National Plan to Address Alzheimer's Disease: 2024 Update

U.S. Department of Health and Human Services

National Plan to Address Alzheimer's Disease: 2024 Update

DEPARTMENT OF HEALTH & HUMAN SERVICES · USA

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Introduction

National Alzheimer's Project Act

On January 4, 2011, the National Alzheimer's Project Act (NAPA) (Public Law 111-375) was signed into law. The Act defines "Alzheimer's" as Alzheimer's disease and Alzheimer's disease-related dementias (AD/ADRD) and requires the Secretary of the U.S. Department of Health and Human Services (HHS) to establish NAPA to:

- Create and maintain an integrated National Plan to overcome Alzheimer's disease.
- Coordinate Alzheimer's disease research and services across all federal agencies.
- Accelerate the development of treatments that would prevent, halt, or reverse the course of Alzheimer's disease.
- Improve early diagnosis and coordination of care and treatment of Alzheimer's disease.
- Decrease disparities in Alzheimer's disease for racial and ethnic minority populations that are at higher risk for Alzheimer's disease.
- Coordinate with international bodies to fight Alzheimer's disease globally.

The law also establishes the Advisory Council on Alzheimer's Research, Care, and Services (Advisory Council) and requires the Secretary of HHS, in collaboration with the Advisory Council, to create and maintain the *National Plan to Address Alzheimer's Disease*.

NAPA offers a historic opportunity to address the many challenges facing people with AD/ADRD and their families and caregivers. Given the great demographic shifts that will occur over the next 30 years, including the doubling of the population of older adults, the success of this effort is of great importance to people with AD/ADRD and their family members, caregivers, public policy makers, and health and social service providers.

Alzheimer's Disease and Related Dementias

More than six million Americans are currently living with Alzheimer's disease (AD), and it is predicted that more than 13 million will be living with the disease by 2060.[1] It slowly destroys brain function, leading to cognitive decline (e.g., memory loss, language difficulty, poor executive function), behavioral and psychological symptoms (e.g., depression, delusions, agitation), and declines in functional status (e.g., ability to engage in activities of daily living [ADLs] and self-care).[2] In 1906, Dr. Alois Alzheimer first documented the disease when he identified changes in the brain tissue of a woman who had memory loss, language problems, and unpredictable behavior. Her brain tissue included abnormal clumps (amyloid plaques) and tangled bundles of fibers (neurofibrillary tangles). In addition to the loss of connections between neurons, these brain plaques and tangles are the main pathological features of AD.[3] However, studies of brain tissue have found that persons living with dementia (PLWD) usually have a mixture of brain changes. They may have the hallmark plaques and tangles of AD mixed with variations typically linked to another related form of dementia, making precise diagnosis difficult.

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[1] Rajan KB, Weuve J, Barnes LL, McAninch EA, Wilson RS, Evans DA. "Population estimate of people with clinical Alzheimer's disease and mild cognitive impairment in the United States (2020-2060)." *Alzheimer's & Dementia*, 2021; 17(12): 1966-1975. doi:10.1002/alz.12362. https://pubmed.ncbi.nlm.nih.gov/34043283/.

[2] Burns A, Iliffe S. "Alzheimer's disease." *BMJ*, 2009; 338: b158.

[3] Alzheimer's Disease Education and Referral (ADEAR) Center. *Alzheimer's Disease Fact Sheet*. U.S. Department of Health and Human Services, National Institutes of Health. 2021; NIH Publication No. 11-6423. https://www.nia.nih.gov/health/alzheimers-disease-fact-sheet.

In addition to AD, this National Plan addresses Alzheimer's disease-related dementias (ADRD) consistent with the approach Congress used in NAPA. ADRD include frontotemporal dementias (FTD), Lewy body dementias (LBD, which include dementia with Lewy bodies and Parkinson's disease dementia), vascular contributions to cognitive impairment and dementia (VCID), and mixed dementias -- especially AD mixed with cerebrovascular disease or Lewy bodies. It is often difficult to distinguish between AD and ADRD in terms of clinical presentation and diagnosis. Some of the basic neurodegenerative processes have common pathways. Many people, especially older adults, have more than one type of pathology in their brains contributing to dementia.[4] People with all forms of AD/ADRD and their families and caregivers face similar challenges in finding appropriate and necessary medical care and community-based services. As such, many of the actions described in this plan are designed to address these conditions collectively.

The first symptom of AD is most often memory impairment; in the ADRDs however, poor attention and executive function, behavioral disorders, visual disturbances, sleep disruption or motor symptoms can often be the presenting symptoms. As the diseases progress, memory declines, and other functions like language skills and decision making become more difficult. Personality and behavior changes often occur. Over time, a person with the disease may no longer recognize family and friends. Eventually, many persons who survive with AD/ADRD are completely reliant on others for assistance with even the most basic ADLs, such as eating, dressing, and bathing.[5]

In more than 90% of people with AD/ADRD, symptoms do not appear until after age 60, and the incidence of the disease increases with age from 5.3% among adults ages 65-74 to 34.6% among adults aged 85 and older.[6] Some conditions, such as FTD tend to begin earlier. AD/ADRD are not completely understood, but researchers have discovered that these age-related conditions usually develop from the combined effects of certain genetic, social, economic, educational, environmental factors as well as co-morbidities such as hypertension, diabetes, stroke, alcohol abuse, and head trauma.[7,8,9,10] The importance of any one of these factors in increasing or decreasing the risk of developing AD/ADRD may differ from person to person. In rare cases, known as early-onset or younger-onset dementia, people develop symptoms in their 30s, 40s, or 50s. The majority of people with Down syndrome develop AD in their 50s or younger, often placing increased burden on their families and caregivers. The risk of developing dementia is higher among people from racial and ethnic minority population. Black Americans are twice as likely and Hispanic or Latino Americans are 1.5 times as likely to develop AD/ADRD

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[4] Kawas CH, Kim RC, Sonnen JA, Bullain SS, Trieu T, Corrada MM. "Multiple pathologies are common and related to dementia in the oldest-old: The 90+ study." *Neurology*, 2015; 85(6): 535-542. doi:10.1212/WNL.0000000000000183.

[5] National Institute on Aging. *What Is Dementia? Symptoms, Types, and Diagnosis*. https://www.nia.nih.gov/health/what-is-dementia.

[6] Rajan KB, Weuve J, Barnes LL, McAninch EA, Wilson RS, Evans DA. "Population estimate of people with clinical Alzheimer's disease and mild cognitive impairment in the United States (2020-2060)." *Alzheimer's & Dementia*, 2021; 17(12): 1966-1975. doi:10.1002/alz.12362. https://pubmed.ncbi.nlm.nih.gov/34043283/.

[7] Barnes DE, Yaffe K. "The projected effect of risk factor reduction on Alzheimer's disease prevalence." *Lancet Neurology*, 2011; 10(9): 819-828. doi:10.1016/S1474-4422(11)70072-2.

[8] Kunkle BW, Grenier-Boley B, Sims R, et al. "Genetic meta-analysis of diagnosed Alzheimer's disease identifies new risk loci and implicates Aβ, tau, immunity and lipid processing." *Nature Genetics*, 2019; 51(3): 414-430. doi:10.1038/s41588-019-0358-2.

[9] Norton S, Matthews FE, Barnes DE, Yaffe K, Brayne C. "Potential for primary prevention of Alzheimer's disease: An analysis of population-based data." *Lancet Neurology*, 2014; 13(8):788-794. doi:10.1016/S1474-4422(14)70136-X.

[10] Yaffe K, Falvey C, Harris TB, Newman A, Satterfield S, Koster A, Ayonayon H, Simonsick E. "Effect of socioeconomic disparities on incidence of dementia among biracial older adults: Prospective study." *BMJ*, 2013; 347. doi:org/10.1136/bmj.f7051.

compared to White Americans.[11,12] The burden is particularly high among American Indian and Alaska Native (AI/AN) populations, where more than half (54%) of people 70+ have cognitive impairment.[13]

AD/ADRD is a major public health issue and will increasingly affect the health and well-being of the United States population. Unless the diseases can be effectively treated or prevented, the number of Americans with AD/ADRD will increase significantly in the next two decades as the population ages. The U.S. Census Bureau estimates that the number of people aged 65 and older in the United States will almost double to 84 million by 2050. The prevalence of people with AD/ADRD doubles for every 5-year interval beyond age 65. Without a preventive treatment or cure, the significant growth in the population over age 85 that is estimated to occur between 2015 and 2050 (from 6.3 million to 19 million) suggests a substantial increase in the number of people with AD/ADRD. In addition, recently blood-based biomarkers have proven very accurate in identifying persons with brain amyloid deposition even years before onset of dementia. Cerebrospinal fluid (CSF) biomarkers have proven very accurate in identifying persons with synuclein aggregates, which are the pathologic signature of LBD and Parkinson's disease. Similar to the case for AD-pathology, synuclein aggregation assays are abnormal many years before symptoms occur. These findings suggest opportunities to intervene earlier in the disease process for those that the biomarker tests indicate are at high risk.

Significant emotional, physical, and financial stress is placed on individuals with AD/ADRD and their family members. Unpaid caregivers, often family members and friends, provide the majority of care for people with AD/ADRD in the community. Unpaid caregivers frequently do not identify themselves as such; they may be a wife, daughter, husband, parent, son, or friend helping a person whom they care about. However, the intensive support required for a person with AD/ADRD can negatively impact the caregiver's emotional and physical health and well-being, and their ability to work. Unpaid caregivers often report symptoms of depression and anxiety, and they have poorer health outcomes than their peers who do not provide such care.[14]

Dementia care costs are significant and often a burden to families and others providing unpaid care. Researchers estimated that the total value of health, long-term care (LTC), and caregiving for a person with probable dementia in the last 5 years of life was $287,000 (in 2020 dollars). These costs are significantly higher than care for a person with heart disease ($175,000) or cancer ($173,000).[15]

Providing care to people with the disease also strains health and LTC systems. Individuals with AD/ADRD use a disproportionate amount of health care resources; for instance, they are hospitalized 2-3 times as often as people of the same age who do not have the disease.[16] Similarly, estimates from national data show that nearly seven out of ten residents in assisted living facilities have some form of cognitive

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[11] Rajan K, Weuve J, Barnes L, Wilson R, Evans D. "Prevalence and incidence of clinically diagnosed Alzheimer's disease dementia from 1994 to 2012 in a population study." *Alzheimer's & Dementia*, 2019; 15(1): 1-7. doi:10.1016/j.jalz.2018.07.216.

[12] Samper-Ternent R, Kuo Y, Ray L, Ottenbacher K, Markides K, Al Snih S. "Prevalence of health conditions and predictors of mortality in oldest old Mexican Americans and non-Hispanic Whites." *Journal of the American Medical Directors Association*, 2012; 13(3): 254-259. doi:10.1016/j.jamda.2010.07.010.

[13] Suchy-Dicey AM, et al. "Epidemiology and prevalence of dementia and Alzheimer's disease in American Indians: Data from the Strong Heart Study." *Alzheimer's & Dementia*, 2024. doi:10.1002/alz.13849.

[14] Mahoney R, Regan C, Katona C, Livingston G. "Anxiety and depression in family caregivers of people with Alzheimer's disease: The LASER-AD Study." *Journal of the American Geriatrics Society*, 2005; 13(9): 795-801.

[15] Kelley AS, McGarry K, Gorges R, Skinner JS. "The burden of health care costs for patients with dementia in the last 5 years of life." *Annals of Internal Medicine*, 2015; 163(10): 729-736. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4809412/.

[16] Magaziner J, German P, Zimmerman SI, Hebel JR, Burton L, Gruber-Baldini AL, May C, Kittner S. "The prevalence of dementia in a statewide sample of new nursing home admissions aged 65 and older: Diagnosis by expert panel." *Gerontologist*, 2000; 40(6): 663-72. doi:10.1093/geront/40.6.663.

impairment.[17] As the number of people with AD/ADRD grows over the next three decades, these conditions will place a major strain on public and private health care providers, as well as Medicare and Medicaid, which fund clinical care and long-term services and supports (LTSS) including both institutional and home and community-based services (HCBS). Although Medicaid, a program for eligible low income Americans, covers LTSS, Medicare only covers limited rehabilitative care. Most Americans underestimate the risk of disability and the need for LTC. More than half of older adults turning 65 today will develop a disability such as AD/ADRD, serious enough to require LTSS, although most will need assistance for less than 2 years. About one in seven will have a disability for more than 5 years. On average, an American turning 65 today will incur $138,000 in future LTSS costs. Families will pay about half of the costs themselves, out-of-pocket with the rest covered by current public programs and private insurance.[18]

The Challenges

The National Plan was designed to address the major challenges presented by AD/ADRD:

1. The United States now has two Food and Drug Administration (FDA)-approved disease-modifying therapeutics that target the underlying amyloid pathology of AD, marking a watershed moment as a result of intensive research. The approved therapies demonstrated amyloid reduction and slowing decline on assessments of cognition and function in the early symptomatic stages of AD. Although slowing disease progression is an important step in the treatment of AD, the drugs do not halt disease progression. This further supports that AD/ADRD are a highly complex and diverse set of diseases. Existing treatments are not sufficient to address all stages of AD and at present have not demonstrated effectiveness in treating all of the pathologic processes that give rise to AD and other forms of dementia. Additional research is needed to identify and test a diverse range of pharmacological and behavioral interventions that may treat, delay, or prevent the onset of dementia in all people.

2. While HHS and other groups have taken steps to develop quality measures to assess dementia care and improve the training of the health and LTC workforces -- for both paid and unpaid caregivers -- there is room for improvement.

3. Family members and other unpaid caregivers, who take on the responsibility of caring for a person with AD/ADRD, also need services and supports. The majority of people with AD/ADRD live in the community, where their families provide most of their care. The toll of caregiving can have major implications for caregivers and families as well as population health, with about one-third of caregivers reporting symptoms of depression.[19,20]

4. Stigmas and misconceptions associated with AD/ADRD are widespread and profoundly impact the care provided to and isolation felt by people with AD/ADRD and their families and caregivers.

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[17] Yaffe K, Fox P, Newcomer R, Sands L, Lindquist K, Dane K, Covinsky KE. "Patient and caregiver characteristics and nursing home placement in patients with dementia." *Journal of the American Medical Association*, 2002; 287(16): 2090-2097. doi:10.1001/jama.287.16.2090.

[18] Favreault M. *Long-Term Services and Supports for Older Americans: Risks and Financing Research Brief*. Washington, DC: U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, 2016. https://aspe.hhs.gov/reports/long-term-services-supports-older-americans-risks-financing-research-brief-0.

[19] Yaffe K, Fox P, Newcomer R, Sands L, Lindquist K, Dane K, Covinsky KE. "Patient and caregiver characteristics and nursing home placement in patients with dementia." *Journal of the American Medical Association*, 2002; 287(16): 2090-2097. doi:10.1001/jama.287.16.2090.

[20] Taylor DH, Ezell M, Kuchibhatia M, Ostbye T, Clipp EC. "Identifying the trajectories of depressive symptoms for women caring for their husbands with dementia." *Journal of the American Geriatrics Society*, 2008; 56(2): 322-327.

5. Public and private sector progress is significant but should be coordinated and tracked. In addition, data to track the incidence, prevalence, trajectory, and costs of AD/ADRD are limited.

Framework and Guiding Principles

The enactment of NAPA provided an opportunity to focus the Nation's attention on the challenges of AD/ADRD. In consultation with partners both inside and outside of the Federal Government, this National Plan represents the blueprint for achieving the vision of a nation free of AD/ADRD.

Central to and guiding the National Plan are the people most intimately impacted by AD/ADRD -- those who have the diseases and their families and other caregivers. Individuals with AD/ADRD and their caregivers may receive assistance from both the clinical health care and LTC systems including primary and specialty care, HCBS, legal services, and other social services. Both the clinical health care and LTC systems need better tools to serve people with AD/ADRD and their unpaid caregivers. Ongoing and future research seeks to identify interventions to assist clinicians, supportive service and HCBS providers, PLWD, and caregivers. All these efforts must occur in the context of improved awareness of the diseases, their risk factors and impacts, as well as opportunities for improvement. The National Plan aims to address these key needs. HHS is committed to tracking and coordinating the implementation of NAPA and making improvements aimed at achieving its ambitious vision.

The National Plan continues to be guided by three principles:

1. **Optimize Existing Resources, and Improve and Coordinate Ongoing Activities**. The first step in developing the National Plan was to set up a federal interagency working group and conduct an inventory of all federal activities involving AD/ADRD. In creating the National Plan, HHS and its partners sought to leverage these resources and activities, improve coordination, and reduce duplication of efforts to better meet the challenges of AD/ADRD. The activities included in the inventory comprise ongoing work and new opportunities. The federal working group process continues to improve coordination and awareness throughout the Federal Government and set in motion commitments for further collaboration. Further, this process has allowed for identification of non-AD-specific programs and resources that may be leveraged to advance AD/ADRD care and prevention.

2. **Support Public-Private Partnerships**. The scope of the challenges of AD/ADRD is so great that partnerships with a multitude of public and private partners are essential to making progress. The original National Plan began the partnership process by identifying areas of need and opportunity. The National Plan continues to rely on the Advisory Council in particular to identify key areas where public-private partnerships can improve outcomes.

3. **Transform the Way We Approach Alzheimer's Disease and Related Dementias**. The National Plan recognizes that this undertaking will require continued, large-scale, coordinated efforts across the public and private sectors. With principles 1 and 2 above, as well as the ambitious vision that the Federal Government has committed to through this Plan, HHS and its federal partners continue to take transformative action needed to address these diseases. With ongoing input from the Advisory Council, the Federal Government continues to identify the most promising areas for progress and marshal resources from both within and outside the government to act on these opportunities.

Goals as Building Blocks for Transformation

Achieving the vision of eliminating the burden of AD/ADRD starts with concrete goals. Below are the six goals that form the foundation of the National Plan:

1. Prevent and Effectively Treat Alzheimer's Disease and Related Dementias by 2025.
2. Enhance Care Quality and Efficiency.
3. Expand Supports for People with Alzheimer's Disease and Related Dementias and their Families.
4. Enhance Public Awareness and Engagement.
5. Improve Data to Track Progress.
6. Accelerate Action to Promote Healthy Aging and Reduce Risk Factors for Alzheimer’s Disease and Related Dementias.

2024 Update

After decades of rigorous scientific research, FDA has now granted approval for multiple therapeutics for the treatment of early symptomatic AD. Most recently, Kisunla (donanemab-azbt) was approved in July 2024. While the Federal Government did not fund the pivotal Phase III clinical trials that led to FDA approvals, federal funding through the National Institutes of Health (NIH) was critical in laying the groundwork for these trials -- by supporting foundational research on amyloid, the protein targeted by these drugs, and supporting the development and validation of amyloid positron emission tomography (PET) imaging, a technology central to these trials.

Although the approval of these drugs represents a significant scientific milestone, additional research is needed to understand how these treatments can be used in the wider population. For example, both drugs were approved with labeling indicating treatment should be initiated in patients with mild cognitive impairment (MCI) or mild dementia stage of disease -- there remains a need to test these and other drugs at different disease stages and in more diverse populations. The drugs do not halt disease progression which motivates research to understand the other processes driving progression of dementia in the absence of brain amyloid. Given the complexity and co-occurrence of AD/ADRD, it is unlikely that any one drug or other intervention will be successful in treating all people. For this reason, the research field aims to generate several approaches that may be used alone or in combination to effectively slow cognitive decline in a more personalized way.

While NIH-funded researchers continue to pursue new drugs to prevent and treat dementia, many behavioral and lifestyle interventions also offer promise in reducing dementia risk and improving cognition and memory. For example, recent NIH-funded clinical trials have found that:

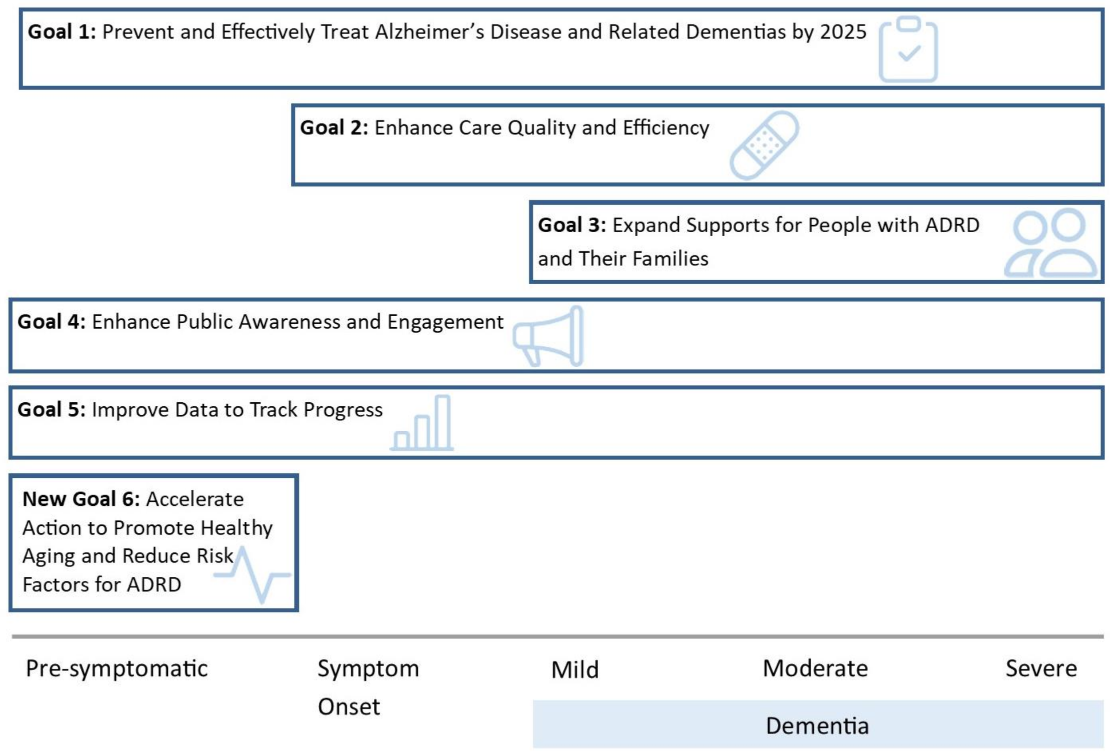
- Aggressive control of blood pressure reduces age-related cognitive impairment.
- Correcting hearing loss with hearing aids reduced cognitive decline over 3 years in a group of older adults with specific risk factors for cognitive decline.
- A daily, broad-spectrum multi-vitamin modestly improved memory in older adults when compared to placebo.
- Personalized health coaching improved cognition and reduced dementia risk in older adults with at least two modifiable risk factors for dementia (e.g., low physical activity, hypertension, diabetes, smoking).

Progress in diagnostic approaches and assessments for AD/ADRD has also been remarkable. With support from NIH, researchers developed a new blood test, PrecivityAD2, that combines measures of amyloid and tau to help physicians make an accurate and timely diagnosis of AD. In addition, NIH-funded research has led to the discovery of a fluid marker that offers promise to help diagnose forms of dementia associated with abnormal accumulation of the TDP-43 protein, such as FTD, limbic-predominant age-related TDP-43 encephalopathy (LATE), and mixed dementias in cases when TDP-43 pathology co-occurs with AD, LBD, and/or vascular pathologies. These new tests have the potential to help reduce cost and time needed to enroll individuals in trials and may help lower barriers to trial participation, with the potential to expand recruitment to broader, more diverse communities. A test on CSF has been shown to have high accuracy in detecting synuclein pathology, which is central to LBD and Parkinson’s disease dementia. In addition, up to 30% of persons with AD show abnormal synuclein aggregation on this “seeding assay.” These fluid biomarkers have the potential to identify thousands of “presymptomatic” individuals who are at high risk for developing one or more of these ADRDs. Thus, they provide an opportunity to intervene with effective therapies many years before symptoms begin and potentially prevent conversion to dementia. They also underscore the urgency to develop effective therapies as individuals are tested and learn about their high risk of dementia.

In addition, progress has been made on care and services for PLWD. With the support of the Indian Health Service (IHS) Alzheimer's Program, Tribal and Urban Indian programs are building models of care for PLWD and their caregivers that are responsive to the unique cultures and needs of their tribes and communities. Tribal, IHS, and Urban Indian programs are taking advantage of the newly developed Indian Health Geriatric Scholars (GeriScholars) and Geriatric Nurse Fellowship programs and the Indian Country Extension for Community Healthcare Outcomes (ECHO) project to build a more dementia-capable primary care workforce. The year-end 2024 award of an Alzheimer's Training and Education contract to provide culturally-relevant, competency-based training and resources will further strengthen the agency's response to the needs of the Indian health workforce and communities.

On October 1, 2024, as this update was being drafted, President Biden signed the NAPA Reauthorization Act to extend this effort through 2035. The legislation also adds additional federal and non-federal members with important perspectives to the Advisory Council on Alzheimer's Research, Care, and Services, and codifies risk reduction as a key area of focus. Throughout 2025, HHS and its federal partners will work with the Advisory Council and others to amend the goals and strategies of the National Plan to reflect not only the progress over the last 13 years, but also a vision for addressing Alzheimer's disease over the next decade.

National Plan Goals Across AD/ADRD Trajectory



https://www.nia.nih.gov/health/what-are-signs-alzheimers-disease

Goal 1: Prevent and Effectively Treat Alzheimer's Disease and Related Dementias by 2025

Research continues to expand our understanding of the causes of and possible prevention and treatment strategies for AD/ADRD. This goal seeks to identify the underlying disease mechanisms to ultimately develop and test potential prevention and treatment interventions. Ongoing research and clinical inquiry can inform our ability to prevent AD/ADRD, minimize its symptoms, and delay its progression. Under this goal, HHS will continue to prioritize and accelerate the pace of scientific research and ensure that as evidence-based solutions are identified, they are quickly translated, put into practice, and brought to scale so that individuals with AD/ADRD can benefit from increases in scientific knowledge. HHS will identify interim milestones and set ambitious deadlines for achieving these milestones to meet this goal.

Strategy 1.A: Identify Research Priorities and Milestones

As noted above, the National Plan describes specific diseases and conditions that are considered to be AD/ADRD based on similarities in clinical symptoms and brain pathologies between these conditions and AD. These ADRDs include FTD, LBD (i.e., dementia with Lewy bodies and Parkinson's disease dementia), VCID, and mixed etiology dementias. At NIH, research applications focused on the AD/ADRD conditions named in the National Plan are eligible for targeted AD/ADRD funds. In addition, NIH staff exercise judgment in identifying AD/ADRD science in all applications, even if such applications are not centrally focused on AD or the National Plan-named ADRD conditions. One way that NIH stays current on AD/ADRD science is through the triennial AD and ADRD Research Summits led by the National Institute on Aging (NIA) and the National Institute of Neurological Disorders and Stroke (NINDS). These summits elicit critical public input on the science that is best positioned to advance the goals of NAPA and the National Plan. For example, the ADRD Research Summits have included emerging topics such as LATE and dementia related to chronic traumatic encephalopathy (CTE) and traumatic brain injury (TBI). These Summits are open to the public and widely attended by the research community, PLWD and their care partners, patient/disease advocacy groups, government staff, and biomedical industry professionals.

There are multiple steps taken to ensure that applications eligible for AD/ADRD targeted funds are scientifically appropriate. Applying this process, NIH has used AD/ADRD funds to support many research applications that advance the goals of NAPA and the National Plan, which are focused on other conditions beyond AD and the named ADRD conditions, including prion diseases (i.e., Creutzfeldt-Jakob disease), Amyotrophic Lateral Sclerosis/Lou Gehrig's disease (ALS), TBI (including CTE), and Down syndrome.

HHS recognizes that there is constant scientific progress in the understanding of AD/ADRD and other neurological conditions. As described above, NIH staff routinely integrate the latest scientific knowledge into grant review and award processes. This ensures that there is a nimble and informed process for identifying the full scope of AD/ADRD science that can help move forward the goals of NAPA and the National Plan.

Research agencies undertake research planning processes on an ongoing basis, but a special effort is needed to identify the priorities and milestones to achieve Goal 1. The activities below serve to help identify the priorities, establish milestones, and ensure that appropriate partners are involved in the planning process aimed at preventing AD/ADRD and minimizing it as a health burden by 2025. During the course of this work, NIH and partner agencies will develop research priorities and a plan for implementing each phase of research in a coordinated manner.

(ONGOING) Action 1.A.1: Regularly convene an Alzheimer's disease research summit to update priorities

Lead Agency: NIH
Partners: National and international experts, public and private stakeholders, academia, industry, professional and advocacy groups

In September 2024, NIA hosted the fifth *Alzheimer's Disease Research Summit*, with previous summits occurring in 2012, 2015, 2018, and 2021. The summits bring together a multi-stakeholder community, including government, industry, academia, private foundations, and advocacy groups, to identify research priorities and further translate AD/ADRD research findings into practice. The goal is to accelerate the development of effective, disease-modifying, and palliative therapies for the cognitive as well as neuropsychiatric symptoms (NPS) of AD/ADRD. Building on the success of previous summits, the 2024 Summit was focused on highlighting progress toward precision medicine and articulating the vision for the continued development of a precision medicine research enterprise. The program included robust discussions of advances and remaining challenges related to disease heterogeneity, the growing biomarker toolkit, risk reduction, and emerging therapeutic approaches. Participants also provided individual input that identified opportunities to better meet the needs of the field today, such as by advancing regulatory science to enable precision approaches, developing precision combination therapies, and better engaging research participants as partners in research.

For more information see:

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

(ONGOING) Action 1.A.2: Solicit diverse community input on Alzheimer's disease research priorities

Lead Agency: NIA

National research summits (including the *Alzheimer's Disease Research Summit*, *Alzheimer's Disease-Related Dementias (ADRD) Summit*, and *National Research Summit on Care, Services, and Supports for Persons with Dementia and their Caregivers*) are held yearly on a rotating basis to gather input from multiple stakeholder groups, including the scientific community, advocacy organizations, and PLWD and their care partners. Individual input from participants at these and other NIH workshops and events help NIH identify research gaps and opportunities that form the foundation for a research strategy. The NIH research plan to reach the NAPA goals is outlined as a series of research implementation milestones, which include success criteria and specific implementation activities to track progress. These milestones and the accompanying milestone database are updated annually based on this diverse input. This planning process and its systematic updates have informed the research community about NIH's interests and priorities in funding projects in AD/ADRD. In April 2023, NIA released an enhanced database for tracking of AD/ADRD Research Implementation Milestones. Updates to the database include improved search performance by enabling the ability to search, sort, and filter milestones.

In March 2024, NIA and NINDS collaborated to host a 3-day workshop entitled *Clinically Meaningful Outcomes in AD/ADRD Trials*. The workshop convened a diverse group of stakeholders, including researchers, clinicians, PLWD and care partners, health economists, regulators, and payers. The goals of the workshop were to explore clinically meaningful change in the context of AD/ADRD trials, identify gaps and research opportunities related to patient-centered outcome assessments, and discuss the criteria used to assess whether an intervention has had a clinically meaningful impact. Additional information about the agenda as well as workshop recordings are available on the NIA website.

In December 2023, NIA organized a workshop titled *Precision Medicine Approaches for Developing Combination Therapies for the Treatment and Prevention of Alzheimer's Disease (AD) and AD-Related Dementias* which brought together experts from academia, biotech industry, non-profit foundations, NIH and FDA. Presentations from speakers highlighted the current and emerging therapeutic landscape for AD/ADRD and discussed opportunities and challenges for the development of combination therapies for the treatment and prevention of AD/ADRD, including the development of combinations of pharmacologic and non-pharmacologic interventions, as precision medicine therapies.

In September 2024, NIA hosted a workshop entitled *APOE Genetics as a Major Determinant of AD Pathobiology*. The workshop brought together lead investigators in APOE genetics and related fields to discuss APOE4 as a toxic gain-of-function molecule associated with the pathobiology of AD/ADRD. Participants discussed APOE-mediated mechanisms of disease, different genetic populations and protective variants, and progress toward APOE4-targeting therapeutics. The workshop generated new mechanistic insights into the impact of APOE in the brain.

NIH also gathers important input on research priorities through activities with the National Academies of Science, Engineering, and Medicine (NASEM). For example, NASEM released a survey report titled *Reducing the Impact of Dementia in America: A Decadal Survey of the Behavioral and Social Science* in August 2021, which included input from subject matter experts, researchers, advocacy organizations, PLWD and care partners. The report provided a blueprint for the next decade of behavioral and social science research in dementia that has informed NIA research priorities. For a full list of funding opportunities and their links, please see Appendix 3.

Additionally, in response to a request from Congress, NIA and NINDS engaged NASEM to conduct a consensus study to identify research priorities to advance the prevention and treatment of AD/ADRD. NASEM assembled an ad-hoc committee of experts to review the evidence and develop recommendations. The committee held a public workshop in January 2024 to explore promising areas of research that could catalyze scientific breakthroughs or accelerate the translation of discoveries into effective prevention and treatment strategies, as well as discuss barriers to research progress. A final analysis report will be released in winter 2024.

For more information see:

- https://aspe.hhs.gov/alzheimers-disease-related-dementias-adrd-summit-2016-prioritized-research-milestones
- https://www.nationalacademies.org/our-work/decadal-survey-of-behavioral-and-social-science-research-on-alzheimers-disease-and-alzheimers-disease-related-dementias
- https://www.nationalacademies.org/our-work/research-priorities-for-preventing-and-treating-alzheimers-disease-and-related-dementias
- https://www.nia.nih.gov/2023-dementia-care-summit
- https://www.nia.nih.gov/2024-alzheimers-summit
- https://www.nia.nih.gov/research/dbsr/workshops/clinically-meaningful-outcomes-ad-adrd-trials
- https://www.nia.nih.gov/research/dn/workshops/precision-medicine-approaches-developing-combination-therapies-treatment-and
- https://www.nia.nih.gov/research/milestones
- https://www.nia.nih.gov/research/workshops/apoe-genetics-major-determinant-alzheimers-disease-pathobiology
- https://www.ninds.nih.gov/news-events/events/adrd-summit-2022

(ONGOING) Action 1.A.3: Regularly update the National Plan and refine Goal 1 strategies and action items based on feedback and input

Lead Agency: ASPE
Partners: NAPA Advisory Council, NIH, NIA

HHS and its federal partners use the diverse input received through the three research summits and other scientific workshops on AD/ADRD to inform implementation of the National Plan. An updated Goal 1 will reflect the priorities, milestones, and timeline elements identified through these processes to accelerate research in this area. These will be incorporated into the next iteration of the National Plan and will be updated on an annual basis with the assistance of consensus advice from the Advisory Council.

(ONGOING) Action 1.A.4: Update research priorities and milestones

Lead Agency: ASPE
Partners: NAPA Advisory Council, NIH, NIA

To ensure that the research priorities and milestones reflect the broad input of the scientific community and the public, one Advisory Council meeting per year will be focused on this area. The Research Subcommittee of the Advisory Council will collect input and recommend priorities and milestones for consideration by the Advisory Council as official recommendations. As appropriate, researchers in the field will also be invited to present at these meetings.

(ONGOING) Action 1.A.5: Create a timeline with milestones for achieving Goal 1

Lead Agencies: NIA, NINDS

Since the advent of the National Plan, NIH's planning process for research on AD/ADRD has expanded in inclusion and scope, to include several NIH Institutes and Centers and stakeholders across the scientific and care communities. Gathering input from the broader community is critical to updating research recommendations, ensuring prioritization is based on important scientific questions, and identifying how federal and other public and private organizations can most effectively collaborate to address research priorities. Ultimately, information obtained through the various research summits results in the formation and/or update of the implementation research milestones, which set forth activities through fiscal year (FY) 2025 to address the goals of the National Plan. Recent updates took place after the 2021 *Alzheimer's Disease Research Summit*, the 2022 *Alzheimer's Disease-Related Dementias Summit*, and the 2023 *Dementia Care and Caregiving Summit*. Additional updates are in progress following the 2024 *Alzheimer's Disease Research Summit*.

For more information see:

- https://www.nia.nih.gov/2024-alzheimers-summit
- https://www.nia.nih.gov/research/milestones
- https://www.nia.nih.gov/sites/default/files/2018-07/fy2020-milestones-chart.pdf

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(ONGOING) Action 1.A.6: Regularly convene an Alzheimer's disease-related dementias summit to review progress on research recommendations, and refine and add new recommendations as appropriate based on recent scientific discoveries

Lead Agency: NINDS
Partners: Academia, industry, professional and advocacy groups

NINDS convened the most recent *Alzheimer's Disease-Related Dementias (ADRD) Summit* on March 22-23, 2022. This was the fourth such summit, with previous summits occurring in 2013, 2016, and 2019. The ADRD Summits complement the Alzheimer's Disease Research and

AD/ADRD Care and Caregiving Summits and are a central piece of NIH's sustained efforts to engage a broad array of stakeholders in setting national ADRD research priorities. Nearly 1,500 people registered to attend the virtual meeting, including academic researchers, clinical practitioners, professionals from government, industry, and non-profit groups as well several patients and caregivers. The Summit addressed research priorities in a range of topics including FTD, LBD, VCID, dementia related to TBI, and multiple etiology dementias (including TDP-43 in common dementias). Broad cross-cutting areas such as health equity and the impact of COVID-19 on AD/ADRD risk were also featured. The output of the Summit was an updated slate of more than 40 prioritized research recommendations that reflect critical scientific opportunities for ADRD research, which were subsequently approved by the NINDS Advisory Council and presented to the NAPA Council in January 2023. The Summit research recommendations have now been incorporated as formal research milestones in the NIH AD/ADRD Research Implementation Milestone Database. Planning is underway for the next ADRD Research Summit, which will be held March 25-26, 2025.

For more information see:

- https://www.nia.nih.gov/research/milestones
- https://www.ninds.nih.gov/news-events/events/adrd-summit-2022
- https://www.ninds.nih.gov/sites/default/files/documents/ADRD%20Summit%202022%20Report%20to%20NINDS%20Council%20FINAL_508C_0.pdf
- https://www.ninds.nih.gov/sites/default/files/documents/ADRD%20Summit%202022%20Research%20Milestones%20and%20Success%20Criteria_508C_0.pdf

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(**UPDATED**) Action 1.A.7: Regularly convene a Research Summit on Care, Services, and Supports for Persons with Dementia and their Caregivers

Lead Agency: NIH
Partners: ASPE, NAPA Advisory Council, academia, industry, professional and advocacy groups

Building on the 2017 and 2020 Summits to review and identify scientific progress, promising innovations, and remaining unmet needs, the third *National Research Summit on Care, Services, and Supports for Persons with Dementia and their Caregivers/Care Partners* [2023 *Care and Caregiving Summit*] took place virtually in March 2023. The event was hosted and sponsored by NIA.

The 2023 *Care and Caregiving Summit* brought together individuals representing a variety of disciplines and backgrounds, including researchers as well as those living with dementia, care partners, providers, and advocates to build on progress of the previous summits to review research progress, highlight innovative and promising research, and identify remaining unmet research needs with individual input provided by researchers, PLWD and their care partners, those who provide health care or services and supports to PLWD, and other stakeholders. The Summit consisted of eight scientific sessions and a plenary. Cross-cutting themes included inclusive science, outcomes that matter to PLWD and their care partners and improving the rigor and reproducibility of dementia care research. The research gaps and opportunities identified during the Summit were informed by the scientific steering committee, research presenters, and by panels consisting of PLWD, caregivers/care partners, direct care workers, and advocacy organization representatives. Additional information about the Summit, including session recordings, identified research gaps and opportunities, new AD/ADRD research implementation milestones informed by the research gaps and opportunities, and a meeting report are publicly available on the Summit website.

For more information see:

- https://www.nia.nih.gov/2023-dementia-care-summit
- https://www.nia.nih.gov/research/milestones/dementia-care-and-impact-disease

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(ONGOING) Action 1.A.8: Regularly review the Congressionally Directed Medical Research Program's Peer Reviewed Alzheimer's Research Program Strategic Plan

Lead Agency: DoD

The U.S. Department of Defense's (DoD's) Congressionally Directed Medical Research Program (CDMRP) is a partnership between the U.S. Congress, the military, and the public to fund innovative and impactful research benefiting service members, veterans, and the American public in targeted program areas. The Peer Reviewed Alzheimer's Research Program (PRARP) is directed by Congress to understand the relationship between TBI and dementia. Since 2014, the program included PLWD, their family members, and/or care partners in all scientific review processes, funding decisions, and prioritization and strategy setting for the program. In 2024, the PRARP will release an updated Strategic Plan identifying high-impact research goals in the areas of TBIs and AD/ADRD as well as summarizing research funding and findings since 2011 though the PRARP program, and identified short, medium, and long-term goals for the program.

Strategy 1.B: Expand Research Aimed at Preventing and Treating Alzheimer's Disease and Related Dementias

HHS and its federal partners will continue to expand clinical trials on pharmacologic and non-pharmacologic interventions, across a diversity of targets, to prevent AD/ADRD and manage and treat its symptoms. The Federal Government is working proactively to address the challenge of enrolling people in clinical trials who are representative of the country's diverse population, including racial and ethnic groups that are at higher risk for AD/ADRD, through continued development of new partnerships and outreach strategies. These actions will build on ongoing research focused on the identification of genetic, molecular, and cellular targets for interventions and build on recent advances in the field.

(UPDATED) Action 1.B.1: Expand research to identify the molecular and cellular mechanisms underlying Alzheimer's disease and related dementias, and translate this information into potential targets for interventions

Lead Agencies: NIA, NINDS
Partners: potential research partners in the public and private sectors

NIH drives the development of new treatments for AD/ADRD by supporting research at all points along the drug and intervention development pipeline, from foundational biological research through clinical trials. This includes genetic, cellular, and molecular biology, comparative research in animals and other systems, target identification and drug discovery, and both preclinical and clinical intervention trials.

Though tremendous progress has been made in our collective understanding of the genetic, cellular and molecular mechanisms underlying AD/ADRD, additional research is needed to fully understand the complex biology of these conditions and to ensure the field is developing diverse treatment and prevention strategies that stand to benefit everyone.

Research on one protein of interest, TDP-43, provides a recent example of progress while also highlighting the need for additional research. For years, NIH-supported research has implicated abnormal aggregation of the TDP-43 protein in multiple neurological diseases, including FTD, ALS, and LATE. Many individuals with AD also have abnormal TDP-43. Recently, it was discovered that abnormalities in TDP-43 function affect the splicing of a number of genes so that normally excluded pieces of the genes (cryptic exons) are expressed in abnormal proteins (cyptic proteins). Not only may this process be toxic to nerve cells, but the cryptic proteins are biomarkers of pathology and can be measured in CSF and blood. A small NIH-funded study in mice showed that a bioengineered molecule called an antisense oligonuceotide was able to counteract some of the effects of TDP-43 aggregation. These findings present a promising new avenue for treatment of conditions associated with TDP-43, but additional research is needed to evaluate, refine, and develop the approach into something that can be tried in humans. To generate more research in this area, a 2024 NINDS funding opportunity will support new projects to investigate distinct and overlapping mechanisms in TDP-43 related conditions, including in LATE, FTD and other ADRDs.

Efforts to better understand the interplay of the brain’s vascular system and dementia presents another example of an evolving research need. It is well known that vascular damage in the brain, in particular small vessel cerebrovascular disease, is common in people with AD/ADRD and exploring VCID continues to be a research priority. In 2024, NINDS released a funding announcement to support a new “center without walls” (CWOW) devoted to studying small vessel cerebrovascular disease mechanisms in ADRD. Furthermore, research to better understand the blood-brain barrier could help researchers identify more effective ways to deliver treatments to the brain. In the last few years, an additional research priority has emerged due to observed side effects of anti-amyloid therapies recently approved for the treatment of AD. A significant percentage of participants in clinical trials for these treatments experienced serious adverse events, including bleeding, swelling, and inflammation of the brain. More research is needed to understand whether these therapeutics can be given safely and effectively in VCID populations or whether these therapies can be modified to help protect the blood-brain barrier during treatment. To promote this type of research, NINDS released a funding opportunity in 2024 for mechanistic research to develop protective strategies to reduce Amyloid Related Imaging Abnormalities after anti-amyloid beta immunotherapy. Persons treated with the recently approved amyloid lowering agents are at risk of developing leakiness of the barrier between the brain blood vessels and the brain tissue. Frequent magnetic resonance imaging (MRI) scans are needed to follow treated patients for signs of localized brain swelling or bleeding due to this blood-brain barrier disturbance. More research is needed to identify promising strategies that can protect the brain when anti-beta-amyloid immunotherapy is delivered.

Other research is exploring how insulin, a hormone in the body that helps to regulate glucose levels, and resistance to this hormone could influence risk for dementia. Investigators from the NIA Intramural Research Program (IRP) have partnered with extramural Investigators of the Diabetes Prevention Program Outcomes Study, a multi-site consortium conducting the long-term follow-up of the original Diabetes Prevention Program study cohort, to employ novel biomarkers to study whether and how peripheral and brain-specific insulin resistance increase the risk of developing cognitive impairment and interplay with AD/ADRD biomarkers. Recent clinical studies conducted by NIA IRP investigators point to behavioral interventions, such as diet (including intermittent fasting), exercise, and the use of ketogenic supplements, for their potential in AD/ADRD treatment and prevention, especially for people with metabolic abnormalities.

Additional NIH research efforts are exploring the role of the immune system in AD/ADRD, Research suggests that dysfunction of the immune system plays an important role in the development of ADRD, including the buildup of amyloid plaques and tau tangles in the brain. For example, researchers compared brain tissues from people with and without AD and found changes in the activity of many genes with known links to the disease in the prefrontal cortex of the brain. These changes most often occurred in microglia, immune cells that engulf and clear waste. Another study showed that more microglia enter an inflammatory state in the AD brain compared to a healthy human brain. These findings suggest a role for microglia and inflammation in AD. NIH continues to fund research to better understand how immune system dysfunction may be involved in the disease processes and identify new disease pathways for further studies to discover potential therapeutic targets.

Expanding our understanding of the toxic protein aggregates involved in AD/ADRD pathology is another area of active interest. Abnormal protein deposits are consistent hallmarks of disease in brains of PLWD, and recent progress has begun to reveal the great structural variability of dementia-associated proteins. Still, considerable work is needed to achieve a full accounting of this diversity. For example, research is needed to understand the structural basis underlying toxicity and spreading of misfolded protein aggregates in AD and to design approaches to prevent this spreading. NIH supports ongoing research to improve the identification and characterization of structurally diverse protein aggregates implicated in the development of ADRD, and this research aims to enable the development of more precise diagnostic and therapeutic approaches.

To support all of these lines of research, NIH supports efforts to develop new tools, resources, and model systems to aid in AD/ADRD research. For example, the Model Organism Development and Evaluation for Late-onset Alzheimer's Disease (MODEL-AD) Translational Centers develop and characterize new mouse models for late-onset AD (LOAD), which serve as essential tools for basic research and drug development. To date, MODEL-AD research teams have created more than 70 genetically modified mouse models. These models are available to the research community through the Jackson Laboratory Center for Alzheimer's and Dementia Research's Mouse Model Resource; all the data, protocols, and other resources are available through the AD Knowledge Portal and the MODEL-AD explorer. In addition, in November 2023, NIH-funded researchers affiliated with MODEL-AD established a framework for selecting optimal pharmaceuticals for preclinical drug testing in AD. This framework can help increase clinical translatability and accelerate drug development efforts.

NIH also supports large, multi-component projects to examine system-level changes in brain cell-types, circuits, and networks associated with AD/ADRD. Building on progress by the Brain Research through Advancing Innovative Neurotechnologies® (BRAIN) Initiative to chart the molecular identities and spatial organization of cell-types in the brains of multiple species, NIA supports a family of projects -- known as AD-Multimodal Atlasing Projects (AD-MAPs) -- that extends this approach to discover how changes in cell-types and in cellular assemblies called circuits underlie aging and AD. The Seattle Alzheimer's Disease Brain Cell Atlas Consortium, a cornerstone of AD-MAPs, utilizes advanced technologies from the BRAIN Initiative with the goal of producing the highest-resolution brain-wide human cell atlas of AD. In addition, NIA published a funding opportunity in May 2024 to promote use of BRAIN Initiative tools to precisely target these cell-types to answer questions related to aging and AD.

NIH researchers at the Center for Alzheimer's and Related Dementias (CARD) have also established two large repositories of induced pluripotent stem cell (iPSC) models that can be used as cellular model systems to study AD/ADRD. The iNDI project (iPSC Neurodegenerative Disease Research Project) will generate over 800 cell lines harboring AD/ADRD disease-relevant genetic variants. Nearly 200 lines have been engineered so far and are available to the research community through Jackson Laboratories. The iDA Project (iPSCs to Study Diversity in Alzheimer's and Alzheimer's Disease-related Dementias) is generating 200 AD patient-derived iPSC lines that are being distributed through National Centralized Repository for Alzheimer's Disease and Related Dementias (NCRAD). More than 80 lines are currently available to researchers.

In 2024, NINDS released a funding opportunity to support the development and validation of human cellular models for ADRDs. NINDS also supports several large grants to develop and validate advanced mammalian models for FTD, VCID, LBD, and mixed dementias/neurodegeneration.

For more information see:

- https://adknowledgeportal.synapse.org/Explore/Experimental%20Tools
- https://modeladexplorer.org
- https://portal.brain-map.org/explore/seattle-alzheimers-disease
- https://pubmed.ncbi.nlm.nih.gov/36927019/
- https://pubmed.ncbi.nlm.nih.gov/37774678/

- https://pubmed.ncbi.nlm.nih.gov/38277467/
- https://www.model-ad.org/

Incentivizing the translation of basic research findings into the discovery and development of new prevention and treatment strategies is another key part of the NIH strategy. To further accelerate discovery, NIH is additionally committed to ensuring that all data and research tools developed through NIH funding are widely available to the research community.

The NIH Accelerating Medicines Partnership® Program for Alzheimer's Disease (AMP®-AD) has transformed the way new targets and biomarkers for AD are discovered by supporting large-scale team science and broad and responsible data and knowledge sharing. The Target Discovery component of the Program applies a systems biology approach to the discovery and validation of new, disease-relevant therapeutic targets in an open science research model. Since its establishment, NIA has supported the discovery of over 900 novel candidate targets for AD through the AMP-AD Target Discovery Program. AMP-AD targets are being pursued by industry and in academic labs for new drug discovery efforts targeting multiple aspects of the disease process, such as neuroinflammation, bioenergetic failure and synaptic pathology.

Importantly, targets and supporting data generated through AMP-AD are available to researchers in academia and in the biotech/pharmaceutical industry through centralized data infrastructure, the AD Knowledge Portal. This Portal securely houses and shares a rich collection of de-identified genomic, proteomic, and metabolomic human data, identified targets, and disease pathway models. These data resources have been used by more than 3,000 researchers from the United States and internationally to advance basic research and therapy development for AD/ADRD. The AD Knowledge Portal also serves as the central repository for a large array of NIA/NIH-supported consortia and translational centers such as the Alzheimer’s Gut Microbiome Project and the TaRget Enablement to Accelerate Therapy development for Alzheimer’s Disease (TREAT-AD) translational centers.

Currently, AMP-AD is also committed to ensuring data are representative of diverse populations, especially those who are disproportionately affected by AD, such as Black and Latino populations. Ongoing work is focused on generating rich multiomic data on brain and fluid samples from diverse donors to understand the heterogeneity of the disease at the molecular level and inform the selection of targets and biomarkers for precision medicine. In June 2023, NIH hosted a workshop exploring opportunities and challenges for nurturing data ecosystems that promote FAIR (i.e., findable, accessible, inter-operable, and reusable) data principles within and across AD/ADRD research data infrastructures and data ecosystems. The workshop also focused on supporting open and inclusive data access and computing resources by researchers and other stakeholders.

For more information see:

- https://adknowledgeportal.synapse.org/Explore/Programs
- https://www.nia.nih.gov/research/amp-ad
- https://www.nia.nih.gov/research/blog/2020/11/open-science-delivers-wealth-ad-adrd-research-data-portal-near-you
- https://www.nia.nih.gov/research/dn/workshops/nih-ad-adrd-platforms-workshop-fairness-within-and-across-data

Established in 2019, the TREAT-AD Translational Centers are a large-scale enterprise focused on diversifying and accelerating therapy development for AD/ADRD through the development of open-source tools, reagents, and methods for robust validation of candidate targets delivered by the AMP-AD program and other target discovery programs and by integrating a set of novel targets into drug discovery campaigns. Each TREAT-AD Center brings together world-class expertise in data science, computational biology, disease biology, structural biology, assay development, medicinal chemistry, pharmacology, and clinical research. Over the first 5 years the TREAT-AD Centers have established a robust pipeline for target prioritization and have developed analytical and research tools known as target enabling packages for over 50 candidate targets. These resources are available to researchers in academia and industry sector and are being used to launch new drug discovery efforts.

For more information see:

- https://www.nia.nih.gov/news/nih-funded-translational-research-centers-speed-diversify-alzheimers-drug-discovery

The NIA Alzheimer's Drug Development Program provides funding support for the preclinical and early-stage clinical (Phase I) development of novel small-molecule and biologic drug candidates that prevent AD, slow its progression, or treat its cognitive and behavioral symptoms. As of July 2024, 21 new drug candidates developed with support from NIA's translational funding initiatives have submitted an Investigational New Drug (IND) to the FDA and human trials have been initiated. In addition to targets related to amyloid beta and tau -- two prominent molecular hallmarks of AD -- these drug candidates act on ten novel and diverse therapeutic targets, such as those implicated in inflammation, synaptic plasticity, resilience, and neuroprotective mechanisms. These drug candidates include a gene therapy drug, two vaccines, one monoclonal antibody and 16 small molecules. Eight of these drug candidates are in or are anticipated to start Phase I clinical trials, ten have advanced to Phase II testing (currently ongoing or anticipated to start), and two have completed Phase II testing with planning ongoing for Phase III trials. NIA has supported or is supporting the clinical development of 15 of these 20 drug candidates. An additional 32 new therapeutic agents are being developed, targeting multiple aspects of the disease. Of these, researchers have applied for IND status for three therapeutic agents in 2024.

For more information see:

- https://grants.nih.gov/grants/guide/pa-files/PAR-24-223.html
- https://grants.nih.gov/grants/guide/pa-files/PAR-22-047.html

NIH's Small Business Innovation Research (SBIR) and Small Business Technology Transfer (STTR) programs are an integral source of capital for early-stage small businesses in the United States that are creating innovative technologies to improve health. These programs help small businesses break into the federal research and development arena, create life-saving technologies, and stimulate economic growth. This funding also helps the private sector bring promising technologies to the consumer market. Through these programs, NIH is leveraging the economic engine of small businesses to enhance scientific innovation.

In the last decade, NIA has funded the development of over 100 different therapeutic approaches to AD/ADRD through SBIR and STTR grants to small businesses. One therapeutic approach funded by the NIA SBIR program addresses low progranulin production, a risk factor for certain neurodegenerative diseases, including FTD. For example, NIA funded the biopharmaceutical company, Alector, in 2015 to support basic research that led to a new investigational monoclonal antibody treatment. Alector has since leveraged research results from their SBIR funding to receive external investment and has advanced this treatment, called latezinemab, through early clinical development and is now collaborating with a larger biopharma company to evaluate the antibody in Phase III clinical trials for the treatment of FTD.

For more information see:

- https://alz-journals.onlinelibrary.wiley.com/doi/10.1002/alz.12392
- https://www.ncbi.nlm.nih.gov/pmc/articles/PMC10292789/
- https://www.nia.nih.gov/news/blood-test-early-alzheimers-detection

The Roy Blunt Center for Alzheimer's Disease and Related Dementias Research, which houses the NIH Intramural CARD, opened its doors in 2022. CARD is a collaborative initiative designed to combine the power of NIH intramural science with the work of researchers around the globe to push boldly ahead in basic, translational, and clinical AD/ADRD research. CARD researchers are building multi-disciplinary collaborations among scientists on the NIH campus and in academia and industry. More than half of CARD staff will be comprised of visiting investigators who will rotate into CARD with new perspectives and ideas to complement the deep AD/ADRD expertise held by permanent CARD staff. In addition, CARD researchers are using cutting-edge technology like artificial intelligence and machine learning (AI/ML) to accelerate discovery and facilitate precision medicine in AD/ADRD. For example, a recently published open resource uses large-scale genetic/genomic data to identify therapeutic targets for neurodegenerative diseases.

CARD also offers multiple opportunities for early career investigators to hone skills needed for the translation of discoveries into therapies through unique opportunities such as the Alzheimer and Related Dementia's Independent Scholars Program and the Research Fellowship Program. CARD has also developed a Master of Professional Studies in Data Science Fellowship to train future biomedical data scientists. The first cohort of students graduated in the spring of 2024.

Looking forward, the CARD Clinical Center is in development on the NIH campus, with construction beginning in early 2025. Occupancy is anticipated by mid-year 2027.

For more information see:

- https://card.nih.gov/
- https://card.nih.gov/job-training-opportunities/alzheimers-dementias-scholars-program
- https://card.nih.gov/job-training-opportunities/training-opportunities
- https://pubmed.ncbi.nlm.nih.gov/38181731/

NIH researchers are also exploring multiple ways to repurpose drugs either alone or in combination with another therapeutic through initiatives such as the NIA Advancing Combination Therapy and Drug Repurposing for Alzheimer's Disease program.

