

## RESEARCH ARTICLE

## Leveraging African American family connectors for Alzheimer's disease genomic studies

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**Abstract**

**Introduction:** The underrepresentation of African Americans (AAs) in Alzheimer's disease (AD) research may limit potential benefits from translational applications. This article describes an approach to recruit AA families into an AD genomic study and characteristics of seeds (family connectors) used to overcome recruitment barriers of AA families into AD research.

**Methods:** A four-step outreach and snowball sampling approach relying on family connectors was used to recruit AA families. Descriptive statistics of a profile survey were gathered to understand the demographic and health characteristics of family connectors.

**Results:** Twenty-five AA families (117 participants) were enrolled in the study via family connectors. Most family connectors self-identified as female (88%), were 60 years of age or older (76%), and attained post-secondary education (77%).

**Discussion:** Community-engaged strategies were essential to recruit AA families. Relationships between study coordinators and family connectors build trust early in the research process among AA families.

**KEYWORDS**

African Americans, Alzheimer's disease, family connectors, genomic studies, recruitment, snowball sampling

**HIGHLIGHTS**

- Community events were most effective for recruiting African American families.
- Family connectors were primarily female, in good health, and highly educated.
- Systematic efforts by researchers are necessary to "sell" a study to participants.

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## 1 | BACKGROUND

Although Alzheimer's disease (AD) occurs in all ethnic and racial groups in the United States (US), African Americans (AAs) are twice as likely as non-Hispanic Whites (NHWs) to have AD.<sup>1-5</sup> The discrepancy in the incidence and prevalence of AD between AAs and NHWs has been attributed to differences in modifiable risk factors, including medical conditions and life experiences.<sup>1,6</sup> Non-modifiable factors, including a family history of AD and genetic risk, increase the likelihood of AD in AAs,<sup>1</sup> extending beyond first-degree biological relatives.<sup>7</sup> Genetic studies have identified multiple genes and loci associated with an increased risk of developing AD.<sup>1,8-12</sup> For example, the apolipoprotein E (APOE)  $\epsilon$ 4 gene increases the risk of late-onset AD.<sup>1,13</sup> Rajan et al. found that a greater proportion of AAs inherited at least one APOE  $\epsilon$ 4 gene from their parents compared to NHWs.<sup>10</sup> Despite substantial advances in identifying genes that are involved in AD risk, the genetic influence on AD requires further study to move the field forward. To ensure that findings are generalizable across populations, genomic studies require the participation of ethnically and racially diverse individuals in which two or more family members have AD (multiplex families).<sup>14-16</sup> Given the complexity of an AD diagnosis and risk factors across populations,<sup>17</sup> in addition to the growing number of older adults from diverse populations in the US,<sup>18</sup> it is vital to assess the influence of genetics on AD in diverse populations.

AD genomic studies to date may have limited relevance to AAs given the disproportionately low numbers of AA participants.<sup>19,20</sup> Although some studies report that AAs have low rates of participation in research,<sup>19,21-24</sup> other studies report that AAs are willing to participate in research studies when appropriate community investments and assurances are provided.<sup>25-27</sup> Often, AA families are willing to engage in research with limited immediate benefits with the hope that future generations can benefit from their time, efforts, risk, and discomfort (i.e., spinal tap).<sup>28</sup> AAs are categorized as a "hard-to-sell" population but often have legitimate concerns, largely derived from mistrust associated with known historical and contemporary mistreatment and abuse in research and healthcare interactions.<sup>29</sup> Passive methods of recruitment based on assumptions that "if we build it, they will come" (e.g., flyers, posters, registries) that are typically effective in AD research with some populations have not yielded representative numbers of AAs in research. Studies that provide insight into strategies for improved recruitment among AAs may better equip investigators with knowledge to effectively recruit and retain AAs in AD genomic studies. An underutilized strategy for the recruitment of AAs is engagement using family connectors, who are key individuals who act as the point of contact for families and aid in the recruitment and enrollment process. The purpose of this article is to (1) describe a four-step outreach and snowball sampling approach to recruit AA families into an AD genomic study (Figure 1) and (2) describe the characteristics of seeds (family connectors) used to overcome recruitment barriers of AA families in AD genomic research at study sites in North Carolina (NC).

