

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

Spring 2024 Meeting



April 29 -30, 2024

U.S. Department of Health and Human Services
Materials available at: <http://tinyurl.com/NAPameetings>



OFFICE OF BEHAVIORAL HEALTH,
DISABILITY, AND AGING POLICY

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Federal Updates

- Administration for Community Living (ACL)
- Agency for Healthcare Research and Quality (AHRQ)
- Office of the Assistant Secretary for Planning and Evaluation (ASPE)
- Centers for Disease Control and Prevention (CDC)
- Centers for Medicare & Medicaid Services (CMS)
- Department of Defense (DoD)
- Indian Health Service (IHS)
- National Institutes of Health (NIH)



OFFICE OF BEHAVIORAL HEALTH,
DISABILITY, AND AGING POLICY

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Administration for Community Living

April 29, 2024

Erin Long, MSW
Team Lead, Alzheimer's & Dementia Programs
Administration on Aging
Administration for Community Living



Administration for Community Living


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**Alzheimer's Disease Programs Initiative (ADPI)
State and Community Program
Notice of Funding Opportunity**

[HHS-2024-ACL-AOA-ADPI-0029](#)

Applications due Tuesday, June 11, 2024

Informational conference call held on Thursday, April 25, 2024, A recording of the call is available at 888-566-0465.



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Center for Dementia Respite Innovation (ADPI Funded October 2023)

- Local respite care providers to develop and improve the quality of available dementia specific respite services
- 50% of funds will go to service providers in underserved communities
- Includes training and technical assistance for grantees
- Evaluation of funded programs

Application Due Date: June 1, 2024, 11:59 p.m. ET

https://www.alz.org/research/for_researchers/grants/types-of-grants/alzheimers-association-cdri

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National Alzheimer's and Dementia Resource Center **UPCOMING WEBINAR**

**Unique Approaches to Support Brain Health and Reduce Risk through
Education, Exercise, Diet, and Art**

May 22, 2024, from 2:00-3:00 p.m. ET

Participants will hear about ACL's Brain Health & Aging resources that can be used to educate the public about brain health as they age. The founder of GrownUps, in Puerto Rico, will discuss the *We Program* designed for the high-risk population they serve combining education, exercise, cooking workshops, arts, and horticulture into a fun and social opportunity for people to learn about brain health and dementia risk reduction techniques.

Register here: [05-22-2024 NADRC Webinar-Unique Approaches to Brain Health](https://www.alz.org/research/for_researchers/grants/types-of-grants/alzheimers-association-cdri)

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National Alzheimer's and Dementia Resource Center

Recent Webinar

Strategies to Address Social Isolation and Loneliness for People Living with Dementia and their Caregivers (Tuesday, April 23, 2024)

(2006 registered/919 attended)

Attendees learned the unique impact of dementia on social isolation and loneliness, tools for measuring these experiences, and common types of programs for addressing it among PLWD and their caregivers. Oakwood Creative Care discussed how they use Memory Cafés to address the needs of PLWD and their caregivers. Information was shared on how participation in Memory Cafés can significantly reduce social isolation and loneliness for both PLWD and their caregivers, and how to launch one.

The recording of the webinar and the presentation deck will be posted at <https://nadrc.acl.gov/home>

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National Alzheimer's and Dementia Resource Center

Recent Webinar

Finding the Way in Dementia Care: Use of Care Navigators for People Living with Dementia and their Caregivers. (February 6, 2024)

CAIz Connect, (California Department of Aging), offers dementia care management services to people living with dementia and their caregivers in Imperial, Marin, and Ventura counties, using the Care Ecosystem (CE) and HomeMeds evidence-based programs.

Kansas, OCCK, Inc. is implementing the CE in rural communities. Cognitive Care Navigators help the CE team understand the day-to-day issues experienced by people living with dementia and their caregivers and provide needed services and supports.

The recording of the webinar and the presentation deck will be posted at <https://nadrc.acl.gov/home>

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NEW LEADERSHIP at
Administration on Aging
Kari Benson
Deputy Assistant Secretary for Aging

Kari comes to AoA after serving as the Director of Aging and Adult Services Division of the Minnesota Department of Human Services and as the Executive Director of the Minnesota Board on Aging. She oversaw the full range of federal- and state-funded HCBS for older adults, their families, and the friends, neighbors, and others who provide informal caregiving support. Prioritizing collaboration with the 11 tribal nations that share geography with Minnesota, as well as organizations reaching rural and underserved communities, was a hallmark of her leadership at the state level. She also partnered with the state's Disability Services Division to coordinate quality assurance and improvement strategies for the Medicaid waiver programs, strengthen maltreatment and critical incident remediation efforts for older adults and people with disabilities, and launch the state's universal LTSS assessment tool.

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Dementia in Lifespan Respite

- The Lifespan Respite Care Act of 2006 has significantly advanced state programs, focusing on comprehensive support for family caregivers. This progress underlines the crucial role respite care programs play in supporting family caregivers across the nation and underscores ACL's goal to enhance the availability and quality of respite services for family caregivers serving individuals of all ages and disabilities.
 - ✓ In February 2024, a [webinar](#) introduced the Alter program, aimed at aiding African American family caregivers and individuals with dementia hosted by The ARCH Volunteer and Faith-based Respite Learning Collaborative.
 - ✓ In April 2024, two funding opportunities were announced for state grants to develop or enhance respite care programs: State Program Enhancement Grants ([HHS-2024-ACL-AoA-LRLI-0019](#)) and Grants to New States and States Re-Establishing Their Core Respite Infrastructures ([HHS-2024-ACL-AoA-LRLR-0020](#)).
 - ✓ Ongoing: lifespan respite care grants to states support family caregivers of those with physical or cognitive limitations, Alzheimer's, or Dementia, and offers assistance for respite, financial support and training for caregiving. For more details on these initiatives, refer to the [Lifespan Respite Technical Assistance and Resource Center](#) and the [ACL Lifespan Respite Care Program website](#).

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New Resources Supporting CHI and PIN Implementation

New Resources

- [Understanding the Medicare Physician Fee Schedule Billing Codes for: Community Health Integration \(CHI\), Principal Illness Navigation \(PIN\), and Principal Illness Navigation – Peer Support \(PIN-PS\)](#)
 - Provides high-level overview of health insurance market, reimbursement models, Physician Fee Schedule Final Rule, CHI and PIN/PIN-PS codes, eligible providers, and time-based billing requirements
- **CHI and PIN/PIN-PS Implementation Guide – COMING SOON!**
 - Comprehensive resource covering topics such as initiating visit requirements, billing codes and rates, time reporting, and business models

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Bridging Aging and Disabilities

Goal of Project

To strengthen the collaboration between aging and disability networks to better support individuals with I/DD and their families as they plan for their future across the lifespan.

- Grants through National Association of Councils on Developmental Disabilities (NACDD)
- Communities of Practice in 17 states.
- NTG trainings. 72 people participated in the NTG training in Hawaii; possible future trainings
- The Alzheimer's Association along with the Hawaii Council/Bridging SAT members are working on silver alert legislation for seniors/people with Alzheimer's/and individuals with IDD.

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Thank you!

Erin Long, MSW
Team Lead, Alzheimer's Disease Programs Initiative (ADPI)
Office of Supportive and Caregiver Services
Administration on Aging
Administration for Community Living

Email: Erin.Long@acl.hhs.gov

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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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The Challenge of Multiple Chronic Conditions (MCC)

- **Disease-specific vs. person-centered approaches.** Disease-specific approach to care delivery and research is misaligned with the **whole person-centered needs** of patients and caregivers.
- **Interoperability obstacles in complex care.** People with MCC require care in multiple settings, from multiple providers. **Data do not easily move across settings of care.**
- **Health equity.** People from low-income backgrounds and under-represented racial or ethnic groups develop MCC at **higher rates and earlier ages.**



People with MCC account for:



NEARLY
1 IN 3 & **4 IN 5**
American Adults & Medicare
Beneficiaries
**ARE LIVING WITH MCC, THE
MOST COMMON CHRONIC
CONDITION**

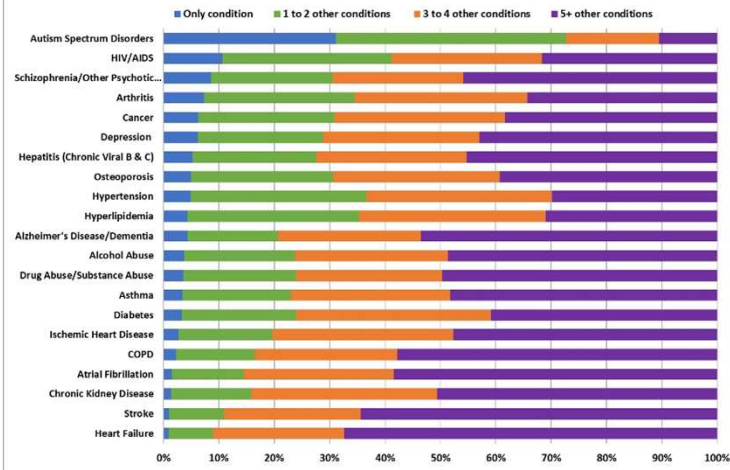
CMS 2018: <https://www.cms.gov/data-research/statistics-trends-and-reports/chronic-conditions/chartbook-and-charts>
 AHRQ 2010: <https://www.ahrq.gov/sites/default/files/wysiwyg/professionals/prevention-chronic-care/decision/mccchartbook.pdf>
 Quiñones, et al. Racial/ethnic differences in multimorbidity development and chronic disease accumulation for middle-aged adults. PLoS One, 2019;14(4). PMID:31206556.

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MCC and Common Chronic Conditions



Figure 15: Co-morbidity among Chronic Conditions for Medicare Fee-for-Service Beneficiaries : 2018



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AHRQ Roundtable Report



Optimizing Health and Function as We Age Roundtable Report

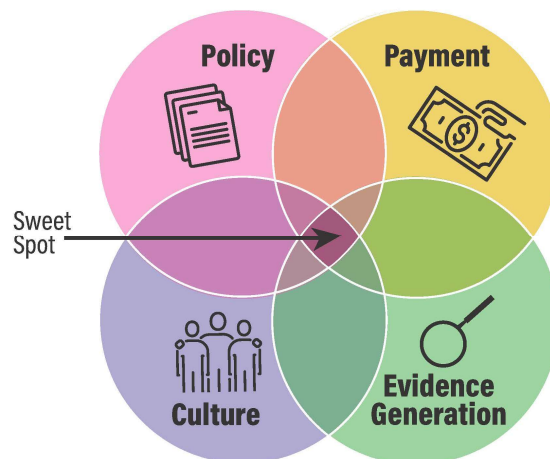


AHRQ's [*Optimizing Health and Function as We Age Roundtable Report*](#) summarizes a roundtable of approximately 40 multidisciplinary experts who discussed how AHRQ can impact the research, dissemination and implementation of evidence to improve the organization and delivery of healthcare with the goal of optimizing the health, functional status and well-being of the U.S. population as it ages.

<https://www.ahrq.gov/news/healthy-aging-roundtable.html>

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Health System Transformation and Aging Well The "Sweet Spot"



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Person-Centered Care

Defining Person-Centered Care



“Person-centered care” means that individuals’ values and preferences are elicited and, once expressed, guide all aspects of their health care, supporting their realistic health and life goals. Person-centered care is achieved through a dynamic relationship among individuals, others who are important to them, and all relevant providers. This collaboration informs decision-making to the extent that the individual desires.

