

RESEARCH ARTICLE

# Factors influencing the participation of Black and White Americans in Alzheimer's disease biomarker research

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## Abstract

**Introduction:** Alzheimer's disease (AD) is a public health priority. AD biomarkers may vary based on race, but the recruitment of diverse participants has been challenging.

**Methods:** Three groups of Black and White participants with and without prior research advocacy or participation were interviewed individually or in focus groups to better understand perspectives related to AD biomarker research participation. A rapid qualitative data analytic approach was used to analyze the data.

**Results:** Identified barriers to AD biomarker research participation included hesitancy due to fear, distrust of research and researchers, lack of relevant knowledge, and lack of research test results disclosure. Drivers for engagement in biomarker research procedures included knowledge about research, AD, and related clinical procedures, perceived benefits of participation, and outreach from trusted sources.

**Discussion:** Participants' comments related to the need for diversity in research and desire for results disclosure suggest opportunities to engage Black individuals.

## KEYWORDS

AD biomarker, health disparity, qualitative research methods, racial diversity, research participation

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### Highlights

- Black Americans experience more salient barriers to Alzheimer's disease (AD) biomarker research participation.
- Concerns about research diversity influence research participation decisions.
- Research test disclosure may affect research participation and retention.

## 1 | BACKGROUND

More than 6 million Americans are diagnosed with Alzheimer's disease (AD), and this number is expected to increase to 12.7 million by 2050.<sup>1</sup> Given the high prevalence of AD and its associated financial, health, and societal impacts, research to reduce the disease burden of AD is a public health priority. The use of AD biomarkers (e.g., amyloid and tau cerebrospinal fluid [CSF] and imaging studies) to facilitate early detection and improved treatment of AD is currently a high-priority research area. However, identification and interpretation of AD biomarkers are complicated by research findings, indicating that they may vary based on race.<sup>2,3</sup> For example, several studies have suggested that Black individuals may need different biomarker diagnostic thresholds because of lower CSF tau levels<sup>4-6</sup> compared to White individuals. Other studies showed that the apolipoprotein E (APOE) gene seems to confer less AD risk among people of African ancestry relative to White individuals,<sup>2,3</sup> suggesting a different AD disease process in this group.

Racial diversity among AD research participants is, therefore, essential to fully understand the role of biomarkers in AD and to ensure the generalizability of AD studies. Such diversity is also important to reduce the disease burden for Black Americans, who are disproportionately impacted by AD, with a prevalence of AD or other dementias roughly double that of White Americans.<sup>7,8</sup> However, recruitment of Black Americans for AD research studies has been a persistent challenge.<sup>9</sup> Only 2.4% of participants in randomized controlled trials targeting cognitive function identified as Black.<sup>10</sup> Yet they have been found to be as willing to participate in research as White individuals.<sup>11</sup>

Several factors have been identified to explain the low study participation rate among Black Americans. These include fear and mistrust of research based on a legacy of research misconduct, scientific exploitation, and racism.<sup>12-14</sup> Other barriers include inequalities in health care systems and clinical trial designs that create financial, social, medical, and cultural barriers to research engagement.<sup>15-18</sup>

Barriers and facilitators specific to AD biomarker research participation are, however, not well understood. Few studies have examined the views on AD biomarker research participation among racially diverse groups.<sup>19,20</sup> Biomarker research may involve additional barriers to participation given that it requires sharing of biological samples and undergoing relatively burdensome procedures such as a lumbar puncture. Prior research has suggested that Black participants are under-represented in drug trials and brain donation

studies due to mistrust and concerns related to "mutilation or disfigurement of the body."<sup>21</sup> It is possible that these concerns also may apply to blood or CSF biomarker studies. With growing recognition of racial disparity in research participation and increased use of biomarkers in AD research, researchers are encouraged to take on a more active role in engaging racially diverse participants in research.<sup>22</sup> In this study, we sought to examine participants' perceived barriers to study participation and drivers of engagement in AD biomarker research, using semi-structured interviews, while seeking to identify differences between Black and White participants.

## 2 | METHODS

### 2.1 | Setting and participants

This study was conducted in a midwestern city. Three groups of participants were invited to participate: Group 1: members of the Alzheimer's Disease Research Center (ADRC)'s Community Advisory Board (CAB). The CAB includes community members, patients, and caregivers who support ADRC research; Group 2: community members and veterans from the local Veterans Affairs (VA) Medical Center with no prior experience in AD research; and Group 3: ADRC research participants with normal cognition. Eligible participants identified as White or Black, were 55 years or older, and lived in the ADRC's catchment area.

