



# Attitudes and experiences regarding genetic research among persons of African descent

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## Abstract

Minorities are underrepresented in genetic research. This study examined the attitudes, experiences, and willingness of persons of African descent related to participation in genetic research. A total of 272 persons of African descent completed a questionnaire about attitudes and experiences associated with genetic research. Descriptive, Chi-square, and logistic regression were used to examine the impact of attitudes and experiences in predicting the odds of willingness to participate in genetic research. A majority of participants (97%) indicated that they have never participated in genetic research; however, a majority also reported that they would be willing to participate in a genetic study specifically for the detection of risk factors for cancer (87%), diabetes (89%), alcohol use disorder (73%), and Alzheimer's disease (88%). Participants who disagreed that "results from genetic research can explain why some diseases are found more often in some ethnic groups than others" were less likely to be willing to participate in studies related to cancer (OR = 0.16), diabetes (OR = .16), alcohol use disorder (OR = 0.27), and Alzheimer's disease (OR = 0.27). Participants reported limited experiences engaging in genetic research; yet, they overwhelmingly acknowledged the importance of genetic research and expressed willingness to participate in multifactorial genetic studies despite concerns about genetic discrimination, stigma, and/or a potentially poor prognosis. Further research on the underlying reasons why persons of African descent choose to participate in genetic research should be explored and addressed to make research more inclusive and ethically sound.

**Keywords** Genetic research · African descent · Willingness to participate

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## Introduction

Advances in genetics and genomics are increasingly informing our approaches to preventing, diagnosing, and treating disease, but greater diversity is needed within the research context. While researchers have long advocated for increased involvement of people of African descent in genetic and genomic research (Dang et al. 2014; Ewing et al. 2015; Halbert et al. 2016; Isler et al. 2013; Ochs-Balcom et al. 2015), participation has remained low compared to persons of European descent (Bustamante et al. 2011; Dang et al. 2014; Popejoy and Fullerton 2016). Underrepresentation of African Americans, Latinos, and other diverse groups in research hinders the discovery of genetic links to diseases that disproportionately affect these populations and delays scientific advancement for all patients (Bentley et al. 2017). This is also true for precision medicine because diversity and inclusion in precision medicine research are necessary to better understand

the social, environmental, and genomic contributors to health outcomes. Meaningful advancements in genomics and precision medicine research will therefore depend on the sufficient and sustained engagement of diverse communities, including those of African descent (Bentley et al. 2017).

In addition, advancements in these fields will be incomplete without individuals with or at risk for different types of diseases, including disorders influenced by varying genes and environmental factors, and conditions associated with stigma. Previous studies have indicated, for instance, that individuals with and without a medical history of a stigmatizing disease expressed a willingness to participate in real time and future genetic research (Laegsgaard et al. 2009; Roberts and Kim 2017). For psychiatric disorders, which are arguably some of the most stigmatizing, intentions to test were positively associated with parental status, trust in researchers, and an expectation that knowledge would increase one's preparedness related to health risk. Such intentions were negatively associated with the fear of psychiatric genetic research, which brought on too many difficult choices and a fear of being able to cope with the results of a psychiatric genetic test (Laegsgaard et al. 2009). For disorders not associated with stigma, willingness to participate in research was related to the way information was presented during recruitment (Lanfear et al. 2011), knowledge, beliefs, and perceptions about genetics, the involvement of providers (Millon Underwood et al. 2013), and understanding of how participation might be used to improve knowledge about environmental factors that affect health disparities (White et al. 2010).

