



Promoting Inclusive Recruitment: a Qualitative Study of Black Adults' Decision to Participate in Genetic Research

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Abstract Underrepresentation of Black individuals in genetic research is a longstanding issue. There are well-documented strategies to improve the enrollment of Black participants; however, few studies explore these strategies—as well as the barriers and facilitators for participation—by sampling Black people who have previously participated in genetic research. This study explores the decision-making process of Black adults who have participated in genetic research to identify best practices in the recruitment of Black subjects in genetic research. We conducted 18 semi-structured interviews with Black adults with prior research participation in genetic studies housed at an urban academic medical center in the United States of America (USA). An online survey was conducted with the participants to gather demographic data and information on prior research participation. Trust in research was ascertained with the Corbie-Smith Distrust in Clinical Research Index. Two participants scored high levels of distrust using the validated index. Using thematic content analysis, 4 themes emerged from the interviews: (1) Participants are active players in health system, (2) information is

power, and transparency is key, (3) therapeutic alliances and study characteristics facilitate participation, and (4) race pervades the research process. The decision to participate in genetic research for the participants in our study was prompted by participants' internal motivations and facilitated by trust in their doctor, trust in the institution, and ease of participation. Most participants viewed their enrollment in genetic research in the context of their own racial identity and the history of medical racism in the USA.

Keywords African American · Research participation · Genetic research · Research recruitment

Background

The lack of representation of Black individuals in research is a longstanding issue in the United States of America (USA); genetic studies are particularly culpable. The majority of genetic research has studied people of European ancestry, with an estimated 81% of genome-wide association study samples originating from subjects of European ancestry and about 2% from African ancestry [1]. Though genetic research has led to many innovations in healthcare, the lack of diversity among research participants reduces the generalizability of these advances for non-European populations, potentially exacerbating health disparities within multiracial societies like the USA [1, 2]. Since the 1990s, there have been efforts, led in part

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by the National Institutes of Health (NIH), to reduce racial disparities in research participation in the USA [3]. Studies of best practices show that active recruitment from trusted community sites, engagement of community advisory boards and partners, inclusion of researchers from similar backgrounds as participants, and optimization of protocols can improve the recruitment of Black participants [4–8]. *All of Us*, a biorepository established by the NIH in 2018, has been successful in increasing the enrollment of traditionally underrepresented populations by using many of these recruitment strategies, with over 50% of participants identifying as non-White [9]. Despite this effort, Black populations continue to be underrepresented in genetic studies.

There are many explanations for the lack of Black participants in genetic research. Studies demonstrate that a minority of Black adults are asked to enroll in research [10–12]. Beyond this, mistrust due to historical and personal experiences of injustice, lack of knowledge of research or health conditions, and logistical barriers (e.g., time, transportation, compensation) hinder Black individuals' participation [13–18]. Specific to genetic research, invasiveness of sample collections, degree of control over specimens, and inconsistencies with cultural understandings of disease serve as additional barriers to participation [19–23]. Studies have shown that the optimization of these factors has increased the theoretical willingness of Black individuals to participate in genetic research [13, 21, 24–28]. However, few studies have sampled people who have themselves participated in genetic research [24, 29]. As a result, little is known about how these factors influence Black adults' ultimate decision to participate in genetic research.

Our study aims to explore the decision-making process of Black adults who have participated in genetic research in the USA. Through a qualitative analysis of interviews, this study will elucidate motivations for participation, explore factors related to the recruitment and research processes that facilitate or hinder participation, and identify best practices that can be implemented in future recruitment and research efforts.

Methods

Study Design and Sample

This is a qualitative study using survey and interview data to explore the decision-making process

used by Black adults who have participated in genetic research. This study obtained approval from the Beth Israel Deaconess Medical Center Committee on Clinical Investigation.

Participants were recruited from registries of adults who had participated in genetic research cohorts at Beth Israel Deaconess Medical Center (BIDMC) in Boston, Massachusetts. Four genetic biobanks were identified for this study, investigating breast cancer (established in 2017), systemic lupus erythematosus (SLE) (established in 2016), cardiovascular disease (established in 2013), and COVID-19 (established in 2020). Participants were included if they: (1) self-identified as Black or African American, (2) participated in a genetic research study, and (3) agreed to be contacted again for future studies. Eligible participants who were employees at BIDMC and those who did not speak English were excluded from this study.

Lists of potential participants were obtained from the principal investigators of the studies. Participants were recruited by phone and email. Participants gave consent to participate at the time of survey administration. Recruitment of participants continued until thematic saturation was achieved.

