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## Perspective on the “African American Participation in Alzheimer Disease Research: Effective Strategies” Workshop, 2018

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## **Abstract**

The Washington University School of Medicine Knight Alzheimer Disease Research Center's "African American Participation in Alzheimer Disease Research: Effective Strategies" Workshop convened to address a major limitation of the ongoing scientific progress regarding Alzheimer disease and related dementias (ADRD): participants in most ADRD research programs overwhelmingly have been limited to non-Hispanic white persons, thus precluding knowledge as to how ADRD may be represented in non-white individuals. Factors that may contribute to successful recruitment and retention of African Americans into ADRD research were discussed and organized into actionable next steps as described within this report.

## I. Introduction

The Washington University School of Medicine Knight Alzheimer Disease Research Center's "African American Participation in Alzheimer Disease Research: Effective Strategies" Workshop (hereinafter Workshop) convened to address a major limitation of the ongoing scientific progress regarding Alzheimer disease and related dementias (ADRD): the cohorts in most ADRD research programs have been limited to non-Hispanic white persons. The failure to include minority populations in ADRD research prevents obtaining the data necessary to understand potential racial differences in ADRD and to address health disparities. Rather than attempting to consider factors related to ADRD research across all underrepresented groups, the Workshop focused exclusively on African Americans. The Workshop addressed the impact that African American underrepresentation in research has on the field of ADRD, including the lack of applicability and generalization of research outcomes to groups that were not part of the participant pools. Other results of underrepresentation include a lack of culturally relevant evidence-based practice and educational materials and the promotion of strategies that may not work for all groups. It is possible that the field does not currently have the correct biological framework for ADRD for all people since the framework was developed without representative inclusion of minorities. One example of how the lack of inclusive data might affect potential treatments for the disease is eligibility for clinical trials of investigational drugs. For Alzheimer disease (AD) clinical trials, increasingly there is the requirement of the presence of a molecular biomarker for AD. If the "cutoff" level for that biomarker is derived from data only from non-Hispanic white persons, the cutoff level may be inappropriate for individuals from other ethnic and racial groups.

The Workshop reviewed current strategies for the recruitment and retention of African American individuals in ADRD research with a goal of developing evidence-based strategies to improve African American research participation. Attended by representatives from all National Institute on Aging (NIA) funded Alzheimer Disease Centers (ADCs), the Workshop brought together leaders in the field of ADRD recruitment and research in minority populations to assess the current state of African American recruitment across Centers. Professionals external to the ADCs who worked in a variety of professions related to ADRD research and patient and family support, as well as community members with an interest in the topics presented also attended the Workshop. Workshop presentations underscored the under-representation of African Americans in ADRD research; reviewed known barriers for African Americans to join ADRD research; and provided examples of successful strategies and projects for increasing numbers of African Americans in ADRD research. This Workshop Perspective reviews relevant points from the Workshop to lay the groundwork for future advances in African American recruitment to ADRD research with information organized to address:

1. The current state of African American participation in ADRD research
2. Current information on potential disparities and racial differences between African Americans and non-Hispanic whites in ADRD
3. Levels for improvement of African American recruitment into ADRD studies

4. Improvement strategies for African American recruitment
5. Workshop Recommendations

## 1. The current state of African American Participation in ADRD Research

African Americans (this paper uses the term African American for consistency although different speakers and researchers used varying terminology) represent 13.4% of the United States population<sup>1</sup> but are underrepresented in research studies. A 2017 meta-analysis of both AD observational studies and clinical trials analyzed the results of 17 studies in which African American participation numbered only 376 (7.3%) of the over 5,100 total study population<sup>2</sup>. In addition to this low participation rate, the authors concluded that African Americans had a 60% greater chance of attrition compared to their white counterparts. An example is the international Phase 3 clinical trial of the anti-Alzheimer antibody to amyloid-beta, solanezumab, in which only 54 (2.6%) of 2052 participants were Black based on self-report.<sup>3</sup> Moreover, even when African Americans are well represented in research cohorts, they are less likely to participate in all ADRD protocols. Although 12.6% of participant assessments submitted to the National Alzheimer's Coordinating Center (NACC) uniform data set are from African Americans, African Americans represent only 3.6% of Alzheimer Disease Center (ADC) neuropathological cases submitted to NACC.<sup>4</sup>

The importance of including diverse populations in research is multifaceted and is connected to the increasing diversity of the United States population. By 2050, it is predicted that over 40% of older adults will be minorities.<sup>5</sup> Increased representation of minorities in research is consistently prioritized in plans and recommendations related to government funding of ADRD research. The United States Department of Health and Human Services advocates for an increase in "the availability, quality, and use of data to improve the health of minority populations".<sup>6</sup> The prioritized research milestones of the National Institutes of Health (NIH) Alzheimer's Disease and Related Dementias Summit 2016 include the comparison of Alzheimer "risk factors (genetic, vascular, behavioral, environmental, social) across diverse populations".<sup>7</sup> The 2019 NIH Alzheimer's Disease and Related Dementias Summit focused on the goal of resolving AD/ADRD health disparities by discovering culturally appropriate pathways to effective prevention and treatments.<sup>8</sup> The NIA ADC Panel Recommendations urge the inclusion of "sufficient numbers of underserved populations...to embrace the heterogeneity inherent in AD and related dementias".<sup>9</sup> The importance of racial inclusivity in ADRD research is paramount not simply to appease NIH guidelines, but also to promote generalizable results, advance the knowledge base, and create innovative treatments that benefit all.

Established ADRD investigators recognize that there are barriers to attenuating the underrepresentation of African Americans in ADRD research<sup>10-12</sup>. These barriers include mistrust of the medical community, stigma surrounding mental health, lack of transportation and time constraints. The challenges surrounding African American recruitment are not unique to ADRD research; other observational and clinical trials face the same struggles<sup>12,13</sup> demonstrating that these barriers impact medical research across various topics.

