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RESEARCH

Barriers, motivators and strategies to increase participation in genetic research among Asian and Black families of autistic individuals

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Abstract

Genetic research can help advance our knowledge of autism and positively impact the progress of care for individuals with autism. Asian American and Pacific Islander (AAPI) and Black participants remain significantly underrepresented in genetic research in autism in the United States, including nationwide, multisite, genetic consortiums like Simons Foundation Powering Autism Research for Knowledge (SPARK). Few studies have explored the unique motivators and barriers that influence participation in genetics research across underrepresented groups with autism and strategies to increase participation. Therefore, the aim of this study was to understand the perspectives of AAPI and Black parents of individuals with autism about participating in genetic research, specifically *motivators* (e.g., desire to know more about the relationship between autism and genetics) and/or *barriers* (e.g., mistrust of research staff) that may impact their decision to participate in genetic research. Using a mixed-methods approach, we collected surveys ($n=134$) across the United States and conducted three focus groups with parents of individuals with autism ($n=16$) who identified as AAPI and Black from two large metropolitan cities. No significant differences were observed in the survey data but findings from the focus groups elucidate shared motivators for participation (e.g., to help advance the autism field for future generations) and nuanced differences in barriers that influence Black and AAPI parents' decision to participate (e.g., different beliefs about the source of autism). Practical suggestions to improve outreach and study engagement in genetic research in autism were identified and discussed.

Keywords Genetics · Autism · Disparities · AAPI · Black or African American

Autism is a complex neurodevelopmental condition with a strong genetic contribution (Bai et al. 2019; Xie et al. 2020). With recent scientific advancements, researchers have identified over 200 genes related to autism, with many more expected (Feliciano et al. 2019; Pinto et al. 2010). Genetic advances are immediately relevant to the progress of care for individuals with autism, as it could speed up the diagnostic process (Shen et al. 2010) and consequently grant earlier and more personalized approaches to treatment (Geschwind 2015). Although the prevalence of autism is consistent across racial and ethnic groups, individuals from racial and ethnic minority groups remain underrepresented in large genetic studies in autism, with most participants being non-Hispanic White (Feliciano et al. 2019; Hilton et al. 2010; Canedo et al. 2019; Fisher et al. 2019). To increase the participation of people of color with autism in genetic research, it is important to understand the motivators and barriers individuals from diverse racial backgrounds encounter that influence their willingness (or lack thereof) to participate.

There are few studies that focus on participants' perspectives on engaging in genetic research in autism. Common motivators for participation include altruism, the desire

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to better understand the cause of their child's autism, and the hope to connect with local medical experts (Lucas et al. 2022; Trottier et al. 2013; Singh 2015). Yet studies have focused only on understanding perspectives of individuals who *completed* participation in genetic research (Lucas et al. 2022; Trottier et al. 2013; Singh 2015). It is not known what barriers individuals who decide *not* to participate encounter, if any. Additionally, the role of race has not been explored in relation to participating in genetic research in autism, making it difficult to understand whether racial background influence attitudes toward participation.

Disparities in genetic research in autism

Black and/or African American (henceforth Black) participants make up a small percentage of the sample in genetic research, especially genetic research in autism (Popejoy and Fullerton 2016; Hilton et al. 2010). No studies have solely focused on Black participants' perceptions and feelings towards participating in genetic research. A few studies explored the motivators and barriers Black individuals face that influence their decisions to participate in genetic research outside of autism. These studies suggest that shared motivators among Black individuals to participate in genetics research are the benefits to greater society (Corbie-Smith et al. 1999) and cultural match with research staff (George et al. 2014). Despite these motivators, fear of racial discrimination and mistrust of medical staff are the biggest barriers that Black participants face related to genetic research participation (Canedo et al. 2019; Corbie-Smith et al. 1999; George et al. 2014). A survey study by Murphy and colleagues (2009) on racial differences in willingness to participate in genetic research for psychiatric conditions showed that mistrust of researchers, wariness about potential uses of their genetic results, and stigma associated with having a psychiatric condition were endorsed by Black participants as barriers to participation. Other barriers that have been identified by Black participants are increased concerns that genetic information will be used to discriminate against them in employment, health insurance, and life insurance (Akinleye et al. 2011; Burnett-Hartman et al. 2020; Buseh et al. 2012; Pettey et al. 2015). The mistrust of researchers could be explained by the longstanding history of misuse of information and discrimination against Black people by the medical system and historical research atrocities (Freimuth et al. 2001). This highlights the need for culturally sensitive methods to recruit and better represent racially diverse groups in genetic research. To do this, we must understand the specific issues that Black individuals face when considering genetic research in autism and how to best support their participation.

Similarly, researchers have found that Asian American and Pacific Islander (AAPI) participants are repeatedly underrepresented in precision medicine research, and genetic research unrelated to autism (Fisher et al. 2019; Katigbak et al. 2016). Notably, a significant barrier to participation in research is the limited literature and resources available in respective Asian languages (George et al. 2014). A study focused on perceptions of genetic testing for deaf children found that AAPI participants' motivations to participate in genetic research were to understand their children's medical conditions, improve their children's medical care, and help with family planning (Palmer et al. 2007). It is unclear whether similar motivations extend to genetic research in autism and what the barriers to participation are among AAPI participants.

