

Advisory Council on Alzheimer's Research, Care, and Services

Fall 2024 Meeting



October 21, 2024

U.S. Department of Health and Human Services

Materials available at: <http://tinyurl.com/NAPAm meetings>



OFFICE OF BEHAVIORAL HEALTH,
DISABILITY, AND AGING POLICY

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AHRQ Updates

Arlene S. Bierman, M.D., M.S.

Director, Center for Evidence and Practice Improvement
Agency for Healthcare Research and Quality

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State-based Healthcare Extension Cooperatives



[National Coordinating Center for AHRQ's Healthcare Extension Service - State-based Solutions to Healthcare Improvement \(U54\)](#)

[National Evaluation Center for AHRQ's Healthcare Extension Service: State-based Solutions to Healthcare Improvement \(U19\)](#)

These notices follow a recent [Notice of Funding Opportunity](#) to award up to 15 grants for state-based [Healthcare Extension Cooperatives](#) to accelerate the dissemination and implementation of patient-centered outcomes research evidence into healthcare delivery. The [National Coordinating Center](#) will provide technical assistance, learning networks and communications and dissemination guidance to the Healthcare Extension Cooperatives.

The [National Evaluation Center](#) will assess program implementation and impact. Information about a technical assistance webinar for this funding announcement is forthcoming. Questions may be submitted to AHRQ_HES@ahrq.hhs.gov.

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Health Extension Service and Person-Centered Care



- There is “interest in interventions that could be **transformational** in nature, providing **whole-person, person-centered care**, potential for **addressing health-related social needs**, and **tailoring interventions across the life course.**”
- There is opportunity for states to propose or incorporate person-centered approaches to improving care. This also provides the opportunity to address the needs of older adults and those living with or at risk for MCC.

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eCarePlanner: Goals

Goals

Noelle, Patricia DOB: 11/1/1963 Race: Black or African American Age: 60
 Sex: Female Ethnicity: Not Hispanic or Latino

Goals Health Concerns Maintenance & Interventions Health Evaluations & Outcomes Care Team

Goal	Achievement Status	Expressed By	Most Recent Result	Importance	Readiness	Confidence	Target Date ↑
Walk around the block without pain	In-Progress	Patricia Noelle	-	6	4	5	04/14/2023
Eliminate or reduce need for pain medication	In-Progress	Dr. Sarah N	-	-	-	-	02/15/2023
Blood pressure < 140/90	In-Progress	Dr. John Carlis	143/91	-	-	-	11/20/2022
Home delivery of dietary-recommended prepared food 3x per week	In-Progress	Sam R	-	-	-	-	01/12/2020

Rows per page: 10 1-4 of 4 < >

Ability for patient to describe their importance, readiness, and confidence ranking for each goal

Person who made the goal (can be patient, clinician, caregiver)

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Person-Centered Care Planning AHRQ RFI Analysis

Person-Centered Care Planning for People Living with or at Risk for Multiple Chronic Conditions



Qualitative study of PCCP for people living with or at risk for MCC, challenges to widescale adoption of PCCP were identified along with strategies to address these challenges including the alignment of payment, policy support, culture change, adoption of meaningful measures, and the need for evidence on strategies to scale and spread PCCP.

<https://jamanetwork.com/journals/jamanetworkopen/fullarticle/2824977>

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Quarterly Updates

Alisha A. Etheredge, MS, MPH
Lead, Alzheimer's Disease Program Team

National Center for Chronic Disease Prevention and Health Promotion
 Division of Population Health, Healthy Aging Branch
 Presented October 21, 2024 at the National Alzheimer's Project Act (NAPA) Advisory Council
 Quarterly Meeting

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Juan Rodriguez, PhD

CDC Healthy Aging Branch Chief



- 18 years in CDC's Division of Cancer Prevention and Control as Senior Epidemiologist, Lead of Epidemiology Team, and Acting Branch Chief in Epidemiology and Applied Research Branch
- BS from University of Central Florida
- MPH in Epidemiology from University of Florida
- MS in Research Methods and Statistics from Georgia State University
- PhD in Behavioral, Social, and Health Education Sciences from Emory University

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CDC Caregiver Publication

Changes in Health Indicators Among Caregivers — United States, 2015–2016 to 2021–2022

Morbidity and Mortality Weekly Report

Health Snapshot of U.S. Caregivers

- 1 in 4 has depression
- 1 in 5 experiences frequent mental distress
- 2 in 3 have a chronic physical health condition

*Based on 2021–2022 survey data.

