

RESEARCH ARTICLE

Barriers and facilitators to participating in Alzheimer's disease biomarker research in black and white older adults

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Abstract

Introduction: The study examined Black and White prospective participants' views of barriers to and facilitators of participation in Alzheimer's disease (AD) biomarker research.

Methods: In a mixed-methods study, 399 community-dwelling Black and White older adults (age ≥ 55) who had never participated in AD research completed a survey about their perceptions of AD biomarker research. Individuals from lower socioeconomic and education backgrounds and Black men were over-sampled to address perspectives of traditionally under-represented groups. A subset of participants ($n = 29$) completed qualitative interviews.

Results: Most participants expressed interest in biomarker research (overall 69%). However, Black participants were comparatively more hesitant than White participants (28.9% vs 15.1%), were more concerned about study risks (28.9% vs 15.1%), and perceived multiple barriers to participating in brain scans. These results persisted even after adjusting for trust and perceived knowledge of AD. Information was a

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primary barrier (when absent) and incentive (when provided) for AD biomarker research participation. Black older adults desired more information about AD (eg, risk, prevention), general research processes, and specific biomarker procedures. They also desired return of results to make informed decisions about their health, research-sponsored community awareness events, and for researchers to mitigate the burden placed on participants in research (eg, transportation, basic needs).

Conclusion: Our findings increase representativeness in the literature by focusing on individuals with no history of AD research experience and those from traditionally underrepresented groups in research. Results suggest that the research community needs to improve information sharing and raising awareness, increase their presence in the communities of underrepresented groups, reduce incidental costs, and provide valuable personal health information to participants to increase interest. Specific recommendations for improving recruitment are addressed. Future studies will assess the implementation of evidence-based, socioculturally sensitive recruitment strategies to increase enrollment of Black older adults into AD biomarker studies.

KEYWORDS

Alzheimer's disease, biomarker research procedures, Black adults, community engaged research, health disparities, minority health, research participation, neuroimaging

HIGHLIGHTS

- Individuals from under-represented groups are interested in Alzheimer's disease (AD) biomarker research.
- After adjusting for trust and AD knowledge, Black participants were still more hesitant.
- Information is a barrier (when absent) to and incentive (when given) for biomarker studies.
- Reducing burden (e.g., transportation) is essential for recruiting Black older adults.

1 | INTRODUCTION

Although Black older adults are twice as likely as White older adults to develop Alzheimer's disease and related dementias (ADRD),^{1,2} their participation rates in Alzheimer's disease (AD) studies are significantly lower.³⁻⁵ Despite interest,⁶ they are often hesitant to enroll in AD studies.⁷⁻¹⁰ Addressing this hesitancy is essential for understanding health disparities in ADRD,¹¹⁻¹³ particularly with increasing focus on biomarkers and precision medicine.

Many studies examining barriers to AD biomarker research participation in Black adults rely on individuals who were already enrolled in AD studies, and have disproportionately female, highly educated, and higher socioeconomic status (SES) samples.^{7,14-18} Historically, those with lower education and SES have been underrepresented despite being at higher risk of AD.¹⁹⁻²¹ As researchers design community-based recruitment strategies to enroll new participants, one challenge is recruiting individuals from these historically underrepresented groups.¹⁵

To address these gaps, we examined barriers and facilitators for participation in AD biomarker research for Black and White older adults who had never participated in AD research. We focused on Black older adults with traditionally lower rates of research participation, including Black men, individuals with <16 years of education, and individuals with lower SES, with the goal to identify potential effective recruitment strategies for this group. We expected race-based differences in perceived barriers and facilitators in AD biomarker research.

2 | METHODS

2.1 | Study design

This was a cross-sectional, sequential explanatory mixed-methods study^{22,23} integrating survey and interview data within the same study for a comprehensive and nuanced understanding of the perspectives of Black older adults of AD biomarker research. The mixed-methods

RESEARCH IN CONTEXT

- 1. Systematic review:** Authors reviewed the literature using PubMed, Google Scholar, and reference lists from relevant papers.
- 2. Interpretation:** Diversity in Alzheimer's disease (AD) biomarker research, including Black older adults, is greatly needed. In a sample of individuals who had never been invited to participate in research, including Black and White older adults from traditionally underrepresented groups (low socioeconomic status, low education, Black men), we examined interest in AD biomarker research, and perceived barriers and facilitators for participation. Black participants were more hesitant about and perceived more barriers to biomarker research than White participants, even after accounting for trust in researchers and perceived knowledge of AD. Qualitative interviews with Black older adults suggested that lack of information drove perception of barriers and return of results was a significant incentive.
- 3. Future directions:** Develop and test socioculturally sensitive strategies with appropriate information and incentives to increase Black older adult participation in AD biomarker studies.

design offered opportunities to evaluate contextual factors such as culture, participants' perceptions, values, and beliefs qualitatively. This study was part of a larger research project—Promoting Cultural Awareness and Diversity in Research about Alzheimer's Disease and Cognitive Health (AD-REACH)²⁴—aiming to generate targeted and culturally sensitive recruitment materials for Black older adults to increase recruitment into AD biomarker studies.

AD-REACH is a three-phase mixed-methods research design involving the development of a novel survey (Phase 1), survey administration (Phase 2), and qualitative interviews (Phase 3; Figure 1). In the first phase of AD-REACH project, we collected qualitative data from focus groups and individual semi-structured and cognitive interviews to develop and refine a survey to assess interests, barriers, and facilitators in AD biomarker research. We then administered the survey to Black and White older adults in the second phase, where we examined differences in their views of research participation based on race to identify barriers and facilitators that may be unique to Black older adults. The third phase involved collection of additional qualitative data from a sub-sample of Black survey completers. In the present study, we report on data from Phases 2 and 3.

In the present study, consistent with sequential explanatory mixed-methods study design,^{22,23} we used the survey data to identify a subsample for interviews to help further explain the data. The subsample consisted of Black survey completers who expressed hesitancy toward research for qualitative interviews. In the Phase 3 interviews,

we examined participants' views of research participation, specifically reasons for hesitancy to gain insights into potential recruitment strategies. Although qualitative data collection from Phase 1 focused on exploring participants' views to inform survey development and selection of specific survey items, Phase 3 interviews addressed the lived experiences of Black older adults and their unique reasons for hesitancy toward AD biomarker research participation.

