



Brain Imaging Study for Alzheimer's

Recruitment and Engagement Webinar

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THE BRAINS BEHIND SAVING YOURS.®

Experts in Minority Recruitment



Peggye Dilworth-Anderson, PhD; Professor of Health Policy and Management, Gillings School of Global Public Health, University of North Carolina

- National leader in minority aging and dementia caregiver research
- Expertise recruiting minorities with cognitive impairment
- Associate Director, Inclusive Science Program
North Carolina Translational & Clinical Sciences Institute



Consuelo H. Wilkins, MD, MSCI; Professor of Medicine, Vanderbilt University and Meharry Medical College

- National leader in recruitment innovation
- Geriatrician and dementia specialist
- Senior Vice President and Senior Associate Dean for Health Equity and Inclusive Excellence
- Principal Investigator, Recruitment Innovation Center

New IDEAS

Study Overview



The overall goal of New IDEAS is to inform amyloid PET coverage decisions by studying the association of amyloid PET with changes in management of Medicare beneficiaries with cognitive impairment



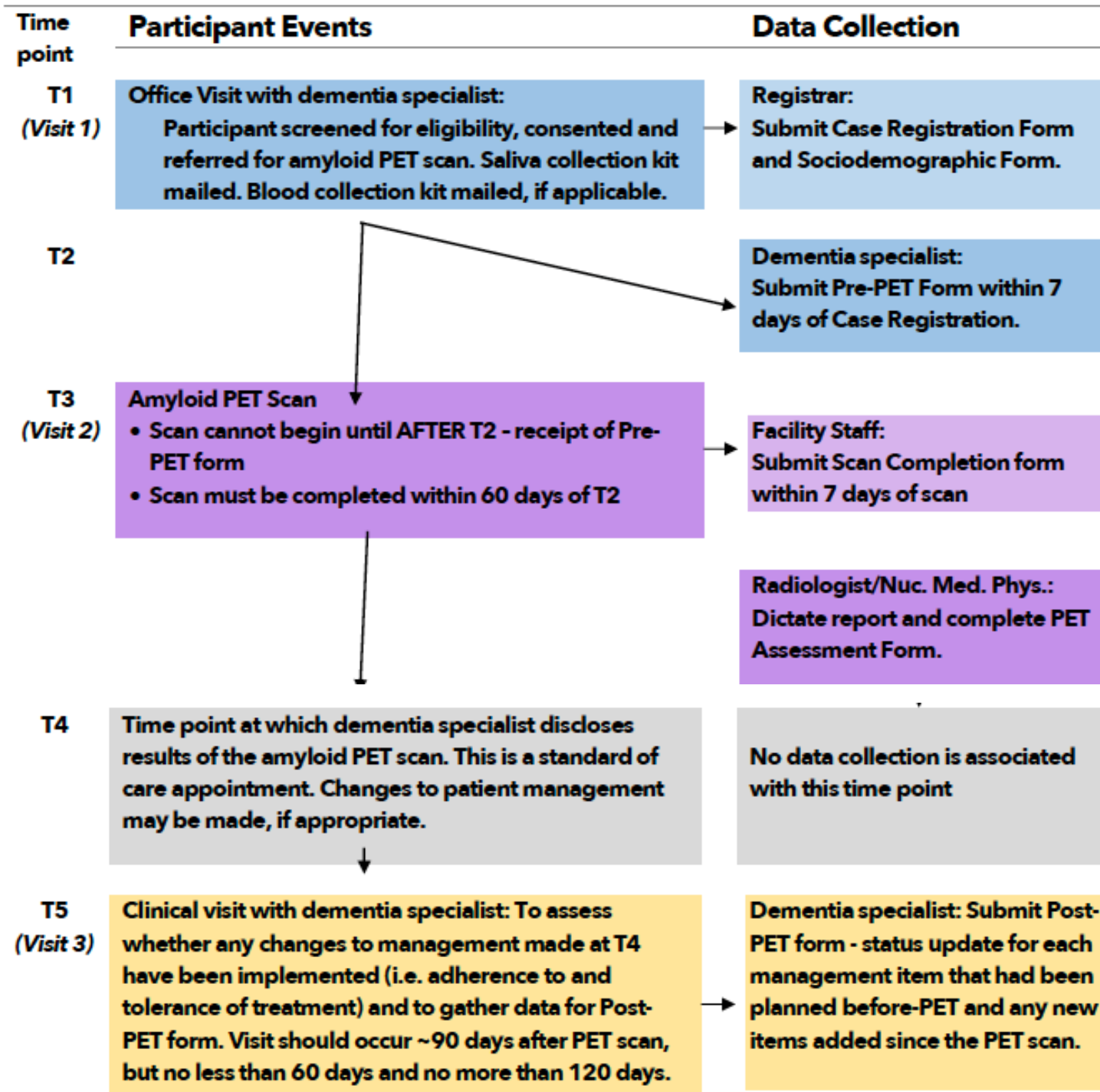
Original IDEAS study recruited 18,500 participants, less than 10% were racial/ethnic minorities