Changes in Health Indicators Among Caregivers — United States, 2015–2016 to 2021–2022

Greta Kilmer, MS¹; John D. Omura, MD¹; Erin D. Boukdin, PhD^{1,2}; Jenny Walker, MS^{1,3}; Katie Spears, MPH^{1,3}; Janelle Gore, MPH⁴; Akilah R. Ali, MPH¹; Lisa C. McGuire, PhD¹

Abstract

Caregivers provide support to persons who might otherwise require placement in long-term care facilities. Approximately one in five U.S. adults provides care to family members or friends who have a chronic health condition or disability. Promoting the well-being of this large segment of the population is a public health priority as recognized by the 2022 National Strategy to Support Family Caregivers. Although negative associations between caregiving and caregiver health are known, changes in the health status of caregivers over time are not. Data from the 2015–2016 and 2021–2022 Behavioral Risk Factor Surveillance System were analyzed to compare changes in the prevalence of 19 health indicators among cross-sectional samples of caregivers and noncaregivers at different time points. Caregivers experienced improvements in prevalence of four health indicators, whereas six worsened. Some health indicators, such as cigarette smoking, improved for both caregivers and noncaregivers, although smoking prevalence remained higher for caregivers (16.6%

caregivers (2). During 2015–2017, caregivers in the generation born during 1946–1964 had more chronic health conditions and more frequent mental distress than noncaregivers of the same age (3). Although studies have described differences in health indicators between caregivers and noncaregivers (4,5), this report compares changes in the prevalence of 19 health indicators among caregivers and noncaregivers from 2015–2016 to 2021–2022.

Methods

Data Source

The Behavioral Risk Factor Surveillance System (BRFSS) is an annual, state-based, random-digit-dialed telephone survey of the noninstitutionalized U.S. adult population aged ≥18 years in all 50 states, the District of Columbia, and U.S. territories.* In addition to core questions administered to all participants, states can include optional modules. Data from the core BRFSS questionnaire and the optional caregiver module during 2015–2016 and 2021–2022 were assessed

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Notice of Funding Opportunity (NOFO) Forecast on Grants.gov

CDC-RFA-DP-25-0014

Public Health Strategies to Address Alzheimer's Disease and Related Dementias: The National Healthy Brain Initiative, BOLD Public Health Centers of Excellence, and Public Health Adoption Accelerator



Notice of Funding Opportunity (NOFO) Forecast on Grants.gov

The screenshot shows the Grants.gov website interface. At the top, there is a navigation menu with links for Home, Learn Grants, Search Grants, Applicants, Grantors, System-To-System, Forms, Connect, and Support. A search bar is located in the top right corner. The main content area is titled "VIEW GRANT OPPORTUNITY FORECAST" and displays details for a specific grant opportunity: CDC-RFA-DP-25-0014. The grant title is "Public Health Strategies to Address Alzheimer's Disease and Related Dementias: The National Healthy Brain Initiative, BOLD Public Health Centers of Excellence, and Public Health Adoption Accelerator". Below the title are several buttons: FORECAST, VERSION HISTORY, RELATED DOCUMENTS, and PACKAGE. A red "Subscribe" button is highlighted with a blue box and a blue arrow pointing to it. A text box next to the button says "Click the red 'Subscribe' button to receive alerts when updates are made to the forecast." The number "13" is visible in the bottom right corner of the screenshot.

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Projects Funded under the National Partners Cooperative Agreement (CDC-RFA-PW-24-0080)

Education for Healthcare Workers Navigating Brain Health and Dementia

Understanding and Advancing State-Level Policies to Support Brain Health and Caregiving

Integrating Brain Health Messaging in Chronic Disease Programs and Facilitating Collaboration among BOLD Public Health Programs

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Projects Funded under the National Partners Cooperative Agreement (CDC-RFA-PW-24-0080)

Development, Implementation, and Evaluation of an Evidence-based Brain Health Approach



NATIONAL ASSOCIATION OF CHRONIC DISEASE DIRECTORS
Promoting Health. Preventing Disease.

Equipping Community Health Workers in Rural Areas to Address Alzheimer's Disease and Related Dementias



NATIONAL ASSOCIATION OF CHRONIC DISEASE DIRECTORS
Promoting Health. Preventing Disease.



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Learning Module for Public Health Now Available

Watch the launch webinar of the new "Understanding the Public Health Impact of Dementia" learning module to learn about the content and how public health professors and professionals plan to use the module.



New Learning Module

UNDERSTANDING THE PUBLIC HEALTH IMPACT OF DEMENTIA

HEALTHYBRAIN INITIATIVE

Curriculum website: alz.org/publichealthcurriculum

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HBI Road Map for American Indian and Alaska Native Peoples

- Development of the next edition of the Road Map for Indian Country – renamed the **Healthy Brain Initiative: Road Map for American Indian and Alaska Native Peoples** – is complete.
- New Road Map is under review in CDC clearance and will be released in November 2024
- [Progress Update](#) available on the Alzheimer’s Association [website](#)

HBI Road Map for Indian Country: Progress Update
Published May 2024

This document represents the progress to create the next version of the Healthy Brain Initiative Road Map for Indian Country – to be renamed the Healthy Brain Initiative: Road Map for American Indian and Alaska Native Peoples – as of May 2024.

