

Developing, Implementing, and Monitoring Penn Memory Center's Multicultural Recruitment and Retention with a focus on African American Participants

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Director of Diversity in Research and Education



Penn Memory Center

- National Institute on Aging designated Alzheimer's disease center
- One of 30 such sites in the nation and *the only* site in our tri-state region
- Interdisciplinary center (neurologists, psychologists, psychiatrists, geriatricians, social workers, public health practitioners, and research coordinators)



Why focus on African Americans?

- To better reflect the ethnic/racial demography of the community in which Penn resides
 - African American demographic of the region in which the PMC serves (PA, DE, and NJ): **17%**
 - African American demographic in Philadelphia: **43%**
- The prevalence of cognitive impairment or AD may be two to three times higher among older African Americans than in older non-Hispanic whites
 - Health Affairs: *“Alzheimer's Disease in African Americans: Risk Factors and Challenges for the Future”* Lisa L. Barnes and David A. Bennett
- National Alzheimer’s Coordinating Center: “NACC” Study

Achieving Diversity in Research

Mission: Develop strategies to increase the Penn Memory Center's multicultural recruitment and retention activities with a particular focus on African American participants

Goals: Achieve the Center's recruitment and retention goals for research studies; in particular, the NACC longitudinal cohort & raise awareness about Alzheimer's disease and brain health in the communities of Philadelphia

Outcomes to achieve:

- Increase awareness
- Increase enrollment
- Increase engagement

Increase Awareness

- Created culturally sensitive outreach materials
- Presented at community centers/events
- Organized a photo exhibit: “Portraits of Alzheimer’s Caregivers” by Raymond Holman Jr.
- Organized healthy brain aging events at First Corinthian Baptist Church and Enon Tabernacle Baptist Church in West Philadelphia
- Collaborated with the African American Network Against Alzheimer's to organize two performances of the play “Forget Me Not” at the Freedom Theater
- Typical Day Photography Project

www.mytypicalday.org



Increase Enrollment

- Collaborated with Dr. Nabila Dahodwala to recruit African American participants from her “Healthy Brain Aging” study
- Collaborating with Penn Geriatric Medicine Practice, which serves predominately West Philadelphia Community
- Developed “PMC: Brain Health Research Registry”

JOIN The Penn Memory Center Brain Health Research Registry
a registry to remember

Do you want to help speed up the search for treatments and cures for brain diseases?
Research is the fastest way to find treatments that work.

By enrolling in the Penn Memory Center's Brain Health Research Registry you'll play a vital role in research. The Registry serves as the research recruitment resource for investigators at the Penn Memory Center who are studying brain diseases such as Alzheimer's disease, which affects over 5 million people in the US.

Who can participate? Individuals age 60 and over with normal memory, Mild Cognitive Impairment or Alzheimer's disease.

How does it work? The Penn Memory Center Brain Health Research Registry is a confidential database that is made up of people like you who have volunteered to consider participation in research studies. We will contact you periodically with a list of research studies that you may consider joining. **Participation is always optional and all information is kept confidential.**

How do I register?
Simply fill out the form on the back of this card! Keep the bottom half for your records.

Penn Medicine | Penn Memory Center | www.pennadoc.org

Fold and Tear Here

Keep this section for your reference

Without ~~research~~ you there is no progress to discover better ways to diagnose and care for patients. Without ~~you~~ there is no research.

The Penn Memory Center Brain Health Research Registry is a confidential database made up of people like ~~you~~ who have volunteered to consider participation in research studies. The goal of the registry is to discover better ways to diagnose and treat brain diseases.

By enrolling in the Penn Memory Center's Brain Health Research Registry you'll be part of the research recruitment resource for investigators at the Penn Memory Center who are studying brain diseases such as Alzheimer's disease, which affects over 5 million people in the US.

We will contact you periodically with a list of research studies that you can consider joining. **Participation is always optional and all information is kept confidential.**

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Name _____

Address _____

Phone _____ Email address _____

Date of birth _____ Gender _____ Male _____ Female

Please check all that describe you: _____ Caucasian _____ Black or African American
_____ Latino _____ Non-Latino _____ Asian _____ Other _____

Do you have a family history of Alzheimer's disease? _____ Yes _____ No

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Fold and Tear Here

Keep this section for your reference

The Penn Memory Center Brain Health Research Registry
a registry to remember

Thank you for joining the Registry!

If you have any questions, please contact:
Tigist Hallu, Coordinator for Diversity in Research
Penn Memory Center
(215) 573-6095 or tigist.hallu@uphs.upenn.edu

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Increase Engagement

- Advisory Board
- Engage research participants
- Dance for Health: Active body, Active mind
- Encourage students from diverse backgrounds and training levels to gain experience in aging research



Penn Minority Scholars in Aging Research

As life expectancy has lengthened, the number and proportion of people suffering from dementia and Alzheimer's disease have increased. This public health challenge disproportionately affects minority populations, particularly older African Americans.

The Penn Memory Center and the Penn Healthy Brain Research Center are committed to assuring that the diverse population of older adults in the U.S. receive the care they need and participate in research that improves that care. To achieve this goal, we need to increase the diversity of clinicians and researchers in the field of aging research.

In response to this need, the Penn Memory Center and the Penn Healthy Brain Research Center are pleased to announce the creation of the Penn Minority Scholars in Aging Research.

Who should apply?

Candidates are students currently enrolled in a medical or doctoral degree program. We invite applicants from minority groups that are underrepresented in the field of aging research: Black or African-American, Hispanic or Latino, American Indian or Alaska Native, Native Hawaiian or other Pacific Islander.

A successful applicant will tell us about their inspiring interest in research or clinical care focused on cognitive health, cognitive impairment (including dementia or mild cognitive impairment), Alzheimer's disease, or other neurodegenerative disorders. We would also like to know how the applicant came to this interest and how this interest shapes the applicant's vision of his or her career.

What is involved?

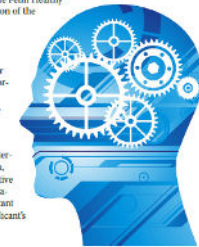
The Penn Minority Scholars in Aging Research Program comprises a paid internship that spans either a 12-week block of full-time effort during the summer or an equivalent block of time during the academic year.

See back of flyer for additional details.

 Penn Memory Center
UNIVERSITY OF PENNSYLVANIA HEALTH SERVICES

 Healthy Brain
Research Center
UNIVERSITY OF PENNSYLVANIA

Penn Memory Center at the University of Pennsylvania | www.pennmemorycenter.org



Lessons Learned

- Transportation and need for some benefit
 - Began to pay NACC participants \$20
- Build relationships with participants
 - Recruits participants
 - Schedules
 - Debriefs
 - Calls/sends birthdays cards
 - Invites participants to events
- Brain donation
 - Partnership with churches to educate the community
 - Discussing during yearly NACC study visits
 - Allow participants to share their story

PMC: Research Advocate



Florence Collins-Hardy, Penn Memory Center NACC study participant and enrolled in the brain donation program

Penn Memory Center

The Perelman Center for Advanced Medicine

Penn Neuroscience Center

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