

# Recruiting Older African Americans to Brain Health and Aging Research Through Community Engagement

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Lessons from the African-American Brain Health Initiative at Rutgers University–Newark.

The African-American Brain Health Initiative (AABHI) at Rutgers University–Newark is a unique university–community partnership combining community engagement, education and training, and brain health research. Partnering with community-based organizations, we promote brain health literacy, Alzheimer’s awareness, brain-healthy lifestyle choices, and participation in brain research for older African Americans in Greater Newark, New Jersey. Our research and training missions bring together undergraduates, graduate students, postdoctoral fellows, faculty, and clinicians for cross-disciplinary efforts that link neuroscience, neurology, public health, social work, and nursing.

African Americans have two to three times the prevalence of Alzheimer’s disease as compared to whites (Barnes and Bennett, 2014; Tang et al., 2001). We do not fully understand the causes of this health disparity, nor how best to

focus future interventional efforts to remediate it. Additionally, African Americans are under-represented in biomedical research (Shavers-Hornaday et al., 1997; Corbie-Smith et al., 1999; Braunstein et al., 2008).

However, as a result of community-engaged outreach efforts, we have enrolled African American community members in several research studies on aging and Alzheimer’s disease. In 2015, we recruited more than a thousand older African Americans of Greater Newark to participate in a short health and lifestyle survey, working in partnership with the New Jersey Department of Health’s Office of Minority and Multicultural Health. Based on their positive experience with this study—which, for most, was their first biomedical or health research experience ever—many agreed to participate in additional research studies at Rutgers.

**→ABSTRACT** The African-American Brain Health Initiative at Rutgers University–Newark is a university–community partnership combining community engagement, education and training, and brain health research. Partnering with community-based organizations, it promotes brain health literacy, Alzheimer’s awareness, brain-healthy lifestyle choices, and participation in brain research for older African Americans in Greater Newark, New Jersey. Our approach to recruitment relies on building trust through long-term relationships; communicating health knowledge through trusted community leaders; recruiting subjects through targeted efforts; and cultivating research participants as ambassadors. | **key words:** *Rutgers University–Newark, research study recruitment, African American, older men, community partnership, brain health*

We have two ongoing research studies within the AABHI. One study, funded by the National Institutes of Health's (NIH) National Institute on Aging, investigates how variations in lifestyle, weight, diet, sleep, and, especially, physical fitness, are correlated with cognitive and brain function in older African Americans, with the goal of identifying early predictors of cognitive decline and future conversion to Alzheimer's disease.

Our other study, funded by the Federal Office of Minority Health in partnership with the New Jersey Office of Minority and Multicultural Health, asks if participating in a bi-weekly dance-based exercise class, hosted by local churches and senior centers, can improve memory and brain function in older African Americans, reducing known biomarkers for Alzheimer's risk. For these two research studies, we recruit and test about 150 people per year, and all are African Americans ages 55 and older. The initial testing takes about two and a half hours and individuals who are medically and physically able may return on another day for optional brain imaging.

### Research Recruitment Tactics

Our approach to research recruitment for both studies relies on extensive community engagement based on the following four key strategies:

✓ **Build trust through long-term relationships that bring value to the community.**

All of our activities build on trust established from more than a decade of community engagement and service in Greater Newark. We have implemented a range of outreach and engagement approaches designed to enhance community health through brain health education programs that support older African Americans in adopting healthier lifestyles. Our community-engaged approach leverages community partnerships to develop a culture of trust between Rutgers and the community (Holland, 2005; Sandy and Holland, 2006; Silka and Renault-Caragianes, 2006; Post et al., 2016).

Key to this external outreach has been a cross-disciplinary partnership at Rutgers University–Newark with the Office of University–Community Partnerships, which is responsible for, and experienced with, external community relations. Community participants recruited to our research have come primarily from long-standing partnerships with local

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### *'African Americans have two to three times the prevalence of Alzheimer's disease compared to whites.'*

churches; senior centers; city, county, and state offices for health and aging; as well as from outreach to public and other low-income housing sites. Representatives from many of these partner organizations make up the AABHI Community Advisory Board, which meets every other month to guide our activities and provide a bridge to community needs and interests.

With these partners, the Rutgers University–Newark AABHI hosts several large events every year, attracting about 250 older African American community members to each. Also, we run around two smaller “Lunch 'n' Learns” per month at our partner sites, which attract twenty-five to fifty people per event. All of these health education programs emphasize six key steps to brain health that our community members can and should take, and lifestyles and habits associated with reducing their risk for Alzheimer's disease: doing regular exercise, keeping mentally active, avoiding unproductive stress, and getting adequate sleep, social support, and proper nutrition.