2.2 | Participants and recruitment

Study participants were community-dwelling older adults who met the following eligibility criteria: (1) self-identified as non-Hispanic White or African-American/Black (including biracial or multiracial), (2) age ≥ 55 years, (3) resided in the Indianapolis-Carmel-Anderson metropolitan area, and (4) had never participated in AD research.

We recruited participants between September 2021 and April 2022. We recruited from the electronic health records at Indiana University School of Medicine and the Roudebush VA Medical Center, the ALLIN4HEALTH research registry (an Indiana University affiliated Clinical and Translational Sciences Institute sponsored research volunteer registry), and the community. We advertised the study online and at community presentations and used snow-ball techniques,²⁵ asking current Indiana Alzheimer's Disease Research Center study participants, advisors, and staff members to refer participants. Potential participants identified via electronic health records were mailed an invitation and followed up with a phone call.

2.3 | Study procedures

Please see Appendix A for description of survey development. Potential survey participants were screened for eligibility and then completed the survey online or over the phone with a study staff member (survey questions in Appendix B). A purposive subsample of Black survey completers who expressed hesitancy about research were invited to participate in qualitative interviews. We oversampled men and individuals from low education and SES backgrounds. We recruited 29 participants for the interview, which is adequate to reach thematic saturation.²⁶ The first author (JE) and two research assistants trained in qualitative research conducted the 30-60 minute interviews.

See Figure 1 for a summary of study activities, samples, and mixed-methods design. The Indiana University Institutional Review Board and Roudebush VA Medical Center Research and Development Committee approved the study. Participants provided informed consent prior to study participation and received \$35 upon survey completion and, if applicable, \$35 upon interview completion.

2.4 | Survey contents and outcome variables

In the survey, we assessed participants' age, sex, education level, and race, which were used as covariates in our analyses. We used the term

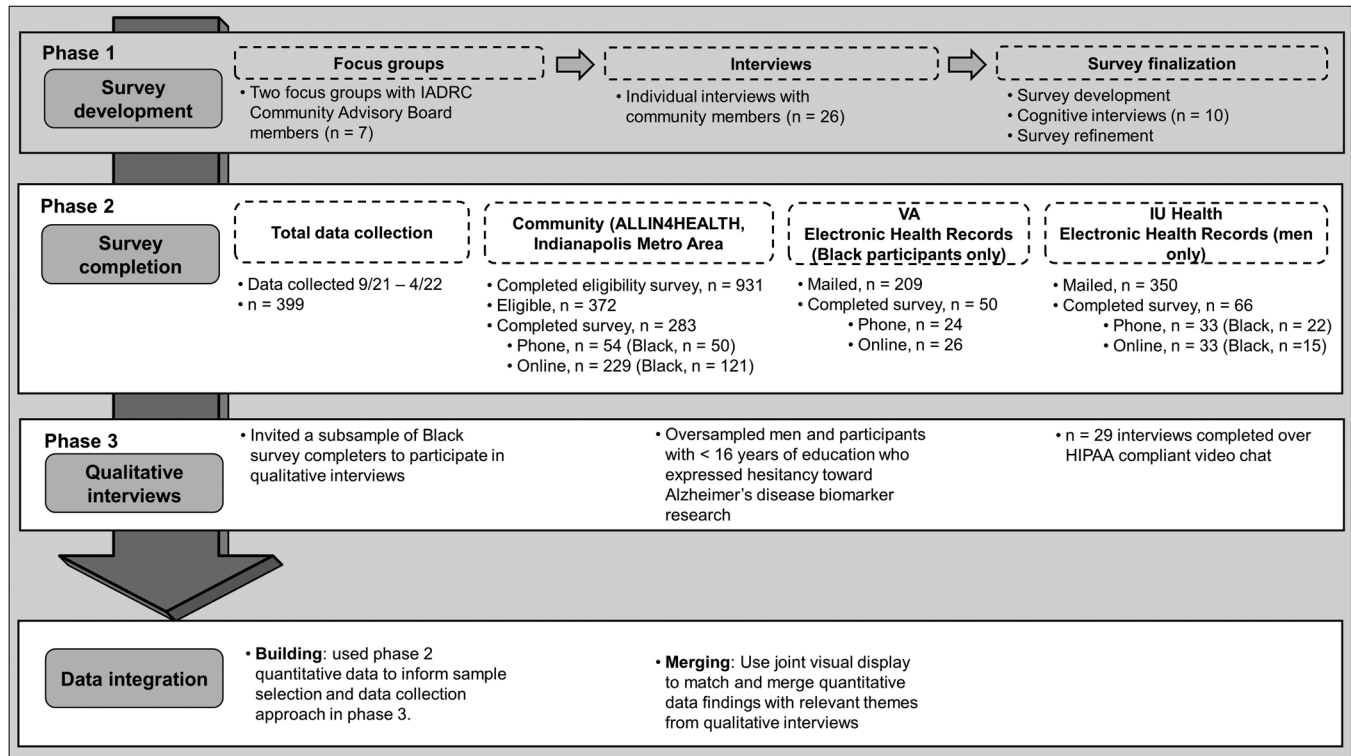


FIGURE 1 Outline of study activities from survey development to survey completion to qualitative interviews. Includes breakdown of eligible and ineligible participants at each stage of the study.

“Black” to describe participants who self-identified as African American, Black, or biracial/multiracial. We dichotomized age (55–64 years vs >65 years), education (<16 years vs ≥16 years), and sex (male vs female) due to institutional review board (IRB) regulations regarding de-identified survey collection. We measured SES with the Area Deprivation Index (ADI) from the Neighborhood Atlas.^{27,28} We also assessed participants perceived knowledge of AD and trust in researchers and included these factors as covariates in our analyses because they vary by race and affect interest in research participation.^{14,29–32} One question assessed perceived knowledge of AD (5-point scale [1 = no perceived knowledge; 5 = highest perceived knowledge]). A sum total of six questions (3-point scale: “agree” = 2, “unsure” = 1, “disagree” = 0) assessed trust of researchers (higher scores = greater trust). The average perceived knowledge of AD in the overall sample was 3.05 (SD = 0.8), indicating participants knew what AD was but not what caused it or how to manage it. Average trust of researchers was 11.02 (SD = 1.8) indicating overall high trust. We dichotomized both variables at their group mean (i.e., AD knowledge: <3 or ≥3 and trust: ≤11 or 12).