“Person-Centered Care: A Definition and Essential Elements” The American Geriatrics Society Expert Panel on Person-Centered Care, December 2015
<https://www.ncbi.nlm.nih.gov/pubmed/26626262>

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AHRQ/NIDDK eCare Plan for Multiple Chronic Conditions (MCC) Project

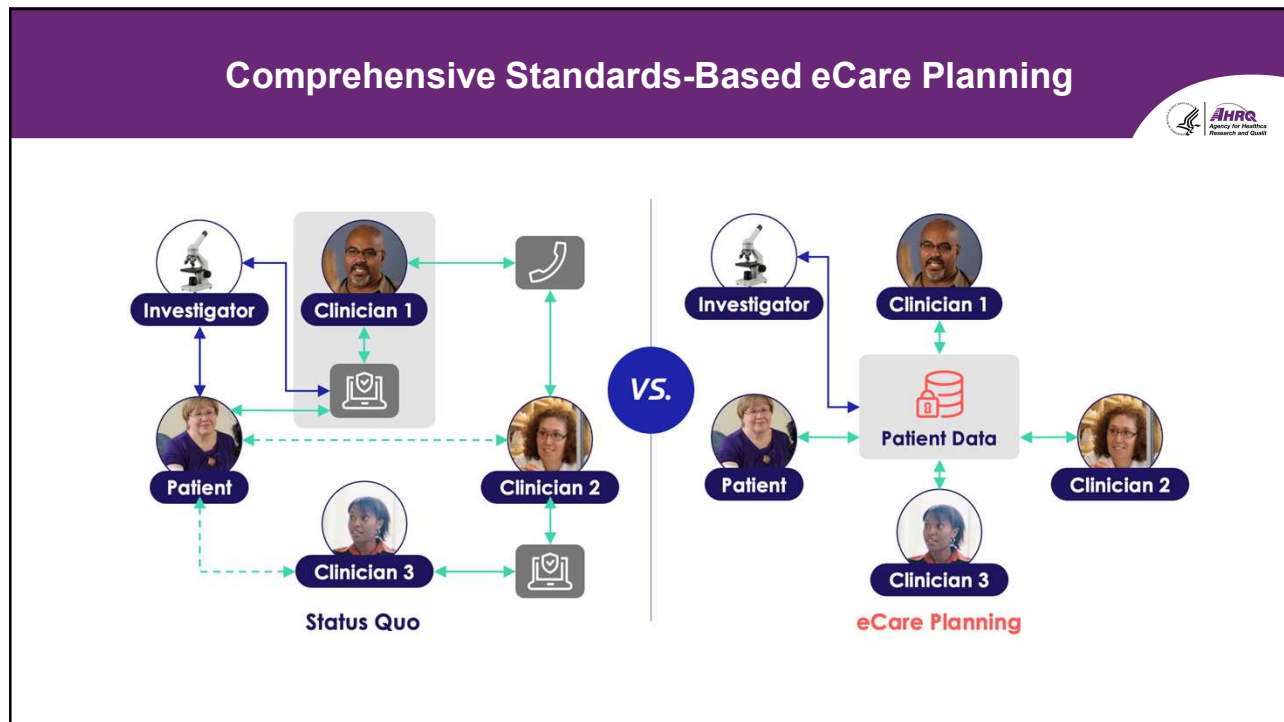


Build capacity for pragmatic, patient-centered outcomes research (PCOR) by developing an **interoperable electronic care plan** to facilitate **aggregation and sharing of critical patient-centered data** across **home-, community-, clinic-, and research-** based settings for people with **multiple chronic conditions (MCC)**.

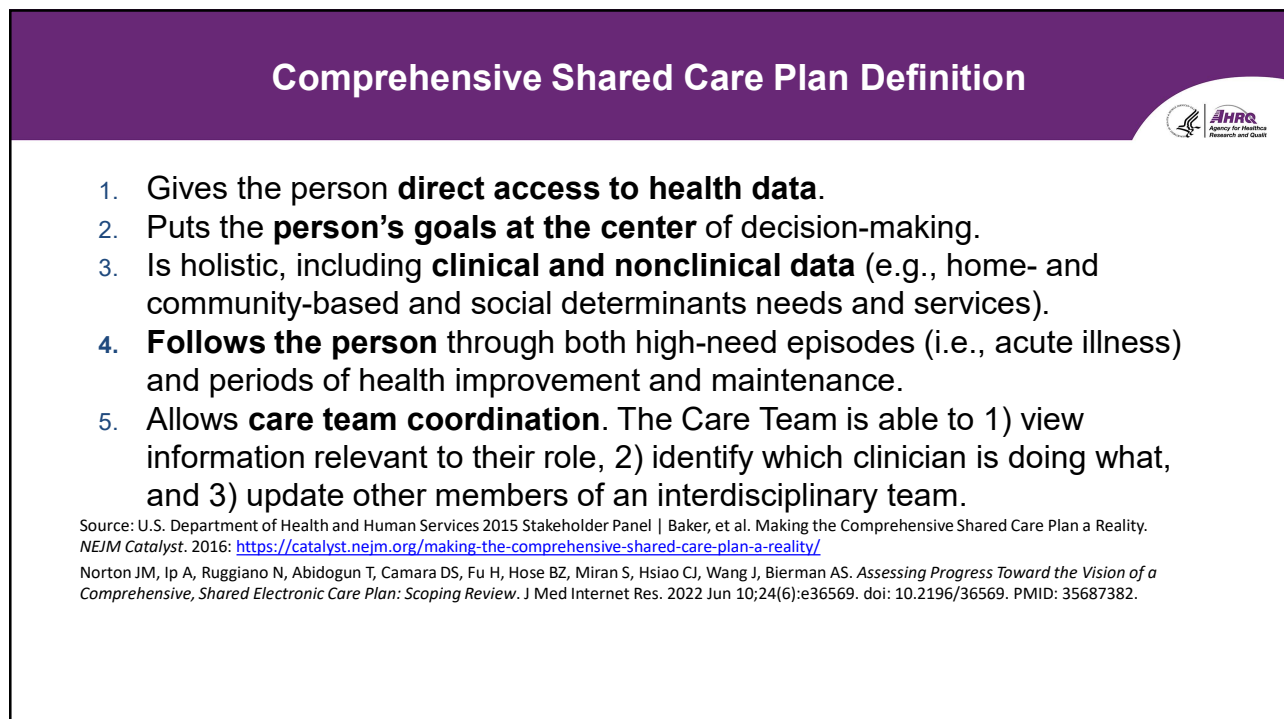
<https://ecareplan.ahrq.gov/collaborate/>



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eCare Apps Support Comprehensive Shared Care Planning




Comprehensive Shared Care Plan Definition*		MCC eCare Plan Applications
1	Gives the person direct access to health data .	→ Apps query EHR and other FHIR endpoints.
2	Puts the person's goals at the center of decision-making.	→ Apps designed around the process of goal-oriented shared decision-making.
3	Is holistic, including clinical and nonclinical data .	→ Apps supports SDOH data and patient/caregiver-reported data.
4	Follows the person through both acute and chronic care.	→ Apps can be used anytime and support transfer of data between acute and primary care contexts.
5	Allows care team coordination .	→ Apps allow caregiver (proxy), patient, and all clinicians to coordinate and plan care.

*U.S. Department of Health and Human Services 2015 Stakeholder Panel | Baker, et al. Making the Comprehensive Shared Care Plan a Reality. *NEJM Catalyst*. 2016: <https://catalyst.nejm.org/making-the-comprehensive-shared-care-plan-a-reality/>

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Care Planning Components



Person & Plan	Health Concerns	Goals	Interventions	Outcomes
Plan type, demographic, administrative and care team information including unpaid caregivers.	Existing or potential health states, conditions, social issues, and risks.	Desired outcomes or conditions to be achieved as a result of the interventions provided for health concerns.	Actions taken to treat health concerns and achieve goals.	Observations about or related to the health concerns with respect to interventions performed and progress towards goals.

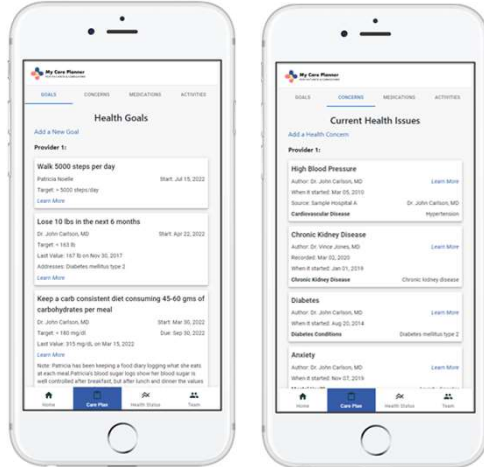
Care Coordination

←—————→

The deliberate organization of patient care activities between two or more participants (including the patient) involved in patient care to facilitate and ensure that the delivery of healthcare services is appropriate, safe, and efficient. Organizing care involves the marshalling of personnel and other resources needed to carry out all required patient care activities, and often is managed by the exchange of information among participants responsible for different aspects of care.

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Goal-Oriented Care Planning



- Place a person's goals at the center of decision-making
- Cross-platform web application
 - JavaScript React app
 - Formatted for mobile device browsers
- Current integration in pilot:
 - Epic, Cerner, VA, NextGen, AthenaPractice

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e-Care Plan: Potential Benefits for Clinical Care



- **Improved communication & care coordination** across the care team
 - ▶ Person/patient
 - ▶ Paid & unpaid caregivers
 - ▶ Home & community-based providers
 - ▶ Diverse clinicians – primary care, specialists, hospitalists, etc.
- Access to **patient/caregiver-reported** and **patient/caregiver-centered** data
 - ▶ Patient & caregiver goals, preferences & priorities
 - ▶ Social determinants of health
- **Improved patient safety**/reduced medical errors
- Reduced redundancy/duplication of orders → **reduced costs**

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e-Care Plan: Potential Benefits for Research



Access to more **complete**, **comprehensive**, **real-world** data for research

Complete

- Aggregation of data across multiple settings
- Reduced “missingness” of data

Comprehensive

- All relevant disease/symptom states
- Inclusive of clinical and contextual (e.g., social determinants) data

Real-world

- Inclusion of people with multiple chronic conditions
- Representative of day-to-day lives

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e-Care Plan: Potential Benefits for Quality Improvement



- More **complete & comprehensive data** for QI efforts
- Better ability to **align QI targets/measures with patient goals/preferences**
 - ▶ Are patients achieving goals?
 - ▶ Do existing QI measures conflict with patient goals/preferences?
- **QI in the context of MCC**
 - ▶ Do existing QI measures align with the needs of people with MCC?
 - ▶ Lack of evidence for optimal care strategies for people with MCC

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MCC eCare Plan FHIR Implementation Guide (IG)



The [HL7® MCC eCare Plan FHIR Implementation Guide \(IG\)](#) defines FHIR R4 profiles, structures, extensions, transactions, and value sets needed to represent, query for, and exchange Care Plan information to support care planning for people with multiple chronic conditions (MCC).

The IG supports the following use cases:

1. Generate and update comprehensive e-care plan in clinical setting.
2. Expose (Share) e-care plan to clinical care team, patient, or caregiver.
3. Identify care team members.

Will be published as an HL7 Standard for Trial Use (STU) in Spring 2024!



Improve care coordination without increasing clinician burden



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Person-Centered Care Planning for People Living With Multiple Chronic Conditions (PCCP4P)



Partner Engagement and Learning Community

- Gather knowledge about the current state of person-centered care planning in practice, including person-centered care planning models in use across diverse health systems, practices, and settings; scale of existing models; implementation barriers and facilitators; and feasible solutions to implementation barriers;
- Identify innovative, feasible models of person-centered care planning that hold promise for further development, testing, dissemination, and implementation;
- Identify innovative digital solutions that have been leveraged as tools to support and facilitate the success of implementing person centered care planning in practice;
- Identify key organizational, policy, payment, technology, cost, and resource requirements for implementing person-centered care planning across diverse health systems, practices, and settings; and
- Identify key research priorities, strategies, recommendations, and next steps to advance AHRQ's mission of disseminating and implementing person-centered care planning as routine and integral practice in the care of persons with MCC.

