

# National Plan to Address Alzheimer's Disease: 2023 Update



U.S. Department of Health and Human Services

# National Plan to Address Alzheimer's Disease: 2023 Update



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## Introduction

### National Alzheimer's Project Act

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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

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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.<sup>1</sup> 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).<sup>2</sup> 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.<sup>3</sup> However, studies of brain tissue have found that people with dementia 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.

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 dementia (FTD), Lewy body

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<sup>1</sup> 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/>.

<sup>2</sup> Burns A, Iliffe S. "Alzheimer's disease." *BMJ*, 2009; 338: b158.

<sup>3</sup> 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>.

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dementia (LBD), 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 have the pathology of more than one type of dementia in their brains.<sup>4</sup> 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/ADRD is often memory impairment; however, poor attention and executive function, behavioral disorders, visual disturbances, sleep disruption or motor symptoms can often be the presenting symptoms. As the disease progresses, memory can decline, 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.<sup>5</sup>

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.<sup>6</sup> The causes of AD/ADRD are not completely understood, but researchers have discovered that these conditions usually develop from the combined effects of certain genetic, social, economic, educational, and environmental factors.<sup>7,8,9,10</sup> 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. A significant number of people with Down syndrome develop dementia in their 50s or younger, often placing increased burden on their families and caregivers. The relative risk of dementia is higher in rural than urban areas, particularly among minority populations. Nationally, Black Americans are twice as likely and Hispanic or Latino (Hispanic) Americans are 1.5-times as likely to develop AD/ADRD compared to White Americans.<sup>11,12</sup>

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 2 decades as the population ages. The Census Bureau estimates that the number of people aged 65 and older in the United States will almost

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<sup>4</sup> 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.000000000000183.

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

<sup>6</sup> 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/>.

<sup>7</sup> 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.

<sup>8</sup> 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.

<sup>9</sup> 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.

<sup>10</sup> 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.

<sup>11</sup> 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.

<sup>12</sup> 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.

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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.

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.<sup>13</sup>

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, 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).<sup>14</sup> Furnishing care to people with the disease also strains health and long-term care 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.<sup>15</sup> Similarly, estimates from national data show that nearly seven out of ten residents in assisted living facilities have some form of cognitive impairment.<sup>16</sup> As the number of people with AD/ADRD grows over the next 3 decades, these diseases will place a major strain 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 long-term care. 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.<sup>17</sup>

## The Challenges

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

1. In 2023, the Food and Drug Administration (FDA) approved Lecanemab for the treatment of Alzheimer's disease, reflecting decades of scientific progress toward effectively treating and preventing AD/ADRD. Still, more research is needed to identify and test other drug candidates, and non-pharmacological interventions, to effectively treat and prevent AD/ADRD in all populations.

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<sup>13</sup> 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.

<sup>14</sup> 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/>.

<sup>15</sup> 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.

<sup>16</sup> 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.

<sup>17</sup> 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>.

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2. While HHS and other groups have taken steps to develop quality measures to assess dementia care and to improve the training of the health and long-term care workforce -- 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.<sup>18,19</sup>
4. Stigmas and misconceptions associated with AD/ADRD are widespread and profoundly impact the care provided to and the isolation felt by people with AD/ADRD and their families and caregivers.
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.

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## Framework and Guiding Principles

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The enactment of NAPA provided an opportunity to focus the Nation's attention on the challenges of AD/ADRD. In consultation with stakeholders 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 system and long-term care system including primary and specialty care, HCBS, legal services, and other social services. Both the clinical health care and long-term care 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 providers, HCBS providers, persons living with dementia, and caregivers. All of these efforts must occur in the context of improved awareness of the diseases, their risk factors, and their 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.

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<sup>18</sup> 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.

<sup>19</sup> 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.

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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 stakeholders 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.

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## Goals as Building Blocks for Transformation

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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.

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## 2023 Update

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Advances in the treatment of Alzheimer's disease and care of people living with AD/ADRD have taken place in the past few years, with significant progress this year. In 2021, the FDA-approved Aduhelm (aducanumab-avwa), the first amyloid beta-directed antibody for AD under accelerated approval. A trial to confirm clinical benefit is ongoing. A second amyloid beta-directed antibody, Leqembi (lecanemab-irmb), was approved under accelerated approval in January 2023, and after a confirmatory trial verified clinical benefit, the approval was converted to traditional approval in July 2023. Leqembi is the first amyloid beta-directed antibody to be converted from an accelerated approval to a traditional approval for the treatment of AD. A third drug in this class (Donanemab) has completed its confirmatory trial and is undergoing FDA review.

On April 7, 2022, the Centers for Medicare & Medicaid Services (CMS) announced they would cover monoclonal antibody treatments for Alzheimer's disease through "Coverage with Evidence Development" (CED). Under CED any drug in this class that demonstrates clinical benefit in a randomized controlled trial and receives FDA traditional approval can immediately be used in one of multiple CMS-approved registries or studies, thus preventing delay in treatment after traditional approval. In addition, drugs that demonstrate a surrogate outcome (brain amyloid reduction) and receive FDA accelerated approval may be covered by Medicare when the patient enrolls in a randomized controlled trial that is conducted under an Investigational New Drug (IND) application for the FDA. Finally, any drug in this class is covered when used according to its FDA-approved indication in any National Institutes of Health (NIH)-supported trial.

On July 6 -- the same day Leqembi received traditional approval from the FDA -- CMS launched a free online registry which clinicians across the country could use for appropriate patients with early AD. Clinicians participating in the registry submit a short form on data such as clinical diagnosis and adverse

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events. This simple registry, along with other, more complex studies and registries occurring at medical centers and in national networks, may contribute to closing current evidence gaps on which types of patients are more or less likely to benefit from these drugs.

While these drugs targeting amyloid are not a cure, and may have serious side effects in some individuals, they are an important step toward achieving the first goal of the National Plan, to prevent and effectively treat AD/ADRD by 2025, and have spurred further private investments in other, including combination, therapies for AD/ADRD.

Ensuring equitable access to this new treatment as well as future therapies currently in development will require changes to the health care system to ensure people are diagnosed early in the disease process using cutting-edge diagnostic and assessment tools, and have access to trained and educated specialists who can help people make decisions weighing the risks and benefits based on their unique conditions and circumstances. This makes the work under the National Plan even more critical, as the United States will need to strengthen health care infrastructure to ensure patients can navigate the safe and appropriate administration of this treatment, as well as research and public health infrastructures to make sure treatments can evolve and reach the correct people.