In the present study, we focused on three main outcomes from the survey: interest, perceived barriers, and facilitators (i.e., motivators and incentives) to AD biomarker research participation. Participants could respond “yes,” “no,” or “maybe in the future” to questions about interest. Participants who answered “yes” were asked about motivators. Participants who answered “no” were asked about barriers. Participants who expressed hesitancy (“maybe in the future”) were asked about both motivators and barriers. Seven questions examined general barriers and four questions examined motivators (responses: “this is a

reason for me,” “this is not a reason for me,” “unsure”). Participants also indicated their interest in completing specific biomarker procedures, including positron emission tomography (PET), magnetic resonance imaging (MRI), and blood draw (responses: “yes,” “no,” “maybe in the future”). Those who responded “no” or “maybe in the future” to any of the procedures answered six additional questions (per procedure) about the perceived barriers. All participants then indicated their preferences for incentives by selecting all applicable responses from a list that included brain health information, transportation/travel vouchers, and return of results (labs, cognitive testing, neuroimaging). Survey respondents were informed that these incentives would be in addition to gift cards, which were not on the list.

2.5 | Qualitative interviews

The interview guide (Appendix C) explored participants’ responses to survey questions, focusing on barriers to and facilitators for AD biomarker research participation.

2.6 | Quantitative data analysis

We used *t-tests* and *chi-square* analysis to compare demographics across groups. In our main analyses—investigating the association between race and survey responses—we used binary logistic regression for outcome variables with only two response options (yes/no; yes

= reference). For outcome variables with three response options, we used ordinal logistic regression (this is not a reason for me/yes = 0, maybe in the future/unsure = 1, or this is a reason for me/no = 2). Odds ratios (ORs; binary) or cumulative ORs (ordinal) and 95% confidence intervals (CIs) for the effect of race were estimated for each model after adjusting for covariates (age, education, sex, perceived knowledge of AD, and trust of researchers). Due to the collinearity of education and ADI, we included only education in the models except for the analysis of the transportation incentive. Here we used ADI instead of education because this had monetary value. All analyses were performed using SPSS Statistics version 28.0. Given the exploratory nature of the study, we did not correct for multiple comparisons.

2.7 | Qualitative data analysis

Interviews were recorded and transcribed for analysis. Four analysts that included the two first authors (JE and AJP) and two trained research assistants analyzed the data using a rapid data analysis approach.^{33–35} Rapid data analysis is a rigorous, applied qualitative research method that facilitates the analysis of targeted qualitative data. It involves summarizing the data based on the interview guide and research questions.³⁶ Two analysts independently generated a summary for each transcript, which included a brief synthesis of participants' responses. To ensure analytical rigor and trustworthiness, the team reviewed and discussed the content and summary of each transcript, resolving inconsistencies by consensus. The larger team collaboratively consolidated the interview summaries by domains to identify commonly occurring themes, and to allow comparisons across participants until we reached data saturation.³⁷

2.8 | Mixed-methods analysis

The process of mixed-methods data integration and reporting is described in Figure 1. Data integration occurred at two points. First, we used the building approach to identify our Phase 3 subsample from the pool of Phase 2 survey completers. We then merged the quantitative survey data with qualitative interviews. Through this process, we matched qualitative themes that expanded on related quantitative findings, especially those that highlighted race-based differences in perceived barriers and facilitators, and corresponding survey domains in a joint visual display (Figure 2). We also focused on participants' recommendations for potential recruitment strategies.

3 | RESULTS

3.1 | Sample characteristics

Two hundred fifty-eight Black ($n = 3$ who identified as biracial or multiracial) and 141 White participants completed the survey. Two

hundred eighty-eight participants completed the survey online and 111 completed it over the phone (Figure 1). Black participants were more likely than White participants to have <16 years of education, less likely to be partnered, and more likely to live in disadvantaged neighborhoods (p 's < .05). Black participants endorsed lower knowledge and trust (p 's < .05) compared to White participants. There were no statistically significant race differences for sex or age. Demographics of survey completers and interviewees are presented in Table 1.

3.2 | Interest in participating in a future AD biomarker study

Most participants, regardless of race, expressed interest in AD biomarker research (overall sample: 69%). However, Black participants were more hesitant than White participants ($p = .045$) (Table 2A). There were no group differences in interest in specific biomarker procedures (p 's > .05).

3.3 | Barriers to participation in AD biomarker research

Black and White participants endorsed the same top two barriers to research participation: needing more information and not knowing enough about AD (p 's > .05). However, Black participants had more concerns about general study risks than White participants did ($p = .029$) (Table 2B). Black participants endorsed multiple barriers to participating in brain scans compared to White participants. For MRI, these included not having enough information ($p = .041$), not knowing the doctors/staff performing the procedure ($p = .038$), and not knowing what would happen to their information ($p = .037$). For PET, Black participants endorsed greater concern about safety ($p = .012$) (Table 2B).

Qualitative data corroborated these findings. For parsimony, we present exemplar quotes for all the themes in Table 3. Many Black participants were unfamiliar with the procedures and indicated that lack of information about them, especially the risks involved, create hesitancy for participation. To address these barriers, participants recommended increasing awareness of AD, and providing education about the various study procedures, their risks and benefits, and the research process in general. They noted that information about AD would be better received if disseminated by a trusted source, such as their primary care providers (PCPs) and through community events (e.g., neighborhood centers, health fairs), and via media campaigns, such as TV ads. Participants also suggested that AD education should be conducted early, starting with school-age children, and in parallel with research education to address stigma and historical trauma associated with research among Black individuals. They underscored that research education should focus on dispelling commonly held myths about participation and emphasize the benefits of research through testimonials from current participants. A few

TABLE 1 Participant demographics.