In fall 2023, the Alzheimer’s Association[®] and the Centers for Disease Control and Prevention (CDC) initiated the development of the second Healthy Brain Initiative (HBI) Road Map for Indian Country. The first-ever HBI Road Map for Indian Country was published in May 2019, to serve as a public health guide for American Indian and Alaska Native leaders to learn about dementia and start discussions throughout their communities. This second edition will be titled Healthy Brain Initiative: Road Map for American Indian and Alaska Native Peoples and will follow the format of the fourth edition of the HBI Road Map for State and Local Public Health.

This new publication will build on the progress and momentum to date and guide professionals working with American Indian and Alaska Native peoples to advance the vision that everyone deserves a life with the healthiest brain possible. This progress update summarizes the Road Map development process and reflects changes that have been made since the conclusion of the open input period (described below) and the in-person meeting of the Leadership Committee.

BROAD ENGAGEMENT

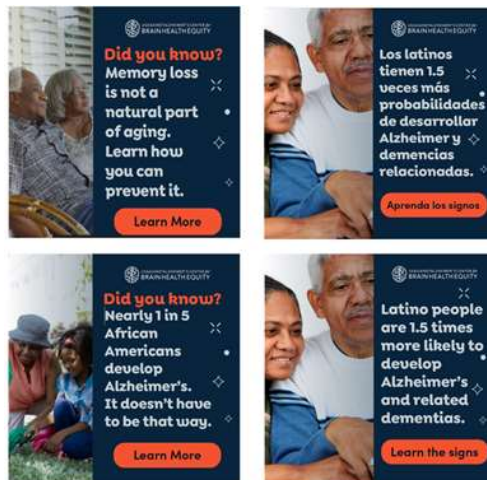
A key feature of the HBI Road Map Series development process is to engage multiple sectors and groups that will utilize the Road Map to identify priorities, inform strategy and support sustainable implementation and impact. Two methods are being used to engage, elicit input and foster collaboration from tribal leaders and communities.

1. **Leadership Committee Conventions.** In October 2023, the Alzheimer’s Association and CDC invited 19 experts and tribal leaders to join the Road Map for Indian Country Leadership Committee. The committee convened virtually in November to inform the open input period (see below) and again in-person in March 2024 to review the feedback and provide input on draft actions for the Road Map. The meetings provided an opportunity to share actions being taken to address brain health in tribal and urban communities and opportunities for the future. Committee members discussed a broad spectrum of significant dementia concerns and the role of public health in addressing these concerns. In-depth topics included national efforts that shape health care and data access, the role of caregivers and community members, workforce training needs and the importance and significance of the graphics and images used in the Road Map.
2. **Listening Sessions and Open Input Period.** The Alzheimer’s Association invited feedback on the existing HBI Road Map for Indian Country from tribal and non-tribal public health organizations and individuals to inform the development of the second edition. The Association received input from 207 individuals through an online feedback form and virtual listening sessions hosted by Leadership Committee members.

Community Education: Digital Media Campaign

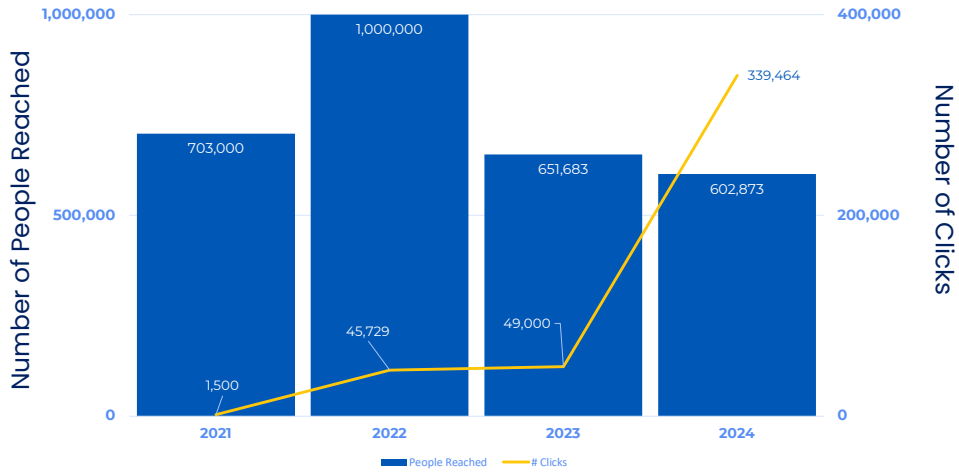


- UsAgainstAlzheimer’s used NADEX¹ and PLACES² to identify 6 cities/metropolitan areas as focus areas for disseminating ADRD prevention messaging
- Disseminated 2 culturally tailored messages per priority population
- Ads lead to custom-created landing page on BrainGuide site with culturally tailored information



¹ National Alzheimer’s Disease Index (NADEX)
² Population Level Analysis and Community Estimates (PLACES)

Despite a decrease in the number of people reached in 2023 and 2024 compared to 2022, the 2024 campaign saw a significant increase in engagement, with over 339,000 clicks – a dramatic rise from previous years, indicating improved effectiveness in capturing audience interest and driving action.