Scholars often argue that African Americans' distrust in biomedical research is one reason for the low participation rate of persons of African descent. Evidence suggests that awareness of historical injustices in research settings may deter current generations of African Americans from volunteering to participate in genetic studies (White et al. 2010). A longstanding distrust of researchers, for instance, may stem from concerns regarding the potential exploitation of members of African American communities and contribute to an unwillingness to participate in genetic research activities (Buseh et al. 2013; Lang et al. 2013; Rencher and Wolf 2013). One study found that men aware of the United States Public Health Service Syphilis Study at Tuskegee were 50% less likely to participate in research compared to those who were not (Lang et al. 2013). Similarly, the story of Henrietta Lacks may cause communities to question the trustworthiness of researchers (Jones et al. 2017). The publication of Mrs. Lacks and her family's experiences has contributed to widespread discussion about the use of genetic data among people in general, regardless of race, including African Americans (Buseh et al. 2013; Jones et al. 2017). The privacy and consent issues prevalent in Henrietta Lacks' story may have generated feelings of skepticism and a sort of "visceral response" in relation to genetic research (Buseh et al. 2013). Other barriers

to recruiting persons of African descent into genetic research include concerns regarding confusion over the use of genetic information, fear of incidental discoveries (Jones et al. 2017), and cultural differences between researchers and potential participants (Parikh et al. 2017).

In fact, willingness to participate in genetic research may be influenced by a variety of factors, and so it is important to explore the attitudes and beliefs of all participants in research, especially those traditionally excluded. In a study by Yu et al., the majority of both African Americans and non-African Americans who participated in focus groups were willing to participate in exome sequencing (ES) and whole genome sequencing (WGS) studies and to receive individual genetic test results. The authors found that expectations of health benefits from WGS/ES affected participant interest in research so significantly that they recommended that return of results communications be carefully managed. Among the fraction of participants uninterested in ES/WGS studies and returning ES/WGS results, African American expressed the least interest (Yu et al. 2013). Thus, the authors suggested that investigators develop and test culturally tailored strategies for returning ES/WGS results to African Americans. Knowledge of the attitudes and experiences of individuals of African descent can inform such strategies.

### Experience with genetic research

Other factors that can affect African Americans' willingness to participate in genetic research include previous experience and proactive engagement by researchers and healthcare providers. In a study of 169 African American participants, only 12% reported that they had previously been approached to participate in genetic research. Of the participants who had previously engaged in genetic research, 86% demonstrated an eagerness to participate further. Of those without previous experience engaging in genetic research, only 30% indicated that they would participate in future genetic research projects (Jones et al. 2017). In another study, persons of African descent "cited not being asked" as the primary reason for not previously enrolling in a study (Millon Underwood et al. 2013).

Other studies have reported that African Americans are willing to participate in research requiring blood and genetic samples (Cottler et al. 2013). A fuller picture of the attitudes and experiences of persons of African descent related to genetic research and the factors that influence participation in research are necessary to maximize sustained interest in such studies and to do so in an ethical manner. The purpose of this study was to examine the attitudes and experiences of persons of African descent with respect to participation and willingness to participate in genetic research.

## Materials and methods

### Recruitment of participants

A non-probability cross-sectional convenience sample of persons who self-identified as members of the African diaspora, ages 18 years and older, were recruited in the Washington, D.C. metropolitan area. Recruitment was completed in Washington, D.C. with an emphasis on Howard University Hospital because it serves a large number of persons of African descent. Additionally, flyers and posters were distributed that included a cell phone number in order that interested participants could contact a research assistant any time of the day to schedule an appointment to complete the survey. To diversify the sample, we administered the survey on various days and at different times and locations, including hospital settings and a community-based partner sites. These recruitment methods led to snowball sampling, a nonprobability sampling technique. Participants were invited to complete a confidential questionnaire administered by trained African American research assistants. The Washington, D.C. metropolitan area was an ideal place to conduct this study because it has an ethnically diverse population where persons of African descent comprise a very large percentage of the population. Respondents were assured that all responses would remain confidential. The study was conducted with the approval of the Howard University Institutional Review Board.

### Participant interview and instrument

The Knowledge, Attitudes, Beliefs and Experiences (KABE) questionnaire was designed to collect information on the knowledge, attitudes, beliefs, and experiences of persons of African descent regarding clinical genetic testing and genetic research. Included in the survey were quantitative measures relevant to the variables of interest with some follow-up, open-ended questions. The items were generated based upon a comprehensive review of relevant conceptual and empirical literature. Some of the survey items were newly constructed with hypothetical scenarios, while others were borrowed from modified versions of questions asked in previous related studies (Powell-Young and Spruill 2013; Scott et al. 2014; Underwood et al. 2013).