Simons Foundation powering autism research for knowledge (SPARK)

The Simons Foundation Powering Autism Research for Knowledge (SPARK) study is a multisite, online research study that aims to recruit families with at least one immediate family member identified with autism and collect both phenotypic and genetic information through saliva samples to increase knowledge of autism (SPARK Consortium 2018). A primary goal of SPARK is to recruit over 50,000 individuals with autism and their biological families to identify genetic causes of autism. An important goal of SPARK is to be a nationally representative cohort. However, the majority of participants identify as White (73.21%; SPARK Consortium 2020). In contrast, 3% of SPARK participants identify as AAPI and 7.11% identify as Black or African American (SPARK Consortium 2020), lagging behind the U.S. Census data (Fig. 1).

Study aims

To inform research-recruitment efforts that more successfully engage families of color in genetic research, the current investigation sought to understand minoritized parents' perspectives about participating in genetic research in autism and to provide insight into motivators (e.g., desire to know more about the relationship between autism and genetics) or barriers (e.g., mistrust of the research staff, time availability) that may be driving their participation rates in the SPARK study. We used a mixed methods approach to (a) assess parents' perceptions of barriers to participating in genetic research in autism using quantitative, survey methodology and (b) examine factors that may influence Black and AAPI

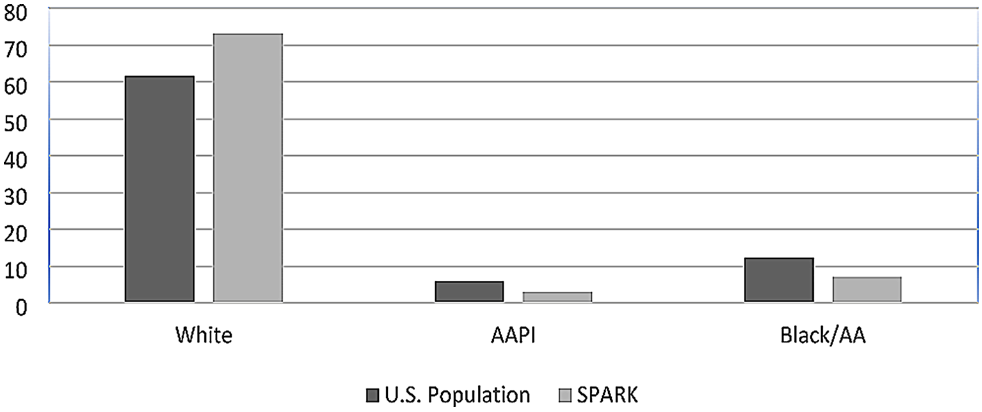

Fig. 1 Race percentages in the United States compared to the SPARK study

Table 1 Demographic characteristics of the survey participants

	Value	*N* = 134 *N* (%)
Participant's Age (years)	18–34	31 (23%)
	35–59	93 (69%)
	60–74	10 (8%)
	75+	0 (0%)
Race	AAPI	16 (12%)
	Black	27 (20%)
	White	69 (51%)
	Multiracial	6 (5%)
	Other	16 (12%)
Ethnicity	Hispanic/Latino	32 (24%)
	Non-Hispanic/Latino	101 (75%)
	No response	1 (1%)
Gender	Male	10 (8%)
	Female	123 (91%)
	Other	1 (1%)
Level of education	No GED Equivalent	1 (1%)
	High School Diploma/GED	8 (6%)
	Some College	24 (18%)
	Associate Degree	9 (7%)
	Bachelor's Degree	46 (34%)
	Master's Degree	32 (24%)
	PhD/MD/JD or equivalent	14 (10%)
Household Income	<$20,000	11 (8%)
	$20,000-$34,999	21 (16%)
	$35,000-$49,999	21 (16%)
	$50,000-$74,999	23 (17%)
	$75,000-$99,999	15 (11%)
	>$100,000	42 (31%)
	No response	1 (1%)
Site	TCH	47 (35%)
	CHOP	50 (37%)
	UCLA	26 (20%)
	UMMC	11 (8%)

parents' decisions to enroll or not enroll their families in SPARK, a genetic study that aims to increase knowledge of autism, using qualitative, focus group methodology.

Method

Participants

Simons Foundation Powering Autism Research for Knowledge is a nationwide study that has partnered with over 30 clinical sites comprised of children's hospitals, medical schools and autism clinic and research centers across the country. Zip code affiliation is used so that when participants sign up, research staff at their nearest clinical site can help them through the process of completing online enrollment and genetic collection, if needed. Four clinical sites were chosen to participate in the current survey study based on a Diversity, Equity, and Inclusion (DEI) supplemental grant application process to study the underrepresentation of participants of color in SPARK. Surveys were emailed to individuals in an existing mailing list who were enrolled in SPARK, or had previously expressed interest in the SPARK study to the four study sites (University of California, Los Angeles [UCLA], Children's Hospital of Philadelphia [CHOP], University of Mississippi Medical Center [UMMC], and Texas Children's Hospital [TCH]). Eligibility criteria in the survey study included being a parent of an individual with autism; all autism diagnoses were based on parent report. Email invitations were sent to approximately 1,400 potential participants. A total of 134 participants completed the surveys (a response rate of about 10%). Of this group, 64% were enrolled in SPARK, 26% had not enrolled, and 10% were unsure of their enrollment status. Survey participant demographics are presented in Table 1.