New CDC Alzheimer's Disease Program Website

An official website of the United States government. Here's how you know



Alzheimer's Disease Program

Q SEARCH

About the Alzheimer's Disease Program

VIEW ALL >



BOLD Infrastructure for Alzheimer's Act
Learn about the BOLD Infrastructure for Alzheimer's Act.



National Healthy Brain Initiative
The Healthy Brain Initiative



<https://www.cdc.gov/aging-programs/index.html>

CDC Alzheimer's Disease Program
<https://www.cdc.gov/aging-programs/about>

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For more information, contact CDC
1-800-CDC-INFO (232-4636)
TTY: 1-888-232-6348 cdc.gov
Follow us on X (Twitter) @CDCgov & @CDCEnvironment

The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the U. S. Centers for Disease Control and Prevention.

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FDA/Duke Margolis Virtual Public Meeting


Mortality and Antipsychotic Use in Dementia-related Behavioral Disorders

December 10, 2024



12:00-4:00 pm ET

<https://duke.is/5/pgva>

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INDIAN HEALTH SERVICE


The IHS Alzheimer's Program – Major Highlights

Division of Clinical and Community Services
Office of Clinical and Preventive Services
Indian Health Service

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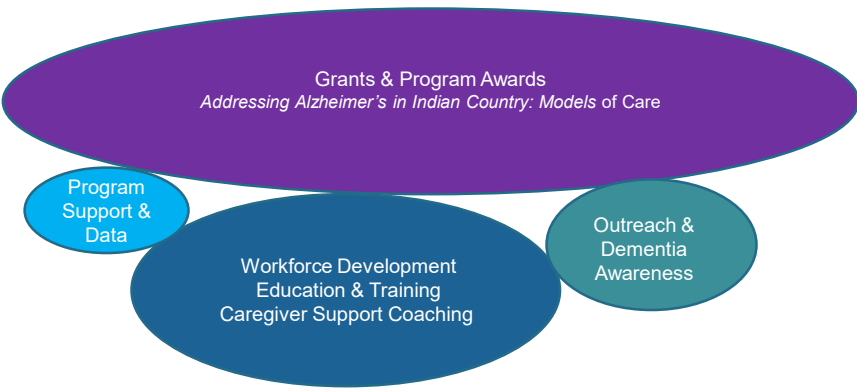
NAPA Advisory Council Federal Update
October 21, 2024

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INDIAN HEALTH SERVICE

IHS Alzheimer's Program



Grants & Program Awards
Addressing Alzheimer's in Indian Country: Models of Care

Program Support & Data

Workforce Development
 Education & Training
 Caregiver Support Coaching

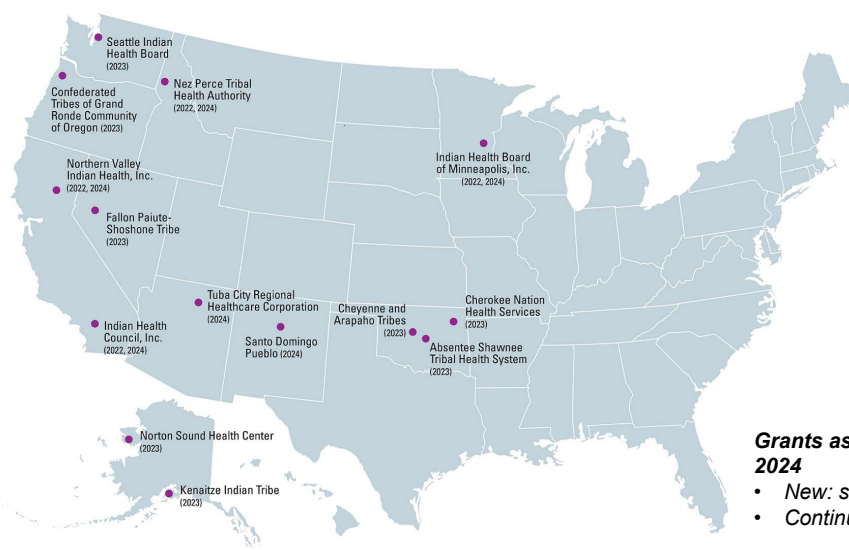
Outreach & Dementia Awareness

Funding:
 FY 2021: \$5M
 FY 2022 - FY 2025: \$5.5M

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INDIAN HEALTH SERVICE

“IHS Awards Nearly \$1.2 Million Addressing Alzheimer’s Disease during World Alzheimer’s Month”



Grants as of September 2024

- *New: six 3-year*
- *Continuing: eight 2-year*

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INDIAN HEALTH SERVICE

Training and Workforce Development Highlights

“IHS Announces Alzheimer’s Program Training and Education Contract Award”



Geriatric Nurse Fellowship – Now Recruiting



Indian Health GeriScholars – New Cohort Selected



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“IHS Alzheimer's Program Promotes Training For Early Dementia Detection”