## RESEARCH IN CONTEXT

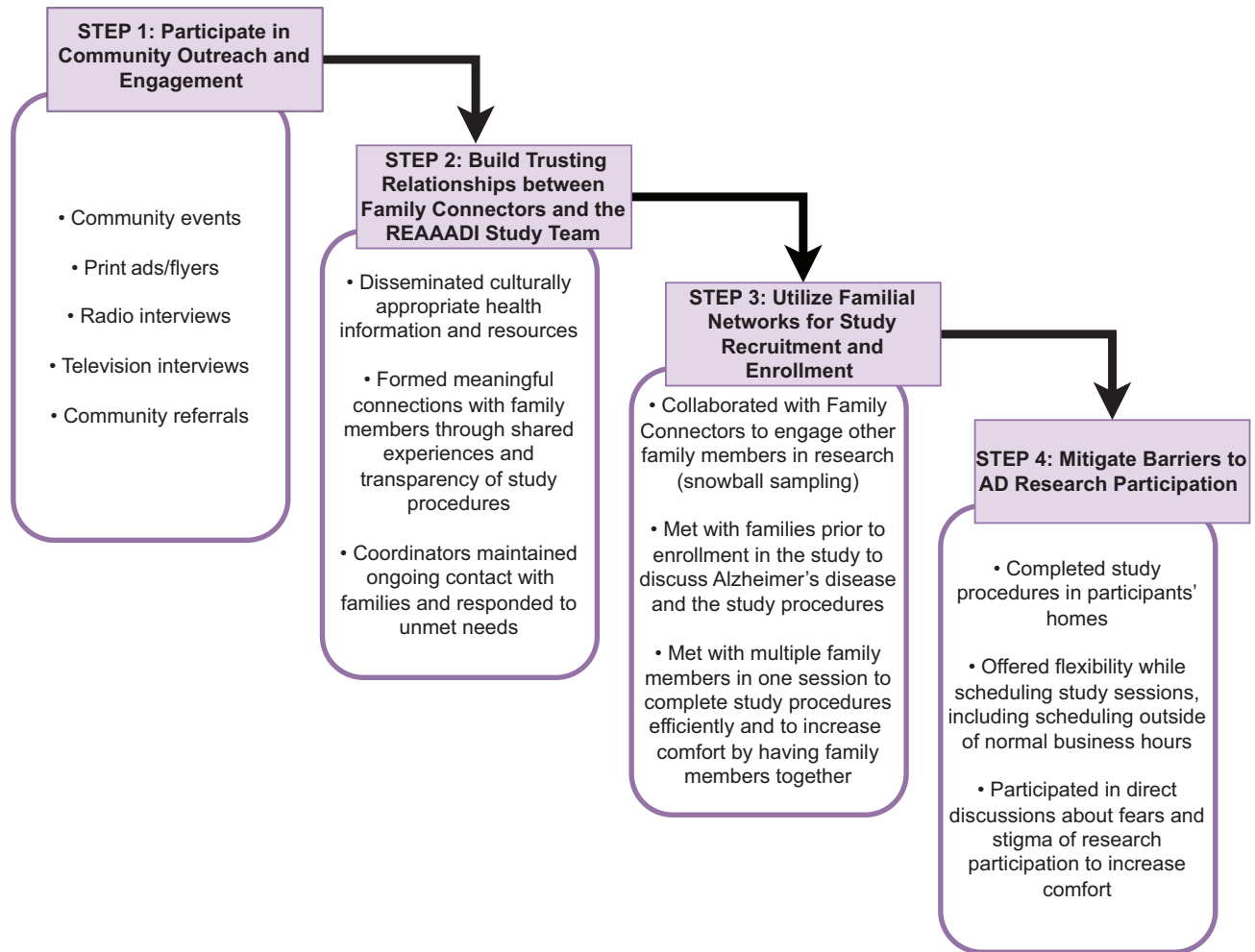
- 1. Systematic Review:** Multiple studies have identified low participation rates and barriers to participation among African Americans (AAs) in Alzheimer's disease (AD) research. However, few studies have focused on how to reduce challenges to recruit and enroll AA families into AD research.
- 2. Interpretation:** Our findings suggest that grassroots community engagement is essential to build rapport and trust through key contacts in families (i.e., family connectors). These contacts enabled our research team to successfully recruit and enroll multiplex AA families in an AD genomic study.
- 3. Future Directions:** Research that addresses the recruitment of AAs should include detailed information to help investigators meet recruitment goals and allow others to replicate successful recruitment strategies, including but not limited to community context for outreach, prospective tracking of intensity, exposure, and impact of recruitment activities, and evaluation of AA retention in AD research.