Survey

An online survey was used to collect demographic data as well as information about participants' research history. Prior exposure to research was assessed by asking whether subjects had previously participated in research and the types of research in which they participated. To ascertain participants' level of trust in research (a major determinant of willingness to participate in research), the Corbie-Smith Distrust in Clinical Research Index was used [30]. This validated index is a 7-item scale that asks questions on respondents' views of potential abuses in clinical research. The survey was conducted using Qualtrics, a web-based survey tool [31]. The survey was piloted with Black adults of similar demographic backgrounds who received their care at BIDMC, and their feedback was integrated into the finalized version of the survey. Quantitative analysis of survey data was performed using Stata 17 [32].

Interview

After the completion of the survey, participants discussed their participation in genetic research in

semi-structured interviews. The interviews, facilitated by JC via video conference, took place from July to September 2021 and lasted 30–45 min. The interview guide contained questions about participants' recruitment, decision-making, and experience with the research process. These questions were developed based on a review of the literature and piloted with the same cohort of participants that piloted the survey. Based on the pilot, the interview guide was revised for clarity and length before being used in the interviews. The audio of the interviews was recorded and transcribed for analysis.

Thematic content analysis was performed to systematically categorize participants' responses [33]. Data analysis was performed using the software Atlas.ti [34]. The data were analyzed independently by two researchers (JC, AK). Responses were read in their entirety to gather a general understanding of the content. Inductive coding was performed on each interview transcript, and open codes were then grouped into categories and higher-order themes. The codebook was developed using an iterative process, with consensus meetings with the research team to discuss discrepancies in the two analyses and determine a final coding scheme. The finalized themes and subthemes are presented.

Results

Participant Characteristics and Research Experiences

Lists from principal investigators included 98 eligible participants. Of these, 40 were able to be contacted. Twenty-two individuals declined participation, most often citing lack of time. Eighteen individuals agreed to participate in the survey and interview for this study. Participants were from a variety of sociodemographic backgrounds (Table 1). The mean age was 53 (range 37–69) years. All participants had health insurance (Table 1). Participants were enrolled in genetic studies investigating COVID-19 (4/18), breast cancer (10/18), cardiovascular disease (3/18), and SLE (1/18). Other than the genetic study in question, most participants had also participated in other types of research (Table 1). When assessed for trust in research, 2/18 participants scored high levels on the Corbie-Smith Distrust Index (Table 1).

Participants were generally recruited for their respective studies by their personal doctor (11/18), with other recruiters being geneticists (2/18) or another member of the research team (5/18). Participants did not report

Table 1 Participant characteristics ($N=18$)

Mean age (SD)	53 (2.03)
Gender	
Male	4 (22%)
Female	13 (72%)
Non-binary/third gender	1 (6%)
Marital status	
Never married	5 (28%)
Currently married or cohabitating	9 (50%)
Separated, divorced, or widowed	4 (22%)
Education	
High school graduate or equivalency GED	4 (22%)
Community college or Associate degree	3 (17%)
Bachelor's degree	3 (17%)
Master's degree	4 (22%)
Doctorate or Professional degree	2 (11%)
Other	2 (11%)
Employment	
Employed full time	11 (61%)
Employed part time	5 (28%)
Retired	1 (6%)
Did not work due to health reasons	1 (6%)
Household Income	
Less than \$20,000	2 (11%)
\$20,000–\$39,999	3 (17%)
\$40,000–\$59,999	2 (11%)
\$60,000–\$79,999	0 (0%)
\$80,000–\$99,999	1 (6%)
More than \$100,000	10 (56%)
Health insurance type	
Private health insurance	12 (67%)
Government-sponsored insurance ^a	5 (28%)
State-sponsored insurance	1 (6%)
Previous participation in research by type ^b	
Survey, interview, or focus group	11 (61%)
Medical record review	2 (13%)
Specimen donation	5 (28%)
Clinical trial	1 (7%)
Corbie-Smith Distrust Index ^c	
Distrustful	2 (11%)

^aInsurance type includes Medicare, Medi-Gap, Medicaid/Masshealth, SCHIP, and Military health. ^bTotal > 100% because respondents could select multiple answers. ^c“Distrustful” denotes > 4 distrustful responses on the Corbie-Smith Distrust Index

use of any additional recruitment strategies when asked about specific best practices (i.e., race-concordance with

recruiters, recruitment from trusted community-based sites or organizations, or education on health, genetics, or research topics). Most participants (13/18) consented to participate in the study at the time they were first approached, with the remainder taking hours up to almost a year to consent for the study. One participant was consented by a healthcare proxy. Half of participants (9/18) reported receiving their personal results from genetic testing. Of those who did not receive results, all but one participant desired to know results of the study. All agreed that they would consider participating in genetic research in the future.