Mini-Cog Video Series & Outreach Activities

CHR Mini-Cog Pilot Program – Now Recruiting



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Research Published



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INDIAN HEALTH SERVICE

Indian Health System Caregiving Workgroup Established



**Take care of
yourself so you can
take care of the
people you love**

#ENDALZ
IHS ALZHEIMER'S PROGRAM



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INDIAN HEALTH SERVICE

For More Info

The IHS Alzheimer's Program

- www.ihs.gov/alzheimers/

Education and training resources and opportunities

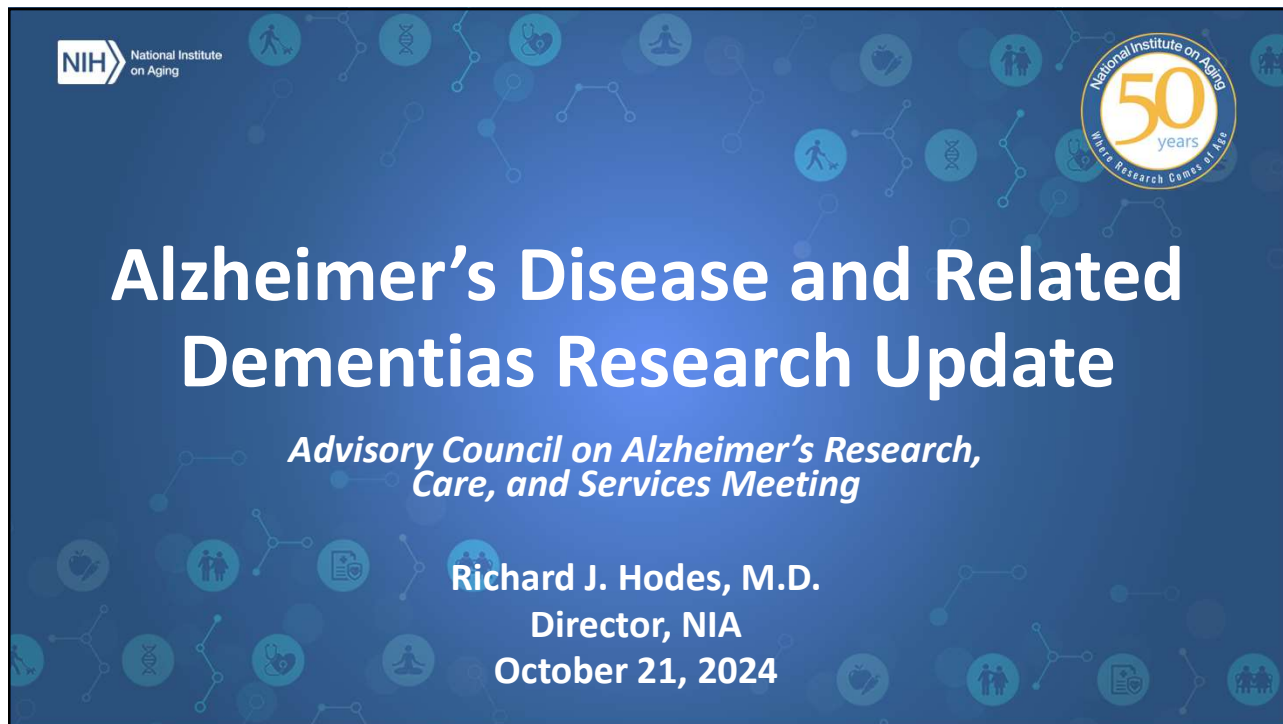
- www.ihs.gov/alzheimers/alztraining/

Dementia information and links


- www.ihs.gov/alzheimers/informationresources/alzdemtiaresources/

Stay Connected and join the [IHS Elder Care Listserv](https://www.ihs.gov/alzheimers/)
at www.ihs.gov/alzheimers/

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NIH National Institute on Aging



Alzheimer's Disease and Related Dementias Research Update

Advisory Council on Alzheimer's Research, Care, and Services Meeting

Richard J. Hodes, M.D.
Director, NIA
October 21, 2024

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NIH National Institute on Aging

NIA Updates

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2024 NIH Alzheimer’s Research Summit



- The 2024 Alzheimer’s Research Summit highlighted a decade of progress towards precision medicine and the vision for future progress.
- Major themes included disease complexity, shared causal mechanisms of dementias, resilience and resistance to Alzheimer’s and bringing advances into the translational space, understanding neuropsychiatric symptoms in AD/ADRD, and more.
- 1100+ in-person and virtual attendees