Survey completers	Black older adults <i>n</i> = 258 <i>n</i> (%)	White older adults <i>n</i> = 141 <i>n</i> (%)
Age (years)		
55-64	109 (42.2)	49 (34.8)
≥65	149 (57.8)	92 (65.2)
Sex		
Female	138 (53.5)	87 (61.7)
Male	120 (42.5)	54 (38.3)
Education		
<16 years	189 (73.3)*	58 (41.1)*
Grades 1-11	16 (6.2)	2 (1.4)
Grade 12/GED	58 (22.5)	10 (7.1)
Vocational/training/some college	79 (30.6)	30 (21.3)
Associates degree	36 (14)	16 (11.3)
≥16 years	69 (26.7)*	83 (58.9)*
College grad/BA—BS	32 (12.4)	40 (28.4)
Some professional school	9 (3.5)	9 (6.4)
Master's degree	24 (9.3)	24 (17)
Doctoral degree	4 (1.6)	10 (7.1)
Relationship		
Partnered	110 (42.6)*	91 (64.5)*
Single	148 (57.4)*	50 (35.5)*
Area deprivation index (ADI)		
Mean (SD)	72.5 (23.1)*	52.8 (23.4)*
Knowledge of AD		
≤2	62 (24.0)*	7 (5.0)*
≥3	196 (76.0)*	134 (95.0)*
Trust of researchers		
≤11	89 (34.5)*	27 (19.1)*
12	169 (65.5)*	114 (80.9)*
Interview completers		
Black older adults <i>n</i> = 29 <i>n</i> (%)		
Age (years)		
55-64	8 (27.6)	
≥65	21 (72.4)	
Sex		
Female	10 (34.5)	
Male	19 (65.5)	
Education		
<16 years	22 (75.9)	
≥16 years	7 (24.1)	
Relationship		
Partnered	14 (48.3)	
Single	15 (51.7)	
Area deprivation index (ADI)		
Mean (SD)	65.4 (21.7)	

Note: **p* < .05 as per chi-square tests. ADI measured via the Neighborhood Atlas.^{26,27}

TABLE 2 Differences in Black and White participants' responses to survey questions (%) and odds ratios (ORs), 95% confidence intervals (CIs), and *p* values for effect of race in logistic regression models

	Black older adults			White older adults			Regression model		
	Yes	No	Maybe future	Yes	No	Maybe future	OR	95% CI	<i>p</i>
A. Interest (n = 385)									
Interest in AD biomarker study	63.0	8.1	28.9	80.6	4.3	15.1	1.75	1.01-3.04	.04
Interest in blood draw	72.5	9.3	18.2	87.2	5.0	7.8	1.70	0.92-3.16	.09
Interest in MRI	66.7	11.2	22.1	79.4	5.0	15.6	1.59	0.94-2.69	.08
Interest in PET	61.6	16.6	21.7	72.3	7.8	19.9	1.56	0.96-2.54	.07
B. Barriers									
	Is a reason	NOT a reason	Unsure	Is a reason	NOT a reason	Unsure	OR	95% CI	<i>p</i>
<i>AD biomarker study (n = 118)</i>									
Do not know enough to decide	39.2	41.8	18.7	29.6	59.3	11.1	0.85	0.33-2.23	.75
It will not make a difference	6.6	71.4	22.0	3.7	85.2	11.1	1.40	0.39-5.01	.34
Worry how information will be used	15.4	57.1	27.5	11.1	74.1	14.8	0.97	0.33-2.84	.95
Worry about abnormal results	16.5	62.6	20.9	14.8	66.7	18.5	0.90	0.33-2.51	.85
Worry about risks	30.8	42.9	26.4	11.1	77.8	11.1	3.27	1.13-9.53	.03
Not interested in AD research	6.6	69.2	24.2	7.4	81.5	11.1	1.17	0.37-3.10	.79
Need more information	49.5	22.0	28.6	51.9	29.6	18.5	1.26	0.51-3.14	.64
<i>Blood draw (n = 89)</i>									
Do not have enough info to decide	64.8	14.1	21.1	44.4	33.3	22.2	2.87	0.96-8.53	.06
Worry procedure is unsafe	9.9	40.8	49.3	11.1	55.6	33.3	1.03	0.34-3.11	.96
People doing procedure unknown	26.8	54.9	18.3	22.2	61.1	16.7	1.03	0.33-3.17	.96
What happens with information	38.0	36.6	25.4	11.1	66.7	22.2	3.16	0.96-10.38	.06
Only done if medically necessary	53.5	29.6	16.9	50.0	27.8	22.2	0.86	0.29-2.57	.78
Worry about abnormal results	14.1	57.7	28.2	16.7	61.1	22.2	0.92	0.30-2.84	.89
<i>MRI (n = 115)</i>									
Do not have enough info to decide	64.0	19.8	16.3	41.4	44.8	13.8	2.59	1.04-6.44	.04
Worry procedure is unsafe	11.6	46.5	41.9	6.9	69.0	24.1	1.40	0.52-3.83	.51
People doing procedure unknown	26.7	51.2	22.1	13.8	79.3	6.9	3.03	1.06-8.63	.04
What happens with information	27.9	47.7	24.4	6.9	82.8	10.3	3.35	1.07-10.44	.04
Only done if medically necessary	62.8	26.7	10.5	44.8	41.4	13.8	1.89	0.76-4.71	.17
Worry about abnormal results	22.1	51.2	26.7	17.2	65.5	17.2	1.06	0.40-2.77	.91
<i>PET (n = 138)</i>									
Do not have enough info to decide	65.7	21.2	13.1	61.5	33.3	5.1	1.26	0.55-2.90	.58
Worry procedure is unsafe	17.2	35.4	47.5	5.1	61.5	33.3	2.93	1.27-6.77	.01
People doing procedure unknown	32.3	49.5	18.2	23.1	69.2	7.7	2.10	0.91-4.85	.08

(Continues)

TABLE 2 (Continued)

