declining according to age and sex which suggests messaging strategies based on demographics may be needed to improve participation.

Efforts have been made to increase African American participation with varying success.^{13,26} The Discovery Project uses approaches found to improve the recruitment of African Americans into genetic research studies. These approaches include personalized contact, leveraging community input, and explaining to participants how their samples will be used.^{13,26,27} Despite this, our success rate was as low as 34.4% at one center (Northwestern University). This speaks to the need for additional strategies to bolster recruitment and ongoing outreach to improve representation of African Americans in pharmacogenomics research.

One potential low-cost solution is to identify strategic messages that promote interest in pharmacogenomic studies among African Americans.⁷ For example, including a participant’s testimonial about their experiences

participating in the study in the recruitment materials may build trust and reduce concerns about potential outcomes. Testimonials can create surrogate social connections that reduce message reactance (ie, message rejection) and engender positive social norms.^{28,29} In addition to testimonials, message framing may matter. For example, focusing on community benefit and recognizing

Consistent with findings from biobank studies,²³ more than 26% of respondents in our study who declined participation cited mistrust of research and concerns about genetic testing.

the importance of including minorities could be an effective messaging strategy.^{17,30,31} However, there is some evidence to suggest that certain types of health messages, which highlight disparities, can create a boomerang effect (ie, cause the message recipient to behave opposite of the advocated behavior).³² Intrinsic benefits such as access to information, health care resources, and close medical monitoring have been identified as facilitators to participation among African Americans.^{17,31,33} Therefore, messages that

focus on benefits for the individual may be more advantageous. Future studies should test these hypotheses.

To build on our study’s findings and test some of the hypotheses about messaging, we have initiated a larger qualitative study to explore African American’s perceptions of pharmacogenomic studies. We anticipate recruitment of 180 participants across our consortium over one year, with each site contributing equal numbers of patients who decline or consent to the Discovery Project. After consenting, patients will undergo an interview about their thoughts regarding pharmacogenomic studies. We hope this will inform future recruitment strategies.

Although not the initial focus of this study, we found recruitment efforts were significantly more successful in the inpatient vs the outpatient setting. We speculate that a variety of factors may explain this, including the ease of providing a blood sample in the inpatient setting, the patient not having additional time constraints that a patient in an outpatient clinic may be facing, and relatedly, the recruiter having more time to explain the study to potential participants. Time constraints within a busy outpatient clinic may limit recruiters’ ability to explain the study to potential participants and fully address concerns. When comparing inpatient and outpatient sites, consideration should be given to study site. Not all centers recruited from both the inpatient and outpatient setting, and differences in patient populations by site may contribute to differences in enrollment.

Research coordinators missed sig-

nificantly more patients in the outpatient setting. The sites from which we recruited patients are high-volume clinical environments, and the number of eligible patients reflects this. We suspect the reasons for the large difference between those approached vs those eligible is due to: 1) high no-show rates of patients to our outpatient clinics; 2) the presence of multiple eligible patients in the clinics at any given time; and 3) canceled clinic appointments. To evaluate for bias within our sample set, we examined differences in demographic data between those approached and those missed by research coordinators, but we found no differences. Of eligible patients approached in the outpatient setting, 33.3% chose to take the informed consent form home to review, rather than enrolling on the spot, compared with 15% in the inpatient setting. Patients in the inpatient setting may have fewer competing obligations, and therefore more time to discuss the study and review the consent when approached. The additional time patients have available in the inpatient setting is likely a contributing factor to the higher recruitment rates in the Discovery Project. Therefore, recruiting from the inpatient population, where the patient has time and no other obligations to attend to, may be an effective recruitment strategy when feasible.

A strength of this study is the multi-center design where patients were recruited from one of four different centers in both inpatient and outpatient settings. Additionally, this study is the first that we are aware of to examine recruitment of African Americans for a pharma-

cogenomic study. The results are also likely to be reliable as the coding categories created were based on the responses of eligible participants.

As with all qualitative research, the views of the patients in this sample cannot be generalized to the larger population. Further, this study is limited by the relatively short responses to the open-ended question. That said, the number of respondents is rather large for a genetic study.^{27,34} One must also consider the location of the study centers when interpreting the results. Finally, our study is limited by the use of a consensus-based approach to coding instead of testing inter-rater reliability.

CONCLUSIONS

Mistrust of research and concerns about genetic testing remain obstacles for recruitment of African Americans. Therefore, additional strategies are needed to improve enrollment among this group. Although previously identified as a barrier in genetic and biobanking studies, collecting blood appears to be a barrier for enrollment in our pharmacogenomic study. Interestingly, the amount of blood was the most significant barrier and not just general concerns about needles or the risks associated with taking blood. This concern may be alleviated by providing more clear information in lay terms about how much blood is being requested. Alternatively, this barrier may be alleviated altogether by using buccal swabs or saliva. One potential approach that deserves future inquiry is the effectiveness of recruiting from inpatient populations.

ACKNOWLEDGMENTS

The research reported in this publication was supported by the National Institute on Minority Health and Health Disparities of the National Institutes of Health under award number U54MD010723.