There is a very large population that will not benefit from the currently approved treatments for various reasons such as their type of dementia, other health conditions that increase the likelihood of serious side effects, high out of pocket costs, or because their dementia is too advanced. Meeting the care and support needs of people living with dementia now has always been a central tenet of the National Plan. To that end, on July 31, 2023, CMS announced the testing of a new model for dementia care through its Center for Medicare and Medicaid Innovation (Innovation Center). The Guiding an Improved Dementia Experience (GUIDE) Model, is a comprehensive care model designed to improve the quality of life for people with dementia, reduce caregiver strain, and delay or avert nursing home placement. The GUIDE model will include a comprehensive package of care management and coordination services, 24/7 access to a health care professional, a health care navigator, caregiver education and support, and some respite to help caregivers get a break. To reduce disparities in access to dementia care services, the GUIDE model will incorporate policies to enhance health equity by working to ensure that under-served communities have equal access to the model intervention. This model is discussed more in [Action 2.E.1](#). It is anticipated that testing this model could have a transformative effect on the delivery of care to people with dementia and the model test offers hope for improved quality of life for the millions of people who want to remain in their homes and communities.

This year also included important advancements around other goals of the National Plan. In April, President Biden further underscored the importance of supporting people with dementia and their families ([Goal 3](#)) through the Executive Order on Increasing Access to High-Quality Care and Supporting Caregivers. This Executive Order highlights how access to affordable, high-quality care is essential not only to supporting people with long-term care needs and their family caregivers, but also communities and society at large. Many of the activities in the Executive Order will further the Goals of the National Plan to develop a high-quality workforce, ensure nursing homes have adequate staffing, support care planning, integrate caregivers into the hospital discharge process, and improve data on the care workforce. In May, the Centers for Disease Control and Prevention (CDC) held the first-ever Dementia Risk Reduction Summit to set an agenda for state, local and tribal public health agencies to address dementia risk factors across the public health prevention spectrum. Over 230 people attended the Summit in person and more than 130 viewed the livestream, resulting in an increase in knowledge about activities and interventions that public health agencies can implement in their communities to reduce dementia risk. A report on the Summit, including options for public health action, was published in late 2023.

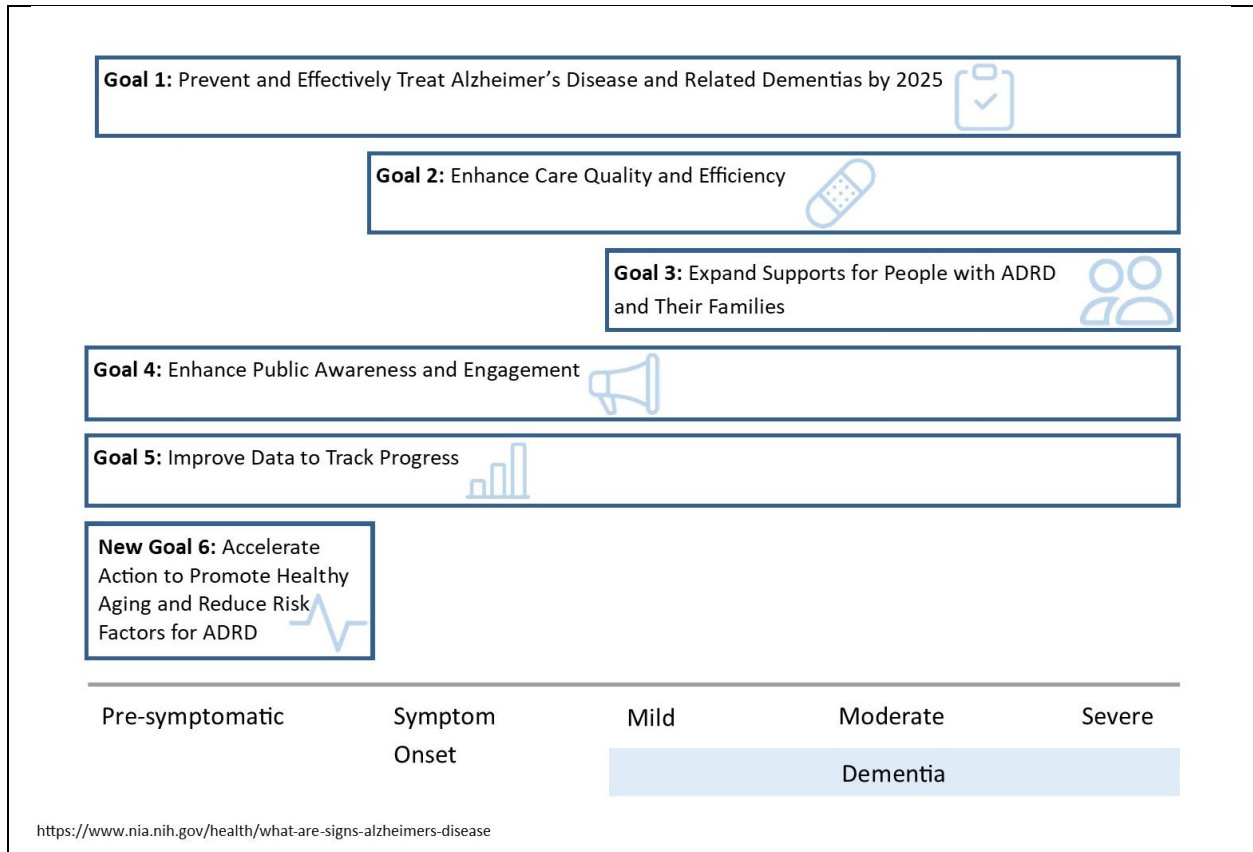
CMS has also recently finalized new Medicare coding and payment for Principal Illness Navigation (PIN) services in the 2024 Physician Fee Schedule, which will be important for individuals with dementia. PIN services involve a person-centered assessment to better understand the patient's life story, care coordination, contextualizing health education, building patient self-advocacy skills, health system navigation, facilitating behavioral change, providing social and emotional support, and facilitating access

to community-based social services to address unmet social determinations of health (SDOH) needs. PIN services are to help people with Medicare who are diagnosed with high-risk conditions like dementia identify and connect with appropriate clinical and support resources.