B. Barriers	Is a reason	NOT a reason	Unsure	Is a reason	NOT a reason	Unsure	OR	95% CI	p
What happens with information	23.2	48.5	28.3	12.8	76.9	10.3	1.94	0.78-4.86	.16
Only done if medically necessary	61.6	21.2	17.2	51.3	30.8	17.9	1.32	0.60-2.92	.49
Worry about abnormal results	23.2	51.0	25.3	17.9	66.7	15.4	1.34	0.59-3.09	.49
C. Motivators (n = 358)									
Loved one or I could be diagnosed	87.2	4.9	8.0	89.5	5.3	5.3	0.96	0.46-2.03	.92
Help find a cure	88.5	3.5	8.0	96.2	0.8	3.0	2.21	0.99-4.91	.05
Learn more about AD	92.0	4.9	3.1	88.0	6.0	6.0	0.51	0.17-1.47	.21
Everyone should do research	54.0	22.1	23.9	60.9	18.8	20.3	0.89	0.56-1.41	.61
D. Incentives (n = 399)									
	Yes	No	Unsure	Yes	No	Unsure	OR	95% CI	p
Return of normal results	91.1	3.9	5.0	92.0	0.7	6.4	0.84	0.35-1.98	.69
Results of routine blood work	76.7	-	-	83.0	-	-	0.90	0.50-1.62	.73
Results of brain scans	84.5	-	-	87.9	-	-	1.13	0.57-2.23	.73
Results of memory tests	85.3	-	-	84.4	-	-	1.36	0.72-2.59	.34
Transportation vouchers	39.5	-	-	19.1	-	-	2.29	1.36-3.86	.002
Information about brain health	77.5	-	-	73.0	-	-	1.32	0.78-2.22	.30

Note: OR = odds ratio; CI = confidence interval. Ordinal logistic regression models adjusting for demographic variables (sex, age, education, knowledge of AD, and trust of researchers) were run for analysis of interest, barriers, and motivators (OR represents cumulative OR). Binary logistic regression models adjusting for demographic variables (sex, age, education, knowledge of AD, and trust of researchers) were run for analysis of incentives. Bolded values represent statistically significant results.

(A) Interest in AD biomarker research, (B) barriers to participation for AD biomarker research, (C) motivators for participating in AD biomarker research, and (D) incentives for participation in AD biomarker research.

participants also suggested that the focus of outreach should be “brain health” rather than AD, as AD can be stigmatizing. Finally, participants expressed interest in having open discussions about the procedures and the research processes with staff, to ensure that their questions are answered and to develop relationships with study staff.

3.4 | Motivators for participation in AD biomarker research

Black and White participants endorsed motivators for research participation at similar frequency (p 's > .05) (Table 2C). In their interviews, Black participants overwhelmingly expressed that information and education were the main motivators for research participation. They desired education about AD (early detection, how to prevent it, and how to help a loved one who has it) and to contribute to understanding the unique sociocultural contributors to AD risk in Black adults. In addition, Black participants expressed that research participation would help raise awareness about AD in the Black community. A few participants expressed developing treatments for AD, destigmatizing the disease, and helping others were motivators for participation.

3.5 | Preferred incentives to increase participation in AD biomarker research

Most participants, regardless of race, were interested in receiving their personal test results, particularly brain scans and cognitive testing, and information about brain health (p 's > .05). Ninety-one percent% of all participants agreed that normal results from biomarker procedures should be shared. Black participants were more likely than White participants to be interested in transportation assistance ($p = .006$) (Table 2D).

In the interviews, health information was the most preferred incentive for Black participants. They viewed research participation as an opportunity to obtain valuable personal health information, particularly brain imaging and cognitive testing, that would help them track their health trajectory overtime and initiate conversations about brain health with their PCPs and loved ones. Participants explained that test results would inform their health decisions and behaviors to prevent cognitive decline, maintain well-being, and improve the ability to manage AD in the future. Participants maintained that results should be shared quickly, in both written and verbal forms, by trusted and knowledgeable study staff members who could explain the results and answer questions. Participants also expressed desire for education about AD (early warning signs and risks, prevention, symptom