Ofstedal and Weir<sup>12</sup> analyzed the success of the Health and Retirement Study's (HRS) recruitment and retention strategies. Although the HRS has success in their efforts to recruit and retain African American especially in response rates to survey questions, the HRS has struggled to continue this trend in biomarker or supplemental study completion<sup>12</sup>. The authors found African Americans were less inclined to consent to the collection of physical measures such as saliva or blood sampling and body mass index or blood pressure collection. They were also less likely than whites to participate in additional supplemental surveys collecting variables such as medication, physical health or psychosocial information. During debriefing, these participants cited mistrust of research studies as the most common reason for declining.<sup>12</sup>

Many studies suggest that African Americans are at an increased risk of ADRD compared with non-Hispanic whites, although other studies report the opposite<sup>14</sup>, thus more research is needed to understand these discrepancies in the risk of African Americans for ADRD. Some data also suggest increased risk of ADRD for Native American/Native Alaskans, Pacific Islanders and Hispanic people compared with non-Hispanic whites, while Asian Americans may have the lowest rates of ADRD.<sup>15</sup> While some takeaways from the Workshop relate directly to increasing African American engagement in research, others are applicable to other underrepresented groups.

Despite the extensive research on barriers to African American recruitment, the ADCs (which represent the leading ADRD research network in the United States) lack any systemic effort to increase research participation by under-represented groups. As the ADCs "are at the nexus of fundamental mechanistic research, clinical trials, population health research, and health services research",<sup>9</sup> they should lead the way in achieving diverse clinical research cohorts. Increasing the continuity of the knowledgebase regarding barriers to recruitment, highlighting current strategies to overcome these barriers and addressing ways to move forward were the goals of the Workshop as well as the goals of this Perspective.

## **2. Current information on potential disparities and racial differences between African Americans and non-Hispanic Whites in ADRD**

While the terms disparities and racial differences are often used interchangeably, they are distinct. There is no consensus on when a difference between two groups becomes a disparity<sup>16</sup>. Disparity is used by some when a difference between groups is caused by an inequity or an injustice rather than being a simple inequality and often only after other factors that might contribute to that difference have been statistically adjusted.<sup>16</sup> Several research reports indicate African Americans are at higher risk of ADRD than non-Hispanic whites. However, a study using Kaiser Permanente data of disparities in dementia incidence in several groups found that African Americans have a 40% higher incidence of dementia than non-Hispanic whites, which is notable but more modest than previous reported studies,<sup>15</sup> but similar to a meta-analysis of prevalence data.<sup>17</sup> Further study with greater representation is warranted to define the amount of the difference and whether there are factors that make these differences disparities. Interestingly, there are age-as-leveler effects in which the surviving members of a disadvantaged group are people with resilient and

strong biological, environmental, psychological or social profiles, such that over time any disparities between the disadvantaged and other groups may get narrower.<sup>18</sup>

The three stages of health disparity research are to detect, understand, and then reduce the health disparities.<sup>19</sup> The National Institute on Minority Health Disparities defines a health disparity as “a health difference, on the basis of one or more health outcomes, that adversely affects disadvantaged populations.”<sup>20</sup> Poorer health outcomes for some groups are indicated by the overall rate of disease incidence, prevalence, morbidity, mortality, or survival in the population as compared with the general population.<sup>20</sup> Health disparities often relate to social determinants of health, such as social inequality, as much as (if not more than) biological differences. The Workshop highlighted a need for the field to examine whether the disparities in ADRD in African Americans compared with non-Hispanic whites are a product of biological differences between groups, social determinants of health, or a mixture of both. Based on the framework stages laid out above, the field must detect what disparities exist and why, in order to reduce the differences between groups and ensure that advances work for all groups.

Research presented at the Workshop highlighted the current work related to racial differences in ADRD between African Americans and Africans, as well as between African Americans and other racial groups in the United States. The Indianapolis-Ibadan Dementia Project compared 4104 elderly African Americans from Indianapolis with 4433 elderly Nigerians, specifically Yoruba living in the city of Ibadan.<sup>21</sup> The purpose of the study was to compare the rates of dementia and AD and the potential risk factors in countries in populations of African origin in different stages of development using identical procedures and harmonious instruments. Participants included in the project had up to seven longitudinal evaluations over 17 years.

A major finding of the study was that Nigerians had about half the rate of ADRD compared with African Americans.<sup>21</sup> The higher ADRD incidence in the African American cohort was associated with the prevalence of cardiovascular risk factors, including higher rates of hypertension, diabetes, stroke, and smoking, higher body mass index (BMI), increased systolic blood pressure, and higher cholesterol.<sup>22</sup> There was a decline in incidence rates over time of dementia in the African Americans that appeared to correspond with improved socioeconomic status and improved management of hypertension.<sup>23</sup> To the extent that the higher dementia incidence in the African Americans relates to cardiovascular risk factors and diabetes, it provides potential points for intervention.

The Indianapolis-Ibadan Dementia Project also looked at the effects of apolipoprotein (*APOE*)  $\epsilon 4$ , a well-established risk factor for late-onset AD, in the two groups.<sup>24</sup> There was a significant association between *APOE*  $\epsilon 4$  and dementia among Nigerians only when there was homozygosity (two copies of the  $\epsilon 4$  allele) but not when there was a single copy of *APOE*  $\epsilon 4$ .<sup>24</sup> In contrast, among African Americans, a single copy of the *APOE*  $\epsilon 4$  allele conferred increased risk for AD.<sup>24</sup> This difference in *APOE*  $\epsilon 4$  risk for these two populations is not understood. The greatest genetic diversity occurs in sub-Saharan Africa, which includes Nigeria. Thus, there may be unique variants in the Nigerian population that may affect protein function and gene expression, which may in turn interact with

environmental factors such as diet. It is noteworthy that the Yoruba diet has been described as low in calories and in lipids. Other studies indicate that *APOE ε4*, the most common AD susceptibility gene, has a smaller effect on African Americans than those of European descent.<sup>25</sup>

Other research indicated a proportion of African Americans present with an AD clinical phenotype but with CSF profiles distinct from non-Hispanic whites with regards to tau-related markers.<sup>26</sup> These findings were replicated in a larger study which enrolled a total of 1,255 participants age >45y, of whom 14% (N=173) were African American. The participants were assessed with at least one brain MRI, and/or positron emission tomography (PET) using Pittsburgh compound B (PET-PIB), and/or CSF assays for amyloid beta (Aβ)42, total tau, and phosphorylated tau181 (p-tau).<sup>27</sup> African Americans and non-Hispanic whites had similar levels of Aβ42 as measured by PET-PIB and CSF assays; however, African Americans had lower CSF total tau and p-tau than whites, regardless of clinical status.<sup>27</sup> Clinical status was measured by the Clinical Dementia Rating (CDR®)<sup>28</sup>, a 5-point scale used to characterize six domains of cognitive and functional performance applicable to ADRD: Memory, Orientation, Judgment & Problem Solving, Community Affairs, Home & Hobbies, and Personal Care with 0 representing normal cognition and greater than 0 representing impairment. The results of this study suggest that analyses of molecular biomarkers of AD should adjust for race. Although numbers were small, the lower CSF concentrations of total tau and p-tau in African American individuals may reflect a significant race by *APOE ε4* interaction, suggesting a differential effect of this Alzheimer risk variant in African American individuals compared with non-Hispanic white individuals.<sup>27</sup>