## 2 | METHODS

## 2.1 | Research in African American Alzheimer's Disease Initiative

The Research in African American Alzheimer's Disease Initiative (REAAADI), a substudy of the Alzheimer's Disease Sequencing Project (ADSP), was a multisite study bringing together investigators at NC Agricultural and Technical (A&T) State University, Wake Forest University School of Medicine, University of Miami, Columbia University, and Case Western Reserve University. REAAADI was designed to identify rare variant enriched genes and genetic pathways associated with AD among AAs. The project was approved by the institutional review boards at each respective collaborator's institution. This article will describe the recruitment methods and results for study sites in NC.

For the family-based ascertainment of REAAADI, interested participants were eligible if they were at least 50 years of age, identified as AA, and had at least two family members with concerns of memory or cognitive problems. All participants (or their legally authorized representative) provided written informed consent prior to enrollment. Standard study procedures consisted of blood sample collection via venipuncture or saliva collection and clinical data collection. The clinical protocol included medical and family history interviews as well as objective measures of cognitive abilities (e.g., assessments from the National Alzheimer's Coordinating Center's Uniform Data Set 2.0), assessment of functional abilities (e.g., dementia staging, activities



**FIGURE 1** Four-step outreach and snowball sampling approach

of daily living), and report of medical, behavioral, and other factors that could cause possible changes in cognition or behavior. The study procedures took approximately 2.5 to 3 hours to complete. Each participant received compensation in the form of a \$50 gift card. These data were summarized and reviewed by an adjudication panel consisting of study coordinators (hereinafter referred to as coordinators), a neurologist and a neuropsychologist who assigned clinical diagnoses based on standard criteria (probable or possible AD, mild cognitive impairment [MCI], Alzheimer's disease and related disorders [ADRD], unaffected, other) according to the National Institute of Neurological and Communicative Disorders and Stroke—ADRD Association criteria.<sup>30</sup>

## 2.2 | Family connectors

Family connectors were trusted individuals within a family who served as a point of contact, supported the recruitment process, and were essential for the ascertainment of AA families. It should be noted that family connectors did not have to meet the eligibility requirements of the study. These family connectors expressed support for

the research project and engaged with coordinators to gather study related information that was subsequently disseminated to eligible family members. The interactions between the coordinators and family connectors served to increase awareness of AD and the contribution of genetic risks for AD as well as to explain the significant role of family participation in the study. Given their critical role in study recruitment and enrollment, a follow-up was initiated with family connectors to help the team better understand the sociodemographic background, health status, caregiver status, and family dynamics around AD in the family connector cohort. The NC REAAADI site developed a 25-item cross-sectional survey based on questions of interest and utilized feedback from community members to assess the acceptability, readability, and comprehensibility of the survey.

## 2.3 | Participation in community outreach and engagement (Step 1)

The family-based ascertainment for REAAADI benefited from its affiliation with the Center for Outreach in Alzheimer's Aging and Community Health (COAACH) at NC A&T State University. The center

**TABLE 1** Activities attended by the African American Alzheimer's Disease Initiative (REAAADI) team.

Activity	Description of activity
Alzheimer's disease (AD) student organization	University students led an organization that aimed to increase AD awareness and provide AD resources among peers.
AD gala and educational forum	An AD campaign educated and empowered more than two million Americans through arts and entertainment, multiple media outlets, and grassroots community-based efforts.
AD Saturday	In partnership with a university marching band, AD awareness was promoted by providing messaging at half-time during football games and AD educational resources for attendees at football games. The band dressed in purple, used purple flags, and wore purple lapels in recognition of AD.
Memory Sunday	AD awareness, the importance of early AD detection, and AD-related community resources were promoted in faith-based institutions. Pastors and congregations dressed in purple.
Book clubs	Community members read AD-related literature and participated in a group discussion with book authors.
Caregiver education conference	An annual AD caregiver conference was hosted to provide information on health, coping strategies, caregiving skills, and recent news related to AD.
Community seminars	Seminars were hosted to provide health education around aging-related health topics.
Health fairs	Health fairs were hosted and co-sponsored to promote health education around health disparities and disorders related to AD (e.g., diabetes, hypertension).
Listening parties	Listening parties were an innovative way to promote AD education and provide AD resources to friends and family members in a desired location.
Lunch and learn series/workshops	A series of workshops were developed during the lunch hour to provide training and education around aging-related topics.
Newsletter	Information was disseminated to community members to provide updates around the REAAADI study.
Non-COAACH community events	Study staff participated in AD caregiver conferences and community events statewide and nationally as presenters or exhibitors to promote AD health education and the REAAADI study.
Stakeholder meetings	Study staff met with community stakeholders to forge trusting relationships and serve as trusted resources throughout the Piedmont Triad area in NC.
State/national advocacy	Members of the REAAADI study team attended state and federal advocacy forums sponsored by the National Alzheimer's Association to inform legislature about the importance of having legislation that will support and assist caregivers and families with AD management, resources, and interventions.
Support groups	In partnership with the Alzheimer's Association, monthly caregiver support groups were hosted to provide education, emotional and social support, self-care practices, and problem-solving skills to caregivers.
Web and social media	Media platforms were utilized to engage intergenerational individuals around aging-related topics and the REAAADI study.