Novel uses for existing drugs can save time and cost in bringing new therapeutics to individuals. Investigators funded through NIA's Drug Repurposing and Combination Therapy Development program, have identified over 20 FDA-approved drugs with a potential to be repurposed in AD. An example is bumetanide, an FDA-approved drug for the treatment of edema, has shown promise in reducing the risk of AD in individuals that carry the APOE4 risk factor gene.

NIA supports big data approaches to drug repurposing and combination therapy development through a targeted funding initiative aimed at developing "connectivity maps" matching the molecular signatures of AD/ADRD with the molecular signatures of FDA-approved drugs in cultured brain cells. This program also invites projects in which academic institutions partner with collaborators from the biotech/pharmaceutical industry aimed at repurposing failed drug candidates for AD treatment and prevention.

Twenty-six early-phase clinical trials testing more than 20 different FDA-approved drugs repurposed for the treatment of AD/ADRD have been supported. Pilot trials for candesartan (an antihypertensive), nicotine (used for smoking cessation) and metformin (a drug used to manage diabetes) showed positive results, and these repurposed drug candidates have been advanced to larger Phase II trials (candesartan and nicotine) and Phase II/III trials (metformin).

For more information see:

- https://adknowledgeportal.synapse.org/Explore/Programs/DetailsPage?Program=ACTDRx%20AD
- https://pubmed.ncbi.nlm.nih.gov/33304987/
- https://reporter.nih.gov/search/Cs_VZiGXQ0eAYG4dF94MNA/projects
- https://www.nia.nih.gov/news/nia-study-identifies-fda-approved-drugs-may-also-be-helpful-dementia

NIH continues to grow the Alzheimer's Disease Preclinical Efficacy Database, a publicly available data resource aimed at increasing the transparency, reproducibility, and translatability of preclinical efficacy studies of candidate therapeutics for AD. The resource now contains curated summaries of more than 1,400 preclinical therapeutic studies to help the research community easily survey existing AD preclinical development efforts, including reports of unpublished studies.

In November 2023, NIH-funded researchers affiliated with MODEL-AD established a data-driven process for selecting promising therapeutic agents for preclinical drug testing in mouse models of LOAD. This process increases the rigor in preclinical testing of therapeutic agents, improves translatability, and accelerates drug development efforts.

For more information see:

- https://alzped.nia.nih.gov/

The AD Knowledge Portal, an informatics data-sharing platform that began as the data repository for the AMP-AD Target Discovery Program, and the portal-linked, open-source platform Agora have enabled access to a vast amount of high-quality molecular data, analytical results, and candidate targets generated by the AMP-AD program and other research teams. The AD Knowledge Portal now includes data and resources from numerous NIA-supported big data programs and translational centers and is open for data contributions from the greater research community.

For more information see:

- https://adknowledgeportal.synapse.org/

NIA and NINDS incentivize basic and translational research, as well as the development of novel tools and approaches in basic and translational research, by regularly issuing funding opportunities to draw attention to key needs. NIH funding, through NIH-issued Notices of Funding Opportunities (NOFOs) and for investigator-initiated research concepts, continues to support a robust portfolio of research across the drug development pipeline. For example, one promising and potentially transformative area of research is the use of genome editing techniques like clustered regularly interspaced short palindromic Repeats (CRISPR) to “repair” mutations that contribute to dementia. In 2024, NIA and NINDS-funded researchers demonstrated the use of CRISPR genome editing in patient-derived pluripotent stem cells to remove the most common genetic mutation in ALS and FTD (called C9orf72), which resulted in a substantial reduction in FTD disease markers. In another 2024 gene therapy report, NIH-funded investigators introduced APOE2 into the brain of animal models as a first step towards a potential gene therapy for AD. APOE is a lipid carrying protein with three different forms that are inherited. The APOE4 form is a strong risk factor for developing AD, while APOE2 may be protective. To further explore the potential of genome editing therapies, NINDS awarded two new projects in 2023 and released another NOFO in 2024 to invite additional projects to optimize various genome editing techniques in intervening in any of the associated ADRDs (FTD, LBD, and VCID). It is expected that these projects will result in FDA IND applications by the end of the study period. In response to a NOFO, NINDS awarded four new projects in 2023 to better understand the potential influence of the gut microbiome on ADRDs and possible use of pre-biotics and pro-biotics as interventions. In 2024, NINDS also invited new research on early-stage therapy development in ADRDs and functional target validation of newly identified therapeutic candidates for ADRDs.

For more information see:

- https://pubmed.ncbi.nlm.nih.gov/38504517/

NIA’s Small Research Grant Program for the Next Generation of Researchers in AD/ADRD Research is designed to encourage future scientists to pursue research and academic careers in AD/ADRD research. NIA seeks to turn fresh ideas from scientists in other fields into pilot studies for innovative AD/ADRD research programs that leverage and build upon their existing expertise and to build a more robust pipeline of committed AD/ADRD researchers. Since its inception in 2018, 181 investigators have received funding through this program.

NIA and NINDS also work collaboratively with other NIH institutes and centers to expand AD/ADRD research. In FY 2023, NIA awarded over $70M across 203 financial supplements to support the expansion of research projects that did not originally include AD/ADRD research. In addition, NIA and NINDS have collaborated with other institutes and centers to support NOFOs designed to promote a diverse AD/ADRD research workforce that have the skillsets related to data science and drug discovery. These opportunities support investigators at three different key career stages: pre-doctoral, post-doctoral, and advanced post-doctoral. Under the AD/ADRD Research Supplements to Promote Diversity in Health-Related Research Notice (NS-24-071), NINDS has awarded more than 50 supplements to date to support high school, undergraduate. and graduate students, as well as post-doctoral and early investigators in AD/ADRD research areas. For a full list of funding opportunities and their links, please see Appendix 3.

(**ONGOING**) Action 1.B.2: Expand genetic epidemiologic research to identify biological and genetic risk and protective factors for Alzheimer's disease and related dementias

Lead Agencies: NIA, NINDS
Partners: research partners in the public and private sectors

The identification of genetic risk and protective factors is important to enable better risk assessment, find new therapeutic targets, and move toward precision medicine for AD/ADRD. In 2010, we knew of just ten genetic areas associated with AD. Today, thanks in large part to the work of NIH-funded researchers, we know of more than 80 regions of the genome that are associated with the disease.

An essential component of this work is the NIA-funded Alzheimer's Disease Sequencing Project (ADSP). Launched in 2012, the ADSP is designed to promote innovative collaboration among scientists to provide genetic samples for sequencing with the goal of identifying from multi-ethnic populations new genetic variants that influence risk and protection from AD/ADRD. This project involves more than 389 international investigators at 61 institutions. Data come from more than 72 cohorts of research participants. The Genome Center for Alzheimer's Disease quality control checks and harmonizes all the genetic data so that when a variant in the genome is uncovered, it can be compared against the data from thousands of other genomes. The NIA Genetics of Alzheimer's Disease Data Storage Site (NIAGADS) serves as the ADSP Data Coordinating Center. In 2017, NIA launched the ADSP Follow-Up Study (FUS), and in 2021 the FUS 2.0. Together, these initiatives are pursuing rare variants in a range of different populations (e.g., Black, Hispanic, AI/AN, Asian). Teams are presently working to recruit new cohorts of ethnically diverse participants.

In keeping with the high-priority that the AD/ADRD genetics community places on diversity, the ADSP plans to have more than 100,000 ethnically diverse study participants by 2027-2028. An important overarching goal of the ADSP FUS is to genetically define subgroups of individuals that carry specific sets of genes and match them with biomarkers, functional genomics, and clinical data. This will define subtypes of the disease and allow for more refined selection of participants for clinical trials. It is particularly important to define ethnic diversity in terms of disease risk because ethnic groups vary widely in the degree of risk at particular locations in the genome and it is likely the clinical trials will need to be designed differently depending upon the ethnicity of the study population.

The 2021 Phenotypic Data Harmonization Initiative is harmonizing clinical data from all of the ethnic cohorts in the ADSP. These data will become a long-lived "legacy" dataset that will be perpetually curated. A network of researchers with expertise in genetics, epidemiology, and clinical specialties are working with the ADSP and with study cohort leads on data harmonization efforts to optimize the ability to identify well-targeted therapeutic approaches for AD/ADRD. These efforts have been expanded to include the U.S. Department of Veterans Affairs (VA)-supported Million Veterans Program (MVP), one of the largest genetic research databases with over 950,000 United States Veterans and substantial racial and ethnic diversity and includes over 650K participants with whole-genome data. The overall goal is to integrate MVP data into the Alzheimer’s Disease Sequencing Project Phenotype Harmonization Consortium (ADSP-PHC) by curating and mapping MVP AD/ADRD phenotype data to be consistent with the established phenotypes in ADSP-PHC. NIAGADS, working with the National Alzheimer’s Coordinating Center (NACC) shares phenotypic and related clinical data with the ADSP. NACC is strongly supporting this initiative.

In 2021, the ADSP also launched a Functional Genomics Consortium. Functional interpretation of genetic variations has been challenging historically and remains a persistent bottleneck in genetic studies of complex diseases. This hinders the discovery of genetic-based targets for therapeutics. To connect genetic variants to downstream effectors and functions, a number of issues will be addressed by this initiative, including the need to: (1) pinpoint causal variants that affect disease susceptibility and/or progression; (2) characterize the molecular and biochemical effect of these variants and identify the target genes on which these variants act and the cell-types and states in which these variants operate; (3) determine links to heterogeneous cellular and pathologic mechanisms; and (4) identify genetic drivers underlying AD endophenotypes that are clinically relevant but difficult to ascertain. Investigators from the AMP-AD program and ADSP-PHC are working together to find intersections between the gene clusters that the ADSP has identified and the functional networks that the AMP-AD program team has reported.

Importantly, the ADSP continues to make additional data available to the broader research community, including a new release of data in December 2023 and the release of 15 much-anticipated genotyping array datasets from participants recruited from the Alzheimer's Disease Research Centers (ADRCs) in February 2024.

NIAGADS now hosts 126 human genetics datasets with 209,664 samples and has a genomics database for cross-referencing and visualizing known genomic variants. All data generated by the ADSP are deposited into NIAGADS. In 2024, NIAGADS aims to release data generated under the initiative to support analysis on over 61,000 quality-controlled and harmonized whole-genomes to find novel genetic variants that modulate AD/ADRD risk.

Using data from NIAGADS and other repositories, scientists have been able to expand the number of known genetic risk factors for AD/ADRD, and several others are under investigation. Over the last several years, NIH has continued to expand NIAGADS with additional data, and in October 2023, NIH-funded researchers published information about the NIAGADS Alzheimer's GenomicsDB, a resource for exploring AD genetic and genomic knowledge.

The NCRAD is an NIA-supported resource to help scientists accelerate and streamline their efforts. NCRAD serves AD/ADRD scientists by banking a wide range of biospecimens, recently including pluripotent stem cells. Through a collaboration with NIAGADS, NCRAD supports state-of-the-art genome and genotyping arrays for samples in several new studies, including the 90+ Study, a longitudinal study of aging and cognition among participants over age 90, and the Amyloid Neuroimaging and Genetics Initiative, an add-on for participants in the Imaging Dementia- Evidence for Amyloid Scanning Study. For a full list of funding opportunities and their links, please see Appendix 3.

For more information see:

- https://www.nia.nih.gov/research/resource/national-centralized-repository-alzheimers-disease-and-related-dementias-ncrad
- https://www.niagads.org/

In addition to ADSP, NIA and NINDS have published several NOFOs that call for research to enhance the ability to uncover the genetic underpinnings of AD/ADRD, furthering our understanding of rare risk and protective variants. Today, thanks in part to the increased investment in AD/ADRD research, scientists have identified at least 80 regions of the genome that are associated with AD. Of these, variants in more than 23 individual genes have been linked to increased risk of LOAD. These genetic regions appear in clusters that point toward what may be highly relevant molecular pathways. By understanding key pathways, researchers may be able to develop prevention strategies and treatments for AD/ADRD. In 2019, NIH-funded researchers discovered a genetic variant of the apolipoprotein E (APOE) gene, known as APOE3 Christchurch (APOEch), that appeared to confer protection against the development of AD in a person with two copies of the variant and a strong genetic predisposition for an early-onset form of the disease. In 2024, new results suggested that having just one copy of this protective variant may be enough to delay cognitive impairment in individuals who are otherwise genetically predisposed to developing early-onset AD.

Other NIH-funded research has identified additional genetic variants, including a variant of the RELN gene called RELN-COLBOS which was discovered in 2023 and may prevent or delay the onset of AD. Together, these findings shed light on cognitive resilience -- and potentially new treatment targets -- that may one day help to delay or even stop progression of AD. For example, researchers are starting to understand how APOEch protects against dementia. In a 2024 NIH-funded study in mice, researchers found that APOEch enhances the activity of immune cells called microglia, leading to reduced tau tangle formation in the brain. In another 2024 NIH-funded publication, researchers reported early results using APOE3ch-inspired antibodies as a potential AD therapeutic.

Additionally, NIH research led to the discovery of a genetic variant observed often in people of African ancestry that may increase a person’s risk of developing AD. The APOE ε3 [R145C] variant, present in more than 4% of African Americans and very rare in people of European ancestry, is associated with an increased risk of AD in adults of African ancestry who also carry a separate version of the APOE gene, called ε4. The findings of this study indicate a potential new biomarker that could be used for AD genetic risk assessment in individuals of African ancestry, a historically underrepresented group in AD genetics research.

Further understanding the role of APOE in AD/ADRD continues to be a top priority. An NIA-funded research program entitled APOE Pathobiology in Aging and Alzheimer’s disease (EPAAD) was established to serve both the research community and the public as a source of existing and new knowledge on APOE. EPAAD provides links to currently available resources, publications and datasets relevant to APOE in aging and AD/ADRD, as well as a forum for discussion.

For more information see:

- https://directorsblog.nih.gov/2024/07/18/study-of-protective-gene-variant-provides-insight-into-delaying-onset-of-alzheimers-dementia/
- https://epaad.org/
- https://pubmed.ncbi.nlm.nih.gov/37791598/
- https://pubmed.ncbi.nlm.nih.gov/38086389/
- https://www.nejm.org/doi/10.1056/NEJMoa2308583
- https://www.nia.nih.gov/news/case-study-unlocks-clues-rare-resilience-alzheimers-disease
- https://www.nia.nih.gov/news/genetic-variant-specific-african-ancestry-associated-increased-alzheimers-risk
- https://www.nia.nih.gov/research/workshops/apoe-genetics-major-determinant-alzheimers-disease-pathobiology

NIA funds early career researchers pursuing translational science careers within the field of ADRD research via four different funding opportunities. The Institutional Training Programs to Advance Translational Research on Alzheimer’s Disease (AD) and AD-Related Dementias (T32) award funds institutional training programs, each of which can train several graduate students or post-doctoral researchers pursuing training in the field of AD/ADRD research. In 2024, NIA funded nine programs, which collectively supported 48 pre-doctoral and post-doctoral researchers. Across three different career levels (pre-doctoral, early post-doctoral and senior post-doctoral), NIA supports funding opportunities to promote diversity in translational research for AD/ADRD, which together supported 16 researchers in 2024.

NIA and NINDS also fund projects to advance further discovery for genetic factors and their related molecular pathways involved in LBD, FTD, and mixed dementias. In 2024, NIA and NINDS intramural investigators, including from the NIH Intramural Center for Alzheimer's and Related Dementias, were part of an international team that reported results from a genome-wide analysis of patients with sporadic FTD, where they found a potential role for the MAPT, MOBP, and APOE gene variants. Intramural and extramural researchers supported by NIA and NINDS have also published several papers on the genetic underpinnings of LBD, identifying five LBD-associated genes (SNCA, APOE, GBA, BIN1 and TMEM175).) Recent genetic studies have also established that LBD shares risk profiles and pathways with AD and Parkinson's disease. For example, a 2022 study from the NINDS-funded LBD CWOW, an international network of ten research labs, found that people living with LBD had increased AD-related pathologies and that APOE4 made these changes worse. With respect to FTD, NIH-funded researchers from two different labs published complementary results in 2022 that helped explain how one of the genetic risk factors for FTD/ALS (mutations in the UNC13A gene) contributed to disease progression. The researchers showed that the messenger RNA from the UNC13A risk variant is misprocessed and alters the function of TDP-43, a protein known to be centrally involved in some cases of FTD, ALS, and other AD/ADRDs. Further research into how TDP-43 and UNC13A work together to affect disease progression could provide new clues for biomarker and therapeutic development.

For more information see:

- https://pubmed.ncbi.nlm.nih.gov/33589841/
- https://pubmed.ncbi.nlm.nih.gov/35197626/
- https://pubmed.ncbi.nlm.nih.gov/35197628/
- https://pubmed.ncbi.nlm.nih.gov/35471463/
- https://pubmed.ncbi.nlm.nih.gov/38889728/

The VA continues to support projects that curate and develop AD phenotypes using VA clinical data. In 2023, a team of VA investigators received a supplemental award from NIA to harmonize VA clinical phenotypes for ADRD with research phenotypic data from an NIA consortium (the ADSP-PHC). In addition, there has been continued support for research projects that utilize veterans' data in the MVP cohort to study the genetic risk factors for AD/ADRD. Examining genetic risk for dementia in previously understudied veterans of African and Hispanic ancestries is the focus of some of the VA-supported efforts.

(UPDATED) Action 1.B.3: Increase enrollment in clinical trials and other clinical research through community, national, and international outreach

Lead Agency: NIA
Partners: ACL, FDA, VA, CDC, HRSA, DoD/CDMRP

NIA continues to lead a broad and collaborative effort to establish goals and strategies to enhance recruitment into clinical research, particularly focusing on underrepresented communities. Released in 2019, the *National Strategy for Recruitment and Participation in Alzheimer's Disease and Related Dementias Clinical Research* outlines practical, proactive approaches to help study sites engage a wider, more diverse population of volunteers.

For more information see:

- https://www.nia.nih.gov/research/recruitment-strategy

A key element to ensure that NIA's clinical trials achieve their enrollment goals is helping research teams plan and monitor study enrollment according to established milestones. NIA grantees and staff utilize the Clinical Research Operations and Management System (CROMS) to track, report, and manage clinical research enrollment and related activities. Officially launched in 2021, CROMS allows real-time monitoring of trial enrollment and provides an opportunity for early intervention in research projects that are falling behind their recruitment goals.

For more information see:

- https://www.nia.nih.gov/research/grants-funding/nias-clinical-research-operations-management-system-croms

In 2024, NIA implemented a policy that prioritizes applications that include a plan to enroll clinical trial participants from minoritized populations and other groups experiencing health disparities. Moving forward, NIA will continue to review and assess clinical trial recruitment and infrastructure and implement new policies and procedures to enhance clinical trial participation.

For more information see:

- https://www.nia.nih.gov/research/grants-funding/nia-guidance-awaiting-receipt-applications-ara-unsolicited-large-budget

In 2024, NIA also awarded a cross-institute contract, the Clinical Research Support Services (CRSS) contract, to provide centralized and integrated administrative, regulatory, logistical, and statistical support for clinical research management across NIA. The CRSS contract will provide the necessary assistance to ensure that NIA's clinical research enterprise addresses all federal requirements in a streamlined manner and that study milestones are met in a timely fashion.

In addition, NIA maintains and updates the Alzheimer's and Dementia Outreach, Recruitment, and Engagement (ADORE) repository, a searchable collection of materials designed to support recruitment and retention into clinical trials and studies. ADORE supports the National Strategy and represents some of the materials and activities that ADRCs, Alzheimer's Clinical Trials Consortium (ACTC), NIA and the broader NIH, and other organizations have developed to engage people in research. ADORE currently houses 550 resources, and NIA receives, reviews, and adds new materials on a quarterly basis. The repository received more than 100,000 visitors from June 2023 through June 2024.

NIA also supports OutreachPro, an online platform developed by NIA to help researchers and research teams create materials to support their AD/ADRD clinical trial recruitment efforts, particularly in underrepresented communities. Through multiple rounds of audience and user testing, the platform has undergone several updates and enhancements, and now includes clinical trial messages and materials for multiple audiences in several languages, including English, Spanish, Simplified Chinese, Tagalog, and Hindi. Through OutreachPro, researchers and research teams can easily produce a "package" of tailored materials and strategies that can be branded locally to increase participant recruitment for clinical studies. The resource currently includes 250 unique materials that can be developed from a combination of designs, health statuses, races or ethnicities, and languages, and has had more than 15,000 unique users. More information about OutreachPro is included under Action 1.B.4.

Furthermore, in 2024, NIA added Recruitment and Retention Resources to its public-facing NIA Clinical Research Study Investigators Toolbox. This section provides investigators and staff the tools and resources from NIH and other federal agencies to address important recruitment and retention topics including how to increase participant engagement, communicating with community partners, and addressing disparities and inclusion of traditionally underrepresented populations.

For more information see:

- https://outreachpro.nia.nih.gov
- https://www.nia.nih.gov/research/adore
- https://www.nia.nih.gov/research/clinical-research-study-investigators-toolbox#Recruitment

NIA continues to promote participation in AD/ADRD clinical trials, studies, and registries through Alzheimers.gov and its Alzheimer's and related Dementias Education and Referral (ADEAR) Center; clinical trials listings and monthly e-alert to more than 42,881 subscribers; social media; infographics; presentations; promotion of ADORE materials; and collaboration with other federal agencies and non-governmental organizations to encourage research participation among older adults, including through a Focus on Aging interagency webinar series. All materials are drafted in plain language for ease of communications.

For more information see:

- https://www.alzheimers.gov/clinical-trials
- https://www.alzheimers.gov/professionals/patients-clinical-trials
- https://www.nia.nih.gov/braindonationtoolkit
- https://www.nia.nih.gov/health/about-adear-center
- https://www.nia.nih.gov/health/clinical-trials-and-studies/could-you-make-difference-dementia-research

NIA-funded AD/ADRD infrastructure -- such as the ADRCs, the ACTC, and the NIA IMbedded Pragmatic Alzheimer's disease and AD-Related Dementias Clinical Trials (IMPACT) Collaboratory -- also provides centralized resources and shared expertise to researchers nationwide to support recruitment into AD/ADRD clinical research.

ACTC, a clinical trials infrastructure designed to harness best practices and latest methods for AD/ADRD trials, includes 35 member sites across the United States along with numerous participating sites in the United States and other countries. ACTC trials are supported by a funding opportunity for Phases Ib-III of pharmacological and non-pharmacological interventions in individuals across the AD/ADRD spectrum from presymptomatic to more severe stages of the disease. A key area of focus for ACTC has been to improve diversity in recruitment of trial participants. The ACTC Minority Outreach and Recruitment Team is developing central and local partnerships with diverse communities to enhance representation of these underrepresented groups in AD/ADRD trials. In addition, the ACTC Inclusion and Diversity Committee has been conducting mentorship activities for ACTC early career investigators and trial study staff.

Additionally, the ACTC Patient Advisory Board has been constituted with a focus on inclusion of people from across the disease spectrum, including individuals from underrepresented groups. Furthermore, ACTC supports the Institute on Methods and Protocols for Advancement of Clinical Trials in AD/ADRD (IMPACT-AD), a comprehensive training program that aims to educate and promote diversity among research professionals and future principal investigators in the field of AD/ADRD research. Sharing of data and biosamples is another key element of the ACTC, and it is part of NIA's enabling infrastructure for data-driven and predictive therapy development. All design, methods, procedures, etc. developed will be shared with the larger research community as will trial data and biosamples per NIA requirements noted earlier. For a full list of funding opportunities and their links, please see Appendix 3.

For more information see:

- https://impactcollaboratory.org/
- https://www.actcinfo.org/
- https://www.nia.nih.gov/health/alzheimers-disease-research-centers

The VA Office of Research and Development (ORD) and NIA have a strong, ongoing collaboration. Among many activities, VA and NIA have partnered on a program launched in 2020 in which NIA provided supplemental funds to five ADRCs co-localized with VA facilities or research centers to increase the recruitment of veterans into NIA-funded studies. Strategic priorities for the pilot include recruiting veterans, especially from diverse populations, and investigating unique risk factors for this population. Research coordinators at each participating ADRC have worked directly with the VA and NIA staff to identify and address challenges, develop pragmatic solutions, and share best practices and materials to increase veteran outreach and sustain enrollment. The pilot program was successful in enrolling 99 veterans into ADRC studies, including 39 individuals from historically underrepresented racial and ethnic groups. The project also registered 172 veterans in AD registries. Results and impact of this pilot program were published in February 2024 and laid the groundwork for future collaborations between NIA and VA. Lastly, tools specific to veteran recruitment have also been included in ADORE.

For more information see:

- https://www.adrc.wisc.edu/dementia-matters/incorporating-cultural-knowledge-improving-alzheimers-disease-research-veterans
- https://www.adrc.wisc.edu/veterans
- https://alz-journals.onlinelibrary.wiley.com/doi/full/10.1002/alz.13725
- https://www.nia.nih.gov/news/nia-va-effort-increases-recruitment-veterans-alzheimers-research
- https://www.nia.nih.gov/research/alzheimers-dementia-outreach-recruitment-engagement-resources/recruitment-and-educational

Since 2020, the VA has been one of the recruitment networks (with over 40 participating medical centers) for the NIA-funded Pragmatic Evaluation of Events and Benefits of Lipid-lowering in Older Adults (PREVENTABLE) trial, which aims to determine whether statins can prevent dementia and disabilities in addition to heart disease and other cardiovascular-related deaths. The VA Cooperative Studies Program Pharmacy Coordinating Center serves as the central pharmacy for the trial to distribute medications to study participants.

In 2019, the Health Resources and Services Administration's (HRSA's) Geriatrics Workforce Enhancement Program (GWEP) NOFO included language calling for applicants to describe how they would educate and train patients, families, caregivers, direct care workers, health care providers, and health professions students, faculty, residents, and fellows on when it is appropriate to recruit older adults into research. This training continues throughout the fifth and final year of the project period. In 2024, the new GWEP NOFO was published and included the same language for the new budget period for the upcoming (2024-2029) GWEP cohort.

For more information see:

- https://grants.hrsa.gov/2010/Web2External/Interface/Common/EHBDisplayAttachment.aspx?dm_rtc=16&dm_attid=3c8db591-9d9e-489b-980a-a44ef4fb9ed9
- https://www.hrsa.gov/grants/find-funding/HRSA-24-018

(ONGOING) Action 1.B.4: Monitor and identify strategies to increase enrollment of racial and ethnic minorities in Alzheimer's disease and related dementias studies

Lead Agencies: NIA, NIMHD
Partner: ACL, DoD/CDMRP

See Action 1.B.3 for updates regarding the National Strategy for Recruitment and Participation in Alzheimer's Disease Clinical Research and efforts to increase enrollment in clinical trials and other clinical research through community, national, and international outreach. This strategy includes approaches to specifically increase enrollment of racial and ethnic minorities in AD/ADRD studies, as recommended by the National Strategy Group's Local, Diverse Working

Group and outlined in the *Alzheimer's Disease and Related Dementias Clinical Studies Recruitment Planning Guide*. In 2022, NIA released a new funding opportunity, RFA-AG-23-020 Building Infrastructure for Precision Medicine Research on Minority Health and Disparities in AD/ADRD, calling for projects to develop or scale up research infrastructure and resources for studies of AD/ADRD in understudied populations. There are currently five awards funded under this program. Additionally, the NIA IRP has initiated a novel collaboration with Ro Health, one of the leading telemedicine providers in the country to create a virtual registry of patients at risk of AD through linkage with their electronic health records (EHRs) and online administration of standardized cognitive testing. This study, called Registry for Equal Access to Clinical Trials in Alzheimer's Disease, aims to test whether telemedicine-based approaches can increase the participation of traditionally underrepresented minorities in AD/ADRD research. For a full list of funding opportunities and their links, please see Appendix 3.

For more information see:

- https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-23-020.html
- https://reporter.nih.gov/search/cqYlI3p1rEWy_E0qHtTZ8A/projects
- https://www.nia.nih.gov/research/recruitment-strategy
- https://www.nia.nih.gov/sites/default/files/2019-05/ADEAR-recruitment-guide-508.pdf

As noted in Action 1.B.3, NIA developed OutreachPro, an online platform that helps researchers and research teams create tailored materials to support their AD/ADRD clinical trial recruitment efforts, particularly in underrepresented communities. The platform offers messaging materials, including videos and other multi-media, print ads, posters, and social media, tailored to diverse populations and available in several languages, including English, Spanish, Simplified Chinese, Tagalog, and Hindi. Importantly, these materials were informed by a series of focus groups, surveys, and stakeholder interviews to ensure materials were appropriately tailored to priority populations. OutreachPro currently offers 250 unique materials that can be developed from a combination of designs, health statuses, race/ethnicities, and languages, and has had more than 15,000 unique users. In addition to OutreachPro, NIA launched a Spanish version of the Alzheimers.gov website and has published its online *Alzheimer's Disease Fact Sheet* in Spanish, Arabic and Chinese.

For more information see:

- https://outreachpro.nia.nih.gov/
- https://www.alzheimers.gov/es
- https://www.nia.nih.gov/health/alzheimers-disease-fact-sheet

The NIA-supported ACTC aims to develop and implement cutting-edge participant recruitment and retention strategies, especially in diverse populations, and to establish a new Minority Outreach and Recruitment Team. This network has 35 member sites in the United States and has participating sites in the United States and abroad. The ACTC is developing and implementing best practices and latest methods for the conduct of AD/ADRD trials, including strategies for improving inclusion and retention of clinical trial participants from diverse populations.

For more information see:

- https://www.nia.nih.gov/news/new-nih-consortium-award-enhance-clinical-trials-alzheimers-disease-related-dementias

NIA also supports 35 ADRCs and two exploratory centers at major medical institutions across the United States. Researchers at these ADRCs are working to translate research advances into improved strategies for prevention, diagnosis, treatment, and care for people living with AD/ADRD. Although each ADRC has its own area of emphasis, these ADRCs also enhance research on AD/ADRD via a network approach that encourages the exchange of new research ideas and approaches. In addition to providing data, biological samples, and genetic information to other major research efforts that advance our understanding of these diseases, the ADRC

Network also refers participants to other studies. The ADRCs also place an emphasis on enhancing and promoting the diversity of research participants. Each ADRC includes an "Outreach, Recruitment and Engagement Core." NIA included additional resources to support full time recruitment specialists at these Cores in the latest ADRC Request for Applications (RFAs) released in January 2023 to further support innovative ideas and opportunities for recruitment in AD/ADRD research. These specialists must have expertise in recruiting individuals from traditionally underrepresented communities and are responsible for outlining engagement, recruitment, and outreach plans for the research projects that leverages the resources of the center and specific populations and expertise local to each center. For example, the University of California at Irvine ADRC has a focus on Asian populations, the Florida ADRC has a focus on Spanish speaking populations, and the Emory ADRC has a focus on Black/African American populations.

An important, major outcome of the ADRC program was the description and investigation of a newly defined disease that is very similar to AD but is even more common in older adults (over the age of 75). NIA has supported three major meetings to advance the understanding of the disease (LATE) and define gaps and opportunities for research on this important contributor to cognitive impairment.

NIA recently funded Foundations of Representative Engagement, Valid, and Effective Recruitment in Alzheimer's Research. Through this project, researchers are developing and implementing novel methods for recruitment, engagement, and retention of minorities as research participants into AD/ADRD studies through community engagement and the ADRCs. The research team is also developing recruitment, engagement, and retention metrics and interventions and establishing communications frameworks to improve literacy for both the general public and research communities. For a full list of funding opportunities and their links, please see Appendix 3.

For more information see:

- https://reporter.nih.gov/search/ixuI3REUAEeJqoU8Xa4hOA/project-details/10094911#description
- https://www.nia.nih.gov/health/what-limbic-predominant-age-related-tdp-43-encephalopathy-late
- https://www.nia.nih.gov/news/nih-expands-nations-alzheimers-and-related-dementias-research-capacity
- https://www.nia.nih.gov/news/workshop-gaps-and-opportunities-related-clinical-detection-limbic-predominant-age-related-tdp
- https://www.nia.nih.gov/research/adc
- https://www.nia.nih.gov/research/dn/late-2022

The long-running Health and Retirement Study (HRS) continues to prioritize enrollment of marginalized populations, NIA funded the renewal award for the HRS and Harmonized Cognitive Assessment Protocol (HCAP) studies in FY 2024, which aim to improve overall response and retention rates to maintain representativeness and add content on social factors to study racial disparities and minority health via life histories. In addition, a second iteration of the AD Sequencing Project (ADSP; see Action 1.B.2) will include a subset of the Black and Hispanic HRS participants, and AD biomarkers for over 1,300 Black and Hispanic participants were made available to the research community at the end of 2023. The National Health and Aging Trends Study (NHATS), which samples Medicare beneficiaries, and its sister study, the National Study of Caregiving (NSOC), has oversampled Black participants since 2011. An administrative supplement awarded in FY 2021 to NHATS/NSOC enabled the study to enroll an additional 2,000 Hispanic individuals and approximately 700 additional Hispanic care partners. The Hispanic add-on sample will allow researchers to study AD care needs and caregiving to older Hispanic adults, contrasting them with experiences of non-Hispanic groups with AD and their caregivers and with Hispanic older adults needing care for other reasons. The NOFO for renewal of the NHATS/NSOC in FY 2024 calls for oversamples of or inclusion of additional Black/African

American and Hispanic/Latino participants to support enhanced research on health disparities in disability and dementia/dementia care, and additional content on social factors to study racial disparities and minority health via Census data linkage and other contextual measures.

NIA has released several NOFOs to fund grants that target gaps in methods and outcomes regarding participant recruitment and retention and spur educational activities that expand the AD/ADRD clinical trial workforce. Some of these efforts are in coordination with other NIH institutes and centers through the NIH-wide UNITE initiative. For example, a funding opportunity entitled Examining Diversity, Recruitment and Retention in Aging Research supported collaborative teams to generate a research resource to advance processes for high-yield recruitment and strengthen outreach and community engagement practices. The program has supported 46 projects over the last 5 years. For example, the Collaborative Approach for Asian Americans and Pacific Islanders Research and Education (CARE) successfully enrolled over 10,000 Asian Americans and Pacific Islanders (AAPI) into a trial recruitment registry and is working to refer, or match, them to approximately 30 different studies. For a full list of funding opportunities and their links, please see Appendix 3.

For more information see:

- https://pubmed.ncbi.nlm.nih.gov/35420258/
- https://reporter.nih.gov/project-details/10273431
- https://www.nia.nih.gov/research/blog/2021/09/unyielding-commitments-research-workforce-diversity
- https://www.nih.gov/ending-structural-racism/unite

The National Institute on Minority Health and Health Disparities (NIMHD) supports the Center for American Indian and Alaska Native Health Disparities project, which provides administrative core research support for responding to the increasing incidence of cognitive impairment, dementia, and AD/ADRD among AI/AN people, and the burden this poses for individuals, caregivers, their communities, and relevant systems of care. Additionally, the NIMHD-funded Effects of Hospital-Community-Public Health Integration on Racial and Ethnic Disparities in Mental Health study will generate evidence on how to expand health information technology (HIT) infrastructure in rural areas to promote health care quality for racialized rural patients with AD/ADRD and risk factors associated with these conditions. NIMHD-funded researchers are also conducting a cluster, randomized controlled trial to evaluate the appropriateness of an intervention that uses a game format for patients with MCI and are at risk for AD/ADRD. Participants in the trial include individuals from diverse communities who are underrepresented in clinical trials.

For more information see:

- https://reporter.nih.gov/search/s8LxXf2FJU-24nxeEUSgpw/project-details/10164617
- https://reporter.nih.gov/search/s8LxXf2FJU-24nxeEUSgpw/project-details/10498316
- https://reporter.nih.gov/search/s8LxXf2FJU-24nxeEUSgpw/project-details/10498912

As noted in Action 1.B.3, NIA recently implemented a policy that prioritizes applications that include a plan to enroll clinical trial participants from minoritized populations and other groups experiencing health disparities. Moving forward, NIA will continue to review and assess clinical trial recruitment and infrastructure and implement new policies and procedures to enhance clinical trial participation overall, with particular attention to representation from populations that are disproportionately affected by AD/ADRD and those that are traditionally excluded from research. This is critical to ensuring that research progress appropriately represents and benefits all people affected by dementia.

For more information see:

- https://www.nia.nih.gov/research/grants-funding/nia-guidance-awaiting-receipt-applications-ara-unsolicited-large-budget

NIA is also supporting research teams in achieving their clinical trial enrollment goals, including meeting diversity objectives, through the CROMS. NIA staff and grantees utilize CROMS to track, report, and manage clinical research enrollment and related activities. Officially launched in 2021, CROMS allows real-time monitoring of trial enrollment and provides an opportunity for early intervention in research projects that are falling behind their recruitment goals.

For more information see:

- https://www.nia.nih.gov/research/grants-funding/nias-clinical-research-operations-management-system-croms

CDMRP's Policy on Inclusion of Women and Minorities requires reporting of racial, ethnic, and gender inclusion for all CDMRP-funded clinical research. The PRARP from CDMRP requires that all funded clinical research addresses the appropriate representation of the population the projects aim to serve. For example, recently funded PRARP projects addresses the role of social determinants on any health or increased risk factors within the military related to AD and other dementias, and risk and resiliency factors and implications for prevention among AI/AN veterans.

For more information see:

- https://cdmrp.health.mil/pubs/pdf/CDMRP%20Policy%20on%20Inclusion%20of%20Women%20and%20Minorities_Updated%20SEP2022.pdf
- https://cdmrp.health.mil/Search.aspx
- https://ebrap.org/eBRAP/public/Program.htm

(**ONGOING**) Action 1.B.5: Conduct clinical trials on the most promising interventions

Lead Agency: NIA
Partner: VA

As of June 2024, NIH supports over 200 pharmacological (drug) and non-pharmacological (non-drug; lifestyle) interventions to enhance cognitive health in older adults and to prevent, treat, or manage AD/ADRD. This includes nearly 70 NIH-supported drug trials for AD/ADRD, the majority of which are in early-phase development (Phase I or II trials) with several late-phase (Phase III) trials also in progress. These interventions are testing a range of drug candidates for a diverse set of therapeutic targets across many disease processes, such as metabolism and bioenergetics, inflammation, oxidative stress, lipid and vascular factors, and protein folding, in addition to new aspects of amyloid and tau biology. Each of these trials is designed to accelerate progress towards effective prevention and treatment strategies. Notably, over half of all NIA-supported pharmacological trials are testing drug candidates for targets other than amyloid and tau.

The NIA-funded ACTC (also see Action 1.B.4) provides critical infrastructure, resources, and expertise to the research community for the purpose of accelerating the development of effective interventions for AD/ADRD. The consortium is currently conducting trials on the FDA-approved treatment, lecanemab, to determine its utility in different study populations or in combination with other treatment approaches, such as those that target the tau protein. The ACTC is also conducting a trial testing cannabinoids for the treatment of agitation in patients with end-stage disease.

In July 2023, results from the Anti-Amyloid Treatment in Asymptomatic Alzheimer's (A4) study, a public-private partnership supported with NIH funding, were released. This Phase III clinical trial of the drug candidate solanezumab, an anti-amyloid immunotherapy, included more than 1,100 cognitively normal older adults who had brain amyloid. Results indicated that the drug did not slow cognitive decline in cognitively healthy people at risk for AD. While the overall results of this prevention trial were negative, data and biosamples from the study are being made available to the research community. This is the first-ever pivotal Phase III trial to make available all pre-trial and post-trial data. The availability of the data and biosamples from the A4 trial has tremendous value in understanding the heterogeneity of disease progression and the factors that contribute to differences in responsiveness to treatment. These data have already led to insights related to differences in the presence of AD biomarkers among participants from different ethnic and racial groups. For example, one recent study analyzed data from the A4 trial to ask whether parental history of memory impairment is associated with beta-amyloid levels in cognitively normal adults. Results showed that paternal history of early-onset memory impairment and maternal history of memory impairment at any age were both associated with increased β-amyloid levels in asymptomatic older adults.

One limitation of FDA-approved anti-amyloid treatments is that they have not been well studied in individuals who have vascular or Lewy body pathologies in addition to amyloid pathology. In 2024, NINDS released two funding opportunities inviting applications on safety and efficacy of anti-amyloid treatment in individuals with MCI and AD who also exhibit vascular pathology or Lewy body pathology.

Additionally, in fall 2023, NIH began funding the Alzheimer's Disease Tau Platform Clinical Trial, which will test the ability of two tau-targeting therapies to reduce brain tau levels, either alone or in combination with a drug that reduces amyloid protein, in patients with early AD. For a full list of funding opportunities and their links, please see Appendix 3.

For more information see:

- https://jamanetwork.com/journals/jamaneurology/fullarticle/2820195?guestAccessKey=ca1f06e1-a860-42c9-aa23-cee2def235ab&utm_source=silverchair&utm_medium=email&utm_campaign=article_alert-jamaneurology&utm_content=etoc&utm_term=081324&utm_adv=null
- https://www.nia.nih.gov/research/ongoing-AD-trials

The Edward R. Roybal Centers for Translational Research in the Behavioral and Social Sciences of Aging (Roybal Centers) support the translation and integration of basic behavioral and social research findings into interventions to promote healthy aging. Roybal Centers are structured within the conceptual framework of the mechanism-focused NIH Stage Model, a model of intervention development aimed at producing potent and scalable non-pharmacological interventions. In 2019, NIA expanded its Roybal Centers to include four new AD/ADRD-specific Roybal Centers for translational intervention development research for AD/ADRD care provider support. In late 2024, NIA plans to award the next iteration of AD/ADRD-specific Roybal Centers in response to RFA-AG-24-007. These centers serve as incubators for the development of behavioral interventions that improve the health, well-being, and/or capacity of PLWD and individuals and/or systems that provide care to persons with AD/ADRD. In this new iteration, Roybal Centers may also support the development of behavioral interventions to help prevent or delay cognitive decline and AD/ADRD.

The NIA IMPACT Collaboratory was established to conduct pragmatic clinical trials to improve the care and health outcomes of PLWD and their care partners in partnership with various health care systems. The IMPACT Collaboratory includes a Pilot Grant Program to generate the preliminary data necessary to design and conduct a future full-scale effectiveness embedded pragmatic clinical trials (ePCTs) and a Demonstration Project Grant Program to generate evidence on effective care delivery practices for persons with dementia that can be expanded and/or implemented in other systems.

NIH also released several NOFOs specifically focused on clinical trials for AD/ADRD. These include pharmacologic as well as lifestyle interventions. For a full list of funding opportunities and their links, please see Appendix 3.

For more information see:

- https://impactcollaboratory.org/
- https://impactcollaboratory.org/demonstration-grants-program/
- https://impactcollaboratory.org/pilot-grants-program/
- https://reporter.nih.gov/search/BklBS7WhL0WXyFh4x0ZUXA/projects?shared=true
- https://www.nia.nih.gov/research/dbsr/nih-stage-model-behavioral-intervention-development

In 2023, VA established a new Alzheimer's Disease Coordinating Center at the Ralph H. Johnson VA Medical Center in Charleston, South Carolina. The main function of this coordinating center is to facilitate research-clinical collaboration and data-sharing within the VA. The coordinating center also serves an important role in identifying and addressing barriers to AD/ADRD clinical research efforts within the VA enterprise.

(ONGOING) Action 1.B.6: Expand research focused on needs related to the intersection of Down syndrome and Alzheimer's disease and related dementias

Lead Agency: NIH

The INvestigation of Co-occurring conditions across the Lifespan to Understand Down syndromE (INCLUDE) project was launched in June 2018 in support of a congressional directive. INCLUDE focuses on three overall goals: (1) conducting targeted, high-risk, high-reward basic science studies on chromosome 21; (2) assembling a large study population of individuals with Down syndrome; and (3) including individuals with Down syndrome in existing clinical trials. INCLUDE supports research projects, scientific infrastructure, and community building efforts to assemble a large study population of individuals with Down syndrome and conduct clinical trials research inclusive of individuals with Down syndrome. The INCLUDE project is developing the standards for inclusivity for this population previously not well represented in, if not explicitly excluded from, clinical research.

NIH is committed to supporting INCLUDE and has created an AD/ADRD clinical trial network for adults living with Down syndrome. This network, the ACTC-Down Syndrome Network aims to utilize the existing depth and breadth of expertise across its ACTC infrastructure to conduct AD/ADRD clinical trials in adults with this condition. The overarching goal of the project is to build an efficient clinical trial network to address the critical need for treatment of AD/ADRD. Through the INCLUDE project, NIH is seeking to fund other research projects focused on AD/ADRD in individuals living with Down syndrome -- including studies to develop or improve animal models for Down syndrome related research. For a full list of funding opportunities and their links, please see Appendix 3.

For more information see:

- https://clinicaltrials.gov/ct2/show/NCT04165109
- https://reporter.nih.gov/project-details/9749625
- https://reporter.nih.gov/project-details/9893363
- https://www.nih.gov/include-project

The Alzheimer's Biomarker Consortium-Down Syndrome (ABC-DS) is a multi-disciplinary, multi-site longitudinal study examining biomarkers of AD in a large cohort of adults with Down syndrome ages 25 and above. ABC-DS was initiated in 2015 by NIA and the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD) with the funding of two groups of research collaborators -- Neurodegeneration in Aging Down Syndrome and Alzheimer's Disease in Down Syndrome. In September 2020, the continuation of ABC-DS was funded by NIA, NICHD and the Trans-NIH INCLUDE Project. ABC-DS researchers followed the cohort of people with Down syndrome to conduct three projects. The next iteration of ABC-DS includes an emphasis on increasing the diversity of individuals in the cohort of adults with Down syndrome. The Alzheimer's Disease/Down Syndrome Outreach, Recruitment, and Engagement Core will rapidly disseminate information to Down syndrome communities and engage underrepresented racial and ethnic groups.

In 2020, NACC developed a Down syndrome-specific clinical and cognitive assessment module, implemented for use in research that is harmonized with some of the ABC-DS clinical and neuropsychological measures and available for use by ADRCs and Intellectual and Developmental Disabilities Research Centers for research purposes. This module is being deployed across the Centers program to further support dementia assessment and diagnosis for the Down syndrome community and to facilitate their participation in AD/ADRD clinical trials. Data and biosamples generated from the participants who are being evaluated with the module will also be available for broader sharing.

For more information see:

- https://naccdata.org/data-collection/forms-documentation/ds-3
- https://www.nia.nih.gov/news/people-down-syndrome-and-alzheimers-show-similar-changes-metabolic-processes-people-late-stage
- https://www.nia.nih.gov/research/abc-ds
- https://www.nia.nih.gov/research/blog/2021/06/teaming-expand-alzheimers-and-down-syndrome-research
- https://www.nichd.nih.gov/research/supported/eksiddrc

NIA and NICHD have also collaborated to produce and disseminate information for people with Down syndrome and their families regarding the interplay of Down syndrome and dementia, and the importance of participating in research. Efforts include a fact sheet, *Alzheimer's Disease in People with Down Syndrome*, and outreach via email and social media.

For more information see:

- https://www.nia.nih.gov/health/alzheimers-disease-people-down-syndrome

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(ONGOING) Action 1.B.7: Issue a joint Department of Veterans Affairs/National Institute on Aging career development award for clinician-scientists in the area of dementia research

Lead Agencies: NIH, NIA
Partner: VA

Since 2021, the VA has funded several research studies in response to the early career physician-scientist mentored research in AD/ADRD funding announcement. This program has been approved through 2024.

(UPDATED) Action 1.B.8: Research the impacts of COVID-19 and Post-COVID Conditions on risk of Alzheimer's disease, Alzheimer's disease and related dementias, cognition, and brain health

Lead Agencies: NIH, NIA

NIH is looking closely at the long-term effects of the COVID-19 infection (also known as Long COVID) through the Researching COVID to Enhance Recovery (RECOVER) Initiative, which was launched in 2021. The RECOVER Initiative has multiple scientific aims, including to understand the full clinical spectrum of Long COVID, and to define distinct subtypes of Long COVID. It will also investigate how COVID-19 affects cognition, cognitive decline, and dementia. Thousands of diverse participants across the lifespan will take part in the national, patient-centered study.

For more information see:

- https://recovercovid.org/about

NIA has been a key contributor in NIH efforts to support research on the social, behavioral, and economic impacts of COVID-19, particularly in vulnerable populations, including individuals with cognitive impairment or dementia.

In late 2023, NIA recently funded a large investigator-initiated project evaluating the interactions of COVID-19 infection and genetic variation on the risk of cognitive decline and AD focusing on older adults from underrepresented groups. The project is establishing an international research consortium to investigate interactions between whole-genome sequence variations and COVID-19 on the risk of cognitive decline in 4,300 individuals recruited in the United States, Nigeria, and Argentina.

In the early days of the COVID-19 pandemic, NIA collaborated with the Centers for Disease Control and Prevention (CDC) via an interdepartmental agreement, which supported the NIA IMPACT Collaboratory Long-Term Care Data Cooperative (an ongoing NIA project) to monitor COVID-19 vaccine-related adverse events among vulnerable nursing home residents. This collaboration allowed researchers to leverage existing IMPACT Collaboratory infrastructure to quickly pivot and effectively respond to the COVID-19 pandemic by supporting the development and conduct of studies to assess the pandemic's acute impact on older adults, particularly PLWD. One key finding using data from nearly 300 nursing homes was that mortality rates of vaccinated nursing home residents were lower than those of unvaccinated residents. This was especially important given that residents of nursing homes were excluded from the first COVID-19 vaccine trials, limiting the data available on vaccine efficacy and side effects for this population.

NIA issued its own Notices of Special Interest (NOSIs) to stimulate much-needed research on aging and COVID-19. NIA has supported several administrative supplements and revision applications on COVID-related topics including: neuroscience and AD/ADRD; aging biology; social, behavioral, and economic research; dementia care and caregiving; and geriatrics and gerontology.

In addition, NIA issued a funding opportunity for COVID-19 clinical trial implementation projects on aging-related topics in at-risk older adult populations, including those with cognitive impairment and AD/ADRD. In 2021, NIA issued a NOSI to stimulate research on neurological and neurocognitive sequelae originating from SARS-CoV-2 infection in aging and age-related neurodegeneration. NINDS issued a funding opportunity titled Impact of COVID-19 on Dementia Risk, Progression and Outcomes in AD/ADRD Populations (NOT-NS-21-037) to solicit research on the effect of COVID-19 exposure on subjects who have, or are at risk for, developing AD/ADRD. The impact of COVID-19 on AD/ADRD risk and outcomes was an area of focus in the 2022 ADRD Summit. In line with COVID-related research milestones that were a product of the Summit, NINDS invited new research in 2023 and again in 2024 to study how COVID-19 interacts with and impacts AD/ADRD -- such studies may focus on how COVID-19 predisposes some individuals to develop AD/ADRD and/or how COVID-19 affects the brain or accelerates AD/ADRD pathology and cognitive deficits in early phases of the condition (PAR-23-214; PAR-24-203).

NIA is also co-sponsoring a variety of other COVID-targeted funding opportunities, such as those specific to the Rapid Acceleration of Diagnostics Underserved Populations Initiative, which seeks to enable and enhance COVID-19 testing in under-served and vulnerable populations (e.g., residents of nursing homes and assisted living facilities, individuals with cognitive impairment or dementia). NIA remains involved in the NIH-funded Social, Behavioral, and Economic Research on COVID Coordinating Center and related consortium of awards and pilots, some of which focus on PLWD. More generally, NIA has provided support to its stakeholders and grantees throughout the COVID-19 Public Health Emergency (PHE), including those who work in the field of AD/ADRD. This support encompasses ongoing communications on COVID-related issues, outreach on federal COVID-19 resources for older adults, and flexibilities for grant applicants whose research has been affected by the pandemic. For a full list of funding opportunities and their links, please see Appendix 3.

For more information see:

- https://impactcollaboratory.org/grants-and-training/supplement-awards/interventionstudies/
- https://reporter.nih.gov/search/1Ka1SysMak2QDAkM_OkLVw/project-details/10628505
- https://www.icpsr.umich.edu/web/pages/sbeccc/
- https://www.icpsr.umich.edu/web/pages/sbeccc/members.html
- https://www.nia.nih.gov/health/government-covid-19-resources-older-adults
- https://www.nia.nih.gov/news/mrna-vaccines-decreased-number-new-covid-19-cases-nursing-home-population
- https://www.nia.nih.gov/research/blog/2020/03/covid-19-adjusting-new-normal
- https://www.nia.nih.gov/research/blog/2020/07/data-harmonization-and-sharing-are-essential-covid-19-research
- https://www.nia.nih.gov/research/dbsr/social-behavioral-and-economic-sbe-research-covid-19-vulnerable-and-health-disparity
- https://www.nih.gov/research-training/medical-research-initiatives/radx/funding#radx-up

Strategy 1.C: Accelerate Efforts to Identify Early and Presymptomatic Stages of Alzheimer's Disease and Related Dementias

Significant advances in the use of imaging and biomarkers in brain, blood, and spinal fluid have made it possible to detect the onset of AD/ADRD and track its progression with the hope that it will be possible to monitor the effect of treatment in people with the disease. Without these advances, these neurodegenerative processes could only be evaluated in non-living tissues. Accelerated research will improve and expand the application of biomarkers in research and practice. These advances have shown that the brain changes that lead to AD/ADRD begin up to 10 years before symptoms. Identifying imaging and other biomarkers in presymptomatic people will facilitate earlier diagnoses in clinical settings, as well as aid in the development of more efficient interventions to slow or delay progression.

(**UPDATED**) Action 1.C.1: Identify imaging and biomarkers to monitor disease progression

Lead Agencies: NIA, NINDS
Partners: ADNI partners, AMP partners

The Alzheimer's Disease Neuroimaging Initiative (ADNI) has contributed to much progress in neuroimaging and biomarker refinement. ADNI, a long-running, NIH-supported study, was designed to develop tools for clinical trials by tracking how neuroimaging and fluid biomarkers change with disease onset and progression. Launched by NIH in 2004, this landmark public-private partnership looks at how the evolution of clinical symptoms and neurocognitive testing in healthy controls, people with MCI, and people with mild AD correlates with changes in multiple biomarkers reflecting disease development. The biomarkers developed and validated in ADNI are being used more and more in clinical trials. ADNI has also pioneered rapid, transparent data-sharing while protecting participants' privacy. Qualified researchers across the world can access ADNI brain scan images and biomarker data through a web-based portal once data are quality-controlled and added to the database. ADNI also shares the blood, CSF, and DNA it has collected with other investigators who are developing novel biomarkers. Now in its 20th year, the three phases of ADNI (ADNI1/GO, ADNI2, and ADNI3) have developed biomarkers for use in selecting clinical trial participants and for assessing treatment outcomes. Subjects recruited into each iteration of ADNI are expected to continue into the next phase called ADNI4 that began in 2022. ADNI4 has added a major new focus on recruiting previously underrepresented minorities as research participants and gathering biomarker and clinical data to understand how AD does or does not differ in African Americans, Hispanics, Native Americans, Asian Americans, rural, and lower socioeconomic status (SES) compared to college-educated, middle and upper SES White Americans. Additionally, ADNI4 has added an innovative social media and community-based approach that provides additional support to disadvantaged individuals to minimize the burden of participating in ADNI4. This new focus will not only add important new information about AD, but it will potentially provide a methodological template for future studies, ensuring that NIA-sponsored research includes a diverse study population. ADNI4 also adds as a priority the systematic collection of autopsied brains from deceased ADNI subjects for additional studies. ADNI has accumulated a great deal of clinical, neuroimaging, cognitive, biofluid biomarker and genetic data, and biofluid samples available to researchers, which has resulted in thousands of publications.

In collaboration with ADNI study investigators and participants, researchers from NIH/CARD have established a potential approach for detecting and studying Lewy body pathology in AD patients.

For more information see:

- http://adni.loni.usc.edu/
- https://pubmed.ncbi.nlm.nih.gov/38770829/

NIA has also funded over 50 different SBIR/STTR grants to small businesses developing novel diagnostic approaches to AD including several companies that have made major advances is plasma diagnostics. For example, one NIA SBIR grant supported the development of the first blood test (PrecivityAD) that can help detect the presence of amyloid plaques in the brain, a hallmark of AD. An NIH-funded study also led to the development of the next-generation version of the blood test, PrecivityAD2, which combines measures of beta-amyloid and tau. Based on the study results, combining these measures appears to achieve diagnostic performance levels comparable to the current clinical gold standards of amyloid PET imaging and CSF tests. Researchers found similar robustness for the PrecivityAD2 test in patients who saw memory care specialists, highlighting the potential of the PrecivityAD2 test to enable AD diagnosis in primary care settings.

NIH-supported research also led to the emergence of a different method to detect toxic amyloid aggregates in the blood, called oligomers, which are precursors to amyloid plaques. Oligomers can form more than a decade before symptoms of AD appear. This new method, called the soluble oligomer binding assay, could make it possible to permit even earlier disease diagnosis and intervention, before plaques can be detected and, importantly, before irreparable brain damage occurs. Several other blood tests are in development. Additionally, advances were made in brain imaging, most notably the FDA-approval of the first PET scan product to detect tau tangles in the brain, another hallmark sign of AD/ADRD. In addition to blood tests, other NIH-supported research projects are designed to look beyond current measures to identify people with dementia earlier in the disease process. These include changes in vision and pupil responses that may signal AD. A recent NIH-funded study also found that declining cognitive function coupled with slowed walking speed is associated with greater dementia risk in older adults than either of these factors alone. These findings indicate that regularly testing both gait speed and memory may help health care providers more clearly identify patients at risk for dementia. For a full list of funding opportunities and their links, please see Appendix 3.

