

African American Participation in Alzheimer Disease Research: Effective Strategies Workshop An Overview

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Thank you!!!

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Agenda

Rationale for inclusion of African Americans in ADRD research.

Examine barriers and facilitators of participation.

Review current ADC-based efforts to recruit and retain African Americans in ADRD research.

Examine strategies to improve faculty and staff diversity.

Encourage multi-site research proposals to test strategies for increase recruitment, retention and engagement of African Americans in ADC research.

Health Disparities and Racial Differences

Workshop highlighted the field needs to tease apart causes of disparities - social determinants vs. biological differences

African Americans have greater likelihood of AD than non-Hispanic whites, but differences may not be as great as widely reported.*

*Mayeda ER, Glymour MM, Quesenberry CP, Whitmer RA. Inequalities in dementia incidence between six racial and ethnic groups over 14 years. *Alzheimers Dement.* 2016;12(3):216–224. doi:10.1016/j.jalz.2015.12.007

Potential Racial Difference in ADRD

- Not comparing apples to apples
- Genetics
- Protein levels in Cerebrospinal fluid (CSF)
- Education
- CVD, diabetes and other risk factors
- Medical management of co-morbidities
- Life stressors

How to deal with admixture when discussing racial differences was raised more than once and is something that needs to be addressed by the field.

Barriers-Tuskegee Isn't Everything

Some top barriers raised in talks and breakout groups include:

- Lack of trust in the medical field, researchers, or particular institutions
- Personal limitations such as health, transportation, not having a study partner
- Lack of information about research studies
- Fear of the unknown
- Cultural or language differences
- No one wants to be a “target” population

Barriers, cont'd.

In an Emory survey of African Americans and non-Hispanic Whites, Tuskegee only came up with minor differences between groups on most reported barriers such as:

- Fear of lumbar puncture
- Claustrophobia (for imaging procedures)
- Too busy
- Other health issues either preclude participation or take precedence
- Lack of family support.

Reasons for Optimism about Participation

In an intergenerational African American cohort more than 50% of respondents in every age cohort indicated willingness to participate in research.*

Top motivators:

- A relative with the disease
- Diagnosed with the disease
- Financial reimbursement**
- Altruism

* 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; 1036: 480–7

**Of note, over the lifespan, financial incentives became a smaller motivator

Innovative Strategies

Engage African American communities in advance of asking for something.

Move away from a focus on deficits in the community and instead find ways to be culturally celebratory.

The Team Matters

It is important for the investigators to meet participants, but peer-to-peer interactions with current participants are important too and they should be a part of the team.

Recruiting team should be able to answer questions about all aspects of the studies they recruit for.

All team members need to be culturally competent.

Personality and warmth and the ability to connect are very important as well.

Takeaways and Next Steps

Move towards a team-based approach to facilitate a cohesive message

Cross-Training: one hand should know what the other is doing across all levels of research. It isn't useful for a culturally competent recruiter to do a hand-off to a culturally incompetent researcher.

Recruitment as Science: we need a common language, best practices, standards of procedure

Create a repository of approaches for investigators to select

Takeaways and Next Steps cont'd.

You cannot just go and be successful without prior long-term investment in communities

Messaging must be straightforward and tailored

Upfront acknowledgment of past wrongs

Communicate the value of participation

Knight ADRC Top 3 Strategies

Dedicated, full-time community outreach coordinator who not only does community talks but supports other community organizations on a regular basis so they know we do not just show up when we need something.

An **active** African American Advisory Board (AAAB)

Use AAAB members and other research participants as a part of your research team.