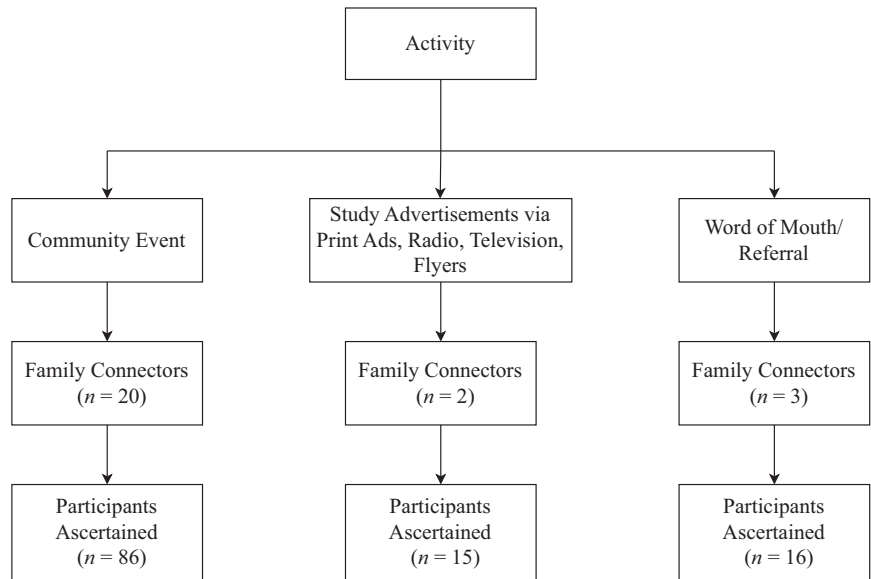
operates as the home for community-based outreach, education, and linkage to AD and caregiving resources for underserved communities in NC. Since opening in 2014, COAACH has served over 40% of the 100 NC counties. Prior to study recruitment, COAACH faculty and staff conducted an assessment of the needs of AA community members in six low-resourced counties in NC through survey instruments and focus group discussions. Briefly, findings indicated that caregivers of AD patients were experiencing stress and were burdened by multiple chronic diseases. Further, there was a deficiency in AD knowledge and a stigma around AD as well as a lack of available resources, such as transportation, medical services, and respite care. Informed by this robust community needs assessment for AD, COAACH developed and sustained programs to improve public understanding of AD, including (1) risk factors, (2) screening and diagnosis, (3) support for caregivers, and (4) the importance of patient and family engagement in research. From January 2017 to July 2019, the NC REAAADI team attended COAACH-sponsored outreach events and other community events in NC. Table 1 lists the outreach activities that REAAADI team members hosted and attended to promote the study.

## 2.4 | Build trusting relationships between family connectors and the REAAADI study team (Step 2)

The NC REAAADI site included a team of five research professionals, including the principal investigator (PI), coordinators, and public health educators, all of African ancestry. At outreach events, the team engaged with community members to provide information and answer questions about AD and other dementias, caregiving, and the REAAADI study. Using this time to authentically engage with community members provided opportunities to share relevant health information, forge meaningful connections, and recruit family connectors.

Potential family connectors who were eligible to participate in REAAADI or had an eligible family member for REAAADI completed interest forms at outreach events. Within 2 weeks of the event, team members contacted prospective family connectors. It was important for the team to be sensitive to time. Family connectors were called at times that were convenient for them, even if the time fell outside normal business hours. Flexibility in scheduling was equally important as

**FIGURE 2** Sources of Family connectors and participants enrolled from African American multiplex families.



family connectors were balancing other duties during the day such as work or childcare. During the initial phone call with family connectors, coordinators reviewed the study protocol and discussed the capacity of the family connectors to assemble family members for participation. To ensure continuity, coordinators were assigned to follow specific families throughout the study. This continuity was maintained for families even when coordinators from other study sites assisted with data collection.