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Person-Centered Care Planning for People Living With Multiple Chronic Conditions (PCCP4P)



- Contract through AHRQ's ACTION IV Network to OHSU
- **Technical Expert Panel**
- **Partner's Roundtable** includes leadership from health systems, state health agencies, payers, professional societies, federal partners
- **Learning Community** includes innovators, implementers, frontline workers, researchers
- **Summit** Spring 2025

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April 2024 Updates



Helen Lamont, Ph.D.
Director, Division of Disability & Aging Policy

U.S. Department of Health and Human Services

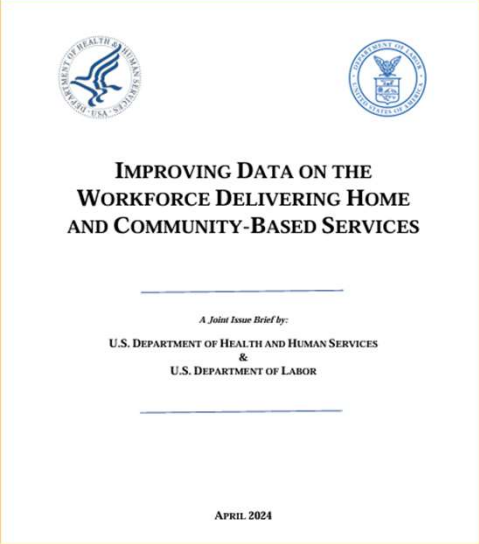


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Improving Data on HCBS Workforce

- President Biden’s EO: *Increasing Access to High-Quality Care and Supporting Caregivers*
- Partnership among HHS (ASPE, ACL, NIH, HRSA, CMS, CDC) and DOL
- Identified key policy questions on this workforce; analyze existing data sources; make recommendations on how to fill key knowledge gaps
- [Issue brief](#)
- [Webinar on May 21 at 1pm EST](#)



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CDC Updates

LISA C. MCGUIRE, PHD

Centers for Disease Control and Prevention

National Center for Chronic Disease Prevention and Health Promotion

Division of Population Health

Presented April 29, 2024, to National Alzheimer's Project Act (NAPA) Advisory Council Quarterly Meeting

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New Healthy Brain Initiative Resource

- Partnership between the Alzheimer's Association and NACCHO
- Brings together the Healthy Brain Initiative and MAPP frameworks
- Focused on community health needs assessment and health improvement planning
- Provides local health departments with information they need to integrate brain health as a priority

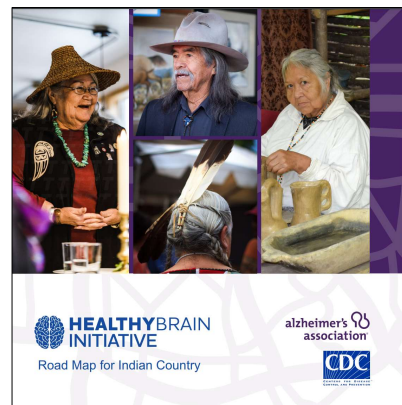


[Download the tool](#) to read more!

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Update: Road Map for Indian Country American Indian and Alaska Native People

- In-person Leadership Committee Meeting in Oklahoma City in March
- Text and graphics are being written and designed based on feedback
- **Opportunity for Full text review this summer**



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International Association for Indigenous Aging (IA²)

- IA² hosted five listening sessions in January to garner feedback on considerations for the next version of the Road Map for Indian Country
- 160 attendees provided input on:
 - General considerations for Tribal communities
 - Core elements for inclusion
 - Terminology, such as the use of “brain health” and “caregivers”
 - Terminology, such as “American Indian and Alaska Natives”, “Indigenous”, “Tribal Nations”, etc.
 - Graphics and visuals
 - Other suggestions for improvement



Copyright © 2021 International Association for Indigenous Aging - IA²

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New Social Determinants of Health Infographics

- To address dementia risk factors for all affected by social determinants of health (SDOH)
- Showcase information on SDOH related to dementia
- Public health strategies that may be leveraged to address these SDOH topics
- Provides local health departments with information to integrate brain health

Find all 5 infographics at alz.org/RiskReduction

ECONOMIC STABILITY

PROMOTING ECONOMIC STABILITY
and equity at the individual and community levels can enhance well-being and may also be protective against dementia.

RISK

At the individual level, evidence shows that **PEOPLE EXPERIENCING POVERTY MAY HAVE AN INCREASED RISK OF DEVELOPING DEMENTIA** compared with those with higher levels of wealth.

LIVING IN DISPROPORTIONATELY AFFECTED NEIGHBORHOODS may also affect brain health. Populations living in neighborhoods that are economically underserved have accelerated cognitive decline and may have increased chances of developing Alzheimer's and dementia.


COMMUNITIES HAVE ADVANCED ECONOMIC STABILITY THROUGH SOME OF THE FOLLOWING ACTIONS:

- Supporting provider payment reform to improve affordable health care access in communities that are economically underserved.
- Creating summer job opportunities for youth and other workforce training programs.
- Promoting financial literacy and education programs in the community.
- Establishing financial incentives to create small businesses in areas that are economically underserved.

HEALTH
EQUITY

alz.org/publichealth
cognitivehealth@alz.org
The Risk: Health Center of Excellence on Dementia Risk Reduction is made possible by the Centers for Disease Control and Prevention of the U.S. Department of Health and Human Services. It is part of a financial innovation pilot program by the CDC. The contents of this infographic are those of the Alzheimer's Association and do not necessarily represent the official view of, nor an endorsement by, CDC/HRSA or the U.S. Government.

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Virtual Roundtable Series
Building a public health community of practice


Successful Public Health Approaches in Dementia Caregiving: *Utah*

A Virtual Roundtable Series


In each episode of this virtual round-table series we will highlight the story of one state that has successfully implemented a state-wide, innovative, and integrative approach to advancing its dementia caregiving goals. The session will begin with an overview of the state's past, current and future efforts in dementia caregiving, followed by an interactive conversation and Q&A with the attendees about key takeaways and ideas for action they can take in their states and communities. This series offers a great opportunity for knowledge exchange, peer-learning and idea generation. In this episode we will present the story of *Utah*.



Kristy Russell, MHL, CHES
Alzheimer's Disease and Related Dementias State Plan Specialist
Utah Department of Health and Human Services



Kate Nederostek, MGS, CDP
Gerontologist and Program Manager for the Caregiver Support Program & Alzheimer's Disease & Related Dementias Program


April 11th, 2024 | 12:00pm-1:30pmET | Zoom
REGISTER: <https://bit.ly/SuccessfulPublicHealthApproaches-Utah> or scan 

- Roundtables highlight public health's role in building the state dementia caregiving infrastructure
- Interactive sessions, designed for peer-learning and knowledge sharing

Watch recordings of our roundtables at https://bolddementiacaregiving.org/library/?_sft_format=webinars-recordings

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Innovative public health approaches for harnessing dementia caregiving data



Using Crowdsourcing to Support Dementia Caregivers: Opportunities For Public Health

Dementia caregivers often find it difficult to find support and resources that are available to them in the community. Crowdsourcing is an innovative approach to mapping community assets that can help identify new caregiver-focused resources and ultimately help connect caregivers to the supportive services and resources they need. However, it also presents a number of challenges related to the quality, sharing and maintenance of data. At this webinar we will explore design solutions to some of these challenges and together, discuss how public health can use crowdsourcing to support its dementia caregiving efforts.




March 18th, 2024 | 10:00am-11:00amCT | Zoom

REGISTER: <https://bit.ly/CrowdsourcingandDementiaCaregiving> 

Dr. Nicole Ruggiano, PhD
Professor and Associate Dean of Research, School of Social Work, University of Alabama-Articulated Scientist, University of Alabama-Birmingham, Alzheimer's Disease Research Center, Lead Researcher, Alabama Caregiver Connect Initiative

Dr. Monica Anderson, PhD
Associate Professor, Department of Computer Science, University of Alabama-Tuscaloosa, Co-Director, Distributed Research Experience for Undergraduates, Member of Board of Directors, Computing Research Association

Dr. Zhe Jiang, PhD
Assistant Professor, Department of Computer & Information Science & Engineering, University of Florida

Watch the recording at https://www.youtube.com/watch?v=X3LDBPALqcg&list=PL3Jsff3FCIMSOysHjHRsbPKjXV_EAgpjY

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Coming Soon...

Webinars

Successful Public Health Approaches in Dementia Caregiving Roundtable series

- June 12th, 2024 – Minnesota
- August 14th, 2024 – New York State

Application of Health Equity in Dementia Caregiving: Policy and Practice

- May 15th, 2024

State Dementia Caregiving Policies

- Date TBD

Toolkits

Disseminating Evidence-Based Programs to Support Family Dementia Caregivers: The Role of Public Health

- Spring 2024

Publications

Regional Differences in Dementia Caregiver Health Outcomes: the Need for Local-Level Data to Tailor Caregiver Programs and Supports in their Communities

- Fall 2024

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© 2023 HealthMatters™ Program

HealthMatters for People with Intellectual and Developmental Disabilities (IDD)

- Virtual HealthMatters Program for 6 Pillars of Brain Health among People with IDD and their Supports
- HealthAdvocacy Training for Structurally Competent Care for Healthy Brains among People with IDD
- International Association for Indigenous Aging (IA2)/HealthMatters Program Talking Circles (April/May 2024)
- UsAgainstAlzheimer's/IA2/HealthMatters Program: Brain Health Equity Nurse Fellows (June 2024)

HealthMatters™ Program

Virtual Coach HealthMatters™ Program Impact

 15 <small>New Organizations</small> 162 <small>since November 2020</small>	 13 <small>States</small> <small>CT, FL, GA, IL, IA, KS, MD, MA, NV, OH, TN, TX, WA</small>	 152 <small>New team members</small>	 18 <small>Already participating organizations</small>
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NTG Updates



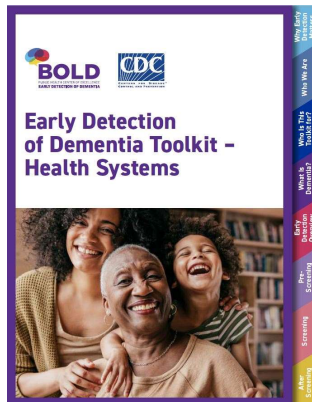
- NTG **2024 Family Caregiver Webinar Series** on ID and Dementia (<https://www.the-ntg.org/family-caregivers>)
- New publications for dissemination:
 1. New GSA Publication Addresses Dementia Care in Adults with I/DD: [Addressing Brain Health in Adults With Intellectual Disabilities and Developmental Disabilities: A Companion to the KAER Toolkit for Primary Care Providers](#) a Gerontological Society of America (GSA) publication addressing the needs of adults with IDD who develop dementia. The **KAER Toolkit** provides resources for **Kickstarting** brain health needs, **Assessing** cognitive impairment, **Evaluating** for dementia, and **Referring** to community resources.
 2. Hillerstrom, H., Fisher, R., Janicki, M.P., et al. (2024). [Adapting prescribing criteria for amyloid-targeted antibodies for adults with Down syndrome](#). Alzheimer's & Dementia: The Journal of the Alzheimer's Association. doi: 10.1002/alz.13778
 3. A seminal report on autism, dementia, brain health titled "[Autism, aging, and dementia: A consensus report of the Autism/Dementia Work Group of the 2nd International Summit on Intellectual Disabilities and Dementia.](#)"

Toolkit for Health Systems

boldementdetection.org/resources/#toolkit



nyuboldcenter@nyulangone.org
boldementdetection.org



Why Early Detection Matters	03	Pre-Screening	22
Who We Are	04	Building Trust	24
Who Is This Toolkit for?	05	Use Positive Framing and Pay Attention to Your Body Language	25
What is Dementia?	06	Prepare Short, Simple Statements	26
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EARLY DETECTION OVERVIEW

The Importance of Early Detection

Dementia affects many aspects of a person's life and the lives of loved ones. By the time dementia can be diagnosed, affected people already need the help of someone else to manage at least some activities that are essential for successful, safe, independent everyday living. Many of these essential activities, such as maintaining a household, scheduling self-care activities and appointments, and sustaining important personal relationships, require cognitive abilities that are impaired in dementia.

Professionals increasingly believe that it's important to detect cognitive impairment at milder stages before a person must rely on others to be their "prosthetic memory." Early detection helps people start preparing for potential changes while they are still able to think ahead and express their values and goals.

Signs and Symptoms of Dementia

Dementia can come to the attention of the person affected, a family member, or a clinician in several ways. A person may notice changes in their memory, or a loved one may be surprised by behavior that isn't usual for the person, unexpected financial errors, an unexplained wander-bender, an episode of confusion in a familiar place. A clinician may notice that a previously dependable patient is missing visits without notice, or that a long-term medicine, the symptoms, and medical tests blood pressure or diabetes, is that forgetting to refill or take

Detection Vs. Diagnosis of Dementia

Most cognitive screening tests – including most of those described in this toolkit – are simple ways of detecting a possible problem with cognition. Screening tests do not diagnose any condition but can point to the need for expanded evaluation, which includes more detailed cognitive examination and additional medical tests.