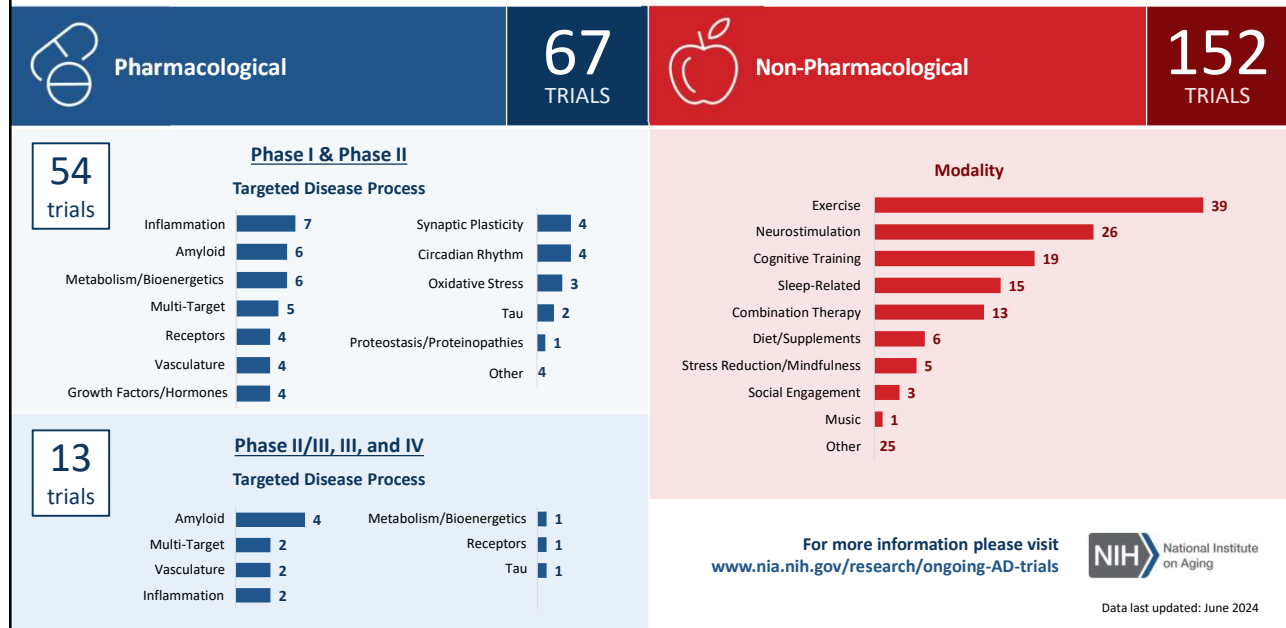


<https://www.nia.nih.gov/2024-alzheimers-summit>

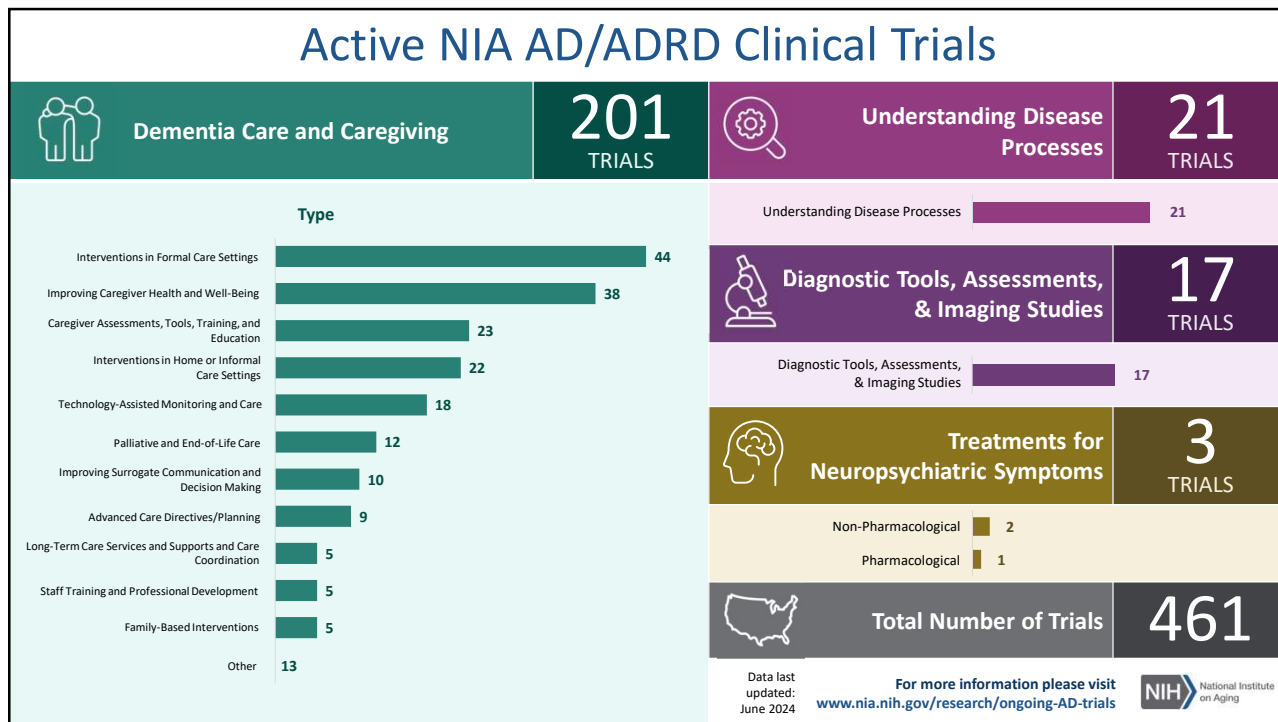
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Active NIA AD/ADRD Clinical Trials