Other researchers examined contributors to ADRD disparities using a life course theory that considered social environment, income inequality, stress, nutrition, lifestyles, gene–environment interaction, public safety, and other factors as flexible pathways for determining health outcomes over time. Life course factors presented at the Workshop include differences in geography, educational experiences, and discrimination. Data from the Kaiser Permanente Northern California (KPNC) Health System cohort indicates increased risk of dementia for people born in states with an increased stroke risk compared to those born outside of these states, and this increased risk was greater for African Americans than non-Hispanic whites.<sup>29</sup> When studying how education might affect ADRD risk across racial lines, it is important to examine educational quality rather than rely solely on years of education, and how it varies by region and racial group.<sup>30,31</sup> African Americans who were educated in the South, even if they migrated to the North later, generally had less time in school.<sup>31</sup> Just looking at years of education is inaccurate because a school year in the South and North were not equivalent; school years in the South were shorter with less class time and this lesser educational duration was associated with later cognitive differences.<sup>31</sup>

Additionally, reading and literacy levels are powerful independent predictors of dementia risk.<sup>32</sup> When looking at racial disparities, literacy level was a stronger predictor of cognitive function than stroke, *APOE*, and years in school.<sup>31</sup> There is a decreasing trend of dementia incidence among African Americans that may relate to secular trends such as increased years of school and higher socioeconomic status in childhood.<sup>33</sup> Other research showed how



perceived stress and discrimination might affect ADRD across racial groups. Everyday discrimination over time causes heightened physiologic stress responses that may lead to a range of adverse health outcomes.<sup>34</sup> One study found that everyday discrimination was associated with shortened telomere length among older African American adults.<sup>35</sup> Telomere length can be a biomarker of cellular damage, which is associated with cognitive decline.<sup>36</sup> A strong case was made at the Workshop and more recently the imperative to incorporate social determinants of health in the examination of possible racial differences in ADRD was emphasized so that researchers can integrate these social determinants into the hypothesis generation and study design to improve the quality of the science.<sup>37</sup>

Brain MRI predictors of cognition differs across racial and ethnic groups.<sup>38</sup> A study of structural MRI differences and cognitive outcomes in African Americans, Hispanics, and non-Hispanic whites, found that white matter hyperintensities (WMH) are more prevalent in African Americans and Hispanics than in non-Hispanic whites.<sup>38</sup> WMH were associated with worse language and speed/executive function in African Americans but not in non-Hispanic whites.<sup>38</sup> The study suggests different pathways to ADRD across race and ethnicity.<sup>38</sup> Whether WMH have a greater impact on cognitive function in some groups because of intervening psychological or environmental factors or for other reasons is unknown.<sup>38</sup>

The lack of clarity as to why these racial differences exist in ADRD with the goal of prevention, treatments and cures in all people will require larger numbers of African Americans participating in all study procedures. Hence, an understanding of the barriers to recruitment and retention of African American participants in ADRD research and of the strategies to overcome these barriers is required.

### 3. Levels for Improvement of African American Recruitment into ADRD Studies

Researchers have identified themes that influence African Americans beliefs about participation in clinical research<sup>39</sup> that were echoed in the Workshop. These themes include experiences of African Americans of unequal treatment and racism; cultural trauma due to both historical events and contemporary experiences; racial identity and cultural norms; and, the importance of cultural competency and representation for those doing recruitment and research.<sup>39</sup> Beyond the infamous Tuskegee Syphilis Study,<sup>40</sup> there is a historical framework of abuse of the research process with African Americans dating back to 1619 with the first enslaved African Americans in the United States.<sup>41</sup> Strategies to address overcoming challenges to recruitment should determine at which level the challenge can exist so that strategies can focus accordingly. The macro level is the realm of legal, political, social, and historical barriers. In the research context, macro level strategies could include addressing past wrongdoing upfront and tightening rules and regulations to protect vulnerable and under-resourced groups. The meso level is the institutional and community level. Strategies at these levels need to examine if historically problematic relationships between a particular institution and the community exist and significant trust building needs to occur to overcome the previous wrongs or a realization that certain opportunities have not been brought to a particular community because of assumptions made about the community as a whole. Increasing the amount of racially and ethnically diverse researchers would be an institutional

improvement at the meso level. Micro level strategies occur at the individual and family level and include addressing things such as a lack of transportation, not having a study partner, the stigma of being part of a study, or even a lack of empowerment for African Americans to understand they have a voice to offer to the research.

#### 4. Improvement Strategies for African American Recruitment

**Lessons Learned from Washington University in St. Louis**—A systematic review of recruitment and retention strategies for increased participation in clinical AD research suggested that the most common and effective recruitment strategies include elements of community outreach and collaboration from health care providers. Building trust through long-term community partnerships and communicating information through trusted community members are two strategies that are successful in meeting recruitment goals.<sup>42</sup> Promising strategies for retention include follow-up communication with participants and maintaining community relationships.<sup>43</sup> Deeper levels of patient, provider, and community engagement lends itself to culturally appropriate approaches to addressing ADRD in African Americans.

**Lessons Learned from North Carolina AT&T University**—To develop strategies that will increase recruitment of African Americans into ADRD research, it is important to understand why persons are motivated to participate in research. In an intergenerational African American cohort, more than 50% of respondents in every age category indicated a willingness to participate in research.<sup>44</sup> Top motivators were having a relative with the disease, having the disease themselves, financial reimbursement, and appeal to civic duty/altruism. Over the lifespan, financial incentives became a much smaller motivator.<sup>44</sup> Intergenerational involvement is important in developing tools and messaging. Building on the findings about motivators for research participation, researchers found that when initiatives focused on community empowerment and community needs, not recruitment, recruitment and enrollment rates increased dramatically. These strategies led to above 90% retention rates, fewer calls/less expense with follow up, and trusting relationships as the recruits came of their own accord.<sup>45</sup> Participants felt dignified because they were a part of something meaningful.