Since effectively trained caregivers can be so important in treating patients with dementia, CMS also finalized a new policy to make payment when practitioners train caregivers to support patients 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 patient's individualized treatment plan or therapy plan of care. This action, consistent with the recent Biden-Harris Administration Executive Order on Increasing Access to High Quality Care and Supporting Caregivers, will help support care for persons with Medicare by better training caregivers.

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## National Plan Goals Across Alzheimer’s Disease and Related Dementias Trajectory



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

Research continues to expand our understanding of the causes and prevention of, and the treatments for, AD/ADRD. This goal seeks to develop additional prevention and treatment modalities by 2025. 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

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 actions below will identify the priorities, establish milestones, and ensure that appropriate stakeholders 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, National Institutes of Health (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 Spring 2024, National Institute on Aging (NIA) will host 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 foundation, 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. The 2021 Summit built on the foundation laid through the work of the previous summit participants. Participants provided individual input that showcased progress to date and identified further gaps and opportunities toward the goal of precision medicine for AD/ADRD treatment and prevention. NIH is committed to regularly updating its research priorities and will encourage broad participation in the 2024 AD Research Summit: *Enabling Precision Medicine for AD Treatment and Prevention*. The Summit will be held on September 23-25, 2024, on the NIH Campus. This Summit will feature progress towards achieving the AD research implementation milestones and towards the development of an integrated multi-disciplinary research agenda necessary to enable precision medicine for AD treatment and prevention. An integral part of the program will be discussions on developing effective risk reduction strategies within a precision medicine research framework.

For more information see:

- <https://www.nia.nih.gov/2021-alzheimers-summit>
- <https://www.nia.nih.gov/research/milestones>

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

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**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 scientific input and identify gaps and opportunities. This information factors into NIH’s research plan for the 2025 goal, which is outlined as a series of research implementation milestones. These milestones and the accompanying milestone database, which includes success criteria and specific implementation activities to track progress, 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 addition to NIH Summits, NIH has also gathered important input on research priorities through activities with the National Academies of Science, Engineering, and Medicine (NASEM). For example, NASEM released a decadal survey report titled *Reducing the Impact of Dementia in America: A Decadal Survey of the Behavioral and Social Science* in August 2021. It was sponsored primarily by NIA with support from NIH’s Office of Behavioral and Social Sciences Research and the Department of Veterans Affairs (VA), the Office of the Assistant Secretary for Planning and Evaluation (ASPE), AARP, Alzheimer’s Association, American Psychological Association, JPB Foundation, and John A. Hartford Foundation. The NASEM-led decadal process included several public workshops and provided opportunities for input from experts, researchers, advocacy organizations, and PLWD and care partners. The report highlights behavioral and social science research opportunities on AD/ADRD for the next 10 years. This report offers a blueprint for the next decade of behavioral and social science research to reduce the negative impact of dementia for America’s diverse population. Reducing the impact calls for research that addresses the causes and solutions for disparities in developing dementia and receiving adequate treatment and support. It calls for research that sets meaningful goals not just for scientists, but for people living with dementia and those who support them.

Additionally, in response to congressional report language, NIA and National Institute of Neurological Disorders and Stroke (NINDS) have engaged NASEM to conduct a consensus study to identify research priorities to advance the prevention and treatment of AD/ADRD. NASEM has assembled an ad-hoc committee of experts to review the evidence and develop recommendations, including identifying specific near and medium-term scientific questions (i.e., in a 3-year to 10-year period) that may be addressed through NIH-supported research. The report will also include strategies for addressing major barriers to progress on these scientific questions.

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/2020-dementia-care-summit>
  - <https://www.nia.nih.gov/2021-alzheimers-summit>
  - <https://www.nia.nih.gov/2023-dementia-care-summit>
  - <https://www.nia.nih.gov/2023-dementia-care-summit#Lived>
  - <https://www.nia.nih.gov/research/milestones>
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- [https://www.nia.nih.gov/sites/default/files/2022-06/2021-06-28\\_virtual\\_workshop\\_implications\\_bsr\\_preclinical\\_markers\\_adrd.pdf](https://www.nia.nih.gov/sites/default/files/2022-06/2021-06-28_virtual_workshop_implications_bsr_preclinical_markers_adrd.pdf)
- <https://www.ninds.nih.gov/news-events/events/adrd-summit-2022>

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

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**Lead Agency:** ASPE

**Partners:** NAPA Advisory Council, NIH, NIA

HHS and its federal partners use the diverse input received through the three research summits 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.

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

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**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.

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

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**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. The latest of these updates took place after the 2020 *Dementia Care and Caregiving Research Summit*, the 2021 *Alzheimer's Disease Research Summit*, and the 2022 *Alzheimer's Disease-Related Dementias Summit*. Updates are in progress following the 2023 *Dementia Care and Caregiving Summit*.

For more information see:

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

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**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 traumatic brain injury (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.

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%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](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**

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**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 the 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 people living with dementia 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 people living with dementia, caregivers/care partners, direct care workers, and advocacy organization representatives. Information about the

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agenda, scientific steering committee, presenters, lived experience and stakeholder panels, and recordings of the event are available on the Summit website. The research gaps and opportunities and a meeting report will be posted on the Summit website in July 2023.

For more information see:

- [https://twitter.com/search?q=%23DementiaCareSummit&src=typeahead\\_click&f=live](https://twitter.com/search?q=%23DementiaCareSummit&src=typeahead_click&f=live)
- <https://www.nia.nih.gov/2020-dementia-care-summit>
- <https://www.nia.nih.gov/2020-dementia-care-summit#Materials>
- <https://www.nia.nih.gov/2023-dementia-care-summit>
- <https://www.nia.nih.gov/research/summit-gaps-opportunities>
- <https://www.nia.nih.gov/sites/default/files/2021-01/DementiaCareSummitReport.pdf>

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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**

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**Lead Agency:** DoD

The Department of Defense's (DoD's) Congressionally Directed Medical Research Programs (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. In 2023, 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 since 2011, and identified short, medium, and long-term goals for the program.