Following survey data collection, Black and AAPI parents of individuals with autism in the greater Los Angeles and Philadelphia areas were invited to participate in focus groups. Focus group participants were recruited independently from those who participated in the survey. Eligibility criteria included: (1) having a child with a diagnosis of autism (confirmed using parent report); (2) identifying as Black and/or AAPI; and (3) having been previously invited to participate in SPARK, though participation in SPARK was not required to be included in the focus groups. Focus group participants included 16 biological parents of individuals with autism who had previously been invited to participate in SPARK. Among this sample, 12% had enrolled and completed SPARK participation, 69% had been invited but did not enroll, and 19% did not disclose whether they participated or not. For each family, only one parent of an individual with autism was required to participate in the focus groups; 94% of participants were mothers. Participants identified as non-Hispanic Black (44%), AAPI (50%), and non-specified other mix between AAPI or Black and a second race (6%). Most participants (75%) were between 35 and 59 years old (no exact ages were collected, only ranges; Table 2), while their children's ages ranged from 4 to 29 years old (M_{age}=18.6 years).

Table 2 Demographic characteristics of the focus group participants

	Value	N=16 N (%)
Participant's Age (years)	18–34	2 (12.5%)
	35–59	12 (75%)
	60–75	2 (12.5%)
	75+	0 (0%)
Race	Black	7 (43.7%)
	AAPI	8 (50%)
	Other	1 (6.3%)
Ethnicity	Hispanic/Latino	0 (0%)
	Non-Hispanic/Latino	7 (43.7%)
	No response	9 (56.3%)
Gender	Male	1 (6.3%)
	Female	15 (93.7%)
Level of Education	Some College	2 (12.5%)
	Associates Degree	3 (18.7%)
	Bachelor Degree	6 (37.5%)
	Master Degree	4 (25%)
	PhD/MD/JD or equivalent	1 (6.3%)
Household Income	<$20,000	0 (0%)
	$20,000-$34,999	1 (6.3%)
	$35,000-$49,999	3 (18.6%)
	$50,000-$74,999	1 (6.3%)
	$75,000-$99,999	3 (18.6%)
	$100,000-$149,999	5 (31.3%)
	$150,000-$199,999	1 (6.3%)
	>$200,000	1 (6.3%)
	No response	1 (6.3%)

Procedures

Approval for this study was obtained by the WIRB Copernicus-Group Institutional Review Board (WCG IRB), which provides regulatory oversight for the multisite SPARK network.

Survey

We first collected survey data with the aim of understanding barriers that deterred families from completing participation in the SPARK research study. Recruitment of the survey data was a multi-site effort between UCLA, CHOP, UMMC and TCH as part of a Diversity, Equity, and Inclusion (DEI) supplemental grant. Research staff at each site sent a mass email to their institutional listservs of people who had expressed interest in or requested information about the SPARK research study at a recruitment event or online. The mass email included information about the current study and a link to complete the survey, which was available in English only. The survey took an approximated time of 20–25 min to complete (based on how long it look some of our research members to complete, including demographic information) and participants were incentivized with a $5 Amazon gift card for returning completed surveys. All data were collected and securely stored via REDCap®. All participants gave consent to participate in the survey study.

Focus groups

Two sites (UCLA and CHOP) partnered for the qualitative portion of the study, which included three focus groups with Black and AAPI participants to gather more information and further understand the low participation rates among these specific groups in the SPARK research study. We partnered with local community-based organizations and medical providers for recruitment and to identify the locations where the focus groups would take place. Two community group leaders from local non-profits that serve Black and Korean families with autism in Los Angeles posted recruitment flyers in their offices and shared information about the study with their community members via email and in person. Additionally, both groups invited the research staff to attend one of their in-person meetings to talk to their members about the focus groups. Researchers at Philadelphia partnered with medical providers who worked closely with individuals with autism to help recruit. Overall, most participants were recruited through emails, flyer distribution at parent support groups, and word-of-mouth. Two focus groups were conducted in Southern California; one included six participants and the other included seven participants. A third focus group was conducted in Philadelphia, Pennsylvania and included three participants.

Participants were asked to fill out demographic forms before the focus groups began; demographic information collected is presented in Table 2. All participants gave written and verbal consent to participate before the focus groups took place. The research coordinators led the audio-recorded focus groups. The format of the focus groups included a five-to-seven-minute overview of the SPARK research study and inclusion criteria (i.e., a genetic study that collects demographic information, diagnostic history, and salivary DNA to understand autism) and a group discussion related to the questions of interest (i.e., thoughts, motivators, and barriers toward participating in genetic research including the SPARK study). For each of the focus groups, one member of the research team at each site took the role of group facilitator, while a second researcher recorded the conversation and took notes to identify salient themes. Focus group discussions were guided using structured interview questions across sites to ensure information was gathered in a systematic way (see focus group protocol description below). Participants were encouraged to share their personal thoughts and opinions with each other, with sessions lasting approximately one hour and 30 min each. Participants received $25 gift cards for their participation in the focus groups.

Measures

Survey

An online survey was created for purpose of this study using REDCap®. The first part of the survey collected participant demographic information including race, ethnicity, age range, gender, level of education, annual household income and whether they had participated in SPARK. Families who had enrolled in the SPARK study may not have completed the entire process at that point (e.g., returned saliva samples to the lab). Each site had a unique distribution link that allowed the study team to document each participant's site affiliation. The second part of the survey included eight questions about participants' thoughts, interests, and barriers to participating in genetic research. Examples of questions asked were, "Do you think a research study like SPARK is beneficial for individuals with [autism]?" and, "Does having a study team member of the same race or ethnicity as you impact your decision about participating in a study?" Questions were multiple choice and were restricted to a single answer or allowed multiple answers. For the current study, only the question, "What are the barrier(s) to participating in genetic research?" was analyzed. Answer choices included knowledge/awareness of the study, fear of being taken advantage of, mistrust of the clinical/research staff, and logistic barriers (e.g., transportation, scheduling, language and/or feasibility). Participants could select as many barriers as they saw fit. A table with the survey questions is included in Appendix A.