**Lessons learned from Rush: NGAGE Model**—The NGAGE model developed at Rush Alzheimer Disease Center refers to Networks, Give first, (then) Advocate for research, Give back and Evaluate. Networking might be done with one-on-one leader meetings or community board meetings.<sup>46</sup> Give first includes partnering in community aging events, healthy aging presentations and health fairs. Advocate for research is accomplished via community presentations, telephone or in-person follow-ups, and the use of ambassadors or research champions. Give back includes a review of study findings with participants and community research updates. Lastly, Evaluate includes pre- and post- presentation surveys. Facilitators for African American participation include: appreciation that they can influence others and provide a unique perspective; having the opportunity to control the narrative; having the opportunity to be altruistic; involvement from the conception of the research, and finding that the research participation is convenient, low risk, and personally beneficial, either financially or with better health outcomes. The retention strategy focused on

decreasing participant burden by implementing home visits, providing incentives in the form of results and tokens of appreciation, and paying for transportation/parking. Social workers and retention specialists maintain contact between visits.

### **Lessons Learned from Emory University-From Center to Community-Based**

**Research**—The Registry for Remembrance was started in 2007 to enhance African American participation in ADRD research, and successful retention began with a dedicated research focus on African American brain health. Emory researchers found it important for the lead investigators, not just staff, to meet potential participants to discuss the value of CSF biomarkers and safety of lumbar punctures (LPs). For example, there are no greater complication rates with LP in African Americans compared with non-Hispanic whites.<sup>47</sup> It is perhaps even more impactful to have peer-to-peer interaction between current/former participants and recruits. These peer-level interactions provide further reassurance related to LPs, claustrophobia (for imaging), return of information, and general trust issues. Investigators' conversations with active and potential research participants also led to focus groups to acknowledge differences between racial groups, as well as biological and social complexity in categorizing people as belonging to one particular race. As research questions and findings developed, additional consultations became necessary to consider topics in racial heterogeneity, including genetic admixture, differences in historical injustice, access to wealth and health, and recent African migration. Finally, Emory investigators found that returning newly generated knowledge at the group level via newsletters, forums and luncheons enhanced retention, but emphasized the need to address physical barriers (transportation, family support) and participant over-commitment in research participation.

### **Lessons Learned from the University of Pittsburgh-Culture-Centric Narrative**

—Traditional recruitment approaches often design their communication messaging strategies around two goals: 1) emphasizing efforts to minimize barriers to participation by offering free transportation, parking and no-cost clinical research evaluations, while stressing confidentiality; and 2) creating a sense of urgency by highlighting cognitive health disparities affecting African Americans. Yet, emphasizing how easy it is to enroll may be insufficient to motivate participation and focusing on disparities may have unintended consequences like engendering guilt or defensiveness within the target audience. A novel recruitment communications strategy is being tested at the University of Pittsburgh in the Recruitment Innovations for Diversity Enhancement (RIDE) study. RIDE combines positive messaging with culture-centric narratives to engage individuals in culturally embedded stories about research participation. This approach is based on studies showing that behavioral responses to narrative content are stronger than those based on educational content alone.<sup>48-51</sup> Ethnographic interviews serve as the basis for identifying cultural narratives from a heterogeneous group of African American AD research participants that can be incorporated into a wide range of recruitment materials. Materials generated from RIDE range from positive quotes about research participation that can be imbedded into informational brochures, to 2-minute videos telling the stories of African American research participants. A narrative campaign using such materials is underway and its effect on African American recruitment is being evaluated.

**Lessons Learned from Oregon Health and Sciences Center: The SHARP**

**Model**—The SHARP (Sharing History through Active Reminiscence and Photo Imaging) Project was designed to create a walking application that older adults perceived as useful, easy, and relevant to intervention tasks and to fulfill the community priority of history preservation rather than as a strategy to improve recruitment.<sup>52</sup> Furthermore, it modeled positive ways to engage the African American community in research in a community-focused manner. The SHARP project created a culture of belonging in African American brain health research that addressed five questions: (1) How to create a culturally celebratory tone throughout the research? (2) How to create new opportunities? (3) How to serve community identified priorities? (4) What tool or service will continue to serve that priority after the research? (5) How does the intervention go beyond cultural relevance to engage and celebrate African American culture? SHARP used focus groups to identify community priorities for residents of a historically African American neighborhood in Portland, Oregon, that are gentrifying. Participants reported increased transportation barriers/isolation, divided families, and dispersed social support. There was also a decrease of walkability in the new neighborhood with the loss of old neighbors and less neighbor trust. The SHARP team aimed to improve social engagement, preserve history, and increase walking. They had participants walk in groups of three, three times a week, in a historically black neighborhood while looking at historical neighborhood images and memorabilia that celebrated black culture. They developed 72 separate walks focused around 27 themes. Each triad of walkers included two cognitively normal walkers and one with mild cognitive impairment. Results were promising for maintained and improved cognitive function according to Montreal Cognitive Assessments at baseline and at 6 months.<sup>53</sup> Improved mood and healing from the trauma of gentrification were other findings.<sup>53</sup>

**Lessons Learned from Maryland Center for Health Equality: Training the**

**Researchers**—Investigators often receive excellent technical training but little to no training on how to work ethically and effectively in communities from whom they often differ by race, ethnicity, social class, and culture.<sup>54</sup> Training for researchers was recommended by the NIH Panel.<sup>9</sup> The Maryland Center for Health Equality developed an online interactive website for training investigators and bringing the issue of research to the community. They launched a summer institute on the process of becoming a “self-reflective” researcher. The website and the training were created to address the complexity with which racism influences both health outcomes for, and knowledge about, minority populations.<sup>55</sup> If researchers are committed to eliminating racial and ethnic health disparities, they need to be equipped with an understanding of how racism influences health outcomes, and how it influences all aspects of the research process. This includes the engagement of community members, the development of research questions, the way data is collected, how analyses are conducted, and how research findings are disseminated.