For more information see:

- <https://cdmrp.army.mil/prarp/default>

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

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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**

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**Lead Agencies:** NIA, NINDS

**Partners:** potential research partners in the public and private sectors

In the past year, NIA and NINDS have issued several funding opportunity announcements (FOAs) focused on research to help develop a better understanding of the growing list of genetic risk factors and molecular pathways that are involved in AD/ADRD. In response to these FOAs and investigator-initiated studies, researchers continue to refine and develop new tools to improve the identification and validation of a variety of targets with therapeutic potential. These

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sophisticated tools allow researchers to collect and integrate layers of biological data in novel ways, opening the door to new insights into the origins and progression of AD/ADRD.

These new tools are also helping researchers gain a clearer picture of the complex underlying mechanisms of these neurological disorders. They are leading to an understanding of the interplay among relevant molecules and systems, the relationship between amyloid and tau proteins, the role of immunity and inflammation, the involvement of metabolic and cerebrovascular pathways, the regulation of cell-type-specific proteome dynamics, the characterization of the preclinical/prodromal phase of alpha-synucleinopathies, the etiology of infectious pathogens in AD/ADRD, and the selective cell and network vulnerability and impact of brain aging in neurodegenerative diseases. For example, in 2022, NIA released a FOA to stimulate research to define and characterize neural cell populations (e.g., neurons and glia), neural activity and circuits, structural and functional networks, and brain regions that are vulnerable (or resistant) in brain aging and AD and the mechanisms underlying such selective vulnerability (PAR-21-040). In 2023, NINDS issued a funding opportunity to promote research on understanding why AD/ADRD shares certain features of prion diseases, where misshapen proteins induce others to misfold and form toxic clumps in the brain (PAR-23-023). This broader view of the basic biology of AD/ADRD could lead to potential breakthroughs. For a full list of relevant Notices of Funding Opportunities (NOFOs) and their links, please see [Appendix 3](#).

While it is known that vascular damage in the brain occurs in over half of AD/ADRD cases and is very common in other forms of dementia, researchers are still working to understand the mechanisms that underlie VCID. More specifically, understanding the brain's complex system involving the blood-brain barrier and the brain's blood vessels could help researchers identify new treatments as well as address side effects of disease-modifying therapies, including anti-amyloid therapies recently approved by the FDA for treatment of AD. A significant percentage of participants in clinical trials for these therapies experienced adverse events, including clinical symptoms indicating more serious concerns like brain bleeds, swelling, and inflammation. 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 funding opportunities in 2022 (and are planning a reissue in 2024) for research in cells and animals to understand how and why the brain's blood vessels can be damaged from anti-beta-amyloid immunotherapy. The goal is to identify promising strategies that can protect the brain when anti-beta-amyloid immunotherapy is delivered. For a full list of relevant NOFOs and their links, please see [Appendix 3](#).

A key part of NIH's strategy for developing new treatments for AD/ADRD is to bolster the translation of basic research findings into discovery and development of new drugs and devices for disease diagnosis, prevention, and treatment. The length of time required for researchers to discover a biological mechanism of disease, such as a gene variant that does not function normally, and then develop an effective treatment without toxic side effects has been 12-15 years. Additionally, few drugs or devices are found to be both safe and effective and approved by the FDA. NIH continues to support a pipeline of funding opportunities aimed at discovering and developing new and diverse candidate devices and drugs for the diagnosis, prevention, and treatment of AD/ADRD. For example, in 2022, NINDS-funded researchers demonstrated promising results in the use of genome editing in mice and pluripotent stem cells to remove the most common genetic mutation in amyotrophic lateral sclerosis (ALS) and FTD, which resulted in a substantial reduction in FTD disease markers. To further explore the potential of genome editing therapies, NINDS invited new research applications in 2023 to apply various genome editing techniques and demonstrate measurable success in intervening in any of the ADRDs (FTD, LBD, and VCID), with the goal of submitting an IND to FDA for human testing by the end of the study (RFA-NS-23-017). In 2022 and 2023, NINDS also invited new research on early-stage therapy development in ADRDs (RFA-NS-22-059) as well as studies that examine the potential influence of the gut microbiome on ADRDs and use of pre-biotics and pro-biotics as an intervention (PAR-22-211).

NIH makes data-informed decisions about possible candidate targets, following scientific progress closely and changing direction, when necessary, based on new evidence. In addition, to accelerate the discovery of effective treatments that will become broadly available to the public, NIH has developed programs to make data, knowledge, and research tools widely available to all researchers. Instead of competing with each other, stakeholders in industry, academia, and government are collaborating to reach a common goal: developing effective treatments for AD/ADRD. In collaboration with other ICs, NIA and NINDS also released targeted 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: predoctoral, postdoctoral, and advanced postdoctoral. For a full list of relevant NOFOs and their links, please see [Appendix 3](#).

For more information see:

- <https://pubmed.ncbi.nlm.nih.gov/36271076/>

Thanks to the substantial investment in AD/ADRD research over the past several years, NIH has increased its drug discovery efforts significantly. Of the many therapeutic programs supported by NIH for AD/ADRD, 18 have now matured through the preclinical development process and are currently being tested in humans in Phase 1 and Phase 2 clinical trials. These drug candidates target multiple aspects of the disease process including neuroinflammation, proteostasis (e.g., abnormal protein folding), neurogenesis, metabolic and vascular dysfunction, etc.

Established in 2019, the TaRget Enablement to Accelerate Therapy development for Alzheimer's Disease (TREAT-AD) Translational Centers are a \$73 million 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 Accelerating Medicines Partnership® Program for Alzheimer's Disease (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.

For more information see:

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

NIH's Small Business Innovation Research (SBIR) and Small Business Technology Transfer (STTR) programs are an integral source of capital for early-stage United States small businesses 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 August 2021, the NIA SBIR team published a paper describing the impact of NIA's \$280 million investment in this research over the past 11 years. During this timeframe, NIA has supported more than 600 grants to more than 230 small businesses in 37 states. 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 led to the development of the next-generation version of the PrecivityAD 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 positron emission tomography (PET) imaging and cerebrospinal fluid tests. NIH-supported research has 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 Alzheimer's disease 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.