In designing the survey items, issues of validity, reliability, and cultural relevance were considered. Face validity and cultural relevance of the survey were addressed by having the instrument reviewed by an external expert in the field of genetics. An external expert of African descent in the field of genetics with expertise in counseling persons of African descent reviewed the instrument and evaluated each item. She evaluated each item in terms of its content and cultural relevance for use with a sample of persons of African descent based upon the survey's appearance, relevance, and representativeness of items for their intended

purpose and population. Feedback from the expert was used to improve the instrument's content validity prior to field testing to ensure not only the measure's ease of use, clarity, and readability but also to enhance its credibility, accuracy, relevance, and breadth of domains covered related to genetic research attitudes and experiences. We also sought to ensure that the survey was culturally relevant and covered issues that were particularly salient for persons of African descent. Additional verification of the instrument's validity and reliability was pilot tested with a sample of 35 adults of African descent who were selected from the target population. The survey was administered to the pilot participants by trained research assistants, exactly as designed for the full study. After the survey was completed, the pilot participants were asked to reflect on the survey in terms of (a) clarity of the items, (b) ordering of the items, (c) length of the survey, (d) ease of procedures, and (e) any other general reflections. Improvements were made to the survey based on the response feedback from the expert and the participants that participated in the pilot. Definitions of genetic research and clinical genetic testing were explained to the participants verbally and in writing to ensure consistency of the terms.

The section of the survey used for this paper includes questions on attitudes about and experiences with genetic research and the handling of pertinent genetic research findings. The attitudinal items included a 5-point Likert scale, ranging from "Strongly Disagree" to "Strongly Agree." The attitudinal items were constructed based upon an extensive review of the relevant literature (Powell-Young and Spruill 2013), particularly studies focusing on African Americans' attitudes and perceptions about genetic research. Questions about experiences included "Yes/No" responses with opportunities available for the respondents to enter comments.

In this study, participants were also asked if they would be willing to participate in a genetic research project specifically for the detection of risk factors for multifactorial genetic research studies, some of which disproportionately affect persons of African descent. The final component of the survey consisted of a series of background questions focusing on demographic characteristics.

### Statistical analysis

Descriptive statistics of relevant variables were evaluated and presented as mean with standard deviation and frequencies with percentages.

In addition, the logistic regression analyses were used to examine the impact of "attitudes" on willingness to participate in genetic research separately for various multifactorial diseases. Results are presented as odds ratios with percentages. Because of the very small cell counts or zero for strongly disagree category, "Strongly Agree" and "Agree" were collapsed and recoded as "agree". Similarly, "Strongly Disagree" and "Disagree" were recoded as "Disagree." Therefore,

instead of the 5 response categories, the categories were reduced to 3-response categories as “Agree”, “Uncertain”, and “Disagree.” For the regression analyses, “Agree” was the baseline comparison group. Data are presented as mean+/SD or *n* (%). In all inferential analyses, statistical significance was declared if two-sided *p* values were < 0.05. The SPSS (Statistical Package for Social Sciences) software was used for all the analyses.

## Description of sample

A total of 300 persons completed the survey and 272 self-identified as persons of African descent. Data reported here are limited to individual responses from those who self-identified as a person of African descent. As shown in Table 1, 93% of the participants were born in the USA 71% were female, 57% achieved a college education or above, 62% had a household income under \$50,000, and 69% had children. The sample mean+/SD age was 50 ± 16 years. We did not assess ethnicity but believe that differences in ethnicity may be relevant in future larger samples.

## Results

### Demographics and willingness to participate in genetic studies

There was an association between the age of the participant and willingness to participate in cancer genetic studies ( $p = .02$ ). Persons who were older were less likely to be interested in cancer genetic studies (OR = .97,  $p = .02$ , CI [0.95, 0.99]). In addition, there was an association between willingness to participate in genetic research exploring risks for alcohol use disorder and parental status ( $p = .02$ ): participants with children were twice as likely to be interested in genetic research studies for alcohol use disorder (OR = 2.115,  $p = .02$ , CI [1.14, 3.91]).