**5. Workshop Recommendations**

The Workshop highlighted the multi-faceted issues tied to the recruitment and retention of African Americans in research. By bringing representatives from each ADC together in one room, the Workshop was an opportunity for Centers to coordinate with and learn from each other to advance the recruitment of African Americans into ADRD research. It is important

to continue the conversation started here by developing ways to increase communication between ADCs and community members. This could be accomplished through ongoing workshops, working groups, and meetings with a goal of promoting continued dialogue and actionable steps. In order to advance this conversation, we must work to understand the challenges at many levels that African Americans face when considering participation in research, as well as the factors that motivate participation. Strategies need to be developed with a firm understanding of the barriers and motivations of the particular group a researcher is trying to recruit.

Workshop recommendations are detailed below in Table 1.

First, African Americans are willing to participate in ADRC research. Simply asking African Americans to participate in ADRC research remains an important recommendation derived not only from the Workshop but cited in the literature as well<sup>44, 56</sup>. Exposing African Americans to available research opportunities is a necessary first step to participation.

Recruitment is a science. Strategies for recruitment must be carefully considered and planned with the same principles that are used when researching other scientific inquiries. A systematic recruitment plan provides a structure to address potential barriers, describe steps to overcome these barriers, and measure the outcomes of their strategies<sup>56</sup>. Researchers should share their methods and results so that others can determine if similar methods might work for communities from which, they are trying to recruit and compare outcomes. Best practices such as standard operating procedures should be implemented. Additionally, the use of varying definitions and language in the field impedes the coordination of efforts and outcome comparison, therefore ADCs should work together to adopt common language.

Transparency is key. It helps to foster trust between the participants and research staff and must be part of any strategy to overcome barriers to African American recruitment. A vital part of building trust through transparency is an acknowledgement of historical wrongdoings.<sup>57-59</sup> The research team should also educate participants and potential participants about each step of the research process, including the Institutional Review Board (IRB), and allow time for questions at every step. Communication in clear, lay language should allow participants to understand the reasons why they are asked to participate in procedures like spinal fluid donation and brain imaging. One method to dispel fears of the unknown is involving community individuals and researchers in sharing “testimony” to increase knowledge of the disease process, what research involves, and to form relationships. There should be clear communication to participants and potential participants regarding how valuable their participation is to the research. Transparency even relates directly to determining shared values, goals, and rules of engagement between researchers, communities, and participants. It includes not only transparency about the goals of the research team but also it should reflect how the research addresses the potential needs of the community to increase wellness and equity. Researchers should give tangible examples of what a participant’s involvement means to them and to the community. For example, showing how biomarkers are collected will enable researchers to improve diagnosis for under-represented groups. Researchers should be honest about the current state

of information and research, and when possible, researchers should provide individual and group results.

The team matters. Centers should move towards a team-based approach to facilitate a cohesive message. This includes cross-team training so that each staff member knows what the others are doing across all research levels. Culturally diverse team members are important partners in overcoming barriers of African American recruitment<sup>58,60</sup> When a culturally competent recruiter hands off a potential participant to a culturally incompetent team, trust vanishes. This new lack of trust may have a domino effect with future participants and the community. Front line recruiters must understand the work for which they are recruiting and trust that their institutions will respect participants. The research team needs training on how racism influences health disparities and the research process. This training should include information on structural, systematic and systemic racism. Personality matters: when hiring and training a person, the trainer needs to observe how an individual interacts with diverse populations and prioritize this ability with anyone who interfaces with participants. The hope is that this level of preparedness will result in culturally appropriate team members who are aware of their implicit and explicit bias that may negatively impact not only the study but future opportunities to engage with the community.

Look to establish long-term community relationships. Building these relationships requires an investment in communities and people prior to asking for their participation in research. Several strategies to build trust within the community were discussed at the Workshop as well as have been published in the literature. Suggestions include formation of a community advisory board to receive community input, use the perspectives of community members and research participants to guide recruitment strategies, collaborate with area organizations to develop relationships, provide an unmet need to the community, educate care providers about dementia and treatments, encourage a positive and welcoming attitude among all who will work with participants, and acknowledge the potential stigma of ADRD<sup>57,61,62</sup>. Active engagement in and with the community requires showing up often and motivating community members to engage in all aspects of the research process. When done properly, community engagement goes beyond just basic observation of the research process to community members participating in and, advocating for the research as a full community research partner. The use of mixed methods approaches, focus groups, cross-sectional surveys and even needs assessments will determine the interests of the community. Making assumptions of the community's needs and interest impedes building sustainable partnerships (i.e., do not make assumptions). Listening to the perspectives of community members and research participants and speaking to those who participate in research and those who choose not to do so. These research processes, combined with wellness-type programs in areas of need such as walking programs or brain health programs, may lead to increased levels of health equity. Moreover, using the perspectives of community members and research participants to inform strategy to test recruitment, retention, and dissemination strategies are key.

Provide incentives for participation. Incentives such as payments for visits or procedures or free transportation can be helpful to offset cost burden but in under-represented groups,

factors of greater weight may include how the research may impact them, their family members, or their community as advances in the field are made<sup>63,64</sup> The community, potential participants, and providers may have insight on the appropriate remuneration. This means insuring that not only the study team but also the IRB is aware of the community's recommendations. In some cases, community advisory boards may offer recommendations that are culturally appropriate. Beyond remuneration, highlight other benefits that may be gained by research participation. For example, a health screening is a direct benefit of participation. As another example, a researcher might explain biomarkers are collected with the goal of improving diagnosis for under-represented groups.

Finally, utilize all tools available for your team. The use of large electronic health records is an under-utilized strategy for studying research questions and these records likely reflect the diversity of the community. Create a repository of approaches for investigators to select for their research. Create an online website to train investigators to bring research to the community. Use straightforward messaging, tailored to African Americans. Last, photographs or infographics in messaging can help make educational and recruitment materials more accessible.

### **Limitations:**

The Workshop and this Perspective are not without limitations. The Workshop was a one-day event and there was not time to present an exhaustive literature review and include all of the work that has been done in the area of recruitment of African Americans into Alzheimer disease research. Just as there is not uniformity in what is meant by African American, there is diversity in what is meant by research. The Workshop did not address the differences in the types of research for which recruitment was sought in much detail and this can be a next step along with the others below.