For more information see:

- https://www.nia.nih.gov/news/blood-test-can-predict-presence-beta-amyloid-brain-new-study-finds
- https://www.nia.nih.gov/news/blood-test-early-alzheimers-detection
- https://www.nia.nih.gov/news/blood-test-method-may-predict-amyloid-deposits-brain-potentially-indicating-alzheimers-disease
- https://www.nia.nih.gov/news/blood-test-shows-promise-predicting-presymptomatic-disease-progression-people-risk-familial

- https://www.nia.nih.gov/news/combined-decline-gait-and-cognition-may-better-predict-dementia-risk-either-factor-alone
- https://www.nia.nih.gov/news/nia-small-business-funding-seeks-find-blood-based-diagnostic-alzheimers-disease

The Health and Aging Brain Among Latino Elders-Amyloid, Tau, and Neurodegeneration (HABLE-AT(N)) study, which enables researchers to collect amyloid and tau PET imaging and other biomarker measures with the goal of better understanding health disparities of brain aging and AD/ADRD between Mexican American and non-Hispanic Whites (NHWs). An additional benefit of HABLE and HABLE-AT(N) is now in its fifth year of funding and the research team has made great progress recruiting participants and conducting PET amyloid and tau scans (total of 1,424 amyloid PET scans and 828 tau PET scans completed). Current data from this study demonstrates that AT(N)-defined biomarkers are differentially prevalent and differentially related to clinical, demographic, medical and sociocultural outcomes among diverse populations. The research team continues to make the data including PET scans available to the scientific community.

For more information see:

- https://www.nia.nih.gov/news/nih-augments-large-scale-study-alzheimers-disease-biomarkers

NIA launched the Pioneering Research for Early Prediction of Alzheimer’s and Related Dementias EUREKA Challenge in 2023 to advance solutions for accurate, innovative, and representative early prediction of AD/ADRD through three challenge phases that successively build on each other. Awards for the first phase will be made in late 2024, and phase II is expected to begin in September 2024.

For more information see:

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

Amyloid and tau fluid biomarkers and PET imaging are already being used in the clinic to detect AD-pathologies. NIH continues to support the development and validation of ADRD biomarkers, including imaging agents and biological samples that can enable better patient stratification, diagnosis, and tracking of disease progression in LBD, FTD, VCID, and dementias with mixed etiologies. For example, NIA and NINDS collaboratively support the ALLFTD initiative -- Advancing Research and Treatment for Frontotemporal Lobar Degeneration (ARTFL) and Longitudinal Evaluation of Familial Frontotemporal Dementia Subjects (LEFFTDS) Longitudinal Frontotemporal Lobar Degeneration research study -- which aims to understand the progression of familial FTD. ALLFTD researchers have demonstrated that the three main genetic causes of familial FTD have their own progression profile, with different biomarkers relevant at different times. These new FTD progression models will aid in planning prevention trials for the disease by helping to select participants and detect treatment effects.

In addition, research teams are working to develop new PET imaging approaches for pathologies specific to LBD and FTD. In order for a PET imaging tracer to be developed, researchers must first “visualize” the three-dimensional shape of the protein that they wish to detect. To this end, NIH is investing substantially in the use of a powerful, cutting-edge technology called cryo-electron microscopy (cryo-EM), which can produce ultra high-resolution pictures of the many misfolded proteins that appear in AD, LBD, FTD, and LATE. For example, in 2023 using cryo-EM, NIH-supported researchers showed that TDP-43 forms different structures depending on different subtypes of FTD. In 2022, NIH-supported scientists used cryo-EM to produce the first complete and exquisitely detailed pictures of abnormally clumped alpha-synuclein, which is a primary component of Lewy bodies. The next step is to develop imaging agents that specifically bind to these different structures. These advances represent a significant step towards developing a broader suite of PET imaging agents that can detect and distinguish between the various dementias. To capitalize further on this progress in 2024, NINDS renewed its CWOW for PET

Ligand Development for ADRDs and invited new applications for researchers to develop multi-modal biomarker approaches (e.g., combining different imaging and biological measures in one test) to differentially diagnose ADRDs for clinical trials. Additionally, NINDS continues to support the Biomarkers for the Lewy Body Dementias Initiative and the Parkinson's Disease Biomarkers Program (PDBP), which are developing biomarkers and enabling broad sharing of clinical data and biospecimens across the research community. More than 300 LBD participants have been enrolled and continue to be followed as part of the PDBP effort. Additionally, investigators through the AMP for Parkinson's Disease initiative are conducting a deep molecular characterization and longitudinal clinical profiling of Parkinson's disease and LBD with data and samples from individuals living with LBD.

The recent discovery of a fluid biomarker that may help diagnose FTD and the related disease, ALS, is a particularly exciting development.

In people with ALS and FTD, a protein called TDP-43 builds up in an abnormal site within cells, causing changes in how genes are read and ultimately generating irregular proteins. Investigators developed a new antibody test which could detect these irregular proteins in human blood and spinal fluid samples. Notably, the test could detect these proteins before symptoms of ALS or FTD appeared. This tool shows tremendous promise for early-stage clinical detection of ALS/FTD. Future studies are needed to determine if the test can also be useful for other conditions that involve TDP-43, including AD, multiple sclerosis, CTE, and LATE.

Progress is also being made in the identification and development of fluid biomarkers for LBD. In 2024, NIH-funded researchers published promising results using immunoassays to measure 665 proteins in the CSF of patients with LBD, AD, and people without cognitive impairment. The team found more than 50 dysregulated proteins in patients with LBD and identified a pronounced increase in the enzyme involved in dopamine biosynthesis (DDC) in LBD patients. High levels of DDC effectively distinguished those with LBD from AD and the control group. For a full list of funding opportunities and their links, please see Appendix 3.

For more information see:

- https://amp-pd.org/
- https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-24-001.html
- https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-24-011.html
- https://pdbp.ninds.nih.gov/
- https://pdbp.ninds.nih.gov/lewy-body-data
- https://pubmed.ncbi.nlm.nih.gov/37704597/
- https://pubmed.ncbi.nlm.nih.gov/38278991/
- https://www.allftd.org/
- https://www.nia.nih.gov/news/new-biomarker-may-help-detect-presymptomatic-als-and-ftd
- https://www.nia.nih.gov/research/alzheimers-dementia-outreach-recruitment-engagement-resources/carl-rinne-lewy-body#:~:text=The%20Carl%20Rinne%20Lewy%20Body,Lewy%20body%20dementia%20in%20Michigan

Research progress and new investments continue to move forward the development of vascular imaging biomarkers and related clinical approaches to detect VCID. Following a 2022 workshop titled *Imaging the Future of In vivo Neuropathological Diagnosis through Postmortem Analyses*, in 2023 NINDS invited researchers to develop innovative technologies and tools that can enhance human neuropathology and neuroimaging research with data about the mechanisms that underly VCID-related in vivo imaging findings. Also, in 2022, the NINDS renewed its largest VCID-related biomarker program, MarkVCID. Now in Phase II, the multi-site study is scaling up to test the most promising biomarkers developed during the first phase, conducting clinical trials in larger, racially, and ethnically diverse populations. It is expected that MarkVCID will determine the effectiveness of these biomarkers in Hispanic, Black/African American, and White populations and become a gold standard for rigorous biomarker assessment. In 2023, NIH began funding eight MarkVCID awards to continue advancing the development of VCID biomarkers. For a full list of funding opportunities and their links, please see Appendix 3.

For more information see:

- https://markvcid.partners.org/
- https://pubmed.ncbi.nlm.nih.gov/33480172
- https://www.detectcid.org/
- https://www.ninds.nih.gov/news-events/events/imaging-future-vivo-neuropathological-diagnosis-through-postmortem-analyses-workshop

In September 2023, NIH began funding a major study which will leverage the existing ADRCs infrastructure to provide state-of-the-art imaging and blood-based biomarkers for researchers around the world to study and advance the field of ADRD. This study will also on advance understanding of mixed or multiple etiology dementias, where more than one neurological disease is contributing to dementia.

For more information see:

- https://naccdata.org/nacc-collaborations/clariti

(**UPDATED**) Action 1.C.2: Maximize collaboration among federal agencies and with the private sector

Lead Agencies: NIA, NINDS
Partner: FDA

The NIA IMPACT Healthcare Collaboratory received COVID-19 supplements to establish partnerships with the nursing home industry (226 organizations and 2,374 facilities enrolled) to establish and develop data-sharing infrastructure and reporting systems to monitor the effects of the COVID-19 vaccines administered to frail older adults, on whom the vaccines were not widely tested prior to authorization for emergency use. Use of EHR data from this initiative provided near real-time insight on vulnerable populations in nursing homes, which was used by the CDC Advisory Committee on Immunization Practices to monitor adverse events of COVID-19 vaccination among vulnerable older adults. In the near future, the nursing home EHR data will be linked with the Centers for Medicare & Medicaid Services (CMS) claims data, which can be used to improve our national response to the pandemic and public health outcomes for older adults in addition to facilitating pragmatic trials.

For more information see:

- https://impactcollaboratory.org/building-infrastructure/
- https://www.nia.nih.gov/research/dbsr/frequently-asked-questions-alzheimers-disease-ad-and-ad-related-dementias-adrd#platform%20data
- https://www.nia.nih.gov/research/dbsr/nia-impact-collaboratory

NIA’s Small Business Programs actively began collaborations with the FDA in 2024. First, NIA joined the National Cancer Institute-led Connecting Awardees with Regulatory Experts Program which is an interagency collaboration with FDA. NIA’s goal in joining this program is to connect NIA SBIR/STTR awardees with FDA and support communications with regulators early in the technology development process. Separately, NIA launched a collaboration with the FDA Center for Devices and Radiological Health (CDRH)’s Medical Device Development Tools (MDDT) program in which NIA published a specific topic in the NIH SBIR Research Contract Funding Solicitation that is titled Digital Technologies as Tools to Screen and Monitor Alzheimer’s Disease (AD) and Related Dementias (ADRD). The goal of this contract topic is to stimulate the participation of small businesses in the FDA's MDDT program to develop and demonstrate the utility of digital technologies as a measure of AD/ADRD screening and monitoring as qualified MDDTs to assess medical devices subject to regulation by CDRH. An MDDT can be a method, material, or measurement used to assess the safety, effectiveness, or performance of a medical device. Digital technologies, in combination with AI/ML, have potential to detect the disease in the early stage and in mass screening and monitoring of the progression of the disease. Potential examples of MDDT are tools that measure sleep, gait, eye movement, speech, mood, activity, driving, keystrokes, and image analysis software. As part of the SBIR funding to potential awardees to this FY 2025 solicitation topic, the awardee would be required to submit to FDA the necessary documents for its two phases of qualification: the Proposal phase and the Qualification phase. The outcome of receiving funding and completing the MDDT processes includes the ability to utilize the NIA funding to develop needed AD/ADRD digital screening and monitoring tools as well as receive qualification of those tools by FDA which will increase their overall utility and impact.

For more information see:
- https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4847536/
- https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5111162/

Also, the International Alzheimer's and Related Dementias Research Portfolio (IADRP) facilitates the tracking of research support in the public and private sectors, including the initiatives mentioned above.

For more information see:
- https://iadrp.nia.nih.gov/

Strategy 1.D: Coordinate Research with International Public and Private Entities

In order to facilitate communication and collaboration, build synergy, and leverage resources, it is imperative that research across nations and across funders be coordinated. The actions below will formalize the coordination process beyond HHS and the Federal Government and make research available to the public for input.

(ONGOING) Action 1.D.1: Inventory Alzheimer's disease and related dementias research investments

Lead Agency: NIA

NIH supports the IADRP, a free, publicly available and searchable database providing a global overview of AD/ADRD research and funding. IADRP is an invaluable tool for assessing the expanding landscape of AD/ADRD research supported by federal and non-federal funding organizations in the United States and internationally. Funding organizations, researchers, and advocates are using IADRP to coordinate strategies, leverage resources, avoid duplication, and identify promising areas of growth. Since NIH launched the database in 2012, in collaboration with the Alzheimer's Association, IADRP has amassed information on over 10,000 unique projects from 2008 through 2023, reflecting more than $22 billion in research funding worldwide. The number of contributors is growing, too. During the past 5 years, more than 40 funding organizations across greater than ten countries have joined the IADRP effort. IADRP continues to expand by bringing additional funding organizations onboard.

For more information see:
- https://iadrp.nia.nih.gov
- https://iadrp.nia.nih.gov/about/cadro

The NIH research plan for reaching the NAPA goals is outlined as a series of research implementation milestones, which include success criteria and specific implementation activities to track progress. These milestones and the accompanying milestone database are updated annually based on this diverse input. This planning process and its systematic updates have informed the research community about NIH's interests and priorities in funding projects in AD/ADRD. In April 2023, NIA released an enhanced database for tracking of AD/ADRD Research Implementation Milestones. Updates to the database include improved search performance by enabling the ability to search, sort, and filter milestones.

For more information see:

- https://www.nia.nih.gov/research/milestones

NIH is committed to data-sharing as a way to synergize research and facilitate collaborative science while ensuring appropriate protections for research involving human data and oversight of research conduct, data quality, data management, data-sharing, and data use. A collaborative approach among the major cohorts could expedite epidemiological discovery by assembling multi-level data collected across the lifespan and by providing a framework for multi-disciplinary research. NIH's aging and AD/ADRD cohorts have been central to this mission, providing pivotal information on healthy aging and factors related to risk of and protection for AD/ADRD. A comprehensive, and publicly accessible inventory of cohorts is fundamental to facilitate collaborative scientific efforts, sharing of data and cost-effective assembly and utilization of resources. In return, this will assist the research community in the planning of new studies and will enable NIA in maximizing the returns on investments. NIA is working with the NIH Center for Information Technology to pilot-test the creation of a database for cohorts supported by NIA. The objectives of this project are to create a user-friendly cohort database of NIA's longitudinal studies which will:

1. Increase transparency and scientific quality and collaboration through public access to the aging and AD/ADRD cohort's descriptive information.
2. Assist the research community in identifying and accessing population resources for research in aging and AD/ADRD.
3. Improve the return on investment in the cohorts' infrastructure for researchers and NIA.
4. Promote collaborative research projects for topics not easily addressed by a single study.

NIH recognizes that the sharing of scientific data expedites the translation of research results into knowledge, products, and procedures to improve human health. Accordingly, the NIH has implemented a new Data Management and Sharing Policy, effective January 23, 2023, that requires researchers to prospectively plan for how scientific data will be preserved and shared through submission of a Data Management and Sharing Plan.

For more information see:

- https://sharing.nih.gov/data-management-and-sharing-policy/about-data-management-and-sharing-policy/data-management-and-sharing-policy-overview#after

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(ONGOING) Action 1.D.2: Expand international outreach to enhance collaboration

Lead Agency: NIA

NIA and NINDS participate in the Alzheimer's Disease Funders' meeting held annually during the Alzheimer's Association International Conference (AAIC), as well as quarterly international funders' calls led by the Alzheimer's Association. Also, IADRP, maintained by NIA, includes data from over 40 public and private funding organizations across more than ten countries and is publicly available for use.

For more information see:

- https://iadrp.nia.nih.gov

NIA supports the long-running HRS as well as an international family of partner studies that collect longitudinal multi-disciplinary data on nationally representative samples of adults over the age of 50. These studies collect information from participants about many factors that influence health and aging, including income and assets, work history, health insurance and expenditures, and others, which researchers can use to better understand how these factors influence health, aging, and dementia risk. In total, HRS studies have been conducted in over 40 countries and cover over 70% of people ages 60+ worldwide. The international family of HRS studies provide representative data for individual countries and also offer the opportunity for cross-national comparisons to identify differences in health and dementia risk in different geographic and cultural contexts. Importantly, the data and tools developed from these studies are harmonized and made widely available to researchers and other stakeholders around the world through a digital library called the Gateway to Global Aging Data.

Beginning in 2016, the HRS family of studies began implementing the innovative HCAP. HCAP utilizes a combination of cognitive tests, interviews, and biological sampling to build a more comprehensive understanding of cognitive function and aging in the United States and around the world.

In 2019, NIA began funding a research network to facilitate collaboration among longitudinal studies of aging around the world to harmonize methods and content. The goal of the HCAP Network is to develop international data resources for the study of AD/ADRD that will expand research opportunities to exploit cross-country variation in key life-course factors that likely affect cognitive function and the risk for AD/ADRD, such as educational attainment, wealth, retirement policies, diet, and the prevalence and treatment of cardiovascular risk factors. Currently, 16 active studies representing countries from all over the world participate in Network activities. The Network is also advising nascent studies in Brazil, Ghana, Egypt, Malawi, Malaysia, the Philippines, and Ivory Coast as well as collaborating with the World Health Organization. The international HCAP studies have made substantial progress over the last year, and HCAP data collected in China, England, India, Mexico, South Africa, and Chile has been publicly released. The data and tools developed from the HRS and HCAP studies are shared with researchers and other stakeholders around the world through a digital library called the Gateway to Global Aging Data.

To further advance health disparities research, the HRS is recruiting 2,000 additional racial and ethnic minority respondents. By continuing to diversify this cohort, researchers using HRS data to provide insights into potential racial or ethnic differences in the incidence, prevalence, and impact of AD/ADRD. Moving forward, these studies aim to improve overall response and retention rates to maintain representativeness and add content on social factors to better study racial disparities and minority health.

NIA is scheduled to renew support for the HCAP Network by the end of 2024.

For more information see:

- https://charls.pku.edu.cn/en/index.htm
- https://g2aging.org/home
- https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-24-035.html
- https://haalsi.org/projects-cores
- https://hcap.isr.umich.edu/
- https://hrs.isr.umich.edu/data-products/hcap
- https://hrs.isr.umich.edu/welcome-health-and-retirement-study
- https://hrsdata.isr.umich.edu/data-products/2016-harmonized-cognitive-assessment-protocol-hcap?_ga=2.202519186.2017360935.1670277481-1021185182.1670277481
- https://lasi-dad.org/
- https://reporter.nih.gov/project-details/9618704

- https://reporter.nih.gov/project-details/10003934
- https://reporter.nih.gov/project-details/10017122
- https://reporter.nih.gov/project-details/10975562
- https://web.sas.upenn.edu/harmonized-cognitive-assessment-protocol-chile/
- https://www.mhasweb.org/DataProducts/AncillaryStudies.aspx
- https://www.nia.nih.gov/research/blog/2019/05/healthy-cognitive-aging-project-major-data-resource-cognitive-epidemiology
- https://www.src.isr.umich.edu/projects/health-and-retirement-study-harmonized-cognitive-assessment-protocol-hrs-hcap/
- https://www.ucl.ac.uk/epidemiology-health-care/research/behavioural-science-and-health/research/psychobiology/healthy-cognitive-ageing-project-elsa#:~:text=The%20Healthy%20Cognitive%20Aging%20Project,Study%20of%20Ageing%20(ELSA).&text=The%20protocol%20was%20designed%20to,dementia%20study%20known%20as%20ADAMS

NIA is a partner funding agency on the Adopting Sustainable Partnerships for Innovative Research Ecosystem program. The program, run by the Japan Agency for Medical Research and Development, aims to foster international research collaboration and fund large-scale research projects in basic, applied, and preclinical research.

For more information see:

- https://www.amed.go.jp/en/news/program/0301B_00028.html

According to the report *Africa Aging: 2020*, the number of older Africans (age 60 years and older) is projected to triple from 74.4 million to 235.1 million between 2020 and 2050, and this growth will outpace that of any other region of the world. As a result, Africa is expected to undergo a significant increase in dementia burden. For this reason, NIA collaborates with the NIH's Fogarty International Center (FIC) to support global research on aging and AD/ADRD in low and middle income countries (LMIC). Research in LMIC will not only help to mitigate AD/ADRD in these countries but will also increase our knowledge of the complexity and heterogeneity of this disease in the global context. Data from these studies may be extrapolated to United States populations that share similar sociodemographic backgrounds to LMIC populations (e.g., race/ethnicity, low-resource, rural, etc.). NIA also collaborates with FIC on the Global Environmental and Occupational Health Program with the aim to support research on environmental and occupational health threats in relation to AD/ADRD. Over the past 20 years, NIA has worked with FIC on the Global Brain and Nervous System Disorders Research Across the Lifespan Initiative, which supports investigator-initiated and exploratory research on brain and other nervous system function and conditions throughout life in LMIC. NIA and FIC are partnering to support LMIC training through the Emerging Global Leader Award (K43) and Institutional Training Program (D43). Through these programs, NIA aims to support the development of early-stage investigators in establishing research programs, building expertise, and becoming leaders poised to change theory, practice, and health outcomes related to the health of older individuals in LMIC. NIA also supports the development of institutional training programs by LMIC institutions through the FIC Chronic, Non-communicable Diseases and Disorders Across the Lifespan (NCD-LIFESPAN) Training Award. NCD-LIFESPAN is expected to strengthen the research capacity of the awarded institution's country by training a cadre of scientists to contribute to important advances in clinical practice and public health policies. NIA participates in the Global Alliance for Chronic Diseases Implementation Research to Reduce NCD Burden in LMIC program, through which NIA will support implementation research addressing risk factors associated with non-communicable diseases in LMIC. Multiple funding opportunities are currently available through this program.

For more information see:

- https://www.census.gov/library/publications/2020/demo/p95_20-1.html

Lastly, several new NIA research concepts focusing on capacity-building and training in LMIC were recently approved by the National Advisory Council on Aging and new funding opportunities in this area are expected to be released before the end of 2024. For example, one new program will build research infrastructure in Africa. The new NIA program will develop or enhance research infrastructure and resources for AD/ADRD research in Africa, support collaboration between United States and African investigators and support pilot studies. NIA aims to support four new awards under this program.

In 2024, NIA released a NOSI entitled "U.S. Health in the International Perspective." The NOSI encourages applications on research that closely examines the underlying causes of the worsening life expectancies and health outcomes in the United States compared to other countries. Of particular interest are projects that examine cross-national and United States cross-regional or cross-state differences in policy context that may drive poor health outcomes. For a full list of funding opportunities and their links, please see Appendix 3.

For more information see:

- https://grants.nih.gov/grants/guide/notice-files/NOT-AG-24-004.html
- https://www.fic.nih.gov/Programs/Pages/brain-disorders.aspx
- https://www.fic.nih.gov/Programs/Pages/chronic-lifespan.aspx
- https://www.fic.nih.gov/Programs/Pages/emerging-global-leader.aspx
- https://www.fic.nih.gov/Programs/Pages/environmental-occupational.aspx
- https://www.nia.nih.gov/approved-concepts
- https://www.nia.nih.gov/research/blog/2021/04/addressing-global-challenges-aging-and-dementia

AD/ADRD is the leading cause of dementia in older adults in all ancestry groups, but the majority of genetic studies for AD/ADRD have been performed in NHWs of European ancestry. Beginning in 2021, the NIA announced the ADSP Diverse Population Initiative Follow-Up Study (ADSP FUS 2.0) to address the need for a more diverse sample set within the ADSP. The long-term goals of the ADSP FUS 2.0 are consistent with the original ADSP study (as discussed in Action 1.B.2), but with a focus on identifying therapeutic targets in diverse populations, and to identify population specific risk or protective genetic factors. FUS 2.0 is an international collaboration that aims to conduct whole-genome sequencing to reach minor allele frequencies ≤1% with 90% certainty in each of the African American, African, Hispanic, and Asian American and Asian populations. The study is collecting samples from the United States, Africa, Mexico, South America, Australia, and Asia to identify rare variants in diverse ancestry populations. The ADSP FUS 2.0 is striving to recruit new cohorts of diverse ancestries and genetic admixtures and provide support to create resources for studying the genetic etiology of AD/ADRD in understudied and under-served populations. Initial data from the ADSP have shown that risk and protective factors can differ across populations. These findings lend credence for the development of genetically driven precision medicine approaches for different populations.

For more information see:

- https://www.nia.nih.gov/research/dn/alzheimers-disease-sequencing-project-consortia#diversity

Strategy 1.E: Facilitate Translation of Findings into Medical Practice and Public Health Programs

Currently, promising research and interventions are published in the research literature and presented at scientific meetings. Additional steps are needed to highlight promising findings and to facilitate dissemination and implementation of effective interventions quickly and accurately to the general public, medical practitioners, the MedTech and pharmaceutical industries, and public health systems.

(UPDATED) Action 1.E.1: Leverage public and private collaborations to facilitate dissemination, translation, and implementation of research findings

Lead Agency: NIA
Partners: FDA, ACL, CDC, partner organizations

NIA continues to educate clinicians about recent research findings and their clinical implications by offering clinical practice tools for assessment, diagnosis, and management of cognitive impairment; training materials; a patient checklist handout in English and Spanish; and other online materials via a portal of resources for professionals.

NIA also continues to promote research findings through news releases, web announcements and statements, research highlights, and short videos.

In collaboration with other Federal Government agencies, NIA has provided leadership support for the Alzheimers.gov website since 2021. In addition to providing information about AD/ADRD, the site also features updates on research advances; information about Federal Government activities; and resources for health professionals, community service providers, and public health workers.

For more information see:

- https://www.alzheimers.gov
- https://www.nia.nih.gov/health/alzheimers-dementia-resources-for-professionals
- https://www.nia.nih.gov/news/featured-research
- https://www.nia.nih.gov/news/news-releases
- https://www.youtube.com/@NIHAging/shorts
- https://www.youtube.com/playlist?list=PLmk21KJuZUM5en04l9gF08T74EMmFSkY5

CARD, a collaborative NIA and NINDS initiative, also publishes study highlights and blogs featuring its research. In 2023, CARD hosted a Reddit Ask Me Anything on a recent study highlighting viral illnesses and neurodegenerative disorders that received more than 100 comments and generated 643 pageviews of the event page.

For more information see:

- https://card.nih.gov/news-events/card-blog
- https://card.nih.gov/news-events/card-meetings/card-reddit-ask-me-anything-virus-exposure-and-neurodegenerative-disease
- https://card.nih.gov/news-events/card-news

(ONGOING) Action 1.E.2: Continue to promote use of the Alzheimer's and related Dementias Education and Referral Center to provide evidence-based information on Alzheimer's disease and related dementias to the public and others

Lead Agency: NIA
Partners: ADEAR, ACL, CDC, FDA, CMS, HRSA, VA, partner organizations

NIA's ADEAR Center educates the public about the latest research findings and provides evidence-based information online, in print, and through an information and referral line. Information about AD/ADRD, participation in clinical trials, and caregiving is freely available. ADEAR provides more than 60 online articles in English and more than 25 in Spanish, along with 15 print publications, six of which are also available in Spanish. NIA disseminates ADEAR's resources through outreach to the general public, conferences and events in the research and care communities, and media and advocacy organizations. NIA, via weekly e-alerts, reaches more than 125,000 subscribers, and its social media accounts reach more than 187,000 followers. In addition, ADEAR is promoted on all Alzheimers.gov educational pages and through postcards at national conferences and local community events. From June 2023 to June 2024, the ADEAR Center responded to more than 2,600 inquiries, distributed more than 500,000 publications, and had approximately 1.6 million website visitors.

In FY 2019, one GWEP grant recipient (University of Southern California) partnered with three ADRCs and continues to do so. The remaining 47 GWEP grant recipients that were funded through June 2024 were encouraged to work with nearby Alzheimer's Disease Centers. The 42 new GWEP grantees that will be funded effective July 1, 2024, will also be encouraged to work with nearby ADRCs.

For more information see:

- https://www.nia.nih.gov/about/bypass-budget-proposal-archive
- https://www.nia.nih.gov/about/stay-connected
- https://www.nia.nih.gov/alzheimers
- https://www.nia.nih.gov/health/about-adear-center

(ONGOING) Action 1.E.3: Facilitate translation of findings into public health practice

Lead Agency: CDC
Partners: private partners

CDC provides funds to the Alzheimer's Association through a cooperative agreement to co-develop a series of Healthy Brain Initiative (HBI) Road Maps to advance cognitive health as an integral component of public health. In 2019, the first-ever *Road Map for Indian Country* was released to serve as a public health guide for AI/AN leaders to learn about dementia and start discussions throughout their communities. In 2023, CDC and the Alzheimer's Association began the process of revising this road map. This second edition is 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, launching in November 2024, will build on the progress and momentum to date and will guide professionals working with AI/AN peoples to advance the vision that everyone deserves a life with the healthiest brain possible.

For more information see:

- https://www.alz.org/media/Documents/HBI-Road-Map-American-Indian-Alaska-Native-Peoples-Progress-Report.pdf
- https://www.cdc.gov/aging-programs/php/nhbi/indian-country-road-map.html
- https://www.cdc.gov/aging-programs/php/nhbi/roadmap.html

CDC provided funds to the Alzheimer's Association through a cooperative agreement to co-develop the fourth edition in the series of HBI Road Maps to advance cognitive health as an integral component of public health. This *Healthy Brain Initiative: State and Local Road Map for Public Health, 2023-2027* was co-authored by experts in public health and brain health, including scientists at CDC. The fourth Road Map in the series outlines how state and local public health agencies and their partners can continue to promote cognitive health, address cognitive impairment for people living in the community, and help meet the needs of caregivers. Specific actions are proposed in four traditional domains of public health: (1) Strengthen Partnerships and Policies; (2) Measure, Evaluate and Utilize Data; (3) Build a Diverse and Skilled Workforce; and (4) Engage and Educate the Public.

For more information see:

- https://www.cdc.gov/aging-programs/media/pdfs/2024/06/HBI-State-and-Local-Road-Map-for-Public-Health-2023-2027-508-compliant.pdf

In 2022, CDC collected evaluation information from 23 Building our Largest Dementia (BOLD) Infrastructure for Alzheimer's Act program awardees on the status of their efforts to implement Road Map activities from the third edition. Preliminary analyses of this data indicated that:

1. Every one of the 25 Road Map actions has been taken up by at least one of the 23 BOLD program awardees. Actions are either being implemented in programmatic activities or are in the process of being added to jurisdiction strategic plans.
2. Road Map activities were balanced across the four traditional domains of public health.
3. As expected, the largest number of awardees are engaged with the required actions P-1 and M-3.
4. The next most actively engaged actions are E-1 and W-3.
5. With respect to prevention focus areas, BOLD awardees are working on Road Map actions in the risk reduction area most frequently by a substantial margin, followed by early detection and diagnosis.

In late FY 2020, CDC released the first awards to three BOLD Public Health Centers of Excellence (PHCOEs) (2020-2025) and 16 BOLD Public Health Programs (2020-2023). An additional seven BOLD Public Health Programs were funded in FY 2021 for 2021-2023. Recipients selected to establish the three PHCOEs are: “Dementia Caregiving at the University of Minnesota”; “Dementia Risk Reduction at the Alzheimer’s Association”; and “Early Detection of Dementia at the New York University (NYU) School of Medicine.”

In 2023, CDC implemented a new 5-year funding opportunity to build infrastructure and increase capacity in the field of AD/ADRD through the BOLD Public Health Programs. CDC awarded funding to 43 different state, Tribal, local, and territorial (STLT) public health agencies. These awards support creating and updating AD/ADRD strategic plans and provide dedicated funding for STLT public health staff to communicate risk reduction strategies and risk factors.

For more information see:

- https://www.cdc.gov/aging-programs/php/bold/index.html
- https://www.cdc.gov/aging-programs/php/bold/phc-recipients.html

CDC supported UsAgainstAlzheimer’s to develop the Brain Health Equity Center to increase tailored messaging related to cognitive impairment, COVID-19, brain health, and AD/ADRD to populations disproportionately affected by AD/ADRD, including African American and Hispanic people across the United States. In the past year, the Brain Health Equity Center engaged community members, including African American and Hispanic populations of focus to identify gaps in knowledge and develop AD/ADRD products to address these gaps with assistance from a core group of advisors from the National Black Nurses Association, the National Association of Hispanic Nurses, and members of Alzheimer’s Los Angeles. In 2024, the third cohort of the Brain Health Equity Nurse Fellowship was launched with 12 fellows and two mentors. The Brain Health Equity Nurse Fellowship empowers nurses, including Black and Latino nurses, to be trusted community Brain Health Ambassadors by providing fellows with tailored brain health knowledge, resources, access to subject matter experts and training specifically on risk reduction and communication strategies. To date, fellows have reached 1,150 peers and community members with culturally-relevant risk reduction strategies that have shown a demonstrable improvement in risk reduction knowledge among attendees.

The Brain Health Equity Center has produced a variety of products including a toolkit, a practical guide for communicating with Hispanic and African American people about AD/ADRD. They have engaged in Twitter chats, held webinars, hosted presentations, seminars, panel discussions, focus groups, and press events all focused on how to address AD/ADRD among Hispanic and African American population.

The Brain Health Equity Center created and disseminated the following products in the past year:

- Development and dissemination of a social media communications toolkit, which puts the evidence-based resource *A Practical Guide: Communicating Brain Health Messages with Latino and African American Communities*, into practice and helps organizations tailor brain health messaging to African American and Latino populations. The social media toolkit was shared with 300 recipients in community-based organizations (CBOs), non-profits working with priority populations, research institutions, and professionals.
- *A Practical Guide: Communicating Brain Health Messages with Latino and African American Communities* was translated into Spanish in April 2024.
- The Center led a digital campaign that purposefully placed ads on websites disproportionately visited by middle-aged and older Black and Latino people. Ads redirect visitors to a Center site that has brain health information specific to priority populations. The campaign reached a total of 2.3 million Black and Latino people and has led to almost 100,000 clicks to the Center site.

For more information see:
- https://www.usagainstalzheimers.org/brain-health-equity-nurse-fellowship
- https://www.usagainstalzheimers.org/center-brain-health-equity

The International Association for Indigenous Aging (IA^2), through CDC's National Healthy Brain Initiative cooperative agreement, hosted the "American Indian & Alaska Native Resource Center for Brain Health" webinar series in June-July 2023. Three webinars featured speakers about brain health, traditional foods relating to brain health, and Tribal resolutions as they pertain to AI/AN communities.

The CDC-funded BOLD PHCOE on Dementia Risk Reduction developed a set of infographics that showcase information on social determinants of health (SDOH) related to dementia, as well as strategies to address these issues. Topics include quality education, economic stability, nutritious foods, social connections, and healthy environment.

For more information see:
- https://www.alz.org/professionals/public-health/public-health-topics/risk-reduction

CDC has updated the "Caregiving and Subjective Cognitive Decline" infographic series. The infographics were developed using Behavioral Risk Factor Surveillance System (BRFSS) data from the Caregiving 2021-2022 modules (available in late 2023) and Subjective Cognitive Decline (SCD) 2019-2020 modules. The infographic populations include national combined data, Black American, AI/AN, AAPI, Hispanic, women, men, rural, LGBT, and veterans. These infographics can be used to educate the public and aid in making decisions on how to allocate resources and funding. The infographics have all been translated to Spanish.

For more information see:
- https://www.cdc.gov/healthy-aging-data/brfss/caregiver.html
- https://www.cdc.gov/healthy-aging-data/brfss/cognitive-decline.html
- https://www.cdc.gov/healthy-aging-data/brfss/index.html
- https://www.cdc.gov/healthy-aging-data/infographics/index.html

CDC updated technical assistance documents meant to provide guidance for BRFSS coordinators and researchers who would like to conduct analyses of the data collected through the BRFSS Caregiver Optional Module and the BRFSS Cognitive Decline Module. These documents provide basic computer code for analyzing the data with a goal to enable consistency in analytic methods and results reported.

For more information see:
- https://www.cdc.gov/healthy-aging-data/brfss/

(ONGOING) Action 1.E.4: Facilitate translation, implementation and ongoing evaluation of effective interventions designed to support people living with dementia and caregivers

Lead Agency: ACL
Partners: HRSA, state and community partner organizations

Administration for Community Living (ACL) continues to fund grants to states and communities through their Alzheimer's Disease Programs Initiative (ADPI). The ADPI requires that grantees implement at least one dementia-specific evidence-based or evidence-informed intervention designed to support PLWD and/or caregivers as part of funded programs. In order to fulfill the requirements, interventions must meet the ACL definitions of which are:

- **Evidence-*based* interventions** must have been tested through randomized controlled trials and are: (1) effective at improving, maintaining, or slowing the decline in the health or functional status of PLWD or family caregivers; (2) suitable for deployment through community-based human services organizations and involve non-clinical workers and/or volunteers in the delivery of the intervention; (3) the research results have been published in a peer-reviewed scientific journal; and (4) the intervention has been translated into practice and is ready for distribution through community-based human services organizations.
- **Evidence-*informed* interventions** must have substantive research evidence that demonstrates an ability to improve, maintain, or slow the decline in the health and functional status of PLWD or family caregivers. An evidence-informed intervention is one that has: (1) been tested by at least one quasi-experimental design with a comparison group, with at least 50 participants; OR (2) is an adaptation or translation of a single evidence-based intervention (EBI).
- **Examples of interventions** that meet ACL standards and have been implemented through the ADPI program can be found in *Grantee-Implemented Evidence-Based and Evidence-Informed Interventions*.

ADPI grantees are afforded the flexibility to choose programs/interventions that meet the unique needs of their communities in terms of target audience, content, and delivery modes, including, for example, in-person, telephonic and virtual/computer-based. Through ACL programming EBIs including, but not limited to, Adult Day Services Plus, Care Ecosystem, Caregiver Stress Prevention Bundle (CSPB), Cognitive Stimulation Therapy, and Home Meds are being made available at the community level. These grant-funded activities support ACL's commitment to making research-based interventions available to support PWLD and their caregivers. The implementation of these programs are coupled with robust evaluations to demonstrate community impact. The National Alzheimer's and Dementia Resource Center (NADRC) each year updates the *Grantee-Implemented Evidence-Based and Evidence-Informed Dementia Interventions*, a compendium of evidence-based and evidence-informed interventions implemented by ACL grantees. In addition to the compendium, the NADRC has also developed tools to support provider selection of interventions to meet the needs of their communities, and a compendium of evaluation instruments to demonstrate program impact.

For more information see:

- https://acl.gov/programs/support-people-alzheimers-disease/support-people-dementia-including-alzheimers-disease

The PRARP offers a funding opportunity targeting interventions supporting PLWD and their care partners, the Transforming Care Award. In addition to partnering with community collaborators, investigators must manualize their research to facilitate transition and implementation of the intervention. In FY 2023, the PRARP funded an organization (University of California Davis) to adapt their intervention to meet the needs of older Black veterans.

For more information see:

- https://cdmrp.health.mil/funding/pa/HT942524PRARPTrCA.pdf
- https://cdmrp.health.mil/Search.aspx

(NEW) Action 1.E.5: Review and approve disease-modifying therapies that slow cognitive decline

Lead Agency: FDA

FDA evaluates drugs intended for human use to ensure that marketed drugs are effective and safe for use under the conditions prescribed in the labeling. A drug may receive *accelerated* approval if it is for a serious or life-threatening disease with an unmet need and demonstrates an effect on an endpoint that is not itself a direct measure of the clinical benefit of interest but is instead reasonably likely to predict that clinical benefit. If a drug receives accelerated approval, subsequent confirmation of clinical benefit is required, after which the drug may be converted to traditional approval. For *traditional* approval, a drug must demonstrate an effect on a direct measure of, or validated surrogate for clinical benefit. Aduhelm (aducanumab-avwa) and Leqembi (lecanemab-irmb) both received accelerated approval from FDA in 2021 and 2023, respectively. In 2024, the manufacturer of aducanumab announced that it would discontinue development and commercialization of the product.

In July 2023, FDA converted Leqembi (lecanemab-irmb), indicated to treat adult patients with AD, to traditional approval following a determination that a confirmatory trial verified clinical benefit. FDA approved another drug in this class Kisunla (donanemab-azbt) injection in July 2024. Both drugs work by reducing amyloid plaques that form in the brain, a defining pathophysiological feature of the disease.

For more information see:

- https://www.fda.gov/drugs/news-events-human-drugs/fda-approves-treatment-adults-alzheimers-disease
- https://www.fda.gov/drugs/special-features/frequently-asked-questions-about-fda-drug-approval-process
- https://www.fda.gov/news-events/press-announcements/fda-converts-novel-alzheimers-disease-treatment-traditional-approval

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(ONGOING) Action 1.E.6 Expand access to disease-modifying therapies to address cognitive decline with data collection

Lead Agency: CMS

CMS continues to support a CMS-facilitated registry that is available nationwide for clinicians to use as part of the Anti-Aβ mAb coverage with evidence development (CED) Study. Additional studies have been approved by CMS for other organizations and more studies may become available in the future. With respect to the CMS-facilitated registry, clinicians across the country are able to submit information through a free online portal that is available for any drug in this class with FDA traditional approval. The portal collects information via an easy-to-use format. Clinicians participating in the registry only need to complete a short data submission with information that should be readily available from the patient’s medical record, such as a clinical diagnosis. Physicians are able to choose the study that works for them and are not required to use the CMS-facilitated registry.

(ONGOING) Action 1.E.7 Expand access to technology to diagnose Alzheimer's disease and related dementia with sufficient evidence of clinical benefit

Lead Agency: CMS

In October 2023, CMS removed the national coverage determination, ending CED for PET beta-amyloid imaging and permitting Medicare coverage determinations for PET beta-amyloid imaging to be made by the Medicare Administrative Contractors. The removal of the national coverage determination also removed the previous restriction of one beta-amyloid PET scan per-beneficiary per lifetime.

For more information see:

- https://www.cms.gov/medicare-coverage-database/view/ncacal-decision-memo.aspx?proposed=N&ncaid=308&fromTracking=Y&ncacaldoctype=all&status=all&sortBy=status&bc=17

Goal 2: Enhance Care Quality and Efficiency

Providing all people with AD/ADRD with the highest-quality care in the most efficient manner requires a multi-tiered approach. High-quality care requires an adequate supply of professionals with appropriate skills, ranging from direct care workers to community health and social workers to primary care providers (PCPs) and specialists. In order to provide culturally and linguistically appropriate services, providers should have the awareness, knowledge, and skills to work and communicate effectively in cross-cultural situations, as well as cultural humility to understand their own biases and privileges, manage power imbalances, and be open to the aspect of another person's cultural identity that is most important to them.[21] High-quality care should be provided from the point of diagnosis onward in settings including doctor's offices, hospitals, people's homes, and nursing homes. Care quality should be measured accurately and coupled with quality improvement tools. Further, care should address the complex care needs that persons with AD/ADRD have due to the physical, cognitive, emotional, and behavioral symptoms of the disease and any co-occurring chronic conditions. High-quality and efficient care depends on: (1) smooth transitions between care settings; (2) coordination among health care and LTSS providers; and (3) dementia-capable health care and LTSS.

Strategy 2.A: Build a Workforce with the Skills to Provide High-Quality Care

The workforce that furnishes care to people with AD/ADRD includes health care and LTSS providers such as: primary care physicians; specialists such as neurologists, geriatricians, and psychiatrists; registered nurses (RNs) and advanced practice nurses; community health workers (CHWs); social workers; psychologists; pharmacists; dentists; allied health professionals; and direct care workers, home health aides, and certified nursing assistants, who provide care across the care continuum. These providers need accurate information about furnishing care to a person with AD/ADRD including the benefits of early diagnosis, how to address the physical, cognitive, emotional, and behavioral symptoms of the disease, and how to assist caregivers as they cope with the physical and emotional aspects of their caregiving responsibilities. Enhanced specialist training is also needed to prepare these practitioners for the unique challenges faced by people with AD/ADRD. In addition, work is needed to expand the capacity of the primary care community to serve people with AD/ADRD. Dementia-specific capabilities within the direct care workforce need to be expanded and enhanced. The actions below will facilitate specific training for care professionals in order to strengthen a workforce that provides high-quality care to people living with AD/ADRD.

(**ONGOING**) Action 2.A.1: Educate health care providers

Lead Agencies: HRSA, VA
Partners: CMS, NIA, CDC, ACL

In FY 2024, HRSA funded 42 new GWEP awards. The total amount of awards was $41.8 million. Of that amount, $14.7 million was for dementia education and training activities. In FY 2023, HRSA funded 48 non-competing continuation GWEP awards. All GWEP awardees are educating and training the workforce on how to care for PLWD. Of the $41.6 million GWEP budget, $8.68 million was for dementia education and training activities. In academic year 2021-2022 (latest available dementia-specific data), GWEP grants provided 673 AD/ADRD courses and trained 130,012 health care providers in AD/ADRD. In FY 2021 the first year (of 2 years) of competitive supplemental funding supported the development of a national curriculum to provide COVID-specific education and training to the nursing home workforce in order to improve care to nursing home residents, including those with dementia diagnoses, during the COVID-19 pandemic. Twelve GWEPs received this supplemental funding and collaborated with an additional 12 GWEPs to develop 21 modules, which were posted to the HRSA dementia website page in

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[21] U.S. Department of Health and Human Services, Office of Minority Health. *Think Cultural Health: Providing CLAS*. https://thinkculturalhealth.hhs.gov/assets/pdfs/resource-library/providing-clas.pdf.

December 2023. Also, in FY 2022 an administrative supplement funded 48 GWEP awardees to develop or enhance nursing curricula on nursing home care using an age-friendly health systems (AFHS) framework (which included training in dementia). Each GWEP grantee was required to partner with at least one School of Nursing, one accredited Certified Nurse Assistance program and at least one nursing home to accomplish the goals of this supplemental funding. A total of 1,124 nursing homes received education and training in dementia by all 48 GWEP grantees in FY 2022.

For more information see:

- https://bhw.hrsa.gov/alzheimers-dementia-training?msclkid=51779f70c0e311ecaf320156eb8631a9

In FY 2024, HRSA funded 25 competing continuation Geriatrics Academic Career Award (GACA) program awards totaling $2.39 million. In FY 2023, HRSA funded 26 competing continuation GACA program awards totaling $2.35 million. GACA supports the career development of junior faculty as academic geriatricians or academic geriatrics specialists, including by providing dementia education and training to the health care workforce.

In FY 2024, HRSA funded eight new awards for the Technology-Enabled Collaborative Learning Program. The purpose of this program is to improve retention of health care providers and increase access to health care services, such as those to address chronic diseases and conditions (including AD) and other care in rural, frontier, Tribal, and under-served populations.

For more information see:

- https://www.hrsa.gov/grants/find-funding/HRSA-24-121
- https://www.hrsa.gov/telehealth/grants/technology-enabled-collaborative-learning-program-fy24-awards

The HRSA Office for the Advancement of Telehealth increases access to quality health care through integrated telehealth services. The Office for the Advancement of Telehealth has released *Telehealth for Older Adults*, a best practice guide for telehealth. Information provided includes developing a telehealth strategy for older adults, preparing older adults for telehealth, and telehealth for behavioral health, for chronic conditions, and for AD.

For more information see:

- https://telehealth.hhs.gov/providers/best-practice-guides/telehealth-older-adults

NIA produced and continues to disseminate *Assessing Cognitive Impairment in Older Patients: A Quick Guide for Primary Care Physicians and Managing Older Patients with Cognitive Impairment*.

For more information see:

- http://www.nia.nih.gov/alzheimers/publication/assessing-cognitive-impairment-older-patients
- https://www.nia.nih.gov/alzheimers/alzheimers-and-dementia-resources-professionals

In 2020, the NIA ACTC (described in Goal 1) launched the IMPACT-AD course that aims to educate and promote diversity among research professionals and future researchers in the AD/ADRD field. Since 2020, the program has been offered three times and over 100 early-stage investigators have participated in the learning experience. NIH also released an active funding opportunity for an Alzheimer’s and Related Dementias Clinical Trials Short Course as a way to expand and diversify the dementia clinical trial workforce through the development of innovative curriculum to train future dementia investigators in clinical research skills. For a full list of funding opportunities and their links, please see Appendix 3.

ACL, through its ADPI program, continues to expand efforts to educate professionals (at all levels) engaged in providing care and services to PLWD and their caregivers. ACL-funded programs are developing and translating tools to educate and support clinicians ranging from micro-learning modules for PCPs and doctors to training programs tailored to CHWs. Several funded programs partner with HRSA-funded GWEP grantees to maximize the impact that both funding streams can have in the communities they support. Since 2017, ACL has collected information on the training of professionals (doctors, nurses, social workers, home health aides, first responders, etc.) through their AD/ADRD grant program. As of August 2023, ACL grantees report having trained in excess of 130,000 professionals through their funded state and community programs. Professionals continue to benefit from training opportunities through the ACL NADRC's annual webinar series. Select training materials developed through ACL-funded AD/ADRD programs can be found on the web page of the NADRC, as well as sample training links.

For more information see:

- https://nadrc.acl.gov/
- https://vda.virginia.gov/dementiacapableVA.htm

The VA's GeriScholars program offers staff training to integrate geriatrics into primary care practices in three training programs: (1) intensive individual training with didactics, quality improvement coaching, and clinical practicum experiences; (2) limited team-based training, including Rural Interdisciplinary Team Training (RITT); and (3) self-directed learning through webinars, simulation learning, case studies, and enduring educational materials (such as dissemination of pocket cards on dementia, delirium and depression). VA GeriScholars includes a wide variety of training activities, many of which include or are focused on dementia training. Examples of FY 2022 trainings include webinars -- such as "Treating PTSD in the Context of Cognitive Impairment"; "Dementia and the Age-Friendly Health Systems Initiative: Integrating the 4M's of Mobility, Mind, Medications, and What Matters into the Care of Older Veterans", and "Enduring Education" -- as well as case studies and virtual geriatrics conferences -- such as *Healthcare Planning and Management for Older Adults with Dementia and Geriatric Patient with Cognitive Impairment*. Other topics include dementia caregiver coordinator education and rural caregiver education.

The Veterans Health Administration's (VHA's) 20 geriatric Centers of Excellence, called Geriatric Research, Education, and Clinical Centers (GRECCs), reported that their FY 2022 work included 78 research grants in dementia covering basic science to clinical care and health services research and 25 clinical innovation projects that directly served veterans with dementia and their families. GRECC faculty have developed numerous clinical programs to aid family members and care providers including e-Consults for Behaviors in Dementia, Health Care Directives for Veterans with Dementia, Reaching Out to Rural Caregivers and Veterans with Dementia Utilizing Clinical Video-Telehealth and Virtual Dementia Caregiver Support Programs. The GRECC Program produced 56 educational programs for staff and trainees on best practices in dementia care including the use of simulation technology to demonstrate techniques for communication and facilitating ADLs for veterans with dementia. Finally, GRECC authors published 259 manuscripts in peer-reviewed journals in FY 2022 on their research and clinical work in dementia.

To increase providers' awareness of brain health, CDC funded the American College of Preventative Medicine (ACPM) to develop and disseminate two brain health courses in 2024. The first course, "Improving Brain Health: A Practical Review of Dementia Risk Reduction Strategies", is designed for preventive medicine physicians, as well as general health care physicians and public health professionals, to apply evidence-based tools and interventions to identify and manage select modifiable risk factors for dementia including obesity, nutrition, physical activity, diabetes, and sleep. The second course, "Heart Healthy is Brain Healthy: Cognitive Decline and Dementia Risk Reduction through Blood Pressure Control", is designed to educate preventive medicine physicians and general health care providers on how to identify risk factors in patients and share effective management strategies associated with MCI and ADRD, emphasizing hypertension management as a crucial component of these preventive measures to promote overall cognitive well-being. Continuing medical education (CME) credits are available for completing the courses.

In July 2024, through a cooperative agreement with CDC, ACPM developed a new toolkit for preventive medicine providers on how to implement and inform their practice around improving brain health within health systems. Designed with preventive medicine physicians and health care professionals in mind, this toolkit offers a structured approach to educate patients about ADRD, mitigate risk factors, and promote cognitive function through strengthened community-clinical partnerships. It provides actionable guidance, illustrative case studies, and educational materials to support the integration of brain health initiatives within health systems.

The American Medical Association (AMA), in collaboration with CDC and the Alzheimer's Association, developed and hosted a three-part webinar series designed for physicians and health care professionals on risk reduction, early detection, and treatment of ADRD. Experts explored critical aspects of ADRD and provided best practices and strategies. Recordings of the series are available, along with CME credits.

For more information see:

- https://edhub.ama-assn.org/science-medicine-public-health/pages/brain-health-dementia-video-series
- https://www.acpm.org/initiatives/brain-health/

(UPDATED) Action 2.A.2: Educate health care providers in the Indian Health Service and Tribal care systems

Lead Agency: IHS
Partners: HRSA, VA, CDC, ACL

In 2022, IHS established the Alzheimer's Program, which was newly funded in the FY 2021 budget. Through Tribal Consultation and Urban Confer IHS recognized the need to build skills and capacity in geriatrics, generally and specifically in the care for PLWD and their caregivers in IHS, Tribal, and Urban Indian Organization (UIO) programs as a major priority. In response, IHS has initiated a set of education and training efforts tied directly to the development of services and to improvement in care for older individuals and those living with dementia and their caregivers. Multiple programs and initiatives aim to support the development of a national network of geriatric and clinical dementia champions. These efforts build on and leverage the significant investments in provider training and education made by our federal partners at HRSA (in the GWEP and Dementia Curriculum for Health Care Professionals and Caregivers), VA (in the GeriScholars Program, the RITT, and education resources on the TRAIN Learning Network), and CDC (in the BOLD Centers of Excellence). Education and training efforts aim to pair didactic education with local system-level improvement in recognition, diagnosis, assessment, and management of care for PLWD and in care for their caregivers.

These efforts include:

- Award of an Alzheimer's Training and Education contract to develop and implement culturally-relevant, competency-based training and resources to the University of Washington (UW).
- Case-based learning and mentoring using the ECHO project model, addressing the needs of clinical staff and of staff providing support to caregivers, in partnership with the Northwest Portland Area Indian Health Board (NPAIHB) Indian Country ECHO Program (see Action 2.A.6 and Action 2.A.7).
- The Indian Health GeriScholars pilot (see Action 2.A.6 and Action 2.A.7).
- The Indian Health Geriatric Nurse Fellowship pilot (see Action 2.A.6 and Action 2.A.7).

- Support for IHS and Tribal Emergency Departments to achieve Geriatric Emergency Department Accreditation (GEDA) (see Action 2.A.6 and Action 2.A.7).
- Training and education in dementia for oral health professionals as part of a pilot project to integrate recognition of cognitive impairment into dental care (see Action 2.A.6 and Action 2.A.7).
- Training and education in dementia and recognition of cognitive impairment for Tribal and UIO Community Health Representatives (CHRs) as part of a planned multi-site pilot (see Action 2.A.6 and Action 2.A.7).
- Local and national trainings in detection, diagnosis, and management of dementia and models of care addressing those living with dementia and their caregivers.
- The education and training pages of the IHS AD and Dementia website provide links for health care providers to the available educational, training, and workforce development resources (see Action 2.B.6).
- Collaboration with the Alzheimer's Association in the development of decision support for diagnosis of dementia in primary care (see Action 2.A.8).
- Collaboration with the VA in the delivery of RITT and the Addressing Behavioral Challenges in Dementia (ABCD) training (see Action 2.A.1).

In late 2024, the IHS awarded UW a contract for discipline-specific dementia training, education, and support for workforce development programs. The UW team is enhanced by experts from Washington State University, the University of Alaska Fairbanks, Western Carolina University, other indigenous-led partner organizations, and two Native-owned small businesses. Six core faculty, staff, and consultants identify as AI/AN. This work also supports Action 2.A.6 and Action 2.A.7.

For more information see:
- https://www.ihs.gov/alzheimers
- https://www.ihs.gov/alzheimers/alztraining

(**ONGOING**) Action 2.A.3: Strengthen state aging, public health, and intellectual and developmental disability workforces

Lead Agency: ACL
Partners: HRSA, CDC

HHS coordinates with states to develop workforces in aging, public health, and intellectual and developmental disability (IDD) that are AD-capable and culturally and linguistically appropriate. ACL collaborated with HRSA to provide AD/ADRD training to the Aging Network.

ACL, through the NADRC, offers an annual dementia-specific webinar series that trains thousands of professionals each year. The series targets AD/ADRD professionals at state and community levels as well as attracting family caregivers. The webinars include information on related dementias, innovative interventions, and a wide variety of caregiving topics. The webinars are archived on the NADRC web page, expanding the reach of the series far beyond the live webinars.

In addition to the webinar series, the ACL and the NADRC develop and publish resources to support professionals including a guide entitled *Intellectual and Developmental Disabilities and Dementia: Practical Strategies for Professionals* which provides background and strategies for professionals working with individuals living with IDD and dementia. Other examples of trainings developed include a number of first responder training tools and *Brain Health: You Can Make a Difference!* The Brain Health training was developed through an ACL, NIA, CDC collaboration to support professionals educating members of the communities they serve. The tools are available on the ACL website. In 2023, a database of evaluation questions to demonstrate the impact of the resource was developed and posted with the training materials. ACL, through the NADRC website, also makes a broad range of grantee-developed trainings and tools available for implementation and co-branding.

NADRC annually develops tools and issue briefs on dementia-specific topics to support paid and unpaid caregivers. New materials are disseminated through the ACL grant programs, as well as at professional conferences and the NADRC website. ACL is constantly adding new tools and issue briefs to its growing library. Topics of materials developed by NADRC include, but are not limited to, advance planning, living alone, compendiums of dementia-specific interventions, and outcome measures. The NADRC website is also home to the materials developed and delivered by ADPI grantees.

The NADRC continues to highlight and make grantee-developed resources and tools available through the resource center website. The *Highlights of Administration on Aging Alzheimer's and Dementia Program Grantee Developed Resources*, guide provides brief descriptions of resources developed and used by ACL home and community-based grantee organizations and states, as well as providing links to facilitate access to the resources.