Focus group demographic form

Before the focus groups began, participants were asked to fill out a demographic form. The form asked about caregivers' race, ethnicity, age range, gender, level of education, household income and whether they had participated in the SPARK study in a set of multiple-choice questions.

Focus group protocol

Researchers at UCLA and CHOP collaborated in the development of a focus group protocol that included 11 open-response questions to capture information about: (a) thoughts about participating in genetic research, including the SPARK study; (b) barriers and fears about participating in genetic research; and (c) motivators and best practices that would encourage families to participate in genetic research (Table 3).

Data analysis

Survey

Frequency counts were used to characterize responses from the survey data. Chi-square tests or Fisher's exact tests were used to compare differences between participants who had enrolled in the SPARK study, those who did not and those who reported they did not know whether they enrolled across each of the four outcomes including the following: (1) knowledge/awareness of the study; (2) being taken advantage of; (3) mistrust of clinical/research staff; and (4) logistic issues (e.g., transportation, scheduling language, and/or feasibility). Next, chi-square tests were run to test for differences in the report of the same four outcomes of interest (i.e., knowledge/awareness of the study, being taken advantage of, mistrust of staff, and logistic issues) between Black, AAPI, White, and those who identified as Other. Additionally, chi-square tests were run to test for site differences in the four outcomes of interest. Post-hoc tests were run if a significant difference between groups was detected in the chi-square results. Survey data were analyzed using the statistical software R (R Core Team 2022).

Table 3 Focus group guide

Focus Group Questions
1. What are your thoughts about participating in research? a. What are the barriers to participating in research?
2. In particular, what are the barriers to participating in genetic research?
3. What scares you about participating in genetic research? a. How can we address those fears?
4. What would motivate you the most to participate in genetic research? (i.e. facts or anecdotes about genetic research, or is the mission of the Disparities pilot enough of a motivator? Provide participant with the mission statement.)
5. Who do you trust the most to learn about research? a. Is it family members, primary care doctors? b. News stories or media publications?
6. How would you like to be introduced to genetic research? a. From whom would you like to hear this information? b. Where do you want to receive this information? (i.e. clinic, social media, community orgs, family, friends, resource fairs)
7. What information should recruitment materials include that is most helpful for you? a. Language focused on data, family, or the individual with autism. b. Language focused on compensation or access to resources. c. Where do you receive most of your information for autism services or events? (Social media, phone calls or non-traditional advertising [text service] versus an email or paper letter, or approach in-clinic)
8. Where do you feel more comfortable to meet with research staff to complete the SPARK study or other genetic studies? (i.e., at home, church, local clinic?)
9. What do you think [UCLA] or [CHOP]/SPARK can do to increase study participation?
10. Do you have any brief closing comments before we end the recording?

Focus groups

All focus groups were audio recorded and transcribed verbatim. In-vivo coding was used to keep the data as similar to the language used by participants and to prioritize participants' voices (Harry et al. 2005; Saldaña 2021). First, two independent coders (first and third author) read through the transcripts several times to generate open codes, quoting participants directly. These researchers came together to discuss the codes until agreement was reached about which discrete codes should be included. Because of the small sample size, if a thought, idea, or belief was shared by at least two participants, it was included as a discrete code. Then, in collaboration with the senior author at UCLA, a final list of categories was created based on the discrete codes. Finally, themes were generated and discussed with all members of the team to ensure group consensus.

Table 4 Percentage of people within race group who selected each of the barriers to research participation

	AAPI ($N=16$)	Black ($N=27$)	White ($N=69$)	Multi-racial ($N=6$)	Other ($N=16$)
Knowledge/awareness of the study	37.5%	37.0%	44.9%	67.0%	43.7%
Fear of being taken advantage of	12.5%	37.0%	24.6%	33.3%	31.3%
Mistrust of the medical/research community	6.3%	33.3%	14.5%	33.3%	25.0%
Logistic issues as barriers	68.7%	37.0%	60.9%	16.7%	43.7%

Results

Survey descriptive data

Overall, 43% of the survey sample identified knowledge/awareness of genetic studies as a barrier to participation, 27% identified fear of being taken advantage of as a barrier, 19% identified mistrust of the clinical/research staff as a barrier, and 52% identified logistical barriers (e.g., transportation, scheduling, language and/or feasibility) to participation. Between participants who enrolled in the SPARK study ($n=62$), those who did not ($n=58$) and those who did not know ($n=13$), there were no differences in reporting of knowledge, mistrust, or logistical issues as barriers to participation ($p=.77$, $p=.62$, and $p=.37$, respectively). There was a significant difference based on participation status and being taken advantage of ($p=.05$). The difference was driven by those who did not know whether they had participated in SPARK, such that no one from that group identified being worried about being taken advantage of as a barrier (the cell size was zero). We did not apply any corrections for multiple comparisons and therefore the risk of a false positive relationship is increased, and this result should be interpreted with some caution. Finally, there were no differences in reporting of knowledge, mistrust, logistical or being taken advantage of as barriers by site ($p>.05$).