CONFLICT OF INTEREST

No conflicts of interest to report.

AUTHOR CONTRIBUTIONS

Research concept and design: Nooruddin, Scherr, Perera, Friedman, Nutescu, Tuck; Acquisition of data: Nooruddin, Subrahmanyam, Banagan, Moreno, Sathyanarayanan, Nutescu, Jeyaram, Harris, Zhang, Rodriguez, Shaazuddin, Tuck; Data analysis and interpretation: Nooruddin, Perera, Friedman, Subrahmanyam, Banagan, Moreno, Sathyanarayanan, Jeyaram, Zhang, Shaazuddin, Tuck; Manuscript draft: Nooruddin, Scherr, Perera, Friedman, Tuck; Statistical expertise: Nooruddin, Perera, Zhang; Acquisition of funding: Perera, Tuck; Administrative: Nooruddin, Scherr, Friedman, Subrahmanyam, Banagan, Moreno, Sathyanarayanan, Nutescu, Jeyaram, Harris, Shaazuddin, Tuck; Supervision: Scherr, Perera, Friedman, Harris, Tuck

REFERENCES

1. Bustamante CD, Burchard EG, De la Vega FM. Genomics for the world. *Nature*. 2011;475(7355):163-165. <https://doi.org/10.1038/475163a> PMID:21753830
2. Taylor HA, Henderson F, Abbasi A, Clifford G. Cardiovascular disease in african americans: innovative community engagement for research recruitment and impact. *Am J Kidney Dis*. 2018;72(5)(suppl 1):S43-S46. <https://doi.org/10.1053/j.ajkd.2018.06.027> PMID:30343723
3. Kaufman JS, Dolman L, Rushani D, Cooper RS. The contribution of genomic research to explaining racial disparities in cardiovascular disease: a systematic review. *Am J Epidemiol*. 2015;181(7):464-472. <https://doi.org/10.1093/aje/kwu319> PMID:25731887
4. Zhang T, Tsang W, Wijesundera HC, Ko DT. Reporting and representation of ethnic minorities in cardiovascular trials: a systematic review. *Am Heart J*. 2013;166(1):52-57. <https://doi.org/10.1016/j.ahj.2013.03.022> PMID:23816021
5. Tang L, Hu Y. Ethnic diversity in the genetics of venous thromboembolism. *Thromb Haemost*. 2015;114(5):901-909. <https://doi.org/10.1160/TH15-04-0330> PMID:26156046
6. Liang J, Le TH, Edwards DRV, et al. Single-