Resources

Please click on each link to visit these resources

- Early Detection and Diagnosis – Alzheimer's Association
- Why Get Checked? – Alzheimer's Association | Spanish Version
- Medical Benefits
 - Emotional and Social Benefits
 - More Time to Plan for the Future
 - Cost Savings

Why early detection matters

- **TIME:** Detecting cognitive impairment at milder stages allows time to adjust and prepare for the future.
- **PARTICIPATION:** Most people in early stages can be active in planning their own care.
- **BETTER CARE:** Early detection opens the door to the right care, if...
 - Everyone's prepared
 - Access is equitable

You'll find hyperlinked resources throughout the toolkit

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Preparing for cognitive screening is as important as screening itself

**PRE-SCREENING:
HOW TO TALK ABOUT
BRAIN HEALTH AND
COGNITIVE ASSESSMENT**

- Build Trust
- Use Positive Framing
- Pay Attention to Your Body Language
- Prepare Short, Simple Statements

**SCREENING:
HOW TO ADMINISTER
COGNITIVE ASSESSMENTS**

- The Difference Between "Detection," "Assessment," and "Diagnosis"
- Tools Used to Detect Cognitive Impairment
- Choosing the Right Cognitive Assessment Tool

What should happen after detection?

Ensure continuity – provide helpful explanations

**AFTER SCREENING:
NEXT STEPS**

- Navigating Conversations About Brain Health After Cognitive Assessment
- Diagnostic Evaluation, Needs Assessments, and Referrals
- Ongoing Communication With the Patient and Family

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Some Screening Tools

Performance-based screening tools


- Mini-Cog
- Saint Louis University Mental Status Examination (SLUMS)
- Clock Drawing Test (CDT)

Function-based screening tools

- 8-Item Informant Interview (AD8)
- Quick Dementia Rating System (QDRS)
- Functional Activities Questionnaire (FAQ)
- Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE)

Purpose of tool	Training requirements
Where to find it	Strengths
Who can administer this tool?	Limitations
Time needed to administer tool	Other considerations
Who is this tool intended for ?	Language or cultural adaptations ?

Table: Features of some selected screening tools

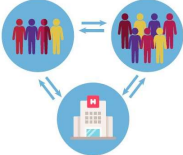


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Our Three-Sector Approach

Health Care + Public Health + Community


Signs of dementia can be detected wherever people are – at home in the kitchen, in the supermarket, at the bank, on the bus, at the park, at the food bank, in the senior center, during a blood draw for lab tests.




In the Pipeline...



Early Detection of Dementia Toolkit - Community-Based Organizations



Early Detection of Dementia Toolkit - Health Departments



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Additional Resources - Webinars

The BOLD Public Health Center of Excellence on Early Detection of Dementia is pleased to offer our series of conversations about interventions to promote earlier dementia detection as a pathway to better care and outcomes.

In February 2024, we spoke with two leaders in the field, Kristen Felten and Dr. Lisa Gibbs, in our webinar "Becoming a Prepared Leader." Watch the short (<2 min) clip to hear what they want you to know.



Visit our *Webinars* page to stay up to date on upcoming webinar announcements and watch our webinar recordings and short clips!
<https://bolddementiadetection.org/webinars/>



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Education Module for Primary Care

Three-part interactive module. Practical. Efficient.

- Free CME, designed for PCPs.
- Essentials for evaluating and managing ADRD in the primary care setting.
- Access online: <https://www.train.org/dctrain>
- Search for "Cognition in Primary Care" or course #WB4803



Evaluate cognition

Set a plan for newly diagnosed patient

Tips for managing MCI and dementia



Cognition in Primary Care

Cognition-PrimaryCare.org

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Paired with Implementation Toolkit For Change in the Clinic

- Structured framework for the evaluation.
- New, easy-to-use tools in the electronic health record: checklists, reminders, focus on maintaining brain health.

Cognitive Checklist	
<input type="checkbox"/>	Harmful med assessment
<input type="checkbox"/>	Alcohol amount _____
<input type="checkbox"/>	Depression considered
<input type="checkbox"/>	Sleep apnea considered
<input type="checkbox"/>	Hearing loss considered



Cognition-PrimaryCare.org

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Brain Health – EHR Checklist

- Alcohol:** Limiting to 0-1 drinks will help your thinking.
- Medications:** Avoid sedating and anticholinergic meds.
- Contributing Conditions:** Sleep apnea, hearing loss.
- Exercise and socialization:** Daily walks with a friend.
- Connect to Community Resources**



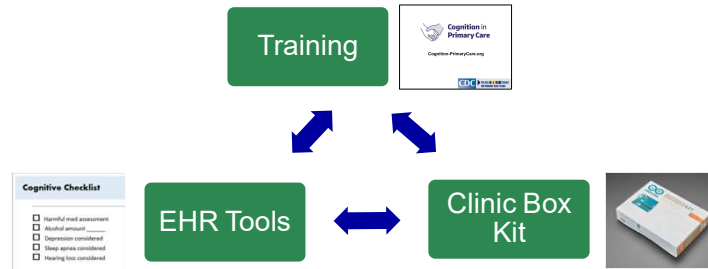
Cognition-PrimaryCare.org

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Cognition in Primary Care

Packaged quality improvement initiative for primary care.
Three integrated components.



Supported by CDC Special Interest Project (SIP20-002)

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Cognition in Primary Care



- **Recorded CME** – High-quality video. With other options which include webinars and e-learning module.
- **EHR implementation guide** – Instructions for adding checklists and essential EHR fields to track MoCA scores.
- **Starter box-kit** – Mailed to clinics to make it easy to put folders into place and put the training into practice.

Supported by CDC Special Interest Project (SIP20-002)

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Latino Nurses as Brain Health Ambassadors: Closing Alzheimer's Knowledge Gaps among Health Care Providers and Promoting Brain Health Across Minoritized Populations

Daphne Delgado, MPH

Sarah Yvonne Jimenez, Ph.D., RN

Introduction

- Nurses are on the frontlines of the healthcare system, yet they often lack information on cognitive decline risk reduction.
- The **UsAgainstAlzheimer's Center for Brain Health Equity** created the **Brain Health Equity Nurse Fellowship** to
 - Better equip nurses to promote brain health tailored to the unique needs of the communities they serve
 - Decrease disparities, and
 - Advance evidence-based knowledge.
- The fellowship, supported by CDC funding, is open only to members of National Association of Hispanic Nurses and/or National Black Nurses Association.

Methodology

- Literature review and data analyses determined knowledge gaps about Alzheimer's disease and brain health among nurses.
- Identified low levels of Alzheimer's knowledge about Alzheimer's and the relationship between healthy behaviors and brain health among nurses.

Results

Across two cohorts, 22 fellows reached 1,150 people (peers and/or community members) through community conversations focused on risk reduction. Among fellows, knowledge increased across 7-to -8 (of 12) domains.



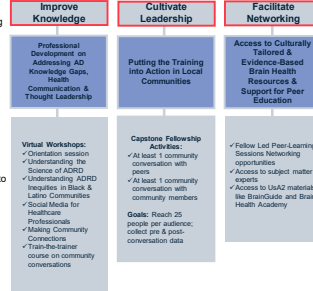
Fellowship Components

The seven-month fellowship included fellows participating in five virtual workshops covering topics like:

- Alzheimer's facts and inequities,
- Building communication skills and trust,
- Using social media to combat misinformation, and
- Delivering culturally tailored presentations.

Fellows hosted at least two brain health community conversations on risk reduction: one with peers and one with community members.

Fellows collected pre- and post-test surveys to assess changes in ADRD knowledge among participants.



Conclusion

Previous research has shown nurses to be the most trusted healthcare professionals in Black and Latino communities. However, many nurses have gaps in Alzheimer's knowledge and cognitive decline risk reduction. **The Brain Health Equity Fellowship prepares Black and Latino nurses to be ambassadors of brain health information.** Preliminary results show increases in brain health knowledge among the fellows and community conversation participants.



DDelgado@UsAgainstAlzheimers.org
www.usagainstalzheimers.org/brain-health-equity-nurse-fellowship



Latino Nurses as Brain Health Ambassadors: Closing Alzheimer's Knowledge Gaps among Health Care Providers and Promoting Brain Health Across Minoritized Populations

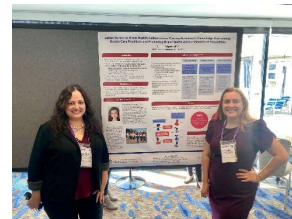
In Their Own Words...

"I was privileged to be a part of the inaugural fellowship and what a phenomenal experience it has been. I have met amazing fellows located across the nation and established great professional friendships for a lifetime. The brain health equity knowledge and tools we have obtained helped me personally and professionally and I will be able to make an impact locally in sharing my knowledge on brain health equity."
 – *Sussie Gonzalez, MHA, MSN, RN, CNML, 2022 fellow/2023 alumni mentor*



Dr. Jimenez, 3rd from right, at GSA 2023 (October 2023)

"The Fellowship opened up many opportunities for me to learn more about Alzheimer's and to connect with subject matter experts. The fellowship allowed me to attend the Gerontological Society of American annual meeting, where I networked with cutting-edge researchers and gave me opportunities for professional growth as a researcher and community educator."
 – *Dr. Sarah Yvonne Jimenez, PhD, RN, 2023 fellow/2024 alumni mentor*



Dr. Jimenez and Ms. Delgado presenting at the Latinos & Alzheimer's Symposium (April 2024)



LISA C. MCGUIRE, PHD
LMCGUIRE@CDC.GOV

HEALTHYBRAIN INITIATIVE



BOLD



Centers for Disease Control and Prevention

National Center for Chronic Disease Prevention and Health Promotion

Division of Population Health

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



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NAPA Advisory Council Federal Update

April 29, 2024

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Four Approved Studies

- Alzheimer's National Registry for Treatment and Diagnostics**
 Sponsor: Alzheimer's Disease and Related Disorders Association, Inc
 Clinicaltrials.gov number: [NCT06170268](#)
 CMS Approval Date: 1/29/2024
- Georgia Memory Net Anti-Amyloid Monoclonal Antibody Registry**
 Sponsor: Emory University
 Clinicaltrials.gov number: [NCT05999084](#)
 CMS Approval Date: 11/14/2023
- A Prospective Comparative Study Of Monoclonal Antibodies For The Treatment Of Alzheimer's Disease**
 Sponsor: Beth Israel Deaconess Medical Center
 Clinicaltrials.gov number: [NCT05925621](#)
 CMS Approval Date: 07/11/23
- Prospective Study on Anti-Amyloid- β Monoclonal Antibodies Directed Against Amyloid for the Treatment of Alzheimer's Disease Coverage of Evidence Development (The Anti-A β mAb CED Study)**
 Clinicaltrials.gov number: [NCT06058234](#)

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CMS Alzheimer's Disease Coverage with Evidence Development CED Study Registry

Home /

Monoclonal Antibodies Directed Against Amyloid for the Treatment of Alzheimer's Disease CED Study Registry

Overview Form Submission Resources Glossary

Monoclonal Antibodies Directed Against Amyloid for the Treatment of Alzheimer's Disease CED Study Registry

This Registry for Monoclonal Antibodies Directed Against Amyloid for the Treatment of Alzheimer's Disease (AD) collects information from providers to facilitate and ensure appropriate patient selection in the use of monoclonal antibodies directed against amyloid (anti-amyloid mAb) approved by the FDA for the treatment of AD based upon evidence of efficacy from a direct measure of

Resources

[View](#)

Glossary

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CMS Behavioral Health Strategy

CMS Behavioral Health Strategy
[Website](#)

CMS Behavioral Health [Fact Sheet](#)

Behavioral Health is a cross cutting initiative under the [CMS Strategic Plan](#).

CMS Behavioral Health Strategy



The CMS Behavioral Health Strategy focuses on three key areas: 1) substance use disorders prevention, treatment and recovery services, 2) ensuring effective pain treatment and management, and 3) improving mental health care and services. These areas are aligned with CMS's overall focus on four health outcomes-based domains: *coverage and access to care, quality of care, equity and engagement, and data and analytics*. Our vision is for all the people we serve to get access to person-centered, timely, and affordable care.

CMS's behavioral health priorities advance the [HHS Roadmap for Behavioral Health Integration](#), the [HHS Overdose Prevention Strategy](#), and the [HHS Pain Management Task Force Report](#).

Behavioral Health Cross Cutting Initiative

CMS has 12 cross-cutting initiatives as part of the [CMS Strategy \(PDF\)](#), including behavioral health. The Behavioral Health Cross-Cutting Initiative investments and outcomes are described in this [Fact Sheet](#).

Our vision is for all the people we serve to get access to person-centered, timely, and affordable care.