### Attitudes toward genetics research and willingness to participate in genetic studies in general

Participants' responses to attitudes regarding genetic research are summarized in Fig. 1. Slightly over one-half (53.3%,  $n = 145$ ) of the participants “Agreed” or “Strongly Agreed” with the statement “It is important for African Americans/Blacks to participate in genetic research.” Further, 62.1% ( $n = 169$ ) agreed” or “Strongly Agreed” that “Results from genetic research can be used to explain why some diseases are found more often in

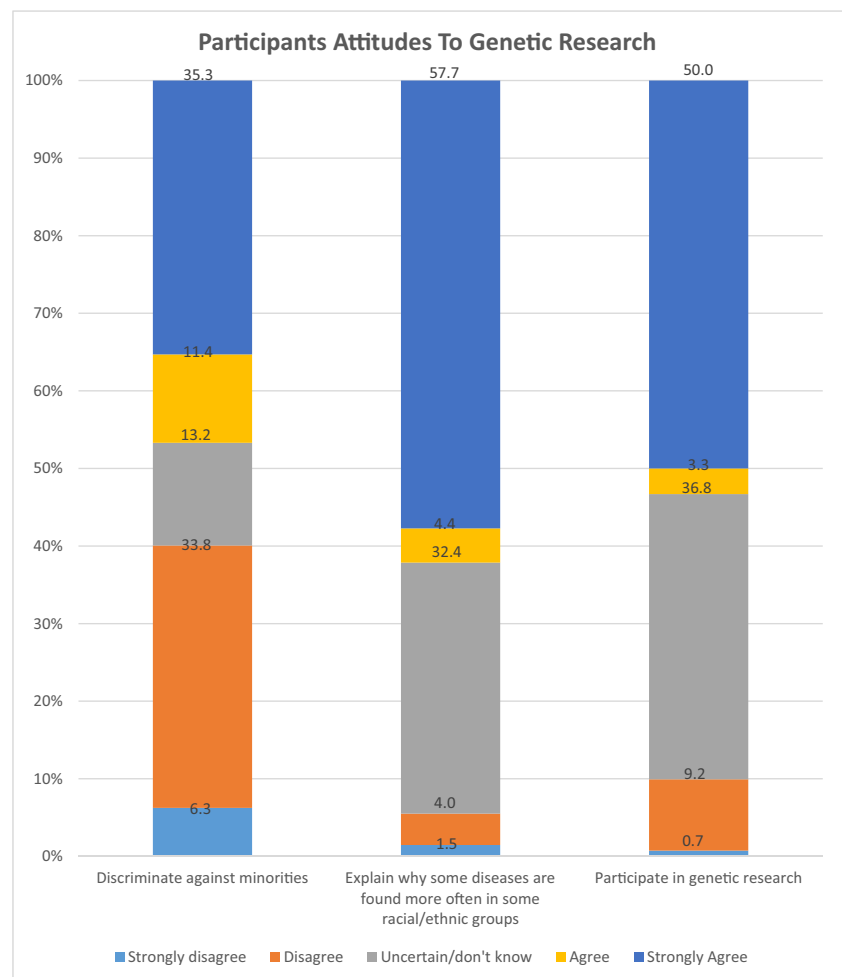
**Table 1** Demographic characteristics of persons of African descent  $N = 272$

Characteristic	<i>n</i> /Mean	%/SD
Gender		
Female	194	71
Male	78	29
Disability		
Yes	103	38
No	166	62
Birth country		
United States	253	93
Age	50	16
Highest level of education		
<High School	22	8.0
High School	85	31
Vocational/technical school beyond high school	9	3
Some college	84	31
Graduate from college (4 years)	30	11
Some graduate work	6	2
Graduate/professional degree	36	13
Marital status		
Single, not with a live-in partner	141	52
Single, with a live-in partner	32	12
Married	38	14
Separated/divorced	37	13.6
Widowed	23	8.5
Have children?		
Yes	186	69
No	85	31
Employment status		
Employed/working full time	88	32.4
Employed part time	30	11.0
Self-employed	12	4.4
Retired	40	14.7
Unemployed	100	36.8
Average household income		
Less than \$25,000 yearly	99	38
\$25,000–\$49,999 yearly	63	24
\$50,000–\$74,999 yearly	45	17
\$75,000–\$99,999 yearly	28	11
Over \$100,000 yearly	29	11
Total responses	272	