New IDEAS is an open, label longitudinal cohort study that will address gaps in original IDEAS study by recruiting 4,000 Black/African American and Latino/Hispanic patients as well as 3,000 from the general population

New IDEAS

SCHEMA and Study Visits



Comprehensive Approach to Minority Recruitment

Goal: Address study-specific and common barriers

Common Barriers

Scientist –level barriers

- lack of innovative recruitment strategies
- lack relationships with community orgs
- few, if any, minority researchers or staff

Participant-level barriers

- perceived harms, fear, mistrust
- costs, transportation, access, convenience
- info unavailable in preferred language

Study-level barriers

- budgets inadequate for recruitment
- no expertise to culturally tailor documents
- lack of culturally congruent research staff

Study-Specific Barriers

- Lack of awareness of study
- Fewer minorities referred to specialists
- Need more information about PET
- Practice sites need support for recruitment
- Need study materials for family involved in decision making
- Co-pay
- Scheduling PET

Heller et al. Strategies addressing barriers to clinical trial enrollment of underrepresented populations: a systematic review. Contemp Clin Trials. 2014;39(2):169-182.

Schmotzer GL. Barriers and facilitators to participation of minorities in clinical trials. Ethn Dis. 2012;22:226–30

Minority Recruitment Focus Areas

Rapid Start-up

Choose 1st area for rapid start-up:
Washington, D.C.

Metro Area Community Engagement

Confirm 9 high feasibility metropolitan areas.

With ALZ Assoc, begin community engagement activities (e.g., **gather feasibility survey data, identify and train ambassadors**)

National Engagement

National Awareness Campaign (e.g., **social media**)

Advisory Board (**solicit community input**)

Culturally-Adapted Recruitment Materials (e.g., **brochures, FAQs**)

Support Dementia Experts & Facilities

Identify Dementia Experts with capacity to enroll minorities (i.e., **pre-registration site feasibility questionnaire**)

Support, training, and materials for experts and facilities (e.g., **Coursera modules**)



Brain Imaging Study for Alzheimer's

Community Engagement Efforts in partnership with the Alzheimer's Association



Community Engagement Metro Areas



New IDEAS Study Champions: Who are They?



ALZ volunteers



Suggested contacts of
ALZ staff and volunteers
that are not yet formally
associated with ALZ



Other contacts from
outreach to
minority-serving or
equity-oriented
organizations

New IDEAS Study Champions: Why are they needed?

- Inform the study team of needs and interests of local communities
- Build and leverage existing trusting relationships of local communities
- Sustain long-term relationships of local communities

New IDEAS Study Champions: What do they do?