All racial groups had similar reports on "knowledge/awareness of the study" as a barrier. About 40% of participants identified "knowledge/awareness of the study" as a barrier across all racial groups (Table 4). A higher proportion of Black participants identified "being taken advantage of" (37%) and "mistrust of clinical/research staff" (33.3%) as barriers compared to all other groups. In contrast, AAPI participants reported "being taken advantage of" (12.5%) as a barrier and "mistrust of the clinical/research staff" (6.3%; Table 4) at the lowest rates. Finally, AAPI participants reported "logistical issues (e.g., transportation, scheduling, language, and/or feasibility)" most frequently (68.7%), while Black participants reported "logistical issues" least frequently (37%) compared to the rest of the groups (Table 4). The number of barriers reported by each racial group is reported in Table 5.

Survey chi-square tests

Chi-square tests of homogeneity were used to determine potential differences across racial groups in the types of barriers endorsed. No significant differences emerged with respect to "knowledge/awareness of the study," (X2 [3, N = 128] = 0.67, p = .881), or "being taken advantage of" (X2 [3, N = 128] = 3.45, p = .327), as barriers. The differences between race and "mistrust of the science community" (X^2 [3, N = 128] = 6.64, p = .084), and race and "logistic issues" (X^2 [3, N = 128] = 6.51, p = .089) both trended toward significance. Data from the multi-racial group (N = 6) were not included in the chi-square analyses because of the small sample size in that group.

Focus group themes

Each theme that arose from the data, stratified by race, is reported in Table 6. There were five themes that arose from the data, including Barriers/Fears, Motivators, Addressing Fears, Promoting Participation, and Recruitment Strategies. These five themes can be further categorized into Barriers/Fears, Motivators and Promoting Participation. Different codes made up each theme; Barriers/Fears was the most common theme endorsed by all of the participants.

Barriers/Fears

All participants reported a barrier or a fear to participating in genetic research. Codes that made up this theme included trust, logistical barriers (i.e., time/priorities and language), helplessness, lack of information, and beliefs about the source of autism. Mostly AAPI participants stated that they did not trust researchers because whenever they participate in research studies, they never hear back from the researchers. One participant stated, "I'm not that interested in research type of requests because they do not give us any results." In contrast, Black participants reported concerns about participating in genetic research studies and their mistrust of research staff due to negative historical events the Black community has experienced. One parent shared her hesitation to enroll her child in the SPARK research study, "… because historically our genetics have been used against us." About half of the participants (both AAPI and Black) reported being concerned about the use of their genetic information and the future implications for their families and their children.

Table 5 Total number of barriers selected by each racial group (%)

# of Barriers	AAPI (N = 16)	Black (N = 27)	White (N = 69)	Multiracial (N = 6)	Other (N = 16)
0 Barriers	12.5%	7.4%	10.1%	0%	12.5%
1 Barriers	62.5%	55.6%	58.0%	33.3%	58.0%
2 Barriers	18.75%	22.2%	16.0%	0.0%	16.0%
3 Barriers	0.0%	14.8%	8.7%	16.7%	8.7%
4 Barriers	6.25%	0.0%	7.2%	50.0%	7.2%

Both racial groups reported logistic barriers that varied by group. Black participants reported lack of time and research participation as their last priority. AAPI participants reported language as a barrier, emphasizing the importance of engaging immigrant communities by translating study materials into various languages. Participants noted that although they can read and understand English, it is often not their native language and can increase the amount of time parents spend on consenting and registering for a research study. One parent suggested, "Have translators in many languages, translate everything…. if I read it in Korean, we can read it easily, but in English – it's a headache."

Both AAPI and Black participants reported feelings of helplessness when it came to genetic research. They stated that regardless of the source of autism (genetic or not), there is nothing that can be done for their children, especially those that are older. A barrier that only came up for Black participants were their beliefs about the source of autism. Three participants reported environmental factors as the primary contributors to autism, which influenced their decisions not to participate in genetic research. One participant said, "It's in the environment, it's in the food, it's in all these cell towers around here. It's environmental. It's not genetic," and others agreed. Meanwhile, three AAPI participants reported they did not see the benefit to acquiring new genetic information about their children with autism, which influenced their decision not to participate.

Motivators

Three participants (19%) reported that their motivation to participate in genetic research studies like SPARK stemmed from their desire to advance the science and find genetic links to autism. Participants were interested in finding genetic links to autism for their own knowledge, their own families, and/or to help future generations, in general. This theme was most strongly endorsed by the two participants that completed participation in the SPARK study. One participant expressed her reason for participating was to learn more about the implications for her other daughter (without a diagnosis) when she decides to have children in the future.

Table 6 Focus group codebook (themes, descriptions, codes, and examples)