<https://www.cms.gov/cms-behavioral-health-strategy>

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Supporting Mental Health in Nursing Homes

- [Center of Excellence](#) for nursing home residents with serious mental illness and/or substance use disorder(s)
 - On-demand training on general care
 - Consultation to assist with specific residents
- Ensuring appropriate diagnosing of schizophrenia
 - Auditing residents' medical records for documentation that supports a diagnosis of schizophrenia
 - Reviewing documentation to ensure facilities attempted nonpharmacological interventions or a gradual dose reduction for residents on an antipsychotic when appropriate

(Strategy 3.D)

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Ensuring Safe and Quality Care in Nursing Homes

- In February 2022, the Biden-Harris Administration announced a comprehensive set of reforms aimed at improving the safety and quality of care in the nation's nursing homes, and part of these reforms included CMS proposing minimum staffing standards.
- The final rule, which was informed by public comment and the totality of available evidence, represents a critical step in addressing this important issue by holding nursing homes accountable for providing adequate staffing supporting a long-term services and supports system where residents can more safely age with dignity

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Ensuring Safe and Quality Care in Nursing Homes (Continued)

The final rule consists of three core staffing requirements:

1. Minimum nurse staffing standards
2. RN onsite 24 hours a day, 7 days a week, and
3. Enhanced facility assessment requirements

Information at: [Nursing Home Resource Center | CMS](https://www.cms.gov/about-cms/what-we-do/nursing-homes) <https://www.cms.gov/about-cms/what-we-do/nursing-homes>

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Ensuring Safe and Quality Care in Nursing Homes (Continued)

Minimum Staffing Standards

- CMS finalized a total nurse staffing standard of 3.48 hours per resident day (HPRD), which must include at least 0.55 HPRD of direct registered nurse (RN) care and 2.45 HPRD of direct nurse aide care
- Facilities may use any combination of nurse staff (RN, licensed practical nurse [LPN] and licensed vocational nurse [LVN], or nurse aide) to account for the additional 0.48 HPRD needed to comply with the total nurse staffing standard

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Ensuring Safe and Quality Care in Nursing Homes (Continued)

Regulatory Flexibility

- CMS finalized that LTC facilities may qualify for a temporary hardship exemption from the minimum nurse staffing standards and 8 hours of the 24/7 RN requirement
- Facilities may qualify for a hardship exemption only if they meet the following criterion:
 - The facility is located in an area where the supply of RN, NA, or total nurse staff is not sufficient to meet area needs as evidenced by the applicable provider-to-population ratio for nursing workforce (RN, NA, or combined licensed nurse and nurse aide), which is a minimum of 20% below the national average, as calculated by CMS using data from the U.S. Bureau of Labor Statistics and the U.S. Census Bureau

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Ensuring Safe and Quality Care in Nursing Homes (Continued)

Staggered Implementation: Non-Rural Facilities

Implementation of the final requirements will occur in three phases over a 3-year period for all non-rural facilities

- Phase 1 — Within 90 days of the final rule publication, facilities must meet the facility assessment requirements
- Phase 2 — Within 2 years of the final rule publication, facilities must meet the 3.48 HPRD total nurse staffing requirement and the 24/7 RN requirement
- Phase 3 — Within 3 years of the final rule publication, facilities must meet the 0.55 RN and 2.45 NA HPRD requirements

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Ensuring Access to Medicaid Services

- Also on April 22, CMS released the final [Ensuring Access to Medicaid Services rule](#) (Access Rule) to strengthen the home and community-based services (HCBS) that make community living possible for millions of people including people living with dementia
- The Access Rule addresses critical dimensions of access across both Medicaid fee-for-service and managed care delivery systems, including for HCBS
- These improvements seek to increase transparency and accountability, standardize data and monitoring, and create opportunities for states to promote active beneficiary engagement in their Medicaid programs with the goal of improving holistic access to care and services

For information see: <https://www.cms.gov/newsroom/fact-sheets/ensuring-access-medicaid-services-final-rule-cms-2442-f>

(Strategy 3.E)

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Some Details on the Access Rule

- **Payment adequacy:** At least 80% of all Medicaid payments for specific HCBS — homemaker services, home health aide services, and personal care services — must be spent on compensation for direct care workers to help address the direct care workforce crisis. States must also report annually on the percentage of payments for those three services (homemaker, home health aide, and personal care), as well as habilitation services, that are spent on compensation for direct care workers. States must also establish an interested parties advisory group to seek input on payment rates for these four services.
- **Access:** States must report information on HCBS waiting lists. They also must report on whether people have timely and full access to homemaker, home health aide, personal care, and habilitation services once services are approved. This data allows a comparison of access to HCBS across states
- **Person-centered planning:** States must demonstrate that, as part of person-centered planning, a reassessment of need is completed at least once a year for people continuously enrolled in HCBS programs. They also must demonstrate that service plans are reviewed and revised annually based on that reassessment
- **Incident management:** States must operate and maintain an electronic incident management system using a common minimum definition for what is considered a “critical incident.” They must also investigate, address, and report on the outcomes of the incidents within specified timeframes
- **Grievances:** States must establish and manage a grievance process for people receiving HCBS in fee-for-service systems. (This already exists in Medicaid managed care systems.) This process will give people a way to notify their state Medicaid agency if they have a complaint about how a provider or state is complying with person-centered planning and HCBS Settings Rule requirements
- **Quality measures:** States must report on a set of nationally standardized quality measures specifically for HCBS established by CMS through a process that includes opportunities for public comment

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The Congressionally Directed Medical Research Programs

FY24 Appropriations and PRARP Funding Opportunities

Sarah N. Fontaine, Ph.D.

29 April 2024



Transforming Healthcare through Innovative and Impactful Research




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For more information, visit cdmrp.health.mil

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CDMRP FY24 Appropriations



Research Program	FY24 \$M	Research Program	FY24 \$M
Alcohol and Substance Use Disorders	\$4.0	Neurofibromatosis	\$25.0
Amyotrophic Lateral Sclerosis	\$40.0	Ovarian Cancer	\$45.0
Arthritis <i>(New for FY24)</i>	\$10.0	Pancreatic Cancer	\$15.0
Autism	\$15.0	Parkinson's	\$16.0
Bone Marrow Failure	\$7.5	Peer Reviewed Alzheimer's	\$15.0
Breast Cancer	\$150.0	Peer Reviewed Cancer (18 Topics)	\$130.0
Combat Readiness Medical	\$5.0	Peer Reviewed Medical (42 Topics)	\$370.0
Duchenne Muscular Dystrophy	\$10.0	Peer Reviewed Orthopaedic	\$30.0
Epilepsy	\$12.0	Prostate Cancer	\$110.0
Glioblastoma <i>(New for FY24)</i>	\$10.0	Rare Cancers	\$17.5
Hearing Restoration	\$5.0	Reconstructive Transplant	\$12.0
Joint Warfighter Medical	\$20.0	Spinal Cord Injury	\$40.0
Kidney Cancer	\$50.0	Tick-Borne Disease	\$7.0
Lung Cancer	\$25.0	Toxic Exposures	\$30.0
Lupus	\$10.0	Traumatic Brain Injury and Psychological Health	\$175.0
Melanoma	\$40.0	Tuberous Sclerosis Complex	\$8.0
Military Burn	\$10.0	Vision	\$20.0
Multiple Sclerosis	\$20.0		
		TOTAL = \$1.51B	

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Funding Opportunities



- Pre-announcements and funding opportunity release notifications
 - CDMRP website and email blasts
- Funding opportunity postings
 - Grants.gov (CFDA 12.420)
 - CDMRP website (cdmrp.health.mil)
 - electronic Biomedical Research Application Portal (eBRAP) system (ebrap.org)
 - SAM.gov (BAAs)
- Quickly find open CDMRP Funding Opportunities on the CDMRP website here:
 - Home > Funding Opportunities > Synopsis of Open Program Funding Opportunities



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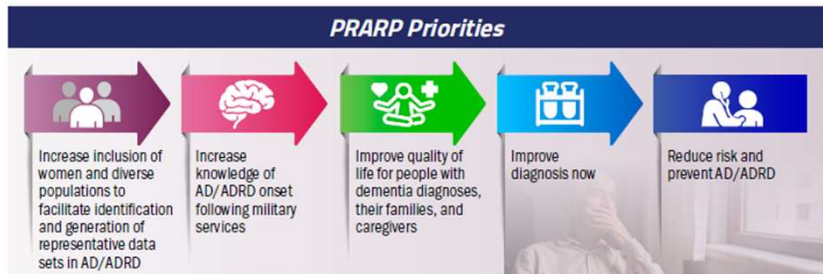
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Peer Reviewed Alzheimer's Research Program



Vision: Mitigate the impact of Alzheimer's and related dementias associated with TBI, military, and diverse risks.

Mission: Fund solutions-oriented research to address critical needs and improve quality of life for Service Members, Veterans, their Families and members of the public living with Alzheimer's disease and related dementias.



For more information, please visit: <https://cdmrp.health.mil/prarp>

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FY24 PRARP Funding Opportunities



Career Initiation or Transition Partnership Option available for all mechanisms. Two investigators may jointly propose a project, but one investigator must be either:

- Career Initiation: Terminal degree and three years experience, no more than seven years into independent position and nominal, if any research support.
- Career Transition: Any level, but new to military health, TBI, and/or AD/ADR fields with nominal publications or research support in their intended field.

Deadlines For All Mechanisms:

Pre-Application/Letter of Intent due by 5:00 pm Eastern Time, **May 22, 2024**

Full Application due by 11:59 pm ET, **June 12, 2024**

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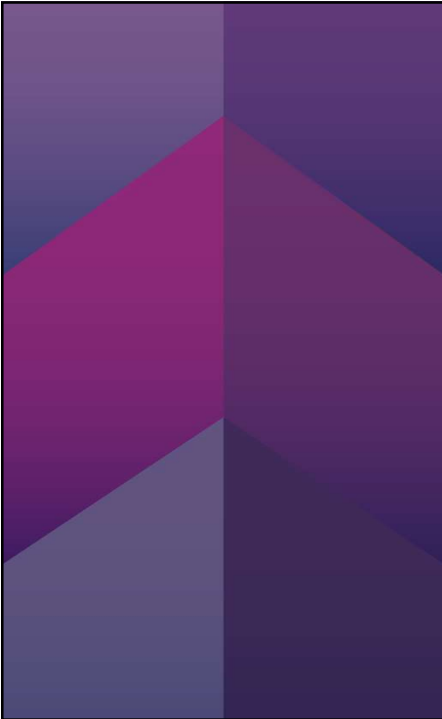
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Questions?
For more information, please visit:
 cdmrp.health.mil