For more information see:

- https://acl.gov/brain-health
- https://acl.gov/news-and-events/announcements/acl-launches-national-center-strengthen-direct-care-workforce
- https://nadrc.acl.gov/

Cross-agency collaborations have enhanced workforce dementia training and expertise. In FY 2023, the 48 HRSA GWEP grantees collaborated with a total of 648 CBOs that provide LTSS, including 50 Area Agencies on Aging (AAAs) and seven quality improvement organizations to strengthen state aging, public health, and IDD workforces. In addition, 19 of the 48 GWEPs collaborated with the VA to assist with training on dementia. These collaborations persist in Year 5 of funding (FY 2023). A new cohort of 42 GWEP recipients successfully competed to be the third cohort of the GWEP program and began program activities on July 1, 2024. The new cohort is required to partner with CBOs that provide LTSS and are expected to have similar partnerships to those created by the second GWEP cohort moving forward.

(ONGOING) Action 2.A.4: Develop and disseminate a unified primary care Alzheimer's disease and related dementias curriculum for clinical professionals and caregivers

Lead Agency: HRSA
Partners: ACL, CDC, CMS, OWH, NIA, VA

HRSA partnered with federal staff at ACL, CDC, CMS, HHS Office on Women's Health (OWH), and VA on a contract to develop the Dementia Curriculum for Health Care Professionals and Caregivers in 2018. The curriculum is designed to build a workforce with the skills to provide high-quality care, ensure timely and accurate detection and diagnosis, and identify high-quality dementia care guidelines and measures across care settings. The modules are available to the public at HRSA's website. Additional modules on caregiving and on nursing home care have subsequently been added to the HRSA dementia web page.

For more information see:

- https://bhw.hrsa.gov/alzheimers-dementia-training

CMS's Resources for Integrated Care (RIC), which partners with health plans and providers, has offered webinars that explore innovative ways that health equity and caregiver support are addressed across ADRD programs supporting dually eligible PLWD.

For more information see:

- https://www.resourcesforintegratedcare.com/
- https://www.resourcesforintegratedcare.com/2022_ric_webinar_innovations_alzheimers_disease_related_dementias_adrd_caregiver_support_programs_building_leveraging_support_systems/

(ONGOING) Action 2.A.5: Ensure aging and public health network providers have access to research-based up-to-date information on Alzheimer's disease and related dementias

Lead Agency: NIA
Partners: CDC, ACL, HRSA, AHRQ, NASEM

CDC has a weekly newsletter that is sent out to over 45,000 subscribers, including public health professionals. The newsletters are a primary channel for disseminating information about new articles, tools, resources, and webinars related to brain health.

For more information see:

- https://tools.cdc.gov/campaignproxyservice/subscriptions.aspx#subscribe

In 2021, NASEM released *Meeting the Challenge of Caring for Persons Living with Dementia and Their Care Partners and Caregivers: A Way Forward*. The report is the culmination of a collaboration among NIA, Agency for Healthcare Research and Quality (AHRQ), and NASEM, to develop a comprehensive understanding of the evidence base for essential care and caregiving interventions for the millions of PLWD and their caregivers. In response to recommendations from these reports, NIA has active funding opportunities to support the development of rigorous, principle-based dementia care interventions that can be delivered with fidelity in a range of care settings. For a full list of funding opportunities and their links, please see Appendix 3.

For more information see:

- https://effectivehealthcare.ahrq.gov/products/care-interventions-pwd/report
- https://www.nap.edu/catalog/26026/meeting-the-challenge-of-caring-for-persons-living-with-dementia-and-their-care-partners-and-caregivers
- https://www.nationalacademies.org/our-work/care-interventions-for-individuals-with-dementia-and-their-caregivers
- https://www.nationalacademies.org/our-work/care-interventions-for-individuals-with-dementia-and-their-caregivers---phase-two

NIA also supports several Roybal Centers that conduct pilot research aimed at strengthening the design of dementia care interventions. In addition, the NIA IMPACT Collaboratory is designed to build the nation's capacity to conduct pragmatic clinical trials of interventions embedded within health care systems. The IMPACT Collaboratory supports pilot studies to inform the design of larger scale pragmatic dementia care trials and demonstration projects to test, measure, and evaluate the effect of care delivery intervention programs in a health care system for people living with AD/ADRD and their care partners.

For more information see:

- https://impactcollaboratory.org/
- https://impactcollaboratory.org/grants-and-training/pilot-grants/pilot-grant-awardees/
- https://www.nia.nih.gov/research/dbsr/edward-r-roybal-centers-translational-research-behavioral-and-social-sciences-aging
- https://www.roybalniaresearchcenters.org/
- https://www.roybalniaresearchcenters.org/funding-opportunities

In 2023, NIA updated its list of cognitive assessment tools and AD/ADRD resources for professionals. NIA also maintains a web page for health care professionals with resources about healthy aging, dementia, and providing care to older patients. In addition, the Alzheimers.gov website offers resources from across the Federal Government for health care providers and community and public health workers.

For more information see:

- https://www.alzheimers.gov/professionals
- https://www.nia.nih.gov/health/alzheimers-dementia-resources-for-professionals
- https://www.nia.nih.gov/health/assessing-cognitive-impairment-older-patients
- https://www.nia.nih.gov/health/health-care-professionals-information/healthy-aging-and-dementia-resources-health-care

The CDC-funded BOLD PHCOE on Dementia Risk Reduction developed a set of infographics that showcase information on SDOH related to dementia, as well as strategies to address these issues. Topics include quality education, economic stability, nutritious foods, social connections, and healthy environment.

For more information see:

- https://www.alz.org/professionals/public-health/public-health-topics/risk-reduction

The CDC funds the Healthy Brain Resource Center Stories from the Field, a series of stories that highlight the work of BOLD and National HBI grant recipients. In 2024, CDC added two new Stories from the Field highlighting the Mississippi BOLD public health program and their work to address SDOH that influence the incidence and mortality rates of ADRD, and the Rhode Island BOLD public health program's provision of technical assistance to health care facilities to meet state statute. These stories serve as blueprints for other public health programs on implementing a public health approach to ADRD.

For more information see:

- https://www.cdc.gov/aging-programs/php/resource-center/index.html

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(UPDATED) Action 2.A.6: Strengthen the ability of Indian health clinical teams and systems to meet the needs of people with Alzheimer's disease and related dementias and their caregivers

Lead Agencies: IHS, CDC
Partners: VA, public and private partners

In 2022, the IHS launched the Indian Health GeriScholars Pilot, developed with the support and collaboration of the VA Office of Rural Health. Modeled after the highly successful VA GeriScholars Program that has built geriatric expertise into the primary care workforce over the past decade, the Indian Health GeriScholars pilot is providing primary care clinicians at IHS, Tribal, and UIO programs with an individual intensive learning track for professional continuing education, including:

- A week-long intensive training in geriatrics through an approved Geriatrics Board Review course.
- A mentored geriatric improvement project at their local facility.
- Mentorship in geriatric practice.
- Ongoing education, training, and peer support as an Indian Health GeriScholar.

During the pilot's first 2 years, 31 providers and pharmacists at 28 sites across ten IHS areas participated in training and finished projects that focused on the detection and diagnosis of dementia, medication safety, fall prevention, and other locally relevant topics. Demand increased for the 2024 cohort to include eight physicians, one nurse practitioner, and 14 pharmacists from

21 sites, representing seven IHS areas. The Indian Health GeriScholars are encouraged to participate in the educational offerings available to the VA GeriScholars.

In November 2023, the IHS launched recruitment for a 2024 Geriatric Nurse Fellowship pilot program patterned after the Indian Health GeriScholars pilot. This fellowship offers nursing professionals in a variety of roles in IHS, Tribal, and UIO health programs funding for protected time and opportunities, including:

- Core and specialty training in geriatric care and the 4Ms (what matters, medication, mentation, and mobility) Age-Friendly framework.
- Mentorship for local project activities.
- Attendance at an in-person culminating presentation experience.
- Additional funding for board certification courses or advanced training.

During the pilot's first year, 15 licensed practical nurses, RNs, and advanced practice nurses at 12 sites across six IHS areas participated in training, and 14 implemented local projects and presented findings during a hybrid event that included participants from the IHS Division of Nursing and National Nursing Leadership Council. Fellow's 4-month projects were picked based on local needs and interests. Topics ranged from sexually transmitted infection health education for older adults to dementia screening. Medication reconciliation and polypharmacy were the most popular topics. Sixteen volunteer mentors from academia, CDC, IHS headquarters, clinics, and other external experts helped support local project work.

In 2024, the IHS continued to partner with the NPAIHB Indian Country ECHO Program to provide two monthly ECHO series specific to AI/AN communities. The monthly Dementia Clinical ECHO series aims to strengthen knowledge and confidence to detect, diagnose, manage, and provide holistic, culturally-appropriate care locally for AI/AN PLWD. The monthly Caregiver Support ECHO series provides information, resources, tools, and mentoring for IHS, Tribal, and UIO staff who provide support and coaching for caregivers. Each session is recorded for asynchronous viewing. During the first 10 months, the Dementia ECHO series reached a total of 709 participants, issued 203 continuing education units (CEUs)/certificates, and extended its reach to more than 27 states in all 12 IHS areas.

In 2024, the IHS Division of Oral Health continued a pilot project aimed at increasing recognition of cognitive impairment in dental settings using a brief screening tool called the Mini-Cog®. Between 2023 and 2024, seven IHS and Tribal sites from five IHS areas participated. Combined, the participating programs conducted a total of 151 Mini-Cog® screenings over the 6-month project period, resulting in 29 referrals to PCPs for a follow-up evaluation (19.2%). In conjunction with this pilot, the Division of Oral Health continues to host asynchronous web-based education addressing core concepts in dementia and the detection of cognitive impairment. The IHS Division of Oral Health is integrating training and resources to support dementia recognition and optimal oral health care for those living with dementia into ongoing continuing dental education and support.

In 2024, the IHS implemented the first pilot year of the Tribal CHR Early Dementia Detection Initiative. This 6-month program, developed in partnership with the IHS National CHR consultant, aimed to evaluate the feasibility of CHRs performing cognitive screenings using the Mini-Cog®. The six participating Tribal locations from six IHS areas collectively conducted 193 screenings, resulting in 34 positive screenings (17.6%). As part of the pilot, IHS collaborated with the University of Oklahoma (OU) Health Sciences' GWEP program to provide core dementia training and developed detailed electronic coding and workflow job aids. As a direct result of pilot participation, one Tribal participant applied for and was awarded a competitive IHS Dementia Models of Care 3-year grant to expand their work.

In 2024, the IHS Division of Nursing continued collaboration with the American College of Emergency Physicians to support efforts by IHS and Tribal Emergency Departments to achieve

GEDA. Accreditation requires change in care structures and processes that improve outcomes for older patients and education and training for emergency department staff. Nine IHS and Tribal sites achieved Bronze Level GEDA in 2023. In 2024, IHS continued recruiting and supporting new sites seeking Bronze Level GEDA. In addition, one Bronze Level accredited site is actively pursuing advancement to the Silver Level accreditation.

For more information see:

- https://www.ihs.gov/alzheimers/pilotsandinitiatives/
- https://www.ihs.gov/doh/index.cfm?fuseaction=home.initiatives

See Action 1.E.3 for information on CDC's partnership with the National Indian Health Board (NIHB) to expand knowledge of public health within AI/AN communities.

(**UPDATED**) Action 2.A.7: Improve educational resources for primary care staff in Tribal and Urban Indian communities caring for individuals with Alzheimer's disease and related dementias and their families

Lead Agency: IHS
Partners: HRSA, ACL

In 2024, the IHS California regional office engaged with the Alzheimer's Association to identify collaborative opportunities. There are more than 100 federally recognized tribes in the state. As a result, the region partnered with the Association and the Dementia Care Aware statewide program for PCPs to host exclusive, live training for multiple staff from more than eight Tribal clinics. The IHS Alzheimer's Program also facilitated a panel at the California IHS best practices conference on emerging models of care, featuring two IHS primary care grant recipients.

The Education and Training pages of the IHS Alzheimer's Disease and Dementia website provides links for health care providers to the HRSA comprehensive dementia curriculum, the VA TRAIN Learning Network, the Indian Country Clinical and Caregiver ECHOs, the VA RITT and ABCD Training, and past IHS webinars. Additional resources, training, and functionality will continue to be added in the coming year.

See Action 2.A.2 and Action 2.A.6 for more information on IHS training and education activities.

In 2020, ACL introduced a new grant program, ADPI: Dementia Capability in Indian Country. The program is designed to bring culturally and linguistically appropriate AD/ADRD training and education and dementia-specific EBIs to Indian Country. Since the inception of the ACL Dementia Capability in Indian Country efforts six tribes/Tribal entities have received funding to deliver supports and services in Tribal communities. Grantees, including the Absentee Shawnee Tribal Health System, developed and continue to provide dementia training to clinical staff, as well as serving as a resource for clinical providers to refer patients for social supports.

For more information see:

- https://www.asthealth.org/seeking-hope
- https://www.ihs.gov/alzheimers/alztraining/

The NPAIHB, funded under CDC's BOLD Public Health Programs to Address ADRD cooperative agreement, hosted a Brain Health & Dementia Summit on August 21-22, 2024, in Portland, Oregon. The Summit presented information, education, and awareness to address brain health and cognitive decline in Indian Country. The information presented was designed to foster the Northwest Tribes Dementia Network and provide awareness and education about ADRD.

For more information see:

- https://www.npaihb.org/bold/

IA², through CDC's National Healthy Brain Initiative cooperative agreement, hosted the American Indian & Alaska Native Resource Center for Brain Health Webinar Series in June and July 2023. Three webinars featured speakers about brain health, traditional foods relating to brain health, and Tribal Resolutions as they pertain to AI/AN communities.

For more information see:

- https://iasquared.org/brain-health/

(UPDATED) Action 2.A.8: Provide decision support for clinicians in Tribal communities

Lead Agency: IHS

The IHS continues integrating support for geriatric care in the IHS HIT modernization effort underway.

In 2024, the IHS also continues to partner with the Alzheimer's Association to adapt Alzheimer's Association resources, providing guidance in dementia diagnosis for IHS and Tribal clinical staff operating in rural and frontier rural settings, and tailor decision support to the unique systems and cultural environments of care. Targeted one-on-one support is provided to current Models of Care grantees to share the existing resources and facilitate the adaptation and implementation of new clinical workflows.

(ONGOING) Action 2.A.9: Develop Alzheimer's disease and related dementias learning platform dedicated to training home and community service providers in Indian Country in the delivery of culturally and linguistically appropriate dementia-capable services.

Lead Agency: ACL

ACL, through their Office of American Indian, Alaska Native and Native Hawaiian Programs continues to work with a variety of culturally-competent AD/ADRD experts to develop and make available a broad range of educational curricula and tools to support increasing the dementia capability of Tribal communities across the nation.

In addition to the learning platform, ACL ADPI Tribal grantee training resources, including videos and webinars, are also located on the NADRC website. Resources include an animated video depicting the dementia experiences of Tribal men and women, a video of elders discussing dementia in their own voices, a webinar on the impact of an experiential EBI and one on the importance of music in dementia care and the introduction of a new evidence-informed intervention.

For more information see:

- https://nadrc.acl.gov/details?search1=20231031114936
- https://nadrc.acl.gov/details?search1=20240808123728
- https://nadrc.acl.gov/details?search1=20240819032500
- https://olderindians.inquisiqlms.com/catalog/

(COMPLETED) Action 2.A.10: Improve the safety and quality of nursing homes

Lead Agency: CMS

In 2022, the White House announced a set of reforms developed by and implemented through HHS to improve the quality and safety of nursing homes, including the need to establish adequate staffing in nursing homes. Following this announcement CMS announced plans to launch a multi-faceted approach to determine the minimum level and type of staffing needed to help enable safe and quality care in nursing homes, including a Request for Information (RFI), a mixed-methods Nursing Home Staffing Study, a stakeholder listening session, and a proposed rule.

Using the information gathered from these actions, on May 10, 2024, CMS issued the Minimum Staffing Standards for Long-Term Care (LTC) Facilities and Medicaid Institutional Payment Transparency Reporting final rule, which establishes comprehensive nurse staffing requirements to help hold nursing homes accountable for providing safe and high-quality care for the over 1.2 million residents receiving care in Medicare and Medicaid-certified LTC facilities each day.

For more information see:
- https://data.cms.gov/summary-statistics-on-use-and-payments/medicare-service-type-reports/cms-program-statistics-medicare-skilled-nursing-facility
- https://public-inspection.federalregister.gov/2023-18781.pdf
- https://www.cms.gov/blog/centers-medicare-medicaid-services-staffing-study-inform-minimum-staffing-requirements-nursing-homes
- https://www.federalregister.gov/documents/2024/05/10/2024-08273/medicare-and-medicaid-programs-minimum-staffing-standards-for-long-term-care-facilities-and-medicaid

Strategy 2.B: Ensure Timely and Accurate Diagnosis

Many people with AD/ADRD are not diagnosed until their symptoms have become severe, particularly people of color and people of low SES. Timely diagnosis gives people with the condition and their families and caregivers time to plan and prepare for the future, leading to more positive outcomes for both. For some, the inability to access health care due to a lack of insurance or limited finances -- especially when facing LTC expenses -- is a major concern. This is particularly important for individuals with younger-onset disease who may not be eligible for Medicare. Even with access to affordable care for individuals, the health care workforce needs tools that can help ensure timely and accurate diagnoses. Research has helped identify some assessment tools that can be used to detect cognitive impairment that may indicate the need for a comprehensive diagnostic evaluation for AD/ADRD. The actions below will facilitate appropriate assessment and give health care providers tools to make timely and accurate diagnoses.

(**UPDATED**) Action 2.B.1: Identify and disseminate appropriate assessment tools

Lead Agency: NIA
Partner: CDC

NIH-supported scientists are making important progress toward developing highly portable, quick, versatile, and comprehensive measures of neurological and behavioral function to identify AD/ADRD at the earliest stages. Efforts include the development and validation of a combination of tests to assess MCI and identify other individuals at risk for developing dementia.

In 2020, NIA funded seven clinical trials responding to a funding announcement calling for low-cost approaches to detecting cognitive impairment. One funded project is validating the Electronic Health Record Risk of Alzheimer's and Dementia Assessment Rule (eRADAR) which uses EHR data to detect unrecognized dementia. eRADAR has the potential to enable earlier detection while also addressing disparities in dementia detection. Another strategy, called ToolBoxDetect, aims to establish an efficient and sensitive screening protocol that can be easily implemented in everyday clinical settings. ToolBoxDetect integrates EHR data with two brief validated and self-administered cognitive screening assessments.

In addition, researchers are expanding the NIH Toolbox® for the Assessment of Neurological and Behavioral Functions, a dynamic set of health assessments that were validated and normalized for use in individuals ages 3-85 years, and in racially and ethnically diverse populations. Available in English and Spanish, more than 480 clinical trials are using the NIH Toolbox, and more than 570 peer-reviewed articles have been published. The NIA-supported “Advancing Reliable Measurement in Alzheimer’s Disease and Cognitive Aging” study validated all NIH Toolbox measures (cognitive, motor, emotion, sensory) for people with MCI and early-stage AD. Through this same effort, researchers have expanded the age range of use for the NIH Toolbox by validating all measurements in adults 86 and older.

For more information see:

- https://neuroscienceblueprint.nih.gov/resources-tools/blueprint-resources-tools-library/nih-toolbox-assessment-neurological-and
- https://pubmed.ncbi.nlm.nih.gov/35906516/
- https://reporter.nih.gov/search/wzlat-HJvEyZ7m74It7ExA/project-details/10091300
- https://reporter.nih.gov/search/wzlat-HJvEyZ7m74It7ExA/project-details/10091959
- https://www.healthmeasures.net/explore-measurement-systems/nih-toolbox
- https://www.nihtoolbox.org/publication-finder/

In 2023, NIA published a new article, “Cognitive Assessment Considerations: Understanding the Evidence,” to present the state-of-the-science on cognitive assessments. NIA also regularly updates its resources for professionals page, which includes information on cognitive assessment tests and tools and guidelines for diagnosis.

For more information see:

- https://www.nia.nih.gov/health/alzheimers-dementia-resources-for-professionals
- https://www.nia.nih.gov/health/assessing-cognitive-impairment-older-patients
- https://www.nia.nih.gov/health/cognitive-assessment-considerations-understanding-evidence

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(**UPDATED**) Action 2.B.2: Support technology to advance mobile monitoring of cognitive changes

Lead Agency: NIA

In 2019, NIA funded two new projects with the goal of producing smartphone applications capable of measuring cognitive status and subtle changes in cognition on mobile devices. These grants were awarded in response to a specific funding announcement seeking projects focused on mobile monitoring of cognitive change. The smartphone Apps supporting the mobile monitoring of cognitive change went into limited release in the summer 2022 and became more widely available to researchers in 2024. In 2022, NIA published a new funding opportunity calling for applications to expand the content, design, and implementation of research infrastructure funded under RFA-AG-18-012, Mobile Monitoring of Cognitive Change (U2C), collectively known as the Mobile Toolbox Project, by addressing the need to: (1) add assessments on mobile devices of non-cognitive socioemotional psychological functions, health states, and contextual factors that may modify cognitive performance; and (2) enable widespread dissemination and support for use of the tools developed for monitoring of age, state, context, or health condition-related changes in cognitive and non-cognitive abilities on mobile devices. Additionally, another funding opportunity (RFA-AG-23-021) called for research to continue the development of the Mobile Monitoring of Cognitive Change platform with expanded content, wider dissemination, and the ability to add study-specific measures, as well as leverage a shared data processing backend. NIA also published a funding opportunity for development and validation of cognitive screening instruments or assessments in clinical settings and translation of these tools into EHR systems to assist physicians in making clinically meaningful care recommendations for patients experiencing cognitive decline. For a full list of funding opportunities and their links, please see Appendix 3.

For more information see:

- https://reporter.nih.gov/project-details/9781454
- https://reporter.nih.gov/project-details/9781463
- https://reporter.nih.gov/search/BOil54h7vEyegzmJqXQYCg/projects?shared=true

Please see the NACC-developed Down syndrome-specific clinical and cognitive assessment module for research described in Action 1.B.6.

(UPDATED) Action 2.B.3: Identify and study effective approaches to increasing detection of cognitive impairment in clinical settings

Lead Agency: NINDS
Partner: NIA

Dementia is often undiagnosed in primary care and often remains unmanaged from a medical standpoint, and untreated, even when diagnosed. Additionally, there is a strong need to increase detection of cognitive impairment and dementia in high-risk populations, including those that experience health disparities, and lessen cultural and logistic barriers that currently impede clinical care and research. NINDS supports the Consortium for Detecting Cognitive Impairment, Including Dementia (DetectCID; RFA-NS-22-009), which is a collaborative research network to develop and validate approaches to detect dementia in primary care or other everyday clinical settings, with a special focus on assessing effectiveness in diverse populations. The detection approaches being tested are designed to be simple to use, standardized, culturally sensitive, and take 10 minutes or less to administer, with the aim to link people effectively and efficiently to follow-up care in ways that fit the local care realities of the individual involved. In 2024, DetectCID investigators reported exciting pragmatic clinical trial results in an urban primary care clinic using the 5-Cog paradigm, which combines three metrics designed to test memory recall, the connection between cognition and gait, and the ability to match symbols to pictures. The study demonstrated significantly improved diagnosis and management in patients with cognitive concerns. Patients assessed with the 5-Cog tool were three times more likely to experience improvements in dementia care actions compared to controls, and patients who received a diagnosis of dementia or MCI were much more likely to receive care within 90 days, such as medications or a specialist referral. For a full list of funding opportunities and their links, please see Appendix 3.

For more information see:

- https://pubmed.ncbi.nlm.nih.gov/35124639/
- https://pubmed.ncbi.nlm.nih.gov/38834847/
- https://www.detectcid.org/
- https://www.nia.nih.gov/health/assessing-cognitive-impairment-older-patients
- https://www.ninds.nih.gov/News-Events/News-and-Press-Releases/Press-Releases/NIH-forms-new-consortium-improve-detection

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(UPDATED) Action 2.B.4: Identify and disseminate information on early detection of dementia

Lead Agency: CDC

The CDC-funded BOLD PHCOE on Early Detection of Dementia brings together a broad coalition of stakeholders across the United States to assure widespread awareness of why early detection of dementia matters.

The BOLD PHCOE on Early Detection of Dementia, in collaboration with the CDC, developed the *Early Detection of Dementia Toolkit -- Health Systems*, to serve as a resource for clinicians, administrators, and patients engaged with large health systems who are interested in promoting early detection of dementia, establishing supportive services, and becoming more "dementia-capable." The toolkit supports a comprehensive approach to dementia detection and includes resources that encompass a broad view of the capacities needed to make health systems' efforts more effective and cultivate a supportive and sustainable care pathway for individuals and their families.

For more information see:

- https://bolddementiadetection.org/resources/#toolkit
- https://bolddementiadetection.org/wp-content/uploads/2024/02/BOLD_Toolkit_HSP_2024.pdf

CDC funded AMA to host a three-part webinar series for physicians on the topics of risk reduction, early detection, and treatment of ADRD. Attendees have the opportunity to earn CME for completing course requirements.

For more information see:

- https://edhub.ama-assn.org/science-medicine-public-health/pages/brain-health-dementia-video-series

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(**UPDATED**) Action 2.B.5: Expand access to new technology to diagnose Alzheimer's disease

Lead Agency: FDA

In May 2022, FDA permitted marketing for the first in vitro diagnostic CSF test for early detection of amyloid plaques associated with AD/ADRD. The Lumipulse G β-Amyloid Ratio (1-42/1-40) test is intended to be used in adult patients, aged 55 years and older, presenting with cognitive impairment who are being evaluated for AD/ADRD and other causes of cognitive decline. Prior to the authorization, doctors could only use PET scans, a potentially costly and cumbersome option, to detect/visualize amyloid plaques in a patient's brain, often years before clinical symptom onset, to aid in diagnosing AD/ADRD.

FDA also cleared for marketing two additional CSF tests, the Elecsys Phospo-Tau (181P) CSF/Elecsys ß-Amyloid (1-42) CSF II test in December 2022 and the Elecsys Total-Tau CSF/Elecsys ß-Amyloid (1-42) CSF II test in June 2023, for the detection of amyloid plaques in patients aged 55 years and older being evaluated for AD. These tests are intended to be used in conjunction with other clinical diagnostic assessments to help health care providers determine whether a patient with cognitive impairment has AD. While a positive test result does not establish a diagnosis of AD or other cognitive conditions, a negative test result reduces the likelihood that a patient's cognitive impairment is due to AD. These Elecsys CSF tests add to the increasing arsenal of clinical laboratory tests available to assist in the evaluation of patients with cognitive disorders such as AD.

For more information see:

- https://diagnostics.roche.com/us/en/news-listing/2022/roche-alzheimers-disease-cerebrospinal-fluid-assays-receive-fda-clearance.html
- https://www.fda.gov/news-events/press-announcements/fda-permits-marketing-new-test-improve-diagnosis-alzheimers-disease
- https://www.fda.gov/news-events/press-announcements/fda-roundup-june-9-2023

(ONGOING) Action 2.B.6: Educate family and service providers of persons with intellectual and developmental disabilities about changes that may indicate the onset of dementia

Lead Agency: ACL

ACL through their ADPI program provides dementia capability training to paid and unpaid caregivers of PLWD, including individuals living with IDD and dementia or at risk of developing dementia, through grants to states and CBOs. ACL collaborates closely with private sector stakeholders and experts to disseminate education on IDD and dementia, as well as implementation of the Early Detection Screen for Dementia tool.

ACL consistently offers educational opportunities and resources in support of both paid and unpaid caregivers of those living with IDD and AD/ADRD or at risk of developing AD/ADRD. IDD and dementia are consistently included in ACL's annual webinar series. Webinars have focused on important topics including early screening, palliative care, family advocacy, and promising practices in care. In 2022, an ADPI grantee created the ONECaregiver website to provide a centralized location of resources that support caregivers, people living with IDD, and others at risk of developing ADRD. It includes relevant resources from local, state, and national organizations. The website is a place where other ACL ADPI grantees have also started posting the resources they develop, to support reaching broader audiences. Another ADPI grantee created a series of video lessons for caregivers of people living with IDD and dementia. The five videos are for direct support professionals, family caregivers, and volunteers.

For more information see:

- https://nadrc.acl.gov/details?search1=20240716101936
- https://onecaregiverresourcecenter.org/

CDC, through its HBI, is funding efforts to tailor dementia public health messaging and resources towards persons with IDD. See Action 2.A.3 for information on CDC's funding of the people with IDD Healthy Brain Initiative (PwIDD-HBI).

For more information see:

- http://aadmd.org/
- https://healthmattersprogram.org/healthybrain/
- https://www.cdc.gov/aging-programs/php/nhbi/recipients.html

The CDC-funded University of Illinois at Chicago (UIC) collaborated with the IA^2 and HealthMatters to develop fact sheets for brain health and dementia care for people with IDD and indigenous communities.

Also see Action 2.A.5.

(UPDATED) Action 2.B.7: Increase awareness of Alzheimer's disease and related dementias in Tribal and Urban Indian communities and of the availability of services for individuals with dementia and their families

Lead Agencies: IHS, CDC, NIA
Partners: ACL, VA

From 2023 through 2024, the IHS has been actively building a communications infrastructure to support Tribal and UIO leadership AD/ADRD priorities, including raising awareness and empowering local communities. In 2024, work commenced on a multi-year contract for program communications support with a tribally-owned small business.

Key 2024 activities include:

- Collaboration with local communities and health facilities in California, Minnesota, South Dakota, and Nebraska for photoshoots of elders, their families, community members, and clinical staff to broaden visual representation in IHS media and training materials.
- Multi-part video training series on the use of the Mini-Cog screening tool in the medical and dental setting, including American Indian clinical staff and patients.
- Design and implement a recurring newsletter with feature stories about Tribal and Urban Indian communities and health systems.
- Integrated social media and communications campaigns incorporating blog posts, public affairs announcements, and weekly Tribal and Urban Indian community updates.
- Major website structural and content updates.

CDC, ACL, NIA, and CDC partner resources are frequently featured by IHS. As a result of the expanded communications effort, web page views have surged, Listserv subscriptions have tripled, and 12 newsletters with unique stories featuring Tribal-specific approaches, accomplishments, and impact will have been disseminated by year's end. In addition, 16 cohesively themed social media messages were distributed across the IHS Facebook, LinkedIn, and Twitter accounts -- boasting more than 84,000 followers -- reaching tens of thousands in 3 months. These activities to increase awareness involved using social media platforms to share blog posts and educational messages related to AD/ADRD, promote recruitment for grants and pilot projects, and spread the word about available training resources. Results indicate a broadening of awareness and engagement in AD/ADRD and aging issues.

In spring 2024, IHS offered a second annual Tribal capacity-building webinar series (four sessions) to increase awareness of funding opportunities and stimulate interest in adapting existing models of care for Tribal and Urban Indian communities. Over 250 individuals from 64 tribes representing 11 IHS areas participated.

Also in 2024, IHS continued collaboration with the NYU BOLD PHCOE to increase use of simple, valid tools to detect cognitive impairment and guide individuals with cognitive impairment toward services and diagnosis and with the University of Minnesota BOLD PHCOE on Dementia Caregiving to develop capability to support caregivers of those living with dementia in Tribal and Urban Indian communities.

In previous years, IHS, with ACL and VA, pilot-tested AD/ADRD awareness strategies in communities in which Resources for Enhancing Alzheimer's Caregivers Health (REACH) into Indian Country was successfully implemented through both health care and aging services settings. The focus of the REACH intervention in its final year was on increasing awareness of AD/ADRD in those communities served by REACH and increasing use of REACH caregiver support services. IHS facilities continue to provide local resources for community-based education and training.

For more information see:

- https://www.ihs.gov/alzheimers/
- https://www.ihs.gov/alzheimers/outreachawareness/newsletter/

ACL continues to bring awareness to AD/ADRD in Indian Country through participation in educational opportunities including presentations to attendees of ACL's Title VI annual conference and webinars. Between 2020 and 2021, ACL funded six Dementia Capability in Indian Country grants, to develop and implement culturally and linguistically appropriate education programs and deliver EBIs in support of elders living with dementia and their caregivers.

In April 2023, ACL hosted a meeting of their ADPI grantees and those of IHS and CDC to provide opportunities for all of the federal grantees doing ADRD work in Indian country to learn of the activities in other Tribal communities. The facilitated day-long meeting coincided with ACL's Title VI Annual Conference which provided an opportunity for tribes not funded through these programs to also learn about AD/ADRD in Indian Country. As a result of the April meeting, new collaborative opportunities were identified, as well as the sharing of resources. In 2024, ACL grantees presented their ADRD work at the annual Title VI conference, providing attendees with insight into opportunities to support their communities with education and awareness. ACL also continues to bring AD/ADRD education to Tribal communities through its Cluster trainings across the Nation, most notably one delivered in Phoenix, Arizona, as well as webinars and educational videos.

For more information see:

- https://nadrc.acl.gov/details?search1=20231031114936
- https://nadrc.acl.gov/details?search1=20240808123728
- https://nadrc.acl.gov/details?search1=20240819032500

CDC, in partnership with National Council of Urban Indian Health (UIH), developed a communication campaign to raise awareness of AD/ADRD for Urban Indian Elders. The campaign includes videos, a social media toolkit, flyer and posters, graphics, and other resources.

For more information see:

- https://ncuih.org/wisdomkeeper/

The NPAIHB, funded under CDC's BOLD Public Health Programs to Address ADRD cooperative agreement, hosted a Brain Health & Dementia Summit on August 21-22, 2024, in Portland, Oregon. The Summit presented information, education, and awareness to address brain health and cognitive decline in Indian Country. The information presented was designed to foster the Northwest Tribes Dementia Network and provide awareness and education about ADRD.

With funding from CDC, AMA produced a series of three webinars on the topic of Navigating Brain Health and Dementia. Webinars addressed screening and diagnosis of dementia, risk reduction, and treatment. Free CME credit is available.

For more information see:

- https://edhub.ama-assn.org/science-medicine-public-health/pages/brain-health-dementia-video-series?ACSTrackingID=FCP_2_USCDC_944-DM132642&ACSTrackingLabel=%5BProof%202%5D%20Community%20Matters%3A%20Understanding%20Social%20Determinants%20of%20Health%20to%20Reduce%20Dementia%20Risk%20and%20Navigating%20Brain%20Health%20&deliveryName=FCP_2_USCDC_944-DM132642

In October 2023, NIA intramural and extramural training staff traveled to the annual meeting of the American Indian Science and Engineering Society, in Spokane, Washington. NIA hosted a booth in the exhibit hall and educated attendees, primarily very early career scientists including undergraduates and graduate students, on opportunities for research training within the NIA IRP, and opportunities for extramural funding for AD researchers.

In November 2023, NIA leadership met on Cherokee sovereign land with the Cherokee Nation chief and Tribal leaders. Leadership from both parties discussed areas of mutual interest and the Cherokee Nation Tribal leadership shared scientific priorities. NIA also subsequently co-hosted the NIA Director's Regional Meeting in partnership with the Cherokee Nation; the Oklahoma State University Center for Health Sciences, Tulsa campus; and eight additional resource-limited institutions throughout the region. These meetings provided valuable opportunities for in-person engagement and relationship building within this important community.

In addition, several of NIA's ADRCs are working in Native Communities and have developed brochures, videos, and other resources that encourage the participation of AI/AN in AD/ADRD clinical trials so that the prevalence of the disease in Native communities can be better understood. ADORE provides an avenue to gather and share these materials and currently offers 17 resources for AI/AN audiences.

Other notable projects to increase awareness of AD/ADRD include the Native Alzheimer's Disease Resource Center for Minority Aging Research and the Addressing Alzheimer's Disease and Related Dementias Disparities: The American Indigenous Cognitive Assessment study.

For more information see:

- https://ireach.wsu.edu/nad-rcmar/
- https://memorykeepersmdt.com/amica-2/
- https://outreachpro.nia.nih.gov
- https://reporter.nih.gov/project-details/10448420
- https://reporter.nih.gov/project-details/10623223
- https://www.nia.nih.gov/news/older-american-indians-may-experience-higher-levels-cognitive-impairment-previously-thought
- https://www.nia.nih.gov/research/adore
- https://www.nia.nih.gov/research/alzheimers-dementia-outreach-recruitment-engagement-resources/term/american-indian-or
- https://www.nia.nih.gov/research/osp/directors-regional-meeting-2023-agenda

Through a contract with CDC, UW's Cognition in Primary Care Program has developed and implemented tools and trainings for PCPs to assist with evaluating cognition among patients. A free online version of this training is available for continuing education on the CDC Train website.

For more information see:

- https://edhub.ama-assn.org/science-medicine-public-health/pages/brain-health-dementia-video-series
- https://edhub.ama-assn.org/science-medicine-public-health/video-player/18872148
- https://familymedicine.uw.edu/cpc/
- https://www.acpm.org/page/brainhealth
- https://www.cdc.gov/aging-programs/php/bold/
- https://www.cdc.gov/aging-programs/php/nhbi/roadmap.html
- https://www.train.org/cdctrain/course/1118093/details

Also see Action 2.A.5 for an update on the work of the CDC with support from the BOLD to create a uniform national public health infrastructure.

Strategy 2.C: Educate and Support People with Alzheimer's Disease and Related Dementias and Their Families upon Diagnosis

Sometimes, even though a physician or another health care provider has identified cognitive impairment, the person and/or his/her family and caregivers are not told of the diagnosis. Further, once a diagnosis is made and disclosed, as few as half of people with dementia and their families/caregivers receive counseling, support, or information about next steps. This information is important, especially for early-stage individuals who may experience positive outcomes when they are involved in planning and receive appropriate services. The Actions below will address this gap by educating physicians and other health care providers, incentivizing discussions with people with AD/ADRD and their families and caregivers and enhancing the ability of other networks to assist people living with AD/ADRD and their families and caregivers to address their needs.

(ONGOING) Action 2.C.1: Educate physicians and other health care providers about accessing long-term services and supports

Lead Agencies: HRSA, CMS, ACL

One barrier to counseling and support is that health care providers may not be aware of available services or how to access them. To increase knowledge of these resources among physicians, nurses, and hospitals, HRSA grantees are working with federal partners, public and private entities, the health care provider community, academic partners, and community organizations that provide LTSS to effectively educate physicians and other health care providers, direct service workers, patients, families, and caregivers about support resources and services available to assist people with AD/ADRD, as well as their caregivers. These activities will continue as part of the training in Action 2.A.1.

Medicare covers cognitive assessment and care planning services for beneficiaries who may have cognitive impairment. A required element of these services is the creation of a care plan, including required referral to community resources as-needed (e.g., rehabilitation services, adult day health programs, support groups), and that the care plan is shared with the patient and/or caregiver with initial education and support. The *Medicare & You* booklet highlights this important service for beneficiaries and caregivers, and CMS also created a related video for providers.

For more information see:

- https://www.cms.gov/medicare/payment/fee-schedules/physician/cognitive-assessment
- https://www.medicare.gov/medicare-and-you
- https://www.youtube.com/watch?v=ugO2p2EvQQw

ACL's state and community ADPI program continues to fund projects that include significant focus on the provision of educational opportunities for physicians and other health care providers. Grantees continue to work toward developing models such as dementia-capable hospitals and federally qualified health centers, including educating providers on the importance of dementia-capable care transitions. Resources resulting from ACL-funded initiatives include, but are not limited to, a series of micro-learning training videos, referral training videos and a clinical provider practice referral tool. All grantee resources created and deemed effective through program evaluations are posted on the website of the NADRC.

For more information see:

- https://nadrc.acl.gov/
- https://vda.virginia.gov/dementiacapableVA.htm

(UPDATED) Action 2.C.2: Connect American Indian and Alaska Native people to Alzheimer's disease and related dementias resources

Lead Agency: IHS
Partners: ACL, CDC, HRSA

IHS collaborated with the CDC and Alzheimer's Association to develop the initial *Road Map for Indian Country* designed specifically for Tribal communities. The Road Map was released and disseminated to multiple stakeholders and Tribal Nations. In 2023, CDC and the Alzheimer's Association began the process of revising this Road Map. 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, launching in November 2024, will build on the progress and momentum to date and guide professionals working with AI/AN peoples to advance the vision that everyone deserves a life with the healthiest brain possible. The IHS collaborated on the second edition of the Road Map.

For more information see:

- https://www.alz.org/media/Documents/HBI-Road-Map-American-Indian-Alaska-Native-Peoples-Progress-Report.pdf
- https://www.cdc.gov/aging-programs/php/nhbi/indian-country-road-map.html
- https://www.cdc.gov/aging-programs/php/nhbi/roadmap.html

IA², through CDC's National Healthy Brain Initiative cooperative agreement, hosted the American Indian & Alaska Native Resource Center for Brain Health Webinar Series in June and July 2023. Three webinars featured speakers about brain health, traditional foods relating to brain health, and Tribal Resolutions as they pertain to AI/AN communities.

IHS continues collaborations in 2024 with the Alzheimer's Association based on a 5-year Memorandum of Understanding (MOU). The MOU promotes joint efforts to address and improve the health and well-being of AI/AN PLWD and their caregivers. Active collaboration and coordination with the Association's public health, DEI (diversity, equity, and inclusion), health research, and health systems staff include ongoing linkages of Association chapters with tribes, UIO health programs, and IHS services. The IHS and the Association actively work to increase awareness about technical assistance, training, and resources available through the Alzheimer's Association and resources available to PLWD and their caregivers. In 2024, over half of current IHS grantees actively partner with their local Alzheimer's Association chapters.

IHS collaborates with HRSA to engage the HRSA-funded GWEPs on strategies to improve recognition and diagnosis of dementia. HRSA GWEPs are currently partnering with federally recognized Tribal organizations and participate in a Native Populations Interest Group for the purpose of exchanging training materials and collaborating regionally on providing education and training to native peoples. Continuing from 2023, the IHS is collaborating with the OU Health Sciences' GWEP program on the OU CHW/CHR dementia training, developed in conjunction with local Tribal community health staff.

The most significant work on this Action is being conducted by the IHS Dementia Models of Care grantees. See Action 2.H.1.

Tribal communities continue to benefit from ACL's state and community AD/ADRD grant programs, including development of culturally-competent dementia care specialists, dementia-friendly community education/awareness initiatives, and translation of the Music and Memory intervention in Indian Country. ACL's Title VI program has significantly increased the AD/ADRD educational offerings at their annual Title VI Training Conference including increasing awareness of CDC's *Road Map for Indian Country*. In 2020, ACL introduced a new ADPI grant program, Dementia Capability in Indian Country, funding four Tribal entities in 2020 and another two in 2021 to develop and implement culturally and linguistically appropriate education programs and deliver EBIs in support of elders living with dementia and their caregivers. The recipients of the ACL Dementia Capability in Indian Country grants include Tribal Senior Services, a Tribal Health System, Inter-Tribal Councils, and a regional association that serves a broad range of Tribal needs.

In April 2023, ACL hosted a meeting of their ADPI grantees and those of IHS and CDC to provide opportunities for all of the federal grantees doing ADRD work supporting Native Americans in communities across the Nation. The facilitated day-long meeting coincided with ACL's Title VI Annual Conference, which provided an opportunity for those not funded through these programs to also learn about ADRD in Native American communities. As a result of the April meeting, new collaborative opportunities were identified, as well as the sharing of resources.

For more information see:

- https://iasquared.org/brain-health/
- https://iasquared.org/brain-health/resource-library/
- https://nadrc.acl.gov/details?search1=20231031114936

- https://nadrc.acl.gov/details?search1=20240808123728
- https://nadrc.acl.gov/details?search1=20240819032500
- https://www.cdc.gov/aging-programs/php/nhbi/indian-country-resources.html
- https://www.cdc.gov/aging-programs/php/nhbi/indian-country-road-map.html

Strategy 2.D: Identify High-Quality Dementia Care Guidelines and Measures Across Care Settings

Guidelines for the delivery of high-quality care and measures of quality care are needed to ensure that people with AD/ADRD receive high-quality, culturally and linguistically appropriate care in the many different settings where they receive services. These guidelines and measures should be tailored to the stages of the disease, address the physical, cognitive, emotional, and behavioral symptoms of AD/ADRD, and cover the myriad of care settings in which care is delivered. These guidelines should also consider how care might be modified for diverse populations and in the context of co-occurring chronic conditions in people with AD/ADRD. Quality measures should be based on evidence-based guidelines and track whether recommended care is being provided. Guidelines and measures need to be free of conflicts of interest. The actions below will advance the development of guidelines and measures of high-quality care, as well as the ability of the provider community to improve the quality of the care they provide. In the future, to facilitate the implementation of quality care guidelines and measurement, HHS will explore development and electronic sharing of clinical decision support interventions in concert with guidelines and measures to provide clinicians the information they need at the point of care and ensure continuity between measurement, evaluation, and practice.

(**UPDATED**) Action 2.D.1: Explore dementia care guidelines and measures

Lead Agency: CMS
Partner: ASPE

CMS has included dementia-related quality measures in the Merit-based Incentive Payment System for eligible clinicians under Medicare such as cognitive assessment and education and support of caregivers. In 2022, CMS released a HCBS quality measure set to promote consistent quality measurement in state Medicaid HCBS programs for older adults and people with disabilities, including people with dementia. CMS finalized a rule in 2024 that puts procedures in place to update the HCBS measure set and mandates state reporting beginning July 9, 2028. CMS maintains the CMS Measures Inventory Tool, which is the repository of record for information about measures in use across its programs. CMS has also launched a National Quality Strategy, which aims to promote high-quality outcomes and safer care for all individuals, using a person-centered approach across providers.

CMS also issued a rule that finalized an “Age-Friendly” Hospital measure that encompasses five domains: (1) Eliciting Patient Healthcare Goals; (2) Responsible Medication Management; (3) Frailty Screening and Intervention; (4) Social Vulnerability; and (5) Age-Friendly Care Leadership. It evaluates hospitals' dedication to enhancing care for patients aged 65 plus across various settings including the ward, operating room, and emergency department. The measure aligns with the framework comprised of a set of four evidence-based elements of high-quality care to older adults, called the 4Ms. The Age-Friendly Structural Measure begins in 2025 reporting period for FY 2027 payment determination.

For more information see:

- https://cmit.cms.gov/cmit/#/
- https://qpp.cms.gov/mips/quality-measures
- https://www.federalregister.gov/documents/2024/05/10/2024-08363/medicaid-program-ensuring-access-to-medicaid-services

- https://www.federalregister.gov/documents/2024/08/28/2024-17021/medicare-and-medicaid-programs-and-the-childrens-health-insurance-program-hospital-inpatient
- https://www.medicaid.gov/federal-policy-guidance/downloads/smd22003.pdf

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(ONGOING) Action 2.D.2: Solicit stakeholder input on meaningful outcomes to drive quality measurement

Lead Agency: CMS
Partners: ASPE

CMS has launched a National Quality Strategy, which aims to promote high-quality outcomes and safer care for all individuals, using a person-centered approach across providers. The CMS National Quality Strategy continues to be a guidepost in operationalizing measures, policies, and processes that CMS to develops, maintains and promotes. Meaningful health outcomes include that which are applicable to PLWD and who may have cognitive impairment.

For more information see:

- https://www.cms.gov/medicare/quality/meaningful-measures-initiative/cms-quality-strategy

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(ONGOING) Action 2.D.3: Clarify and disseminate information on privacy, autonomy, and safety issues to physicians

Lead Agency: HRSA

HRSA worked to develop information for physicians on privacy, autonomy, and safety issues around AD/ADRD. These resources are intended to help providers better understand these issues and the balance between safety, privacy, and autonomy. HRSA continues to disseminate this information through the trainings provided by the GWEP and GACA awardees.

(ONGOING) Action 2.D.4: Improve nursing home care guidelines and transparency

Lead Agencies: CMS, VA
Partner: SAMHSA

CMS has continued to take steps to help keep nursing home residents and staff healthy and safer, working closely with other HHS partners, including CDC. CMS regularly updates Long-Term Care Surveyor Guidance to help improve care for people with mental disorders including substance use disorders (SUDs), and better address situations where nursing home residents are potentially given an inaccurate diagnosis or assessment. The Substance Abuse and Mental Health Services Administration (SAMHSA), working with CMS, has established the Center of Excellence for Behavioral Health in Nursing Facilities (COE-NF), a national center of excellence for building capacity in nursing homes to furnish care to residents with behavioral health conditions which supports focused resource development and dissemination, training and technical assistance, and workforce development to staff in nursing homes for people with serious mental illness (SMI), serious emotional disturbance, SUDs, and co-occurring conditions. The Center has many training opportunities on topics ranging from co-occurring disorders to suicide.

CMS includes ownership and operatorship affiliation on the Nursing Home Compare website, and publishes aggregate nursing home performance data (e.g., combined inspection, staffing, quality, and other performance measures across groups of nursing homes with shared ownership and operatorship). Allowing consumers to see information about a nursing home’s affiliated entities directly supports data transparency and dissemination, and allows consumers and their caregivers to make more informed decisions about care.

For more information see:

- https://nursinghomebehavioralhealth.org
- https://www.cms.gov/files/document/qso-23-18-nh.pdf
- https://www.cms.gov/files/document/qso-22-19-nh-revised-long-term-care-surveyor-guidance.pdf
- https://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/GuidanceforLawsAndRegulations/Nursing-Homes
- https://www.medicare.gov/care-compare/?providerType=NursingHome
- https://www.samhsa.gov/grants/grant-announcements/sm-22-011

Strategy 2.E: Explore the Effectiveness of New Models of Care for People with Alzheimer's Disease and Related Dementias

Work is underway at a number of agencies to identify models that provide more effective and efficient care for people with AD/ADRD.

(**ONGOING**) Action 2.E.1: Evaluate the effectiveness of relevant Innovation Center models for people with Alzheimer's disease and related dementias

Lead Agency: CMS
Partner: NIA

In 2023, CMS announced the testing of the GUIDE Model which aims to improve the quality of life for PLWD, reduce strain on unpaid caregivers, and help people remain in their homes and communities through a package of care coordination and management, caregiver education and support, and respite care. The GUIDE Model was designed with significant stakeholder input and includes a comprehensive package of care coordination and care management, caregiver education and support, and respite services. The Model aims to define a standardized approach to dementia care delivery, provides a monthly per-beneficiary payment to support team-based collaborative care, provides caregiver training and respite care services, and helps ensure that the health-related social needs of beneficiaries are assessed and people in need are connected to local, CBOs to address the needs. The model launched in July 2024 with 390 participants who are expected to serve nearly 200,000 PLWD across all 50 states, the District of Columbia, and the U.S. territories during the model performance period from July 2024 through June 2032.

For more information see:

- https://www.cms.gov/priorities/innovation/innovation-models/guide

Separately, NIA and the Patient-Centered Outcomes Research Institute funded a pragmatic trial as a follow-on to one of the CMS Innovation awardee programs focused on a comprehensive care model for PLWD. The Dementia Care study is ongoing and is assessing two different comprehensive models of dementia care and usual care, and will evaluate the cost effectiveness of each intervention.

NIH recently renewed the NHATS and the NSCO to continue data collection, development, and dissemination in both studies. These studies provide insights into trends in the functional status of older populations, including PLWD, and the care they receive from family, friends, and the health care system.

NIH funded ten awards in 2023 for the development of methods and measures for capturing expanded definitions of “family” and related concepts relevant to informal caregiving for PLWD, and for the implementation of these measures in new and existing studies.

For more information see:

- https://pubmed.ncbi.nlm.nih.gov/32949145/
- https://pubmed.ncbi.nlm.nih.gov/35553424/
- https://reporter.nih.gov/search/s6vRgr3jpE2xSXQLAdNqjA/project-details/10665547
- https://www.nhats.org/researcher/nhats
- https://www.nhats.org/researcher/nsoc

(ONGOING) Action 2.E.2: Evaluate the effectiveness of the Independence at Home Demonstration

Lead Agency: CMS

The Independence at Home Demonstration tested the effectiveness of delivering comprehensive primary care services at home for Medicare beneficiaries with multiple chronic conditions. CMS released evaluation results from Year 8 of the demonstration in 2024.

For more information see:

- https://innovation.cms.gov/innovation-models/independence-at-home

(UPDATED) Action 2.E.3: Understand the role of certified community behavioral health clinics in providing access to care

Lead Agency: ASPE

In April 2014, the Protecting Access to Medicare Act created the Certified Community Behavioral Health Clinic (CCBHC) demonstration under Medicaid. The demonstration establishes a standard definition for CCBHCs and requires participating states to use prospective payment systems (PPS) that reimburse CCBHCs for the total cost of providing comprehensive services to all individuals who seek care. The Office of the Assistant Secretary for Planning and Evaluation (ASPE) is managing a multi-year evaluation of this demonstration to answer research questions on how CCBHCs improve access to care, whether they implement a full scope of services, how they improve the quality of care, whether the PPS covers the full cost of care, and how the demonstration impacts costs and utilization in Medicaid. Reports to Congress are due annually, and reports are posted on ASPE's website. The first Report to Congress was published in 2017; six additional Reports to Congress have been transmitted, and two interim reports were published in September 2020 and one in December 2021. Since the demonstration was extended and expanded several times, including most recently in the Bipartisan Safer Communities Act, ASPE is undertaking further evaluation of the extended and expanded demonstration.

For more information see:

- https://aspe.hhs.gov/reports/ccbhc-demonstration-program

(NEW) Action 2.E.4: Improve whole-person person-centered, coordinated care delivery for people living with dementia

Lead Agency: AHRQ

In May 2024, AHRQ released a Special Emphasis Notice (SEN) to announce its interest in Health Services Research to Improve Care Delivery, Access, Quality, Equity, and Health Outcomes for Older Adults. The SEN informed the research community of AHRQ's strong and continued interest in receiving health services research grant applications that advance the Nation's goal of improving care delivery, access, quality, equity, and health outcomes for older adults health, emphasizing research that addresses questions related to the development, implementation, evaluation, and scale of person-centered models of care to optimize physical and mental health, functional status, and the well-being among older adults including those living with or at risk for

ADRD. Specific areas of interest include research on: Coordination of care for older adults and patients with multiple chronic conditions across providers and settings of care, with attention to inequities in health and health care; Person-centered, whole-person health care delivery that address the needs, health goals, and priorities of older adults, including those with multiple chronic conditions and those from socially disadvantaged communities and populations; Developing, evaluating, and implementing models of primary care to optimize health, functional status, and well-being among older adults and to better integrate and coordinate care which may include the effectiveness of payment models to achieve these aims; Design of effective models of care that foster well-being and reduce burden on clinicians and interdisciplinary teams, including health care staff, patients, and caregivers. in the co-design of interventions and generation of evidence of what works in different contexts; Design of effective models of care that integrate the voices of older adults, caregivers, and communities, including them in the co-design of interventions and the generation of evidence of what works in different contexts; Innovations in health care delivery to address behavioral health needs of older adults and their caregivers, including integration of behavioral health into primary care; Addressing health-related social needs, including collaboration and integration between health care, social and community services, and public health; Interventions that address caregiver's needs and reduce burden on patients and their caregivers; Developing effective and efficient ways to collect and use person-centered data, increase electronic information exchange with providers across settings of care, and social and community service organizations and identify meaningful measures that address what is most important to older adults.

For more information see:

- https://grants.nih.gov/grants/guide/notice-files/NOT-HS-24-013.html

Strategy 2.F: Ensure that People with Alzheimer's Disease and Related Dementias Experience Safe and Effective Transitions between Care Settings and Systems

People with AD/ADRD have higher rates of emergency department visits and hospitalizations, two settings where they are vulnerable to stress, delirium, and unnecessary complications. A transition between providers and care settings is a complex time of care delivery for all people, but especially for frail older adults and people with AD/ADRD, who often have multiple chronic conditions. Transitions include moves into acute care hospitals; from hospitals to post-acute care settings such as skilled nursing facilities or the home; or from nursing facilities to hospitals. People with AD/ADRD are at high risk of adverse events due to poor communication and other care process deficiencies during transitions and need support to help them determine the best timing for transition and site of care.

(ONGOING) Action 2.F.1: Expand efforts to support effective care transitions for people with Alzheimer's disease and related dementias

Lead Agency: CMS
Partner: ACL

CMS's Accountable Health Communities Model was based on addressing health-related social needs through enhanced community linkages. In 2022, CMS posted a "spotlight" report on making the case for addressing health-related social needs.

For more information see:

- https://innovation.cms.gov/media/document/ahc-reading-hosp-spotlight

In 2023, CMS released guidance on an opportunity for states to address health-related social needs for Medicaid beneficiaries through the use of "in lieu of services and settings" in the Medicaid managed care delivery system. This is an innovative option states can consider employing to reduce health disparities and address a range of unmet health-related social needs, such as housing instability and food security and help enrollees improve their health outcomes.

CMS also released three informational bulletins addressing coverage options for services and supports to address health-related social needs.

For more information see:

- https://www.medicaid.gov/federal-policy-guidance/downloads/cib11162023.pdf
- https://www.medicaid.gov/federal-policy-guidance/downloads/mh-sud-med-chip-enrol-expncg-hmles.pdf
- https://www.medicaid.gov/health-related-social-needs/downloads/hrsn-coverage-table.pdf
- https://www.medicaid.gov/sites/default/files/2023-01/smd23001.pdf

CMS updated guidance for Medicare's annual wellness visit (AWV) and "Welcome to Medicare" Visit to note that under advance care planning, advanced directives can include psychiatric advance directives.