## 2.5 | Utilize familial networks for study recruitment and enrollment (Step 3)

To recruit AA multiplex families, an adaptation of the snowball sampling recruitment technique was used. Traditionally, snowball sampling is a method of purposive sampling in which a research participant links an investigator to another potential participant for a study; the referred participant then joins the study and in turn links the investigator to another potential participant.<sup>31,32</sup> This process is repeated until the desired sample is achieved. Initial contacts, usually referred to as seeds in snowball sampling,<sup>33</sup> are referred to as family connectors in this study.

Most family connectors (80%) came to the REAAADI study via community events and were associated with the ascertainment of 86 of the 117 participants (Figure 2). Family connectors informed family members about REAAADI and encouraged participation. In addition, family connectors requested that the team engage with family members to further discuss the study. Another strategy organized by family connectors was to gather family members interested in participating in the study at one or more locations to facilitate discussion of the study or ascertainment. It was not uncommon for family connectors to host multiple family members in their own home for study engagement. For these events, coordinators met with participating family members during home visits to undergo study procedures. Once family mem-

bers became involved in the study, several took the initiative to serve as additional family connectors and provided linkage to other family members who would be willing to participate in the study, which created several layers of trust and opportunity for intergenerational ascertainment.

## 2.6 | Mitigate barriers to AD research participation (Step 4)

REAAADI leveraged lessons learned from studies that reported barriers for AA research participation.<sup>28,29,34–36</sup> To facilitate family enrollment, coordinators traveled to participant homes to complete study procedures, providing a private, familiar setting, as opposed to a medical setting. In addition, study procedures were completed at convenient times for participants, even if these times fell outside of traditional office hours.

The team was comfortable with conversing about AA-related content and culture, enabling team members to connect to the AA community through shared experiences. As per protocol, coordinators thoroughly explained the study, potential benefits and risks, costs, compensation, storage of records, blood sample management, how data would be used, and who would have access to the data. To build trust in the team and institution, coordinators provided a safe space for participants to engage in explicit discussions about fears of research participation. Additionally, coordinators addressed the stigma associated with research by increasing AD awareness among AAs through education and by encouraging family members to speak with the team and health care providers regarding concerns about changes in memory. Coordinators also linked families to AD support groups and workshops where they could openly discuss concerns and acquire tools to assist with caregiving duties. After the study procedure, participants were compensated for their time and participation. The team developed and sustained relationships with participants after study

participation ended through thank you notes, newsletters, and family conference calls.

### 3 | RESULTS

#### 3.1 | Community outreach

The NC REAAADI team leveraged more than 100 events to recruit AA families into this study. As noted earlier, the most effective recruitment events for participants were community events; 20 of the 25 (80%) family connectors recruited first learned about the study at a community event. The opportunity for face-to-face interactions at these events fostered interest in the study among family connectors.

#### 3.2 | Family connectors

Over a period of 2 years, family connectors facilitated the recruitment of 117 individuals from 25 families. As seen in Table 2, most of the family connectors identified as female (88%), and 76% were older than 60 years of age. In addition, family connectors were well educated as 80% had completed post-secondary education. Finally, 44% of family connectors reported an annual income greater than \$40,000, with most falling in the \$40,000–\$59,999 category (32%).

Table 3 shows the health and familial characteristics of family connectors. Among family connectors, 32% had a background in health science. The family connectors were in good health: 80% self-reported having good or excellent health. However, an equally high number of individuals (84%) reported concern for personal risk of developing AD. More than half of family connectors served as a primary caregiver for a family member with AD. In addition, 88% of family connectors reported having had a conversation about AD with family members. Only 20% of family connectors found discussions about AD difficult.

#### 3.3 | Multiplex African American families

To ascertain 25 multiplex AA families, coordinators traveled to 16 states and the District of Columbia (Figure 3) to complete 65 family visits (Supplement 1). Although coordinators connected with family connectors in NC, some family members resided in other states. Therefore, NC-based coordinators were not restricted to the enrollment of family members in NC only. In 10 families, the team was not able to ascertain both affected persons and an unaffected person in the study; additional eligible family members were not available to participate in the study due to age or mortality. Nonetheless, multiple relatives had been diagnosed with dementia in these families. Seventy-nine family members were female (43 affected cases; 36 unaffected controls), and 33 were male (21 affected cases; 12 unaffected controls). All families ( $n = 25$ ) had relatives affected by AD over 2 generations, and 6 families had multiple relatives affected by AD in a single generation. In the largest family recruited ( $n = 14$ ), AD-affected family members spanned 3 generations; one female affected by AD produced 8 children with AD and 4 grandchildren with AD.