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INDIAN HEALTH SERVICE

The IHS Alzheimer's Grant Program

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

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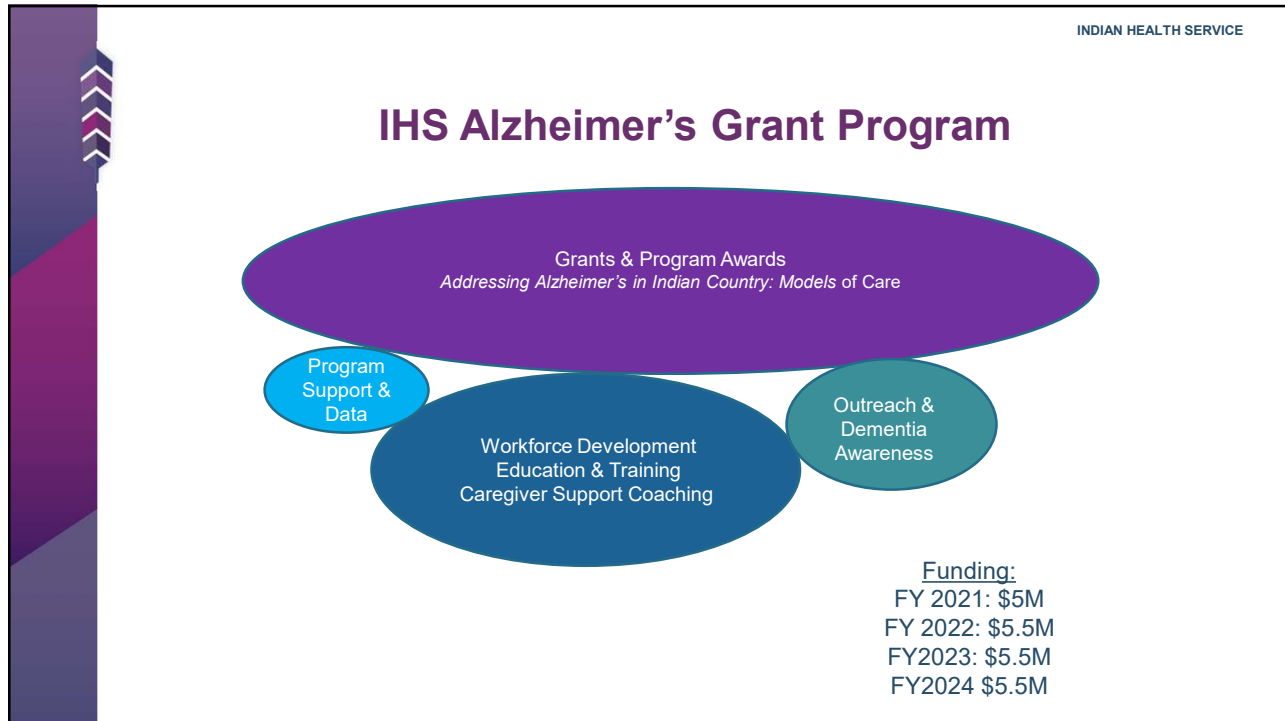
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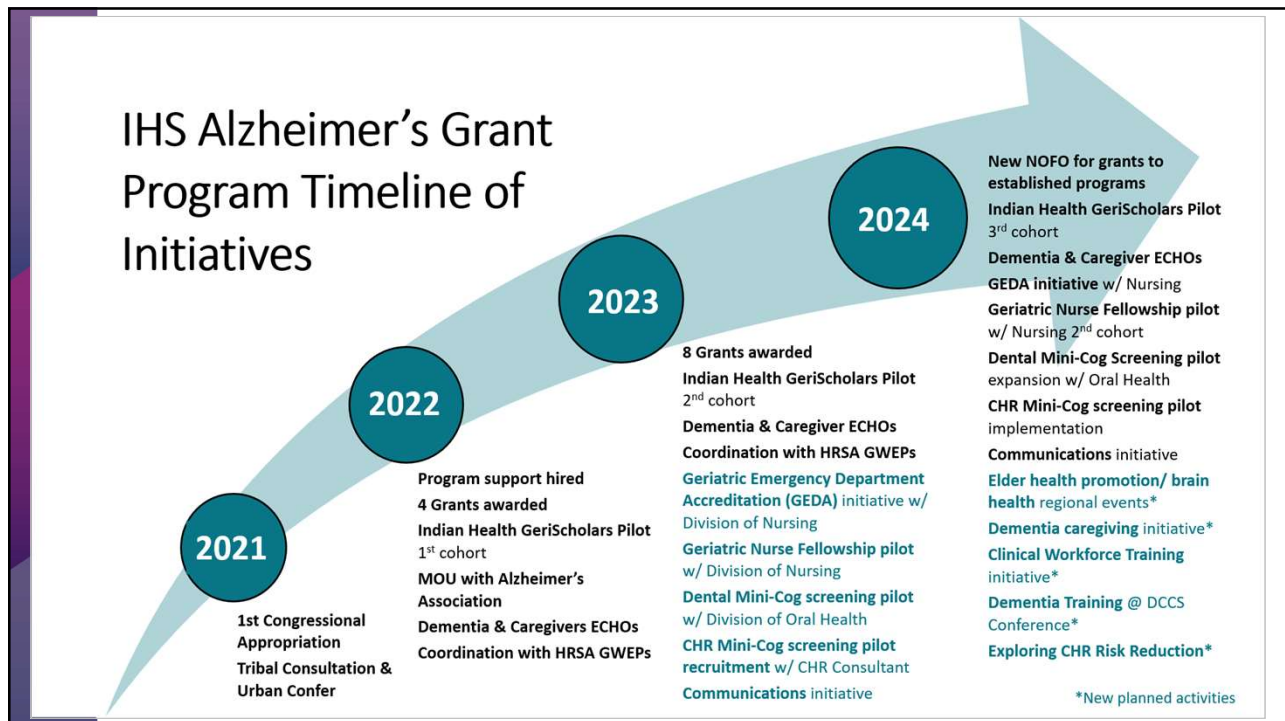
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NAPA Advisory Council Federal Update
April 29, 2024

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INDIAN HEALTH SERVICE

Grants and Program Awards Addressing Dementia in Indian Country: Models of Care

“...to support the development of models of comprehensive and sustainable dementia care and services in Tribal and Urban Indian communities that are responsive to the needs of persons living with dementia and their caregivers.”

2023 – 8 Awards

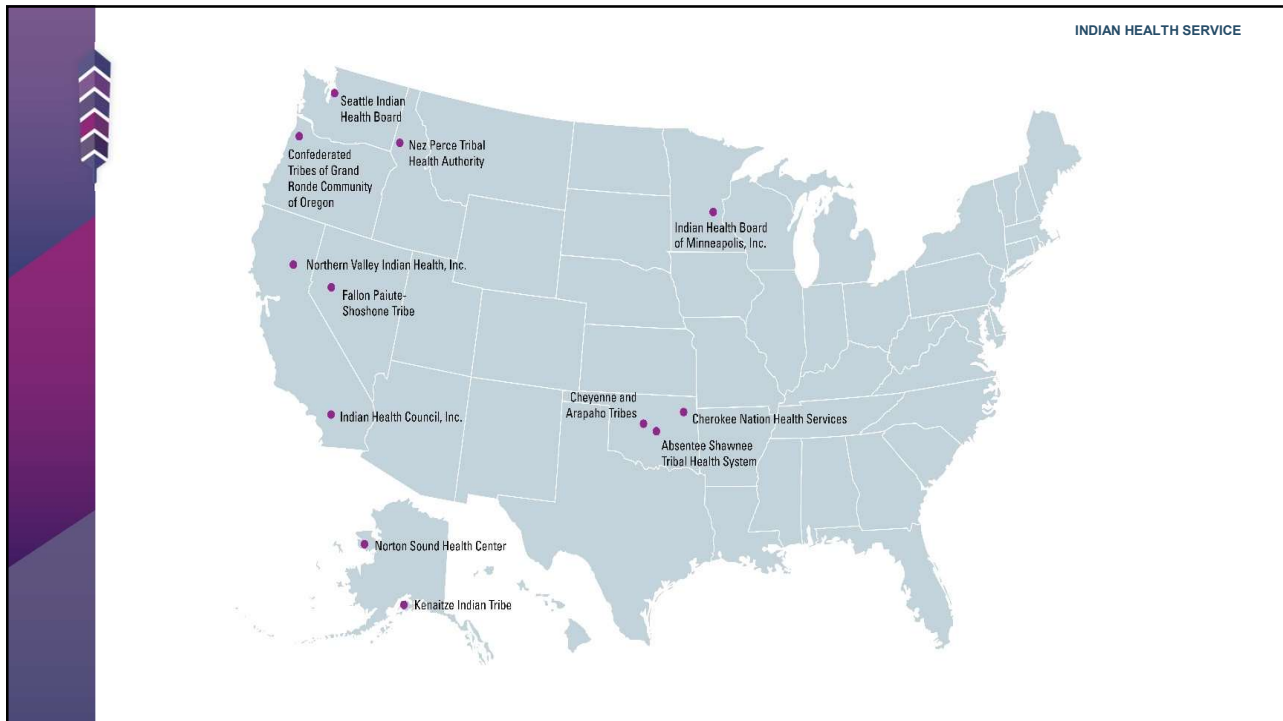
- Absentee Shawnee Tribal Health System (OK)
- Cherokee Nation Health Systems (OK)
- The Cheyenne and Arapaho Tribes (OK)
- The Confederated Tribes of Grand Ronde Community of Oregon (OR)
- The Fallon Paiute-Shoshone Tribe (NV)
- The Kenaitze Tribe (AK)
- The Norton Sound Health Center (AK)
- The Seattle Indian Health Board (WA)

2022 - 4 Awardees – entering into their 2nd year


- The Indian Health Board of Minneapolis, Inc. (MN)
- The Indian Health Council, Inc. (CA)
- The Nez Perce Tribal Health Authority (ID)
- The Northern Valley Indian Health (CA)

- TA visits to each grantee
- Targeted TA to clinical services for grantees
- Learning Collaborative for grantees
- Grantee presentation at the IHS CA Best Practices Conference, May 22, 2024
- Cross-grantee analysis of programs underway

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INDIAN HEALTH SERVICE


Grants and Program Awards Addressing Dementia in Indian Country: Models of Care

“...to support the development of models of comprehensive and sustainable dementia care and services in Tribal and Urban Indian communities that are responsive to the needs of persons living with dementia and their caregivers.”

2024 – Anticipated Notice of Funding Opportunity (Forecast)

- Targeted toward programs with established efforts to address dementia
- 3 years additional funding support
- Further development of the models of care
- Sustainability

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INDIAN HEALTH SERVICE

Workforce Development and Capacity Building

Dental Clinic Early Dementia Detection Initiative Continues

- Partnership with IHS Division of Oral Health
- 2nd round of 5 IHS and Tribal facilities
 - Support to integrate cognitive assessment and referrals into dental care

Community Health Representatives (CHR) Dementia Detection Initiative Launched

- Partnership with IHS CHR program
- 6 Tribal sites from 6 IHS areas selected and funded to train CHRs to integrate detection of cognitive impairment into their usual workflow
 - Training in use of tools to detect (e.g. mini-cog)
 - Follow-up referrals and support services
 - Partner with Oklahoma University Dementia Care Network (GWEP) for dementia training

Geriatric Emergency Department Accreditation (GEDA) Initiative Continues

- Partnerships with IHS Division of Nursing
- Currently 9 IHS and Tribal sites with Bronze accreditation
- New cohort recruited - 4 sites engaged
 - New (Bronze) and advancing (Silver)

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Workforce Development

Indian Health Geriatric Scholars Pilot

- 2023 GeriScholars from 14 sites, (7 IHS, 6 Tribal, and 1 Urban) representing 7 IHS Areas have completed intensive training and completing local projects
 - Addressing: dementia recognition, evaluation and diagnostic process, polypharmacy, annual wellness visit with cognitive assessment, goals of care discussions, and social isolation
- 3rd Cohort recruitment (physicians, NPs, RNs, and Pharmacists) this summer

Geriatric Nurse Fellowship Pilot Launched in partnership with IHS Division of Nursing

- APRNs, RNs, and LPNs from 9 states and 7 IHS regions
- Training options for nurses in a variety of roles
- Completing local projects
 - Addressing: medication safety, education, and compliance; palliative care and advanced directives, cognitive screenings, falls prevention, STIs, aging well

Clinical and Community Services 2024 Meeting in planning

- Training in detection of cognitive impairment
- Opportunity for growing community of “champions”, including grantees, GeriScholars, Nurse Geriatric Fellows, CHRs, and Oral Health professionals to share with each other and others

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Workforce Development

Indian Country Dementia Clinical and Caregiver ECHOs

- Monthly with archives for viewing
- Clinical: case-based learning to strengthen primary care knowledge and confidence
- Caregiver: training and mentorship for Indian Health staff providing coaching and support for caregivers
- 526 participants from 27 states and all 12 IHS regions in since launch in May 2023
- Greatest training need: care planning, management, and referrals (72%)

Training and Technical Assistance Contract RFP - in process

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Outreach and Awareness

- Regional elder-focused health and wellness events in partnership with the Health Promotion and Disease Prevention program – Brain Health focus
- Communications support contract
 - e-news, video and photo assets, website development
- National Caregiver Month blog and social media campaign
- Alzheimer's and older adult observances via social media
- Tribal leader updates highlighting work across IHS, Tribal, and Urban Indian communities
- YouTube channel for training and webinars
- Online calendar of events
- Listserv and community continue to grow!