For more information see:

- https://www.cms.gov/Outreach-and-Education/Medicare-Learning-Network-MLN/MLNProducts/preventive-services/medicare-wellness-visits.html
- https://www.samhsa.gov/sites/default/files/a_practical_guide_to_psychiatric_advance_directives.pdf

ACL's state dementia system grants continue to require a care transitions component and an evaluation of the effectiveness of these programs. Numerous innovative evidence-based and evidence-informed models of care transitions interventions are presently being implemented through ACL's state projects. Information on promising program practices is disseminated through the NADRC.

Through the ADPI state and community grants program, the ACL funds the piloting of innovations in care transitions programs. In Nevada, ACL has funded a successful Hospital2Home intervention to deliver dementia-capable supports as PLWD being discharged from the hospital, which is presently being translated into an Indiana AAA. In 2021, an AAA in Indiana received funding to implement Hospital2Home in support of dementia-capable care transitions in the community they serve. The University of Hawaii developed their Care Coordination Practice Tool to support clinicians through the identification of cognitive impairment and dementia care coordination.

For more information see:

- http://hospital2home.org/about/
- https://nadrc.acl.gov/details?search1=20240716103151

(ONGOING) Action 2.F.2: Disseminate person-centered practices and systems

Lead Agency: ACL
Partner: CMS

National Center on Advancing Person-Centered Practices and Systems (NCAPPS), an initiative between CMS and ACL to implement person-centered practices, issued a tool, the Health Care Person-Centered Profile. The template includes essential health information and a format for outlining what is important to the person who may be hospitalized and unable to communicate their wants, needs, and preferences. NCAPPS has other resources on direct support professional recruitment and retention, person-centered planning facilitation, and inclusion.

For more information see:

- https://ncapps.acl.gov/

In 2023, CMS's RIC resource held a webinar on Promising Practices for Promoting Person-Centered Communication and Care Coordination for dually eligible Medicare-Medicaid beneficiaries. Health plans shared their promising practices for promoting person-centered care coordination, with an emphasis on communication-focused strategies that can be used to overcome common barriers to care coordination across the team.

For more information see:

- https://www.resourcesforintegratedcare.com/2023_ric_webinar_promising-practices-for-promoting-person-centered-communication-and-care-coordination/

Strategy 2.G: Advance Coordinated and Integrated Health and Long-Term Services and Supports for People Living with Alzheimer's Disease and Related Dementias

Coordinating the care received by people with AD/ADRD in different settings by different providers can help reduce duplication and errors and improve outcomes. Despite a general consensus that care coordination is important, more research is needed to determine how best to provide such care in a high-quality and cost-efficient manner. The Actions under this Strategy will focus on learning from the existing evidence regarding care coordination and using this information to implement and evaluate care coordination models for people with AD/ADRD.

(ONGOING) Action 2.G.1: Implement and evaluate care coordination models

Lead Agency: CMS

CMS makes payment for care management and coordination services, including complex chronic care management and transitional care management. Care coordination models can be a critical component of care in Medicare that can contribute to better health outcomes and higher beneficiary satisfaction.

For more information see:

- https://www.cms.gov/about-cms/agency-information/omh/health-equity-programs/c2c/ccm
- https://www.cms.gov/Outreach-and-Education/Medicare-Learning-Network-MLN/MLNProducts/Downloads/ChronicCareManagement.pdf

Also see Action 2.E.1 on the GUIDE model.

(ONGOING) Action 2.G.2: Advance the use of health information technology standards to support the needs of persons with Alzheimer's disease and related dementias

Lead Agency: ONC
Partners: CMS, ASPE

HIT is an essential tool to facilitate enhanced care coordination and communication between health care and human service providers that support patients with AD/ADRD. The Office of the National Coordinator for Health Information Technology (ONC) publishes an annual *Interoperability Standards Advisory* (ISA) to bring public awareness to inter-operability standards and implementation specifications that can be used by industry, including standards that support care plans and transitions in care, among others. The annual comment period for the ISA was open from June 12, 2024, to August 12, 2024, and will be used to inform the 11th Annual ISA Reference Edition in January 2025. The ISA will be updated by the end of 2024. In 2024, ONC will launch a new Interoperability Standards Platform to house ISA and other important standards initiatives. The PDF version of ISA will no longer be published after the transition to the web only platform.

For more information see:

- https://www.healthit.gov/isp/

(NEW) Action 2.G.3: Promote quality of care through caregiver support

Lead Agency: CMS

In 2023, CMS established Medicare coding and Physician Fee Schedule (PFS) coding and payment under the Medicare PFS for principal illness navigation (PIN) services beginning in 2024, which could be important for people at high risk including individuals with dementia. PIN services involve a person-centered assessment to better understand the person's life story, care coordination, contextualizing health education, building self-advocacy skills, health system navigation, facilitating behavioral change, providing social and emotional support, and facilitating access to community-based social services to address SDOH needs. PIN services can assist people with Medicare and identify and connect them with appropriate clinical and support resources.

CMS also established coding and CY PFS final rule payment policies under the PFS for other services that support health equity beginning in 2024:

- Caregiver Training Services, where practitioners can train and involve caregivers in supporting people with certain conditions (e.g., dementia) under an individualized treatment plan or therapy plan of care.
- SDOH risk assessment provided as a stand-alone service, as an optional element of the AWV or with a when furnished with an evaluation and management or behavioral health visit.
- Community health integration services to help address unmet health-related social needs that interfere with the patient's diagnosis or treatment.

In the 2025 PFS proposed rule, CMS issued a broad RFI on services addressing health-related social needs the coding and policies established for these services to engage interested parties on additional refinements for CMS to consider in future rulemaking. For example, CMS sought information on whether there are other types of auxiliary personnel (including clinical social workers), other certifications and/or training requirements that are not adequately captured in current coding and payment for these services, and how to improve utilization of these services in rural areas. CMS also proposed to establish new coding and payment under the PFS beginning in 2025 for Caregiver Training Services to describe training and supports for direct care (e.g., dressing changes, medication administration), and safety planning for intervention services for people who may be experiencing a mental health crisis.

For more information see:

- https://www.cms.gov/files/document/mln9201074-health-equity-services-2024-physician-fee-schedule-final-rule.pdf-0
- https://www.cms.gov/newsroom/fact-sheets/calendar-year-cy-2025-medicare-physician-fee-schedule-proposed-rule

Strategy 2.H: Improve Care for Populations Disproportionately Affected by Alzheimer's Disease and Related Dementias, and for Populations Facing Care Challenges

Some populations are unequally affected by AD/ADRD, including racial and ethnic minorities and people with IDD. Most racial and ethnic minority groups are at greater risk for developing AD/ADRD and face barriers to obtaining a diagnosis and services after onset. People with Down syndrome almost always develop AD/ADRD as they age. In addition, because AD/ADRD primarily affects older adults, the population with younger-onset AD/ADRD faces unique challenges with diagnosis, care, and stigma. HHS will undertake the Actions below to better understand the unique challenges faced by these groups and create a plan for improving the care that they receive, which will be integrated into the broader efforts to improve care for all people with AD/ADRD.

(**UPDATED**) Action 2.H.1: Create funding opportunities for organizations to improve care for Tribal populations

Lead Agency: IHS
Partner: ACL

Initially funded in FY 2021, the IHS established the Alzheimer's grants program in May 2022 following Tribal Consultation and Urban Confer. Since 2022, the IHS has awarded 12 cooperative agreements to develop models of comprehensive and sustainable dementia care and services in Tribal and Urban Indian communities. In August 2022, IHS awarded 2-year cooperative agreements to three tribes and one UIO, and in August 2023 IHS awarded a second round of funding to eight additional tribes, Tribal organizations, and UIOs. The care and services developed through these 12 awards are improving care locally and will eventually serve as model for Tribal and UIO programs nationally. The 12 grant recipients collectively serve just over 60,000 adults ages 55 and older.

In 2024, IHS offered a new NOFO for tribes, Tribal organizations, and UIOs that are already offering dementia care and services. These new awards provide 3 years of funding to support their further expansion and sustainability of programs and services. Awards for six recipients were announced in September 2024.

IHS also anticipates offering small program awards and pilot initiatives with IHS, Tribal and UIO programs for the development of specific services addressing care for those living with dementia and their caregivers in the coming year.

For more information see:

- https://www.ihs.gov/alzheimers/
- https://www.ihs.gov/newsroom/announcements/2024-announcements/funding-available-to-address-dementia-in-tribal-and-urban-indian-communities/
- https://www.ihs.gov/newsroom/ihs-blog/june-2024-blogs/ihs-alzheimers-grants-helping-put-the-puzzle-together-for-tribal-and-urban-indian-communities/
- https://www.ihs.gov/newsroom/pressreleases/2023-press-releases/ihs-awards-1-5-million-to-address-alzheimers-disease-on-world-alzheimers-day/
- https://www.ihs.gov/sites/newsroom/themes/responsive2017/display_objects/documents/2024_Letters/DTLL_DUIOLL_060524.pdf

As of 2024, ACL has funded a total of 193 AD/ADRD state and community-based projects, in support of PLWD and their caregivers, including training professional, since 2014 when funding was expanded beyond states. Included in the 193 are six Tribal entities which applied for and received funding beginning in 2020.

Profiles of ACL-funded projects are available for viewing on the NADRC website. Future grants through ADPI are contingent on availability of funding.

For more information see:

- https://nadrc.acl.gov/
- https://nadrc.acl.gov/details?search1=20210907025132

(UPDATED) Action 2.H.2: Improve detection, diagnosis, and care for Alzheimer's disease and related dementias in Tribal and Urban Indian health systems

Lead Agency: IHS

IHS supports not only grants, but also offers other pilot programs and initiatives that are responsive to the needs of PLWD and their caregivers. This approach is in accordance with the provisions of the FY 2021 Consolidated Appropriations Act, indicating the main priority is to allocate resources directly to tribes, Tribal organizations, UIOs, and IHS direct service hospitals and clinics. IHS awardees are developing comprehensive and sustainable approaches to address AD/ADRD, including detection, diagnosis, assessment, management, and support for caregivers, and are creating best practice models for replication by others. The IHS Alzheimer's Program further supports these efforts with training and technical assistance in the detection, diagnosis, and management of dementia in primary care, support for caregivers, an increased awareness and recognition of dementia in Tribal and Urban Indian communities, and development of data resources using the clinical data available through IHS.

The programs and activities of the IHS Alzheimer's Program are identified in this National Plan under Action 2.A.2, Action 2.A.6, Action 2.A.7, Action 2.A.9, Action 2.A.10, Action 2.B.7, Action 2.C.2 and Action 2.H.1 and elsewhere under Goal 3, Goal 4, and Goal 6.

For more information see:

- https://www.ihs.gov/alzheimers/

(ONGOING) Action 2.H.3: Target resources towards the intellectual and developmental disability and dementia population

Lead Agency: ACL

Through its AD/ADRD grant programs and NADRC, ACL continues to target program resources to addressing IDD and dementia. For example, the NADRC includes an IDD and dementia-specific webinar in their annual webinar series, which can be found on the NADRC website.

ACL-funded grantees use their resources to develop tools designed to support people living with IDD and dementia and their caregivers, both paid and unpaid. ACL grantees develop and test programs and resources to support people living with IDD and dementia and their caregivers. They also bring IDD competency to existing resources to support their delivery in the IDD community. Tools that demonstrate positive impact on the intended audience are made available to the public through the NADRC website.

ACL grantees continue to create a broad range of resources to include an implementation manual of the evidence-based CSPB intervention which describes how the original CSPB intervention was replicated through a university-community partnership and modified to be delivered by AAA front line staff to PLWD and their family caregivers. The manual includes insights on necessary adaptations to support caregivers of individuals aging with IDD. A grantee that provides serves to the Asian American community developed a 1-hour presentation for providers that addresses the risk of dementia among individuals living with IDD, early screening and diagnosis, advance planning, and resources and support for individuals and families. Another grantee developed a 1-hour training for hospital and home transitions coaches that provides an overview of dementia, communication strategies, issues related to caregiving, and strategies for working with people living with IDD and dementia and their caregivers. These, and many other resources to support people living with IDD and dementia and their caregivers, are available on the NADRC website.

For more information see:

- https://nadrc.acl.gov
- https://nadrc.acl.gov/details?search1=20240508085151
- https://nadrc.acl.gov/details?search1=20240716101936
- https://nadrc.acl.gov/details?search1=20240716103151

Also see Action 2.A.3 for information on CDC's funding of the PwIDD-HBI.

Goal 3: Expand Supports for People with Alzheimer's Disease and Related Dementias and Their Families

People with AD/ADRD and their families and caregivers need support that go beyond the care provided in formal settings such as doctors' offices, hospitals, or nursing homes. Families and unpaid caregivers play a central role. Supporting people with AD/ADRD and their families and caregivers requires giving them the tools that they need, helping to plan for future needs, and helping to ensure that safety and dignity are maintained. Under this Goal, the Federal Government and partners will undertake Strategies and Actions that will support people with the disease and their caregivers.

Strategy 3.A: Ensure Receipt of Culturally and Linguistically Appropriate Education, Training, and Support Materials

Caregivers often report that they feel unprepared for some of the challenges of caring for a person with AD/ADRD; for example, caring for a person with sleep disturbances, behavioral changes, in need of physical assistance, or with advanced dementia can be an enormous challenge. Giving caregivers the information and training that they need in a culturally and linguistically appropriate manner helps them better prepare for these and other challenges. The Actions to achieve this Strategy include identifying and addressing areas of training and educational needs, creating culturally and linguistically appropriate materials, and distributing these materials widely to caregivers.

(**UPDATED**) Action 3.A.1: Distribute federally-developed educational materials

Lead Agencies: NIA, ACL
Partners: ADEAR, public partners

NIA's ADEAR Center continues to update and offer free information in English and Spanish on AD/ADRD to caregivers in print and online, as well as through its information and referral helpline, a bimonthly email alert highlighting caregiving issues, and social media. (See Action 1.E.2 for more information on ADEAR.) NIA also operates several social media platforms and regularly conducts outreach efforts to share federally-developed educational materials on AD/ADRD. For example, during National Family Caregivers Month in November 2021 and Alzheimer's & Brain Awareness Month in June 2022, 2023, and 2024, NIA showcased dementia materials and resources for caregivers, PLWD, and older adults via multiple formats such as a highly popular social media storytelling series featuring caregivers, a social media campaign in Spanish and English, and email alerts to key audiences.

In addition, NIA has developed a series of videos on understanding AD/ADRD and caregiving information and tips. Alzheimers.gov also provides information to help support people with dementia and their families, including the popular page, Tips for Caregivers and Families of People With Dementia.

For more information see:

- https://order.nia.nih.gov/view-all-alzhemer-pubs
- https://twitter.com/NIHAging
- https://www.alzheimers.gov/life-with-dementia/tips-caregivers
- https://www.facebook.com/NIHAging
- https://www.nia.nih.gov/health/alzheimers-and-dementia
- https://www.nia.nih.gov/health/alzheimers/caregiving
- https://www.youtube.com/playlist?list=PLmk21KJuZUM5wCk3NS3nq8kJRsG44DAQ_
- https://www.youtube.com/playlist?list=PLmk21KJuZUM6_VZioOHoOvmrATf-OwzxN

ACL's NADRC develops and makes available resources in support of both paid and unpaid caregivers. The origin of the resources include the NADRC, as well as organizations that received federal funding to develop tools and trainings. Examples of federally-developed resources include but are not limited to:

- *Promising Programs and Services for People Living Alone with Dementia*.
- *Promoting Brain Health and Reducing Dementia Risk Factors*.
- *Addressing Social Isolation and Loneliness of People Living with Dementia and Their Caregivers*.
- *NADRC Highlights of Administration on Aging Alzheimer's and Dementia Program Grantee-Developed Resources*, 2nd Edition.
- *Intellectual and Developmental Disabilities and Dementia: Practical Strategies for Professionals*.
- *Guide to Billing Codes for Dementia Services* (to be updated in 2025).

In addition to developing new resources each year, the NADRC also undertakes regular updates of existing resources to ensure that they are making available tools with relevant, current information. The library of NADRC-developed and ACL grantee-developed resources for persons living with AD/ADRD and their caregivers can be found online.

For more information see:
- https://nadrc.acl.gov/
- https://nadrc.acl.gov/details?search1=20230719035406
- https://nadrc.acl.gov/details?search1=20230905035531
- https://nadrc.acl.gov/details?search1=20231010050445
- https://nadrc.acl.gov/details?search1=20240808122611

The CDC-funded BOLD PHCOE on Dementia Risk Reduction developed a set of infographics that showcase information on SDOH related to dementia, as well as strategies to address these issues. Topics include quality education, economic stability, nutritious foods, social connections, and healthy environment.

For more information see:
- https://www.alz.org/professionals/public-health/public-health-topics/risk-reduction

CDC-funded partners, IA^2 NPAIHB are developing, tailoring, and disseminating AD/ADRD materials and resources to AI/AN communities.

For more information see:
- https://www.cdc.gov/aging-programs/php/nhbi/recipients.html

Also see Action 1.E.3 for updates on the Caregiving and SCD infographics.

(**ONGOING**) Action 3.A.2: Utilize health information technology for caregivers and persons with Alzheimer's disease and related dementias

Lead Agency: NIA, NINDS, VA

NIA and NINDS have supported initiatives to advance progress toward NIH AD/ADRD research implementation milestone 13.I, which calls for research on technology-based dementia assessment, care, and management. NIA funded three Artificial Intelligence and Technology Collaboratories (AITCs) at the end of FY 2021. These centers serve as a national resource to promote the development and implementation of artificial intelligence approaches and technology to improve care and health outcomes for older Americans, including PLWD and their care partners. The centers have received a significant response to calls for pilot research and were able to award 33 pilot projects in the first cohort. NIA has also issued two NOSIs focused on digital health and 27 projects citing these NOSIs have been awarded.

NIA actively supports the joint National Science Foundation (NSF)/NIH Smart Health and Biomedical Research in the Era of Artificial Intelligence and Advanced Data Science (SCH) Program. In FY 2024, NIA has funded two new R01s through this program aimed at developing new methods for the early detection of cognitive decline and AD/ADRD.

In 2023, NINDS invited research applications to support the creation and validation of digital tools, for example digital biomarkers, for monitoring symptoms or aspects of ADRD that affect quality of life. For a full list of funding opportunities and their links, please see Appendix 3.

For more information see:

- https://new.nsf.gov/funding/opportunities/smart-health-biomedical-research-era-artificial
- https://reporter.nih.gov/search/dCAsh6HZiEelEK8OJ4SWpA/projects?shared=true
- https://www.a2collective.ai/
- https://www.a2collective.ai/awardees
- https://www.nia.nih.gov/research/milestones/dementia-care-and-impact-disease/milestone-13-i
- https://www.ohsu.edu/collaborative-aging-research-using-technology

NIA's SBIR/STTR team has also funded several projects that have become commercial successes. For example, NIA funded the development of several platforms and software applications that have the potential to improve early detection of AD/ADRD and revolutionize the aging-at-home experience for older adults and caregivers. NIA funding also supported the development of devices, such as a wearable device that monitors activity and location to help with the proactive management of NPS of dementia and/or falls.

For more information see:

- https://www.nia.nih.gov/research/sbir/nia-small-business-showcase/digital-health-sensing-technologies

In May 2022, NIA convened an exploratory workshop, Gaps and Opportunities for Real-World Data (RWD) Infrastructure. The workshop considered gaps that exist in current RWD infrastructure and opportunities to expand the availability of RWD sources for aging and AD/ADRD research. Several themes emerged throughout the workshop including improving and expanding RWD infrastructure, improving randomized controlled trials, and improving demographic, SDOH, and health disparities analyses. Stakeholders focused on opportunities that exist in current RWD infrastructure that could drive the field forward.

For more information see:

- https://www.nia.nih.gov/gaps-opportunities-stakeholder-workshop

The VA Caregiver Center, located at the Memphis VA Medical Center and supported by the VA's Caregiver Support Program (CSP), implemented a supportive texting intervention for caregivers of veterans with dementia. Caregivers receive information about managing dementia behaviors and their own stress and coping through Annie, the VA's text messaging platform managed by the Office of Connected Care. National roll-out of the protocol occurred in March 2021. As of September 2024, 3,918 caregivers of veterans have been enrolled in the dementia subscription of Annie.

Strategy 3.B: Enable Family Caregivers to Continue to Provide Care while Maintaining Their Own Health and Well-Being

Even though unpaid caregivers usually prefer to provide care in their home or other community settings, often the round-the-clock care needs of the person with AD/ADRD proves very challenging. While they are providing care, supports for families and caregivers can help lessen feelings of depression and stress and help delay or avert institutional care. The Actions below will further support unpaid caregivers by identifying their support needs, developing and disseminating interventions, giving caregivers information they need, particularly in crisis situations, and assisting caregivers in maintaining their health and well-being.

(ONGOING) Action 3.B.1: Develop and disseminate evidence-based interventions for people with Alzheimer's disease and related dementias and their caregivers

Lead Agency: NIA
Partners: AHRQ, CMS, CDC, ACL, DoD, VA

NIA continues to fund research on and for dementia caregivers. In 2019, NIH funded the IMPACT Collaboratory to meet the urgent public health need to deliver high-quality, evidence-based care to PLWD and their caregivers. Through this effort, researchers develop and test care interventions in real-world settings such as hospitals, assisted living facilities, nursing homes, and adult daycare centers.

In just a few short years, the IMPACT Collaboratory has become a national resource for pragmatic trials, providing a network of researchers with broad expertise, connections with national health care systems, and disseminating best practices in research methods. As of May 2024, the Collaboratory has funded a total of 24 pilot pragmatic clinical trials.

The IMPACT Collaboratory has also established a Long-Term Care Data Cooperative, the largest integrated database of EHR data from nursing homes in the United States. To date, the Cooperative has enrolled more than 2,500 nursing homes totaling more than two million residents, complete with linkages to data from CMS, making this an invaluable resource for research to improve the lives of PLWD.

The IMPACT Collaboratory continues to expand with multiple career development and pilot and demonstration funding opportunities to support investigators interested in conducting ePCTs in health care systems, assisted living facilities, adult day programs, emergency departments, hospitals, home care, nursing homes, and other settings.

For more information see:

- https://impactcollaboratory.org/
- https://impactcollaboratory.org/grants-and-training/grants-and-training-overview/
- https://impactcollaboratory.org/grants-program/pilot-grant-awardees/
- https://reporter.nih.gov/project-details/9774609

In 2019, NIA expanded its Edward R. Roybal Centers for Translational Research to include four new AD/ADRD-specific Roybal Centers for translational intervention development research for AD/ADRD care provider support. In 2024, NIA plans to award the next iteration of AD/ADRD-specific Roybal Centers in response to RFA-AG-24-007. These centers serve as incubators for the development of behavioral interventions that improve the health, well-being, and/or capacity of PLWD and individuals and/or systems that provide care to persons with AD/ADRD. In this new iteration, Roybal Centers may also support the development of behavioral interventions to help prevent or delay cognitive decline and AD/ADRD.

Key publications can be found on the Roybal publications website. For a full list of funding opportunities and their links, please see Appendix 3.

For more information see:

- https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-24-007.html
- https://reporter.nih.gov/search/BklBS7WhL0WXyFh4x0ZUXA/projects?shared=true
- https://www.nia.nih.gov/research/dbsr/edward-r-roybal-centers-translational-research-behavioral-and-social-sciences-aging
- https://www.roybalniaresearchcenters.org/
- https://www.roybalniaresearchcenters.org/publications

In 2021, NIA awarded three AITC for Aging Research awards to Johns Hopkins University, University of Massachusetts Amherst, and University of Pennsylvania. The AITCs have pilot cores that will support projects to develop, validate, and disseminate innovative artificial intelligence technology for monitoring persons living with AD/ADRD in their home and community settings and enhance connections between older adults, care partners, and clinicians. The AITCs serve as a national resource to promote the development and implementation of artificial intelligence approaches and technology through demonstration projects to improve care and health outcomes for older Americans, including PLWD and their care partners. These three centers have received a significant response to calls for pilot research and funded 99 projects across the first three cohorts and are already making progress. For example, AITC researchers developed a low-cost, universal attachment for use with a smartphone to measure blood pressure from their fingertips. The "BPClip" is designed for at-home access to blood pressure monitoring, especially for people who find it difficult to access health care services. While more research is needed before the BPClip becomes available, this early pilot study demonstrates the potential of smartphone-based blood pressure devices, which could help improve the accessibility of long-term blood pressure monitoring. For a full list of funding opportunities and their links, please see Appendix 3.

For more information see:

- https://aitc.jhu.edu/
- https://massaitc.org/
- https://www.a2collective.ai/
- https://www.a2collective.ai/awardees
- https://www.pennaitech.org/
- https://www.nia.nih.gov/news/smartphone-clip-attachment-may-help-some-people-self-monitor-blood-pressure
- https://www.nia.nih.gov/research/dbsr/artificial-intelligence-and-technology-collaboratories-aging-research

In addition to these activities, NIA released several NOFOs calling for research to improve the care of persons living with AD/ADRD and their caregivers, and continued to solicit research in this area under several opportunities issued in previous years. Two specific funding opportunities (PAR-21-307 and PAR-21-308) emphasize research that improves rigor and real-world applicability across broad and diverse populations. So far nine research projects have been awarded under these funding opportunities. Funded projects include Dementia Care and Caregiver Support Interventions Research and Pragmatic Trials for Dementia Care and Caregiver Support. Another example funding opportunity is Triadic Interactions in Clinical Encounters Involving People with Alzheimer's Disease and Alzheimer's Disease-Related Dementias (AD/ADRD), Clinicians, and Care Partners (RFA-AG-22-020), which yielded four awards. For a full list of funding opportunities and their links, please see Appendix 3.

For more information see:

- https://reporter.nih.gov/search/Ohb3vluOcU6IU1qXds2tDQ/projects?shared=true

ACL's ADPI and NADRC continue to support the translation, implementation, and evaluation of dementia-specific EBIs in states and communities across the Nation. ACL programs support community translation and implementation of 19 EBIs, preparing some to be taken to scale across the Nation. For example, NIA funded research related to dementia-specific interventions BRI Care Consultations, Care of People with Dementia in their Environments (COPE), Powerful Tools for Caregivers, REACH Community, and most recently Cognitive Stimulation Therapy, all of which are being translated through ACL-funded provider pilot programs, supporting caregivers and PLWD. The NADRC has created a tool to support community decision making in the selection of the EBI that will meet the needs of the community they serve. This resource provides a series of questions and considerations to assist ADPI grantees in the selection and implementation of dementia-specific evidence-based or evidence-informed interventions.

The NADRC developed and regularly updates a compendium resource that consists of a list of dementia-specific evidence-based and evidence-informed interventions that meet ACL criteria and have been implemented by AD program grantees in 2007-2022. ACL-funded programs are also evaluated to demonstrate the impact of the interventions on those who participate. To support comprehensive, third-party evaluation of community implemented interventions the NADRC developed and regularly updates a compendium of outcome evaluation tools.

For more information see:

- http://nadrc.acl.gov

The DoD's CDMRP PRARP is committed to funding research that develops or leverages tools or psychological interventions to improve the quality of life of individuals living with dementia and their care partners. PRARP recently has funded an intervention that teaches care partners coping, stress management, and problem solving skills aimed specifically for care of individuals living with TBI and dementia (WeCAN). Other ongoing projects focus on developing easily accessible digital tools to improve quality of life in care partners and individuals living with dementia. The REACH Hope study supports caregivers of veterans with both TBI and dementia one-on-one in real-time. REACH Hope reduces the burden and anxiety for highly burdened and anxious caregivers. The VA's CSP will implement the program as REACH TBI and Dementia at all VA Medical Centers in FY 2025. Recently, the study team received a second award from CDMRP after submitting a proposal focused on caregivers of veterans with TBI only. The study is being conducted by investigators at the VA Caregiver Center at the Memphis VA Medical Center, Virginia Commonwealth University, and the University of Virginia.

For more information see:

- https://cdmrp.health.mil/search.aspx

VA continues to support research focused on improving the support for caregivers for those living with dementia by improving caregiver support tools, increasing shared decision making, and improving caregiver engagement.

(ONGOING) Action 3.B.2: Provide effective caregiver interventions through Alzheimer's disease and related dementias-capable systems

Lead Agency: ACL
Partner: CMS

ACL's grant programs to states and communities are designed to develop and enhance dementia-capable HCBS systems. ACL's grant programs to states and communities are designed to develop and enhance dementia-capable HCBS systems. All grantees are required to include evidence-based or evidence-informed interventions in their funded programs. As of 2023, ACL has funded a total of 193 AD/ADRD state and community-based projects, in support of PLWD and their caregivers, including training professional, since 2014 when funding was expanded beyond states. Included in the 193 are six Tribal entities received funding beginning in 2020.

Profiles of ACL-funded projects are available for viewing on the NADRC website. Subject to appropriations, ACL programs continue to increase the availability of dementia-specific EBIs across the country.

For more information see:

- http://nadrc.acl.gov

Trainings for unpaid caregivers can be important in improving the lives of PLWD, and CMS finalized a new policy beginning in January 2024 to make payment when practitioners train caregivers to support people with certain diseases or illnesses like dementia in carrying out a treatment plan. Medicare will pay for these services when furnished by a physician or a non-physician practitioner (nurse practitioners, clinical nurse specialists, certified nurse midwives, physician assistants, and clinical psychologists) or therapist (physical therapist, occupational therapist, or speech language pathologist) as part of the individualized treatment plan or therapy plan of care. For 2025, CMS has proposed payment for caregiver training for direct care services and supports. The topics of trainings could include, but would not be limited to, techniques to prevent decubitus ulcer formation, wound dressing changes, infection control, special diet preparation, and medication administration along with proposed new coding and payment for caregiver behavior management and modification training that could be furnished to the caregiver(s) of an individual.

For more information see:

- https://www.cms.gov/newsroom/fact-sheets/calendar-year-cy-2024-medicare-physician-fee-schedule-final-rule
- https://www.cms.gov/newsroom/fact-sheets/calendar-year-cy-2025-medicare-physician-fee-schedule-proposed-rule

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(**ONGOING**) Action 3.B.3: Collaborate to share information on long-term services and supports with Tribal providers

Lead Agency: ACL
Partners: IHS, CMS

HHS uses multiple mechanisms to share information on LTSS and care of the person and family with AD/ADRD with Tribal providers. IHS, ACL, and CMS developed a joint website on LTSS for Tribal providers. IHS regularly conducts presentations on LTSS for people with AD/ADRD at conferences, including the Older Americans Act (OAA) Title VI annual conference, and conferences for Tribal Health Directors and Planners (NIHB), Tribal Leaders (National Council on American Indians), and Tribal Elders (National Indian Council on Aging [NICOA]). IHS also regularly fields inquiries from Tribal communities and health system staff seeking guidance and information on LTSS and Models of Care grantees are actively working to bridge clinical and community services and expand information and referral networks, including LTSS.

In 2020, ACL introduced a new grant program, ADPI: Dementia Capability in Indian Country. The program is designed to bring culturally-appropriate AD/ADRD training and education to Indian Country. Since its inception in 2020, six tribes have applied for and received 3-year awards. Throughout the period of performance of the ACL-funded programs, grantees continue to build awareness of LTSS available in their communities, providing education opportunities to exiting providers and students, reinforcing the benefits of dementia-capable LTSS while building relationships with Tribal providers.

(ONGOING) Action 3.B.4: Continue to promote use of the National Alzheimer's Call Center to provide information, advice, and support to people with dementia or their caregivers

Lead Agency: ACL
Partners: private partners

ACL continues to provide funding toward and promote use of the National Alzheimer's Call Center to provide information, advice, and support about AD/ADRD. In 2024, the funding for the Call Center was increased substantially, allowing them to expand the breadth and depth of the resources that the Center makes available. The Call Center provides 24-hour access, 7 days a week via a toll-free number (1-800-272-3900). Support varies from simple referrals to crisis intervention. Complex and crisis calls are handled by master's level social workers and counselors who provide reflective listening, problem solving, education, action planning, and crisis intervention. The Call Center provides assistance in over 170 languages.

(ONGOING) Action 3.B.5: Make behavioral symptom management education and training available to caregivers

Lead Agency: ACL
Partner: CMS

ACL continues to expand efforts to develop more dementia-capable LTSS systems designed to meet the needs of AD/ADRD caregivers. ACL requires that all ADPI community grants include behavioral symptom management and expert consultations to support caregivers in their programs. For example, a grantee created IDEA!, a simple three-step strategy designed to help caregivers understand a specific behavior with approaches for addressing it. IDEA! covers the following: IDentify the problem or challenging behavior, Explore the behavior, and Adjust your response. The training has tip sheets to support caregivers implement what they learn. ACL grantees support the dissemination of the intervention to a wide variety of cultural communities, having translated the materials into Korean and Japanese.

Another grantee developed a series of 11 videos to empower caregivers by showing how a personalized approach can preserve dignity, convey a sense of safety, and enhance quality of life. The videos include real-life scenarios that strive to provide compassionate care and response to behavioral symptoms.

For more information see:

- https://nadrc.acl.gov/
- https://nadrc.acl.gov/details?search1=20210907025132
- https://nadrc.acl.gov/details?search1=20240716102406

(ONGOING) Action 3.B.6: Develop and disseminate information to caregivers on Alzheimer's disease and related dementias and caregiving

Lead Agency: CDC
Partner: ACL

CDC developed a downloadable care planning tool to assist people with AD/ADRD and their caregivers. Care plans can reduce emergency department visits, hospitalizations, and improve overall medical management for people with a chronic health condition, like AD/ADRD, resulting in better quality of life for all care recipients.

CDC has developed a series of web features and podcasts on topics including helping people with AD/ADRD and their caregivers stay physically active, developing care plans for older adults and their caregivers, and the truth about aging and dementia.

For more information see:

- https://www.cdc.gov/alzheimers-dementia/php/resource-center/
- https://www.cdc.gov/caregiving/media/pdfs/complete-care-plan-form-5081.pdf

UIC, funded under CDC's National Healthy Brain Initiative cooperative agreement, educated paid caregivers in CBOs, public health and health care professionals on sources of reliable information about brain health and ways to use the information to inform people with IDD and their unpaid caregivers. UIC partnered with Oakwood Creative Care to implement an evidence-based program for caregivers of people with IDD who have dementia, COPE.

ACL, through the NADRC and its grant programs, continues to develop and make available web content on issues relevant to paid and unpaid caregivers. In addition to hosting ten webinars on a broad range of AD/ADRD topics, the NADRC has developed several resources:

- *Promising Programs and Services for People Living Alone with Dementia*.
- *Promoting Brain Health and Reducing Dementia Risk Factors*.
- *Addressing Social Isolation and Loneliness of People Living with Dementia and Their Caregivers*.
- *NADRC Highlights of Administration on Aging Alzheimer's and Dementia Program Grantee-Developed Resources* 2nd Edition.

On the NADRC website, ACL also makes available resources tools developed by the organizations funded through the ADPI program. The tools selected for inclusion on the site are those that demonstrate positive impact through the ACL-funded multi-year ADPI demonstration programs.

For more information see:

- https://nadrc.acl.gov/
- https://nadrc.acl.gov/details?search1=20230719035406
- https://nadrc.acl.gov/details?search1=20230905035531
- https://nadrc.acl.gov/details?search1=20231010050445
- https://nadrc.acl.gov/details?search1=20240808122611
- https://www.nia.nih.gov/health/alzheimers/caregiving

(ONGOING) Action 3.B.7: Support enhanced financial literacy and preparedness of family caregivers

Lead Agency: ACL
Partners: Private Partners, NIA

Family caregivers often lack adequate information and resources to properly manage the financial concerns of their loved ones. In 2018, ACL introduced a new program to address the need to advance understanding financial literacy of family caregivers. The ongoing program addresses that need through the development and testing of new interventions, as well as identification and dissemination of best practices.

In addition, NIA provides information for caregivers, including checklists and worksheets, to help with legal and financial planning.

For more information see:

- https://nih.us19.list-manage.com/subscribe?u=3dca973015582e3c417f6296c&id=dbcca54d87
- https://www.nia.nih.gov/health/advance-care-planning

- https://www.nia.nih.gov/health/legal-and-financial-planning/managing-money-problems-people-dementia
- https://www.nia.nih.gov/health/long-term-care/paying-long-term-care

(ONGOING) Action 3.B.8: Provide caregivers of veterans living with dementia with information about Department of Veterans Affairs Caregiver Support Program resources available to them

Lead Agency: VA

VA's Caregiver Support Program (CSP) offers multiple activities, education, tools, and resources that are geared towards all caregivers, and can provide specific information and support to caregivers of veterans living with dementia. The CSP website connects caregivers to diagnosis specific tools and handouts, and the following resources are examples of what CSP provides:

- REACH-VA -- intervention delivered directly to the caregiver 1:1 or via telephone groups.
- Caregiver Support Line -- clinical staff to connect caregivers to resources and staff for coordination; monthly presentations (live and recorded) and handouts.
- Building Better Caregivers -- workshops to help the caregiver manage challenging emotions, self-care, stress, etc.
- Peer Support Mentoring (PSM) -- peer support, as well as monthly PSM/Spirituality Calls.
- Caregiver Resources by Topic.
- National Family Caregivers Month -- local CSP Teams may offer dementia-related focused topics, speakers, activities.

For more information see:

- https://www.caregiver.va.gov/
- https://www.caregiver.va.gov/help_landing.asp
- https://www.caregiver.va.gov/Publications_Resources_Topic.asp
- https://www.caregiver.va.gov/support/Communicating_Managing_Emotions.asp
- https://www.caregiver.va.gov/support/New_CSC_Page.asp
- https://www.caregiver.va.gov/support-line/handouts.asp

(NEW) Action 3.B.9: Identify, adapt or develop, and support implementation of culturally-appropriate and locally relevant caregiver services and supports in Tribal and Urban Indian communities

Lead Agency: IHS
Partners: ACL, CDC

In 2024, IHS introduced an interdisciplinary caregiver workgroup that includes IHS, Tribal, and UIO staff. Participants also include Tribal ACL ADPI grantees and invited staff from ACL, the Alzheimer's Association, the NPAIHB, a CDC Bold grantee, and AI/AN experts in caregiving. The workgroup's objectives are to:

- Review existing EBIs for caregivers to assess potential interventions for relevance, adaptation, fitness for use, and likelihood of success in IHS, Tribal, and UIO health programs.
- Develop recommendations for criteria to assist IHS, Tribal, and UIOs in selecting caregiver EBIs.
- Identify culturally-relevant elements of caregiver coaching systems and supports, and provide feedback on caregiver coach roles and responsibilities.
- Provide practical recommendations for IHS programming, training, and resources to best meet Tribal and Urban Indian caregiver service and support needs.

Other workgroup activities include a formal literature review of AI/AN caregiver research and key informant interviews to support workgroup activities. This follows work in 2023 conducting an environmental scan of existing dementia caregiver interventions and reviewing IHS and Tribal programs experience in the REACH into Indian Country Pilot of Caregiver Coaching and Support from 2013-2018.

(NEW) Action 3.B.10: Support caregivers by expanding the availability of dementia-specific innovative models of dementia care

Lead Agency: ACL
Partners: private partners

In 2024, ACL funded a new grant program entitled Supporting State and Community Innovations in Dementia-Specific Respite Programs and Services designed to increase the availability of innovative models of dementia-specific respite in communities across the Nation. The program is designed to make subgrants available to HCBS providers to pilot and evaluate much-needed respite models dedicated to meeting the needs of the PLWD and caregivers. The program targets historically under-served populations and focuses on the development of low-cost, high-impact models of care delivered by providers trained in dementia-specific care and support for PLWD and their caregivers.

The grantee, the Alzheimer's Association, received a 5-year cooperative agreement award to support the development and implementation of dementia-specific community-based respite programs to support improving the quality of life for PLWD and their caregivers. During the grant period, the grantee will dedicate no less than 80% of the funding to subgrants to HCBS providers for the development and implementation a community dementia-specific respite program. In addition to the community subgrant program, the Alzheimer's Association will use a portion of the remaining 20% of grant funding to deliver training and technical assistance to advance the national capacity to provide such services to PLWD (of any age) and their caregivers.

Preceding the award of the respite innovation grant, ACL commissioned a paper to gain insight into innovative models of respite care for PLWD and their family caregivers. The report supports ACL's efforts to advance supports for family caregivers through the availability and provision of innovative models of respite care in local communities. The report also supports the National Family Caregiver Strategy, a product of the RAISE Family Caregivers Act, enacted in 2018. To better understand the existing landscape of respite care targeting family caregivers of PLWD, ACL contracted with RTI International to conduct a two-pronged approach, consisting of a literature and programmatic document review, to address the following questions:

- What are the common methods and models of respite care for family caregivers of PLWD?
- Under what circumstances or conditions are these methods and models most beneficial to family caregivers and PLWD?
- What are common barriers to accessing respite care for family caregivers and PLWD?

For more information see:
- https://grants.gov/search-results-detail/349601
- https://nadrc.acl.gov/details?search1=20230313024756
- https://www.alz.org/professionals/professional-providers/center-for-dementia-respite-innovation

Strategy 3.C: Assist Families in Planning for Future Care Needs

The vast majority of people do not think about or plan for the LTSS they will need until they experience a disability or AD/ADRD. Many Americans incorrectly believe that Medicare will cover most of the costs of these supportive LTC services like nursing home care and HCBS. Unfortunately, by the time care is needed, it is difficult to get coverage in the private LTC insurance market and financing options are limited. Educating people about their potential need for LTSS and the significant advantages of planning ahead for these services encourages timely preparation. Planning ahead can help ensure that individuals with AD/ADRD and others receive care in the setting they prefer, preserve individual and family assets, and maintain dignity.

(**ONGOING**) Action 3.C.1: Empowering people to make better informed health care decisions

Lead Agency: CMS

CMS's Care Compare provides a single user-friendly interface that patients, caregivers, and consumers can use to make informed decisions about health care based on cost, quality of care, volume of services, and other data, for nursing homes, home health, hospice, hospitals, and other provider types, as well as staffing information in nursing homes.

For more information see:

- https://www.medicare.gov/care-compare/

(**ONGOING**) Action 3.C.2: Expand availability of care planning tools for people with dementia

Lead Agency: CDC

CDC developed a downloadable care planning tool to assist people with AD/ADRD and their caregivers. Care plans can reduce emergency department visits, hospitalizations, and improve overall medical management for people with a chronic health condition, like AD/ADRD, resulting in better quality of life for all care recipients.

For more information see:

- https://www.cdc.gov/caregiving/media/pdfs/complete-care-plan-form-5081.pdf

Early detection and proactive care create a framework for helping individuals and families learn how to live with dementia as a manageable chronic health condition. A toolkit created by the CDC-funded BOLD PHCOE on Early Detection of Dementia, can help CBOs build strategies for early detection into their workflows. The toolkit is designed to support all types of CBOs -- whether they serve one specific community, focus only on older adults, or already provide services for PLWD and their care partners. CBOs have unique roles to play in educating communities and reducing stigma and misunderstanding of cognitive decline and dementia. Accurate information and appropriate community care and support can mitigate many of the burdens of dementia, especially in low-resource communities.

The CDC-funded BOLD PHCOE on Early Detection of Dementia is working with a team funded by the California Department of Public Health to create and disseminate a consumer-facing healthy brain toolkit to help people distinguish between normal cognitive aging and signs of possible cognitive disorder, with the goal of promoting "conversations with your doctor." Initial trial dissemination is expected in September 2024.

Through a cooperative agreement with CDC, ACPM developed a brain health landing page featuring several CDC-funded resources, including two brain health courses for health care providers and a Community-Clinical Linkages to Promote Brain Health toolkit designed for preventive medicine providers to implement and inform their practice around improving brain health within health systems.

For more information see:

- https://www.acpm.org/initiatives/brain-health/

Strategy 3.D: Maintain the Dignity, Safety and Rights of People with Alzheimer's Disease and Related Dementias

People with AD/ADRD are particularly vulnerable to financial exploitation, physical or emotional abuse, and neglect both at home and in care facilities. Reports of elder abuse are handled by state Adult Protective Services (APS), which investigate allegations, provide protective services, and refer cases to law enforcement when appropriate. Not all APS programs cover residents of LTC facilities. State survey and certification agencies receive funding from CMS to survey Medicare or Medicaid-certified nursing facilities and to investigate abuse complaints, among others, in these facilities. State licensing agencies may investigate complaints of abuse in other types of facilities, such as assisted living. State LTC ombudsmen programs advocate for residents of nursing homes and other adult care facilities, and work to resolve complaints on behalf of residents, including those related to abuse, neglect, and exploitation. The Actions below will help ensure that people with AD/ADRD have their dignity, safety, and rights maintained.

(ONGOING) Action 3.D.1: Monitor, report and reduce inappropriate use of antipsychotics in nursing homes

Lead Agency: CMS

CMS's National Partnership to Improve Dementia Care in Nursing Homes has a mission to deliver health care that is person-centered, comprehensive, and interdisciplinary with a specific focus on protecting residents from being prescribed antipsychotic medications unless there is a valid, clinical indication and a systematic process to evaluate each individual's need.

For more information see:

- https://store.samhsa.gov/product/Guidance-on-Inappropriate-Use-of-Antipsychotics-Older-Adults-and-People-with-Intellectual-and-Developmental-Disabilities-in-Community-Settings/PEP19-INAPPUSE-BR
- https://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/SurveyCertificationGenInfo/National-Partnership-to-Improve-Dementia-Care-in-Nursing-Homes

CMS continues the Civil Money Penalty Reinvestment Program (CMPRP), an effort to drive improvements in quality of life and quality of care for nursing home residents. CMPRP is funded by the federal portion of civil monetary penalty funds to conduct activities that support and protect nursing home residents. This program builds on other CMS initiatives such as the National Partnership.

For more information see:

- https://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/SurveyCertificationGenInfo/LTC-CMP-Reinvestment.html

CMS has taken action to reduce the inappropriate use of antipsychotic medications and to bring greater transparency about nursing home citations to residents, families, caregivers, and the public by conducting targeted off-site audits to determine if nursing homes are accurately assessing and coding people with a schizophrenia diagnosis; residents for whom a diagnosis is erroneously applied are at risk of poor care.

For more information see:

- https://www.cms.gov/files/document/qso-23-05-nh-adjusting-quality-measure-ratings-based-erroneous-schizophrenia-coding-and-posting.pdf

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(ONGOING) Action 3.D.2: Incorporate elder abuse awareness into Aging Network activities

Lead Agency: ACL
Partners: private partners

ACL continues to expand awareness and detection of elder abuse and neglect among the population of people with dementia. ACL encourages the Eldercare Locator and other Aging Network and prevention program providers to become knowledgeable about warning signs of abuse. These providers will also disseminate information on elder abuse, with a particular focus on the vulnerable population of people with AD/ADRD.

In 2021, the NADRC hosted a webinar entitled “Elder Abuse in People Living with Dementia: Prevention, Detection, and Intervention,” in which a physician and an attorney discussed indicators that should raise concern, provided practical tips on when and how to intervene, and pay particular attention to the complicated issue of capacity.

ACL ADPI grantees actively engage in training APS providers and first responders in dementia education, including the ways to support PLWD and reduce their risk of abuse, neglect and financial exploitation.

For more information see:

- https://nadrc.acl.gov/
- https://nadrc.acl.gov/details?search1=20220303023121
- https://ncea.acl.gov/

(ONGOING) Action 3.D.3: Translate and disseminate information on abuse of people with dementia

Lead Agency: ACL
Partners: NIA, DoJ, private partners

ACL, NIH, and the U.S. Department of Justice (DoJ) have funded research focused on the abuse, neglect, and exploitation of older adults. HHS will work with the private sector to translate these findings into educational materials and resources, as well as other intervention programs related to the abuse of people with AD/ADRD.

ACL continues to fund programs designed to address elder abuse. The National Center on Elder Abuse is funded by ACL and, through their programs, addresses all facets of elder abuse, including the abuse of individuals living with dementia.

For more information see:

- https://ncea.acl.gov/

NIA produces online content on elder abuse, including an infographic *Spotting the Signs of Elder Abuse* and a web page, to educate the public and disseminate information about identifying and addressing types of elder abuse and dealing with caregiver stress. In the past year, the web page was updated to include ways that long-distance caregivers can recognize signs of elder abuse. In addition, the NIA Information and ADEAR centers respond to roughly 90 inquiries per year related to elder maltreatment and make appropriate referrals.

For more information see:

- https://www.nia.nih.gov/health/elder-abuse

NIA is also currently supporting new research in this area. For example, NIA supports multiple awards under a funding opportunity entitled Primary Care-Based Screening and Intervention Development for Prevention of Abuse in Older and Vulnerable Adults in the Context of AD/ADRD (RFA-AG-22-024 and RFA-AG-24-048). This research is developing evidence-based primary care screening tools and behavioral interventions to prevent mistreatment in at-risk older and vulnerable adults with MCI and AD/ADRD and their families. With RFA-AG-22-020 (Triadic Interactions in Clinical Encounters Involving People with AD/ADRD, Clinicians, and Care Partners) and RFA-AG-20-006 (Interpersonal Processes in Alzheimer's Disease and Related Dementias Clinical Interactions and Care Partnerships [R01 - Clinical Trial Optional]), NIA invited research on clinician screening tools for abuse and behavioral interventions for unhealthy caregiving relationships. NOT-AG-20-039 (Notice of Special Interest: Fundamental and Translational Research on Decision Making in Aging and/or AD/ADRD) invited research focused on social and other factors that render older adults vulnerable to financial exploitation and other forms of mistreatment and abuse.

NIA released a funding opportunity (RFA-AG-23-007) to establish a network to develop better measures of decision capacity in individuals with cognitive impairment and to help identify opportunities to intervene at earlier stages and teach skills that would directly enhance the current level of decision making quality or provide support to establish safeguards against fraud or facilitate programs to establish power of attorney relationships to help extend the interval during which independence could be maintained. An award was made in FY 2023 to establish the Advancing Reliable Measurement in Cognitive Aging and Decision-making Ability research network and integrate efforts to adapt, develop, validate and norm measures to assess decision making functionality in an aging population. For a full list of funding opportunities and their links, please see Appendix 3.

For more information see:

- https://reporter.nih.gov/project-details/10663728
- https://reporter.nih.gov/search/mRv4AX7TAkay_MZUE5zhUA/projects?shared=true
- https://reporter.nih.gov/search/RcQlAlM89U-n4oAd__2qKg/projects?shared=true
- https://reporter.nih.gov/search/Srp1dhzIWEi2j7vz_Wq3cg/projects?shared=true
- https://www.nia.nih.gov/health/elder-abuse

DoJ's National Institute of Justice (NIJ) maintains a web page featuring NIJ-funded elder abuse research entitled Overview of Elder Abuse, and another page specifically on financial exploitation entitled Financial Exploitation of the Elderly.

For more information see:

- https://nij.ojp.gov/topics/articles/financial-exploitation-elderly
- https://nij.ojp.gov/topics/articles/overview-elder-abuse

The Elder Justice Initiative (EJI) website hosts the Elder Abuse Resource Roadmap dedicated to identifying where to report financial exploitation in addition to information resources on a variety of financial exploitation topics. The website also hosts an elder justice research web page featuring foundational articles, some of which address elder abuse and dementia.

For more information see:

- https://www.justice.gov/elderjustice

(ONGOING) Action 3.D.4: Improve the ability of legal services to address the needs of people with Alzheimer's disease and related dementias

Lead Agency: ACL
Partners: NLRC, legal assistance developers

ACL has a number of related activities underway to improve legal services for people with AD/ADRD. The ACL National Legal Resource Center (NLRC) website includes a special section addressing advance planning and end-of-life issues, a resource for legal and aging/disability service professionals and family caregivers assisting people with AD/ADRD or other causes of diminished capacity.

ACL-funded state and community grants programs include pilot programs designed to make dementia-capable legal services available to persons with dementia and their caregivers. Program participants are providing dementia training to legal services providers, as well as implementing voucher programs to aide in advance planning.

ACL grants to states and communities include pilot programs designed to make dementia-capable legal services available to persons with dementia and their caregivers. Program participants are providing dementia training to legal services providers, as well as implementing voucher programs to aide in advance planning.

The NADRC partnered with the American Bar Association Commission on Law and Aging to develop a series of guides, *Advance Planning for People Living with Dementia*, to empower people to make their own decisions about important topics like finances, health care, and living arrangements before the need arises. The guides support PLWD and their family members or other care partners in knowing what to plan for and how to get started. The guides cover four topics: (1) health care planning; (2) financial planning; (3) care planning; and (4) supporting someone living with dementia in making decisions.

The partnership also resulted in the creation of *The Handbook for Helping People Living Alone with Dementia Who Have No Known Support*. The Handbook includes practical strategies for identifying people who are living alone without support, assessing risk, building trust, identifying family and friends willing to help, determining decision making capacity, options for helping the person maintain their independence, and the basics of guardianship or conservatorship.

For more information see:

- https://ncler.acl.gov/

(UPDATED) Action 3.D.5: Educate law enforcement and other first responders about interacting with individuals with Alzheimer's disease and related dementias

Lead Agency: DoJ
Partner: ACL

DoJ continues to educate law enforcement and public safety professionals about how to interact appropriately with missing persons with AD/ADRD and to provide current information and resources to help law enforcement agencies and the communities they serve. This education includes how to prevent persons with AD/ADRD from wandering and becoming lost, as well as information on locating those who do wander and become lost. The training and resources are provided through projects funded by the DoJ Office of Justice Programs' Bureau of Justice Assistance.

ACL grantees are using grant funds to engage with and train law enforcement and other first responders. In recent years a grantee in Texas has brought dementia education to law enforcement cadets, bringing dementia capability to over 400 cadets in their service area. Examples of resources available include a series of well-received law enforcement training videos to address wandering, driving, and encountering disoriented individuals on “house calls.” Another grantee has developed Gun Violence Restraining Order training and partnered with the Deputy City Attorney for its delivery.

The NADRC website is home to a number of grantee-developed training materials and other resources dedicated to bringing dementia capability for first responder agencies. ACL ADPI grantees consistently include first responder education in their funded programs. Recent advances include efforts to engage and train Tribal law enforcement in dementia education, through ACL’s Dementia Capability in Indian Country grantee efforts.

For more information see:

- https://nadrc.acl.gov/resources
- https://www.alzoc.org/professionals/training/

The EJI continues its commitment to ensuring law enforcement has the training and tools to respond to victims of elder abuse robustly and appropriately, including persons with AD/ADRD. For example, EJI currently hosts relevant resources on the law enforcement web page, including:

- *Safe Return: Alzheimer’s Disease Guide for Law Enforcement* (Alzheimer’s Association).
- *A Booming Problem: Alzheimer’s, Dementia, and Elder Abuse* (DoJ Office of Community Oriented Policing Services).
- *Approaching Alzheimer's: First Responder Training Program* (Alzheimer’s Association).
- *Communicating with Someone with Dementia* (Alzheimer’s Association).

For more information see:

- http://cops.usdoj.gov/html/dispatch/05-2015/alzheimers_dementia_elder_abuse.asp
- http://www.alz.org/care/alzheimers-first-responder.asp
- https://www.alz.org/help-support/caregiving/daily-care/communications
- https://www.justice.gov/elderjustice/law-enforcement-1

(ONGOING) Action 3.D.6: Work with communities to develop best practices for protecting people with Alzheimer’s disease and related dementias

Lead Agency: ACL
Partners: DoJ, CDC ACL, NADRC, and dementia grantees

ACL and partners will continue to make the provision of dementia-specific education of first responders a priority in their funded programs. The NADRC website is home to a number of grantee-developed training materials and other resources dedicated to bringing dementia capability for first responder agencies. ACL ADPI grantees consistently include first responder education in their funded programs. The NADRC developed a guide for first responders entitled *Working Together: How Community Organizations and First Responders Can Better Serve People Living with Dementia*. The Guide helps community organizations collaborate with first responders to better serve PLWD, a need increasingly recognized by first responder agencies. This Guide explains why this issue is gaining attention, provides strategies for building successful partnerships, and describes the types of programs that can benefit PLWD. Also included are resources such as training materials, sample policies, tip sheets and more.

In addition to the Guide, ACL grantees developed a training session on the basics of dementia for first responders which includes descriptions of dementia, the changes that accompany dementia (e.g., communication, behavior), and important safety and wandering issues related to dementia. Alzheimer’s San Diego created a referral form that law enforcement can use to refer an individual or family member to Alzheimer’s San Diego for support or education. A complement to these resources is the four-part training series of videos developed by Alzheimer’s Orange County which present educational vignettes to address wandering, driving, and encountering disoriented individuals on "house calls" involving actual first responders and actors portraying PLWD and reminders about how to handle the interactions and any follow-up.

For more information see:

- https://nadrc.acl.gov/resources
- https://www.alzoc.org/professionals/training/

EJI's Multidisciplinary Team (MDT) Technical Assistance Center provides educational offerings and technical assistance to elder abuse MDTs on the topic of detecting and providing appropriately tailored elder abuse interventions for older adults with AD/ADRD.