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A4 Study Clinical Trial Data is Available

- Trial data and biosamples from the pivotal **Anti-Amyloid Treatment in Asymptomatic Alzheimer’s (A4) Study** are now available for download and exploration by the scientific community.
- Part of the Accelerating Medicines Partnership® Program for Alzheimer’s Disease, the A4 study was a multisite trial that tested whether the investigational anti-amyloid drug solanezumab would slow cognitive decline in the earliest stages of Alzheimer’s.
- Although the results of the A4 trial demonstrated that the drug did not meet its primary endpoints, its early and sustained data and biosample sharing set a new precedent.



Access the data in three easy steps.

- 01 Register with the site and set up an authenticator.
- 02 Fill out a profile with personal and project information.
- 03 Sign a data use agreement and request access to the desired dataset.



www.a4studydata.org

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Recent AD/ADRD Cleared Concepts From NACA Meetings

Approved concepts indicate areas of special interest for NIA and often evolve into funding opportunity announcements to spur activity in given areas of research.

Select Concepts:

- Digital Technologies as Tools to Screen and Monitor AD/ADRD
- Data Coordinating Center for the Aging and Alzheimer's Disease Mouse Brain Atlas (AD-MBA)
- Dementia Care and Caregiver Support Intervention Research — Stage I Only
- Dementia Care and Caregiver Support Intervention Research — Stages II through V
- Interdisciplinary Research to Understand the Complex Biology of Resilience to AD/ADRD Disease Risk
- Institutional Research Training Award for AD/ADRD And Aging Research in Low- and Middle-Income Countries (LMICs)
- National Alzheimer's Coordinating Center (NACC)
- National Centralized Repository for Alzheimer's Disease and Related Dementias (NCRAD)
- Translational Center for Accelerating the Use of Digital Technologies in AD/ADRD Research



For the full list of cleared concepts: <https://www.nia.nih.gov/approved-concepts>

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EUREKA Challenge for Early Prediction of AD/ADRD

- The PREPARE: Pioneering Research for Early Prediction of Alzheimer's and Related Dementias EUREKA Challenge **seeks to advance solutions for accurate, innovative, and representative early prediction of AD/ADRD.**
 - **Phase I: Find IT!** – Identifying, accessing, and/or building representative, inclusive, open, shareable datasets that can be used for early prediction of AD/ADRD. **Five winners were announced in September 2024.**
 - **Phase II: Build IT!** – Advancing state-of-the-art, ethical, and inclusive algorithm and analytic approaches with an emphasis on explainability of predictions. **Launching soon!**
 - **Phase III: Put IT all together!** – Demonstrating algorithmic approaches on diverse datasets and sharing results.



PREPARE: Pioneering Research for Early Prediction of Alzheimer's and Related Dementias EUREKA Challenge



Intended cash awards totaling \$650,000



<https://www.challenge.gov/?challenge=prepare-challenge>

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NINDS Updates

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First National Center Without Walls (CWOW) for the Science of Vascular Contributions to Cognitive Impairment and Dementia (VCID)

6 CWOWs established under [RFA-NS-24-027](#):

- White matter lesions, inflammation, impact on circuits
- CAA mechanisms and targets, multiple etiology dementias
- Atherosclerosis, hyperlipidemia, inflammation/immune
- CAA, microglial dysfunction, ApoE
- White matter lesions, arteriolosclerosis, CAA, AD pathology
- CADASIL, CAA, neurovascular uncoupling

Goal: To generate, via a collaborative CWOW, foundational VCID knowledge via parallel discovery and confirmation in human- and model-based small vessel VCID studies for future development of interventions including for prevention and better clinical outcomes.

VCID CWOW: NS139972-01 (Hinman), NS139948-01 (Howell), NS139949-01 (Arispe), NS139975-01 (Yang), NS139970-01 (Lee), NS140137-01 (Dabertrand).

- Sites
- Cross CWOW Coordinating Team
- Subcontracts

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Alzheimer's Disease-Related Dementias Summit 2025

Scientific Chair:
Dr. Katherine Possin, UCSF



The purpose of the Alzheimer's Disease-Related Dementias (ADRD) Summit is to set consensus national research recommendations that reflect critical scientific priorities for ADRD research.