Program Support and Data

- Enhanced Technical Assistance to IHS Grantees
- Data Dashboard in development
- First Annual Report to Congress - **in review**

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For More Info

The IHS Alzheimer's Grant Program

- www.ihs.gov/alzheimers/

2024 Alzheimer's Grant Program funding opportunities

- <https://www.ihs.gov/alzheimers/fundingopps/2024fundingopp/>

Education and training resources and opportunities

- www.ihs.gov/alzheimers/alztraining/

Dementia information and links

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

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

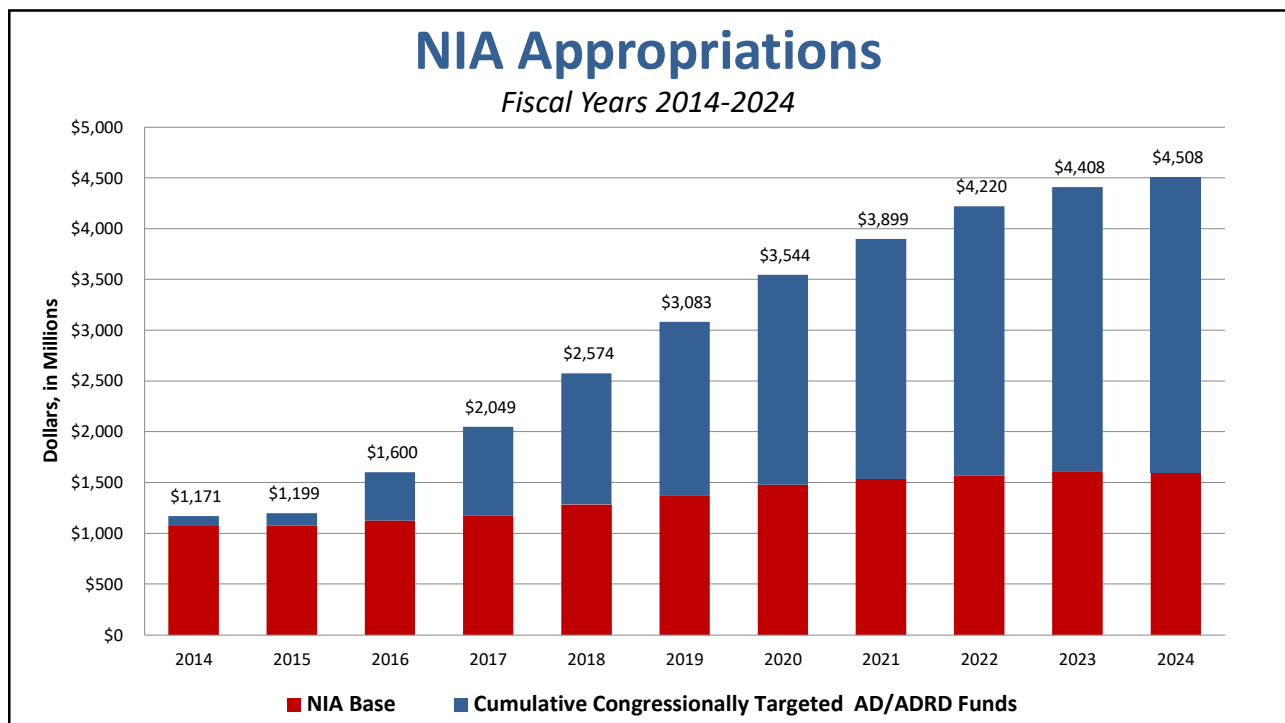
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Alzheimer’s Disease and Related Dementias Research Update

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

Richard J. Hodes, M.D.
 Director, NIA
 April 29, 2024

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NIH AD/ADRD Appropriations

2011	2012	2013	2014	2015	2016	2017	2018	2019	2020
National Alzheimer's Project Act (NAPA)	\$50 M* redirected within NIH budget	\$40 M* redirected within NIH budget	\$100 M additional approp.	\$25 M additional approp.	\$350 M additional approp.	\$400 M additional approp.	\$414 M additional approp.	\$425 M additional approp.	\$350 M additional approp.
2021	2022	2023	2024						
\$300 M additional approp.	\$289 M additional approp.	\$226 M** additional approp.	\$100 M** additional approp.						

*One-year money; years displayed are fiscal years.

**These totals reflect funds appropriated to both NIA and NINDS (FY 2023: NIA \$151M, NINDS \$75M; FY 2024: NIA \$90M, NINDS \$10M).



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Current Allocations for Competing Research Grant Awards, FY 2024

CSR-Reviewed Research Applications (Percentile Based)				
	General Payline, <\$500K	General Payline, ≥\$500K	AD/ADRD Payline, <\$5M	AD/ADRD Payline ≥\$5M
All applications; except below	16%	13%	17%	14%
N.I. R01s	19%	16%	20%	17%
E.S.I. R01s	21%	18%	22%	19%

New Investigator (N.I.): An applicant who has not received a prior R01 award or its equivalent.

Early-Stage Investigator (E.S.I.): A new investigator who is within 10 years of finishing research training.

AD/ADRD: Research on Alzheimer's disease and Alzheimer's disease-related dementias.



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Current Pay Lines, FY 2024

NIA-Reviewed Applications (Overall Impact Score Based)		
	General Payline	AD/ADRD Payline
Program projects	25	25
Other NIA-reviewed research	25	25
Career development awards	22	30
Fellowship awards	30	35



New Dementia Care and Caregiving Research Implementation Milestones

- **Additional Dementia Care and Caregiving Research Implementation Milestones** were generated from the 2023 National Research Summit on Care, Services, and Supports for Persons Living with Dementia and Their Care Partners/Caregivers.
- The new milestones cover:
 - Outcomes that Matter
 - Comprehensive Care Models
 - Health IT Consequences and Disparities
 - Identifying Care Partners
 - Caregiver Resilience and Wellbeing
 - Community-Engaged Research
 - Workforce Impact on Outcomes
 - Healthcare Decision Making
- These will be added soon to the AD and ADRD Research Implementation Milestones database: <https://www.nia.nih.gov/research/milestones>



<https://www.nia.nih.gov/2023-dementia-care-summit>

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Recently Published AD/ADRD Funding Opportunities

- **Multi-Scale Models Bridging Levels of Analysis in AD/ADRD/[RFA-AG-25-016](#)**- to establish multi-scale computational models recapitulating dynamic changes associated with aging and AD/ADRD. (expires June 14, 2024)
- **Open Measurement Coordinating Network for Non-Pharmacological AD/ADRD Primary Prevention Trials/[RFA-AG-25-005](#)**- to establish a national network to serve as a centralized hub for developing, validating, standardizing, and disseminating measures and measurement methods for AD/ADRD primary prevention trials. (expires June 16, 2024)
- **Notice of Special Interest (NOSI): Administrative Supplements for NIA-VA Mentored Physician and Clinical Psychologist Scientist Award in AD/ADRD/[NOT-AG-23-054](#)**- to attract early-stage physician-scientists and clinical psychologist-scientists from the U.S. Department of Veterans Affairs to an AD/ADRD research career. (expires Dec. 31, 2024)



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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:

- Access and Manipulation of Brain Cell Subtypes Implicated in Aging and AD/ADRD
- Alzheimer’s Drug Development Program (Renewal)
- Biomarkers of Cognitive Decline and Dementias of Aging in Individuals Within the Autism Spectrum
- Deciphering the Impact of RNA Modifications on Brain Aging and AD/ADRD
- Investigating Mitochondrial-Nuclear Communication in Brain Aging and AD/ADRD
- Short Courses Promoting Cross-National Analyses Using Data from the International Health and Retirement Study and Harmonized Cognitive Assessment Protocol



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

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NASEM Study on Research Priorities for Preventing and Treating AD/ADRD

Task order established :
March 27, 2023

Committee Established:
September 20, 2023

3 Public Meetings:
Oct 2023 – Jan 2024

4 Working Group Sessions:
Oct 2023 – Feb 2024

Final Report Anticipated:
Jan – Mar 2025

The agreement directs NIA, working with NINDS, to **enter into an agreement with NASEM within 60 days of enactment of this Act to identify research priorities for preventing and treating AD/ADRD.** An ad hoc committee of NASEM will conduct a study and recommend research priorities to advance the prevention and treatment of AD/ADRD. In conducting its study, the committee will:

- 1) Examine and assess the current state of biomedical research aimed at preventing and effectively treating AD/ADRD, along the R&D pipeline from basic to translational to clinical research;
- 2) Assess the evidence on nonpharmacological interventions aimed at preventing and treating AD/ADRD;
- 3) Identify key barriers to advancing AD/ADRD prevention and treatment (e.g., infrastructure challenges that impede large scale precision medicine approaches, inadequate biomarkers for assessing response to treatment, lack of diversity in biobanks and clinical trials), and opportunities to address these key barriers and catalyze advances across the field;
- 4) Explore the most promising areas of research into preventing and treating AD/ADRD.



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EUREKA Challenge for Early Prediction of AD/ADRD

- A challenge prize competition to **discover the best data, methods, and strategies for the early prediction of Alzheimer’s and related dementias** launched in September 2023.
- The challenge will offer cash awards totaling \$650,000 across three phases.
- **NIA received 40 submissions for Phase 1; prizes to be awarded in fall 2024.**



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



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

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NIA’s Healthy Aging Start-Up Challenge

- In support of ongoing efforts to **foster diversity in aging research and innovation**, NIA launched the inaugural **Healthy Aging Start-Up Challenge** in 2022 and held the second iteration in 2023.
- Special interest in solutions that **address health disparities** in aging populations.
- The 2023 Challenge winners were selected from 20 finalists and each received a **\$60,000 prize and continued coaching and mentorship with NIA entrepreneurs-in-residence.**

2023 Challenge Winners:



Gravitrex, LLC

Mechanically powered assisted walking device for accessible mobility rehabilitation



AgingSense

Wearable technology to monitor for worsening heart failure symptoms and for responses to treatment



POPHEC TECHNOLOGIES

Medical/digital device providing remote patient monitoring to predict surgical complications and improve post-op care



CARDIOST
LEFT ATRIUM UNLOADING DEVICE

Implantable medical device to treat cardiovascular conditions including advanced-stage heart failure



LANTERN
LUMINOUS CARE

Novel precision medicine device / platform using EEG biomarkers to guide real-time dosing of pain relievers in OR and ICU



Voice-It, Inc.

Interactive conversational artificial intelligence that uses machine learning to assist with pain symptom management



<https://www.nia.nih.gov/research/sbir/startup-challenge>

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Save the Date:
2024 NIH Alzheimer's Disease Research Summit



National Institute on Aging

2024 NIH Alzheimer's Disease Research Summit: Path to Precision Medicine for Treatment and Prevention

September 23-25, 2024



NIH National Institute on Aging

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NIA's 50th Anniversary

- 2024 marks the **50th anniversary** of the National Institute on Aging
- Since 1974, NIA has led **broad scientific efforts** to understand the **nature of aging** and to extend the **healthy, active years** of life
- Learn about **major milestones** in NIA's history: www.nia.nih.gov/50years



To celebrate, NIA is conducting a series of activities throughout 2024 to **highlight progress** over the past 50 years and to **inspire future generations** of aging researchers.



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Join Us in Celebrating NIA's 50 Years of Progress!

- Learn about **current research and future projects** via the Inside NIA blog
- Explore and **share training and career development** opportunities to advance aging research careers
- Read and share aging research career stories from NIA staff and grantees on NIA's **X** and **LinkedIn**
- Post about your aging research journey on social media (hashtag **#NIAWhereResearchComesOfAge**)



Learn more at www.nia.nih.gov/50years.



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NINDS Response in Collaboration with NIA to The National Plan to Address Alzheimer's Disease

NINDS AD/ADRD Program

AD
LBD
FTD
VCID

\$407M in FY22
AD/ADRD appropriated & NINDS base funds

NINDS ADRD Summits and Roundtables

ADRD Summits
2013, 2016, 2019, 2022

- FTD
- Health Equity
- LBD
- Multiple Etiology Dementias
- VCID

>90 NINDS ADRD Funding Opportunities (FY15-FY24)

CTE/TBI Center Without Walls

detectCID

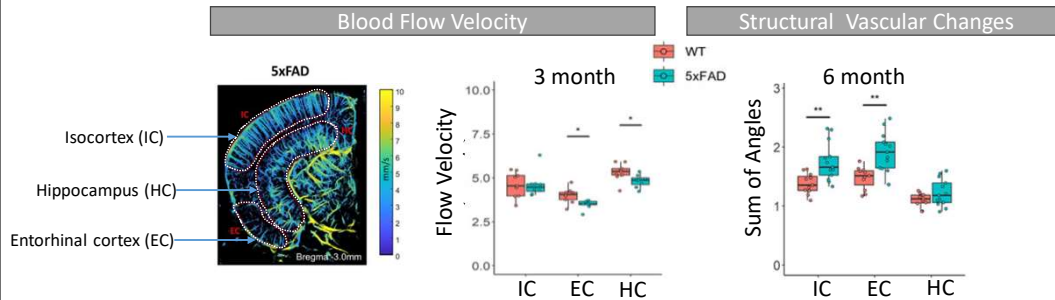
Tauopathy and TDP-43 Proteinopathy Structural Biology Using Cryo-EM & Mass Spectrometry

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VCID Advances: Microvascular Deficits Appear Early in an Alzheimer’s Disease Mouse Model as Revealed by Novel Super-Resolution Ultrasound Localization Microscopy



Novel full brain depth visualization that complements traditional pathology based on FDA-approved perfluten liquid microsphere-enhanced ultrasound used for clinical applications, e.g., cardiac ultrasound.