For more information see:

- <https://alz-journals.onlinelibrary.wiley.com/doi/10.1002/alz.12392>
- <https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-21-025.html>
- <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC10292789/>
- <https://www.nia.nih.gov/news/blood-test-early-alzheimers-detection>
- <https://www.nia.nih.gov/news/nih-small-business-funding-boosts-alzheimers-science-advances>

NIH's AMP-AD program and AMP<sup>®</sup> program for Parkinson's Disease (AMP<sup>®</sup>-PD) programs have transformed the way new targets and biomarkers are discovered by supporting large-scale team-science and rapid and broad sharing of data and knowledge. NIH announced in 2021 the next stage of the AMP-AD program (AMP-AD 2.0). During the first phase, the AMP-AD program's open science, big data approach enabled research teams to identify and make publicly available more than 500 unique candidate targets for this complex disease. In the second phase, NIH is leading research efforts to enable a precision medicine approach to discovery of novel therapeutic targets and biomarkers. AMP-AD 2.0 is also focusing on generating data from diverse cohorts, specifically Black and Latino cohorts who are disproportionately affected by the disease. All data and analytical tools will be made available to the wider research community through a centralized data infrastructure, the AD Knowledge Portal. The AD Knowledge Portal also serves as the central repository for a series of NIH-supported open science target discovery consortia, such as Molecular Mechanisms of the Vascular Etiology of Alzheimer's Disease, Resilience-AD, and Psych-AD.

For more information see:

- <https://www.nia.nih.gov/news/nih-invests-next-iteration-public-private-partnership-advance-precision-medicine-research>
- <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/alzheimers-disease-sequencing-project-study-design>
- <https://www.nih.gov/research-training/accelerating-medicines-partnership-amp>
- <https://www.ninds.nih.gov/Current-Research/Focus-Disorders/Accelerating-Medicines-Partnership-Parkinsons-Disease-AMP-PD>

As of July 2023, NIA is funding 15 projects through its Alzheimer's Drug Development Program (ADDP). These projects are focused on developing new drug candidates for the treatment and prevention of AD/ADRD that target different biological process, such as brain inflammation, lipid metabolism, metabolic and hormonal dysregulation among others. Investigators funded through many of these projects aim to submit an IND Application to FDA to test promising new therapeutics in humans. Since its inception in 2006, the ADDP program has supported 45 projects for development of new drug candidates for a diverse portfolio of therapeutic targets. Twelve compounds developed through the ADDP have been submitted to the FDA for IND authorization and are currently being tested in Phase I and II human clinical trials. For a full list of relevant NOFOs and their links, please see [Appendix 3](#).

The Roy Blunt Center for Alzheimer's Disease and Related Dementias Research, which houses the NIH Center for Alzheimer's and Related Dementias (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 now 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 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.

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>

NIH supports the Model Organism Development and Evaluation for Late-Onset Alzheimer's Disease (MODEL-AD) Translational Centers to develop and characterize new mouse models for late-onset AD (LOAD), essential tools for basic research and therapy development. To date, MODEL-AD research teams have created more than 60 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.

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://reporter.nih.gov/search/WqMML-IKk6bM4TRVlbtlg/projects?shared=true>
- <https://www.model-ad.org/>

The MODEL-AD centers and other NIH open science programs such as AMP-AD consortia and the TREAT-AD centers have transformed the way that scientists collaborate and share their data and knowledge to discover new biological mechanisms of disease and find new drug candidates for testing.

For more information see:

- <https://www.model-ad.org/>
- <https://www.nia.nih.gov/news/nih-funded-translational-research-centers-speed-diversify-alzheimers-drug-discovery>
- <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>

One way that NIH works to find effective ways to treat dementia is by considering drugs that FDA has already deemed safe for people with other conditions. The NIA Intramural Research Program (IRP) has recently launched the Drug Repurposing for Effective Alzheimer's Medicines (DREAM) study. DREAM is a collaboration with researchers at Harvard Medical School, Rutgers University, and Johns Hopkins University School of Medicine to repurpose FDA-approved drugs for treatment of dementia. This unique consortium of centers of excellence in pharmacoepidemiology leverages real-world clinical data from two large datasets (Insurance claims from the Medicare program in the United States and Clinical Practice Research Datalink in the United Kingdom) with drug exposure and clinical outcome data available in more than 20 million older individuals. NIA IRP investigators have tested whether AD drug targets discovered by proteomic and metabolomic analyses are associated with a lower the incidence of AD in the DREAM study. Investigators from this study have discovered that hydroxychloroquine, a commonly used drug to treat rheumatoid arthritis, appears to reduce the incidence of AD in patients with rheumatoid arthritis. 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 (ACTDRx AD) program.

For more information see:

- <https://adknowledgeportal.synapse.org/Explore/Programs/DetailsPage?Program=ACTDRx%20AD>

NIA also funds drug repurposing research at its grantee institutions. NIA released an active funding initiative in 2017 called Translational Bioinformatics Approaches to Advance Drug Repositioning and Combination Therapy Development for Alzheimer's Disease, which aims to leverage the power of big data and open science in advancing drug repurposing and combination therapy development. Through this initiative, NIA has funded over 40 projects applying computational approaches to identify drug repositioning candidates for AD/ADRD. For a full list of relevant NOFOs and their links, please see [Appendix 3](#).

For more information see:

- <https://pubmed.ncbi.nlm.nih.gov/33304987/>
- <https://pubmed.ncbi.nlm.nih.gov/36577843/>
- [https://reporter.nih.gov/search/Cs\\_VZiGXQ0eAYG4dF94MNA/projects](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>

NIA established the Alzheimer's Disease Preclinical Efficacy Database (AlzPED) to improve the rigor and reproducibility of preclinical testing studies of candidate therapeutics for AD/ADRD by making preclinical animal data publicly available and searchable in a knowledgebase. AlzPED is a partnership among NIA, NIH Library, Alzheimer's Association, Alzheimer's Drug Discovery Foundation, and Sage Bionetworks, hosting over 1,200 studies on preclinical testing of candidate therapeutics for AD/ADRD. AlzPED also provides a platform for sharing studies with negative findings.

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 research teams. The AD Knowledge Portal now includes data and resources from numerous NIA-supported programs and is open for data contributions from the greater research community.

For more information see:

- <https://adknowledgeportal.synapse.org/>

NIA's Small Research Grant Program for the Next Generation of Researchers in AD/ADRD Research Program is designed to encourage future scientists to pursue research and academic careers in neuroscience, AD/ADRD, and healthy brain aging. 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, 129 investigators have received funding through this program. For a full list of relevant NOFOs and their links, please see [Appendix 3](#).