Note: Sample is based on those self-identified as African American/Black. Characteristics' *n* may not total 272, due to missing data. Percentages are rounded

some racial/ethnic groups (such as diabetes, hypertension) and not in others.” Finally, 46.7% ( $n = 127$ ) either “agreed” or “strongly agreed” that “Information from genetic research can be used to discriminate against minorities.”

**Fig. 1** Participants' responses to attitudes regarding genetic research. Listed above each segment is the percentage (%) of participants who strongly agree, agree, are uncertain, disagree strongly agree with proposed attitudes associated with genetic research



### Attitudes towards genetics research and willingness to participate in multifactorial genetic studies

Participants' attitudes toward genetic research and willingness to participate in multifactorial genetic studies are shown in Table 2. Results show that there was an association between attitudes toward genetic research and willingness to participate in a genetic study for cancer, diabetes, alcohol, and Alzheimer's disease. Participants who disagreed that genetic research results explain racial/ethnic differences in some diseases were 84% less likely to be willing to participate in a genetic study for cancer, 84% less likely to participate in a study about diabetes, 73% less likely to participate in a study for alcohol use disorder, and 73% less likely to participate in a research study on Alzheimer's disease compared to those who agreed with the statement.

In addition, there was an association between the belief that it is important for African Americans to participate in genetic research and willingness to participate in a genetic study for Alzheimer's disease. Participants who disagreed with the statement that "it is important

for persons of African descent to participate in genetic research" were 73% less likely to participate in a genetic study for Alzheimer's disease than those who agreed. Even though 47% of the participants agreed or strongly agreed that information from genetic research can be used to discriminate against minorities there was no association between this attitude and willingness to participate in genetic research for cancer, diabetes, alcohol use disorder, and Alzheimer's disease.

When participants were asked questions about a hypothetical genetic study, 94% of the participants indicated that if a genetic test revealed that they had a disease or risk factor for the disease being studied, but they were not aware it, they would want the researcher to disclose the information. Only 2% responded "No" and for another 2% they indicated that their desires would depend on the availability of treatment, how well the treatment is understood, how bad the risk is, what and how much they are told about it, and whether it is going to take "my life." Among those within this 2%, some also indicated that they would prefer to get the information from their doctors.

**Table 2** Attitudes and willingness to participate in genetic research for multifactorial diseases

Attitude	Willingness to participate in genetic research involving							
	Cancer		Diabetes		Alcohol use disorder		Alzheimer's disease	
	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI
Results from genetic research can be used to explain why some diseases are found more often in some racial/ethnic groups and not in others								
Disagree	0.16	.004–0.56*	0.16	0.04–0.61*	0.27	0.08–0.92*	0.27	0.10–0.77*
Uncertain/do not know	1.30	0.54–3.11	0.90	0.36–2.27	1.55	0.80–3.02	1.66	0.61–4.52
Agree	1	–	1	–	1	–	1	–
It is important for African Americans/Blacks to participate in genetic research								
Disagree	0.39	0.14–1.14	0.35	0.11–1.12	0.50	0.20–1.25	0.27	0.10–0.77*
Uncertain/do not know	1.43	0.58–3.50	1.01	0.39–2.62	1.07	.568–2.000	1.66	0.61–4.52
Agree	1	–	1	–	1	–	1	–
Information from genetic research can be used to discriminate against minorities								
Disagree	1.41	0.51–3.88	1.80	0.58–5.59	1.497	0.73–3.06	2.49	0.84–7.37
Uncertain/do not know	0.41	0.15–1.13	0.36	0.13–1.03	.495	0.22–1.12	0.59	0.21–1.65
Agree	1	–	1	–	1	–	1	–

\*Significance was established at  $p < 0.05$

## Willingness to participate in genetic research

Only 17% of the study sample reported ever having a genetic test and of those only 3% indicated the genetic test was for a research study. Although the majority of participants reported no experience participating in genetic research, the majority also reported that they would participate in a genetic research project specifically for detection of risk factors for cancer (87%), diabetes (89%), alcohol use disorder (73%), and Alzheimer's disease (88%).