### 2.2 | Recruitment and data collection

Participants were recruited either by direct outreach via e-mail, followed by a phone call, or with snow-balling techniques,<sup>23</sup> that is, asking enrolled participants to refer potentially eligible participants. Data were collected from January to March 2021. We conducted two, 90-minute focus groups with CAB members; other study participants engaged in 45- to 60-minute semi-structured individual interviews. We used the framework of the Theory of Planned Behavior to develop our interview guide, which explored perceptions of AD research and assessed both drivers for engagement and barriers to participation in AD biomarker research studies.<sup>24</sup> The interview guide was reviewed by two CAB members who did not participate in the focus groups. The first author (J.E.), who identifies as a Black female, facilitated the focus group discussions, whereas the study coordinator (C.O.), who is

a White female, and two trained research assistants (one White and one Black, both female) in addition to J.E. conducted the individual interviews. Participants were compensated for their time and provided verbal consent prior to study participation. This study was approved by the university institutional review board and the VA Medical Center Research and Development Review Committee.

### 2.2.1 | Data analysis

Audio recordings of the focus groups and interviews were transcribed verbatim and reviewed for accuracy. A team of four analysts (J.E., C.O., and two research assistants) analyzed the data using a rapid data analysis approach, which involved summarizing the interview data into matrix summaries based on the interview guide and research questions.<sup>25,26</sup> Rapid data analysis is a rigorous, applied qualitative research method that facilitates the analysis of targeted qualitative data on a shorter timeline.<sup>27</sup> In this study, which was a 1-year pilot project, it facilitated timely and comparative analysis of various groups of participants, and the identification of key barriers and drivers to participants' engagement in AD biomarker research. We pilot tested the template with three transcripts and used team feedback to finalize it. Then we generated a summary for each transcript, which included a brief synthesis of participants' answers, as well as indications of their sex, race, and type of participant (e.g., CAB, community, or veteran) to complete the matrix (see [Appendix A](#)). To ensure analytical rigor and trustworthiness, the team reviewed and discussed the content and summary of each transcript, resolving inconsistencies by consensus. We also established strategies such as peer debriefing meetings, facilitated by K.A.C., who was not involved in the data collection and matrix development, and audit trails, performed by the project manager (C.O.) and the first author (J.E.) to maintain consistency in our coding.<sup>28</sup> The analytical team consolidated the interview summaries by domains, participant types (e.g., CAB, existing research participants), and races (White, Black) to identify commonly occurring themes and to allow comparisons by race. We then identified broad themes and categories derived from the domains and conducted inductive thematic analysis<sup>29</sup> within each category. The larger team reviewed the summaries for each category and collaboratively identified new themes until we reached data saturation.<sup>30</sup>

## 3 | RESULTS

### 3.1 | Participants

The study included 32 participants: 7 CAB members, 5 veterans, 10 ADRC participants, and 11 community members. As shown in [Table 1](#), among the community and ADRC participants, 15 were female (57.7%), all were non-Hispanic, and 15 (57.7%) self-identified as Black or African American. Forty-two percent (41.7%) were 60- to 69-years-old. Most (68.2%) had completed at least a 4-year college degree. We did not collect demographic data other than race from ADRC CAB members.

### RESEARCH IN CONTEXT

- 1. Systematic Review:** The authors reviewed the current literature using PubMed and other search engines. Prior research investigated barriers to minority group research participation and examples of successful outreach efforts exist. Less is known about the perceptions and implications of Alzheimer's disease (AD) biomarker research participation specifically, with much of what exists focused primarily on apolipoprotein E (APOE) genotyping.
- 2. Interpretation:** Our findings add to a growing consensus regarding barriers to research participation in Black Americans and suggests possible opportunities to better connect with this community. One promising strategy could be increased disclosure of results to facilitate trust and research participation.
- 3. Future Directions:** The under-representation of Black Americans in AD research threatens to exacerbate existing health disparities. Future studies should improve understanding of relevant sociocultural factors and work toward the implementation of targeted strategies to meet the needs of diverse groups and demonstrate congruence of AD biomarker research participation with participant values and culture.

Overall, participants identified four key barriers to AD biomarker research participation: (1) hesitancy due to fear; (2) hesitancy due to distrust of research and researchers; (3) lack of knowledge about research, AD, and related clinical procedures; and (4) lack of disclosure of research test results. In turn, drivers for engagement in biomarker research procedures included (1) knowledge of research, AD, and related clinical procedures; (2) perceived benefits to individuals and community; and (3) outreach from trusted sources. Below we expand on each of these themes. For parsimony and clarity, we noted differences identified across participant groups and based on race, where applicable.