Four themes emerged from the qualitative interviews: (1) Participants are active players in healthcare system, (2) information is power, and transparency is key, (3) therapeutic alliances and study characteristics facilitate participation, and (4) race pervades the research process. These themes and their subthemes are described in the following sections and summarized with representative quotes in Table 2.

Participants Are Active Players in the Healthcare System

Participants described their enrollment in genetic research within the context of their involvement in the healthcare system. Many expressed a sense of control over their health decisions, emphasizing the importance of being their own “health advocate.” Some participants had longstanding engagement with the healthcare system. Others became more engaged with the healthcare system because of an inciting event such as changes in health status or experiences with loved ones. Many participants also disclosed involvement in acts of health-related altruism, including enrolling in organ donation registries, allowing trainees to participate in care, and providing peer support for people with similar health conditions. As a result of their own experiences, several participants suggested that studies should incorporate education on the benefits of research participation, along with general health information, into the recruitment process.

Information Is Power, and Transparency is Key

Several participants were motivated to engage in research to learn more about their health, viewing research as a way to become empowered—and empower others—with health knowledge. Other participants were primarily concerned about the implications of their disease for family

members. In such cases, genetic testing was an opportunity to gather information about their family’s genetic history and assess the risk of disease for future generations. Because of this, participants strongly desired to obtain the results of genetic testing. For those who did have their results returned, oftentimes those results determined participants’ future care and testing for family members. In select cases, the return of results contributed to the emotional and mental well-being of the participant. However, most participants who did not receive results reported feeling that the research was “incomplete” or “dropped in the air.” Given its importance to individuals, several participants recommended that research studies incorporate return of results into their protocols.

Therapeutic Alliances and Study Characteristics Facilitate Participation

A number of participants expressed that their decision to enroll in research studies was facilitated by pre-existing relationships with doctors, researchers, and the institution. Many acknowledged that trust established within these relationships made them more comfortable with the research while alleviating some concerns they had regarding study participation. Participants also noted that the studies were minimally invasive (often a single blood sample), had few requirements (i.e., giving samples, filling out questionnaires), and coincided with scheduled healthcare. Participants noted that researchers should prioritize the context of participants’ lives—recruiting using trusted people and institutions and conducting research in coordination with other care.

Race Pervades the Research Process

For most participants, race was a consideration for participation in genetic research. All but one participant mentioned the history of exploitation in research or healthcare disparities for Black people in the USA; a few cited Henrietta Lacks and the use of Black women for gynecological surgery research. Many were interested in advancing health knowledge to improve healthcare for other Black individuals. Others expressed a desire to combat stereotypes or dispel myths about Black people through improved representation in research. Some participants (6/18) did not consider their race at all when deciding to participate, instead citing their personal health

Table 2 Themes and subthemes with representative quotes

Themes and subthemes	Representative quotes
<i>Participants are active players in the health system</i>	
Participants as own health advocate	<p>“A lot of our decisions are based on talking to someone else and then their experience... So I tend to be an advocate for my own healthcare.” [Participant 2]</p> <p>“People will feel obligated: ‘well doctor said this’ or ‘I have to do this.’ Well, no, that’s not the truth... So that’s something that’s always stuck with me—why I asked questions and why I know I can walk out at any time. That I have the final say in what happens to me.” [Participant 14]</p>
Participants engaged in healthcare system	<p>“I am a...kidney transplant recipient, but beyond that I went through years of dialysis and medical care... so maybe I’m just immune to concerns? You know, as [opposed to] a person who [is]... naive to the healthcare system.” [Participant 5]</p> <p>“...Later on, kidneys started to fail... And that’s why I’m so easy going now. You asked me this 10–15 years ago, I would have done none of this. But today, you just have to ask.” [Participant 1]</p> <p>“I had a friend who actually died of cervical cancer and [if] it was detected much, much earlier and she could have been saved... Part of that just kind of made me realize that I really do need to participate in this, I really need to understand more, you know, how the system work[s], particularly now I’m getting older.” [Participant 15]</p>
Incorporate health/research education into recruitment	<p>“Education helps with that and when you understand something then you can just make an informed decision. It doesn’t mean that you necessarily have to go along with it, but you can make an informed decision.” [Participant 2]</p>
<i>Information is power, transparency is key</i>	
Motivation to gather health information about participants/family	<p>“So for me, first and foremost I’ve got two children that I need to make sure if, God forbid, they have to deal with this, then I did my part to make it easier or help you know.” [Participant 9]</p>
Return of results were important to health/wellbeing of participants	<p>“... Screening things that I probably wouldn’t have been doing before I do now.... Based off of that information I did get my children tested because I wanted to know ahead of time.” [Participant 18]</p> <p>“And I just felt better. I felt like I could breathe.” [Participant 17]</p>
Lack of results made research incomplete	<p>“I just felt like it kind of—it was just dropped in the air. I don’t know if they stopped the research and what the conclusion of whatever the information that I provided... I kind of felt like what’s the use of pursuing it if you weren’t going to, you know, wrap it up...” [Participant 15]</p> <p>“I expected to get some feedback to say, ‘this is what we found.’ I haven’t... Even if it was just a summary of the findings, would have been nice.” [Participant 5]</p>
<i>Therapeutic alliances and study characteristics facilitate participation</i>	
Comfort with research team/institution	<p>“...I was a lot more open to do it because I’m familiar with Beth Israel and I’m familiar with [my doctor] and I felt a lot more comfortable with them handling my information than [an institution] who doesn’t know me.” [Participant 5]</p> <p>“What made the whole thing so easy for me is because of the trust I had with my doctors... I can rightly call them my friends.” [Participant 6]</p>