Each event also includes a presentation on the benefits and importance of research participation by African Americans. Whenever possible, these presentations on research participation are given by African American students at Rutgers University–Newark (often they are students who grew up in Newark) who are working on our AABHI research studies as part of their

undergraduate or graduate training. For some of these events, we also partner with other local organizations with complementary missions, including the American Heart Association, the American Stroke Association and the Alzheimer's Association.

✓ **Communicate health information through known and trusted community leaders.**

We hire and train known and trusted community leaders as health educators to deliver information about brain health and research information to community members at the events described above. These Community Brain Health Educators often are leaders from our partner churches and senior centers, including church deacons and pastors, as well as retired teachers, nurses, and other community advocates. In addition to leading and presenting at our brain health education events, they assist in nurturing, managing, and expanding our relationships with community organizations, while serving as locally “embedded” brain health experts.

✓ **Recruit older black men through targeted efforts.**

Attracting older men to health education and research participation has been a challenge; in and around Newark, African American women ages 55 and older outnumber men by more than two to one, and the ratio is even more extreme within the community and church groups from which we recruit (the ratio is less extreme in senior public housing). We have developed a range of outreach and engagement approaches specifically designed to enhance recruitment of older black men to our research studies.

These approaches embody both of the first two strategies noted above, but re-focused specifically on men. These include the following: supporting the growth of a network of church men's ministries who offer a monthly “Men's Health and Wellness Breakfast Club,” led by our Community Brain Health Educators; running health education programs for barbers to enlist them as ambassadors for brain health and

brain research (see also Releford, Frencher, and Yancey, 2010); hosting an annual classic car show and men's brain health fair; supporting a summer picnic and health fair for older residents of public housing in partnership with the Newark Housing Authority; partnering with a local seniors bowling league; and hiring black men from the community, including local black graduate students, and black male nurses recruited through the Northern New Jersey Black Nurses

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***All of our activities build on trust established from more than a decade of community engagement.'***

Association, to work as our ambassadors and Community Brain Health Educators for recruiting men to our research. Through this multi-pronged approach, we are attracting increasing numbers of men to our studies.

The need for additional efforts in recruiting men to our programs demonstrates that, even when working with an underrepresented population, additional, more targeted outreach may be necessary to capture a particular group within a population of interest. For example, we have found it useful to develop targeted programs for residents of low-income public and federally subsidized housing. As we become increasingly sensitive to the needs and interests of the many sub-communities within our broader community of older African Americans in Greater Newark, we have come to appreciate that a range of strategies may be required for each.

✓ **Cultivate research participants as ambassadors for brain research.**

Once participants have participated in research, they become AABHI VIPs: Very Important Participants. All VIPs receive regular contact from us via phone and mail throughout the year. By hearing from us and seeing us in their churches and community-based organizations, participants know they are valued members of an ongoing university–community

partnership, in which Rutgers is committed to them, their community, and their health needs for years to come. All are asked to spread the word about brain health and to encourage friends and acquaintances to participate in our research studies. About 25 percent of recent participants in our studies have come via word-of-mouth from other participants, showing that the community members become engaged not only in the research, but also in working with us to expand recruitment through their own social networks.

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**Summary**

The AABHI at Rutgers University–Newark began in 2006 as an occasional series of community brain health education events co-sponsored with local churches. Over the last few years, it has expanded in scope and impact so that it now integrates all three of our university’s missions: community engagement, teaching and training, and research and scholarship. Each of these missions is a key part of the Rutgers University–Newark AABHI. Community engagement provides opportunities for Rutgers students and postdoctoral fellows to get interdisciplinary training, while working with faculty mentors and community members to pursue fundamental behavioral and biomedical research on aging and Alzheimer’s disease.


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All the strategies described herein are readily implementable by other universities and medical research centers doing aging and brain health research that are interested in working with African Americans and other under-represented communities. All require a long-term commitment of time and effort to build trust and partnerships with local community organizations and community members. 

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## Family Matters: Older Adults Caring for Others and Each Other

Mercedes Bern-Klug, **Guest Editor**

The topic for the Fall 2018 issue is caregiving, but with a slightly different twist. When the words "older adults" and "caregiving" are used in the same sentence, most people assume that the older adults being referred to are on the receiving end of the caregiving stick. Often (and more increasingly), however, older adults are the ones who are assuming the caregiver role and doing the work of caregiving.

This issue of *Generations* focuses on older adults as caregivers to family members and friends, and aims to sensitize readers to situations in which older adults are continuing the role of caregiver (perhaps for an adult child or a sibling with a disability) or are newly arrived to the caregiving role (perhaps for an ill spouse or a friend with a debilitating injury). Nearly two dozen articles will discuss issues that can impact older adult caregivers, such as retirement, legacy and estate planning, caring for children with a disability and-or problems with substance abuse, guardianship, family conflict, debt, and more.

COMING UP IN  
**Fall 2018**

# Generations