## Discussion

This study provides empirical data on the attitudes and experiences of persons of African descent in relation to genetic research. A key finding is that contrary to narratives that persons of African descent are unwilling to participate in research for various reasons, there are instances when such individuals may be very interested and willing to participate in genetic research. African ancestry alone does not predict disinterest in genetic research. Despite concerns about discrimination, participants expressed belief that there are instances when genetic research can be beneficial to their communities.

### Attitudes

In general, participants viewed genetic research as important. This finding is consistent with previous reports that persons of African descent believe that there are clear benefits for advancing genetic and science (Walker et al. 2014). The majority of the

participants in this study would be willing to participate in a genetic research study specifically for the detection of multifactorial diseases, such as cancer, diabetes, alcohol use disorder, and Alzheimer's disease. It should be noted that contrary to some narratives about persons of African descent having low levels of interest in genetic research, there was a high level of interest in genetic research overall. In addition, persons were willing to participate in a study related to Alzheimer's disease, a disorder that currently has a poor prognosis. These results are consistent with previous reports that participants would be interested in genetic research for complex diseases such as heart disease (Walker et al. 2014), diabetes, and depression (Roberts and Kim 2017). Further qualitative research could elucidate the underlying causes of African Americans' willingness to participate in genetic research. Examples might include an interest to know more, a desire to improve health, and/or an interest in addressing the causes of a disease and finding solutions.

A concordant finding, for instance, is that participants in this study desired a level of access to their own genetic information in certain circumstances, such as, when results could detect susceptibility for a disease that was being investigated. The aforementioned study by Yu et al. (2013) similarly found that the majority of African Americans who participated in focus groups would participate in studies and receive individual genetic results although as a whole, African Americans were less interested in such studies than other racial and ethnic groups. According to the authors this was due in part to different expectations of health benefits from exome sequencing (ES)/whole genome sequencing (WGS) and how results should be managed. In this study reported here, participants favored disclosure related to cancer, diabetes, alcohol use disorder, and Alzheimer's disease risk.

Within this study, participants were willing to participate in genetic research for multifactorial disorders but expressed some concern about genetic discrimination against minorities. Hence, an important research question for the future might be to explore the role of history, culture, and experiences on perspectives about stigma and discrimination. Understanding these dynamics and possibly other previously undiscovered influences on persons of African descent and in particular, their attitudes about genetics, motivators, and barriers to participation could assist with recruitment, but also, discussions about justice, fairness, and generational shifts in views about genetic research. There may be some misunderstandings about participants' interest in research or as others have found insufficient effort to locate willing participants.

In addition, participants in this study who did not believe results from genetic research can explain why some diseases are found more often in some ethnic groups were less willing to participate in studies for multifactorial disorders. As noted in a study that investigated intentions to participate in genetics research among African American smokers, education on the benefits and impact of genetic research in minorities may increase interest and participation (Halbert et al. 2006).

## Experience

Participants in this study noted that two of the major reasons why persons had not participated in genetic testing which includes genetic research are because they never thought about it or their physician never mentioned it. This agrees with the study by Million Underwood et al. (2013) that indicated that persons of African descent “cited not being asked” as the primary reason for not previously enrolling in a genetic research study (Millon Underwood et al. 2013). Physicians may be aware of current studies that are available and may not inform their patients, potential research participants, for various reasons. Perhaps, future studies could actively investigate healthcare providers' attitudes and experiences with genetic research and how it effects their willingness to inform their patients about genetic research studies. In addition, researchers and physicians should consider participatory research to engage the community.