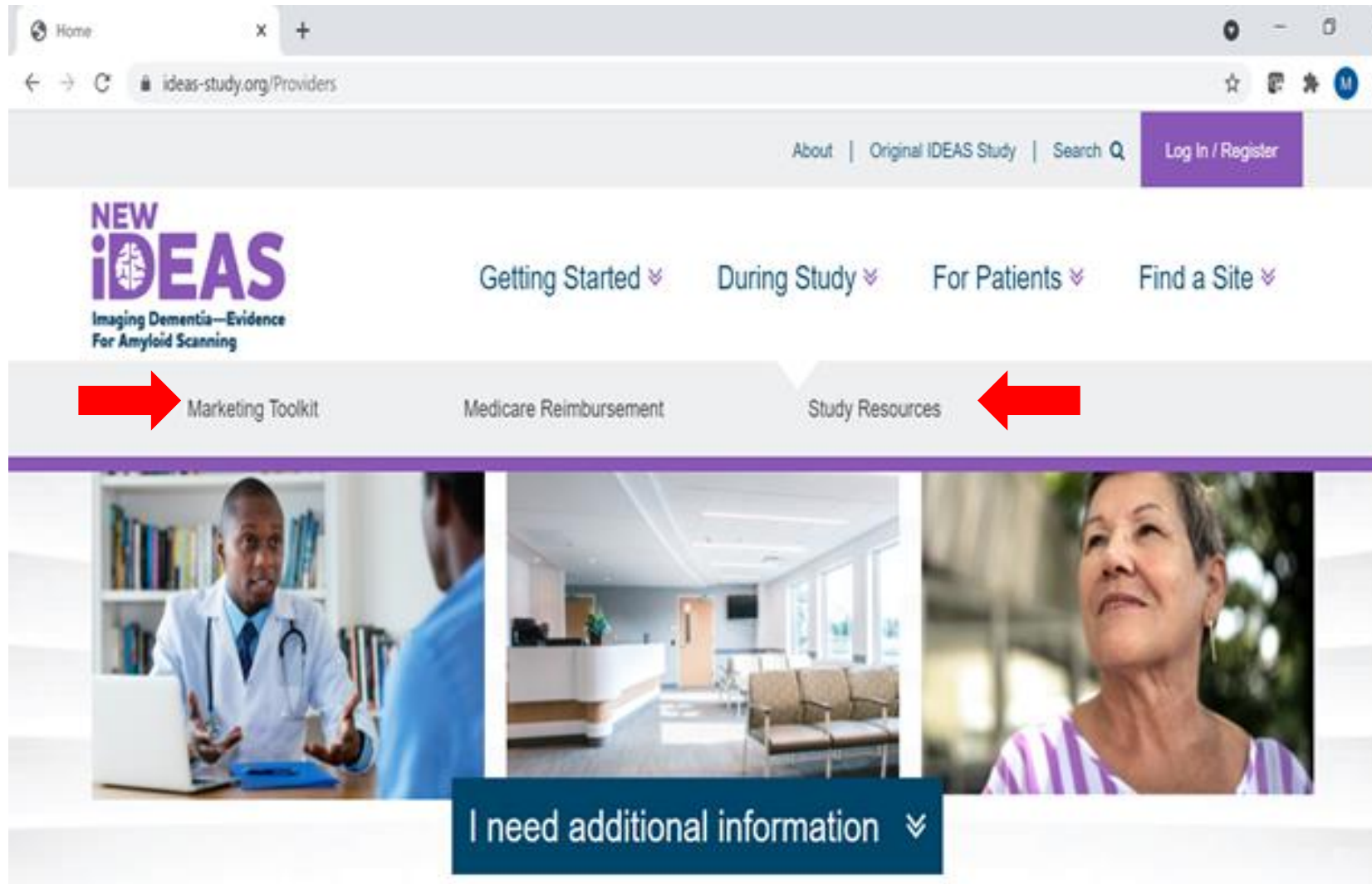


Brain Imaging Study for Alzheimer's

Recruitment Materials and Resources



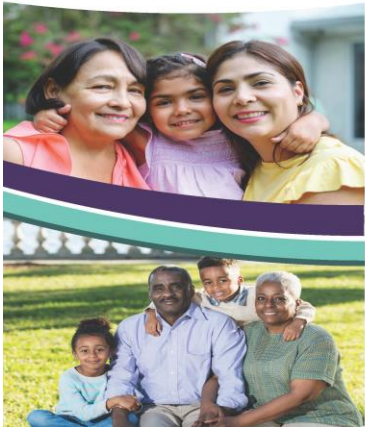
Recruitment Materials



Brochure, Poster and Flyer

Why should I join?