**TABLE 2** Demographics of family connectors,  $n = 25$ .

Characteristics	Overall	
	<i>n</i>	(%)
Gender		
Female	22	(88%)
Male	3	(12%)
Race		
African American	24	(96%)
Mixed race	1	(4%)
Age (years)		
<40	1	(4%)
40–49	2	(8%)
50–59	3	(12%)
60–69	13	(52%)
>70	6	(24%)
Education		
Some high school	1	(4%)
High school diploma	0	(0%)
Associate's degree	1	(4%)
Bachelor's degree	10	(40%)
Master's degree	7	(28%)
Doctoral degree	2	(8%)
Other	4	(16%)
Annual income		
Below \$10,000	3	(12%)
\$10,000–\$19,999	3	(12%)
\$20,000–\$39,999	2	(8%)
\$40,000–\$59,999	8	(32%)
\$60,000–\$79,999	2	(8%)
>\$80,000	1	(4%)
No response	6	(24%)

Leveraging the support and hard work of family connectors was vital to recruiting participants and helping coordinators work more efficiently. Only one participant dropped out, yielding a 96% completion rate when family connectors were used. All families requested additional information about AD or wanted to know how to remain connected to the REAAADI team. Families followed up with the team to provide updates on loved ones, including progression to AD, deaths, and family interest in brain donation. Additionally, the team shared aggregated study findings with participants of the study through community forums, family meetings, and newsletters.

### 4 | DISCUSSION

Most AD genomic studies have been conducted among NHWs,<sup>6</sup> even though AAs have worse AD health outcomes and the greatest disease burden.<sup>37</sup> Understanding community-level investments that yield

**TABLE 3** Health and familial characteristics of family connectors, *n* = 25

Characteristics	Overall	
	<i>n</i>	(%)
Health science background		
Family connector	8	(32%)
Other family members	12	(48%)
Family connector current health		
Excellent	3	(12%)
Good	17	(68%)
Fair	2	(8%)
Poor	3	(12%)
Caregiver experience		
Yes	21	(84%)
Primary caregiver <sup>a</sup>		
Yes	14	(67%)
Concerned for personal risk for AD		
Yes	21	(84%)
Concern of AD risk influenced decision to get family involved <sup>b</sup>		
Yes	19	(90%)
Family connector with healthcare power of attorney	12	(48%)
Family discussion about AD		
Yes	22	(88%)
Rate the AD conversation with family <sup>c</sup>		
Extremely difficult	0	(0%)
Difficult	5	(20%)
Neither difficult nor easy	1	(4%)
Easy	8	(32%)
Very easy	8	(32%)

<sup>a</sup>The count and percentage were based on the 21 Family Connectors who reported having caregiver experience.

<sup>b</sup>The count and percentage were based on the 21 Family Connectors who expressed a concern for Alzheimer's disease risk.

<sup>c</sup>The count and percentage were based on the 22 Family Connectors who discussed Alzheimer's disease with their families.