For more information see:

- https://www.justice.gov/elderjustice/mdt-tac

(ONGOING) Action 3.D.7: Develop a supported decision-making model as an alternative to guardianship

Lead Agency: ACL

ACL continues to support the National Resource Center for Supported Decision-Making (NRC-SDM) which builds on and extends the work of Quality Trust's Jenny Hatch Justice Project by bringing together vast and varied partners to ensure that input is obtained from all relevant stakeholder groups including older adults, people with IDD, family members, advocates, professionals, and providers. The NRC-SDM partners bring nationally recognized expertise and leadership on SDM, representing the interests of and receiving input from thousands of older adults and people with IDD. They have applied SDM in groundbreaking legal cases, developed evidence-based outcome measures, successfully advocated for changes in law, policy, and practice to increase self-determination and demonstrated SDM to be a valid, less-restrictive alternative to guardianship.

In September 2020, ACL extended its commitment to keeping SDM as a priority with the award of a cooperative agreement to the University of Massachusetts Boston to implement a national Alternatives to Guardianship (AtG) Youth Resource Center. The AtG is a new initiative focused on diverting high school students with IDD away from guardianship to SDM, which allows individuals with disabilities to make decisions for themselves and choose the level of support they need from people and organizations they trust.

For more information see:

- http://www.supporteddecisionmaking.org/

Strategy 3.E: Assess and Address the Long-Term Services and Supports Needs of People with Alzheimer's Disease and Related Dementias

LTSS are essential to helping people with AD/ADRD receive the assistance that they need. HCBS help people with AD/ADRD remain in their homes in the community, where many prefer to be. For those who need additional support, a residential care or nursing facility may be a better fit. Through the Actions below, HHS will assess the availability and quality of services across residential settings to ensure all people with AD/ADRD receive the care they need in the setting they prefer.

(UPDATED) Action 3.E.1: Understand contributing factors to and policy implications of nursing facility closures

Lead Agency: ASPE

In spring 2022, ASPE completed an evaluation of nursing facility closures over the last decade. Nursing facility closures can have negative effects on residents and affect access to care in this setting. Although a certain proportion of nursing facility closures is expected and may be considered an appropriate market response to poor performance or oversupply, stakeholders are concerned with recent news of increases in the number of closures and how that may limit access to necessary LTC services in some circumstances. This study explored the incidence rate of nursing facility closures per year over the last decade and described factors that may be contributing to those closures. The study found that closures were relatively stable from 2011 to 2017, averaging 121 facilities or 0.82% per year. Conversely, openings decreased from 2011 to 2019, averaging 135 facilities (0.91%) per year from 2011 to 2018 and then dropping to 87 facilities (0.59%) in 2019. In the aggregate, the nursing home supply may be appropriately meeting demand; however, there may be cases where closures could cause immediate access problems for people who need this level of care.

In order to understand whether nursing homes closed due to the significant financial impacts of the COVID-19 pandemic, ASPE replicated these analyses on data from 2020 and 2021. The analysis found that closures did not increase during 2020 and 2021. There is, however, some evidence that nursing homes that were more impacted by COVID-19 were more likely to close. Nursing home characteristics associated with higher likelihood of closure included size, occupancy rate, and percentage of residents with Medicare as the primary payer. Explanations for the absence of additional closures during 2020 and 2021 include several strategies by nursing home providers to mitigate staffing shortages, including freezing admissions and closing portions of facilities, and federal and state financial assistance to nursing homes that likely prevented or delayed closure.

For more information see

- https://academic.oup.com/healthaffairsscholar/article/1/2/qxad025/7227995
- https://aspe.hhs.gov/reports/nursing-home-closures-during-covid-19

(ONGOING) Action 3.E.2: Determine progress made in rebalancing Medicaid long-term services and supports toward home and community-based services among older adults

Lead Agency: ASPE

Through this project, launched in fall 2021, ASPE is assessing the use of HCBS as a share of Medicaid LTSS use (i.e., rebalancing) between 2016 and 2019. Using the Transformed Medicaid Statistical Information System (T-MSIS) data, ASPE is estimating rebalancing measures, nationally, by state, and by select subpopulations (e.g., older adults with and without IDD and younger adults with and without IDD). Analyses will involve identifying state characteristics that correlate with greater use of HCBS. This research is informed by a panel of federal and non-federal experts which convened in October 2023 and March 2024 to provide feedback and preliminary findings from the quantitative analysis. The findings from this project are expected to be released in 2025.

(UPDATED) Action 3.E.3: Measure differences in medical and long-term care use and expenditures of older adults over time

Lead Agency: ASPE

Newly available data linkages between T-MSIS (which includes both fee-for-service claims and managed care encounter data), Medicare Advantage encounter data, and the NHATS longitudinal data present an opportunity for researchers to learn more about the medical and LTC service use patterns and patient outcomes of older Americans with complex care needs, and to evaluate the effectiveness of interventions and services. This ASPE project follows Medicare-Medicaid dual eligible and Medicare-only respondents of the NHATS over the period of 2015-2019, to measure differences in medical and LTC use and expenditure patterns over time. The analysis has two separate but related focal points: (1) the impact of growth in enrollment in Medicare and Medicaid managed care plans on acute and LTC service use patterns for both Medicare-only and Medicare-Medicaid dual eligible older adults (aged 65+); and (2) factors associated with older adults, both Medicare-only and dual eligible, transitioning from the community to long-stay nursing home care that may potentially be subject to policy interventions (e.g., supports for family caregivers). Results are expected in 2025.

(ONGOING) Action 3.E.4: Strengthen states' ability to provide and sustain dementia-capable home and community-based services

Lead Agency: ACL

ACL's ADPI program continues to make funds available to states to develop and implement dementia-capable HCBS. Through the ADPI program, states are able to pilot programs in support of persons living with AD/ADRD and their caregivers in an effort to develop evidence for sustainability post-grant funding.

Since 2017, ACL has required grantees and partners to complete an annual dementia capability assessment tool to measure the improvement in dementia capability over time. The short tool is designed to measure change in the dementia-capability of the systems within which funded organizations are operating. Over time, the tool data represents the positive impact of the ACL ADPI program on participants over time. The tool is available for non-grantees on the NADRC website.

For more information see:

- https://nadrc.acl.gov/

(ONGOING) Action 3.E.5: Fill service gaps in dementia-capable systems by expanding the availability of specialized services and supports to target previously under-served populations

Lead Agency: ACL
Partner: CMS

Since 2014, ACL has funded AD/ADRD programs designed to fill service gaps at the community level. This program was initiated to supplement long-standing state managed programs. Target areas for the community programs were chosen to align with gaps identified by the NAPA Advisory Council. Funded organizations are required to target program activities designing and delivering supportive services to persons living alone with AD/ADRD, improving quality and effectiveness of services for individuals aging with IDD and AD/ADRD or those at high-risk, and delivery of behavioral symptom management training and expert consultations for family caregivers. ACL grantees also bring culturally-competent resources to the communities they serve. In addition to adapting tools for cultural competence, they are also interpreted and tested with native speakers (as appropriate) to ensure the translations are communicated as intended. ACL's NADRC presently has resources in Chinese, Japanese, Korean, Russian, Spanish and Tagalog and expect to soon add Farsi and Arabic language resources.

Profiles of ACL-funded projects are available for viewing on the NADRC website. Subject to appropriations, ACL anticipates continuing the programs to increase the availability of EBIs across the country.

For more information see:

- https://nadrc.acl.gov/

(ONGOING) Action 3.E.6: Improve home and community-based services provided through state Medicaid waivers

Lead Agency: CMS

In 2024, CMS released the final Ensuring Access to Medicaid Services rule (Access Rule) which includes new requirements related to the direct care workforce, access to HCBS, health and safety protections, payment adequacy, quality measures, person-centered planning, and more. In addition, states are expected to use state funds equivalent to the funding received under Section 9817 of the American Rescue Plan Act by March 31, 2025, to enhance, expand, and strengthen Medicaid HCBS, promoting community living for older adults and people with disabilities, including people with dementia.

For more information see:

- https://www.cms.gov/newsroom/fact-sheets/ensuring-access-medicaid-services-final-rule-cms-2442-f
- https://www.medicaid.gov/federal-policy-guidance/downloads/smd22002.pdf

(ONGOING) Action 3.E.7: Expand resources to support person-centered care

Lead Agency: ACL

NCAPPS is an initiative from ACL and CMS that helps states, tribes, and territories implement person-centered thinking, planning, and practice. NCAPPS supports the provision of technical assistance in the delivery of person-centered care, including dementia care. In 2023, NCAPPS developed a series of short videos and a companion guide on Culture and Person-Centered Practices. The videos support acknowledging and understanding the importance of people’s racial and cultural identities. In the videos, people share their thoughts on how their racial and cultural identities shape their expectations and views of support systems.

NCAPPS is managing a Self-Direction Learning Collaborative which is an opportunity for participants to learn about, test, and implement specific systems change efforts focused on enhancing the availability, quality, and access to self-direction.

For more information see:

- https://ncapps.acl.gov/docs/Shorts/Culture_PCP_Shorts_Companion508.pdf
- https://ncapps.acl.gov/home.html
- https://ncapps.acl.gov/learning-collaboratives.html
- https://ncapps.acl.gov/ncapps-shorts.html

Goal 4: Enhance Public Awareness and Engagement

Most of the public is aware of AD/ADRD; more than 85% of people surveyed can identify the disease and its symptoms. AD/ADRD is also one of the most feared health conditions, yet there are widespread and significant public misperceptions about diagnosis and clinical management. Misperceptions lead both to delayed diagnosis, and to people with the disease and their caregivers feeling isolated and stigmatized. Enhancing public awareness and engagement is essential because it forms the basis for advancing the other goals of the National Plan. A better understanding of AD/ADRD will help engage stakeholders who can work to address the challenges faced by people with the disease and their families. These stakeholders include a range of groups such as health care providers who care for people with AD/ADRD and their caregivers, employers whose employees request flexibility to care for a loved one with the disease, groups whose members are caregivers, and broader aging organizations. The Strategies and Actions under this Goal are designed to educate these and other groups about the disease.

Strategy 4.A: Educate the Public about Alzheimer's Disease and Related Dementias

Greater public awareness of AD/ADRD can encourage families to seek assessment, reduce isolation and misunderstanding felt by caregivers, and help link people in need to accurate information, resources, and services.

(ONGOING) Action 4.A.1: Enhance public outreach about Alzheimer's disease and related dementias

Lead Agencies: ACL, NIA, CDC, IHS
Partners: multiple cross-agency and funded partners

Through its grant programs and the NADRC, ACL continues to conduct outreach and build awareness of AD/ADRD. All ACL grantees include awareness and outreach in their programs. Numerous grantee programs include dementia-friendly community activities in their projects, partnering with established AD/ADRD stakeholders, as well as training volunteer educators of community organizations including, but not limited to, faith-based organizations, business leaders and grass roots volunteer organizations like Rotary Clubs.

ACL's NADRC website is an established hub for resources to support community outreach and education efforts. The website offers a broad range of resources to support the development and implementation of community-based AD/ADRD education programs.

For more information see:

- https://nadrc.acl.gov

NIA operates the ADEAR center, the primary Federal Government resource for information about AD/ADRD, research, and caregiving. See Action 1.E.2 for more information about ADEAR.

NIA also maintains and updates the Alzheimers.gov website, available in English and Spanish, which receives more than 130,000 visits monthly. In 2024, leveraging advanced technology, NIA launched the Alzheimers.gov Virtual Assistant, a web-based tool that provides the public, including PLWD, caregivers, and families, with quick and easy access to information on dementia, clinical trials, and more, as well as the ADEAR center.

In addition, NIA frequently shares AD/ADRD information with the public through its social media channels, the development of infographics and videos, and regular outreach efforts. Examples of outreach efforts include:

- **June 2022**: #AlzScience Twitter Chat highlight current and future progress in dementia research that received more than 3.7 million impressions (people reached).
- **June 2024**: NIA led a social media campaign on Alzheimer's in Spanish and English. The hashtag generated 2.6 million impressions and the campaign drove more than 2,200 visits to NIA's dementia resources.

NIA also developed new videos and generated thousands of views on ADRD topics. Examples include:

- How Alzheimer's Changes the Brain (995K views; Spanish version: 423K views).
- What is Dementia? (66K views; Spanish: 6K views).
- What is Frontotemporal Dementia? (17K views; Spanish: 6K).
- What is Lewy Body Dementia? (5.9K views; Spanish version pending).

NIA also developed and continues to update the Alzheimer's and Related Dementias Press Kit that serves as a resource for journalists as well as other audiences to help raise awareness of AD/ADRD research. NIA additionally alerted members of the media about NIA-funded research specific to AD/ADRD via news releases, research highlights, and media availabilities.

For more information see:
- https://www.alzheimers.gov/
- https://www.alzheimers.gov/es
- https://www.nia.nih.gov/about/stay-connected
- https://www.nia.nih.gov/aging-alzheimers-resources-multimedia/alzheimers-press-kit
- https://www.nia.nih.gov/news/all

CDC's Alzheimer's Disease Program publishes web features, a series of podcasts, weekly newsletters to more than 45,000 subscribers, and social media to more than 27,000 followers with the goal of increasing awareness and engagement by the public and its stakeholders about AD/ADRD. CDC also publishes short podcasts aimed at bringing awareness of dementia for various audiences.

For more information see:
- https://podcasts.apple.com/us/podcast/ep38-cdc-highlights-social-isolation-loneliness-among/id1508046828?i=1000501704755

CDC is also collaborating on several projects to reduce social isolation and maintain mental health among older adults. CDC works closely with the CDC Foundation and other partners to ensure that disproportionately impacted communities receive the resources and technical assistance necessary to provide COVID-related services to older adults.

The CDC's BOLD Public Health Programs support state, county and city health departments to help establish or strengthen 45 ADRD Coalitions in the United States, including coalitions in 37 states, eight counties and cities, the District of Columbia, and Puerto Rico. These Coalitions have established or will establish state, county or city ADRD Strategic Plans by mid-2025 or earlier. The ADRD Strategic Plans will be implemented by the Coalitions and supporting organizations to sustainably address ADRD by advancing health equity, increasing awareness and understanding of ADRD, enhancing community-clinical linkages, ensuring early detection and diagnosis, reducing risk of cognitive impairment, and supporting caregivers. The 45 ADRD Coalitions on average have approximately 51 members and represent an average of approximately 35 organizations/affiliations, or a total of 2,173 members and 1,522 organizations/affiliations for all 45 Coalitions nationwide. The organizations or affiliations represent state and local health departments, state and local aging services, subject matter experts, academia, primary care practice, health care providers, health systems, CBOs, policy makers, caregivers, individuals with dementia, LTC providers, and organizations representing high-risk groups.

IHS continues to develop resources to support internal and public outreach on AD and dementia tailored to Tribal and Urban Indian populations.

For more information see:

- https://www.ihs.gov/alzheimers/
- https://www.ihs.gov/newsroom/ihs-updates/

The Focus on Aging: Federal Partners' Webinar Series is a collaboration of nine of the federal agencies that support the health and wellness of older adults in the United States: ACL, AHRQ, ASPE, CDC, CMS, HRSA, IHS, NIA, and VA. The series addresses contemporary topics in aging with relevance to public health and health care professionals, aging services organizations, the research community, and other stakeholders in aging. In addition to general topics of interest for older adults and those who work with them, each webinar includes information specific to individuals with AD/ADRD and their caregivers. All prior webinars are made available to the public on the Focus on Aging: Federal Partners' Webinar Series website.

For more information see:

- https://www.nia.nih.gov/focus-aging-federal-partners-webinar-series

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(ONGOING) Action 4.A.2: Facilitate translation of data and surveillance to inform the public

Lead Agency: CDC

Since 2019, CDC has translated the national caregiving and SCD infographics into Spanish and developed corresponding infographics for Black, AI/AN, AAPI, Hispanic, and LGBT individuals, as well as women, men, residents of rural areas, and veterans. These infographics can be used to educate the public and aid in making decisions on how to allocate resources and funding.

For more information see:

- https://www.cdc.gov/healthy-aging-data/brfss/index.html

Additionally, CDC developed infographics in collaboration with the Alzheimer's Association and IHS. These resources are marketed on the Alzheimer's Association website and distributed to a national network of state Alzheimer's Association offices, public health professionals, and decision makers.

The State of Aging and Health in America: Data Brief Series are topic-specific documents focusing on public health issues related to older adults developed by CDC and the National Association of Chronic Disease Directors (NACDD). These briefs provide public health professionals with the most recent data available on health and aging-related conditions, including the importance of brain health, the management of chronic conditions, and caregiving burdens, to help identify needs and mitigate the future effects of a growing older population. The briefs also provide data by important breakdowns such as by state, age, gender, and ethnicity which can be useful for states and other stakeholders in making informed decisions and policies related to these issues. The next in the Data Brief series are expected to be released in late 2024 and will provide updated data on cognitive decline and caregiving topics.

For more information see:

- https://www.cdc.gov/healthy-aging-data/brfss/index.html

CDC also supported the Alzheimer's Association to develop the *Needs Assessment Toolkit: Guidance and Resources for State Public Health Agencies on Comprehensive Needs Assessments Related to Alzheimer's and Other Dementias*. This document aims to increase the use of information and insights to appropriately respond to the growing public health burden associated with AD/ADRD through comprehensive needs assessments. These are at the core of a state's ability to effectively use information to develop, implement, and maintain state plans that are focused either exclusively on AD/ADRD, or more broadly on the incorporation of cognitive health and impairment into other state public health plans. Public health agencies have a high-level of expertise related to developing and conducting needs assessments. This Toolkit has been developed to help states leverage their expertise in conducting needs assessments so as to enhance their ability to gather and use information specifically related to AD/ADRD.

Also see Action 1.E.3 for information on resources developed using BRFSS data.

Strategy 4.B: Work with State, Tribal, and Local Governments to Improve Coordination and Identify Model Initiatives to Advance Alzheimer's Disease and Related Dementias Awareness and Readiness across the Government

State, Tribal, and local governments are working to help address challenges faced by people with AD/ADRD and their caregivers. Forty-nine states and a handful of local entities have published plans to address AD/ADRD that cover many of the same issues as the National Plan. Leveraging the available resources and programs across these levels of government will aid in the success of these efforts.

(ONGOING) Action 4.B.1: Continue to convene federal partners

Lead Agency: ASPE
Partners: CDC, NIH/NIA, ACL, CMS, HRSA, AHRQ, IHS, SAMHSA, OASH, VA, NSF, DoD

The Interagency Group on Alzheimer's Disease and Related Dementias, convened on an ongoing basis since April 2011, provides a forum for discussion of AD/ADRD efforts across federal departments and agencies. Participants in this group have gained a better understanding of the roles and responsibilities of other departments and agencies for addressing AD/ADRD. Together, the group has identified existing resources and new opportunities for collaboration, best practices, and initiatives. HHS will continue to convene federal partners to collaborate on AD/ADRD. The group will share research findings, innovative or best practices, and information about new or upcoming initiatives.

(ONGOING) Action 4.B.2: Build upon lessons learned to improve the dementia-capacity of state and local service systems

Lead Agencies: ACL, CDC
Partner: CMS

Improvement of the dementia capability of state and community service systems is at the core of the ACL's ADPI grant program and the mission of the NADRC. ACL and NADRC have developed the Dementia Capability Assessment Tool designed to measure the dementia capability of the LTSS in various organizations and measure improvement over time.

Through the NADRC and the resources they develop, ACL effectively communicates lessons learned in the delivery of dementia supports and services. In addition to making promising grantee-developed tools available on the NADRC website, the NADRC also compiles the lessons learned into topic-specific issue briefs highlighting best practices related to topics such as supporting people living alone with ADRD, volunteerism and social isolation and loneliness. To support dissemination of existing resources the NADRC also promotes best practices through their annual webinar series and their regularly updated program highlight compendium.

For more information see:

- https://nadrc.acl.gov/
- https://nadrc.acl.gov/details?search1=20221214124825
- https://nadrc.acl.gov/details?search1=20230719035406
- https://nadrc.acl.gov/details?search1=20230905035531
- https://nadrc.acl.gov/details?search1=20231010050445

CDC BOLD public health program awardees are funded to create and maintain jurisdiction-wide coalitions to collaborate on setting AD/ADRD priorities informed by data for their jurisdictions. Examples of CDC-funded activities include:

- With a pressing need for specialized care and accurate data on dementia prevalence, the Virginia Department of Health (VDH), a CDC BOLD public health program awardee, embarked on a groundbreaking initiative. Supported by CDC funding, VDH awarded four mini-grants to enhance community education, caregiver training, and the development of a state-of-the-art dementia registry: the Virginia Dementia Patient Registry. This registry, one of only four in the country, provides valuable insights into dementia prevalence among different groups. By leveraging this information, social and medical services can be tailored to meet the specific needs of individuals living with dementia.
- Dementia Friendly Washoe County has a program to host performances where attendees, including PLWD and care partners, can engage with a talented performer, socialize, and connect to community resources. There were 86 cumulative attendees for this program from February 2024 to June 2024.
- The CDC-funded Maryland BOLD public health program awardee facilitated an Alzheimer's Disease and Related Dementias forum in June 2024. The virtual learning event hosted over 80 attendees, providing an opportunity to learn more about the HBI Road Map and the Maryland ADRD Action Plan accomplishments. The forum also offered networking among statewide partners working to reduce the burden of ADRD in Maryland.

The BOLD Center on Risk Reduction provided a technical assistance document with sample actions and activities that could be included in jurisdictional plans, as well as information on the scientific evidence and the potential public health impact for each risk factor.

For more information see:

- https://www.alz.org/media/Documents/compiled-evidence-based-reports.pdf
- https://www.alz.org/professionals/public-health/public-health-approach/alz-association-efforts#phcoe

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(UPDATED) Action 4.B.3: Get Tribal input on Alzheimer's disease and related dementias and support improved coordination between Indian Health Service, Tribal, and Urban Indian Health programs and the Tribal aging network

Lead Agencies: IHS, ACL
Partners: ASPE, VA

IHS undertook Tribal Consultation and Urban Confer to gain insight into needs and opportunities to improve the care and services for AI/AN PLWD and their caregivers and guide the allocation of resources for the IHS Alzheimer's Program. IHS continues to use meetings of the Direct Services and Contracting Tribes, Self-Governance Tribes, and UIOs and other venues to update Tribal and UIO leaders on the work underway through the IHS Alzheimer's Program and solicit ongoing feedback.

(ONGOING) Action 4.B.4: Develop and update a public health road map for assisting state, Tribal, and local health departments in prioritizing actions

Lead Agency: CDC

CDC provided funds to the Alzheimer's Association through a cooperative agreement to co-develop the fourth in the series of HBI Road Maps to advance cognitive health as an integral component of public health. This *Healthy Brain Initiative: State and Local Road Map for Public Health, 2023-2027* was co-authored by experts in public health and brain health, including scientists at CDC. The fourth State and Local Public Health Road Map in the series outlines how state and local public health agencies and their partners can continue to promote cognitive health, address cognitive impairment for people living in the community, and help meet the needs of caregivers. Twenty-four specific actions are proposed in four traditional domains of public health: Strengthen Partnerships and Policies, Evaluate and Utilize Data, Build a Diverse and Skilled Workforce, Engage and Educate the Public.

In 2019, the first-ever *Road Map for Indian Country* was released to serve as a public health guide for AI/AN leaders to learn about dementia and start discussions throughout their communities. In 2023, CDC and the Alzheimer's Association began the process of revising this Road Map. 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, launching in November 2024, will build on the progress and momentum to date and guide professionals working with AI/AN peoples to advance the vision that everyone deserves a life with the healthiest brain possible. IHS actively collaborated in the planning and development of the revised Road Map.

In collaboration with Alzheimer's Association and CDC, IA^2 will lead the strategic planning for the CDC *HBI Road Map for American Indian and Alaska Native Peoples Implementation Guide*. The Implementation Guide will complement the Road Map for American Indian and Alaska Native Peoples designed for public health systems serving AI/AN and Native Hawaiians.

For more information see:

- https://www.cdc.gov/aging-programs/media/pdfs/2024/06/HBI-State-and-Local-Road-Map-for-Public-Health-2023-2027-508-compliant.pdf
- https://www.cdc.gov/aging-programs/php/nhbi/indian-country-resources.html
- https://www.cdc.gov/aging-programs/php/nhbi/indian-country-road-map.html
- https://www.cdc.gov/aging-programs/php/nhbi/roadmap.html

Strategy 4.C: Coordinate United States Efforts with Those of the Global Community

Many nations have developed dementia plans of their own that involve improved care and supports for people with AD/ADRD and their caregivers, as well as enhanced research and public awareness. In implementing the Actions in this National Plan, HHS and its federal partners will coordinate with global partners to enhance these plans, avoid duplication of effort, and optimize existing resources.

(ONGOING) Action 4.C.1: Work with global partners to enhance collaboration

Lead Agencies: ASPE, NIA

In October 2023, the Dutch Ministry of Health, Welfare and Sports, in collaboration with the World Dementia Council, hosted an international meeting to discuss the challenges dementia poses to society and the urgency of dementia; highlight the swift progress that could be made in care delivery, diagnosis and drug discovery; and to agree on concrete actions to improve dementia care and to drive research forward, not least by increasing global public investment in dementia research. ASPE leadership participated in the event and shared about United States efforts highlighted throughout this National Plan.

See Action 1.D.2 for more information on how NIA/NIH engages with global partners, including details about the HRS HCAP initiative, an innovative approach to assessing trends in cognitive function and aging in the United States and worldwide.

For more information see:

- https://g2aging.org/
- https://hcap.isr.umich.edu/
- https://hrsdata.isr.umich.edu/data-products/2016-harmonized-cognitive-assessment-protocol-hcap?_ga=2.118334926.654419972.1601312536-181621991.1601312536
- https://www.nia.nih.gov/research/blog/2019/05/healthy-cognitive-aging-project-major-data-resource-cognitive-epidemiology

Goal 5: Improve Data to Track Progress

The Federal Government is committed to better understanding AD/ADRD and its impact on people with dementia, families, the health and LTC systems, and society as a whole. Data and surveillance efforts are paramount to tracking the burden of AD/ADRD on individual and population health and will be used to both identify and monitor trends in risk factors associated with AD/ADRD and assist with understanding health disparities among populations such as racial and ethnic minorities, low income populations, rural residents, and sexual and gender minorities. HHS will make efforts to expand and enhance data infrastructure and make data easily accessible to federal agencies and other researchers. This data infrastructure will help HHS in its multi-level monitoring and evaluation of progress on the National Plan.

Strategy 5.A: Enhance the Federal Government's Ability to Track Progress

The Federal Government needs improved data on people with AD/ADRD, their caregivers, and the care and supports that they use to address policy questions and plan and evaluate new initiatives. HHS and its partners will identify the policy questions that cannot be answered with existing data, as well as questions likely to arise in the future. These questions will provide a mechanism for identifying gaps, challenges, and changes or additions to data collection.

(**UPDATED**) Action 5.A.1: Identify needed changes or additions to data

Lead Agency: ASPE
Partners: CMS, CDC, NIA, ACL, VA, IHS

HHS will work with federal partners and researchers to identify the data and data infrastructure needed to address new policy issues. These changes or additions may include new or improved measures, new data collection efforts, or links between existing datasets.

CDC submitted proposals for new content in the 2025 National Health and Nutrition Examination Survey (NHANES), resulting in two questions regarding SCD being successfully accepted for inclusion on the questionnaire. Additionally, a caregiving question will be added to the 2025 National Health Interview Survey.

CDC led a project to cognitively test caregiving questions by the National Center for Health Statistics (NCHS) Collaborating Center for Questionnaire Design and Evaluation Research, and a summary report is now available online. Another evaluation is underway to compare two different versions of the BRFSS cognitive decline module.

For more information see:

- https://wwwn.cdc.gov/QBank/report/MacFadyen_2024_NCHS_Caregiving.pdf

CDC continually seeks to identify gaps in data regarding brain health and pursues opportunities to fill them. For example, CDC utilizes various HealthStyles surveys to examine priority topic areas, including early detection of dementia and dementia risk reduction knowledge and practices among PCPs, dementia and caregiving among United States adults, dementia and caregiving among Hispanic adults, and brain health knowledge and perceptions among youth.

(UPDATED) Action 5.A.2: Make needed improvements to data

Lead Agency: ASPE
Partners: CDC, NCHS, NIA

HHS will address the identified data needs or possible improvements and develop questions to be fielded for data collection. These questions may be added to existing studies, be part of supplements to existing studies, or form the basis of a new study.

CDC provided funding to the Alzheimer's Association, through the National Healthy Brain Initiative cooperative agreement, to assist in revision of the cognitive decline module of the BRFSS with individual input from subject matter experts, on information that should be considered in the revision. The revised module was presented to the BRFSS state coordinators in spring 2022 and was approved for use in the 2023 survey as an optional module. The 2023 data from the revised cognitive decline module are expected to be available in winter 2024.

CDC provided funding to the Alzheimer's Association, through the National Healthy Brain Initiative cooperative agreement, to assist in revision of the caregiver module of the BRFSS with individual input from subject matter experts, and presented the revised module to the BRFSS state coordinators for administration in spring 2023. The revised module was approved for use in the 2024 survey as an optional module.

Accurate, timely data is critical to answering key questions about the workforce and driving data-informed policy decisions to improve the quality of and access to HCBS for the millions of Americans who are receiving or need these services. Additional data are needed to better understand the workforce and emerging trends, and to quantify linkages between workforce investments and quality outcomes, both for workers and individuals receiving services. Filling these gaps requires engagement from many entities, including the Federal Government, states, the research community, non-profits, and private sector businesses, who all have an important role to play in building this data infrastructure. ASPE, in partnership with several other federal agencies (e.g., ACL, NCHS, NIA, CMS, DoL) initiated the HCBS Forward initiative to identify, compare, and support the development and improvement of HCBS workforce data. This cross-agency effort was not specific to dementia, but dementia care workforce data is included. The workgroup released an issue brief summarizing their recommendations to federal and state agencies, non-profit organizations, and research institutions to improve data infrastructure and information on the HCBS workforce.

For more information see:

- https://acl.gov/sites/default/files/Direct%20Care%20Workforce/improving-hcbs-workforce-data-issue-brief.pdf

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(ONGOING) Action 5.A.3: Summarize data on cognitive impairment across states

Lead Agency: CDC

CDC continues to summarize and provide infographics from data on cognitive impairment across states. See Action 4.A.2 for a description of the State of Aging and Health in America Data Brief Series, developed by CDC in collaboration with NACDD, through a cooperative agreement. The next in the Data Brief Series are expected to be released in late 2024 and will provide updated data on cognitive decline and caregiving topics.

To bolster data activities, CDC is supporting a large data strategy project with MITRE's Health Federally Funded Research and Development Center (FFRDC). The purpose of this project is to identify and develop, test, and evaluate a public health analytic methodology and process based on the principles of data science that leverages the benefits of a combined, comprehensive suite of existing data sources to better support programmatic activities and address public health use cases. Several key milestones have been achieved to date. First, listening sessions were conducted with a broad range of AD/ADRD subject matter experts that have knowledge of the landscape of public health data and research to gain an understanding of gaps, needs, and opportunities for use in relation to public health data for the AD community. In total, 105 individuals were invited to join a listening session with 58 individuals ultimately participating. Input from participants was used to develop summative conclusions which were then used to inform the development of public health use cases. Multiple data sources are being assessed and will be incorporated to fulfill the public health use cases. These data will then be processed and integrated into the CDC environment with the end goal of developing a platform and prototype to display these data.

(ONGOING) Action 5.A.4: Summarize existing data on people with Alzheimer's disease and related dementias and their caregivers

Lead Agencies: CDC, ODPHP
Partners: ASPE, NCHS, NIA, ACL

CDC, NIA, and ACL provided new data benchmarks and goals related to AD/ADRD through Healthy People 2020 and Healthy People 2030. During the Healthy People 2020 close-out, more recent data was provided for DIA-1 (Increase the proportion of adults aged 65 years and older with diagnosed AD/ADRD, or their caregiver, who are aware of the diagnosis) and DIA-2 (Reduce the proportion of preventable hospitalizations in adults aged 65 years and older with diagnosed AD/ADRD). For Healthy People 2030, the dementia workgroup successfully retained DIA-1 and DIA-2 and added a third core objective, DIA-3 (Increase the proportion of adults with SCD who have discussed their confusion or memory loss with a health care professional). These three objectives each set new and ambitious targets to be achieved during the next decade to improve health and quality of life for people with dementia, including AD/ADRD. Cognitive health and caregiving were added as variables to CDC's Chronic Disease Indicators.

For more information see:

- https://www.cdc.gov/alzheimers-dementia/healthy-people-2030/

Also see Action 4.A.2 for a description of the State of Aging and Health in America Data Brief Series developed by CDC in collaboration with NACDD, and Action 1.E.3 for update on the caregiving and SCD infographics.

NIA-funded Centers on the Demography and Economics of Alzheimer's Disease and Related Dementias developed and released United States dementia trends fact sheets and related materials, including a report on the demography of dementia and dementia caregiving and infographics on United States aging and dementia trends and on family caregiving for people with dementia.

For more information see:

- https://www.nia.nih.gov/research/dbsr/centers-demography-and-economics-aging
- https://www.prb.org/resources/fact-sheet-u-s-dementia-trends/

(ONGOING) Action 5.A.5: Provide analysis of Behavioral Risk Factor Surveillance System data on Alzheimer's disease and related dementias and their caregivers in user-friendly formats

Lead Agency: CDC
Partner: NACDD

CDC funded NACDD through a cooperative agreement to create a series of data briefs addressing topic-specific public health issues related to older adults. These briefs provide public health professionals with the most recent data available on health and aging-related conditions including the importance of brain health, the management of chronic conditions, and caregiving burdens to help identify needs and mitigate the future effects of a growing population of older adults. The briefs also provide data by important breakdowns such as by state, age, gender, and ethnicity which can be useful for states and other stakeholders in making informed decisions and policies related to these issues. These briefs are in the process of revision in 2022-2023.

For more information see:

- https://www.cdc.gov/healthy-aging-data/brfss/index.html

(UPDATED) Action 5.A.6: Leverage data to better understand racial, ethnic, and other sociodemographic disparities in Alzheimer's disease and related dementias

Lead Agency: CMS, IHS

CMS continues to refine its Mapping Medicare Disparities Tool, a starting point to help understand racial and ethnic differences in health outcomes by population (including dementia) and geography.

For more information see:

- https://data.cms.gov/tools/mapping-medicare-disparities-by-population

IHS continues to explore opportunities to identify and use data to promote evidence-based practices (EBP) and enhance clinical care for AI/AN people served by the Indian health system. This is a program priority established during Tribal Consultation and Urban Conferral in 2021. In 2024, the IHS began developing an internal data dashboard to provide regularly updated diagnostic data based on methods outlined in an August 2024 published research article.

The IHS study, released in collaboration with the CDC and the Alzheimer's Association, provided dementia diagnostic rate estimates for AI/AN populations who receive medical care at IHS, Tribal, and UIO programs, or through Purchased/Referred Care. This is the first study of ADRD among AI/AN populations using IHS data. The top-line research finding is that 14% of AI/AN IHS patients with a dementia diagnosis had early-onset dementia (between the ages of 45 and 64) during the study period of 2016-2020. Globally, 9% of cases are early-onset.

For more information see:

- https://agsjournals.onlinelibrary.wiley.com/doi/full/10.1111/jgs.19058

Strategy 5.B: Monitor Progress on the National Plan

The National Plan is intended to be a road map for accomplishing its six goals. It is a document that is designed to be updated regularly. HHS is committed to tracking progress and incorporating findings into an updated National Plan.

(ONGOING) Action 5.B.1: Track National Plan progress

Lead Agency: ASPE

HHS will monitor progress to determine whether actions are being completed as stated in the National Plan, and the extent to which implemented actions contribute to the desired outcomes and changes associated with each strategy. HHS and its federal partners will identify challenges to the successful completion of Strategies and Actions and make recommendations for how they can be addressed. For each strategy, HHS will monitor available population-based data, such as the NHATS, Medicare Current Beneficiary Survey, or the BRFSS to assess the extent to which progress is being made. HHS will use data from both the public and private sectors, as appropriate, to track progress on the National Plan. Additionally, HHS will work to incorporate measures related to AD/ADRD into other surveillance efforts to monitor population health, such as Healthy People 2030 which incorporate objectives related to AD/ADRD.

For each Action, HHS will track implementation to determine whether actions are completed in a timely and successful manner. Progress on each of these actions will be reported to the Advisory Council.

(**ONGOING**) Action 5.B.2: Update the National Plan

Lead Agency: ASPE

Tracking progress will help HHS and the NAPA Advisory Council monitor progress towards the goals of the National Plan and make recommendations for priority actions and updates to the National Plan. HHS will incorporate its findings and the recommendations of the Advisory Council to update the National Plan on an annual basis.

Goal 6: Accelerate Action to Promote Healthy Aging and Reduce Risk Factors for Alzheimer's Disease and Related Dementias

While there is currently insufficient evidence that dementia can be prevented, a growing body of research has identified modifiable risk factors for AD/ADRD and suggests that strategies to reduce the burden of these risk factors may delay onset or slow progression of AD/ADRD and its symptoms. The relationship between hypertension management and cognitive health is among the most robust studied; activities to address other potential risk factors for AD/ADRD include cognitive training and engaging in physical activity. These same activities to preserve cognitive health are also conducive to healthy aging overall. Evidence on the relationship between modifiable risk factors and the incidence of AD/ADRD is evolving, as is research on the effectiveness of interventions to reduce risk.

Under this Goal, the Federal Government will accelerate research on risk factors for AD/ADRD and strengthen the infrastructure that is necessary to rapidly translate and disseminate information about risk factors, interventions to reduce the burden of risk factors, and related health promotion activities to health care providers, community-based providers, and public health networks.

The burden of risk factors for AD/ADRD is disproportionately high among certain racial and ethnic groups (e.g., Black, Hispanic, and AI/AN populations), and among adults with lower SES. These disparities in the prevalence of risk factors -- which are grounded in generations of structural inequality in health care -- contribute to disparities in the incidence of AD/ADRD that are further amplified by disparities in AD/ADRD diagnosis, treatment, and access to care and resources. It is therefore of critical importance that research, interventions, and infrastructure to address modifiable risk factors for AD/ADRD are culturally responsive and grounded in improving equity by addressing the SDOH. Accordingly, future efforts to reduce the burden of risk factors for AD/ADRD will focus on understanding not only what actions individuals can take to reduce their risks, but also what community and system-level investments are needed to facilitate risk reduction and support healthy aging.

Strategy 6.A: Identify Research Priorities and Expand Research on Risk Factors for Alzheimer's Disease and Related Dementias

While NIH has supported dementia risk reduction research for decades, identifying the priorities and milestones to achieve Goal 6 requires increased attention by the research community. Much of the current evidence on modifiable risk factors is low to moderate quality, so more research is needed to better understand the relationship between potential risk factors and AD/ADRD. The Actions below will identify the priorities, establish milestones, and ensure that appropriate stakeholders are involved in the planning process aimed at identifying and addressing modifiable risk factors. Through this work, NIH and partner agencies will develop research priorities and a plan for implementing each phase of research in a coordinated manner.

(UPDATED) Action 6.A.1: Enhance the focus on risk reduction in existing research summits

Lead Agencies: NIA, NINDS, NIH
Partner: CDC

Under Action 1.A.1, NIH convenes a series of annual research summits to address a wide range of critical research issues in AD/ADRD, including basic, translational, and clinical research, as well as research on care and care services and supports. Gaps and opportunities identified by participants providing individual input at these summits are used to inform research planning at NIH. In order to advance research on risk reduction, NIA and NINDS have begun incorporating discussions on risk reduction into the annual summits.

At the 2022 ADRD Summit, risk reduction and SDOH were strong themes in the first cross-cutting session of the Summit, which was dedicated to developing research recommendations to improve health equity in AD/ADRD. Summit participants discussed several related research priorities, for example, the need to identify life-course risk factors (including social, structural, and systemic factors) and multi-level pathways to AD/ADRD inequities, as well as using such discoveries to reduce or prevent these inequities. Each AD/ADRD disease-focused session (e.g., FTD, VCID, LBD) also discussed prioritizing risk factor research, SDOH, and the need to greatly increase representation of minoritized populations in clinical and prevention research. Similarly, a conversation on Enabling a Precision Environmental Health Approach to Risk Reduction and Disease Prevention was a critical component of the 2024 Alzheimer's Research Summit.

The BOLD PHCOE on Risk Reduction hosted a free public meeting on the impact of the SDOH on AD/ADRD, as a preconference event at AAIC 2022. This meeting presented the latest science with presentations from experts on each of the identified risk factors. The BOLD Center will be providing the session as enduring content for those unable to attend.

For more information see:

- https://www.nia.nih.gov/2024-alzheimers-summit
- https://www.ninds.nih.gov/news-events/events/adrd-summit-2022

(UPDATED) Action 6.A.2: Monitor and improve access to public health surveillance data to identify risk factors and establish research priorities

Lead Agency: CDC

CDC monitors data from the Cognitive Decline Module of the BRFSS and the Cognitive Performance and SCD module to the NHANES. In 2022, CDC published a report in the *Morbidity and Mortality Weekly Report* titled, "Modifiable Risk Factors for Alzheimer Disease and Related Dementias Among Adults Aged ≥45 Years - United States, 2019." Based on key findings from this report, a follow-up analysis using novel cognitive functioning data from the 2019-2020 NHANES is underway.

To improve access to the monitoring capabilities of the BRFSS data, in early 2021, CDC released a revised Technical Assistance Document for both the Caregiving and Cognitive Decline Modules designed to provide guidance for BRFSS coordinators and researchers who would like to conduct analyses of the data collected through the 2015-2020 BRFSS Caregiver or Cognitive Decline Optional Modules. These documents provide basic computer code for analyzing the data with a goal to enable consistency in analytic methods and results reported. The BRFSS data is publicly available for users. Updated versions of these technical assistance documents are under development and are expected to be released when new data are made available to assist with the revised versions of the modules.

CDC has made data from the BRFSS Caregiver and Cognitive Decline Modules available in user-friendly formats, to facilitate broader use of these data. These include a searchable data portal, data briefs, and infographics with national estimates, by state, sex, rural status, veteran status, and race/ethnicity.

CDC has also received input from topical and surveillance experts to provide feedback on existing Caregiver and Cognitive Decline Module questions, identify gaps, and suggest improvements to the modules to better align with current literature and needs. Revised versions of these modules have been fielded as optional modules on the BRFSS beginning in 2023 for the Cognitive Decline Module and 2024 for the Caregiver Module.

For more information see:

- https://www.cdc.gov/healthy-aging-data/brfss/index.html
- https://www.cdc.gov/healthy-aging-data/index.html

(ONGOING) Action 6.A.3: Expand and diversify clinical research studies on promising interventions to reduce individual and community-level risk

Lead Agencies: NIA, NINDS, NIH

NIH is funding a wide range of clinical research studies and trials designed to better understand the complex interplay of risk and protective factors for AD/ADRD, and to test interventions to reduce the burden of those risk factors and ultimately decrease the incidence of disease downstream and promote cognitive health. Based on progress in identifying key risk factors, NIH continues to support a range of behavioral intervention trials that are testing the ability of various lifestyle changes to lower the risk of AD/ADRD. Types of interventions currently under investigation include cognitive training, exercise/physical activity, and changes in diet/nutrition. Additional information on some of these studies and the progress made can be found under Action 6.A.7.

To expand NIH's interventional research aimed at decreasing health disparities in AD/ADRD, in 2023 NINDS invited researchers to propose new pragmatic clinical trials in everyday clinical settings aimed at decreasing or preventing VCID outcomes in populations that experience health disparities (RFA-NS-23-001). Proposed interventions are required to be culturally tailored and could include strategies such as blood pressure control implementation, lifestyle modification to promote healthy behaviors, and early detection and treatment of vascular risk factors for AD/ADRD.

Both NIA and NINDS will continue to monitor emerging evidence in the field, including newly identified risk and protective factors, and expand future research investments in the most promising areas. For a full list of funding opportunities and their links, please see Appendix 3.

For additional information see:

- https://www.nia.nih.gov/research/ongoing-AD-trials

(UPDATED) Action 6.A.4: Enhance research to better understand the varying levels of or types of dementia risk across demographic groups

Lead Agencies: NIA, NINDS, NIH

Emerging research suggests that differences in the risks of AD/ADRD reflects differences in both modifiable (e.g., social determinants and intrapersonal factors such as physical activity and education) and non-modifiable factors (e.g., genetics). NIH's strategic planning efforts around AD/ADRD reflect a prioritization of issues related to the racial, ethnic, socioeconomic, and geographic disparities of these conditions. For example, NIA has developed a National Strategy to improve recruitment of racial and ethnic minorities in the research it conducts and funds (referenced above).

NIH continues to expand its portfolio of research on social and structural determinants of health across all conditions. In 2024, NINDS invited applications for clinical research to uncover social, ethical, and behavioral implications and barriers for health equity research in ADRD (RFA-NS-25-013). Applications to this NOFO should focus on establishing clinical trial readiness for community-driven interventions to understand and develop solutions addressing barriers to equity in ADRD. Both NIA and NINDS will continue to invest in these areas of research at the basic, translational, clinical, and epidemiological levels to understand these risk factors and the impact they have on disparities in AD/ADRD between these populations.

Several new and ongoing clinical studies are seeking to determine risk profiles for AD/ADRD, especially regarding vascular risk factors. NIH-funded research is expanding our understanding of how SDOH can drive substantial disparities in vascular health, especially in midlife, that lead to later disparities in dementia. For example. Liu et al. showed that more education was associated with a lower risk of dementia, a result that was substantially mediated through differences in midlife vascular risk factors (i.e., high blood pressure).[22] For approximately 20 years, NINDS has supported the Reasons for Geographic and Racial Differences in Stroke (REGARDS), a longitudinal prospective study of stroke risk in racial and ethnic minorities as well as low SES and rural populations. NINDS and NIA have expanded the study's goals to include understanding disparities in the risk for dementia and cognitive decline as well as stroke. In a 2024 publication, REGARDS researchers examined whether blood levels of vascular lipoprotein(a) [Lp(a)], which has been linked to risk of stroke and heart disease, differed between White and Black participants and whether those differences corresponded to higher risk of cognitive impairment. They showed that higher Lp(a) was associated with increased risk of cognitive impairment in Black but not White individuals.

A variety of exposures in the environments where people live, work, pray, and play across their lives shape health outcomes, including cognitive health and AD/ADRD risk. Together, this comprehensive set of exposures across domains (e.g., physical, chemical, social, psychological, economic) constitute the "exposome." In FY 2022, NIA awarded more than $15 million in grants to support the development of research infrastructure for exposome studies in AD/ADRD, building the foundation for new centers for exposome studies by coordinating work across existing programs and other efforts. Additionally, in response to an FY 2022 funding opportunity (PAR-22-048), NINDS and NIA are collaboratively funding seven projects that examine how known neurotoxicants -- chemicals and other substances that have toxic effects on the nervous system -- may influence the onset and progression of AD/ADRDs. In 2024, NINDS released a funding opportunity for research on the role of environmental stressors, such as heat, crowding, air pollution, noise, violence, and psychosocial stress, on the health inequities in ADRDs (RFA-NS-24-024).

NIA supports nationally representative cohorts that capture data on environmental factors for dementia risk, including the HRS and the HCAP in the United States. NIA also supports studies harmonized to HRS in several other countries. HRS collects demographic, economic, behavioral, cognitive, and contextual information as well as objective health measures via collection of blood samples for approximately 20,000 people ages 50 and older. The HCAP enables researchers to measure and understand dementia risk in ongoing longitudinal studies of aging around the world by using similar methods. In 2024, NIA renewed HRS and HCAP. The renewal includes larger samples of Black/African American and Hispanic/Latino populations in HCAP; contextual data to capture new elements of the exposome, ranging from microscopic to macro-level exposures; and expanded aging and AD/ADRD-relevant blood-based biomarkers.

NIH/CARD scientists are collaborating with the Multi-Partner Consortium to Expand Dementia Research in Latin America to understand whether there are unique genetic risk factors for dementia in Latin American countries, compared to United States populations.

NIA also supports educational cohort studies seeking to understand education and other social factors as risk and protective factors for dementia across the life-course. In addition, NIA funded four awards beginning in 2022 that are working to enhance measures of educational exposures and cognitive assessments in existing studies. In 2024, NIA awarded a grant to create a new Exposome Coordinating Center to foster collaboration and accelerate life-course research on the

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[22] Liu C, Ma Y, Hofman A, Waziry R, Koton S, Pike JR, Windham BG, Power MC, Sharrett AR, Gottesman RF. "Educational Attainment and Dementia: Mediation by Mid-Life Vascular Risk Factors." *Ann Neurol*, 2023; 94(1): 13-26. doi:10.1002/ana.26647.

social, behavioral, economic, and environmental exposures that shape AD/ADRD outcomes and inequities.

NIA has also funded 16 administrative supplements to support research infrastructure on exposome studies in AD/ADRD. To spark new advances in the field, NIA issued several funding opportunities in FY 2024 to fund exposome research as part of NIA's larger efforts to enable a precision environmental health approach to risk reduction and disease prevention. These funding opportunities will support projects that characterize the impact of toxicants, like air pollution, metals, per-fluoroalkyl and polyfluoroalkyl substances, and pesticides, on brain aging and dementia. For a full list of funding opportunities and their links, please see Appendix 3.

For more information see:

- https://pubmed.ncbi.nlm.nih.gov/35234529/
- https://pubmed.ncbi.nlm.nih.gov/36966451/
- https://pubmed.ncbi.nlm.nih.gov/37694266/
- https://reporter.nih.gov/project-details/9918026
- https://reporter.nih.gov/project-details/10118228
- https://reporter.nih.gov/project-details/10975562
- https://www.nia.nih.gov/research/dbsr/global-aging/hrs-international-family-studies-and-harmonized-cognitive-assessment-protocol#protocol
- https://www.nia.nih.gov/sites/default/files/2021-12/Understanding-the-Role-of-the-Exposome-Meeting-Summary.pdf

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(UPDATED) Action 6.A.5: Expand research on traumatic brain injury as a risk factor for neurodegeneration

Lead Agencies: DoD, NINDS, NIH
Partner: VA

Several research studies have suggested a connection between TBI and later incidence of dementia, but additional investigation is needed to confirm and better understand the mechanism involved. DoD, NINDS, and VA are supporting further research to understand the brain changes resulting from TBI, including CTE, and potential relationships with subsequent neurodegeneration. For example, in 2022 NINDS funded new research that examines the association of dementia risk with biological and clinical measures of TBI-related and CTE-related progressive neurodegeneration and neurocognitive decline. Published in 2023, NINDS-funded researchers assessed the presence of various neuropathologies in brain tissue from 571 donors with a history of repetitive head impacts. Similar to what has been found in dementia, cognitive impairment following repetitive head injury is often associated with multiple neuropathologies. For example, CTE was commonly present with cerebrovascular pathology and TDP-43 inclusions. These findings suggest that diagnosis and eventual treatment of TBI-related dementia should target the patient-specific combinations of pathologies. In 2023, NINDS invited new research to develop and characterize experimental models of post-TBI dementia (PAR-23-218) and plans to make multiple awards under this funding opportunity by the end of 2024. Data from these studies, which will be made publicly available, will help researchers better understand the prevalence of TBI-associated dementia and cognitive decline and understand why brain injury can lead to long-term dementia outcomes. NINDS also provides awards to promote cross-training in the fields of TBI and AD/ADRD. A key goal of this research is to identify protective factors or interventions that can improve the course and/or severity of neurodegenerative outcomes.

The CDMRP PRARP continues to support preclinical and clinical research investigating the intersection of military service, TBIs, and long-term effects, such as AD/ADRD. Recently funded research includes projects assessing genetic risk factors, blood biomarkers, and multi-domain risk models predictive of AD following TBI. In FY 2024, the focus areas for the program include care support for the individuals, families, and care partners, prevention and risk reduction, and improving diagnosis and prognosis of AD/ADRD.

The VA ORD continues its multi-pronged approach for TBI-related AD/ADRD. Key initiatives include longitudinal epidemiological studies, intramural and extramural research consortia, and therapeutics.

VA continues to provide intramural investigators the opportunity to conduct studies on the Chronic Effects of Neurotrauma via a RFA. The RFA encourages researchers to work on chronic injury models of TBI with emphasis on the long-term effects of co-occurring conditions. Funding is provided over a 5-year period. The mechanism encourages the development of databases, identification of functional outcomes for rehabilitation, epidemiological studies, and the exploration of co-morbid psychological conditions.

The VA partners with DoD through the Long-term Impact of Military-relevant Brain Injury Consortium/Chronic Effects of Neurotrauma Consortium (LIMBIC-CENC). LIMBIC is the continuation of the original CENC Initiative that began in 2013. With over a dozen study sites nationally (current sites: 12 VA, nine DoD, five academic) and a cohort of 2,500+ veterans and service members, these participants are characterized longitudinally using neuroimaging, fluid, and physiological biomarkers. The biomarkers are coupled to neurobehavioral testing, and all assessments are done every 2 years after the initial baseline for each participant. LIMBIC-CENC also focuses on estimating the frequency of dementia occurring in veterans and service members with a medical history of TBI. Further discoveries will draw upon multiple VA-centered datasets (EHRs, utilization of VA clinical care services, and pharmacy data) to develop TBI phenotypes and to determine clinical trajectories that track progression from MCI to dementias.

VA also supports an intramural, two-site center, the Translational Research Center for TBI and Stress Disorders (TRACTS). The TRACTS veteran cohort has over 800 participants, each has been longitudinally and deeply characterized since TRACTS inception in FY 2010. Veterans have participated in studies that have helped advance a variety of TBI-related research domains that include cognitive neuroscience, diagnostics, epidemiology, cerebrovascular risk factors, neuropsychological/physiological assessments, psychiatry, and ADLs. TRACTS provides veterans direct access to promising non-pharmacological interventions.

VA has been supporting a collaborative research program to examine blast-induced tau- related pathological changes, leveraging the VA Open-Field Blast Core facility. Specific focus is on CTE and AD-pathology using animal models and human post-mortem tissues.

In addition, VA also maintains strategic investments in chronic TBI therapies, with an emphasis on reducing the co-morbid conditions chronic TBI shares with progressive dementias. The pharmaceutical preparation of allopregnanolone has the potential to block neuroinflammation-related neurodegeneration and may also be effective in treating chronic pain and depression. Additionally, VA investigators are assessing the effects of human growth hormone replacement on common TBI-related co-morbidities. The primary and secondary outcomes for quality of life impacts in this study are brain health-related, which may represent a nexus between TBI and dementias. The outcomes include obesity, cardiovascular disease, fatigue, sleep disturbances, cognitive deficits, chronic pain, and depression. For a full list of funding opportunities and their links, please see Appendix 3.

For additional information see:

- https://pubmed.ncbi.nlm.nih.gov/37921042/

(ONGOING) Action 6.A.6: Expand research on the impact of emerging potential risk factors such as COVID-19

Lead Agencies: NINDS, NIA, NIH

Over the past 2 years it has become evident that many diverse individuals who have contracted SARS-CoV-2 experience either a greatly prolonged period of illness (i.e., long COVID) or longer-term post-acute sequelae following acute COVID-related illness (i.e., Post-acute Sequelae of COVID-19 [PASC]) that include but are not limited to neuropathological insult and significant cognitive changes. To investigate these further, NIH launched RECOVER, a research initiative designed to understand, prevent, and treat the post-acute effects of SARS-CoV-2. NINDS and NIA will continue to participate actively in this critical effort and will consider gaps emerging from PASC findings for future investments at the institute level. Additional information is provided under Action 1.B.8.

For more information see:

- https://recovercovid.org/

(UPDATED) Action 6.A.7: Continue clinical trials on the most promising health promotion interventions

Lead Agency: NIA
Partner: VA

Based on progress in identifying key risk factors, NIH continues to support a range of clinical trials that are testing the ability of various behavioral/lifestyle interventions in preventing or delaying the onset of dementia. Types of interventions currently under investigation include cognitive training, exercise/physical activity, and changes in diet/nutrition.

NIA is funding over 150 clinical trials evaluating the ability of various non-pharmacological interventions to enhance cognitive health, and to prevent, treat, or manage AD/ADRD. Promising approaches include addressing modifiable risk factors such as diet, exercise, cognitive training, and sleep.

Results from these non-pharmacological intervention trials show promise for how to potentially reduce one's risk for dementia. For example, the NIH-funded clinical trial found that hearing aids appeared to reduce cognitive decline over 3 years in a group of older adults with specific risk factors for cognitive decline. However, hearing aids did not appear to slow cognitive decline in people without these risk factors. Researchers are now conducting a trial to understand the long-term effects of hearing aid use on brain health.

Another example of an intervention is the NIA-funded the Cocoa Supplement and Multivitamin Outcomes Study for the Mind (COSMOS-Mind) study. The COSMOS-Mind clinical trial evaluated the ability of nutritional supplements to reduce dementia risk revealed that a daily broad-spectrum multi-vitamin can modestly improve memory and cognition in older adults when compared to placebo. The study included participation from more than 3,500 adults ages 60 and older. When the study began, the participants took a series of web-based online tests to assess their cognitive abilities. The tests were then repeated annually for 3 years. At the end of the first year, people taking the daily multi-vitamin had significantly higher scores compared to the people taking a placebo pill. Notably, participants with a history of cardiovascular disease had lower scores at the start of the study compared to those without such history. But after 1 year of taking multi-vitamins, the scores of those with cardiovascular disease improved significantly, becoming comparable to those without the disease. Additionally, an analysis of three trial substudies found that 2 years of daily multi-vitamin use resulted in better global cognition compared to placebo. Additional research is needed to determine if these results are widely generalizable.