### 3.2 | Barriers to AD biomarker research participation

#### 3.2.1 | Hesitancy due to fear

Hesitancy due to fear was the most frequently reported barrier to AD biomarker research across all participant groups. Identified fears included fear of the unknown about research and fear of a potential AD diagnosis, as illustrated by the following quote from a White female participant (205): *"I think it would be scary knowing for sure if I have the markers ... You know, if I can't find my car keys, then I'll be sure that it's beginning."*

**TABLE 1** Participants' demographics

	Total (N = 26) n, %
Gender	
Male	11 (42.3%)
Female	15 (57.7%)
Age*	
55–59	4 (16.7%)
60–69	10 (41.7%)
70–79	8 (33.3%)
80+	2 (8.3%)
Race	
White	10 (38.5%)
Black	15 (57.7%)
Multi	1 (3.8%)
Hispanic	0 (0%)
Non-Hispanic <sup>a</sup>	23 (100%)
Education <sup>a</sup>	
HS/GED <sup>b</sup>	2 (9.1%)
Some college/2 years	5 (22.7%)
4-year college degree	7 (31.8%)
>4 years college	8 (36.4%)
Veteran	6 (23.1%)
Non-Veteran	20 (76.9%)

<sup>a</sup>Has missing values.

<sup>b</sup>GED: General Education Development.

### 3.2.2 | Hesitancy due to distrust of research and researchers

Participants reported distrust in AD biomarker research, with variation in contributors to distrust noted based on race. Specifically, Black participants emphasized the *lack of research transparency* as a key barrier to AD research participation and maintained that detailed information should be shared with participants during the early phase of the study to demystify the research process and develop trust. Participants also reported distrust in research due to *data safety and confidentiality concerns*. They explained that data collected from AD biomarker studies, such as genetic information, are sensitive, reflecting that any breach of confidentiality would have significant social, health, and legal implications not only for them personally, but also for their families. For example, one Black male veteran shared: *"I wouldn't want to have the image done of my brain, and it being released to the insurance companies without my knowledge"* (403).

Both White and Black participants discussed how *racial bias and health care disparities* undermine trust in research. However, this theme was particularly salient in Black participants' interviews. Many drew upon historical cases as well as their lived experiences and news reports of racial bias in health care to inform their opinions about

AD biomarker research participation. As in the next excerpt, they questioned whether research can be truly benevolent toward communities of color and underscored the *"hurt"*—the emotional aftermath of racial bias and resulting stigma that undermine community support for research.

*There is a hurt and a stigma in the Black community. They were guinea pigs for research. And that has come through generations of Black people, those stories are told through our community.* – Black female participant (311).

### 3.2.3 | Lack of knowledge about research, Alzheimer's disease, and related clinical procedures

Both Black and White participants reported that limited knowledge about research and its value is a key barrier to research participation. They noted that this lack of knowledge may lead to uninterest and apathy in the research enterprise. To illustrate, a Black female ADRC research participant stated: *"I would say a lack of education in that area (is a barrier) and that they [Black participants] probably don't feel like doing it is going to make a difference"* (209). Participants also discussed how limited knowledge about the AD biomarker clinical procedures, such as brain imaging and positron emission tomography (PET) scan, may deter potential participants from engaging in research. In addition, several stated that older adults often have medical conditions and are hesitant to undergo unnecessary procedures that may exacerbate those conditions or put them at additional health risks.

### 3.2.4 | Lack of research test results disclosure

For most ADRC participants, previous ADRC research experiences when they did not receive test results was viewed as a barrier to future research participation and study retention:

*I think any part of the study that you do, you ought to receive feedback because that's going to encourage people to continue ... when we go through those sessions, but we don't hear results back, that causes me to not want to do the extra because the reason I'm participating in this study is to help give you information. And part of that information I want to know myself personally. So, that's an important aspect.* – Black female ADRC participant (206)

CAB members and study participants with no prior research experience expressed similar views. Participants conveyed their perception that failure to receive test results, including normal results, can serve as a barrier to AD biomarker research participation: *"I think people need to be made aware of [test results]... [if] they're not going to know... that will make people hesitant."* – Black male CAB member (107)

### 3.3 | Common facilitators/motivators to AD biomarker research participation

Participants identified several drivers for engagement in AD biomarker research studies, which included knowledge of research, perceived benefits, and sources for research outreach. We elaborate on each driver below. Although we asked participants during the interviews about their perspectives on each biomarker study procedure, such as blood drawn for genetic testing, brain magnetic resonance imaging (MRI), PET scans, and lumbar puncture, their responses were consistent regardless of the type of study procedure.