- Joining New IDEAS is currently the only way Medicare will cover the cost of your amyloid PET scan.
- Your memory care doctor can use your PET scan results to help diagnose and treat your memory condition.
- Your participation could lead to better care for you. It could also help your family and many others with memory loss in the future.



To learn more about the New IDEAS Study,

please contact:



866-507-7254

newideas-participant@alz.org

or visit us at:



Ideas-Study.org/PatientHome

Scan here with



smartphone camera

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Centers for Medicare &
Medicaid Services (CMS)



Have you or a loved one noticed changes in your memory and thinking?

Join us on our journey to improve medical care for people with memory loss.

New IDEAS is a research study looking for better ways to diagnose and care for people with memory loss by using FDA-approved brain imaging.

You may be able to join if:

- you or a loved one has noticed changes in your memory and thinking,
- you are seeing a memory care doctor who is part of the study, and
- you have Medicare as your primary insurance.

Taking part in New IDEAS is up to you. If you join, you can leave the study at any time.

For more information,
please contact:

866-507-7254

newideas-participant@alz.org

Potential benefits:

- Joining New IDEAS is currently the only way Medicare will cover the cost of your amyloid PET scan.
- Your memory care doctor can use your PET scan results to help diagnose and treat your memory condition.
- Your participation could lead to better care for you. It could also help your family and many others with memory loss in the future.

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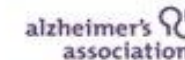
Ideas-Study.org/PatientHome



Scan here with
smartphone camera



Directed by:



Advised by: Centers for Medicare & Medicaid Services (CMS)

Sponsored and Managed by:



- Gives overview of the study & contact information
- Place in clinic areas where eligible patients may be
- Has QR code that link to participant website for more information

[IDEAS-Study.org](https://Ideas-Study.org)



What to Expect with the New IDEAS Research Study



The purpose of the New IDEAS study is to learn if your PET brain scan results help guide your memory care doctor in diagnosing and treating your memory loss.

Taking part in New IDEAS is up to you. You can leave the study at any time.

If you have any questions about the study, please be in touch!

NEW IDEAS
Brain Imaging Study for Memory Loss

1



First Study Visit

When: During a regular memory care visit

What to expect:

Your memory care doctor will help you decide if the study is right for you.

If you join the study, you will:

- answer some questions about yourself
- review your medical history and current care plan
- be given instructions for:
 - mailing in 1 saliva sample
 - having 1 **optional** blood draw at a local Quest laboratory (to be stored for future research)

2



Two More Visits

When: 2 months and 5 months after your first visit

What to expect:

You will have 2 visits:

- 1 visit for an amyloid PET brain scan
- 1 follow-up visit with your memory care doctor to review your scan results and create a personalized treatment plan

After you finish these 2 visits:

- You will continue seeing your doctor for your care.
- The study team will gather information from your health records, such as changes in diagnosis or medications you take for your memory loss. This will:
 - not take any additional time for you or your family
 - happen over the next 1-3 years
 - help us see if the PET scan results lead to better memory care for you

3



Study Updates & Findings

When: throughout study/end of study

What to expect:

We will share study updates and final study results on the New IDEAS website: Ideas-Study.org/PatientHome.

Study Costs:

- PET scan cost is covered by Medicare
- You will be responsible for:
 - PET scan deductible and copay
 - Copays for visits with your memory care doctor

Compensation:

- There is no compensation for the overall study.
- If you choose to have the optional blood draw, you will receive \$75.