TABLE 3 Examples of quotes from the qualitative interviews

Theme	Quotes
BARRIERS	
Lack of Information	<p>2007 "They don't publicize it [AD] on TV. They don't have any classes where you can get knowledge. And unless you talk to people or around someone that has experienced someone with Alzheimer's disease, you know nothing."</p> <p>1887 [referring to MRI] "I imagine it wouldn't be that bad but just a little hesitant just probably needed to know a little more about what it really entails."</p> <p>2009 [referring to blood draw] "Well, blood. I don't know. There's so many other things that you can get out of that. And I don't know what you would do with all of that additional information that you could get out of that. ... there's something about blood that I'm just suspicious, more so about all the myriad of things that you might be able to do with that."</p>
Concerns about risk	<p>1126 [referring to PET] "I was concerned about how safe that was, and what type of lasting, or if any, side effects that would be on my health. ... I mean anytime you injecting something in someone I have a concern about that. Doesn't mean I totally wouldn't do it, but I would have to have some like guarantees on not affecting myself in any kind of way."</p>
Addressing historical trauma and stigma	<p>2009 "I guess I'm very suspicious of that looking back over the Black history, Tuskegee and people doing experiment on Black people. They either put stuff in their body or they took stuff out. I'm still suspicious about that type of thing being performed."</p>
Recommendations	<p>2007 "I'm not gonna go to medical school for a hundred years to figure out what it is that they're actually saying, but when you have good people, good nurses, good doctors who actually break it down to you, then you become more receptive to doing these things that you think may help the Black community."</p> <p>1086 "There could be information put out there, fraternities and college campuses that would be a good place to hit the youth. if you do hit the young Black male, and their dad, and their grandfather, they would be able to communicate information to them on, Dad, you know what? We had this conversation about Alzheimer's. And Grandpa seems to, you know...."</p> <p>1916 "Well, I'd say within the Black community educating them on what the research is. You know, there's a lot of stigma in the Black community on medical research. It's like ok, once again, they're coming to use us as Guinea pigs. I know a lot of people in the Black community go back to the Tuskegee experiment, the Henrietta Lacks situation. You know, it's just giving them more information about what you're trying to do and how it's gonna be used. Will it be published? Who will have access to the data that's gathered from the research project?"</p>
MOTIVATORS	
Information about AD, signs, risks, prevention, and management	<p>1583 "I would say prevention first. And then what it means, the warning signs of what it means to have it, what causes it. Get all those myths away because you know with the height of misinformation you would want to make sure that they know what it is, the definition, the intervention what you can do to prevent it. And in terms that they can understand. Not medical terms that they don't understand. Things that they can relate to and not feel like it's going over their head. 'Cause sometimes when things are too complicated, and it's written in a way or presented in a way that's too complicated then you lose people. You lose their interest, and they think you're not on their level to explain it well enough. And be able to answer questions, no matter how small the question is or how large the question is."</p>
Raise awareness, particularly in the Black community	<p>2067 "I know one particular benefit is awareness. Well, this is the most important of getting it out to the community where they can understand what's really going on with Alzheimer's.... And another is how to seek treatment, and without feeling it wouldn't do no good."</p> <p>1135 "To get information on what's going on with this disease. I would want to know as much as possible... the fact there's a lot of trauma in the Black community that has never been addressed. And I guess I don't know the statistics about how it affects or who it affects more but seems like everything that people say it always affects the Black community more. So, I'm assuming that you're saying that this does too. And I wouldn't be surprised because the trauma and the different day-to-day oppressions that we have to deal with would cause anybody that type of harm."</p>
Helping others	<p>1846 "And I just feel like if I helped, that would help the Black community or whatever, whoever it can help you know. It's just such a small sacrifice on my part, you know, to do that. So, you know, I don't mind doing stuff to help other people."</p>
Destigmatizing	<p>1668 "Well, first thing is, once getting this information out there gotta let people know it's a benefit to them and they're not alone. And this disease is not a stigma. Gotta figure out it's not a stigma. They just gotta know it's a common thing, and you guys are trying to help."</p>

(Continues)

TABLE 3 (Continued)

Theme	Quotes
INCENTIVES	
Test results	
Empower health decision making	1342 "Because if I had a test say in the next two years. And five years from now, they say I have Alzheimer's then I could say, you know what? Here's the last scan I had, so can you compare with the scan that you just did and tell me how in those two years it differs? You always need that base." 1894 "Since there's been people in my family that had Alzheimer's and dementia, I want to know the results of these tests that I take, and I want to know what I can do to help myself, you know, kind of prevent it or prolong or you know something like that. [...] So that's why the results are important, so I know where I stand or what my future looks like? [...] Give me all the information at a way that I can understand it in layman's terms."
Discuss results in writing and face-to-face	1333 "feel like the best way to get that feedback is through face to face [<i>clarifies: video or phone call, or in person</i>]. Like you and I are talking, call me up and give me that feedback. Follow-up by something in writing so I can have that in my record, in my folder"
Transportation	
Reduce financial and resource burden on participants	1894 "I mean with the gas prices so high, a gas card. Every little bit helps. If you're driving to the appointment, you know, if it's possible." 2003 "How many people would you know that would catch the bus, pay the bus fare to take the bus to go research and then catch the bus to come back home? I don't think it would be too many people that would do that." 2067 "I don't want to have to pay to give you information. ... I'm talking about the system. If you want something that's valuable to you from me, don't make me pay for it. I'm not gonna pay for you to stick a needle up my arm. No way. I'm going to pay for you to stick my head in a tube? No. No thanks."
Meet basic needs	
	1126 "I think it would help if needs were met without the struggle so much. Which I really believe had me so consumed with life in general, trying to survive. ... Being so consumed with the things that you have to do, you really don't have room for a lot of other things unless it's affecting you or going to affect you. It just seems like your mind it can't lend to anything else."

TABLE 4 Association between incentives and interest in participating in an AD biomarker study ($n = 399$)

	OR	95% CI		p	OR for interest to participate in study
		Lower	Upper		
Results of routine blood work	0.25	0.15	0.42	<.001	4.02
Results of brain scans	0.22	0.12	0.40	<.001	4.50
Results of memory tests	0.28	0.16	0.50	<.001	3.58
Transportation vouchers or free rideshares	0.67	0.40	1.01	.120	1.50
Information about brain health	0.44	0.26	0.72	.001	2.29

Note: OR = odds ratio; CI = confidence interval. Cumulative OR and 95% CI were calculated using ordinal logistic regression models to examine the association between interest in an incentive and hesitancy to participate in an AD biomarker study. OR for interest to participate in an AD biomarker study was calculating by taking the inverse of the cumulative OR. Questions about monetary incentives were not included in this survey.

management, resources to find help) and general and personalized information about brain health.

Interviewees viewed transportation assistance as a facilitator to research participation for individuals from underrepresented communities who may experience transportation barriers. Relatedly, they expressed that poverty is a significant barrier to research participation. Therefore, work is needed to meet the basic needs of Black community members so that they may have the financial, emotional, and cognitive capacity to engage in research. Several participants emphasized that incentives should be equivalent to participant's time and effort.

In post hoc binary logistic regression analyses, we examined associations between incentives and interest in participating in AD biomarker research (Table 4). Return of results for all types of

procedures was consistently associated with a 3- to 4-fold higher interest (all p 's < .05). Information about brain health was associated with a 2-fold higher interest. Transportation was not significantly associated with interest ($p = .12$).