#### 3.3.1 | Knowledge of research, Alzheimer's disease, and clinical procedures

Participants explained that prior experience with specific clinical procedures and/or research knowledge is a strong driver for future research participation. Many participants, across all groups and from diverse racial backgrounds, who expressed interest in participating in AD biomarker research reported prior positive research experiences, familiarity with the clinical procedures, and/or a health care background: *"I had a PET scan recently, of my abdomen. So, it would be the same experience. I would be willing to do that because I have tried it .... I can handle that."* – White Male Community participant (306)

#### 3.3.2 | Perceived benefits to individuals and community

Participants reported that perceived benefits from AD biomarker studies are drivers for their engagement in research. Specifically, they identified benefits at both the individual and community levels that contribute to their willingness to engage in research.

*Individual benefits* – Most Black and White participants reported having a family member or friend with a history of AD; this personal connection to AD appeared to be a significant motivator for research participation. This was most notable among ADRC participants. They expressed interest in AD biomarker research because of the potential of learning about their family history and health status, and gaining insights into how they can reduce their risks of developing AD.

My mother had early onset Alzheimer's. ... she was 57... [research participation] it's just important to me because I'm certainly not out of the woods, and none of my kids, and for anybody who, and their caregivers who might be affected, I just want to help in any way I can. ... *if my mother had not had this disease, I doubt that I would have even thought about volunteering.* – White Female ADRC participant (206)

*Community benefits* – Black and White participants, including those with no prior history of AD research participation, also reported

without probing that they are interested in research involvement because of their desire to increase research diversity. However, this theme was most salient among Black participants. Many Black participants cited well-documented disparities in research and health care. As exemplified in the excerpt below, they stated they want to do their part to ensure that AD research studies are generalizable and equitable.

Because people of color are consumers of medicine, we're going to need that [knowledge]. And if you've only tested something [on] a White male between the ages of 18 and 25, what does that mean for my mother or my grandmother, who didn't fit into that category? So, I've always felt very strongly about representation... that's the primary reason [for research participation]. – Black female ADRC participant (201)

Moving beyond discussions about disparities in research and individual research incentives, Black participants specifically emphasized the need of research projects to address how the studies benefit Black communities. They advocated for early engagement of community members to create buy-in for the studies and for researchers to share the "wealth"—as in knowledge and resources with Black communities to facilitate trust and meaningful engagement.

A lot of times we're not at the table... But if there is an understanding from the beginning all the way through, then I think you have more buy-in, you have people that are more committed to it. And then they can talk from a place of how important and valuable it is for a person to be involved in that research. – Black CAB Member

#### 3.3.3 | Outreach from trusted sources

Personal outreach from trusted sources was identified as a major driver for engagement across all study groups. Participants underscored that learning about AD biomarker research studies from individuals with lived experiences as research participants would be most helpful. Black participants further emphasized the need for research team members to reflect the sociocultural and racial backgrounds of their participants to facilitate trust. Some specifically discussed the need for the entire team, including investigators, to reflect the diversity of the community and maintained that researchers must personally engage with potential participants to facilitate trust. A Black female CAB member explained:

There's no way that I think anyone would have surgery if you just talked to a nurse, to a secretary...and didn't meet that doctor. I don't know why in a research situation the research doctor doesn't think a person wants to talk to him or her. I want to talk to the person that's doing it on me. ... I need to eyeball you. I need to see if we can connect. If I can't connect with you in



conversation, I can't "allow you to experiment on my body."

## 4 | DISCUSSION

Our study identified hesitancy due to fear, distrust, and lack of knowledge about research as barriers to AD biomarker research participation. These findings are consistent with previous reports of barriers to AD biomarker research among racially diverse groups.<sup>19,20</sup> For example, Williams et al.<sup>20</sup> wrote more than a decade ago about how mistrust in and limited knowledge of research were fundamental reasons for nonparticipation in AD biomarker research among Black Americans. Many of these barriers such as lack of knowledge of AD are modifiable factors. Yet, they continue to persist. A recent Alzheimer's Association study reported that 62% of Black Americans believe that medical research is biased against people of color.<sup>1</sup> Together, these findings point to the continuing need for more effective recruitment and outreach strategies and better implementation of evidence-based engagement methods. Intentional and sustained efforts to engage research participants also may help to address barriers related to confidentiality, transparency, and trust in research.