For more information see:

- <https://reporter.nih.gov/search/NLkaHTHIS0CqS2B125xnvg/projects>
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**(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**

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**Lead Agencies:** NIA, NINDS

**Partners:** research partners in the public and private sectors

Another key component in the growing toolkit of precision medicine for AD/ADRD is the Alzheimer's Disease Sequencing Project (ADSP), an international resource of genetics data from multiple centers and studies. 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, and in 2021 the Follow-Up Study 2.0. Together, these initiatives aim to pursue rare variants in a range of different populations (e.g., Black, Hispanic, American Indian/Alaska Native [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 Follow-Up Study is to genetically define subgroups of subjects that carry specific sets of genes and match them with biomarkers, functional genomics, and clinical data. This will define subtypes of the disease. Defining subtypes will allow better selection of subjects for clinical trials because outcomes of drug therapies can be better targeted toward groups of individuals who have similar characteristics. 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. 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.

The ADSP also launched a Machine Learning/Artificial Intelligence Initiative in 2019. The amount of genetic data that now is available is massive and it has been extraordinarily difficult to analyze using classical methods because the data are so complex. This initiative supports the development of fast and efficient Machine Learning/Artificial Intelligence approaches to identify the genetics that increase risk of or protection against AD/ADRD. The emphasis is on the development and sharing of transformative Machine Learning/Artificial Intelligence-based systems, emerging tools, and modern technologies for the analysis of genetic data.

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

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relevant but difficult to ascertain. Investigators from the AMP-AD program and ADSP Consortia 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.

NIAGADS now hosts 98 human genetics datasets with 183,003 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 2022, NIAGADS aims to release data generated under the initiative to support analysis on approximately 55,000 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.

The National Centralized Repository for Alzheimer's Disease and Related Dementias (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 relevant NOFOs 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/>
- <https://www.niagads.org/adsp/content/home>

In addition to ADSP, NIA and NINDS has several ongoing FOAs 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 variants in more than 70 regions of the genome that are associated with the disease. 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*, that appears to confer protection against the development of Alzheimer's in a person with a strong genetic predisposition for an early-onset form of the disease. In 2023, NIH-funded researchers identified a second such variant, currently known as *Reelin-COLBOS*, that seems to provide extreme resilience to this rare genetic form of early-onset Alzheimer's. These findings shed important light on cognitive resilience -- and potentially new treatment targets -- that may one day help to delay or even stop progression of Alzheimer's. 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 Alzheimer's disease. 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 Alzheimer's 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 Alzheimer's genetic risk assessment in individuals of African ancestry, a historically underrepresented group in Alzheimer's genetics research. For a full list of relevant NOFOs and their links, please see [Appendix 3](#).



For more information see:

- <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>

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. Intramural and extramural researchers supported by NIA and NINDS have 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 Center Without Walls (CWOW) 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://www.mayo.edu/research/centers-programs/discovery-translation-labs-brain-program/lewy-body-dementia-center-without-walls>

The VA continues to support projects that curate and develop AD phenotypes using VA clinical data. These projects will produce pilot data for VA's collaboration with the NIA on their Phenotypic Data Harmonization Initiative. In addition, there has been continued support for research projects that utilize veterans' data in the Million Veteran Program 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.

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### **(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

Starting in 2016, NIA led an effort to develop comprehensive goals and strategies to enhance recruitment into clinical research, particularly focusing on underrepresented communities, with facilitation by the Alzheimer's Association and in close collaboration with experts from government, private, and academic sectors. To ensure broader input, NIA gathered feedback on the recruitment strategies through the IdeaScale crowdsourcing platform. These efforts resulted in the National Strategy for Recruitment and Participation in Alzheimer's Disease and Related Dementias Clinical Research.

For more information see:

- <https://www.nia.nih.gov/research/recruitment-strategy>
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In 2019, NIA launched Alzheimer's and Dementia Outreach, Recruitment, and Engagement Resources (ADORE), 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 Alzheimer's Disease Research Centers (ADRCs), Alzheimer's Clinical Trials Consortium (ACTC), NIA and the broader NIH, and other organizations have developed to engage people in research. In addition, NIA developed several collateral materials to include in ADORE, including a recruitment planning guide, a series of testimonial videos, and an easy-to-read booklet to promote older adult research participation. ADORE currently houses 480 resources, and NIA receives, reviews, and adds new materials on a quarterly basis. The repository received more than 34,000 visitors in 2022, and over a total of 200,000 visitors since its initial launch in 2019.

NIA has developed Outreach Pro, an online platform that helps researchers and research teams create materials to support their AD/ADRD clinical trial recruitment efforts, particularly in underrepresented communities. Since its launch in 2021, 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, Mandarin, Tagalog, and Hindi. Through Outreach Pro, researchers can easily produce a "package" of tailored materials and strategies that can be branded locally to increase participant recruitment for clinical studies. Since 2021, the platform has grown to include 230 unique materials that can be developed from a combination of designs, health statuses, race/ethnicities, and languages, and has had more than 10,000 unique users. More information about Outreach Pro is included under [Action 1.B.4](#).

For more information see:

- <https://outreachpro.nia.nih.gov>
- <https://www.nia.nih.gov/news/nih-unveils-new-online-tool-improve-alzheimers-clinical-trials-recruitment>
- <https://www.nia.nih.gov/research/adore>

NIA continues to promote participation in AD/ADRD clinical trials, studies, and registries through [Alzheimers.gov](https://www.alzheimers.gov) and its Alzheimer's Disease Education and Referral (ADEAR) Center; clinical trials listings and monthly e-alert to more than 39,450 subscribers; social media; infographics; presentations; promotion of ADORE materials; and collaboration with other federal agencies and advocacy organizations to encourage research participation among older adults, including through a Focus on Aging interagency webinar series. All materials are drafted in plain language formats for ease of communications.