Theme	AAPI participants	Black participants
Barriers/ Fears	*Trust* “I’m not that interested in research type of requests because they do not give us any results” *Helplessness* “This type of test will be more valuable to families that have younger kids. Not like me -- 29-year-old kid” *Logistic – Language* “I mean I think it’s the language barrier” *Lack of Information* “Not enough information about the study in their area” *Fears* “…I’m concerned about the repercussions of the outcome. If we have that information, how can it be used in a positive manner and how can it be used in a negative manner?”	*Trust* “But unknowingly putting him in some genetics because historically our genetics have been used against us.” *Helplessness* “That still goes to the point of – no matter how much genetic testing you do, our kids are going to still be autistic. You’re not going to change that. So, I don’t – even if I were willing to do it, what purpose does it serve?” *Logistic – Time/Priorities* “We’re in a constant fight for basic services that other families that are Caucasian or European, … they don’t have to fight [for]. They’re not up at 11:00 pm writing letters to the state regarding the lack of services.” *Source of Autism* “It’s in the environment, it’s in the food, it’s in all these cell towers around here. It’s environmental. It’s not genetic.” *Fears* “Like after the research it’s going to take a while, so what are you guys going to do with that information?”
Motivators	*Advancing Science* “If we have more knowledge or information for future generations then I think it’s helpful.”	*Advancing science* “Because I have a daughter and we want to know if there is something. And if she has children…”
Addressing Fears	*Transparency* “…I would want to know the possible benefits. Like why is it important for me to do this?”	*Transparency* “…But without a purpose or a plan, I just don’t see it.”
Promoting Participation	*Resources for Specialty Care* “By providing other resources like um, therapies, and doctors,”	*Policy* “Now, if you come with research that’s going to address disparities, and you’re going to say, ‘Hey, we’re going to go to the state of California and push them to start servicing our kids.’ And financially put in money behind our kids, this room would probably be full, you know. “ *Resources for Specialty Care* “Whether it’s genetic or not, it doesn’t stop my son from being autistic. It’s the services I can get for him to improve the quality of his life.”
Recruitment Strategies	*Trusted Source* “Doctors, MD” “Parent support groups” “Community leaders” *Location* “In the home, or local community center” *Better Marketing* “Better PR, “Because they don’t like too much wording” in reference to flyers on Facebook.”	*Trusted Source* “I think I will trust a parent “ *Location* “So, coming to the community, whether it’s here or in people’s homes. You have to make it convenient for people…” *Timing* “ And be on time.” “…it’s either 9:00 or 1:00. It’s not between 9:00 and 1:00.”

Addressing fears

Participants (25%) reported that working with research staff who are completely transparent and provide detailed information about what participation entails and the goals of the study would make them more willing to participate, and all other parents agreed. One participant illustrated this by saying, “But, I think if they were to give us some – what? When? How? Where? What’s going to happen the study? Some more information as to what we’re going to do. What you’re going to do with it… I think that maybe we could be a little bit more at ease, if you will, about it.”

Promoting participation

To promote participation in genetic research, all focus group participants noted the importance of giving back to participants in tangible ways, including creating and providing resources for their families and children with autism. Many parents expressed that they would like to be connected to resources tailored to their children. This appeared especially important to parents of older individuals with autism, where fewer resources are available in areas related to social skills, higher education, and job training. Moreover, participants discussed a desire to foster a continuous relationship with the research institution in hopes that their participation in research would help to shape policy addressing disparities within autism. Specifically, Black participants expressed their willingness to participate in genetic research only if their children's basic needs are met first. One parent stated, "We're in a constant fight for basic services that other families that are Caucasian or European, … they don't have to fight [for]. They're not up at 11:00 pm writing letters to the state regarding the lack of services." Moreover, participants mentioned they were more likely to participate if researchers were willing to advocate on their behalf to address disparities. A participant highlighted this by stating, "Now, if you come with research that's going to address disparities, and you're going to say, 'Hey, we're going to go to the state of California and push them to start servicing our kids,' and financially put in money behind our kids, this room would probably be full, you know. "

Recruitment strategies

Parents trusted different community sources of information, depending on their racial and/or ethnic background. For example, AAPI parents reported trusting information about genetic research that comes directly from physicians. One participant stated, "I would be very skeptical, but I would trust an M.D." Additionally, AAPI participants expressed more willingness to participate in genetic research if other parents of individuals with autism shared their personal experiences in research, "A testimony is real and has more impact to our families."

Although Black parents acknowledged their mistrust of research because of historical events, such as the Tuskegee Syphilis Study (George et al. 2014), they largely endorsed trust in learning about genetic research from fellow parents. A participant illustrated the impact of shared experiences, "If there is someone that walked through the woods already…I would take that advice and trust that [person] because they've been through it. Someone that doesn't have children and has a PhD telling me [to participate] – they don't know the bumps and the bruises of a special needs parent."

AAPI and Black parents also acknowledged the effect trusted community members can have on genetic research recruitment. A parent noted, "The endorsement gives [the researcher] the warm handoff or the rapport that that [community] ambassador has. That rapport is passed on to you." This parent described that parents are more likely to trust a researcher when a trusted community member introduces the parent to that researcher.

Both AAPI and Black parents reported that doing a study in a community center or in the participants' homes would be the most convenient. Additionally, Black participants highlighted the importance that researchers arrive on time during research appointments in the participants' homes. Families emphasized that they do not have time to spare, especially if the staff is late. Caregivers emphasized that they need to be certain about an appointment in advance and guarantee that researchers will be on time because they would have spent time preparing their children in advance about the study, sharing specific details about the participation procedure, such as the time, the name of the person, and what they will look like.

Participants gave feedback on how to improve physical and electronic recruitment materials for genetic research studies. They expressed their desire for clear and explicit explanations of the research process about the study from start to end. For example, a parent stated, "Everything needs to be [broken down]. First, we have to collect the data, next we need to study and then we need to spread the results…." Moreover, parents suggested that it would be beneficial to illustrate the entire research process for prospective participants. More specifically, a parent shared, "I think that it could be [illustrated] in a pocket card or in a section of your materials… Literally [show] pictorially it's [genetic material] going to be in the tube, it goes to the center, and then this information is on the computer." Overall, participants agreed that step-by-step information aided by illustrations may help to broaden the study's accessibility to families from diverse cultural and linguistic backgrounds.