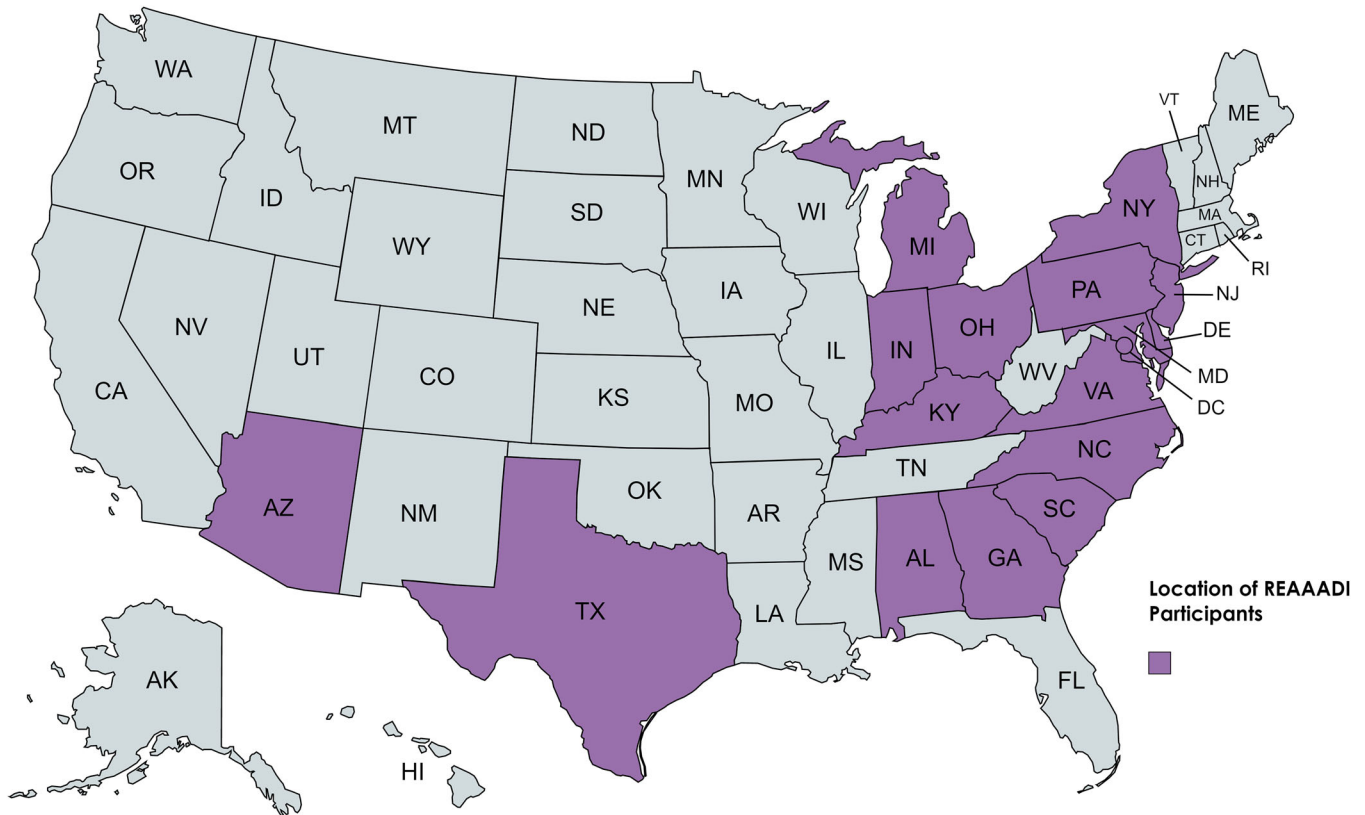
human capital that replaces misinformation with health literacy ultimately increases the enrollment and completion of AD studies among AAs. This process allows for increased external validity of AD studies toward the development of an ecologically valid biological framework of AD in all populations.<sup>6,38</sup> In this ongoing study, we successfully recruited and ascertained 25 multiplex AA families (117 AA participants) to participate in REAAADI using a four-step outreach and snowball sampling approach that relied on family connectors. This recruitment experience shows that building relationships with family connectors through culturally relevant community engagement can build family trust and remove research participation barriers to recruit and enroll multiplex AA families in AD genomic studies.

Establishing a physical presence in AA communities was important for recruiting AAs into this study. While study recruitment was not the primary reason for founding COAACH, the trust established between the center and the AA community enabled successful recruitment of family connectors during community events. These recruitment efforts were expanded through collaborations with university-affiliated organizations and community organizations. The grassroots community engagement allowed the team to reach families across communities, including participants from rural, urban, and socioeconomically disadvantaged geographic locations. The NC REAAADI team built trusting relationships upon the understanding of the AA community's social and historical structures for engagement.<sup>39</sup> The team provided education about AD, as well as the importance of research and clinical trial participation, which gave family connectors the opportunity to make informed decisions about study participation. While recruiting AAs for genomic studies has been challenging, implementing innovative, community-based, culturally relevant strategies in AA communities can increase AAs participation in AD research.<sup>26,29,37,40–46</sup>

The engagement of the family connector was essential to the recruitment and completion of the REAAADI study procedures among AA multiplex AD families. Family connectors were trusted individuals that had a positive rapport among family members. Building trust between the team, family connectors and other family members improved study completion to nearly 100%. Their influence on the recruitment of families was especially important for the recruitment of geographically dispersed family members. Specifically, family connectors aided coordinators in bringing family members together and linking coordinators to family members, including those who lived outside the state of NC. For these families, coordinators then traveled to these family members to complete the study procedures, increasing the enrollment of participants.

A key element in the use of family connectors was the trusting relationship established between the family connectors and the REAAADI team. This facilitated the initial encounters between the team and the family members. Further, as the team and other family members interacted, there was a corresponding building of trust, as reflected in the behaviors of the family members (e.g., ease of disclosing information). The willingness of multiple family members to participate in the study was noteworthy. The family's decision to participate in REAAADI was multifaceted and not made by a single family connector. The family connectors stated an interest in helping their families and other people.