4 | DISCUSSION

This study adds to the understanding of barriers and facilitators to participating in AD biomarker research in Black and White older adults. Our findings increase representativeness in the literature by focusing on individuals with no history of AD research experience and those from traditionally underrepresented groups in research (Black men,

Quantitative findings	Corresponding survey items	Themes from qualitative interviews	Sample Quotes	Interpretation and recommendations
<p>Barriers to AD biomarker research participation</p> <p>Black participants were more likely than White participants to be interested in transportation assistance</p> <p>OR = 2.29, 95%CI = 1.36 – 3.86, $p = .002$</p>	<p>If you were to participate in an Alzheimer's disease research study and had to do blood draw, brain MRI, and PET scans, what incentives would you like to receive in addition to a gift card?</p> <p>Option: transportation vouchers or free rideshares such as Uber or Lyft</p>	<p>Lack of transportation is a barrier to AD research participation.</p> <p><i>Suggestions to address this barrier:</i> Reduce financial and resources burden on participants</p> <p>Address participants' unmet basic needs</p>	<p>"How many people would you know that would catch the bus, pay the bus fare to take the bus to go research and then catch the bus to come back home? I don't think it would be too many people that would do that."</p>	<p>Transportation voucher is perceived more as a reimbursement than an incentive. It helps reduce participant burden, especially with individuals of lower SES backgrounds.</p> <p>Consider sliding scale of need to reimburse costs associated with research participation</p>
<p>Barriers to AD biomarker research participation</p> <p>Black participants had more concerns about risks than White participants</p> <p>OR = 3.27, 95%CI = 1.13 – 9.53, $p = .03$</p>	<p>Which of the following statements are reason(s) you WOULD NOT CONSIDER OR ARE UNSURE ABOUT participating in Alzheimer's disease research?</p> <p>Option: I worry about the risks of the study</p>	<p>Safety concerns about research practices in general and about specific procedures (e.g., PET) were identified as barriers.</p> <p>Historical trauma associated with research participation.</p> <p>Uncertainties related to potential risks of procedures.</p>	<p>"I guess I'm very suspicious of that looking back over the Black history, Tuskegee and people doing experiment on Black people. ... I'm still suspicious about that type of thing being performed."</p> <p>[referring to PET] "I was concerned about how safe that was, and what type of lasting, or if any, side effects that would be on my health."</p>	<p>Researchers should address historical traumas during recruitment</p> <p>Partner with trusted community members (e.g., PCPs, community leaders) to provide community-based education about AD research practices, including risks and benefits</p>
<p>Facilitators to AD biomarker research participation</p> <p>Black and White participants were similarly interested in receiving their personal test results, particularly brain scans and cognitive testing</p> <p>$ps > .33$</p>	<p>If you were to participate in an Alzheimer's disease research study and had to do blood draw, brain MRI, and PET scans, what incentives would you like to receive in addition to a gift card?</p> <p>Options: Results of routine blood work Results of brain scans Results of memory tests</p>	<p>Empower health decision making</p> <p>Desire for results to be shared quickly – face-to-face (or over zoom or phone) and in writing</p>	<p>"If I had a test say in the next two years. And five years from now, they say I have Alzheimer's then I could say, you know what? Here's the last scan I had, so can you compare with the scan that you just did and tell me how in those two years it differs?"</p> <p>"I feel like the best way to get that feedback is through face to face ... follow up by something in writing so I can have that in my record."</p>	<p>Returning of results may help build trust and transparency between researchers and participants</p> <p>Participants want personal health information to be shared with them so they can track their health and feel empowered to make appropriate health decisions for themselves</p>

FIGURE 2 Joint display to provide a visualization of the integration of qualitative and quantitative data.

lower education, and SES). Regardless of race, most expressed interest in participating in AD biomarker research, which is consistent with prior research in samples of mostly White, non-Hispanic participants and those who were already enrolled in AD research.⁶ This points to opportunity to further engage these groups and highlights that a clear first step in inclusion is to simply invite individuals, regardless of their demographics, to participate.

Although most Black and White participants indicated interest in AD biomarker research, Black participants expressed comparably more hesitancy. Prior work has suggested that differences in trust and AD knowledge underlie race differences in willingness to participate in research.^{14,32,38} However, our findings persisted after accounting for trust and perceived knowledge, suggesting additional factors in race-based differences in participation hesitancy.

Race is a social construct representing ancestry and an accumulation of experiences. Racialization shapes the way that institutions interact with patients and vice versa. Several Black participants discussed how misconceptions about research due to past historical trauma and structural racism contribute to hesitancy. Systems of social oppression that create unequal access to education, healthy living

conditions, and quality health care influence Black adults' attitudes toward, knowledge of, and experience with biomedical research.²⁴ In their narratives, participants specifically called for researchers to address past traumas and increase attention to Black participants' basic needs, including better access to health care to facilitate trust and capacity for research participation.

Our results suggest research barriers that are the result of not meeting basic needs may be particularly important to address when recruiting individuals from low SES and education backgrounds. Although a single research team cannot address a system of social inequity, research teams can work with local organizations to address community needs. Furthermore, educating the research team about these disparities and preparing those doing community outreach to have these conversations with potential participants is advised. At minimum, researchers should work to ensure that there is little to no financial or resource burden on individuals for research participation. For example, our survey results show a desire for transportation assistance. Responses from interviewees, however, suggest that this is a desire from a reimbursement/burden reduction perspective rather than an incentive.³⁹ Providing assistance such as gas or grocery cards,

TABLE 5 Recommendations for recruitment strategies to increase Black older adults' participation in AD biomarker research