- trait and multi-trait genome-wide association analyses identify novel loci for blood pressure in African-ancestry populations. *PLoS Genet*. 2017;13(5):e1006728. <https://doi.org/10.1371/journal.pgen.1006728> PMID:28498854
7. Scherr CL, Ramesh S, Marshall-Fricker C, Perera MA. A review of African Americans’ beliefs and attitudes about genomic studies: opportunities for message design. *Front Genet*. 2019;10:548. <https://doi.org/10.3389/fgene.2019.00548> PMID:31258547
8. Ochs-Balcom HM, Jandorf L, Wang Y, et al. “It takes a village”: multilevel approaches to recruit African Americans and their families for genetic research. *J Community Genet*. 2015;6(1):39-45. <https://doi.org/10.1007/s12687-014-0199-8> PMID:25112899
9. Bishop MR, Shah A, Shively M, et al. Establishment of the Alabama Hereditary Cancer Cohort - strategies for the inclusion of underrepresented populations in cancer genetics research. *Mol Genet Genomic Med*. 2018;6(5):766-778. <https://doi.org/10.1002/mgg3.443> PMID:29962060
10. McNeill LH, Reitzel LR, Escoto KH, et al. Engaging black churches to address cancer health disparities: Project CHURCH. *Front Public Health*. 2018; 6:191.
11. Walker ER, Nelson CR, Antoine-LaVigne D, et al. Research participants’ opinions on genetic research and reasons for participation: a Jackson Heart Study focus group analysis. *Ethn Dis*. 2014;24(3):290-297. PMID:25065069
12. Buseh AG, Stevens PE, Millon-Underwood S, Townsend L, Kelber ST. Community leaders’ perspectives on engaging African Americans in biobanks and other human genetics initiatives. *J Community Genet*. 2013;4(4):483-494. <https://doi.org/10.1007/s12687-013-0155-z> PMID:23813337
13. Johnson VA, Powell-Young YM, Torres ER, Spruill IJ. A systematic review of strategies that increase the recruitment and retention of African American adults in genetic and genomic studies. *ABNF J*. 2011;22(4):84-88. PMID:22165568
14. Callier SL, Cunningham BA, Powell J, McDonald MA, Royal CDM. Cardiologists’ perspectives on race-based drug labels and prescribing within the context of treating heart failure. *Health Equity*. 2019;3(1):246-253. <https://doi.org/10.1089/heap.2018.0074> PMID:31289785
15. *What is ACCOuNT?* Last accessed November 1, 2019 from <https://precisionmedicine4all.com/>
16. Hsieh HF, Shannon SE. Three approaches to qualitative content analysis. *Qual Health Res*. 2005;15(9):1277-1288. <https://doi.org/10.1177/1049732305276687> PMID:16204405
17. George S, Duran N, Norris K. A systematic review of barriers and facilitators to minority research participation among African Americans, Latinos, Asian Americans, and Pacific Islanders. *Am J Public Health*. 2014;104(2):e16-e31. <https://doi.org/10.2105/AJPH.2013.301706> PMID:24328648
18. Potter WJ, Levine-Donnerstein D; Potter & Levine-Donnerstein. Rethinking validity and reliability in content analysis. *J Appl Commun Res*. 1999;27(3):258-284. <https://doi.org/10.1080/00909889909365539>
19. Bussey-Jones J, Garrett J, Henderson G, Moloney M, Blumenthal C, Corbie-Smith G. The role of race and trust in tissue/blood donation for genetic research. *Genet Med*. 2010;12(2):116-121. <https://doi.org/10.1097/GIM.0b013e3181cd6689> PMID:20098329
20. McQuillan GM, Porter KS, Agelli M, Kington R. Consent for genetic research in a general population: the NHANES experience. *Genet Med*. 2003;5(1):35-42. <https://doi.org/10.1097/00125817-200301000-00006> PMID:12544474
21. Schulz A, Caldwell C, Foster S. “What are they going to do with the information?” Latino/Latina and African American perspectives on the Human Genome Project. *Health Educ Behav*. 2003;30(2):151-169. <https://doi.org/10.1177/1090198102251026> PMID:12693521
22. Furr LA. Perceptions of genetics research as harmful to society: differences among samples of African-Americans and European-Americans. *Genet Test*. 2002;6(1):25-30. <https://doi.org/10.1089/109065702760093889> PMID:12180073
23. Goddard KA, Smith KS, Chen C, McMullen C, Johnson C. Biobank Recruitment: motivations for Nonparticipation. *Biopreserv Biobank*. 2009;7(2):119-121. <https://doi.org/10.1089/bio.2009.0006> PMID:22087353
24. Martin A, Downing J, Maden M, et al. An assessment of the impact of pharmacogenomics on health disparities: a systematic literature review. *Pharmacogenomics*. 2017;18(16):1541-1550. <https://doi.org/10.2217/pgs-2017-0076> PMID:29095091
25. Wang SS, Fridinger F, Sheedy KM, Khoury MJ. Public attitudes regarding the donation and storage of blood specimens for genetic research. *Community Genet*. 2001;4(1):18-26. PMID:11493749
26. Ewing A, Thompson N, Ricks-Santi L. Strategies for enrollment of African Americans into cancer genetic studies. *J Cancer Educ*. 2015;30(1):108-115. <https://doi.org/10.1007/s13187-014-0669-z> PMID:24882437
27. Patterson AR, Davis H, Shelby K, et al. Successful strategies for increasing African American participation in cancer genetic studies: hopeful signs for equalizing the benefits of genetic medicine. *Community Genet*. 2008;11(4):208-214. <https://doi.org/10.1007/s12687-013-0155-z>

Why African Americans say “No” - Nooruddin et al

- org/10.1159/000116881 PMID:18417968
28. Moyer-Gusé E. Toward a theory of entertainment persuasion: explaining the persuasive effects of entertainment-education messages. *Commun Theory*. 2008;18(3):407-425. <https://doi.org/10.1111/j.1468-2885.2008.00328.x>
 29. de Wit JB, Das E, Vet R. What works best: objective statistics or a personal testimonial? An assessment of the persuasive effects of different types of message evidence on risk perception. *Health Psychol*. 2008;27(1):110-115. <https://doi.org/10.1037/0278-6133.27.1.110> PMID:18230021
 30. Jones BL, Vyhldal CA, Bradley-Ewing A, Sherman A, Goggin K. If we would only ask: how Henrietta Lacks continues to teach us about perceptions of research and genetic research among African Americans today. *J Racial Ethn Health Disparities*. 2017;4(4):735-745. <https://doi.org/10.1007/s40615-016-0277-1> PMID:27664025
 31. Hughes TB, Varma VR, Pettigrew C, Albert MS. African Americans and clinical research: evidence concerning barriers and facilitators to participation and recruitment recommendations. *Gerontologist*. 2017;57(2):348-358. <https://doi.org/10.1093/geront/gnv118> PMID:26553736
 32. Balls-Berry JE, Hayes S, Parker M, et al. The effect of message framing on African American women's intention to participate in health-related research. *J Health Commun*. 2016;21(5):527-533. <https://doi.org/10.1080/10810730.2015.1103333> PMID:27077665
 33. Luebbert R, Perez A. Barriers to clinical research participation among African Americans. *J Transcult Nurs*. 2016;27(5):456-463. <https://doi.org/10.1177/1043659615575578> PMID:25754929
 34. Ridgeway JL, Han LC, Olson JE, et al. Potential bias in the bank: what distinguishes refusers, nonresponders and participants in a clinic-based biobank? *Public Health Genomics*. 2013;16(3):118-126. <https://doi.org/10.1159/000349924> PMID:23595106