Another benefit of family connectors and working with family members in one setting was that coordinators were able to obtain a comprehensive family medical history and progression of AD for affected family members. The development of a positive, family-friendly atmosphere was created where families were given a voice<sup>6</sup> and could tell their family's history in their own words. Through their participation in REAAADI, participants were able to honor their families' past and present. Family members felt that they were a part of something meaningful and important. AA communities see no value in so-called drive-by research<sup>29</sup>; they are interested in research that invests in the needs of their community. The research team is the face of this promise and must demonstrate it through their actions.



**FIGURE 3** Research in African American Alzheimer's Disease Initiative (REAAADI) recruitment areas

In addition to community engagement and trust building, it was vital for the team to remove barriers to research participation for AAs at individual, relationship, organizational, and community levels. At the individual level, the simplest barrier to overcome was increasing awareness of studies and asking for participation. The assumption should not be made that AAs are unwilling to participate in research as it is well established that AAs are enthusiastic about and willing to participate in research.<sup>25,26,41,47,48</sup> In addition, participants received compensation for their time to help offset the burden of research participation and were not required to travel to complete the study procedure. Rather, study team members traveled extensive distances, covering 16 US states and DC to meet participants in their homes. However, in some instances, given the trust that was built among the team, the family connector, and family members, some unaffected family members were willing to travel long distances to congregate with family members and complete study procedures. For example, one individual from the largest family enrolled in REAAADI drove 2 h to participate.

Community awareness, interpersonal skills, clinical skills, and racial composition of the NC REAAADI team also aided in the reduction of barriers at relationship, organizational, and community levels. This team was composed of persons of African ancestry at all levels, including the PI, coordinators, and supporting staff. Previous studies reported that racial and ethnic concordance between study personnel and the population of interest, in addition to maintaining the same staff over time, was beneficial when recruiting minority populations

for research participation.<sup>36,49</sup> Nonetheless, having a research team that looks like the population of interest is not sufficient. AAs are not monolithic. Differences within the population must also be considered, such as socioeconomic status, recency of immigration to the United States, health status, and life experiences. Investigators must be able to navigate differences within populations of interest and differences between investigators and the population of interest. Clearly, there is more to working with different populations than concordance of race between investigators and populations of interest, as suggested by Fryer et al.: "I think it certainly can open doors initially, but those doors will quickly close if as people sort of get to know you, if it's very clear that you don't have the genuine interest of the community at heart."<sup>49</sup>

The NC REAAADI team demonstrated authentic interest and investment in AA communities affected by AD through actions such as designing culturally relevant advertisements and educational materials (available in [Supplement 1](#) and [Supplement 2](#)), participating in health education activities, and providing presentations at community events, many of which were predominantly attended by AAs. At the same time, the team acquired knowledge about historical injustices in biomedical research, racism, implicit bias, and explicit bias. In meeting with families, the REAAADI team was open to discuss these injustices in a transparent way.

With respect to family connectors, this sample is small and may not be representative of the larger population of AAs who are burdened with AD. Family connectors were largely female, in good or excellent health, highly educated, and had a background in health science.

Furthermore, due to disease burden in the families, some participants were hopeful that their participation could help future generations. Despite the willingness of these families to participate in this study, challenges were encountered. While some family members were ready to engage in conversations around AD and the study, others expressed a lack of awareness or fear about the burden of disease in the family. Coordinators had to navigate different family dynamics, which at times were challenging, and learn to create relationships for cooperation. Further, the coordination of scheduling interviews, conducting several interviews within a small timeframe, managing intensive study procedures (including obtaining blood samples), and traveling to study interviews may require additional personnel to recruit larger numbers of families. These duties can become taxing on the study team. Moreover, appropriate funding is necessary to aid coordinators in traveling to various states to complete study procedures with participants. NC REAAADI coordinators traveled to 16 states and DC to acquire the participants enrolled in this study.

Family connectors served as liaisons between family members and coordinators to aid in the enrollment of AAs with varying demographics. Recruiting multiplex AA families in AD genomic studies is challenging but necessary to increase the generalizability of study results and guide the direction of new discoveries, interventions, and therapies for AAs. Grassroots community engagement and education, family trust, and removal of barriers to research participation are essential to recruiting multiplex AA families for genomic studies. Culturally relevant recruitment strategies that build trust between AAs in the community and investigators through increased investigator transparency and accountability should be developed early on in research study planning to “sell” the study to potential AA participants. Recruitment is a science; therefore, systemic efforts are necessary to increase AA participation in AD research.<sup>6</sup>

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## CONFLICT OF INTEREST STATEMENT

The authors have no conflicts of interest to declare. Author disclosures are available in the supporting information.

## CONSENT STATEMENT

All participants provided informed consent prior to participating in this study.

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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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