Recent findings from the Systematic Multi-domain Alzheimer's Risk Reduction Trial showed modest reductions in known AD/ADRD risk factors. This pilot study was the first United States randomized trial to test the ability of personalized health interventions and coaching in AD risk reduction in adults ages 70 and older. Participants in the trial chose from several interventions depending on their specific risk factors (e.g., becoming more physically active, adopting a healthier diet, blood pressure control). After 2 years of personalized coaching, participants experienced modest improvements in cognition, quality of life, and dementia risk factors when compared to a control group that received health education materials, but no coaching. These results support the use of personalized health coaching in reducing dementia risk in older adults, though further investigation in a larger trial is warranted.

For more information see:

- https://pubmed.ncbi.nlm.nih.gov/37244291/
- https://pubmed.ncbi.nlm.nih.gov/37478886/
- https://pubmed.ncbi.nlm.nih.gov/38010725/
- https://www.nia.nih.gov/news/daily-multivitamin-may-enhance-memory-older-adults

As noted above, NIA funds many clinical trials on health-related behaviors and dementia, including combinations of healthy behaviors. Because these behaviors may need to start decades before disease onset, understanding the factors that support long-term adherence to lifestyle change will be critical. In early 2021, NIA released new funding opportunities to support research, including behavior change clinical trials, on the psychology of motivation, value-based decision making, and social support. The hope is that findings from this line of research will help investigators develop ways to help people adopt and sustain healthy behaviors over many years. NIA also supports trials exploring cognitive training as a risk reduction strategy. Data analyses from the Advanced Cognitive Training in Vital Elderly study demonstrated that a specific cognitive intervention, speed of processing training, may significantly delay the incidence of cognitive impairment across 10 years. As a follow up, NIA funded the Preventing Alzheimer’s with Cognitive Training trial to determine whether this cognitive training technique successfully delays the onset of clinically defined MCI or dementia across 3 years.

See Action 1.B.5 for additional updates regarding the ACTC and ongoing clinical trials supported by NIA.

NIA has also released NOFOs specifically focused on promoting healthy lifestyle changes, including RFA-AG-23-034 (Mechanism-Focused Research to Promote Adherence to Healthful Behaviors to Prevent Mild Cognitive Impairment and AD/ADRD). For a full list of funding opportunities and their links, please see Appendix 3.

For more information see:

- https://clinicaltrials.gov/ct2/show/NCT03848312
- https://hscweb3.hsc.usf.edu/blog/2021/04/06/usf-awarded-five-year-44-4-million-nih-grant-to-test-whether-computerized-brain-training-can-reduce-dementia-risk-in-older-adults/
- https://reporter.nih.gov/project-details/10334504
- https://www.nia.nih.gov/research/ongoing-AD-trials#section3

Also see Action 1.D.2.

Since 2020, VA has been one of the recruitment networks for the NIA-funded the PREVENTABLE trial, which aims to determine whether statins can prevent dementia and disabilities in addition to heart disease and other cardiovascular-related deaths. The VA CSP Pharmacy Coordinating Center serves as the central pharmacy for the trial to distribute medications to study participants. VA continues to support clinical trials of interventions to reduce risks for developing AD/ADRD or alleviating the symptoms.

VA continues to support clinical trials that aim to prevent the progression of MCI to dementia and to promote brain health. Interventional approaches include water-based exercise and non-invasive brain stimulation coupled with cognitive training to improve cognitive function in veterans diagnosed with MCI. In addition, VA continues to support studies on promising approaches that could lead to health promotion interventional trials.

In 2023, VA established a new Alzheimer's Disease Coordinating Center at the Ralph H. Johnson VA Medical Center in Charleston, South Carolina. The main function of this Coordinating Center is to facilitate research-clinical collaboration and data-sharing within the VA. The Coordinating Center also serves an important role in identifying and addressing barriers to AD/ADRD clinical research efforts within the VA enterprise.

For more information see:

- https://pubmed.ncbi.nlm.nih.gov/34880498/

Strategy 6.B: Facilitate Translation of Risk Reduction Research Findings into Clinical Practice

As understanding of potential modifiable risk factors emerges, the Federal Government will quickly disseminate information and educate health care providers about risk factors and interventions to reduce their burden, so that when appropriate measures can be considered in clinical settings through informed and shared decision making. Dissemination of research findings to clinical settings will also provide individuals with information about what may help in delaying the onset and/or slowing the progression of AD/ADRD, and resources available to support them.

(**ONGOING**) Action 6.B.1: Educate the health care workforce about risk reduction

Lead Agencies: HRSA, CDC
Partner: ACL

It is essential for the health care workforce to understand the risk factors for dementia in order to promote risk reduction among adults. HRSA will use its network of GWEPs to develop and disseminate curricula to train the health care workforce in using a "whole-person" approach that encompasses all of the patient's needs to address individuals' brain and behavioral health. HRSA requires geriatrics workforce development programs to include training on the AWV. In FY 2023, HRSA also required that the primary care partners of the geriatrics workforce development programs work to obtain/maintain Level 1 and Level 2 AFHS recognition, which includes addressing the 4Ms for all older adults in their practices. As of January 2024, 272 primary care partners (representing all 48 GWEPs) had achieved Level 1 AFHS recognition, and 144 primary care partner sites (representing 31 GWEPs) had achieved Level 2 AFHS recognition.

To increase health care providers' awareness of brain health, CDC supported the ACPM to develop two Brain Health Continuing Education Courses regarding brain health and dementia risk deduction to increase physician and health care professionals' knowledge and facilitate improvements in clinical practice.

In 2022-2023, CDC supported the National Association of Community Health Centers to complete a three-part webinar series on provider awareness and brain health and a self-guided micro-learning course on the aging population and dementia. Resources, materials, and reimbursement strategies were demonstrated and discussed. The sessions also included multiple national partners with a demonstrated history in working with populations at a higher risk for developing ADRD, who shared educational materials culturally tailored for these populations.

CDC's BOLD PHCOE in Early Detection of Dementia has developed an early detection of dementia toolkit for health systems. The toolkit is a resource for anyone who wants to learn more about recognizing dementia in health care settings -- outpatient clinics, hospitals, emergency departments, and other services.

The BOLD PHCOE in Dementia Caregiving has provided a series of webinars including "The Value of State Dementia Registries for Public Health Action in Dementia Caregiving" and "Public Health and Faith." A toolkit on public strategies in Dementia Caregiving for public health agencies in under development. The toolkit will provide potential strategies and interventions that public health agencies can implement to support and elevate the work of family dementia caregivers in their jurisdictions, that are consistent with the HBI RM4. Public health agencies may use the toolkit as a source of ideas and inspiration when decided what strategies and actions to take.

For more information see:

- https://bolddementiadetection.org/wp-content/uploads/2024/02/BOLD_Toolkit_HSP_2024.pdf
- https://www.acpm.org/initiatives/brain-health/
- https://www.acpm.org/initiatives/brain-health/brain-health-resources/
- https://www.sciencedirect.com/science/article/pii/S0749379721002002?via%3Dihub

With funding from CDC, AMA addressed risk reduction of ADRD at a live educational event. Free CME credit is available and a recording can be found on AMA's Ed Hub. The event featured tips for blood pressure control in primary care. AMA's Chief Health and Science Officer also provided a 2-minute video on the importance of risk reduction.

For more information see:

- https://edhub.ama-assn.org/science-medicine-public-health/pages/brain-health-dementia-video-series

CDC-funded BOLD public health program awardees develop their own health care workforce education and trainings based on EBP and latest research. Awardees have developed webinars and trainings for primary health care providers, CHWs, first responders, and other professionals. These trainings adhere to national guidelines and make continuing education credits available to participants. For example:

- The Virginia BOLD public health program offers CHW trainings through its site: Working with Clients Living with Dementia - Brain Health Virginia. Hundreds of CHWs have received this training statewide.
- The CDC-funded Tennessee BOLD public health program awardee developed the Healthy Brain Toolkit for Public Health, designed to educate public health professionals about the intersection of chronic disease and AD.
- The Minnesota BOLD public health program awardee educated CHWs on the oral health needs of people living with ADRD by developing a curriculum and partnering with institutions that train these workers. It also partnered with local officials to ensure emergency preparedness plans at assisted living facilities adequately support the needs to PLWD in an emergency.
- ACPM, through a cooperative agreement with CDC, developed a brain health landing page featuring several CDC-funded resources including two brain health courses -- "Heart Healthy is Brain Healthy: Cognitive Decline and Dementia Risk Reduction through Blood Pressure Control" and "Improving Brain Health: A Practical Review of Dementia Risk Reduction Strategies" -- and the Community-Clinical Linkages to Promote Brain Health toolkit.

ACL's ADPI grantees are advancing a broad range of risk reduction initiatives in grant programs across the nation. The ACL grantees are educating communities across the lifespan on the importance of brain health, as well as modifiable and non-modifiable risk factors and the actions that they can take to reduce their risk. In 2024, the NADRC published a new resource paper highlighting the work of ADPI entitled *Promoting Brain Health and Reducing Dementia Risk Factors*.

ACL also maintains their Brain Health You can Make a Difference web page which is home to a variety of training resources developed in a collaboration between ACL, HRSA and CDC and includes evaluation tools developed by grantees implementing the trainings.

For more information see:

- https://nadrc.acl.gov/details?search1=20240808122611%20
- https://www.acpm.org/initiatives/brain-health/
- https://www.vdh.virginia.gov/brain-health/working-with-clients-with-dementia/

(**ONGOING**) Action 6.B.2: Disseminate research on co-occurring chronic conditions and dementias

Lead Agency: CDC

CDC has partnered with NACDD to develop a series of customizable Rack Cards for distribution at public health and other medical clinics and other appropriate areas, including health fairs or other health promotional events. These Rack Cards, which are in both Spanish and English, are designed to educate patients about risk reduction practices related to AD/ADRD, including the importance of blood pressure control, physical activity, healthy diet, and blood sugar management. Three new cards on hearing loss, TBI, and sleep were developed in late 2023. The Rack Cards are being adapted by state health departments with technical assistance from CDC and NACDD. These risk reduction messages can then be integrated alongside existing health promotion messaging efforts among states and other partners.

In collaboration with the Alzheimer's Association, Association of State and Territorial Health Officials (ASTHO), and IA^2, CDC developed a series of four customizable templates and two instruction guides for Healthy Heart, Healthy Brain for use by health care providers and public health professionals. The templates include steps patients can take to promote heart, brain, and overall health.

For more information see:

- https://chronicdisease.org/healthy-aging/resources-for-action/risk-reduction-rack-cards/
- https://www.cdc.gov/aging-programs/php/nhbi/indian-country-resources.html

(ONGOING) Action 6.B.3: Encourage treatment of co-occurring behavioral health conditions

Lead Agency: SAMHSA
Partners: CMS, HRSA, ACL

Behavioral health conditions, including depression, other mental illnesses, and SUD, are risk factors for AD/ADRD.[23,24,25] Approaches to treatment for depression can be found in SAMHSA's Treatment of Depression in Older Adults Evidence-Based Practices (EBP) Kit. The kit offers information about an array of EBP for treatment and services to improve outcomes for older adults experiencing depression, including dysthymia. It considers planning, implementation, and maintenance. Treatment approaches for older adults with dementia or other cognitive impairments are included in the case examples.

If a person is in an early stage of AD/ADRD, psychosocial therapies for SMI may still be effective, although the interventions may not be appropriate if a person is in a more advanced stage of dementia. SAMHSA's guide for practitioners on psychosocial interventions for older adults with SMI provides considerations and strategies for interdisciplinary teams, peer specialists, clinicians, RNs, behavioral health organizations, and policy makers in understanding, selecting, and implementing EBIs that support older adults with SMI. In addition, SAMHSA, CMS, HRSA, and ACL collaborated to publish *Guidance on Inappropriate Use of Antipsychotics: Older Adults and People with IDD in Community Settings*. The Guidance reviews non-pharmacologic behavioral approaches and strategies to avoid and reduce prescribing of antipsychotics whenever possible for older adults with dementia and people with IDD.

SAMHSA, in collaboration with CMS, established the COE-NF. While not specifically focused on older adults or people with AD/ADRD, the new COE-NF will provide evidence-based resources to assist nursing home staff to assist residents of all ages in need of mental health and substance use treatment and support.

For more information see:
- https://nursinghomebehavioralhealth.org/
- https://store.samhsa.gov/product/Guidance-on-Inappropriate-Use-of-Antipsychotics-Older-Adults-and-People-with-Intellectual-and-Developmental-Disabilities-in-Community-Settings/PEP19-INAPPUSE-BR
- https://store.samhsa.gov/product/psychosocial-interventions-older-adults-serious-mental-illness/PEP21-06-05-001

Some individuals with AD/ADRD may have SUD, which should also continue to be treated. As we age, the body's ability to process alcohol and other substances becomes less effective; cognitive impairment can also alter the impacts of alcohol and other substances. Effective treatment approaches can be found in Treatment Improvement Protocol (TIP) 26: Treating SUD in Older Adults. TIP 26 is designed to help providers better understand how to identify, manage, and prevent SUD in older adults. The TIP describes the unique ways in which the signs and symptoms of SUD may manifest in older adults, drug and alcohol use disorder screening tools, assessments, and treatments tailored for older adults' needs, the interaction between SUDs and cognitive impairment, and strategies to help providers improve their older clients' social

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[23] Ahearn EP, Szymanski BR, Chen P, Sajatovic M, Katz IR, McCarthy JF. "Increased risk of dementia among veterans with bipolar disorder or schizophrenia receiving care in the VA health system." *Psychiatric Services*, 2020; 71(10): 998-1004. doi:10.1176/appi.ps.201900325.

[24] Kuring JK, Mathias JL, Ward L. "Risk of dementia in persons who have previously experienced clinically-significant depression, anxiety, or PTSD: A systematic review and meta-analysis." *Journal of Affective Disorders*, 2020; 274: 247-261. doi:10.1016/j.jad.2020.05.020.

[25] Rehm J, Hasan OSM, Black SE, Shield KD, Schwarzinger M. "Alcohol use and dementia: A systematic scoping review." *Alzheimer's Research Therapy*, 2019; 11(1). doi:10.1186/s13195-018-0453-0.

functioning and overall wellness. A related resource from SAMHSA is the toolkit, Get Connected: Linking Older Adults with Resources on Medication, Alcohol, and Mental Health. The toolkit is designed for organizations that provide services to older adults and offers information and materials to help understanding the issues associated with substance misuse and mental illness in older adults.

SAMHSA partnered with HRSA to develop *Growing Older: Providing Integrated Care for an Aging Population*. The report is designed for clinicians and explains approaches to providing integrated care to older adults living with SUD and mental illness. It highlights the importance of assessing patients for cognitive deficits and adapting behavioral interventions to help improve treatment outcomes. The report also stresses the importance of including family caregivers, when possible, in the diagnostic and treatment process.

For more information see:

- https://store.samhsa.gov/sites/default/files/sma03-3824_2.pdf
- https://store.samhsa.gov/sites/default/files/sma16-4982.pdf
- https://store.samhsa.gov/sites/default/files/tip-26-pep20-02-01-011.pdf

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Strategy 6.C: Accelerate Public Health Action to Address the Risk Factors for Alzheimer's Disease and Related Dementias

While clinical health focuses on the individual, public health focuses on a population with the aim of protecting and promoting healthy people and communities. Developing the public health infrastructure and educating the public health workforce about AD/ADRD risk factors can ensure that as high-quality research emerges, public health systems can more rapidly advance interventions and investments targeting communities with greatest need to achieve more equitable outcomes.

(ONGOING) Action 6.C.1: Convene summit to establish public health priorities for reducing Alzheimer's disease and related dementias risk factors

Lead Agency: CDC

To establish and update priorities and milestones, CDC convened a National Summit on Risk Reduction on May 16-17, 2023. This Summit included academic and public health partners gathering, as well as public health practitioners, state, local, and Tribal public health officials, ASTHO, and National Association of County and City Health Officials (NACCHO). The Summit covered a list of public health strategies determined to be most appropriate for translation based on the state of the latest science, to be implemented by state, local, and Tribal public health entities.

(UPDATED) Action 6.C.2: Accelerate dissemination of information on risk reduction to public health entities

Lead Agencies: CDC, ODPHP
Partners: NACDD, ASTHO, NACCHO

CDC supported the NACDD to develop brain health messaging that could be integrated into existing public health messaging. The initial Rack Cards were released in 2020 for four key risk factors related to brain health, in 2021 these are now customizable. Through a cooperative agreement, NACDD has developed guidance for health departments to integrate these messages within state and local public health departments. Three new Rack Cards were developed in late 2023.

In September 2023, CDC implemented a new 5-year funding opportunity to increase funding for AD/ADRD through the BOLD Public Health Programs. These awards nearly doubled the previous awards, which now reach 43 different STLT public health agencies. These awards support creating and updating ADRD strategic plans and provides dedicated funding for STLT public health staff to implement activities that promote understanding and action for dementia across the life-course, including risk reduction.

In 2023, the Alzheimer's Association PHCOE for Dementia Risk Reduction, with support from CDC, held the Dementia Risk Reduction Summit. This Summit was organized around the Spectrum of Prevention, a framework for a comprehensive approach to public health prevention efforts. Public Health professionals and others from across the country gathered to promote and discuss and understand new and emerging science, and discuss successful, comprehensive approaches to addressing dementia risk reduction.

For more information see:

- https://alz.org/risk-reduction-summit/overview.asp
- https://chronicdisease.org/healthy-aging/resources-for-action/risk-reduction-rack-cards/
- https://www.astho.org/topic/report/od2a-bpi-federal-award-spenddown-analysis/
- https://www.cdc.gov/aging-programs/php/bold/php-recipients.html
- https://www.cdc.gov/aging-programs/php/nhbi/indian-country-resources.html

CDC's weekly newsletter, *Alzheimer's Disease and Healthy Aging*, disseminated information on brain health, risk reduction, caregiving, SCD, general health, emergencies and care planning, to over 45,000 subscribers, which includes many public health professionals. The newsletters are a primary channel for disseminating information about new articles, tools, resources, and webinars related to brain health to an active and engaged audience.

Through the Alzheimer's Association Alzheimer's and Dementia Care ECHO Program, CDC-funded BOLD public health program recipients partner with the Alzheimer's Association to connect their state's multi-disciplinary dementia care experts with health care teams in a free continuing education series of interactive, case-based video conferencing sessions. Many of these education series focus on risk reduction strategies for ADRD. CDC-funded Alzheimer's Association has provided technical assistance to multiple CDC BOLD public health program recipients to create their own Project ECHO trainings to meet the needs of state, county and local health care teams.

For more information see:

- https://www.alz.org/professionals/health-systems-medical-professionals/echo-alzheimers-dementia-care-program

The Missouri, Washington, Rhode Island, California, Texas, Arizona, Louisiana, Florida, Hawaii, Indiana, Tennessee and Iowa BOLD public health programs, among other recipients, have been successful in reaching hundreds of health care practitioners and local health department representatives in their own states with their ECHO trainings. For example, the Tennessee Dementia ECHO on its first training opportunity was successful in getting 232 registered local state health departments of which 113 attended the training. The Tennessee Dementia ECHO offers a virtual platform for PCPs to collaborate with subject matter experts, dissecting real patient cases, while refining management strategies, improving clinical proficiency, and increasing confidence to care for aging patients experiencing cognitive decline and dementia. The program also facilitates connections with community resources and support services, empowering providers with comprehensive knowledge and tools to better serve PLWD and their caregivers. Additionally, participants earn up to 12 CME credits, providing an excellent opportunity for professional development while addressing critical health care needs.

For more information see:

- https://www.vumc.org/vmac/tn-dementia-echo

The CDC-funded Missouri BOLD public health program recipient, in partnership with the University of Missouri, will convene a national meeting on dementia in October 2024. The conference will provide opportunities for CDC-funded BOLD public health recipients to showcase work in and inform about dementia risk factors, early detection, and caregiver support.

On May 14-15, 2024, the Wake Forest University School of Medicine, in partnership with the BOLD PHCOE on Dementia Risk Reduction, held a Research Roundtable in Charlotte, North Carolina. The Roundtable brought together researchers and public health officials to review and discuss the scientific evidence and how to best drive effective public health action. The Roundtable included sessions by academic researchers on what the science tells us about:

- The most effective ways to get individuals to change behavior.
- Where to best reach people from various communities with prevention messaging and interventions.
- The economics of public health prevention and the return on investment, and how to communicate that.
- The best ways, and processes to undertake, to effect policy and system change.

The CDC-funded BOLD PHCOE on Dementia Caregiving hosts a virtual roundtable series that highlight different public health approaches to building the state dementia caregiving infrastructure, one state at a time. These are interactive sessions, designed for peer-learning and knowledge sharing. The Center held roundtables featuring Minnesota, Utah, New York, and Colorado. The Center also held several webinars, including Successful Public Health approaches in Dementia Caregiving: Minnesota featuring the Remember Project. . The Remember Project events help educate people about dementia by creating space for communities to learn and share their experiences.

The BOLD PHCOE on Dementia Caregiving released a new toolkit in July 2024, Disseminating Evidence-based Programs to Support Family Dementia Caregivers: The Role of Public Health. As part of the release, they hosted a webinar focused on key actions public health agencies can take to disseminate supportive programs and resources for caregivers. The session introduced the new toolkit and discussed key actions public health can take to help disseminate programs for caregivers. It also highlighted the crucial role of public health in ensuring accessibility to these services.

For more information see:

- https://bolddementiacaregiving.org/wp-content/uploads/2024/07/UofMN_PHCOE-DC_Toolkit_DisseminatingProgramsToGuideFDC_v6.pdf

In June 2022, the BOLD PHCOE for Dementia Caregiving, funded by the CDC, convened the national meeting *Public Health Opportunities and Challenges of Dementia Caregiving* in Minneapolis, Minnesota. This meeting brought together over 400 public health professionals and partners to explore dementia caregiving through the public health lens and discuss opportunities for collaboration across sectors that can advance the national agenda for supporting family caregivers of PLWD. Sessions included best practices, testimony from those with dementia and their caregivers, and opportunities to share successes and challenges amongst participants.

For more information see:

- https://bolddementiacaregiving.org/wp-content/uploads/2024/07/UofMN_PHCOE-DC_Toolkit_DisseminatingProgramsToGuideFDC_v6.pdf

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(ONGOING) Action 6.C.3: Educate the public health workforces on Alzheimer's disease and related dementias risk factors

Lead Agency: CDC

CDC, the Alzheimer's Association, and Emory University, through a cooperative agreement, developed a Public Health Curriculum, a comprehensive course addressing cognitive health, cognitive impairment, and dementia, for use by undergraduate faculty in schools and programs of public health and related disciplines. This curriculum is aligned with the Core Competencies for Public Health Professionals. The curriculum is available free of charge and consists of four modules designed to be used individually or as a whole, each with slides and a faculty guide. The curriculum is also relevant to other audiences for broader reach. The course was updated in late 2019, with additional enhancements, including video modules, added in 2021. In 2023, new interactive modules were added, including Health Equity in Dementia -- Using a Public Health Lens to Advance Health Equity in Alzheimer's and Other Dementias, which addresses health equity in ADRD from a population-based, life-course approach to reduce risk and ensure that everyone can live their best life after a diagnosis. Public Health and Dementia Caregiving was also added in 2023, an interactive online course module that covers who dementia caregivers are, why dementia caregiving is a public health issue, and what public health organizations can do about dementia caregiving. In September 2024, a new learning module on Understanding the Public Health Impact of Dementia was added.

In 2023, the Alzheimer's Association PHCOE for Dementia Risk Reduction, with support from CDC, held the *Dementia Risk Reduction Summit*. This Summit was organized around the Spectrum of Prevention, a framework for a comprehensive approach to public health prevention efforts. Public health professionals and others from across the country gathered to promote and discuss and understand new and emerging science, and discuss successful, comprehensive approaches to addressing dementia risk reduction.

For more information see:

- http://www.phf.org/resourcestools/Pages/Core_Public_Health_Competencies.aspx
- https://alz.org/risk-reduction-summit/overview.asp
- https://www.cdc.gov/aging-programs/php/training/adph-curriculum.html

CDC is collaborating with the Dementia Risk Reduction BOLD PHCOE to translate existing and emerging science around modifiable risk factors for cognitive decline and dementia into actionable and targeted public health interventions, messaging, and campaigns; make these approaches highly accessible to the public health community and the general public; work with public health agencies and their partners to increase the use of these risk reduction strategies; and continuously update and improve the approaches through feedback, evaluation, and quality improvement.

For more information see:

- https://www.cdc.gov/aging-programs/php/bold/phc-recipients.html

Through the Alzheimer's Association Alzheimer's and Dementia Care ECHO Program, CDC-funded BOLD public health program recipients partner with the Alzheimer's Association to connect their state's multi-disciplinary dementia care experts with health care teams in a free continuing education series of interactive, case-based video conferencing sessions. Many of these education series focus on risk reduction strategies for ADRD. CDC-funded Alzheimer's Association has provided technical assistance to multiple CDC BOLD public health program recipients to create their own Project ECHO trainings to meet the needs of state, county and local health care teams. The Missouri, Washington, Rhode Island, California, Texas, Arizona, Louisiana, Florida, Hawaii, Indiana, Tennessee and Iowa BOLD public health programs, among other recipients, have been successful in reaching hundreds of health care practitioners and local health department representatives in their own states with their ECHO trainings. For example, the

Tennessee Dementia ECHO on its first training opportunity was successful in getting 232 registered local state health departments of which 113 attended the training. The Tennessee Dementia ECHO offers a virtual platform for PCPs to collaborate with subject matter experts, dissecting real patient cases, while refining management strategies, improving clinical proficiency, and increasing confidence to care for aging patients experiencing cognitive decline and dementia. The program also facilitates connections with community resources and support services, empowering providers with comprehensive knowledge and tools to better serve PLWD and their caregivers. Additionally, participants earn up to 12 CME credits, providing an excellent opportunity for professional development while addressing critical health care needs.

For more information see:

- https://www.alz.org/professionals/health-systems-medical-professionals/echo-alzheimers-dementia-care-program
- https://www.vumc.org/vmac/tn-dementia-echo

(ONGOING) Action 6.C.4: Improve nutrition by facilitating lowering sodium content in food

Lead Agency: FDA

Excess sodium can raise blood pressure, which can increase the risk for multiple chronic conditions including AD/ADRD. Lowering blood pressure has been found to reduce the risk of developing cognitive impairment, a common precursor of AD/ADRD. According to the Dietary Guidelines for Americans, people living in the United States consume on average 3,400 milligrams (mg) of sodium per day -- nearly 50% more than the 2,300mg limit recommended for people 14 years and older. The majority of sodium consumed comes from processed, packaged, and prepared foods, which makes it difficult to limit sodium intake.

To address this, the FDA is taking a data-driven, iterative approach that includes establishing voluntary sodium reduction targets for industry, monitoring and evaluating progress, and engaging with stakeholders, in order to facilitate the gradual reduction of sodium in the food supply, including processed and restaurant foods. In October 2021, FDA issued a final guidance for industry with voluntary short-term targets for reducing sodium in commercially processed, packaged, and prepared food over the next 2.5 years. The approach supports sodium reduction efforts already made by industry, provides common targets for defining and measuring progress, and provides companies with the flexibility and time to meet these targets. The FDA issued draft, revised Phase II sodium reduction targets in August 2024 to continue the process to facilitate a gradual, iterative process to help reduce sodium intake.

Complementing the goals of this process, in March 2023 the FDA proposed to amend the standards of identity (SOIs) to permit the use of salt substitutes in foods for which salt is a required or optional ingredient. The proposed rule would provide manufacturers with flexibility and facilitate industry innovation to reduce sodium in standardized foods. The proposed rule would use a “horizontal” approach for SOIs, under which a single rule would apply to multiple SOIs across several categories of standardized foods. Specifically, the proposed rule would amend the 80 SOIs that specify salt as a required or an optional ingredient.

For more information see:

- https://www.fda.gov/food/cfsan-constituent-updates/fda-propose-permit-salt-substitutes-reduce-sodium-standardized-foods
- https://www.fda.gov/SodiumReduction

(ONGOING) Action 6.C.5: Promote physical activity among older adults

Lead Agency: ODPHP

HHS released the *Physical Activity Guidelines for Americans* second edition in 2018. The Guidelines is a flagship resource for health professionals and policy makers that provides recommendations on how everyone can improve their health through regular physical activity. The Guidelines describe the brain health benefits of physical activity, including reduced risk of AD/ADRD and improved cognition (executive function, attention, memory, crystallized intelligence, and processing speed).

The Physical Activity Guidelines Advisory Committee Brain Health subcommittee examined the literature related to physical activity and cognition, identified key research recommendations and rationales for future exploration.

HHS intends to release a midcourse report in 2023 focused on strategies to increase physical activity among older adults.

Building off the evidence for the protective effect of physical activity on brain health outcomes, the Office of Disease Prevention and Health Promotion (ODPHP) is leading the development of a Physical Activity Guidelines midcourse report, which will focus on what works to improve physical activity behaviors in the older adult population. The Science Board subcommittee of the President's Council on Sports, Fitness and Nutrition conducted a systematic literature review in 2022 to inform the midcourse report. HHS expects to release the midcourse report in 2023. While it does not focus specifically on any health outcomes (i.e., AD/ADRD), it will highlight evidence-based settings and strategies that facilitate increased physical activity among older adults.

For more information see:

- https://health.gov/
- https://health.gov/our-work/nutrition-physical-activity/physical-activity-guidelines/current-guidelines
- https://health.gov/sites/default/files/2019-09/09_F-3_Brain_Health.pdf
- https://health.gov/sites/default/files/2019-09/Physical_Activity_Guidelines_2nd_edition.pdf

Strategy 6.D: Expand Interventions to Reduce Risk Factors, Manage Chronic Conditions, and Improve Well-Being through the Aging Network

The Aging Network is a national structure of state and local agencies that provide services to older adults with the aim of helping them remain in their homes and communities. Many older adults are already connected to Aging Network providers in their communities. These existing connections of trust provide an invaluable foundation for spreading awareness and implementing interventions on risk reductions to older adults, tribes, communities, states, and territories. By engaging with existing community organizations, risk reduction interventions can be tailored to fit the sociocultural needs of local communities.

(ONGOING) Action 6.D.1: Ensure older adults have access to nutritious meals through home-delivered and congregate meal programs

Lead Agency: ACL

Through the OAA Nutrition Program, ACL's Administration on Aging (AoA) provides grants to states to help support nutrition services (home-delivered and congregate meals) for older people throughout the country. Nutrition services provide an opportunity to link to other supportive in-home and community-based supports from which older people may benefit.

Designed to promote the general health and well-being of older individuals, the services address hunger, food insecurity and malnutrition of older adults; promote health and well-being; promote healthy nutrition behaviors. The onset of COVID-19 highlighted the increased nutritional needs of the Nation's older adults, bringing hidden hunger and the needs of under-served individuals into the spotlight.

(ONGOING) Action 6.D.2: Expand the delivery of health and wellness programs to older adults in every community

Lead Agency: ACL

Through their Capacity-Building and Sustainable Systems initiatives ACL continues to expand delivery of health and wellness programs in more communities across the Nation. The Capacity-Building grants support building capacity in areas with no or limited program infrastructure to introduce and deliver evidence-based health and wellness programs, as well as chronic disease self-management support programs within under-served geographic areas and/or populations. The Sustainable Systems grants focus on the development of integrated, sustainable systems for delivering evidence-based self-management support programs. Expanded availability of health and wellness programs in historically under-served communities, many of whom are at high risk of developing cognitive impairment.

(ONGOING) Action 6.D.3: Identify the most promising health promotion and disease prevention interventions for dissemination through the Aging Network

Lead Agency: ACL

ACL, through grants with the National Council on Aging and the Evidence-Based Leadership Council, supports the vetting and identification of promising health and wellness community-based evidenced-based programs to support older adults and people with disabilities remaining in their homes and communities. Interventions are assessed to determine whether they meet the OAA Title III-D criteria for evidence-based programs, thus making them eligible for funding with OAA Title III-D dollars.

(ONGOING) Action 6.D.4: Expand access to evidence-based health promotion and disease prevention programs

Lead Agency: ACL

The OAA, under Title III, makes funds available to support the delivery of evidence-based programs designed to improve health and well-being, and reduce disease and injury. Through Title III, the aging services network is able to advance wider implementation of disease prevention and health promotion evidence-based programs demonstrated to improve the health of older adults. ACL developed an evidence-based definition to assist states in developing their own Title III-D guidance, through which a variety of interventions are implemented and older adults are educated on how to manage chronic conditions (diabetes, heart disease, arthritis, chronic pain, and depression) which are known to contribute to increased risk for cognitive impairment later in life.

Strategy 6.E: Address Inequities in Risk Factors for Alzheimer's Disease and Related Dementias Among Marginalized Populations

Black, Hispanic, and low income populations face a higher risk of AD/ADRD. Structural inequities are an important cause of this difference, including but not limited to underinvestment in education systems, less walkable communities, decreased access to nutritious food, barriers to health care access and low quality of care in their communities. To reduce existing disparities in the incidence of AD/ADRD risk reduction, interventions should be tailored to meet the needs of each community with cultural competence and equity as the primary focuses. This requires that addressing SDOH, entrenched systemic racism, and other forms of discrimination be prioritized, rather than focusing solely on individual behaviors.

(ONGOING) Action 6.E.1: Support the development of programs and materials designed to increase awareness of the importance of brain health in culturally and linguistically appropriate ways

Lead Agency: CDC
Partner Agency: ACL

In 2020, CDC funded three organizations for 5 years (2020-2025) to tailor brain health messaging for four populations disproportionately affected by dementia: persons with IDD and Hispanic, Black, and AI/AN peoples. Current activities include creating informational resources for their respective audiences, engaging state and local partners to adopt Road Map action items, developing training materials for current and future professionals about ADRD, and disseminating effective messages related to brain health. National Healthy Brain Initiative activities promote brain health, address cognitive impairment including ADRD, and support the needs of caregivers (unpaid persons providing care or assistance to someone with ADRD).

For more information see:

- https://www.cdc.gov/aging-programs/php/nhbi/index.html

The CDC-funded Minnesota BOLD public health program awardee supports a project titled: Restoration for All (REFA). Minnesota works with African refugee and immigrants and plans to expand outreach and advocacy to increase early detection and develop a communications campaign. REFA specializes in culturally-relevant conversations and education materials about memory loss and dementia risk reduction and connects caregivers to community resources. Also, the Minnesota BOLD recipient supports the Remember Project. This is a program that produces and performs theatrical plays to encourage audience members to talk about memory loss and help PLWD process their stories. With the Healthy Brain Community Grant, the Remember Project plans to expand their work with Black, Indigenous and communities of color in the Twin Cities metro area. The Remember Project will host a virtual tour of "Mango Songs", a theatrical video of an autobiographical play that explores the intersections of identity, migration, memory and belonging. Handouts, materials and resources that focus on dementia risk reduction, caregiver well-being, and early diagnosis will be available at these dissemination events.

Research suggests that individuals engaged in faith and religious practices may live 4-14 years longer. Building on this understanding, the CDC-funded Tennessee BOLD public health program awardee supported a partnership to engage faith, religious, and community leaders through the INDEED (Intrastate Network to Deliver Equity and Eliminate Disparities) Program. This initiative empowers leaders to support aging individuals affected by chronic illnesses, dementia, and SDOH within their congregations. This collaboration has supported congregational needs assessments, action planning, and increased resource capacity in rural and under-served communities.

UIC, funded under CDC's National Healthy Brain Initiative cooperative agreement, provided ten free webinars supporting the six pillars of brain health and family/caregiving issues related to aging and dementia for people with IDD through their HealthMatters Webinar series. The webinars series reached over 5,000 registrants, with 12,837 YouTube views on the Health Matters Program YouTube Playlist.

UIC, in collaboration with Illinois Enhancement of Geriatric Care for All GWEP, developed three training modules for dissemination:

- HealthAdvocacy: Structurally Competent Healthcare for People with Disability.
- 6 Pillars for Brain Health: Promoting Health Equity for People with Intellectual and Developmental Disabilities.
- Alzheimer's Disease and Other Dementias: Promoting Brain Health Equity for People with Intellectual and Developmental Disabilities.

The group also developed fact sheets/compendium for the GWEP CEU modules, identifying needs related to brain health for people with IDD with culturally-relevant materials for people with IDD with and without dementia, their supports, and their environments on brain health messages and strategies for the six-pillars of brain health where they live, learn, work, play, and love.

Through ACL's ADPI program, grantees are developing and disseminating culturally tailored trainings and resources to support dementia risk reduction. Many ADPI grantees target populations that are at a high risk of developing dementia, including, but not limited to, African Americans, Hispanic Americans, Native Americans and individuals with IDD. The grantees are developing resources designed to meet the needs of the communities they serve.

For more information see:
- https://nadrc.acl.gov/details?search1=20240808122611%20
- https://nadrc.acl.gov/home

(UPDATED) Action 6.E.2: Support the development of programs and materials designed to increase awareness of the importance of brain health for Tribal and Urban Indian communities in culturally sensitive ways

Lead Agencies: CDC, IHS
Partners: private organizations, ASTHO

Through CDC's HBI IA^2 provides information tailored to AI/AN peoples and the public health departments and health professionals that serve them. Their website, AI/AN Brain Health, features a robust online brain health resource library. IA^2 has collaborated with the Dementia Friends Program to provide tribes, UIH organizations, and Alaska Native communities with training and content from this program. IA^2 also gathers, creates, and distributes information and resources developed by and for AI/AN communities to improve the public health response to AD/ADRD. These resources are continuously updated to their brain health resource library for Tribal and UIH organizations.

Multiple sessions and trainings on AD/ADRD were featured at the *American Indian Elders Conference* hosted by NICOA on September 25-29, 2023, in Cherokee, North Carolina. This conference brought together over 2,000 participants from across the country to listen to the needs of the AI/AN elders. Sessions on caregiving, health equity and dementia, among other topics were discussed.

For more information see:
- https://www.nicoa.org/biennial-conference/previous-conferences/2023-conference/

There has been increased Tribal representation on the CDC HBI Road Map for American Indian and Alaska Native Peoples workgroup, which serves to update the 2019 *Road Map for Indian Country*. The Alzheimer's Association, in collaboration with CDC, has engaged Tribal organizations such as NPAIHB and IA^2 to increase Tribal representation and feedback on updates to the Road Map. IA^2 will lead the strategic planning for the *Road Map for American Indian and Alaska Native Peoples Implementation Guide*. The new *Road Map for American Indian and Alaska Native Peoples* will be released in November 2024.

For more information see:

- https://www.alz.org/media/Documents/HBI-Road-Map-American-Indian-Alaska-Native-Peoples-Progress-Report.pdf

CDC and the Alzheimer's Association, in collaboration with IHS, have produced infographics sharing data from the BRFSS cognitive decline and caregiving modules describing the impact of these issues among AI/AN adults.

For more information see:

- https://www.cdc.gov/healthy-aging-data/infographics/index.html

In 2024, IHS continued its collaboration with the CDC BOLD PHCOE and other subject matter experts on dementia risk reduction to explore potential multi-domain dementia risk reduction interventions that could be adapted for use by the Tribal CHR workforce.

In 2023, the IHS Alzheimer's and Health Promotion and Disease Prevention programs provided support to the Oklahoma City Area Office to pilot an elder-focused community event promoting physical activity and incorporating brain health and dementia content. Building on these successes, in 2024, the IHS expanded pilot efforts to plan, implement, and evaluate regional "All Elders Moving" interactive events in additional IHS areas. The initiative aims to increase dementia awareness and promote staying active, preventive screenings, healthy eating, immunizations, and improving brain health. Four events held in 2024 in Minnesota, Oklahoma, and New Mexico reached more than 1,500 participants, with four additional events planned in additional IHS areas.

As of 2024, multiple IHS AD grantees have implemented or planned brain health and risk reduction-focused activities in direct response to community and elder requests. Our grantees continue to leverage their learning and experiences engaging their local communities for feedback on community needs and direction on local services and supports. As previously reported, one of the new IHS grantees reported a shift in community outreach promotion and engagement away from stigmatized terminology, including "dementia" and "Alzheimer's," as a result of community feedback during the first year of their grant. Promotional language and resources now use brain health and health promotion messaging and they have revised their project manager position, with a job title of "Cognitive Wellness" nurse manager. They actively use risk reduction resources provided by the IA^2, a CDC partner, and local associations such as Rack Cards for healthy eating. In 2024, grant funding was used to purchase a mobile unit to support cognitive screenings, wellness visits, and dementia-focused training and education. The unit will enable them to travel deeper into remote parts of the nine Tribal communities they serve, reaching community members who often limit regular health system contacts.

For more information see:

- http://www.aianbrainhealth.org/
- https://iasquared.org/brain-health/resource-library/
- https://www.cdc.gov/aging-programs/php/nhbi/indian-country-resources.html
- https://www.cdc.gov/aging/partnership/partner-resources/index.html
- https://www.dfamerica.org/

Strategy 6.F: Engage the Public about Ways to Reduce Risks for Alzheimer's Disease and Related Dementias

Greater public awareness about potential risk factors and steps to modify those risk factors may encourage individuals and families to make changes that preserve cognitive health and promote healthy aging overall and connect them to resources and services that can help. Dementia is one of people's most feared health conditions, which may influence an individual's views about risk reduction messages and their interest in interventions to reduce their individual burden of risk factors for AD/ADRD. Furthermore, sharing information on SDOH and system-level risk factors can focus and help coordinate facilitate positive community and infrastructure changes.

(ONGOING) Action 6.F.1: Target and coordinate public health campaigns aimed at reducing risk factors

Lead Agencies: ACL, NINDS, NIA, NIH, CDC

Several federal agencies have developed public messaging campaigns to raise awareness of actions that individuals and communities can take to improve brain health and potentially reduce the risk of dementia. Federal agencies will expand partnerships and coordinate messaging efforts across public and private entities. Recent efforts have also included a stronger emphasis on tailoring messages to at-risk individuals, such as Black and Hispanic individuals and women. New and ongoing public messaging efforts should continue to enhance the cultural competence and assess the effectiveness of messaging across different populations.

NIA produces a series of materials to educate the public about modifiable risk factors for dementia, including an infographic, brochure, online articles, and a video. These materials are promoted through NIA's e-alerts and social media channels. In addition, Alzheimers.gov features an article on dementia prevention.

For more information see:

- https://order.nia.nih.gov/publication/reducing-your-risk-of-dementia
- https://www.alzheimers.gov/life-with-dementia/can-i-prevent-dementia
- https://www.nia.nih.gov/health/alzheimers-causes-and-risk-factors/thinking-about-your-risk-alzheimers-disease-five
- https://www.nia.nih.gov/health/infographics/making-healthy-lifestyle-choices-may-reduce-your-risk-dementia
- https://www.nia.nih.gov/health/preventing-alzheimers-disease-what-do-we-know
- https://www.nia.nih.gov/health/what-do-we-know-about-diet-and-prevention-alzheimers-disease

(ONGOING) Action 6.F.2: Provide information to the public on brain health

Lead Agencies: CDC, HRSA, NINDS, NIA, NIH, ACL

CDC disseminates a weekly newsletter, *Alzheimer's Disease and Healthy Aging*, to more than 45,000 subscribers. It is a primary channel for disseminating information about new articles, tools, resources, and webinars related to brain health.

CDC has a second newsletter, *Alzheimer's Disease and Healthy Aging Tribal Newsletter*, is sent regularly to more than 470 subscribers interested in issues for AI/AN elders.

CDC produces a podcast series titled Aging and Health Matters that includes short discussions on issues in older adult health, including AD/ADRD and caregiving. Past topics have included: the relationship between brain and body health; how healthy behaviors can moderate disease risk even for people with a genetic risk for AD; and when a person should discuss memory loss with their doctor among others.

CDC partners with the ASTHO to produce a series of products to support public health agencies in identifying priorities, areas of synergy within existing or upcoming jurisdictional plans, and opportunities for integrating cognitive health into public health efforts as guided by the HBI Road Maps. Products designed to facilitate implementation of the HBI Road Maps include a series of HBI Action Institutes across the country in each HHS region, health communication materials for AI/AN communities, and a series of recorded webinars to promote the importance of public health in addressing brain health.

For more information see:

- https://tools.cdc.gov/medialibrary/index.aspx#/podcastseries/id/302101

Grant recipients of HRSA's GWEP are expanding their social media footprint by developing social media posts, public service announcements, videos, podcasts, and public radio and television spots. In 2024, HRSA grantees continued to incorporate approaches to identify and mitigate AD/ADRD risk factors into their training materials and disseminate information on risk reduction through social media channels.

NIA maintains online materials on cognitive health and publishes lay-audience-friendly stories that highlight recent research results in brain and cognitive health, including 12 stories in 2023.

For more information see:

- https://www.nia.nih.gov/health/topics/cognitive-health
- https://www.nia.nih.gov/news/topics/cognitive-health

NIA operates the ADEAR Center, the primary Federal Government resource for information about AD/ADRD, research, and caregiving. See Action 1.E.2 for more information about ADEAR.

ACL, in partnership with NIH/NIA, HRSA and CDC, created their Brain Health: You Can Make a Difference! curriculum/toolkit, and in 2023 a database of evaluation questions was created to support understanding the impact of these brain health trainings. The curriculum/toolkit includes modules on brain health basics; medications and the brain; brain injury; and dementia, as well as complimentary evaluative tools to demonstrate training outcomes. Through ADPI, ACL's grantees use these tools to boost the dementia-capable services and supports in their states and communities. The available tools provide information on the risk factors associated with developing dementia, knowledge of the signs of cognitive impairment, and management of symptoms of PLWD. In 2024 the NADRC published a new resource paper highlighting the work of ADPI entitled *Promoting Brain Health and Reducing Dementia Risk Factors*.

For more information see:

- https://nadrc.acl.gov/details?search1=20240808122611%20

In 2023, all of the 48 HRSA-funded GWEPs were educating and training the public on brain health, including by sharing resources.

In 2021, the VA provided information about brain health on its Office of Geriatrics and Extended Care website. The information was developed by the VA GRECC program.

For more information see:

- https://www.va.gov/geriatrics/brain/
- https://www.va.gov/GERIATRICS/docs/GRECCBrainHealthBooklet.pdf
- https://www.va.gov/GERIATRICS/pages/memory_loss_and_brain_health.asp

The State of Aging and Health in America: Data Brief Series, developed in collaboration with NACDD and CDC are topic-specific documents focusing on public health issues related to older adults. These briefs provide public health professionals with the most recent data available on health and aging-related conditions, including the importance of brain health, the management of chronic conditions, and caregiving burdens, to help identify needs and mitigate the future effects of a growing older population. The briefs also provide data by important breakdowns such as by state, age, gender, and ethnicity which can be useful for states and other stakeholders in making informed decisions and policies related to these issues. These briefs are currently under revision.

For more information see:

- https://www.cdc.gov/aging-programs/php/nhbi/indian-country-resources.html
- https://www.cdc.gov/healthy-aging-data/brfss/index.html
- https://www.cdc.gov/healthy-aging-data/index.html

CDC BOLD-funded recipients promote social media campaigns through popular social media applications, as well as advertisement campaigns through the use of billboards, promotional materials at medical office waiting rooms, libraries, memory centers and other appropriate organizations, and public service announcements through radio and television broadcasts. Many BOLD recipients contract out services with professional agencies to support the promotion of brain health messages through these various means. BOLD funded states like Missouri, Tennessee, Virginia, Michigan, Montana, Minnesota, and Iowa have promoted these campaigns during the summer of 2024.

IA^2, funded under CDC's National Healthy Brain Initiative cooperative agreement, is preparing to release the "Native Brain Health and Dementia Risk Reduction Social Media Toolkit," an AI/AN media resource guide for members of the community, public health professionals, and leaders working towards Brain Health Awareness.

(**UPDATED**) Action 6.F.3: Enhance the reach and effectiveness of public health messaging on blood pressure control

Lead Agencies: NINDS, NIH, CDC

Researchers and public health officials have identified hypertension as one of the most modifiable risk factors for brain health and potentially dementia. CDC's Million Hearts® as well as NIH's The Heart Truth® and Mind Your Risks® all educate the public on the importance of reducing blood pressure among other modifiable risk factors. The Mind Your Risks® campaign further educates the public on the connection between high blood pressure, stroke, and dementia. Creative materials and messaging are tailored towards Black men ages 28-45, the group at highest risk for developing high blood pressure, to encourage and motivate them to take charge of their health. Campaign materials include a website, videos, graphics, social media messaging, and educational resources including an informational flyer and discussion guide for medical appointments. NINDS is focusing now on partnerships to enhance dissemination of the campaign, including holding events with historically Black colleges and universities and other community organizations.

In addition, NIA coordinated an Expert Q&A with CDC's Million Hearts and National Health, Lung, and Blood Institute in September 2023 on Heart Health and Aging that covered the link between brain and heart health. The event video continues to gain interest with more than 6.6K views. NIA also offers educational resources, including an article and an infographic, to help the public understand the importance of blood pressure control and health risks related to hypertension.

For more information see:

- https://millionhearts.hhs.gov/
- https://www.mindyourrisks.nih.gov/
- https://www.mindyourrisks.nih.gov/resources.html
- https://www.nia.nih.gov/health/high-blood-pressure/high-blood-pressure-and-older-adults

- https://www.nia.nih.gov/health/high-blood-pressure/what-know-about-high-blood-pressure-you-age
- https://www.youtube.com/watch?v=mJi9srnvI3Q
- https://www.youtube.com/live/klL1ZAHp8G4

Appendix 1: List of Participating Departments and Agencies

Administration for Children and Families (ACF)
Administration for Community Living (ACL)
Administration on Aging (AoA)
Administration on Intellectual and Developmental Disabilities (AIDD)
Agency for Healthcare Research and Quality (AHRQ)

Centers for Disease Control and Prevention (CDC)
Centers for Medicare & Medicaid Services (CMS)
Consumer Finance Protection Bureau (CFPB)

Department of Defense (DoD)
Department of Health and Human Services (HHS)
Department of Housing and Urban Development (HUD)
Department of Veterans Affairs (VA)

Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD)

Food and Drug Administration (FDA)

Health Resources and Services Administration (HRSA)

Indian Health Service (IHS)

National Institute of Neurological Disorders and Stroke (NINDS)
National Institute on Aging (NIA)
National Institute on Minority Health and Health Disparities (NIMHD)
National Institutes of Health (NIH)
National Science Foundation (NSF)

Office of Global Affairs (OGA)
Office of Intergovernmental and External Affairs (IEA)
Office of the Assistant Secretary for Health (OASH)
Office of the Assistant Secretary for Public Affairs (ASPA)
Office of the Assistant Secretary for Planning and Evaluation (ASPE)
Office of the National Coordinator of Health Information Technology (ONC)
Office of the Surgeon General (OSG)
Office on Disability (OD)

Substance Abuse and Mental Health Services Administration (SAMHSA)

Appendix 2: National Plan to Address Alzheimer's Disease Milestones and Achievements Timeline

2012

HHS released the *National Plan to Address Alzheimer's Disease*, as required by the National Alzheimer's Project Act (NAPA) of 2011.

- https://aspe.hhs.gov/collaborations-committees-advisory-groups/napa/napa-documents/napa-national-plans

NIH convened the first *Alzheimer's Disease Research Summit*.

HHS created alzheimers.gov as a resource for people living with AD/ADRD and their caregivers.

- https://www.alzheimers.gov/

CDC developed Healthy People 2020 baseline measures for dementia, including AD, in collaboration with federal partners.

- https://www.healthypeople.gov/2020/
- https://www.healthypeople.gov/2020/topics-objectives/topic/dementias-including-alzheimers-disease

2013

NIH convened the first *Alzheimer's Disease-Related Dementias Research Summit*.

VA created Veterans with Dementia: Skills for Managing Challenging Behaviors video in collaboration with South Central Mental Illness Research Education and Clinical Center (MIRECC).

- https://youtu.be/hgVMKEnkvHo

HRSA and ASPE developed the continuing education course Case Challenges in Early Alzheimer's Disease.

- https://www.medscape.org/viewarticle/806464_4

IHS, ACL, and VA launched REACH into Indian Country Pilot of Caregiver Coaching and Support, 2013-2018.

CDC published the second *Healthy Brain Initiative: The Public Health Road Map for State and National Partnerships (2013-2018)*.

- https://www.alz.org/media/Documents/road-map-2013-2018.pdf

2014

NIH researchers developed the first Alzheimer's model containing amyloid and tau, the two proteins that are hallmarks of AD/ADRD.

- https://www.nia.nih.gov/news/groundbreaking-alzheimers-model-petri-dish-points-amyloid-disease-trigger

NIH launched the Accelerating Medicines Partnership® Program for Alzheimer's Disease (AMP®-AD).

- https://www.nia.nih.gov/research/amp-ad

ACL, NIH, and CDC collaborated on the development and delivery of Brain Health Resources (curriculum) for delivery in community and professional environments.

- https://acl.gov/brain-health

ACL, with funding from the Affordable Care Act expanded its long-standing Alzheimer's Disease Supportive Services Program (ADSSP) state grant program.

- https://acl.gov/programs/support-people-alzheimers-disease/support-people-dementia-including-alzheimers-disease

2015

NIH launched the Mind Your Risks® health campaign to educate the public about the importance of controlling blood pressure to help reduce the risk of having a stroke and developing dementia later in life.

- https://www.mindyourrisks.nih.gov/index.html

In partnership with CMS, the VA disseminated *Hand-in-Hand Training* to Community Living Centers (CLCs), with 76% of CLCs adopting training.

- https://qsep.cms.gov/data/AnD/Hand_in_Hand_Instructors_Guide.pdf

CDC made Cognitive Decline and Caregiving modules optional additions to states' annual Behavioral Risk Factor Surveillance System (BRFSS) survey.

ACL launched the National Alzheimer's and Dementia Resource Center (NADRC) website, making a broad range of grantee and center-developed resources available to the general public.

- https://nadrc.acl.gov/

2016

VA deployed Virtual Dementia Simulation for acute care providers.

HRSA and the Office of Women's Health (OWH) launched the continuing education course Bidirectional Impact of Alzheimer's Disease and Common Comorbid Conditions, which focused on assessing, managing, and treating AD/ADRD in the context of multiple chronic conditions.

HRSA released a 16-module AD/ADRD curriculum for health care workers to learn about dementia, including diversity and equity issues.

- https://bhw.hrsa.gov/alzheimers-dementia-training

NIH launched MarkVCID to develop biomarkers to detect vascular damage related to dementia.

- https://markvcid.partners.org/

2017

NIH convened the first *National Research Summit on Dementia Care and Services*.

- https://aspe.hhs.gov/collaborations-committees-advisory-groups/napa/napa-additional-information/napa-caregiver-summit/2017-national-caregiver-summit

The Madison, Wisconsin, VA Medical Center was recognized as the first dementia-friendly VA facility.

NIH established the Model Organism Development and Evaluation for Late-Onset Alzheimer's Disease (MODEL-AD) consortium to develop new animal models of LOAD.

- https://www.model-ad.org/

NIH launched the Alzheimer's Clinical Trials Consortium (ACTC), a clinical trials infrastructure designed to accelerate and expand studies for therapies in AD/ADRD.

- https://www.nia.nih.gov/research/dn/alzheimers-clinical-trials-consortium-actc

VA's Caring for Older Adults and Caregivers at Home (COACH) program was awarded a Gold Status practice by the VHA Diffusion of Excellence.

- https://www.ruralhealth.va.gov/docs/COACH_Issue_Brief_Final.pdf

IHS and VA released a Rural Interdisciplinary Team Training (RITT) to rural IHS and Tribal sites.

CDC began the *Alzheimer's Disease and Healthy Aging Newsletter*.

ACL created and launched their Dementia Capability Assessment for long-term support systems.

- https://nadrc.acl.gov/details?search1=117

2018

NIH released the National Strategy for Recruitment and Participation in Alzheimer's and Related Dementias Clinical Research.

- https://www.nia.nih.gov/research/recruitment-strategy

NIH-funded first large-scale genetic study of LBD revealed that there is a strong genetic component of LBD with a unique genetic profile that is different from those of AD or Parkinson's disease.

- https://pubmed.ncbi.nlm.nih.gov/29263008/

CDC published the third *Healthy Brain Initiative: State and Local Public Health Partnerships to Address Dementia, the 2018-2023 Road Map*.

CDC released four State of Aging and Health in America Data Briefs.

- https://www.cdc.gov/healthy-aging-data/brfss/index.html

ACL created the Alzheimer's Disease Programs Initiative (ADPI), by consolidating separate AD/ADRD state and community grant programs to create a new single program.

- https://acl.gov/programs/support-people-alzheimers-disease/support-people-dementia-including-alzheimers-disease

An NIH study reported that clearing senescent cells -- cells that are alive but no longer divide or perform their designated functions -- in the brain decreases tau pathology and cognitive decline in animal models.

- https://www.nia.nih.gov/news/clearing-senescent-cells-brain-mice-preserves-cognition

2019

An NIH study found that a blood test of neurofilament light chain, a protein released when nerve cells are damaged, predicted disease progression and loss of nerve cell function in the brain among cognitively normal people at risk for familial AD/ADRD.

- https://www.nia.nih.gov/news/blood-test-shows-promise-predicting-presymptomatic-disease-progression-people-risk-familial

NIH's Systolic Blood Pressure Intervention Trial (SPRINT) Memory and Cognition in Decreased Hypertension (MIND) study demonstrated that intensive high blood pressure control may significantly reduce the buildup of white-matter lesions in the brain and the occurrence of MCI, a precursor of dementia.