### **Next Steps:**

1. Adopt uniform language and standards of procedure to use in the science of recruitment
2. Create a manual for "best practices" with a goal of sharing this with all ADCs and allowing for collaboration.
3. Host future Workshops that provide topic information in advance to promote discussion and include African American community members as speakers.
4. Ask each ADC to engage their stakeholders, participants and community partners on the appropriate ways to determine linguistic and cultural differences between African Americans and other races as well as within African American cultural groups
5. Develop a robust program related to addressing health disparities linked directly to social determinants of health and structural vulnerability that is often seen in the African American community

6. Learn new process of community and participant engagement to increase our likelihood to receive additional funding support and capacity to address ADRD health disparities in the African American community
7. Create a shared vision related to increasing health equity of African Americans and other under-resourced communities that empowers active engagement in the research process from design, implementation, analysis, and dissemination
8. Develop new processes to educate the next generation of diverse researchers to engage in ADRD research

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## References

1. United States Census Bureau. In. Washington, DC 2017 7 1.
2. Kennedy RE, Cutter GR, Wang G, Schneider LS. Challenging Assumptions About African American Participation in Alzheimer Disease Trials. *Am J Geriatr Psychiatry*. 2017;25(10):1150–1159. [PubMed: 28554539]
3. Doody RS, Thomas RG, Farlow M, et al. Phase 3 trials of solanezumab for mild-to-moderate Alzheimer's disease. *N Engl J Med*. 2014;370(4):311–321. [PubMed: 24450890]
4. Besser L, Kukull W, Knopman DS, et al. Version 3 of the National Alzheimer's Coordinating Center's Uniform Data Set. *Alzheimer Dis Assoc Disord*. 2018;32(4):351–358. [PubMed: 30376508]
5. Barnes LL, Bennett DA. Alzheimer's disease in African Americans: risk factors and challenges for the future. *Health Aff (Millwood)*. 2014;33(4):580–586. [PubMed: 24711318]
6. HHS Action Plan to Reduce Racial and Ethnic Disparities: A Nation Free of Disparities in Health and Health Care. In: Services HaH, ed 2017.
7. Corriveau RA, Koroshetz WJ, Gladman JT, et al. Alzheimer's Disease-Related Dementias Summit 2016: National research priorities. *Neurology*. 2017;89(23):2381–2391. [PubMed: 29117955]
8. Schneider J Scientific Chair; Jeon Sophia; Gladman Jordan T.; Corriveau Roderick A., NINDS/NIH Lead ADRD Summit 2019 Report to the National Advisory Neurological Disorders and Stroke Council. National Institute of Neurological Disorders and Stroke;2019.
9. Aging NIO. NIH Alzheimer's Disease Centers Panel Recommendations <https://www.nia.nih.gov/news/expert-panel-offers-transformative-recommendation-nih-alzheimers-research-centers> 2017 Accessed on August 2, 2017 2017.
10. Arean PA, Gallagher-Thompson D. Issues and recommendations for the recruitment and retention of older ethnic minority adults into clinical research. *J Consult Clin Psychol*. 1996;64(5):875–880. [PubMed: 8916614]



11. Hinton L, Carter K, Reed BR, et al. Recruitment of a community-based cohort for research on diversity and risk of dementia. *Alzheimer Dis Assoc Disord*. 2010;24(3):234–241. [PubMed: 20625273]
12. Ofstedal MB, Weir DR. Recruitment and retention of minority participants in the health and retirement study. *Gerontologist*. 2011;51 Suppl 1:S8–20. [PubMed: 21565822]
13. Murthy VH, Krumholz HM, Gross CP. Participation in cancer clinical trials: race-, sex-, and age-based disparities. *JAMA*. 2004;291(22):2720–2726. [PubMed: 15187053]
14. Xiong C, Luo J, Coble D, Agboola F, Kukull W, Morris JC. Complex interactions underlie racial disparity in the risk of developing Alzheimer’s disease dementia. *Alzheimers Dement*. 2020;16(4):589–597. [PubMed: 32067357]
15. Mayeda ER, Glymour MM, Quesenberry CP, Whitmer RA. Inequalities in dementia incidence between six racial and ethnic groups over 14 years. *Alzheimers & Dementia*. 2016;12(3):216–224.
16. Hebert PL, Sisk JE, Howell EA. When does a difference become a disparity? Conceptualizing racial and ethnic disparities in health. *Health Aff (Millwood)*. 2008;27(2):374–382. [PubMed: 18332492]
17. Steenland K, Goldstein FC, Levey A, Wharton W. A Meta-Analysis of Alzheimer’s Disease Incidence and Prevalence Comparing African-Americans and Caucasians. *Journal of Alzheimer’s disease : JAD*. 2016;50(1):71–76. [PubMed: 26639973]
18. Zahodne LB, Manly JJ, Azar M, Brickman AM, Glymour MM. Racial Disparities in Cognitive Performance in Mid- and Late Adulthood: Analyses of Two Cohort Studies. *J Am Geriatr Soc*. 2016;64(5):959–964. [PubMed: 27225354]
19. Kilbourne AM, Switzer G, Hyman K, Crowley-Matoka M, Fine MJ. Advancing health disparities research within the health care system: a conceptual framework. *American journal of public health*. 2006;96(12):2113–2121. [PubMed: 17077411]
20. Alvidrez J, Castille D, Laude-Sharp M, Rosario A, Tabor D. The National Institute on Minority Health and Health Disparities Research Framework. *American Journal of Public Health*. 2019;109(S1):S16–S20. [PubMed: 30699025]
21. Hendrie HC, Ogunniyi A, Hall KS, et al. Incidence of dementia and Alzheimer disease in 2 communities: Yoruba residing in Ibadan, Nigeria, and African Americans residing in Indianapolis, Indiana. *JAMA*. 2001;285(6):739–747. [PubMed: 11176911]
22. Deeg M, Baiyewu O, Gao S, et al. A comparison of cardiovascular disease risk factor biomarkers in African Americans and Yoruba Nigerians. *Ethnicity & disease*. 2008;18(4):427–433. [PubMed: 19157246]
23. Gao S, Ogunniyi A, Hall KS, et al. Dementia incidence declined in African-Americans but not in Yoruba. *Alzheimers Dement*. 2016;12(3):244–251. [PubMed: 26218444]
24. Hendrie HC, Murrell J, Baiyewu O, et al. APOE epsilon4 and the risk for Alzheimer disease and cognitive decline in African Americans and Yoruba. *Int Psychogeriatr*. 2014;26(6):977–985. [PubMed: 24565289]
25. Tang MX, Stern Y, Marder K, et al. The APOE-epsilon4 allele and the risk of Alzheimer disease among African Americans, whites, and Hispanics. *Jama*. 1998;279(10):751–755. [PubMed: 9508150]
26. Howell JC, Watts KD, Parker MW, et al. Race modifies the relationship between cognition and Alzheimer’s disease cerebrospinal fluid biomarkers. *Alzheimers Res Ther*. 2017;9(1):88. [PubMed: 29096697]
27. Morris JC, Schindler SE, McCue LM, et al. Assessment of Racial Disparities in Biomarkers for Alzheimer Disease. *JAMA Neurol*. 2019;76(3):264–273. [PubMed: 30615028]
28. Berg L. Clinical Dementia Rating (CDR). *Psychopharmacol Bull*. 1988;24(4):637–639. [PubMed: 3249765]
29. Gilsanz P, Mayeda ER, Glymour MM, Quesenberry CP, Whitmer RA. Association Between Birth in a High Stroke Mortality State, Race, and Risk of Dementia. *JAMA Neurol*. 2017;74(9):1056–1062. [PubMed: 28759663]
30. Brenowitz WD, Manly JJ, Murchland AR, et al. State School Policies as Predictors of Physical and Mental Health: A Natural Experiment in the REGARDS Cohort. *Am J Epidemiol*. 2019.