Stage	Goal	Recommendations
Outreach/Engagement	Establish relationships with community organizations	Connect with local community centers, gathering places, and organizations to establish strong relationships prior to attempts to recruit individuals for studies.
	Establish relationships with primary care offices	Connect with primary care providers in predominantly Black communities to facilitate "buy in" about the importance of inclusion in AD biomarker research
	Establish presence in community through outreach	<p>Establish recurring education and informational workshops through local organizations/institutions.</p> <p>Reach out to high schools and colleges in the area to provide education and informational workshops.</p> <p>Solicit feedback from community members about preferred topics to ensure they are meeting the community's needs.</p> <p>Partner with community leaders (i.e., trusted sources) to provide this information (with training) and include key research personnel so communities can begin to establish relationships with researchers.</p>
	Increase awareness of AD (and reduce stigma), research processes and procedures, and brain health	<p>During community talks focus on:</p> <p>(1) information about brain health and prevention (e.g., healthy lifestyle choices), early warning signs and risk of AD (especially in the Black community), and symptom management and resources for where to find help if a loved one is experiencing symptoms of AD.</p> <p>(2) the research process including goals of research, how information is shared and confidentiality, who conducts these procedures, rights as a research participant, types of studies (e.g., clinical trials vs observational studies), and specific types of procedures (especially MRI, PET)</p> <p>Address historical treatment of Black individuals in research and help dispel myths about research participation (e.g., being "guinea pigs"), discuss right to withdraw at any point to emphasize participants' rights and autonomy.</p>
Recruitment	Recruitment from the community via outreach	<p>Leave pamphlets at PCP offices with whom pre-existing relationships exist (see above)</p> <p>Ask these PCPs to discuss research opportunities their patients who have cognitive impairment (and provide referral), regardless of demographics</p> <p>Consider media ad campaign (e.g., TV, radio)</p> <p>Continue all activities listed under "pre-recruitment" and discuss current research opportunities at outreach events</p>
	Minimize cost to participants	<p>Provide transportation vouchers and assistance, gas cards, grocery cards, childcare options, etc., to minimize cost to the participant (researchers could consider developing a scale of need for their participants that provides different levels of assistance to cover the incidental and often unrecognized cost of research participation).</p> <p>For longer study visits, provide food.</p>
	Provide appropriate incentives	<p>Magnitude of incentives should reflect the time and effort participants commit to the study</p> <p>Return of clinically actionable results, normal or abnormal, especially brain scans and memory testing</p> <p>Provide clinically actionable results quickly (e.g., end of a multi-day visit) in both a face-to-face discussion and as a written summary (hard copy, mailed). Results should be in plain language that participants can understand and should be delivered by someone who is knowledgeable and can answer questions.</p> <p>Consider providing clinically actionable results to participants' clinical providers if desired by the participant</p> <p>Include general brain health information and personalized brain health "plans" based on results from testing.</p>
	Establish trusted relationships with knowledgeable study staff	<p>Consider including one individual from the study staff with whom a participant will interact over the course of the study (i.e., a "point person"). This is a person who is involved in initial recruitment, and who will then follow the participant throughout the course of the study (ie, someone the participant can contact at any point to discuss questions or concerns, and who will be present at all their appointments).</p>
Retention/Continued Engagement	Continuing community involvement, relationships with PCPs, and raising awareness of AD and brain health in the community	<p>Maintaining relationships with the Black community to help demonstrate that there is a reciprocal relationship between community and researchers and that researchers are invested in the community's health and well-being. The goal being to help the community develop trust in researchers, assist in dispelling myths about goals of research, and continue efforts to destigmatize AD diagnosis (and potentially encourage people to go see their doctors sooner when there are concerns).</p>

transportation, and child care may help minimize the cost of research participation. Researchers could consider developing a scale of need that provides different levels of assistance to cover the incidental and often unrecognized cost of research participation.

Reasons for hesitancy are complex but understanding them is essential for inclusion and representation in AD research. Barriers specifically to *biomarker* research is especially important for addressing equitable application of early detection models and precision medicine.^{11,15,17,40} Our findings show that lack of information was the largest and most consistently endorsed barrier across groups. Black participants, specifically, explained that they were hesitant to participate in AD biomarker procedures such as brain MRI and PET scans because they lacked information about the study procedures and were concerned about risk. These findings corroborate previous work highlighting the importance of appropriate information dissemination^{3,19,41,42} and provide additional key insights that could facilitate greater reach to potential Black participants. In Table 5 we outline recommendations for outreach and recruitment strategies based on these insights and highlight a few key recommendations below.

First, Black participants desire AD information from trusted sources such as their PCPs. Partnerships between PCPs and researchers could, therefore, help connect patients to AD information and research opportunities. Second, AD education should be paired with research education as many participants expressed hesitancy due to lack of knowledge and concerns about the research process (e.g., biomarker procedures, use of information, level of risk, personnel conducting procedures). Finally, participants expressed a need for community infrastructure, with researchers partnering with (trained) community leaders to provide AD education. Participants expressed a need to build relationships with the researchers themselves, suggesting that key research personnel should be present at community events.

Facilitators were also largely driven by a desire for education and information, particularly clinically actionable test results, which were strongly associated with willingness to participate in AD biomarker research. Although some have suggested returning results can cause harm,^{15,16,43-47} others show it helps build transparency and trust between researchers and participants from underrepresented groups.^{17,47} Views from our Black interviewees were strongly in line with the latter. They expressed that obtaining results—in written and oral formats—would empower them in decision-making about their health care. Results should be shared by a knowledgeable provider as soon as possible (e.g., at the end of a multi-day visit). For guidelines on ethical return of results see the National Academy of Sciences guidelines⁴⁸ and Grill and Karlawish.⁴⁹

4.1 | Strengths and Limitations

Major strengths of our study include the mixed-methods design and size and the diversity of participants who have been traditionally underrepresented in AD biomarker research but who are at higher

risk of AD, including Black men and those with lower SES and education backgrounds. Furthermore, the perspectives captured in this study are from individuals who have never participated in AD biomarker research. Our findings are relatively consistent with the prior literature with research-aware participants. However, the perspectives of research-naïve individuals from these under-represented groups are essential to ensuring representation in understanding barriers and facilitators to AD biomarker research.

Our findings are not necessarily generalizable as we restricted our survey population to older adults residing in the Indianapolis metropolitan area. Future studies should include urban and rural populations of different geographical areas. Additional work is needed to understand how different sociocultural and geographical contexts may influence views of AD research participation. Results likely reflect the perspectives of individuals who were highly motivated to complete the survey (i.e., selection bias) as we did not rely on random sampling. Finally, we did not correct for multiple comparisons due to the exploratory nature of the study.

5 | CONCLUSION

In summary, our study showed that most research-naïve individuals want to participate in AD biomarker research. However, the research community needs to improve information sharing and raising awareness, increase their presence in the communities of underrepresented groups, reduce incidental costs, and provide valuable personal health information to participants to increase interest. Future studies will assess the implementation of evidence-based, socioculturally sensitive recruitment strategies to increase enrollment of Black older adults into AD biomarker studies.

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CONFLICTS OF INTEREST

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CONSENT STATEMENT

All human subjects provided written informed consent.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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