

# Caregivers Reactions and Experience: Imaging Dementia Evidence for Amyloid Scanning CARE IDEAS

<https://neurodegenerationresearch.eu/survey/caregivers-reactions-and-experience-imaging-dementia-evidence-for-amyloid-scanning-care-ideas/>

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### Country

USA

## Title of project or programme

Caregivers Reactions and Experience: Imaging Dementia Evidence for Amyloid Scanning  
CARE IDEAS

## Source of funding information

NIH (NIA)

## Total sum awarded (Euro)

€ 1,355,777.06

## Start date of award

01/09/2016

## Total duration of award in years

1

## The project/programme is most relevant to:

Alzheimer's disease & other dementias

## Keywords

Acquired Cognitive Impairment... Aging... Alzheimer's Disease... Alzheimer's Disease including Alzheimer's Disease Related Dementias (AD/ADRD)... Behavioral and Social Science...

Bioengineering... Brain Disorders... Caregiving Research... Clinical Research... Clinical Research - Extramural... Dementia... Diagnostic Radiology... Health Services... Neurodegenerative... Neurosciences... Palliative Care... Prevention

## **Research Abstract**

**ABSTRACT** An estimated 5.3 million Americans have Alzheimer's Disease (AD) in 2015. Barring scientific innovations, the number of Americans with AD is expected to increase to over 7 million by 2025 and to 13.8 million by 2050. In 2013 the Centers for Medicare and Medicaid Services (CMS) established that amyloid PET scans would be covered under the CMS Coverage with Evidence policy and the Imaging Dementia – Evidence for Amyloid Scanning (IDEAS) study was established. IDEAS examines how amyloid PET scans can guide doctors in diagnosing AD and other dementias, early in disease progression, where the cause is ambiguous, leading to changes in clinical management. With recruitment of 18,500 Medicare beneficiaries scheduled to begin in early 2016, supplemental studies expanding on the rich clinical data are being proposed. Thus, with full support of the IDEAS Executive Committee and the Alzheimer's Association, we propose the 5 year Caregiver Reactions and Experiences – IDEAS supplemental study (CARE IDEAS). It will fill important gaps in our understanding of how spouses serving as caregivers/advocates and patients react to the results of amyloid PET scans. We propose to recruit and interview, at baseline (phone), 6-9 months (phone and web), and 18 months (phone) a sample of 3500 Medicare eligible patients and their Medicare eligible spouses from among patients in the IDEAS study with positive and negative Amyloid PET scans. Using the National Health and Aging Trends Study as the survey core, we will ask patients' about their social circumstances, behavioral consequences of memory deficits and how and why they sought to confirm a diagnosis of AD via amyloid PET. We will also characterize spouses' health literacy, the breadth and resiliency of their support system and their involvement in seeking a PET scan. Using these survey data merged with IDEAS clinical and Medicare claims data, we will: (Aim 1) estimate the relationship between a positive Amyloid PET scan and patients' receipt of Medicare reimbursed AD related diagnostic tests and health care expenditures, controlling for selected patient and spouse characteristics. Second, we will (Aim 2) estimate the effect of primary care integration and engagement with patients' earlier diagnostic testing experience on the receipt of Medicare reimbursed AD related diagnostic tests and health care expenditures in future years; Third, (Aim 3) we will estimate the effect of amyloid PET scan results on patients' participation in care and life planning at follow-up (i.e. completing advanced directives, altered medical treatment plans and undertaking estate planning), controlling for patient and spouse characteristics. Fourth, (Aim 4) we will estimate the effect of the patients' test results on spouses' symptoms of depression and mental health service use. Finally, (Aim 5) we will use a web-based survey and follow up phone calls at 6 to 9 months post-enrollment to characterize intermediate changes in medical care use, life planning and other adjustments patients and spouses attribute to hearing and understanding their amyloid PET scan test results.

## **Lay Summary**

**PROJECT NARRATIVE** The proposed CARE IDEAS study will fill important gaps in our understanding of how informal caregivers and patients react to the results of Amyloid PET scans. We propose to recruit and interview, at baseline (phone), 6 months (phone and web), and 18 months (phone) a sample of 2500 Medicare eligible patients and their spouses in the IDEAS cohort from among patients with positive and negative Amyloid PET scans. This study of patients receiving experimental amyloid PET scan diagnostic tests for Alzheimer's Disease

seeks to understand the influence of having a positive test result on the decision to seek additional diagnostic testing and whether some patients and their spouses are more or less likely to pursue more testing.

**Further information available at:**

**Types:**

Investments > €500k

**Member States:**

United States of America

**Diseases:**

Alzheimer's disease & other dementias

**Years:**

2016

**Database Categories:**

N/A

**Database Tags:**

N/A