31. Liu SY, Manly JJ, Capistrant BD, Glymour MM. Historical Differences in School Term Length and Measured Blood Pressure: Contributions to Persistent Racial Disparities among US-Born Adults. *PLoS One*. 2015;10(6):e0129673. [PubMed: 26076495]
32. Arce Renteria M, Vonk MJ, Felix G, et al. Illiteracy, dementia risk, and cognitive trajectories among older adults with low education. *Neurology*. 2019.
33. Noble JM, Schupf N, Manly JJ, Andrews H, Tang MX, Mayeux R. Secular Trends in the Incidence of Dementia in a Multi-Ethnic Community. *Journal of Alzheimer's disease : JAD*. 2017;60(3):1065–1075. [PubMed: 28984588]
34. Barnes LL, De Leon CFM, Wilson RS, Bienias JL, Bennett DA, Evans DA. Racial Differences in Perceived Discrimination in a Community Population of Older Blacks and Whites. *Journal of Aging and Health*. 2004;16(3):315–337. [PubMed: 15155065]
35. Liu SY, Kawachi I. Discrimination and Telomere Length Among Older Adults in the United States. *Public Health Rep*. 2017;132(2):220–230. [PubMed: 28147207]
36. Devore EE, Prescott J, De Vivo I, Grodstein F. Relative telomere length and cognitive decline in the Nurses' Health Study. *Neuroscience letters*. 2011;492(1):15–18. [PubMed: 21295115]
37. Hulette C, Mirra S, Wilkinson W, Heyman A, Fillenbaum G, Clark C. The Consortium to Establish a Registry for Alzheimer's Disease (CERAD). Part IX. A prospective cliniconeuropathologic study of Parkinson's features in Alzheimer's disease. *Neurology*. 1995;45(11):1991–1995. [PubMed: 7501147]
38. Zahodne LB, Manly JJ, Narkhede A, et al. Structural MRI Predictors of Late-Life Cognition Differ Across African Americans, Hispanics, and Whites. *Curr Alzheimer Res*. 2015;12(7):632–639. [PubMed: 26027808]
39. Lincoln KD, Chow T, Gaines BF, Fitzgerald T. Fundamental causes of barriers to participation in Alzheimer's clinical research among African Americans. *Ethnicity & health*. 2018:1–15.
40. Adashi EY, Walters LB, Menikoff JA. The Belmont Report at 40: Reckoning With Time. *Am J Public Health*. 2018;108(10):1345–1348. [PubMed: 30138058]
41. Ighodaro ET, Nelson PT, Kukull WA, et al. Challenges and Considerations Related to Studying Dementia in Blacks/African Americans. *Journal of Alzheimer's disease : JAD*. 2017;60(1):1–10. [PubMed: 28731440]
42. Gluck MA, Shaw A, Hill D. Recruiting Older African Americans to Brain Health and Aging Research Through Community Engagement: Lessons from the African-American Brain Health Initiative at Rutgers University-Newark. *Generations (San Francisco, Calif)*. 2018;42(2):78–82.
43. Roger W, Takashi A, Shih-Yin L, Yuanjin Z, Nancy M-H. Strategies for the Recruitment and Retention of Racial/Ethnic Minorities in Alzheimer Disease and Dementia Clinical Research. *Current Alzheimer Research*. 2019;16(5):458–471. [PubMed: 30907319]
44. Lang R, Kelkar VA, Byrd JR, Edwards CL, Pericak-Vance M, Byrd GS. African American participation in health-related research studies: indicators for effective recruitment. *Journal of public health management and practice : JPHMP*. 2013;19(2):110–118. [PubMed: 23358288]
45. Byrd GS, Edwards CL, Kelkar VA, et al. Recruiting intergenerational African American males for biomedical research Studies: a major research challenge. *J Natl Med Assoc*. 2011;103(6):480–487. [PubMed: 21830630]
46. Glover CM BD, Barnes LL, Aggarwal NT, Marquez DX, Leurgans S, & Shah RC. . The NGAGE Model: Facilitating Engagement and Outreach with Diverse Older Adults Regarding Cognitive Aging. In Preparation.
47. Howell JC, Parker MW, Watts KD, Kollhoff A, Tsvetkova DZ, Hu WT. Research Lumbar Punctures among African Americans and Caucasians: Perception Predicts Experience. *Front Aging Neurosci*. 2016;8:296. [PubMed: 27994549]
48. Larkey LK, Hecht M. A model of effects of narrative as culture-centric health promotion. *Journal of health communication*. 2010;15(2):114–135. [PubMed: 20390982]
49. Botvin GJ, Schinke SP, Epstein JA, Diaz T. Effectiveness of culturally focused and generic skills training approaches to alcohol and drug abuse prevention among minority youths. *Psychology of Addictive Behaviors*. 1994;8(2):116–127.