- https://www.nia.nih.gov/news/intensive-blood-pressure-control-may-slow-age-related-brain-damage

NIH funded the IMbedded Pragmatic Alzheimer's Disease and AD-Related Dementias Clinical Trials (IMPACT) Collaboratory, which is designed to spur innovation to meet the challenges of the complex care management for people living with AD/ADRD.

- https://impactcollaboratory.org/

NIH established Alzheimer's and Dementia Outreach, Recruitment, and Engagement (ADORE), an online, searchable database of resources for engagement, recruitment, and retention of study participants.

- https://www.nia.nih.gov/research/alzheimers-dementia-outreach-recruitment-engagement-resources

CDC and IHS published the first *Healthy Brain Initiative: Road Map for Indian Country* published.

- https://www.cdc.gov/aging/healthybrain/indian-country-roadmap.html

ACL convened the Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregiving Advisory Council.

- https://acl.gov/programs/support-caregivers/raise-family-caregiving-advisory-council

2020

With partial funding from the NIH, the first blood test for amyloid, PrecivityAD, became commercially available.

- https://www.nia.nih.gov/report-2020-2021-scientific-advances-prevention-treatment-and-care-dementia/biomarker-research#spotlight

FDA-approved flortaucipir is the first radioactive tracer to show the presence of tau protein tangles.

An NIH-funded study led to an advance in the development of a blood test to help detect pathological AD in people showing signs of dementia. The blood test detects the abnormal accumulation of a form of tau protein (ptau181).

- https://www.nia.nih.gov/news/blood-test-method-may-predict-alzheimers-protein-deposits-brain

NIH launched the Center for Alzheimer's Disease and Related Dementias (CARD).

- https://card.nih.gov/

NIH launched the Drug Repurposing for Effective Alzheimer's Medicines (DREAM) study to determine whether medicines currently used to treat conditions other than dementia can help prevent or treat AD/ADRD.

- https://www.nia.nih.gov/news/nia-study-identifies-fda-approved-drugs-may-also-be-helpful-dementia

An NIH-funded study found that individuals who made multiple healthy lifestyle choices (physical activity, not smoking, light-to-moderate alcohol consumption, a high-quality diet, and cognitive activities) may have a much lower risk for AD/ADRD.

- https://www.nia.nih.gov/news/combination-healthy-lifestyle-traits-may-substantially-reduce-alzheimers-disease-risk

ACL expanded Alzheimer's Disease Programs Initiative (ADPI) programming to dedicate resources to expanding dementia capability in Indian Country, launching grant and education programs in tribes and Tribal consortiums.

2021

HHS added a sixth goal to the *National Plan to Address Alzheimer's Disease* -- Accelerate Action to Promote Healthy Aging and Reduce Risk Factors for Alzheimer's Disease and Related Dementias.

- https://aspe.hhs.gov/reports/national-plan-2021-update#goal-6

IHS, in collaboration with Northwest Portland Area Indian Health Board (NPAIHB), created a dementia-focused Extension for Community Healthcare Outcomes (ECHO) Project for clinicians and caregiver support staff in Indian Country.

The Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregiving Advisory Council delivered its initial Report to Congress.

- https://acl.gov/programs/support-caregivers/raise-family-caregiving-advisory-council
- https://acl.gov/RAISE/report

NIH launched the second iteration of the AMP Program for Alzheimer's Disease (AMP-AD 2.0).

- https://www.nia.nih.gov/news/nih-invests-next-iteration-public-private-partnership-advance-precision-medicine-research

NIH revamped the Mind Your Risks® health campaign to focus more on health equity. The primary audience is now African American men, who are most at-risk for midlife high blood pressure and late-life dementia.

- https://www.mindyourrisks.nih.gov/index.html

2022

IHS published a funding opportunity, Addressing Dementia in Indian Country: Models of Care, and announced the availability of $5 million to target resources directly to tribes, Tribal organizations, UIOs, and IHS direct service facilities to address AD/ADRD and awarded four first-time grants.

- https://www.federalregister.gov/documents/2022/04/18/2022-08249/addressing-dementia-in-indian-country-models-of-care
- https://www.hhs.gov/about/news/2022/05/09/indian-health-service-funding-provides-resources-address-alzheimers-disease.html

VA launched the Dementia Education Portal for VHA dementia educators.

IHS created a collaborative to support Geriatric Emergency Department Accreditation (GEDA) for IHS and Tribal entities.

IHS collaborated with VA to establish the Indian health GeriScholars programs.

IHS launched the clinical dementia and caregiver ECHO series.

CDC established the Healthy Brain Resource Center (HBRC).

- https://www.cdc.gov/aging-programs/php/resource-center/index.html

The DoD Congressionally Directed Medical Research Program (CDMRP) Peer Reviewed Alzheimer's Research Program (PRARP) required community collaboration (inclusion of persons with dementia, their care partners and/or family members) in all clinical research projects proposed to the program.

- https://cdmrp.health.mil/prarp/default

NIH renewed the Consortium for Detecting Cognitive Impairment, Including Dementia (DetectCID) to conduct clinical trial testing on early dementia detection approaches in primary care.

- https://www.detectcid.org/

2023

FDA converted Leqembi (lecanemab-irmb), indicated to treat adult patients with AD to traditional approval, following a determination that a confirmatory trial verified clinical benefit. This is the first-ever treatment for AD to receive traditional FDA approval.

- https://www.fda.gov/news-events/press-announcements/fda-converts-novel-alzheimers-disease-treatment-traditional-approval

CDC announced its newest Healthy Brain Initiative (HBI) *State and Local Road Map for Public Health* (4th edition). This Road Map incorporates input from 100+ experts spanning health, non-profit, academia, and private sectors. The Road Map and its implementation resources guides the public health effort to promote brain health by creating a framework for public health action. It advances health equity and the importance of partnerships to guide public health action.

- https://www.cdc.gov/aging-programs/php/nhbi/roadmap.html

CMS announced Medicare coverage of lecanemab when a physician and clinician team participate in a registry, which collects evidence about how drugs work in the real world.

- https://qualitynet.cms.gov/alzheimers-ced-registry
- https://www.cms.gov/newsroom/press-releases/statement-broader-medicare-coverage-leqembi-available-following-fda-traditional-approval

CMS announced its Guiding and Improved Dementia Experience (GUIDE) Model, which aims to improve the quality of life for PLWD, reduce strain on unpaid caregivers, and help people remain in their homes and communities through a package of care coordination and management, caregiver education and support, and respite services.

- https://innovation.cms.gov/innovation-models/guide

CMS announced new actions to reduce the inappropriate use of antipsychotic medications and to bring greater transparency about nursing home citations to residents, families, caregivers, and the public.

- https://www.cms.gov/files/document/qso-23-05-nh-adjusting-quality-measure-ratings-based-erroneous-schizophrenia-coding-and-posting.pdf

IHS awarded $1.5M for eight new dementia Models of Care grants to Tribal and UIO recipients.

- https://www.ihs.gov/newsroom/pressreleases/2023-press-releases/ihs-awards-1-5-million-to-address-alzheimers-disease-on-world-alzheimers-day/

IHS initiated a pilot dementia screening program in the dental setting.

- https://www.ihs.gov/doh/index.cfm?fuseaction=home.cog

IHS awarded a multi-year communications contract to an Indian-owned Small Business for program support with outreach and awareness building.

NIA awarded more than $15 million in grants to support the development of research infrastructure for exposome studies in AD/ADRD, building the foundation for new centers for exposome studies by coordinating work across existing programs and other efforts. NINDS and NIA are also collaboratively funding several other projects to spark new advances in the research community's understanding of the exposome and its effect on dementia.

- https://grants.nih.gov/grants/guide/notice-files/NOT-AG-22-022.html
- https://www.nia.nih.gov/exposome

NIH funding led to the development of the next-generation version of the PrecivityAD blood test, PrecivityAD2, which combines measures of beta-amyloid and tau. Preliminary data suggest that combining these measures could help achieve diagnostic performance levels comparable to the current clinical gold standards of amyloid PET imaging and CSF tests.

- https://pubmed.ncbi.nlm.nih.gov/37932961/

An NIH-funded clinical study found that participants taking a multi-vitamin for 1 year scored significantly higher on a cognitive test compared to those taking a placebo pill. Notably, the cognitive test scores of participants with a history of cardiovascular disease improved significantly, becoming comparable to those without the disease. Although these initial findings are promising, further research is needed to see if this effect can be replicated in more diverse populations.

- https://www.nia.nih.gov/news/daily-multivitamin-may-enhance-memory-older-adults

2024

ACL announced the funding of the Innovations in Dementia-Specific Respite Programs and Services grant. The program provides $5,000,000 per year for 5 years (pending the availability of funds) to support the piloting of innovative dementia-specific respite models to support PLWD and their caregivers. Eighty percent of the program funding is dedicated to a subgrant program to support implementation of innovative community-based models and the other 20% is for the provision of technical assistance and education, as well as a third-party evaluation of the funded programs. The grant is being fulfilled through the recently created Center for Dementia Respite Innovation at the Alzheimer's Association.

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

ACL released a forecast for a new grant program entitled Developing Dementia-Capable Community Health Worker Programs in the National Aging Network. The new program will provide resources to the National Aging Network to expand the reach of CHWs in dementia care.

- https://grants.gov/search-results-detail/355842

AHRQ has funded the Person-Centered Care Planning for People with Multiple Chronic Conditions initiative through its ACTION IV Network with the goal to identify strategies to widely implement, scale, and spread person-centered care planning as a routine component of clinical practice. The initiative includes a Technical Expert Panel, Partner's Roundtable, National Learning Community, and Environmental Scan. A Summit bringing these groups together will develop an action plan aimed at fostering the widespread uptake of evidence-based person-centered care planning.

NIH-funded research uncovered rare forms of genes that may help protect against AD, including a variant of the RELN gene called RELN-COLBOS and a variant of the APOE gene called APOE3ch. Understanding how these variants promote dementia resilience may result in new approaches to prevention and treatment.

- https://www.nia.nih.gov/news/case-study-unlocks-clues-rare-resilience-alzheimers-disease
- https://pubmed.ncbi.nlm.nih.gov/38086389/

NIH-funded research provided new evidence to support behavioral and lifestyle interventions that may improve cognition and reduce dementia risk. For example, an NIA-funded clinical trial revealed that correcting hearing loss with hearing aids reduced cognitive decline over 3 years in a group of older adults with specific risk factors for cognitive decline. In addition, personalized health coaching improved cognition and reduced dementia risk in older adults with at least two modifiable risk factors for dementia.

- https://www.nia.nih.gov/news/hearing-aids-slow-cognitive-decline-people-high-risk
- https://pubmed.ncbi.nlm.nih.gov/38010725/

NIH-funded researchers developed a new, low-cost approach to monitoring blood pressure, a well-known risk factor for dementia, using a smartphone. The “BPClip” is designed for at-home use, employing a low-cost, universal smartphone attachment.

- https://www.nia.nih.gov/news/smartphone-clip-attachment-may-help-some-people-self-monitor-blood-pressure

NIH-funded research has led to the discovery of a fluid marker that may help diagnose forms of dementia associated with abnormal accumulation of the TDP-43 protein, such as FTD and LATE.

- https://www.nia.nih.gov/news/new-biomarker-may-help-detect-presymptomatic-als-and-ftd

NIA established a new Exposome Coordinating Center to foster collaboration and accelerate life course research on the social, behavioral, economic, and environmental exposures that shape AD/ADRD outcomes and inequities.

- https://reporter.nih.gov/search/WLWlOjvBqkyikzB1jhR9-w/project-details/10975562

FDA granted approval of Kisunla (donanemab-azbt) in the treatment of adult patients with AD in July 2024.

- https://www.fda.gov/drugs/news-events-human-drugs/fda-approves-treatment-adults-alzheimers-disease

IHS issued a third NOFO for six additional Models of Care grants focused on expansion and sustainability.

- https://www.ihs.gov/dgm/funding/

IHS implemented a new Geriatric Nurse Fellowship pilot in collaboration with the Division of Nursing.

- https://www.ihs.gov/alzheimers/pilotsandinitiatives/geriatricnursefellowship/

IHS awarded the Alzheimer’s Training and Education multi-year contract to the University of Washington.

- https://www.ihs.gov/newsroom/announcements/2024-announcements/ihs-announces-alzheimers-program-training-and-education-contract-award/

Appendix 3: Notices of Funding Opportunities, Notices of Special Interest, and Related Announcements

Action 1.B.1: Expand research to identify molecular and cellular mechanisms underlying Alzheimer's disease and related dementias, and translate this information into potential targets interventions

Notice of Special Interest: Genetic Underpinnings of Endosomal Trafficking as a Pathological Hub in Alzheimer's Disease and Alzheimer's Disease-Related Dementias (AD/ADRD) (NOT-AG-21-034)

- https://grants.nih.gov/grants/guide/notice-files/NOT-AG-21-034.html

Notice of Special Interest: Common Mechanisms and Interactions Among Neurodegenerative Diseases (NOT-AG-21-037)

- https://grants.nih.gov/grants/guide/notice-files/NOT-AG-21-037.html

Notice of Special Interest: In vivo Synaptic Function in Alzheimer's Disease and Related Dementias (NOT-AG-21-038)

- https://grants.nih.gov/grants/guide/notice-files/NOT-AG-21-038.html

Notice of Special Interest: Understanding Alzheimer's Disease in the Context of the Aging Brain (NOT-AG-21-039)

- https://grants.nih.gov/grants/guide/notice-files/NOT-AG-21-039.html

Notice of Special Interest: Selective Cell and Network Vulnerability in Aging and Alzheimer's Disease (NOT-AG-21-040)

- https://grants.nih.gov/grants/guide/notice-files/NOT-AG-21-040.html

Notice of Special Interest: Capturing Complexity in the Molecular and Cellular Mechanisms Involved in the Etiology of Alzheimer's Disease (NOT-AG-21-041)

- https://grants.nih.gov/grants/guide/notice-files/NOT-AG-21-041.html

Notice of Special Interest (NOSI): Deciphering the Glycosylation Code of Alzheimer's Disease (NOT-AG-21-042)

- https://grants.nih.gov/grants/guide/notice-files/NOT-AG-21-042.html

Notice of Special Interest (NOSI): Infectious Etiology of Alzheimer's Disease (NOT-AG-21-043)

- https://grants.nih.gov/grants/guide/notice-files/NOT-AG-21-043.html

Notice of Special Interest (NOSI): Sleep Disorders and Circadian Clock Disruption in Alzheimer's Disease and other Dementias of Aging (NOT-AG-21-051)

- https://grants.nih.gov/grants/guide/notice-files/NOT-AG-21-051.html

Notice of Special Interest (NOSI): Human Cell Biology of Alzheimer's Disease Genetic Variants (NOT-AG-21-052)

- https://grants.nih.gov/grants/guide/notice-files/NOT-AG-21-052.html

Notice of Special Interest (NOSI): Role of Age-Associated Metabolic Changes in Alzheimer's Disease (NOT-AG-21-053)

- https://grants.nih.gov/grants/guide/notice-files/NOT-AG-21-053.html

Notice of Special Interest (NOSI): Investigation of Biomolecular Condensates in Aging and Alzheimer's Disease (AD) and AD-related Dementias (ADRD) (NOT-AG-23-037)

- https://grants.nih.gov/grants/guide/notice-files/NOT-AG-23-037.html

Microphysiological Systems to Advance Precision Medicine for AD/ADRD Treatment and Prevention (RFA-AG-24-040)

- https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-24-040.html

Chimeric Antigen Receptor (CAR) Approaches to AD/ADRD (RFA-AG-24-046)

- https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-24-046.html

Multi-Scale Models Bridging Levels of Analysis in Aging and Alzheimer's Disease (AD) and AD-Related Dementias (ADRD) (RFA-AG-25-016)

- https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-25-016.html

Exploring Proteogenomic Approaches to Unravel the Mechanisms of Mis-Folded Protein Accumulation in Tauopathies (RFA-AG-25-017)

- https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-25-017.html

Deciphering the Impact of RNA Modifications on Brain Aging and AD/ADRD (RFA-AG-25-022)

- https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-25-022.html

Deciphering the Impact of RNA Modifications on Brain Aging and AD/ADRD (RFA-AG-25-023)

- https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-25-023.html

Access and Manipulation of Brain Cell Subtypes Implicated in Aging and AD/ADRD (RFA-AG-25-024)

- https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-25-024.html

Blueprint Neurotherapeutics Network (BPN): Small Molecule Drug Discovery and Development of Disorders of the Nervous System (PAR-24-043)

- https://grants.nih.gov/grants/guide/pa-files/PAR-24-043.html

NIA Postdoctoral Fellowship Award to Promote Diversity in Translational Research for AD/ADRD (PAR-21-217)

- https://grants.nih.gov/grants/guide/pa-files/PAR-21-217.html

NIA Predoctoral Fellowship Award to Promote Diversity in Translational Research for AD/ADRD (PAR-21-218)

- https://grants.nih.gov/grants/guide/pa-files/PAR-21-218.html

NIA Advanced Postdoctoral Career Transition Awards to Promote Diversity in Translational Research for AD/ADRD (PAR-21-220)

- https://grants.nih.gov/grants/guide/pa-files/PAR-21-220.html

NINDS Alzheimer’s Disease and Alzheimer’s Disease-Related Dementias (AD/ADRD) Advanced Postdoctoral Career Transition Award to Promote Diversity (PAR-24-212)

- https://grants.nih.gov/grants/guide/pa-files/PAR-24-212.html

Alzheimer's Drug-Development Program (PAR-22-047)

- https://grants.nih.gov/grants/guide/pa-files/par-22-047.html

Alzheimer's Drug-Development Program (PAR-24-223)

- https://grants.nih.gov/grants/guide/pa-files/PAR-24-223.html

Small Research Grant Program for the Next Generation of Researchers in AD/ADRD Research (PAR-23-179)

- https://grants.nih.gov/grants/guide/pa-files/PAR-23-179.html

New Approaches for Measuring Brain Changes Across Longer Timespans (R01 - Clinical Trial Optional) (PAR-24-160)

- https://grants.nih.gov/grants/guide/pa-files/PAR-24-160.html

New Approaches for Measuring Brain Changes Across Longer Timespans (R21 - Clinical Trial Optional) (PAR-24-161)

- https://grants.nih.gov/grants/guide/pa-files/PAR-24-161.html

Development and Validation of Human Cellular Models for Alzheimer's Disease-Related Dementias (ADRD) (RFA-NS-24-032)

- https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-24-032.html

Mechanistic Investigations into ADRD Multiple Etiology Dementias (PAR-24-147)

- https://grants.nih.gov/grants/guide/pa-files/PAR-24-147.html

Small Research Grant Program for the Next Generation of Researchers in AD/ADRD Research (R03 - Clinical Trial Optional) (PAR-23-179)

- https://grants.nih.gov/grants/guide/pa-files/PAR-23-179.html

Mechanistic Investigations into ADRD Associated Protein Structures in Biological Settings (PAR-24-234)

- https://grants.nih.gov/grants/guide/pa-files/PAR-24-234.html

Functional Target Validation for Alzheimer's Disease-Related Dementias (RFA-NS-25-011)

- https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-25-011.html

VCID Center Without Walls (CWOW) for Understanding and Leveraging Small Vessel Cerebrovascular Disease Mechanisms in ADRD (RFA-NS-24-027)

- https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-24-027.html

Mechanisms of Cognitive Fluctuations in ADRD Populations (RFA-NS-25-014)

- https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-25-014.html

Novel Mechanism Research on Neuropsychiatric Symptoms (NPS) in Alzheimer's Dementia (PAR-23-207)

- https://grants.nih.gov/grants/guide/pa-files/PAR-23-207.html

Novel Mechanism Research on Neuropsychiatric Symptoms (NPS) in Alzheimer's Dementia (PAR-23-208)

- https://grants.nih.gov/grants/guide/pa-files/PAR-23-208.html

Protective Strategies to Reduce Amyloid Related Imaging Abnormalities (ARIA) After Anti-Amyloid Beta Immunotherapy (R01 - Clinical Trial Not Allowed) (PAR-24-198)

- https://grants.nih.gov/grants/guide/pa-files/PAR-24-198.html

Access and Manipulation of Brain Cell Subtypes Implicated in Aging and AD/ADRD (R61/R33 - Clinical Trial Not allowed) (RFA-AG-25-024)

- https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-25-024.html

Optimization of Genome Editing Therapeutics for Alzheimer's Disease-Related Dementias (ADRD) (U01 - Clinical Trials Not Allowed) (RFA-NS-24-009)

- https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-24-009.html

Impact of the Microbiome-Gut-Brain Axis on Alzheimer's Disease and Alzheimer's Disease Related Dementias (R01 - Clinical Trial Not Allowed) (PAR-22-211)

- https://grants.nih.gov/grants/guide/pa-files/PAR-22-211.html

Early-Stage Therapy Development for Alzheimer's Disease-Related Dementias (ADRD) (R61/R33 - Clinical Trial Not Allowed)

- https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-24-010.html

Functional Target Validation for Alzheimer's Disease-Related Dementias (R61/R33 - Clinical Trial Not Allowed)

- https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-25-011.html

Notice of Special Interest (NOSI): Administrative Supplements to Promote Diversity for NINDS ADRD Awardees

- https://grants.nih.gov/grants/guide/notice-files/NOT-NS-24-071.html

Investigating Distinct and Overlapping Mechanisms in TDP-43 Proteinopathies, including in LATE, FTD & other ADRDs (R01 - Clinical Trial Not Allowed) (PAR-24-148)

- https://grants.nih.gov/grants/guide/pa-files/PAR-24-148.html

Chimeric Antigen Receptor (CAR) Approaches to AD/ADRD (R61/R33 Clinical Trial Not Allowed) (RFA-AG-24-046)

- https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-24-046.html

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Action 1.B.2: Expand genetic epidemiologic research to identify biological and genetic risk and protective factors for Alzheimer's disease and related dementias

Cognitive Systems Analysis of Alzheimer's Disease Genetic and Phenotypic Data (PAR-19-269)

- https://grants.nih.gov/grants/guide/pa-files/PAR-19-269.html

NIA Renewal and Competing Revision Cooperative Agreements in Aging Research (U01 - Clinical Trial Optional) (PAR-22-362)

- https://grants.nih.gov/grants/guide/pa-files/PAR-22-362.html

Limited Competition: Alzheimer's Disease Sequencing Project Follow-Up Study 2.0 (ADSP FUS 2.0): The Diverse Population (PAR-21-212)

- https://grants.nih.gov/grants/guide/pa-files/PAR-21-212.html

NIA Renewal and Competing Revision Cooperative Agreements in Aging Research (PAR-22-362)

- https://grants.nih.gov/grants/guide/pa-files/PAR-22-362.html

Integrative Research to Understand the Impact of Sex Differences on the Molecular Determinants of AD Risk and Responsiveness to Treatment (U01 - Clinical Trial Optional) (PAR-23-082)

- https://grants.nih.gov/grants/guide/pa-files/PAR-23-082.html

Research Collaboration Network in Structural Racism Measurement and Modeling (RFA-AG-25-003)

- https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-25-003.html

Notice specifying a high-priority topic of interest for PAR-22-093 "Research on Current Topics in Alzheimer's Disease and Its Related Dementias" and PAR-22-094 "Research on Current Topics in Alzheimer's Disease and Its Related Dementias"

- https://grants.nih.gov/grants/guide/pa-files/PAR-22-093.html
- https://grants.nih.gov/grants/guide/pa-files/PAR-22-094.html

Notice of Special Interest (NOSI): Genetic Underpinnings of Endosomal Trafficking as a Pathological Hub in Alzheimer's Disease and Alzheimer's Disease-Related Dementias (AD/ADRD) (NOT-AG-21-034)

- https://grants.nih.gov/grants/guide/notice-files/NOT-AG-21-034.html

Notice of Special Interest (NOSI): Opportunities for Research in Epidemiology of Alzheimer's Disease and Alzheimer's Disease-Related Dementias (AD/ADRD) and Cognitive Resilience (NOT-AG-21-045)

- https://grants.nih.gov/grants/guide/notice-files/NOT-AG-21-045.html

Notice of Special Interest (NOSI): Sex and Gender Differences in Alzheimer’s Disease and Alzheimer’s Disease-Related Dementias (AD/ADRD) (NOT-AG-21-050)

- https://grants.nih.gov/grants/guide/notice-files/NOT-AG-21-050.html

Notice of Special Interest (NOSI): Human Cell Biology of Alzheimer's Disease Genetic Variants (NOT-AG-21-052)

- https://grants.nih.gov/grants/guide/notice-files/NOT-AG-21-052.html

NIA Renewal and Revision Cooperative Agreements in AD/ADRD Research (U54 - Clinical Trial Optional) (PAR-22-077)

- https://grants.nih.gov/grants/guide/pa-files/PAR-22-077.html

NIA Renewal and Revision Cooperative Agreements in AD/ADRD Research (U24 - Clinical Trial Not Allowed) (PAR-22-110)

- https://grants.nih.gov/grants/guide/pa-files/PAR-22-110.html

NIA Renewal and Competing Revision Cooperative Agreements in Aging Research (U01 - Clinical Trial Optional) (PAR-22-362)

- https://grants.nih.gov/grants/guide/pa-files/PAR-22-362.html

Action 1.B.3: Increase enrollment in clinical trials and other clinical research through community, national, and international outreach

NIA Announces New Policy and Procedures for the Reporting of Human Subjects Enrollment Data for NIA Clinical Research Trials/Studies (NOT-AG-21-029)

- https://grants.nih.gov/grants/guide/notice-files/NOT-AG-21-029.html

Action 1.B.4: Monitor and identify strategies to increase enrollment of racial and ethnic minorities in Alzheimer’s disease and related dementias studies

Limited Competition: Alzheimer’s Disease Sequencing Project Follow-Up Study 2.0 (ADSP FUS 2.0): The Diverse Population Initiative (PAR-21-212)

- https://grants.nih.gov/grants/guide/pa-files/PAR-21-212.html

Alzheimer's Disease Research Centers (RFA-AG-24-001)

- https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-24-001.html

Research Collaboration Network in Structural Racism Measurement and Modeling (RFA-AG-25-003)

- https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-25-003.html

Clinical Trial Readiness to Understand and Develop Solutions to Social, Ethical, Behavioral Implications and Barriers to Health Equity in ADRD (R01 - Clinical Trial Not Allowed) (RFA-NS-25-013)

- https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-25-013.html

Notice of Special Interest: Health Disparities and Alzheimer's Disease (NOT-AG-21-033)

- https://grants.nih.gov/grants/guide/notice-files/NOT-AG-21-033.html

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Action 1.B.5: Conduct clinical trials on the most promising interventions

Alzheimer's Clinical Trials Consortium (ACTC) Clinical Trials (RFA-AG-25-010)

- https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-25-010.html

Open Measurement Coordinating Network for Non-Pharmacological Alzheimer's Disease (AD) and AD-Related Dementias (ADRD) Primary Prevention Trials (RFA-AG-25-005)

- https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-25-005.html

Early and Late Stage Clinical Trials for the Spectrum of Alzheimer's Disease/Alzheimer's Related Dementias and Age-related Cognitive Decline (PAR-21-359)

- https://grants.nih.gov/grants/guide/pa-files/PAR-21-359.html

Dementia Care and Caregiver Support Intervention Research (PAR-21-307)

- https://grants.nih.gov/grants/guide/pa-files/PAR-21-307.html

Pragmatic Trials for Dementia Care and Caregiver Support (PAR-21-308)

- https://grants.nih.gov/grants/guide/pa-files/PAR-21-308.html

NIA Multi-site Clinical Trial Implementation Grant (R01 - Clinical Trial Required) (PAR-23-057)

- https://grants.nih.gov/grants/guide/pa-files/PAR-23-057.html

Pilot Studies for the Spectrum of Alzheimer's Disease/Alzheimer's Disease-Related Dementias and Age-Related Cognitive Decline (R61 - Clinical Trial Optional) (PAR-23-083)

- https://grants.nih.gov/grants/guide/pa-files/PAR-23-083.html

Analytical and Clinical Validation of Biomarkers for Alzheimer's Disease (AD) and AD-Related Dementias (ADRD) (U01 - Clinical Trial Optional) (PAR-23-258)

- https://grants.nih.gov/grants/guide/pa-files/PAR-23-258.html

Seamless Early-Stage Clinical Drug Development (Phase 1 to 2a) for Novel therapeutic Agents for the Spectrum of Alzheimer's Disease (AD) and AD-related Dementias (ADRD) (UG3/UH3 - Clinical Trial Required) (PAR-23-274)

- https://grants.nih.gov/grants/guide/pa-files/PAR-23-274.html

NIA Renewal and Revision Cooperative Agreements in AD/ADRD Research (U54 - Clinical Trial Optional) (PAR-22-077)

- https://grants.nih.gov/grants/guide/pa-files/PAR-22-077.html

NIA Renewal and Revision Cooperative Agreements in AD/ADRD Research (U24 - Clinical Trial Not Allowed) (PAR-22-110)

- https://grants.nih.gov/grants/guide/pa-files/PAR-22-110.html

NIA Renewal and Competing Revision Cooperative Agreements in Aging Research (U01 - Clinical Trial Optional) (PAR-22-362)

- https://grants.nih.gov/grants/guide/pa-files/PAR-22-362.html

Roybal Centers for Translational Behavioral Research on Dementia Care, Caregiver Support, and Prevention of Alzheimer's Disease and Related Dementias (AD/ADRD) (RFA-AG-24-007)

- https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-24-007.html

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 (U01 - Clinical Trial Required)

- https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-25-010.html

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)

- https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-24-013.html

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Action 1.B.6: Expand research focused on needs related to the intersection of Down syndrome and Alzheimer's disease and related dementias

Development of Animal Models and Related Biological Materials for Down Syndrome Research (PAR-23-067)

- https://grants.nih.gov/grants/guide/pa-files/PAR-23-067.html

Alzheimer's Disease Research Centers (P30 - Clinical Trial Not Allowed) (RFA-AG-24-001)

- https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-24-001.html

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Action 1.B.8: Research the impacts of COVID-19 and Post-COVID Conditions on risk of Alzheimer's disease and related dementias, cognition, and brain health

Emergency Award: Social, Behavioral, and Economic Research on COVID-19 Consortium (U01 - Clinical Trial Not Allowed) (PAR-21-213)

- https://grants.nih.gov/grants/guide/pa-files/PAR-21-213.html

Neuropathological Interactions Between COVID-19 and ADRD (PAR-24-203)

- https://grants.nih.gov/grants/guide/pa-files/PAR-24-203.html

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Action 1.C.1: Identify imaging and biomarkers to monitor disease progression

NIA Medicine, Science, Technology, Engineering and Mathematics (MSTEM): Advancing Diversity in Aging Research (ADAR) through Undergraduate Education (PAR-24-135)

- https://grants.nih.gov/grants/guide/pa-files/PAR-24-135.html

Tools and resources to understand the vascular pathophysiology of in vivo neuroimaging findings in ARIA (U24 - Clinical Trials Not Allowed) (RFA-NS-24-034)

- https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-24-034.html

Notice of Special Interest: Development of Radiotracers for Diagnosis and Clinical Studies in Alzheimer's Disease (AD) and AD-Related Dementias (ADRD) (NOT-AG-22-032)

- https://grants.nih.gov/grants/guide/notice-files/NOT-AG-22-032.html

Analytical and Clinical Validation of Biomarkers for Alzheimer's Disease (AD) and AD-Related Dementias (ADRD) (U01 - Clinical Trial Optional) (PAR-23-258)

- https://grants.nih.gov/grants/guide/pa-files/PAR-23-258.html

Notice of Special Interest (NOSI): Novel Approaches to Diagnosing and Studying Clinical Alzheimer's Disease and Related Dementias (NOT-AG-21-036)

- https://grants.nih.gov/grants/guide/notice-files/NOT-AG-21-036.html

Notice of Special Interest (NOSI): Sensory and Motor System Changes as Predictors of Preclinical Alzheimer's Disease (NOT-AG-21-044)

- https://grants.nih.gov/grants/guide/notice-files/NOT-AG-21-044.html

Action 1.C.2: Maximize collaboration among federal agencies and with the private sector

Notice of Special Interest (NOSI): Administrative Supplements for NIA-VA Mentored Physician and Clinical Psychologist Scientist Award in Alzheimer's Disease (AD) and AD-Related Dementias (ADRD) (NOT-AG-23-054)

- https://grants.nih.gov/grants/guide/notice-files/NOT-AG-23-054.html

Action 1.D.2: Expand international outreach to enhance collaboration

Limited Competition: The Health and Retirement Study and Harmonized Cognitive Assessment Protocol (U01 - Clinical Trial Not Allowed) (RFA-AG-24-010)

- https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-24-010.html

Global Brain and Nervous System Disorders Research Across the Lifespan (PAR-22-097)

- https://grants.nih.gov/grants/guide/pa-files/PAR-22-097.html

Global Brain and Nervous System Disorders Research Across the Lifespan (PAR-22-098)

- https://grants.nih.gov/grants/guide/pa-files/PAR-22-098.html

Chronic, Non-Communicable Diseases and Disorders Across the Lifespan: Fogarty International Research Training Award (NCD-LIFESPAN) (PAR-22-104)

- https://grants.nih.gov/grants/guide/pa-files/PAR-22-104.html

Notice of Special Interest (NOSI): Opportunities for Research in Epidemiology of Alzheimer's Disease and Alzheimer's Disease-Related Dementias (AD/ADRD) and Cognitive Resilience (NOT-AG-21-045)

- https://grants.nih.gov/grants/guide/notice-files/NOT-AG-21-045.html

Notice of Special Interest (NOSI): U.S. Health in the International Perspective (NOT-AG-24-004)

- https://grants.nih.gov/grants/guide/notice-files/NOT-AG-24-004.html

Building Neuroscience Research Infrastructure for Alzheimer's Disease (AD) and AD-Related Dementias (ADRD) in Africa (RFA-AG-24-027)

- https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-24-027.html

Enhancing Use of Harmonized Cognitive Assessment Protocol (HCAP) Data (RFA-AG-24-032)

- https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-24-032.html

Implementation Research on Noncommunicable Disease Risk Factors among Low- and Middle-Income Country and Tribal Populations Living in City Environments (R01 - Clinical Trial Optional) (PAR-23-319)

- https://grants.nih.gov/grants/guide/pa-files/PAR-23-319.html

Implementation Research to Reduce Noncommunicable Disease (NCD) Burden in Low- and Middle-Income Countries (LMICs) and Tribal Nations During Critical Life Stages and Key Transition Periods (R01 - Clinical Trial Optional) (PAR-22-132)

- https://grants.nih.gov/grants/guide/pa-files/PAR-22-132.html

Unveiling Health and Healthcare Disparities in Non-Communicable and Chronic Diseases in Latin America: Setting the Stage for Better Health Outcomes Across the Hemisphere (R01 - Clinical Trials Not Allowed) (PAR-23-303)

- https://grants.nih.gov/grants/guide/pa-files/PAR-23-303.html

Action 2.A.1: Educate health care providers

Grants for Early Medical/Surgical Specialists' Transition to Aging Research (GEMSSTAR) (R03 - Clinical Trial Optional) (RFA-AG-25-021)

- https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-25-021.html

Research Training in Aging for Medical Students (T35) (RFA-AG-25-009)

- https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-25-009.html

Action 2.A.5: Ensure aging and public health network providers have access to research-based up-to-date information on Alzheimer’s disease and related dementias

Dementia Care and Caregiver Support Intervention Research (PAR-21-307)

- https://grants.nih.gov/grants/guide/pa-files/PAR-21-307.html

Pragmatic Trials for Dementia Care and Caregiver Support (PAR-21-308)

- https://grants.nih.gov/grants/guide/pa-files/PAR-21-308.html

Action 2.B.2: Support Technology to Advance Mobile Monitoring of Cognitive Changes

Notice of Special Interest (NOSI): Digital Technology for Early Detection and Monitoring of Alzheimer’s Disease and Related Dementias (NOT-AG-21-048)

- https://grants.nih.gov/grants/guide/notice-files/NOT-AG-21-048.html

Action 2.B.3: Identify and study effective approaches to increasing detection of cognitive impairment in clinical settings

Notice of Special Interest: Digital Technology for Early Detection and Monitoring of Alzheimer’s Disease and Related Dementias (NOT-AG-21-048)

- https://grants.nih.gov/grants/guide/notice-files/NOT-AG-21-048.html

Notice of Special Interest (NOSI): Telehealth for People and Families Living with Alzheimer's Disease (AD) and AD-Related Dementias (ADRD) (NOT-AG-23-060)

- https://grants.nih.gov/grants/guide/notice-files/NOT-AG-23-060.html
- https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-22-009.html

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Action 2.H.1: Create funding opportunities for organizations to improve care for Tribal populations

Addressing Dementia in Tribal and Urban Indian Communities: Enhancing Sustainable Models of Care (HHS-2024-IHS-ALZ-0001)

- https://grants.gov/search-results-detail/349555

Addressing Dementia in Indian Country: Models of Care (HHS-2023-IHS-ALZ-0001)

- https://www.federalregister.gov/documents/2023/03/29/2023-06455/addressing-dementia-in-indian-country-models-of-care

Addressing Dementia in Indian Country: Models of Care (HHS-2022-IHS-ALZ-0001)

- https://www.federalregister.gov/documents/2022/04/18/2022-08249/addressing-dementia-in-indian-country-models-of-care

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Action 3.A.2: Utilize health information technology for caregivers and persons with Alzheimer’s disease and related dementias

Notice of Special Interest: Digital Technology for Early Detection of Alzheimer’s Disease and Related Dementias (NOT-AG-20-017)

- https://grants.nih.gov/grants/guide/notice-files/NOT-AG-20-017.html

Notice of Special Interest: Digital Technology for Early Detection and Monitoring of Alzheimer’s Disease and Related Dementias (NOT-AG-21-048)

- https://grants.nih.gov/grants/guide/notice-files/NOT-AG-21-048.html

Notice of Special Interest (NOSI): Telehealth for People and Families Living with Alzheimer's Disease (AD) and AD-Related Dementias (ADRD) (NOT-AG-23-060)

- https://grants.nih.gov/grants/guide/notice-files/NOT-AG-23-060.html

Validating digital health technologies for monitoring biomarkers in ADRD clinical trials (R61/R33 - Clinical Trials Optional) (RFA-NS-24-026)

- https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-24-026.html

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Action 3.B.1: Develop and disseminate evidence-based interventions for people with Alzheimer’s disease and related dementias and their caregivers

Notice specifying a high-priority topic of interest for PAR-22-093 "Research on Current Topics in Alzheimer's Disease and Its Related Dementias" and PAR-22-094 "Research on Current Topics in Alzheimer's Disease and Its Related Dementias"

- https://grants.nih.gov/grants/guide/pa-files/PAR-22-093.html
- https://grants.nih.gov/grants/guide/pa-files/PAR-22-094.html

Notice of Special Interest (NOSI): Behavioral and Social Science Priority Areas in Dementia Care Partner/Caregiver Research (NOT-AG-21-047)

- https://grants.nih.gov/grants/guide/notice-files/NOT-AG-21-047.html

Notice of Special Interest (NOSI): Dementia Care Research: Programs and services for persons with dementia (NOT-AG-21-046)

- https://grants.nih.gov/grants/guide/notice-files/NOT-AG-21-046.html

Notice of Special Interest: Dementia Care Workforce for Those Living with Alzheimer's Disease and Alzheimer's Disease-Related Dementias (AD/ADRD) (NOT-AG-21-049)

- https://grants.nih.gov/grants/guide/notice-files/NOT-AG-21-049.html

Dementia Care and Caregiver Support Intervention Research (PAR-21-307)

- https://grants.nih.gov/grants/guide/pa-files/PAR-21-307.html

Pragmatic Trials for Dementia Care and Caregiver Support (PAR-21-308)

- https://grants.nih.gov/grants/guide/pa-files/PAR-21-308.html

Dissemination and Implementation Research in Health (PAR-22-105)

- https://grants.nih.gov/grants/guide/pa-files/par-22-105.html

Dissemination and Implementation Research in Health (PAR-22-106)

- https://grants.nih.gov/grants/guide/pa-files/PAR-22-106.html

Dissemination and Implementation Research in Health (PAR-22-109)

- https://grants.nih.gov/grants/guide/pa-files/PAR-22-109.html

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Action 3.D.3: Translate and disseminate information on abuse of people with dementia

Notice specifying a high-priority topic of interest for PAR-22-093 "Research on Current Topics in Alzheimer's Disease and Its Related Dementias" and PAR-22-094 "Research on Current Topics in Alzheimer's Disease and Its Related Dementias"

- https://grants.nih.gov/grants/guide/pa-files/PAR-22-093.html
- https://grants.nih.gov/grants/guide/pa-files/PAR-22-094.html

Notice of Special Interest (NOSI): Dementia Care Research: Programs and services for persons with dementia (NOT-AG-21-046)

- https://grants.nih.gov/grants/guide/notice-files/NOT-AG-21-046.html

Notice of Special Interest (NOSI): Behavioral and Social Science Priority Areas in Dementia Care Partner/Caregiver Research (NOT-AG-21-047)

- https://grants.nih.gov/grants/guide/notice-files/NOT-AG-21-047.html

Notice of Special Interest (NOSI): Research on Addressing Violence to Improve Health Outcomes (NOT-OD-22-167)

- https://grants.nih.gov/grants/guide/notice-files/NOT-OD-22-167.html

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Action 4.C.1: Work with global partners to enhance collaboration

Global Brain and Nervous System Disorders Research Across the Lifespan (PAR-22-097)

- https://grants.nih.gov/grants/guide/pa-files/PAR-22-097.html

Global Brain and Nervous System Disorders Research Across the Lifespan (PAR-22-098)

- https://grants.nih.gov/grants/guide/pa-files/PAR-22-098.html

Chronic, Non-Communicable Diseases and Disorders Across the Lifespan: Fogarty International Research Training Award (NCD-LIFESPAN) (PAR-22-104)

- https://grants.nih.gov/grants/guide/pa-files/PAR-22-104.html

Notice of Special Interest (NOSI): U.S. Health in the International Perspective (NOT-AG-24-004)

- https://grants.nih.gov/grants/guide/notice-files/NOT-AG-24-004.html

Short Courses Promoting Cross-National Analyses Using Data from the International Health and Retirement Study (HRS) and Harmonized Cognitive Assessment Protocol (HCAP) (R25 - Clinical Trial Not Allowed) (RFA-AG-25-025)

- https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-25-025.html

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Action 6.A.3: Expand and diversify clinical research studies on promising interventions to reduce individual and community-level risk

Clinical Trial Readiness to Understand and Develop Solutions to Social, Ethical, Behavioral Implications and Barriers to Health Equity in ADRD (R01 - Clinical Trial Not Allowed)

- https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-25-013.html

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Action 6.A.4: Enhance research to better understand the varying levels of or types of dementia risk across demographic groups

ADRD Risk and Disease Following Nervous System Exposures at Biological Interfaces with the Environment (R01 - Clinical Trial Not Allowed)

- https://grants.nih.gov/grants/guide/pa-files/PAR-24-270.html

Interaction Between Environmental Factors and Lewy Body Dementia (R01 - Clinical Trial Not Allowed)

- https://grants.nih.gov/grants/guide/pa-files/PAR-24-249.html

Limited Competition: Alzheimer's Disease Sequencing Project Follow-Up Study 2.0 (ADSP FUS 2.0): The Diverse Population Initiative (U01 - Clinical Trial Not Allowed) (PAR-21-212)

- https://grants.nih.gov/grants/guide/pa-files/PAR-21-212.html

Clinical Trial Readiness to Understand and Develop Solutions to Social, Ethical, Behavioral Implications and Barriers to Health Equity in ADRD (R01 - Clinical Trial Not Allowed) (RFA-NS-25-013)

- https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-25-013.html

Role of Environmental Stress in the Health Inequities of Alzheimer's Disease-Related Dementias (ADRD) (R01 - Clinical Trial Not Allowed) (RFA-NS-24-024)

- https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-24-024.html

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Action 6.A.5: Expand research on traumatic brain injury as a risk factor for neurodegeneration

Adding TBI Assessments to AD/ADRD Cohorts

- https://grants.nih.gov/grants/guide/notice-files/NOT-NS-22-002.html

Clinical and Biological Measures of TBI-related Dementia Including Chronic Traumatic Encephalopathy

- https://grants.nih.gov/grants/guide/pa-files/PAR-22-024.html

Development & Characterization of Experimental models of post-TBI ADRD

- https://grants.nih.gov/grants/guide/pa-files/PAR-23-218.html

Training Award to Promote Cross-Training in the Fields of Traumatic Brain Injury (TBI) as a Risk Factor for Alzheimer’s Disease/Alzheimer’s Disease Related Dementias (AD/ADRD)

- https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-22-061.html

Tools and resources to understand the vascular pathophysiology of in vivo neuroimaging findings in TBI-related dementia and/or VCID

- https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-23-002.html

Assessment of TBI-related ADRD Pathology Related to Cognitive Impairment and Dementia Outcomes

- https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-24-003.html

Action 6.A.7: Continue clinical trials on the most promising health promotion interventions

Alzheimer's Clinical Trials Consortium (ACTC) Clinical Trials (RFA-AG-25-010)

- https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-25-010.html

Open Measurement Coordinating Network for Non-Pharmacological Alzheimer's Disease (AD) and AD-Related Dementias (ADRD) Primary Prevention Trials (RFA-AG-25-005)

- https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-25-005.html

Notice of Special Interest (NOSI): Developing and Testing Multi-level Physical Activity Interventions to Improve Health and Well-Being (NOT-OD-24-058)

- https://grants.nih.gov/grants/guide/notice-files/NOT-OD-24-058.html

Notice of Special Interest (NOSI): Development and Preliminary Testing of Health-related Behavioral Interventions (NOT-OD-22-203)

- https://grants.nih.gov/grants/guide/notice-files/NOT-OD-22-203.html

List of Acronyms Used

4Ms	What Matters, Medication, Mentation, and Mobility
A4	Anti-Amyloid Treatment in Asymptomatic Alzheimer's study
AAA	Area Agency on Aging
AAIC	Alzheimer’s Association International Conference
AAPI	Asian Americans and Pacific Islanders
ABC-DS	Alzheimer’s Biomarker Consortium-Down Syndrome
ABCD	Addressing Behavioral Challenges in Dementia
ACL	Administration for Community Living
ACPM	American College of Preventive Medicine
ACTC	Alzheimer’s Clinical Trials Consortium
AD	Alzheimer's disease
AD-MAP	AD-Multimodal Atlasing Project
ADEAR	Alzheimer’s and related Dementias Education and Referral
ADL	Activity of Daily Living
ADNI	Alzheimer’s Disease Neuroimaging Initiative
ADORE	Alzheimer’s and Dementia Outreach, Recruitment, and Engagement resources
ADPI	Alzheimer’s Disease Programs Initiative
ADRC	Alzheimer's Disease Research Center
ADRD	Alzheimer's Disease and Alzheimer's Disease-Related Dementias
ADSP	Alzheimer's Disease Sequencing Project
ADSP-PHC	Alzheimer’s Disease Sequencing Project Phenotype Harmonization Consortium
AFHS	Age-Friendly Health System
AHRQ	Agency for Healthcare Research and Quality
AI/AN	American Indian and Alaska Native
AI/ML	Artificial Intelligence and Machine Learning
AITC	Artificial Intelligence and Technology Collaboratory
ALLFTD	Advancing Research and Treatment for Frontotemporal Lobar Degeneration (ARTFL) and Longitudinal Evaluation of Familial Frontotemporal Dementia Subjects (LEFFTDS) Longitudinal Frontotemporal Lobar Degeneration research study
ALS	Amyotrophic Lateral Sclerosis/Lou Gehrig’s disease
AMA	American Medical Association
AMP®-AD	Accelerating Medicines Partnership® Program for Alzheimer's Disease
AoA	Administration on Aging
APOE	Apolipoprotein E gene
APS	Adult Protective Services
ASPE	HHS Office of the Assistant Secretary for Planning and Evaluation
ASTHO	Association of State and Territorial Health Officials
AtG	Alternatives to Guardianship
AWV	Annual Wellness Visit
BOLD	Building Our Largest Dementia Infrastructure for Alzheimer's Act
BRAIN	Brain Research through Advancing Innovative Neurotechnologies®
BRFSS	Behavioral Risk Factor Surveillance System
CARD	Center for Alzheimer’s and Related Dementias
CARE	Collaborative Approach for Asian Americans and Pacific Islanders Research and Education
CBO	Community-Based Organization
CCBHC	Certified Community Behavioral Health Clinic
CDC	Centers for Disease Control and Prevention
CDMRP	Congressionally Directed Medical Research Program

CDRH	Center for Devices and Radiological Health
CED	Coverage with Evidence Development
CEU	Continuing Education Unit
CHR	Community Health Representative
CHW	Community Health Worker
CLC	Community Living Center
CME	Continuing Medical Education
CMPRP	Civil Money Penalty Reinvestment Program
CMS	Centers for Medicare & Medicaid Services
COE-NF	Center of Excellence for Behavioral Health in Nursing Facilities
COPE	Care of People with Dementia in their Environments
COSMOS-Mind	Cocoa Supplement and Multivitamin Outcomes Study for the Mind
COVID-19	2019 Novel Coronavirus
CRISPR	Clustered Regularly Interspaced Short Palindromic Repeats
CROMS	Clinical Research Operations and Management System
CRSS	Clinical Research Support Services
cryo-EM	cryo-electron microscopy
CSF	Cerebrospinal Fluid
CSP	Caregiver Support Program
CSPB	Caregiver Stress Prevention Bundle
CTE	Chronic Traumatic Encephalopathy
CWOW	Center Without Walls
DDC	dopamine biosynthesis
DEI	diversity, equity, and inclusion
DetectCID	Consortium for Detecting Cognitive Impairment, Including Dementia
DNA	Deoxyribonucleic Acid
DoD	U.S. Department of Defense
DoJ	U.S. Department of Justice
DoL	U.S. Department of Labor
EBI	Evidence-Based Intervention
EBP	Evidence-Based Practices
ECHO	Extension for Community Healthcare Outcomes project
EHR	Electronic Health Record
EJI	Elder Justice Initiative
EPAAD	APOE Pathobiology in Aging and Alzheimer's Disease
ePCT	Embedded Pragmatic Clinical Trial
eRADAR	Electronic Health Record Risk of Alzheimer’s and Dementia Assessment Rule
FAIR	findable, accessible, inter-operable, and reusable
FDA	Food and Drug Administration
FIC	Fogarty International Center
FTD	Frontotemporal Dementia
FUS	Follow-Up Study
FY	Fiscal Year
GACA	Geriatrics Academic Career Award
GEDA	Geriatric Emergency Department Accreditation
GeriScholars	Geriatric Scholars
GRECC	Geriatric Research, Education, and Clinical Center
GWEP	Geriatrics Workforce Enhancement Program
HABLE	Health and Aging Brain Among Latino Elders
HABLE-AT(N)	Health and Aging Brain Among Latino Elders-Amyloid, Tau, and Neurodegeneration
HBI	Healthy Brain Initiative

HCAP	Harmonized Cognitive Assessment Protocol
HCBS	Home and Community-Based Services
HHS	U.S. Department of Health and Human Services
HIT	Health Information Technology
HRS	Health and Retirement Survey
HRSA	Health Resources and Services Administration

IA2	International Association for Indigenous Aging
IADRP	International Alzheimer's and Related Dementias Research Portfolio
iDA	iPSCs to Study Diversity in Alzheimer's and Alzheimer's Disease-related Dementias
IDD	Intellectual and Developmental Disability
IDEA!	IDentify the problem or challenging behavior, Explore the behavior, and Adjust your response
IHS	Indian Health Service
IMPACT	Imbedded Pragmatic Alzheimer’s disease and AD-related dementias Clinical Trials
IMPACT-AD	Institute on Methods and Protocols for Advancement of Clinical Trials in AD/ADRD
INCLUDE	INvestigation of Co-occurring conditions across the Lifespan to Understand Down syndromE
IND	Investigational New Drug
iNDI	iPSC Neurodegenerative Disease Research Project
INDEED	Intrastate Network to Deliver Equity and Eliminate Disparities program
iPSC	Induced Pluripotent Stem Cell
IRP	Intramural Research Program
ISA	Interoperability Standards Advisory

LATE	limbic-predominant age-related TDP-43 encephalopathy
LBD	Lewy Body Dementia
LGBT	Lesbian, Gay, Bisexual, and Transgender
LIMBIC-CENC	Long-term Impact of Military-relevant Brain Injury Consortium/Chronic Effects of Neurotrauma Consortium
LMIC	Low and Middle Income Countries
LOAD	Late-Onset Alzheimer's Disease
LTC	Long-Term Care
LTSS	Long-Term Services and Supports

MCI	Mild Cognitive Impairment
MDDT	Medical Device Development Tools
MDT	Multidisciplinary Team
mg	milligrams
MODEL-AD	Model Organism Development and Evaluation for Late-onset Alzheimer's Disease
MOU	Memorandum of Understanding
MRI	Magnetic Resonance Imaging
MVP	Million Veterans Program

NACC	National Alzheimer's Coordinating Center
NACCHO	National Association of County and City Health Officials
NACDD	National Association of Chronic Disease Directors
NADRC	National Alzheimer's and Dementia Resource Center
NAPA	National Alzheimer's Project Act
NASEM	National Academics of Science, Engineering and Medicine
NCAPPS	National Center on Advancing Person-Centered Practices and Systems
NCD	Non-Communicable Disease
NCD-LIFESPAN	Chronic, Non-Communicable Diseases and Disorders Across the Lifespan
NCHS	National Center for Health Statistics
NCRAD	National Centralized Repository for Alzheimer’s Disease and Related Dementias
NHANES	National Health and Nutrition Examination Survey

NHATS	National Health and Aging Trends Study
NHW	Non-Hispanic White
NIA	National Institute on Aging
NIAGADS	National Institute on Aging Genetics of Alzheimer's Disease Data Storage Site
NICHD	National Institute of Child Health and Human Development
NICOA	National Indian Council on Aging
NIH	National Institutes of Health
NIHB	National Indian Health Board
NIJ	National Institute of Justice
NIMHD	National Institute of Minority Health and Disparities
NINDS	National Institute of Neurological Disorders and Stroke
NLRC	National Legal Resource Center
NOFO	Notice of Funding Opportunity
NOSI	Notice of Special Interest
NPAIHB	Northwest Portland Area Indian Health Board
NPS	Neuropsychiatric Symptoms
NRC-SDM	National Resource Center for Supported Decision-Making
NSF	National Science Foundation
NSOC	National Study of Caregiving
NYU	New York University
OAA	Older Americans Act
OASH	HHS Office of the Assistant Secretary for Health
ODPHP	HHS Office of Disease Prevention and Health Promotion
ONC	HHS Office of the National Coordinator for Health Information Technology
ORD	VA Office of Research and Development
OU	University of Oklahoma
OWH	HHS Office on Women's Health
PASC	Post-Acute Sequelae of COVID-19
PCP	Primary Care Provider
PDBP	Parkinson's Disease Biomarkers Program
PDF	Portable Document Format
PET	Positron Emission Tomography
PHCOE	Public Health Center of Excellence
PIN	Principal Illness Navigation
PFS	Physician Fee Schedule
PLWD	Persons Living with Dementia
PPS	Prospective Payment Systems
PRARP	Peer Reviewed Alzheimer's Research Program
PREVENTABLE	Pragmatic Evaluation of Events and Benefits of Lipid-lowering in Older Adults
PSM	Peer Support Mentoring
PwIDD-HBI	People with IDD Healthy Brain Initiative
REACH	Resources for Enhancing Alzheimer's Caregivers Health
REACH-VA	Resources for Enhancing Alzheimer's Caregivers Health in the VA
RECOVER	Researching COVID to Enhance Recovery initiative
REFA	Restoration for All
REGARDS	Reasons for Geographic and Racial Differences in Stroke
RFA	Request for Application
RFI	Request for Information
RIC	Resources for Integrated Care
RITT	Rural Interdisciplinary Team Training
RN	Registered Nurse
RWD	Real-World Data

SAMHSA	Substance Abuse and Mental Health Services Administration
SARS-CoV-2	Severe Acute Respiratory Syndrome Coronavirus 2
SBIR	Small Business Innovation Research
SCD	Subjective Cognitive Decline
SDM	Supported Decision Making
SDOH	Social Determinants of Health
SEN	Special Emphasis Notice
SES	Socioeconomic Status
SMI	Serious Mental Illness
SOI	Standard of Identity
STLT	State, Tribal, Local, and Territorial
STTR	Small Business Technology Transfer
SUD	Substance Use Disorder
T-MSIS	Transformed Medicaid Statistical Information System
TBI	Traumatic Brain Injury
TDP-43	Transactive response DNA binding protein of 43 kDa
TIP	Treatment Improvement Protocol
TRACTS	Translational Research Center for TBI and Stress Disorders
TREAT-AD	TaRget Enablement to Accelerate Therapy development for Alzheimer’s Disease
UIC	University of Illinois at Chicago
UIH	Urban Indian Health
UIO	Urban Indian Organization
UW	University of Washington
VA	U.S. Department of Veterans Affairs
VCID	Vascular contributions to Cognitive Impairment and Dementia
VDH	Virginia Department of Health
VHA	Veterans Health Administration
WHO	World Health Organization

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