Discussion

As genetic research in autism becomes more common and critical for our understanding of the neurodevelopmental condition, it is important that efforts are made to include participants from all racial backgrounds. Currently, racial minorities with autism tend to be underrepresented in genetic research. There is limited empirical data on the perceived barriers and motivators to genetic research participation. Through quantitative and qualitative methods, we aimed to better understand of the perceived barriers and fears to participation. Additionally, through the use of focus groups, we explored factors that motivate Black and AAPI parents of people with autism to participate in genetic research, and identified culturally sensitive strategies that researchers can adopt to address barriers and promote participation in genetic research.

Barriers/Fears influencing genetic research participation

We assessed parents' perceptions of barriers to participating in genetic research in autism by race using survey methodology. Differences by race in perceived barriers including knowledge/awareness of the study, fear of being taken advantage of, mistrust of the science community, and logistic issues were not statistically significant. It is unclear whether the lack of differences were truly because all racial groups were affected by the same barriers or because the study was underpowered. The follow-up focus group study helped to clarify that Black and AAPI participants may be influenced by similar barriers, though the nuances may be different, highlighting the importance of mixed-methods research.

During the focus groups, the most common theme was Barriers/Fears to participating in genetic research. Both Black and AAPI participants discussed the lack of trust that exists toward the medical and research communities. Strikingly, the source of mistrust in genetic research was different for both AAPI and Black participants. AAPI participants were reluctant to participate in genetic research because they felt as though researchers take their information and do not share updates or results from the study, despite their interest in continued relationships with the researchers and the research project. Prior research shows that participants value the return of genetic results (Lucas et al. 2022; Trottier et al. 2013), though it might be a higher priority for AAPI participants. It is important that researchers engaged in genetic work consider participants' desire to be involved in the research as much as possible and receive continued updates, as this may influence rapport between the participant and the researcher, their willingness to participate, and their attitudes toward the project. In contrast, Black participants reported that lack of trust was rooted in the history and injustices that have been inflicted on Black participants by the medical community (Scharff et al. 2010; Brandt 1978; Shavers et al. 2002). The medical and research communities should consider culturally sensitive approaches to recruiting communities of color, including matching the race of research staff with those of the target families (Shavers et al. 2002).

There was a subtheme of helplessness within the main theme of Barriers/Fears. Participants from both groups expressed that, regardless of whether autism has a genetic etiology or not, there was nothing that results from genetic testing could do for their children. These feelings of resignation were also reported in a separate study on clinical-genetic testing in populations with autism (Reiff et al. 2017), though demographic factors including race and/or ethnicity for the sample were not reported. In a different study using a Norwegian sample, the primary reason caregivers refused clinical-genetic testing for their children with autism was because of the perceived lack of benefits that genetic testing could provide (Johannessen et al. 2017). The benefit of genetic testing for older individuals with autism may not be as evident, especially when caregivers are more concerned with accessing services that may directly benefit their young adults (Shattuck et al. 2012). Similarly, prior research has shown that caregivers believe that genetic testing should happen early in life, when children first show delays in development (Johannessen et al. 2017).

Logistic barriers also arose as a subtheme from the Barriers/Fears *arriers/* larger theme. There was a contrast between groups, though, in that AAPI participants reported that the most common logistic barrier was *linguistic*, with materials being in English and not accessible in their first language (in this case, Korean). Language as a barrier to autism research participation has not been widely documented, but language differences as a barrier to autism information and services has been identified previously (Grinker et al. 2015; Singh and Bunyak 2019). In contrast, Black participants reported their primary logistic barrier was *time*. They reported that on their priority list, genetic research is at the bottom because they have other, more time-sensitive issues to worry about, such as advocating for behavioral and medical services for their children. This highlights the barriers in access to services that Black families often experience (Mandell 2002), leaving no time for other activities like research participation.

A specific barrier that came up for Black participants only were the beliefs about the etiology of autism. Over half of Black participants in the focus groups reported that they believe autism is mostly caused by environmental factors. Prior survey research has suggested that Black participants are more likely to endorse sociological causes for mental illnesses, like the influences of American culture instead of biopsychosocial causes (i.e., a condition the child was born with; Yeh et al. 2004). Additionally, Black parents of individuals with autism also endorse sociological beliefs about the cause of their children's autism, such as it being a product of the child's poor relationship with their mother (Castillo et al. 2020). If parents believe that the cause of their children's autism has no genetic component, this may influence their willingness to participate in genetic research. Additional research is needed around beliefs of etiology among racially and ethnically diverse communities. This area of research may help guide the development of educational strategies to better inform the public about known, evidence-based causes of autism and the rationale for continued investigation of etiological factors.

Motivators for participation in genetic research

Motivators for participation in genetic research were to advance autism knowledge, and to have more information that could help future generations within their own families among Black and AAPI participants. Prior literature has also found that advancing autism knowledge and family planning are motivators to participating in genetic testing and research (Chen et al. 2013; Lucas et al. 2022; Trottier et al. 2013).

Promoting genetic research participation

To address fears and promote participation in genetic research, parents emphasized the importance of transparency about participation steps and study purpose. Participants emphasized the importance of learning about research from their own trusted sources, although who was considered "trusted" varied by racial group. AAPI participants identified the medical community and local community leaders and organizations as their trusted sources, whereas Black participants trusted community leaders or family members who had previously participated in the study. This finding aligns with existing research (Maye et al. 2021; Rivers, 2013). In a systematic review of 31 studies, one of the five key elements to clinical-trial participation amongst Black participants was whether their friends or relatives previously participated in or recommended the study (Rivers, 2013). Researchers should work with local communities to establish networks of communication between providers, parents, and institutions to promote research participation (Maye et al. 2021).