Our findings also highlight participants' discussion about the disclosure of AD biomarker test results as a tool for research recruitment and engagement. Most participants, across all participant groups, identified non-disclosure of both normal and abnormal results as a significant barrier to research participation and stated their belief that sharing of the results may drive engagement in AD biomarker studies. These findings are noteworthy for several reasons. Previous studies on disclosure of genetic risks in research studies have focused almost exclusively on White participants.<sup>31,32</sup> Our findings add the perspectives of Black participants to this important discussion. Our findings also show that disclosure of research test results is a critical issue that may impact active participants' retention and participation in future studies.

Moreover, research centers vary widely in their practice of the disclosure of AD research test results to study participants, with biomarker data less commonly disclosed than cognitive test results.<sup>33</sup> Researchers have raised concerns regarding the potential psychological impact of disclosure, particularly for those receiving news of increased AD risk in the absence of a broadly available disease-modifying treatment. However, some studies also suggest that the risk of psychological harm is relatively low, especially with the provision of genetic counseling,<sup>29,30,32,33</sup> and efforts are underway to optimize disclosure protocols for dementia risks to research participants.<sup>34</sup> Although our findings indicate some support for sharing research test results with study participants, they also point to emerging views about the type of data participants want disclosed, such as both normal and abnormal results as well as non-genetic test results. Disclosure of test results with research participants undoubtedly raises ethical, financial, and procedural concerns for research institutions. However, as our findings indicate, it may also create opportunities for meaningful engagement with underserved communities and opportunities for community-wide health promotion.

Furthermore, our findings expand on discussions of health disparities as barriers to AD research participation. They showed that ongoing reports of health care disparities and personal, lived experiences of racial bias in medicine influence participants' perspectives of research participation. An implication of this finding is that research engagement efforts must address not only the historical legacies of racial discrimination in research but also individuals' present and personal experiences of racial bias in health care services.

Outreach from a trusted source was also reported as a motivator for engagement. Specifically, participants expressed wishes to engage with principal investigators prior to consenting to a study, suggesting that such engagement would provide greater research transparency and could instill trust among participants. Moreover, they identified research participants themselves as a potential powerful source for engagement given their lived experiences with AD biomarker research. Adapting a peer support<sup>35,36</sup> or peer navigator<sup>37-41</sup> model that involves hiring individuals with lived research experiences to facilitate research outreach, education, and engagement in AD biomarker is a strategy to address these suggestions.

Several limitations should be considered in interpreting the results of this study. This study included mostly participants with high educational attainment, from one midwestern city. As such, responses may not represent the full range of perspectives of patients eligible for biomarker studies. The use of three distinct participant groups sought to capture a varied sample, but the perspectives obtained on research participation carry some inherent bias because these voices represent a group agreeable to at least a low-risk form of research engagement. In addition, participants' perspectives may not reflect their future behaviors. Other than race, demographic data were not collected from focus group participants to limit concerns about self-disclosure that might have interfered with engagement during the group interview. Despite these limitations, the study offers several contributions and incorporates various strengths such as the inclusion of diverse participant groups with and without previous research experience. Building on our findings, future studies should further assess the sociocultural factors that may impact the views of diverse groups of AD biomarker research participation. Development and testing of targeted strategies to meet the needs of diverse groups, and to address their specific barriers to AD biomarker research participation are warranted.

In summary, as with medical decision-making, personal decisions about research participation often hinge on a perceived risk-benefit analysis. Our findings illustrate how one's individual experience may influence the identified risks and benefits of AD biomarker participation. Culturally attuned engagement strategies may amplify those perceived benefits and diminish the perceived risks by building knowledge and bridging the barriers that separate the research community from potential participants.

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### CONFLICT OF INTEREST

None of the investigators has a conflict of interest. Dr. Wang receives book royalties from the American Psychiatric Publishing Inc (APPI) and Data Safety and Management Board (DSMB) consultant fees (total less than \$2000/year). Dr. Saykin receives support from Avid Radiopharmaceuticals, a subsidiary of Eli Lilly (in kind contribution of PET tracer precursor); Bayer Oncology (Scientific Advisory Board); Eisai (Scientific Advisory Board); Siemens Medical Solutions USA, Inc. (Dementia Advisory Board); Springer-Nature Publishing (Editorial Office Support as Editor-in-Chief, *Brain Imaging and Behavior*). Dr. Cameron receives consultant fees from EPI-Q, Inc. Author disclosures are available in the [supporting information](#).

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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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