Table 2 (continued)

Themes and subthemes	Representative quotes
Participation was convenient	<p>“But they were taking blood [at the] same time, they didn’t have to put another needle in me. They just stuck another tube in and it was a ten second thing and that was it.” [Participant 13]</p> <p>“I had another appointment coming up, if I remember correctly... so it didn’t feel like I was taking a special day separate from my normal appointments.” [Participant 7]</p>
<i>Race pervades research process</i>	
Race as motivator	<p>“... ‘Okay, so, if I can help other Black Americans kind of figure out this process or maybe help... doctors learn the best way to help Black Americans with whatever diseases or conditions, then maybe that would be a good thing.’” [Participant 12]</p> <p>“And this was just one little thing to say, you know, this is a human being. Yes, this is the DNA of an African American, a person of color, who had this and this problem or whatever, and they’re just like everybody else, in that sense. Because they’re human.” [Participant 7]</p>
Concerned about misuse of genetic information	<p>“The question of ownership and control and who has access to what plays a part... We want the data to be helpful, but it can be used to produce a level of harm today that it hasn’t been able to produce in the past... I do consider that.” [Participant 16]</p> <p>“But I guess that thought, in the back my mind, is always there is like, ‘Oh, are they using my DNA for not necessarily nefarious reasons, but for you know commercial reasons and then I’m not going to be a part of it?’” [Participant 12]</p>
Concerns informed by history of exploitation of Black people	<p>“One [reason for concern] is because of our history...where they use us to take care of not other African Americans, but other people.... So they get to benefit from the research that they’ve done on us...Was that fair to us? No. It never was.” [Participant 8]</p> <p>“It’s a concern. It’s not big, but it is a concern because it’s what America is about basically.” [Participant 7]</p>

conditions or concern for their family as motivation for participation.

Despite reassurance by researchers that their information would remain private, many participants expressed concern about the control and use of their genetic information. Beyond concern for their own privacy, some participants worried that the research would not benefit the Black community or be used to further marginalize Black individuals. Participants who reported concerns about the control and use of genetic information most often cited historical injustices as the basis for their apprehension.

Overall, participants felt that it was important to increase the representation of Black individuals in genetic research. Many acknowledged that recruitment of Black participants is difficult given the mistrust in research caused by past and present injustices. Participants emphasized intentional recruitment within the Black community. To build trust, participants

highlighted the value of “understanding your subject” and recommending research participation “specifically based on who I am.” One participant warned against “trying too hard” to recruit Black participants, because this could increase skepticism. Other suggested strategies included featuring Black individuals in recruitment materials, including greater racial and ethnic diversity on research teams, and conducting research that focuses on health issues important for Black people.

Discussion

In this qualitative study of USA Black participants in genetic research, we found that the decision to participate in research studies involves an interplay of characteristics related to both the participant and the research study. This interaction is informed by

participants' prior experience with healthcare and research, in addition to the legacy of racism that underlies these experiences. This study builds off of the work of McDonald et al. (2014), which investigated Black individuals' hypothetical decision-making process for a genetic research study [26]. By interviewing Black people who have previously participated in genetic research, this study offers new insights into the types of people who participate in research and how they think about their participation.