AAPI participants suggested that better materials be used for recruitment purposes, stating that flyers often have too many words. They encouraged that researchers come talk to them in-person, in their preferred language, to discuss the participation process. Similarly, findings from prior research suggest that consent should not be a one-time thing, but rather an ongoing conversation (George et al. 2014; Corrigan 2003). Participants recommended using something similar to a pocket card to make the materials clearer and not too overwhelming (Banda et al. 2012; Kiernan et al. 2018). In addition, increasing access to research through the dissemination of materials in the participants' native language proved to be a major theme. AAPI participants expressed the need for the study to be translated into different languages. Indeed, research has shown that having the study available in different languages (not just translated, but culturally adapted) is one of the most common ways to increase participation among culturally diverse participants in research studies (Levkoff and Sanchez 2003; Skaff et al. 2002), in addition to hiring bilingual research assistants (Bonevski, 2014).

Both AAPI and Black participants stressed the need for research studies to connect families directly to valued local resources, such as intervention and social-skills groups and to provide them with new information relevant to their children with autism, such as a research summary or report. Referrals to community resources from researchers may play a pivotal role in facilitating participation in genetic research among racial minorities, which has been the case in clinical trials (Schmotzer 2012). While genetic research is important to advance our understanding of autism, the implications of such participation may still seem distant to participants. Results from genetic studies may not immediately benefit participants but connecting them to resources that are instantly accessible might. Instead of or in addition to providing gift cards, researchers could identify local resources that may confer direct benefits to participants. This could also help strengthen the bidirectional relationship that some participants seek to have with researchers (Trottier et al. 2013), and positively affect recruitment and retention of racial minorities as a result (George et al. 2014).

Limitations and future directions

Study results offer insights into the different perspectives about participating in genetic research among Black and AAPI participants. However, a few limitations should be noted when interpreting results. The survey data only covered perceived barriers to participating in genetic research and did not include questions about motivators or strategies for how to address fears and barriers. Additionally, the low response rates to the surveys may indicate a lack of representation in the sample included, and thus may limit generalizability of results. Despite these limitations, we believe these exploratory analyses provide an important contribution in a relatively understudied area. These analyses should be replicated with larger and more representative samples. The focus groups were conducted at two different geographical locations with different study staff; therefore, conversations may have varied slightly at each site. Although saturation of themes and significant overlap across the sites was achieved, a larger sample of participants across varied geographical regions may yield even more generalizable findings. Further, there is great diversity within the Black and AAPI communities across geographic regions, which may be important for future studies to disentangle. The AAPI group primarily included Korean participants. Larger and more diverse samples are needed within racial groups to assess whether differences would be observed based on language and cultural differences. In order to include more diverse participants in focus group conversations, future studies on the topic should consider having facilitators who speak other languages. The qualitative results from the current study could inform the creation of more comprehensive surveys to quantify participant's perspectives about genetic research among an extensive audience. Finally, the current study focused on the perspective of caregivers, but future studies should consider recruiting autistic individuals and other stakeholders to include diverse perspectives on genetic research.

Conclusion

This study provides initial insight into AAPI and Black caregivers' perceived attitudes and barriers about participating in genetic and offers suggestions to improve outreach and study engagement. Despite the striking disparity in participation rates among racial minorities in genetic research, studies have shown that racial minorities are as willing to participate in clinical research as White individuals (Wendler et al. 2005). Therefore, it is important to address the barriers and factors preventing racial minorities from engaging in genetic research. Adapting recruitment strategies that are culturally sensitive could have a large impact and boost engagement amongst underrepresented populations and help researchers better understand genetic factors associated with autism across diverse samples.

Appendix A

Table A1 Survey questions

Questions	Response options
1. Have you or the individual with autism participated in the SPARK research study?	- Yes - No - I don't know
2. Have you or the individual with autism ever participated in research studies other than SPARK?	- Yes - No - I don't know
3. Do you think a research study like SPARK is beneficial for individuals with autism?	- Yes - No - I don't know
4. Of the following, which type of gift card is more appealing as compensation for your time?	- Prepaid debit card - Retail Store (Target, Walmart) - Amazon - None of the above
5. What are the barrier(s) to participating in genetic research? Select all that apply.	- Knowledge/awareness of study - Being taken advantage of - Mistrust of clinical/research staff - Logistical (transportation, scheduling, feasibility, etc.) - Other
6. What is the best way for you to hear about a research study for the first time? And why?	- Phone call from the study team - Email from the study team - Paper letter to your home - Social Media or News Media - Other
7. Does having a study team member of the same race or ethnicity as you impact your decision about participating in a study?	- Yes - No
8. What types of resources, aside from payment for your time, would you prefer to receive as a participant in a research study? Select all that apply.	- Access to webinars on various topics - Articles and updates on research findings at CAR - Support from a social worker to gain access to services - Parent/caregiver support groups - Other

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Data availability No datasets were generated or analysed during the current study.

Declarations

Ethics approval and consent to participate All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2000 (5). Informed consent was obtained from all patients for being included in the study. Approval for the survey and focus group studies was obtained by the WIRB Copernicus-Group Institutional Review Board (WCG IRB; #20151664), which provides regulatory oversight for the multisite SPARK network.

Competing interests The authors declare no competing interests.

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