- 3-month AD mouse has significantly decreased flow velocity in entorhinal cortex and hippocampus versus age-matched controls
 - In addition, 6-month AD mouse has increased blood brain vessel tortuosity

Open funding opportunity to elucidate hemodynamic, cellular, and molecular mechanisms that underlie diffuse white matter disease related to VCID outcomes: [PAR-24-196](#)

Lowerison et al., *The Journal of Neuroscience* 44(9):e1251232024, (2024) (Supported by NIH grants R56NS131516, R21DC019473, R21AG077173, and R03AG059103; the Kiwanis Neuroscience Research Foundation)

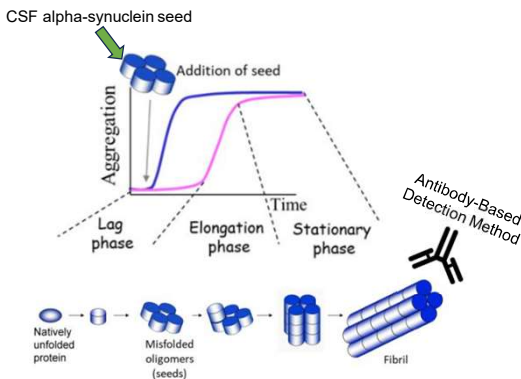


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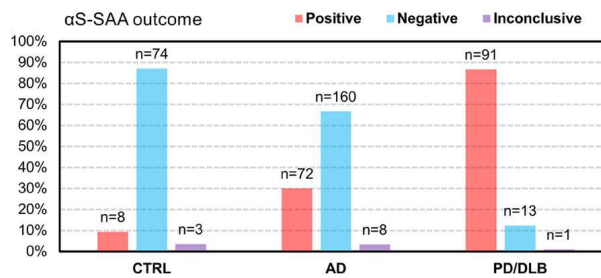
Emerging Biomarker Development: α -Synuclein Proteinopathy 30% of Those Positive for AD Pathology are Also Positive for α -Synucleinopathy



α -synuclein seed amplification assay (α S-SAA)



α -synuclein seed amplification results in Controls, AD, PD/LBD



Stratifying people based on CSF α S-SAA may help in selecting more homogeneous cohorts for clinical studies.

Bellomo G, Toja A, Paoletti F, et al. *Alzheimer’s & Dementia*. 2023 NOV 30 Supported by (Parkinson’s Foundation, Grant/Award Number: PF-PFF-934916; Marie Skłodowska-Curie actions, Grant/Award Number: 860197; Michael J Fox Foundation, Grant/Award Number: 3MIFF-021233; European Union—Next Generation EU, Grant/Award Number: PNRR-MAD-2022-12376035)

Also see: Concha-Marambio L, et al. *Nat Protoc*. 2023 JAN 18 Partially supported by grants from the NIH (R01AG055053, R01AG061069 and R01AG059321) to C.S., R21NS114884 to M.S., and R01 NS119689 to M.S. and S.P., as well as grants from the Michael J. Fox Foundation for Parkinson’s disease to C.S. and S.P., and a grant from the American Parkinson Disease Association to M.S.



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Priority: Biomarker Development for AD/ADRD with TDP-43 Proteinopathy

- Nuclear TDP-43 function is needed for mRNA splicing; loss of function results in mis-splicing
- Cryptic exons and peptides resulting from dysfunctional cytoplasmic TDP-43 may serve as disease-specific biomarkers

TDP-43 loss

mis-splicing

Exon **CE** Exon

mRNA

Cryptic Exon

TDP-43 Pathology in AD/ADRD

ALS – ~97%

FTD – ~50%

AD Dementia – ~50%

LATE – 100%

proteo-genomics

Cryptic Peptide

Cryptic exons detected via RNA-seq and proteomic analyses.

Seddighi, S. *et al.* Sci Transl Med. 2024 Feb 14. NIH awards include: ALLFTD U19AG063911, R01AG062171 and RF1AG062077, U54NS123743, P01NS084974, 5P30AG0062677, T32GM136577, RF1NS120992, F12GM142475 and NIH CARD

National Institute on Aging
National Institute of Neurological Disorders and Stroke

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NINDS Alzheimer’s Disease-Related Dementias (ADRD) Program

NINDS has 23 open/planned ADRD funding initiatives.

For more information see NINDS Focus on Alzheimer's Disease and Related Dementias page : <https://www.ninds.nih.gov/Current-Research/Focus-Disorders/Alzheimers-Related-Dementias>

No RFA is needed to apply!! NINDS special AD/ADRD payline applies to investigator-Initiated research applications to the NIH Parent R01 and the NINDS R21 (PA-21-219)

Published funding announcements will also be shared via the **NINDS ADRD Listserv**
Email kiara.bates@nih.gov to sign up!

Training & Career

Research Resource

Disease Mechanisms

Translation

Clinical Trials, Clinical Research

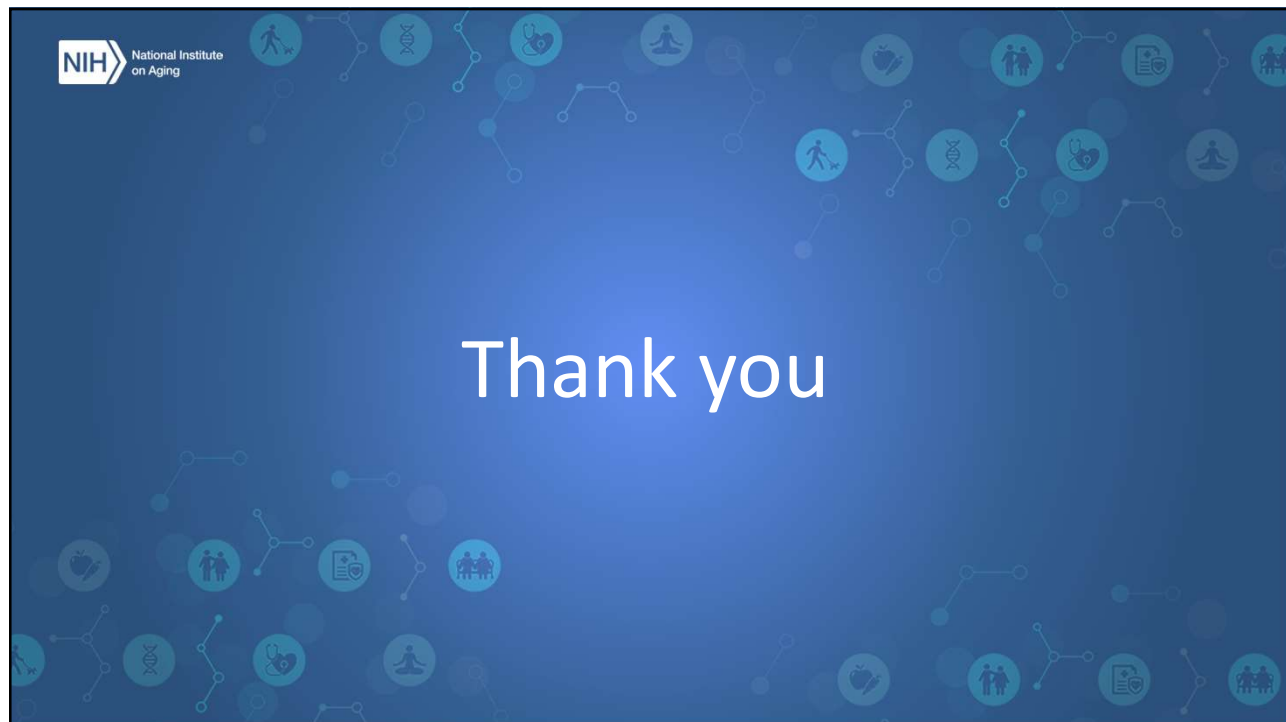
National Institute of Neurological Disorders and Stroke

National Institute on Aging


AD/ADRD Research Supplements to Promote Diversity in Health-Related Research

NOT-NS-24-071, PA-23-189

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NINDS ADRD Current and Planned Funding Announcements 		
Category	Title	PO Lead
Training & Career	PAR-22-022 AD/ADRD Advanced Postdoctoral Career Transition Award to Promote Diversity (K99/R00); Due Date: June 12, 2024	<i>Ullrich/Gubitzi</i>
	PAR-23-113 NINDS Institutional AD/ADRD Research Training Program (T32); Due Date: May 25, 2024	<i>Korn</i>
	NOT-NS-24-071 Administrative Supplements to Promote Diversity for NINDS ADRD Awardees; Expiration Date: February 15, 2027	<i>McCartney</i>
	<i>(Concept approved)</i> NINDS ADRD Advanced Postdoctoral Career Transition Award	<i>McCartney</i>
Disease Mechanisms	PAR-24-147 Mechanistic Investigations into ADRD Multiple Etiology Dementias (R01); Due Dates: June 04, and October 04, 2024	<i>McGavern</i>
	PAR-24-148 Investigating Distinct and Overlapping Mechanism in TDP-43 Proteinopathies, including in LATE, FTD & other ADRDs (R01); Due dates: June 04, and October 04, 2024	<i>McGavern</i>
	PAR-24-196 Mechanistic & Hemodynamic Basis of Diffuse White Matter Disease in VCID (R01); Due Date: October 04, 2024	<i>Corriveau</i>
	PAR-24-198 Protective Strategies to Reduce Amyloid Related Imaging Abnormalities (ARIA) After anti-A β Immunotherapy (R01); Due date: October 04, 2024	<i>Bosetti</i>
	RFA-NS-25-014 Mechanisms of Cognitive Fluctuations in ADRD Populations (R01); Due Date: June 24, 2024	<i>Babcock</i>
	<i>(Re-issue of PAR-23-214)</i> Neuropathological Interactions Between COVID-19 and ADRD	<i>Daley</i>
	<i>(Concept approved)</i> Interaction Between Environmental Factors and Lewy Body Dementia	<i>Jett</i>
	<i>(Concept approved)</i> Mechanistic Investigations into ADRD Associated Protein Structures in Biological Settings	<i>Umanah</i>
<i>(Concept approved)</i> Integrative Multi-omic Profiling for Lewy Body Dementia	<i>Swanson-Fischer</i>	
<i>(Concept approved)</i> ADRD Risk & Disease Following Nervous System Exposures at Biological Interfaces with the Environment	<i>Jett</i>	

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NINDS ADRD Current and Planned Funding Announcements



Category	Title	PO Lead
Translation	(Re-issue of RFA-NS-22-055) Functional Target Validation for Alzheimer's Disease-Related Dementias	Laeng
	(Re-issue of RFA-NS-24-009) Optimization of Genome Editing Therapeutics for ADRD	Lavaute
Research Resource	RFA-NS-24-032 Development and Validation of Human Cellular Models for ADRD (R01); Due Dates: June 20, and October 21, 2024	McGavern/ Shewmaker
	RFA-NS-24-034 Tools and resources to understand the vascular pathophysiology of in vivo neuroimaging findings in ARIA (U24); Due Date: May 31, 2024	Faraco
Clinical Trials Clinical Research	RFA-NS-24-013 Efficacy and Safety of Amyloid-Beta Directed Antibody Therapy in Mild Cognitive Impairment and Dementia with Evidence of Both Amyloid-Beta and Vascular Pathology (U01 - Clinical Trial Required); Due Date: May 20, 2024	Hommer
	(Concept approved) Safety and Efficacy of Amyloid-Beta Directed Antibody Therapy in Mild Cognitive Impairment and Dementia with Evidence of Lewy Body Dementia and Amyloid-Beta Pathology	Hommer
	(Concept approved) Including ADRD Biomarker Measures and APOE Genotype Status to ADRD Human Subjects Research Studies (Admin. Supplement)	McCartney
	(Concept approved) Clinical Trial Readiness to Understand and Develop Solutions to Social, Ethical, and Behavioral implications (SEBI) Barriers to Health Equity in ADRD	Benson/Hommer/ Mendoza-Puccini
	(Concept approved) IND-enabling Studies and Clinical Trials for Genome Editing Therapeutics for ADRD	Lavaute

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