## Study benefits and limitations

This study should be interpreted considering its strengths and limitations. The participants were recruited from a large community sample of persons of African descent with various ages and socioeconomic levels. In addition, the questionnaire was administered by trained research assistants and participants were able to express the logic behind their responses.

The few limitations include that while quite diverse, this population still might not be representative of the general population of persons of African descent across the country. In

addition, since this study investigated hypothetical genetic research involvement, the results might be an overestimation. Future studies should involve mixed-methods in real-world genetic research studies that involve the option of submitting a biospecimen for analysis and interpretation.

This study revealed the importance of digging deeper to understand disparities in participation in genetic research. Our results revealed a willingness to participate in genetic studies for multifactorial disorders, even for conditions associated with a stigma, a poor prognosis, or both. The slightly lower percentage of willingness to participate in research related to alcohol use disorders could relate to stigma, but also a known history of alcohol use disorder in the family, or complex memories and associations with alcohol. Further qualitative research on this topic would help inform discussion and policy on willingness to engage in genetic research. As we look forward to the future of integrated healthcare and precision medicine, it is important to address the attitudes and research experiences of persons of African descent to increase the number of persons willing to participate in genetic studies with the ultimate goal of decreasing health disparities. In addition, just as it is important to translate the intent to participate in research into actual participation, we must consider the reasons that underlie willingness to participate so that investigators can ensure congruence with community goals; therefore, future studies could explore reasons why persons of African descent express a willingness to participate in genetic research.

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## Compliance with ethical standards