For more information see:

- <https://www.alzheimers.gov/clinical-trials>
- <https://www.nia.nih.gov/health/about-adear-center>

A key factor for improving enrollment is to help researchers monitor actual recruitment against planned milestones. To achieve the ability to track, report, and manage enrollment data, NIA relies on its Clinical Research Operations and Management System (CROMS) to provide NIA staff and grantees with real-time tracking, reporting, and management of clinical research enrollment data, study documents, and activities. Through CROMS, NIA now tracks, manages, and reports on enrollment data and activities made possible via the NIA-funded clinical research portfolio. CROMS will provide critical and real-time information to ensure that NIA-supported clinical studies are making appropriate progress toward reaching their inclusion recruitment goals related to multiple underrepresented groups. Additionally, the analyses of the data from CROMS identifies grant recipients who are successfully enrolling participants from diverse backgrounds, including those from traditionally underrepresented populations, to inform the development and coordination of guidelines for best practices that work in the field. These analyses also identify grant recipients who are experiencing challenges so that NIA program staff may provide substantial support and guidance for enhancing trial enrollment. These activities are expected to

increase the effectiveness and impact of staff management of NIA's quickly expanding clinical research portfolio.

For more information see:

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

NIA-funded AD/ADRD infrastructure -- such as the ACTC, the ADRCs, 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.

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. As part of the program, the VA and NIA are partnering with the NIA-funded ADRCs to increase veteran participation in research. 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 completed in 2023. Results and impact of this program are reported in a manuscript (currently in revision). 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://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 (CSP) 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) Notice of Funding Opportunity 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 into the fifth year of funding (FY 2023).

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://grants.hrsa.gov/2010/Web2External/Interface/Common/EHBDisplayAttachment.aspx?dm_rtc=16&dm_attid=3c8db591-9d9e-489b-980a-a44ef4fb9ed9)

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**(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**

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**Lead Agencies:** NIA, NIMHD

**Partner:** ACL

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 2023, NIA will fund awards from RFA-AG-23-020 *Building Infrastructure for Precision Medicine Research on Minority Health and Disparities in AD/ADRD*, which calls for projects to develop or scale up research infrastructure and resources for studies of AD/ADRD in understudied populations. Additionally, NIA IRP investigators have 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 relevant NOFOs and their links, please see [Appendix 3](#).

For more information see:

- <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 Outreach Pro, 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. Since its launch in summer 2021, 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, Mandarin, Tagalog, and Hindi. To develop these messages and materials, NIA conducted several rounds of focus groups, surveys, and stakeholder interviews to tailor recruitment materials for clinical studies to reach underrepresented populations more effectively. Using the findings from this research, NIA has developed a set of materials and messaging, including videos and other multi-media, print ads, posters, and social media, tailored to diverse populations, including Black and Hispanic, in both English and Spanish, and Chinese Americans, Indian Americans, and Filipino Americans in both English and their respective languages. Since its launch in 2021, Outreach Pro has grown to include 230 unique materials that can be developed from a combination of designs, health statuses, race/ethnicities, and languages, and has had more than 10,000 unique users. Materials developed are made available to the public in both ADORE and Outreach Pro. NIA has also recently launched a Spanish version of the *Alzheimers.gov* website. In addition, NIA recently published its *Alzheimer’s Disease Fact Sheet* online in Arabic and Chinese; this fact sheet was previously available in English and Spanish. The content includes information on participating in clinical research.

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For more information see:

- <https://outreachpro.nia.nih.gov/>
- <https://www.alzheimers.gov/es>
- <https://www.nia.nih.gov/health/alzheimers-disease-fact-sheet>
- <https://www.nia.nih.gov/news/alzheimers-gov-website-now-available-spanish>

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 33 ADRCs 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.

To further incentivize innovative ideas and opportunities in AD/ADRD research, NIA has funded four exploratory ADRCs. These new centers will broaden current ADRC research initiatives with research participants from underrepresented populations such as Black Americans, Native Americans, and those in rural communities -- all of which have different risk factors for developing these diseases. Another goal of these exploratory ADRCs is to broaden the ADRC program geographically and scientifically.

An important, major outcome of the ADRC program was the description and investigation of a newly defined disease that is very similar to Alzheimer's disease but is even more common in older adults (over the age of 75). NIA has supported three major meetings to advance our understanding of the disease (limbic-predominant age-related TDP-43 encephalopathy) 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 relevant NOFOs and their links, please see [Appendix 3](#).

For more information see:

- <https://reporter.nih.gov/search/ixul3REUAEeJqoU8Xa4hOA/project-details/10094911#description>
- <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6249084/>
- <https://www.nia.nih.gov/health/what-limbic-predominant-age-related-tdp-43-encephalopathy-late>
- <https://www.nia.nih.gov/news/guidelines-proposed-newly-defined-alzheimers-brain-disorder>
- <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>

NIA is investigating the possibility of developing a practice-based research network (PBRN) as a long-term solution to create sustainable and mutually beneficial relationships with under-served communities to address barriers in participating in AD/ADRD and aging clinical trials. PBRNs are networks of health care clinicians and practices working together to answer community-based health care questions, to translate research findings into practice, and to directly engage diverse and under-served communities. After hosting a virtual meeting in April 2021 to discuss PBRNs to address AD/ADRD clinical trial recruitment and retention disparities, NIA has been working to organize an external group of researchers and community organizations to offer input, feedback, and recommendations on how to develop a successful AD/ADRD PBRN. As part of this effort, NIA issued a Request for Information (RFI) in March 2022 to seek input on the Capacity and Support Needed to Increase Community-based Research Networks Participation in AD/ADRD Clinical Trials (NOT-AG-22-018). This RFI sought pragmatic insights and recommendations on the challenges and potential opportunities to build capacity for these networks and engage a wider, more diverse group of participants in AD/ADRD clinical trials. Respondents to the RFI discussed challenges associated with developing sustainable community partnerships and increasing NIA's research presence in communities. They also offered ideas to build, increase, and sustain community engagement with current or future AD/ADRD clinical trials. NIA is currently developing a white paper that combines the findings from the RFI with outcomes of relevant NIA activities and learnings from other model community networks to develop a framework for advancing the use of PBRNs and a community-based research network (CBRN) to foster community engagement in AD/ADRD clinical trials. This framework will provide practical guidance and best practices relevant to the dementia community to increase use of PBRN and CBRN models and ultimately improve diverse enrollment in AD/ADRD clinical trials. For a full list of relevant NOFOs and their links, please see [Appendix 3](#).