Trust was a major theme in our study. Participants endorsed trust in their own doctors, the research team, and the healthcare institution, which facilitated their participation. In fact, most participants agreed to their respective genetic studies immediately, relying on their initial feelings about the study team along with their prior attitudes about research to make their decision. This underscores that comfort is a major determining factor in research participation for Black adults, independent of the requirements of the study. Our results are consistent with prior research that demonstrates the role of trust in research participation among Black individuals [21, 24, 27]. Utilizing therapeutic alliances fostered with participants must be balanced with the risk of undue pressure to participate: physicians and other members of the team must clearly distinguish between research and healthcare activities and affirm individuals' rights to refuse participation in the consent process.

Prior studies have also shown that Black people may have additional, unique concerns with participating in research when compared to individuals of other races, including exploitation and manipulation of participants, lack of control over use of genetic information, and physical or financial harm to participants [21]. Participants in our study shared these concerns, particularly with regard to the control and use of samples. In many cases, these concerns were overcome by strong personal motivations for participation, comfort with the research team, and ease of participation. However, when reflecting after their participation in the studies, many participants thought that they should have asked more questions about their concerns during the consent process. Given this, researchers should revisit the details of the study with participants and provide dedicated time for participants to ask questions throughout every stage of the research process.

Many participants reported enrolling in these studies to gain knowledge of genetic information and understand the implications for their health and their families' health; however, only half of participants received their personal results. For these people, return of results improved health knowledge, provided emotional reassurance, and even determined future medical care. These findings, along with past studies, emphasize the importance of study follow-up—including return of results—for Black participants [35, 36]. Participants endorsed the return of results as a way to engage participants in the research process and maintain transparency with researchers. Thus, return of results offers a powerful yet underestimated mechanism to foster trust between researchers and Black communities. Return of results, however, can be more complicated in genetic studies compared to other types of research because the results of genetic sequencing or genotyping may have an undetermined significance. Although return of results may be limited in genetic research involving novel genes, alleles, or variants, studies should offer participants the option to obtain results (particularly when these results are clinically actionable) in line with national consensus guidelines [37, 38]. The possibility of results of unknown significance should be explained to participants to set expectations and guide participants' interpretation of results. In cases where personal results are not available or are uninterpretable, updates and follow-up about the study should still be provided to participants.

Notably, beyond recruitment by one's own doctor, few recruitment strategies demonstrated in the literature to increase participation among Black individuals were implemented in these genetic studies. This trend was seen despite the fact that all of the studies in which the participants were enrolled began after 2012, after the implementation of the NIH policy on minority recruitment and the publication boom documenting best practices for conducting research with marginalized groups [3, 6, 8]. This highlights the discrepancy between the research community's stated value of diversity among participants and the reality of study recruitment. The Black participants in our study received their care at an academic medical center, were able to navigate the healthcare system, and had a strong internal motivation for engaging in research. However, Black individuals who are less connected to care or are more ambivalent about

participation may be overlooked for these studies. If genetic research is meant to reflect the diversity of the population, more intentional recruitment is required from research teams and healthcare institutions. Researchers should implement well-documented strategies for recruitment in communities of color, in line with the principles of community-based participatory research [8]. Such interventions include using trusted community members, organizations, and sites for recruitment; creating community advisory boards; and embedding recruitment of participants in healthcare workflows to ensure that all eligible participants are approached [6–8, 39]. Furthermore, government agencies and non-governmental organizations are increasingly investigating and funding innovations to improve representation in research for traditionally marginalized groups. More emphasis must also be placed on the dissemination and integration of these innovations into current research practices.

Limitations

This study relied on interviews about past events, and there may be recall bias in the responses. Given that the study population includes only those who have previously participated in research, participants may have a more positive view of research and more willingness to participate in research at baseline than the general population of Black Americans. This is supported by the fact that the majority of participants endorsed trust in research. Furthermore, there were substantially more women than men or non-binary people in our study. One of the research cohorts that this study recruited from was a breast cancer study where most participants in the cohort were women, resulting in the unequal distribution of gender in our study. Our study enrolled participants from an urban academic medical center in the USA, and many of the historical and social contexts of the participants' experiences are specific to the USA. Additionally, all participants had health insurance and were relatively well-educated, increasing the accessibility of research when compared to other people. These factors limit the generalizability of our study to the general population of Black adults. However, our hope is that this study will serve as a starting point for additional studies investigating interventions to support the recruitment of Black participants in the USA in genetic research.

Conclusions

The decision to participate in genetic research for the participants in our study was prompted by participants' internal motivation and facilitated by trust in their doctor and healthcare institution, as well as overall ease of participation. This study contributes to the literature by better characterizing how Black participants in research have overcome barriers to participation such as concern over control of genetic information. By seeking to understand the motivations, considerations, and concerns for participants in genetic studies, researchers can better prioritize types of recruitment interventions to optimize conditions for participation for Black communities.

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