Save the Date: March 25th-26th, 2025

NIH Lead: Dr. Amber McCartney (amber.mccartney@nih.gov)
Summit website: <https://www.ninds.nih.gov/news-events/events/adrd-summit-2025>






NINDS ADRD funding opportunities:
<https://www.ninds.nih.gov/current-research/focus-disorders/focus-alzheimers-disease-and-related-dementias>



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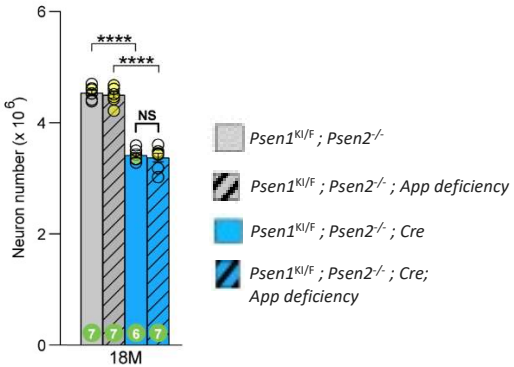


New finding: Neurodegeneration caused by loss of presenilin function in mouse model of genetic AD

Report suggests that neurodegeneration in a genetic form of Alzheimer's disease dementia occurs in absence of beta-amyloid

- In this study, a severe familial Alzheimer's gene, called *Psen1* L435F, was studied in mice
- This research tested the hypothesis that beta-amyloid and APP are required for neurodegeneration caused by *Psen1* L435F
- Removing APP, and thus beta-amyloid, completely from mouse models and found no impact on neurodegeneration caused by *Psen1* L435F

APP deficiency does not affect neurodegeneration caused by *Psen1* mutations



Neuron number (x 10⁶)


18M

- Psen1*^{KI/F}; *Psen2*^{-/-}
- Psen1*^{KI/F}; *Psen2*^{-/-}; App deficiency
- Psen1*^{KI/F}; *Psen2*^{-/-}; Cre
- Psen1*^{KI/F}; *Psen2*^{-/-}; Cre; App deficiency

NIH National Institute of Neurological Disorders and Stroke

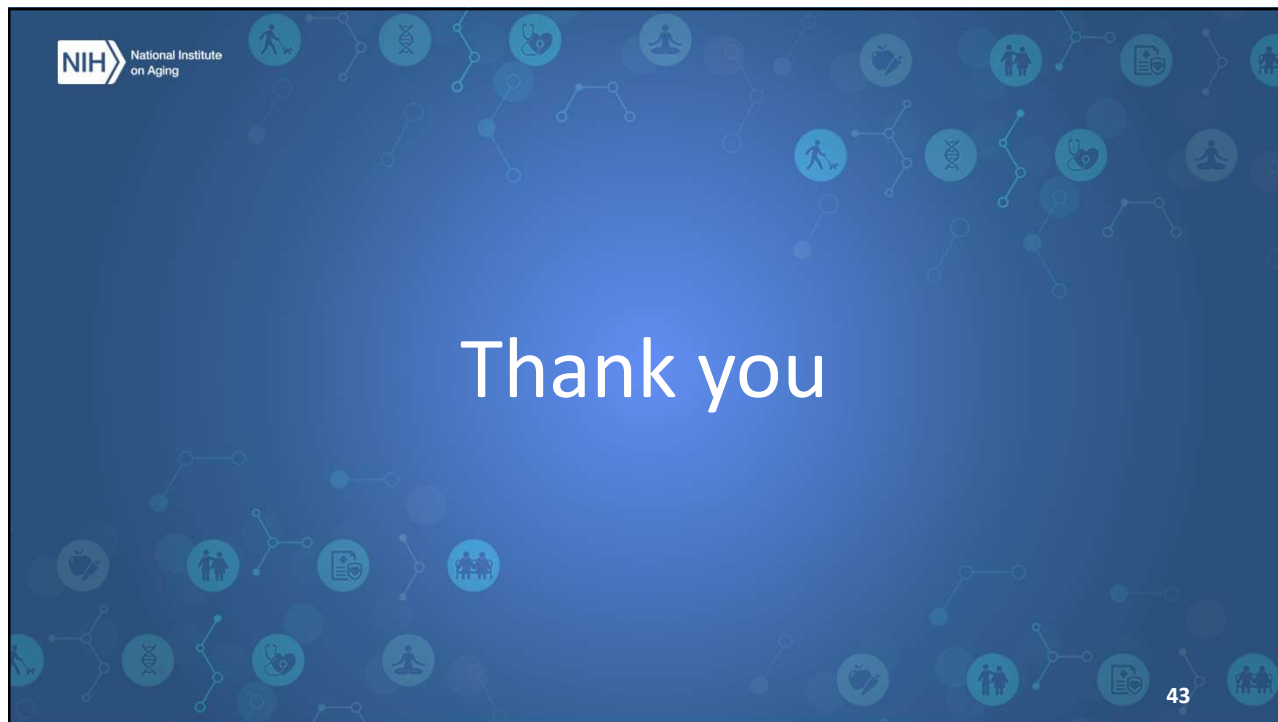
NIH National Institute on Aging

Kuo Yan *et al.*, *Proc Natl Acad Sci U S A.*, 121(34):e2409343121 (2024)
(Supported by NIH grants R01NS041783 and RF1AG063520)



Read more in the NINDS News Brief

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