**Conflict of interest** The authors declare that they have no conflict of interest.

**Animals** This article does not contain any studies with animals performed by the authors.

**Human participants** All procedures performed in these studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

## References

- Bentley AR, Callier S, Rotimi CN (2017) Diversity and inclusion in genomic research: why the uneven progress. *J Community Genet* 8(4):255–266. <https://doi.org/10.1007/s12687-017-0316-6>
- Buseh AG, Stevens PE, Millon-Underwood S, Townsend L, Kelber ST (2013) Community leaders' perspectives on engaging african americans in biobanks and other human genetics initiatives. *J Community Genet* 4(4):483–494. <https://doi.org/10.1007/s12687-013-0155-z>
- Bustamante CD, Burchard EG, De la Vega FM (2011) Genomics for the world. *Nature* 475(7355):163–165. <https://doi.org/10.1038/475163a>
- Cottler LB, McCloskey DJ, Aguilar-Gaxiola S, Bennett NM, Strelnick H, Dwyer-White M et al (2013) Community needs, concerns, and perceptions about health research: findings from the clinical and translational science award sentinel network. *Am J Public Health* 103(9):1685–1692. <https://doi.org/10.2105/AJPH.2012.300941>
- Dang JH, Rodriguez EM, Luque JS, Erwin DO, Meade CD, Chen MS Jr (2014) Engaging diverse populations about biospecimen donation for cancer research. *J Community Genet* 5(4):313–327. <https://doi.org/10.1007/s12687-014-0186-0>
- Ewing A, Thompson N, Ricks-Santi L (2015) Strategies for enrollment of african americans into cancer genetic studies. *J Cancer Educ* 30(1):108–115. <https://doi.org/10.1007/s13187-014-0669-z>
- Halbert CH, Gandy OH, Collier A, Shaker L (2006) Intentions to participate in genetics research among african american smokers. *Cancer Epidemiol Biomark Prev* 15(1):150–153. <https://doi.org/10.1158/1055-9965.EPI-05-0437>
- Halbert CH, McDonald J, Vadaparampil S, Rice L, Jefferson M (2016) Conducting precision medicine research with african americans. *PLoS One* 11(7):e0154850. <https://doi.org/10.1371/journal.pone.0154850>
- Isler MR, Sutton K, Cadigan RJ, Corbie-Smith G (2013) Community perceptions of genomic research: implications for addressing health disparities. *N C Med J* 74(6):470–476
- Jones BL, Vyhldal CA, Bradley-Ewing A, Sherman A, Goggin K (2017) 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* 4(4):735–745. <https://doi.org/10.1007/s40615-016-0277-1>
- Laegsgaard MM, Kristensen AS, Mors O (2009) Potential consumers' attitudes toward psychiatric genetic research and testing and factors influencing their intentions to test. *Genet Test Mol Biomarkers* 13(1):57–65. <https://doi.org/10.1089/gtmb.2008.0022>
- Lanfear DE, Jones PG, Cresci S, Tang F, Rathore SS, Spertus JA (2011) Factors influencing patient willingness to participate in genetic research after a myocardial infarction. *Genome Med* 3(6):39. <https://doi.org/10.1186/gm255>
- Lang R, Kelkar VA, Byrd JR, Edwards CL, Pericak-Vance M, Byrd GS (2013) African american participation in health-related research studies: indicators for effective recruitment. *J Public Health Manag Pract* 19(2):110–118. <https://doi.org/10.1097/PHH.0b013e31825717ef>
- Millon Underwood S, Buseh AG, Kelber ST, Stevens PE, Townsend L (2013) Enhancing the participation of african americans in health-related genetic research: findings of a collaborative academic and community-based research study. *Nurs Res Pract* 2013:749563. <https://doi.org/10.1155/2013/749563>
- Ochs-Balcom HM, Jandorf L, Wang Y, Johnson D, Meadows Ray V, Willis MJ, Erwin DO (2015) "It takes a village": multilevel approaches to recruit african americans and their families for genetic research. *J Community Genet* 6(1):39–45. <https://doi.org/10.1007/s12687-014-0199-8>
- Parikh R, O'Keefe L, Salowe R, Mccoskey M, Pan W, Sankar P et al (2017) Factors associated with participation by african americans in a study of the genetics of glaucoma. *Ethn Health*:1–11. <https://doi.org/10.1080/13557858.2017.1346189>
- Popejoy AB, Fullerton SM (2016) Genomics is failing on diversity. *Nature* 538(7624):161–164. <https://doi.org/10.1038/538161a>
- Powell-Young YM, Spruill IJ (2013) Views of black nurses toward genetic research and testing. *J Nurs Scholarsh* 45(2):151–159. <https://doi.org/10.1111/jnu.12015>
- Rencher WC, Wolf LE (2013) Redressing past wrongs: changing the common rule to increase minority voices in research. *Am J Public Health* 103(12):2136–2140. <https://doi.org/10.2105/AJPH.2013.301356>
- Roberts LW, Kim JP (2017) Receptiveness to participation in genetic research: a pilot study comparing views of people with depression, diabetes, or no illness. *J Psychiatr Res* 94:156–162. <https://doi.org/10.1016/j.jpsychires.2017.07.002>
- Scott DM, Nwulia E, Kwagyan J, Cain G, Marshall VJ, Kalu N et al (2014) Genetic testing for the susceptibility to alcohol dependence: interest and concerns in an african american population. *Genet Test Mol Biomarkers* 18(8):538–545. <https://doi.org/10.1089/gtmb.2013.0417>
- Underwood SM, Buseh AG, Stevens PE, Townsend L, Kelber ST (2013) Reflections and perspectives of african-american community leaders regarding genetics and genomics research: sentiment and wisdom of sankofa. *J Natl Black Nurses Assoc* 24(1):16–23
- Walker ER, Nelson CR, Antoine-LaVigne D, Thigpen DT, Puggal MA, Sarpong DE, Smith AM (2014) Research participants' opinions on genetic research and reasons for participation: a Jackson heart study focus group analysis. *Ethn Dis* 24(3):290–297
- White DB, Koehly LM, Omogbehin A, McBride CM (2010) African americans' responses to genetic explanations of lung cancer disparities and their willingness to participate in clinical genetics research. *Genet Med* 12(8):496–502. <https://doi.org/10.1097/GIM.0b013e3181e5e513>
- Yu J, Crouch J, Jamal SM, Tabor HK, Bamshad MJ (2013) Attitudes of african americans toward return of results from exome and whole genome sequencing. *Am J Med Genet A* 161A(5):1064–1072. <https://doi.org/10.1002/ajmg.a.35914>

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