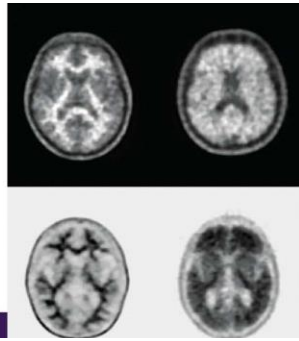
Study Info Sheet

- Brief summary of study, aims, and study procedures
- Used as an aid in the informed consent process and to provide additional study information
- Space to add label with practice contact information

NEW IDEAS
Brain Imaging Study for Alzheimer's

What is an Amyloid PET Scan?

An amyloid [am-uh-loid] PET scan is a type of medical brain imaging approved by the U.S. Food and Drug Administration (FDA). Doctors use it to find a buildup of amyloid proteins in the brain. Your doctor may refer to these as amyloid plaques [plaks]. People with Alzheimer's disease have a buildup of these proteins.

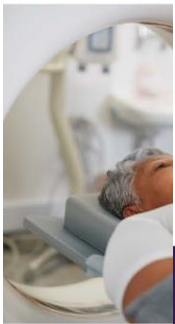


How does it work?

The scan uses a machine that uses a tiny amount of a radioactive marker. The marker is injected into the brain and causes a small amount of radiation.

Why is an amyloid PET scan important?

- It helps doctors determine if a person has Alzheimer's disease, or if they have another type of dementia.
- It can detect amyloid plaques in the brain.
- No other tests can detect amyloid plaques in the brain.



*The amyloid PET scan

What can I expect during an Amyloid PET Scan?

This outpatient procedure takes a total of about 1-2 hours to complete. You:

- can take your regular medicines the day of your appointment
- do not have to stop eating or drinking before your scan
- can have a loved one be with you up until the time you have the scan done

PET facilities can vary a bit, but generally the scan includes the following steps:

- 1 A member of the radiology staff with expertise in PET scans will be there to help you before, during, and after the scan.
- 2 You will be given a tiny amount of the imaging marker through an IV. It takes about 30-60 minutes for the marker to attach to any amyloid protein buildup in your brain. During this time, the staff member will have you lay back and relax, and make sure you are comfortable while you wait.
- 3 Once you are ready, the staff member will help you lay down on a padded table for the scan. The table will slowly move you into the scanner. You will be asked to be fairly still for a short period of time while the PET scanner takes images of your brain (10-20 minutes).
- 4 When the scan is complete, the radiology staff member will review your scan to make sure it is of good quality, and then you are all done!

What can I expect after the scan?

- You can carry on with your regular activities (unless your memory care doctor tells you differently).
- You will need to drink lots of water to wash the imaging marker out of your body. (Your local PET facility will send recommendations about fluid amounts to you before your appointment.)
- Your memory care doctor will contact you as soon as your amyloid PET scan results are available.
- You will go over the amyloid PET scan results with your memory care doctor at a follow-up visit and receive a personalized treatment plan.

Amyloid PET Scan Info Sheet

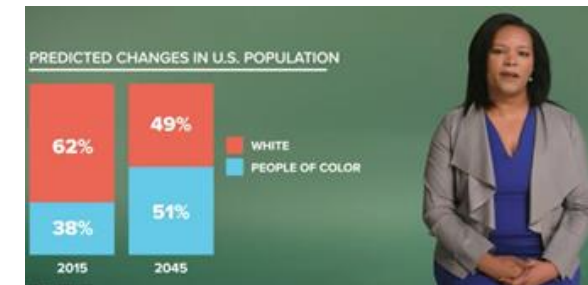
- Defines Amyloid PET scan and procedure
- Purpose is to alleviate fears and dispel myths surrounding PET Scans
- Give to patients during, before, or after informed consent, whenever most appropriate

Recruitment Resources

- FasterTogether
 - Free course on Coursera
<https://www.coursera.org/learn/recruitment-minorities-clinical-trials>
 - Enhance recruitment of racial and ethnic minorities in clinical trials
- Community Outreach Guide
 - How to "normalize" clinical trials in your communities



What are your recruitment barriers and challenges?
How can we assist?





Brain Imaging Study for Alzheimer's

New IDEAS Recruitment and Engagement Email
newideas_recruitment@vumc.org