50. Hopfer S. Effects of a narrative HPV vaccination intervention aimed at reaching college women: a randomized controlled trial. *Prevention science : the official journal of the Society for Prevention Research*. 2012;13(2):173–182. [PubMed: 21993613]
51. Perez M, Sefko JA, Ksiazek D, et al. A novel intervention using interactive technology and personal narratives to reduce cancer disparities: African American breast cancer survivor stories. *Journal of cancer survivorship : research and practice*. 2014;8(1):21–30. [PubMed: 24030573]
52. Croff RL, Witter Iv P, Walker ML, et al. Things Are Changing so Fast: Integrative Technology for Preserving Cognitive Health and Community History. *Gerontologist*. 2019;59(1):147–157. [PubMed: 29961887]
53. Croff R, Francois E, Hedmann M, Towns J, Pruitt A, Kaye J. I'M BEGINNING TO REMEMBER: THE SHARP STUDY'S NEIGHBORHOOD APPROACH TO AFRICAN AMERICAN BRAIN HEALTH. *Innov Aging*. 2018;2(suppl\_1):439–439.
54. Quinn SC, Kass NE, Thomas SB. Building trust for engagement of minorities in human subjects research: is the glass half full, half empty, or the wrong size? *American journal of public health*. 2013;103(12):2119–2121. [PubMed: 24134371]
55. Butler J 3rd, Fryer CS, Garza MA, Quinn SC, Thomas SB. Commentary: Critical Race Theory Training to Eliminate Racial and Ethnic Health Disparities: The Public Health Critical Race Praxis Institute. *Ethnicity & disease*. 2018;28(Suppl 1):279–284. [PubMed: 30116099]
56. Williams MM, Meisel MM, Williams J, Morris JC. An interdisciplinary outreach model of African American recruitment for Alzheimer's disease research. *Gerontologist*. 2011;51 Suppl 1:S134–141. [PubMed: 21173436]
57. Dancy BL, Wilbur J, Talashek M, Bonner G, Barnes-Boyd C. Community-based research: barriers to recruitment of African Americans. *Nursing outlook*. 2004;52(5):234–240. [PubMed: 15499312]
58. Lambe S, Cantwell N, Islam F, Horvath K, Jefferson AL. Perceptions, knowledge, incentives, and barriers of brain donation among African American elders enrolled in an Alzheimer's research program. *Gerontologist*. 2011;51(1):28–38. [PubMed: 20679141]
59. McLennon SM, Habermann B. Accruing the sample: strategies for recruiting older adult and African Americans caregivers for persons with Alzheimer's disease. *Appl Nurs Res*. 2012;25(1):e1–6. [PubMed: 21945377]
60. Levkoff S, Sanchez H. Lessons learned about minority recruitment and retention from the Centers on Minority Aging and Health Promotion. *Gerontologist*. 2003;43(1):18–26. [PubMed: 12604742]
61. Barnes LL, Shah RC, Aggarwal NT, Bennett DA, Schneider JA. The Minority Aging Research Study: ongoing efforts to obtain brain donation in African Americans without dementia. *Curr Alzheimer Res*. 2012;9(6):734–745. [PubMed: 22471868]
62. Graham LA, Ngwa J, Ntekim O, et al. Best strategies to recruit and enroll elderly Blacks into clinical and biomedical research. *Clin Interv Aging*. 2018;13:43–50. [PubMed: 29317809]
63. Williams MM, Scharff DP, Mathews KJ, et al. Barriers and facilitators of African American participation in Alzheimer disease biomarker research. *Alzheimer Dis Assoc Disord*. 2010;24 Suppl:S24–29. [PubMed: 20711059]
64. Schnieders T, Danner DD, McGuire C, Reynolds F, Abner E. Incentives and barriers to research participation and brain donation among African Americans. *Am J Alzheimers Dis Other Demen*. 2013;28(5):485–490. [PubMed: 23728297]

**Table 1.**

## Recommendations from the Workshop

<p><b>1. African Americans are willing to participate in research</b></p> <ul style="list-style-type: none"> <li>• Do not assume someone is unwilling to participate</li> <li>• Create awareness about available research opportunities</li> </ul>
<p><b>2. Recruitment is a science</b></p> <ul style="list-style-type: none"> <li>• Carefully design recruitment protocols and measure the outcomes</li> <li>• Publish the findings to share what strategies were or were not successful to create evidenced-based recruitment strategies</li> <li>• Recruiters/researchers benefit from standardized language and definitions</li> </ul>
<p><b>3. Be transparent to build trust</b></p> <ul style="list-style-type: none"> <li>• Be quick to acknowledge past research atrocities</li> <li>• Educate participants about each step of the research process</li> <li>• Clearly explain reasons for study and reasons their participation is needed to advance science</li> <li>• Share outcomes of studies with your participants</li> <li>• Create a shared vision for the research that is culturally appropriate</li> </ul>
<p><b>4. Your team matters</b></p> <ul style="list-style-type: none"> <li>• Have members of your team who look like the community from which you are recruiting</li> <li>• Cross-train your team members so the recruiters understand the studies and the researchers understand the community whom they want to engage</li> <li>• Personality and training are both important for anyone interacting with participants</li> <li>• Provide training that acknowledges racism, microaggressions, implicit and explicit bias</li> </ul>
<p><b>5. Community relationships</b></p> <ul style="list-style-type: none"> <li>• Long-term relationships require an investment in communities/people before asking for their participation</li> <li>• Consider community advisory boards as a research engagement tool</li> <li>• Educate care providers within communities you are recruiting from about brain health/ADRD</li> <li>• Develop partnerships that include building relationships with community cultural brokers</li> <li>• Determine the community's interest to develop research programs that address their needs</li> </ul>
<p><b>6. Incentivize</b></p> <ul style="list-style-type: none"> <li>• Incentives include payments for visits, free transportation, sharing results or providing a health service such as a diabetes screening</li> <li>• Consider using various research approaches like focus groups, cross sectional surveys and key informant interviews to discover culturally appropriate incentives</li> <li>• Engage the IRB in a dialog about the community recommended incentives to ensure they meet the regulatory standards of the institution</li> </ul>
<p><b>7. Tools and materials</b></p> <ul style="list-style-type: none"> <li>• Consider utilizing large electronic health records to help recruit potential participants</li> <li>• Use straightforward messaging tailored to group being recruited</li> <li>• Photographs and infographics in messaging can make educational and recruitment materials more accessible</li> <li>• Partner with the community, participants, and other stakeholders to develop culturally appropriate tools and materials for use throughout the research process</li> </ul>