For more information see:

- <https://impactcollaboratory.org/event/nia-virtual-meeting-development-of-an-nia-practice-based-research-network-to-conduct-ad-adrd-clinical-research/>
- <https://videocast.nih.gov/watch=41795>

An administrative supplement to the Health and Retirement Study (HRS) has allowed an increased enrollment of marginalized populations to help to meet this overarching goal. Approximately 6,700 Black Americans and 5,400 Hispanic Americans are being recruited and added to the prospective longitudinal cohort study. The FOA to renew the HRS and the Harmonized Cognitive Assessment Protocol (HCAP) in FY 2024 calls for improved response and retention rates to maintain representativeness and additional studies on social factors to examine racial disparities and minority health via life histories. In addition, the ADSP 2.0 effort will now

include a subset of the Black and Hispanic HRS participants, and AD biomarkers will be available to researchers for over 1,300 Black and Hispanic participants by the end of calendar year (CY) 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 RFAs 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 also has released several FOAs to fund grants that target gaps in methods and outcomes regarding participant recruitment and retention and spur educational activities that expand and diversify the AD/ADRD clinical trial workforce. Some of these efforts are in coordination with other NIH Institutes and Centers through the NIH-wide Uniting Tribal Nursing Homes in Excellence (UNITE) initiative. For example, notice of funding opportunity PAR-18-749 encouraged collaborative teams to generate a research resource to advance processes for high-yield recruitment and strengthen outreach and community engagement practices. For example, PAR-18-749 supported the design and launch of the Collaborative Approach for Asian Americans and Pacific Islanders Research and Education (CARE), a recruitment registry for AD/ADRD, aging, and caregiver-related research. CARE has successfully enrolled over 7,000 Asian Americans and Pacific Islanders (AAPI) into the registry and is working to refer, or match, them to approximately 30 different studies. For a full list of relevant NOFOs 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/unchanging-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 mild cognitive impairment (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>

The PRARP from CDMRP requires that all funded clinical research addresses the appropriate representation of the population the projects aim to serve. For example, a recently funded PRARP project addresses the role of social determinants on any health or increased risk factors within the military related to AD and other dementias.

For more information see:

- <https://cdmrp.army.mil/prarp/default>
- <https://ebrap.org/eBRAP/public/Program.htm>

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

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**Lead Agency:** NIA

**Partner:** VA

As of March 2023, NIH supports approximately 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 approximately 70 NIH-supported drug trials for AD/ADRD, the majority of which are in early-phase development (Phase 1 or 2 trials) with several late-phase (Phase 3) trials also in progress. These interventions are testing a range of diverse drug targets, including but not limited to amyloid, cell metabolism, inflammation, tau, and vasculature. Each of these trials are designed to accelerate progress towards effective prevention and treatment strategies.

The ACTC, a next-generation 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 disease. A key area of focus for ACTC has been to improve diversity in recruitment and in the clinical trial workforce. 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. 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 individuals from underrepresented populations as well as from across the disease spectrum. 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 relevant NOFOs and their links, please see [Appendix 3](#).

For more information see:

- <https://impact-ad.org/about/>
- <https://www.actcinfo.org/>
- <https://www.nia.nih.gov/news/new-nih-consortium-award-enhance-clinical-trials-alzheimers-disease-related-dementias>
- <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

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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, the Roybal Center program was expanded to conduct clinical trials on the development of interventions for dementia care. Four of the 15 Roybal Centers focus on dementia care and conduct clinical trials on a wide range of interventions, including interventions aimed at transforming residential palliative care for persons with dementia, technological interventions to improve care support intervention development, interventions to decrease care provider loneliness and isolation, and interventions to help strengthen informal caregiving skills.

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 FOAs specifically focused on clinical trials for AD/ADRD. These include pharmacologic as well as lifestyle interventions. For a full list of relevant NOFOs 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://www.nia.nih.gov/research/dbsr/nih-stage-model-behavioral-intervention-development>

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### **(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 relevant NOFOs and their links, please see [Appendix 3](#).

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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>
- <https://www.nih.gov/include-project/funding>

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. So far, approximately 50 individuals living with Down syndrome have been evaluated by an ADRC trained research professional using the new standardized module. Soon, this module will be deployed more broadly 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://health.ucsd.edu/news/releases/Pages/2016-01-13-clinical-trial-alzheimers-characteristics-in-down-syndrome.aspx>
- <https://naccddata.org/data-collection/forms-documentation/ds-3>
- <https://pubmed.ncbi.nlm.nih.gov/33337378/>
- <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**

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**Lead Agencies:** NIH, NIA

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.

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**(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**

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**Lead Agencies:** NIH, NIA

NIH is looking closely at the long-term effects of COVID-19 infection (also known as Long COVID) through the recently launched Researching COVID to Enhance Recovery (RECOVER) Initiative. 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>
- <https://www.nih.gov/news-events/news-releases/nih-builds-large-nationwide-study-population-tens-thousands-support-research-long-term-effects-covid-19>

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.

NIA issued its own Notices of Special Interest (NOSI) to stimulate much-needed research on aging and COVID-19. NIA has supported several administrative supplements and revision applications on COVID-19 related topics include 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 also 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 the new COVID-19 related research milestones that were a product of the Summit, NINDS invited new research in 2023 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).

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

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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/DRD. 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.

NIA also collaborated with the CDC via an interdepartmental agreement, which supported the NIA IMPACT Collaboratory Long-Term Care Data Cooperative (an NIA grant) to monitor COVID-19 vaccine-related adverse events among vulnerable nursing home residents. For a full list of relevant NOFOs and their links, please see [Appendix 3](#).

For more information see:

- <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/research/blog/2020/03/covid-19-adjusting-new-normal>
- <https://www.nia.nih.gov/research/blog/2020/04/new-funding-opportunities-join-fight-against-covid-19>
- <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.nia.nih.gov/research/grants-funding/nia-covid-19-response>
- <https://www.nih.gov/research-training/medical-research-initiatives/radx/funding#radx-up>

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

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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/DRD 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/DRD 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**

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**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, cerebrospinal fluid, and DNA

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it has collected with other investigators who are developing novel biomarkers. Now in its 19th 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 Alzheimer's disease 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 Alzheimer's, 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, resulting in more than 4,756 publications.

For more information see:

- <http://adni.loni.usc.edu/>

The AMP-AD program, as noted above, is an NIH-led precompetitive public-private partnership to identify and validate the most promising biological targets of AD to advance diagnostic and drug development. The first phase, the AMP-AD program 1.0, consisted of two components: The Biomarkers Project and the Target Discovery and Preclinical Validation Project. The Biomarkers Project incorporated tau PET imaging into two NIH-funded prevention trials (Anti-Amyloid Treatment in Asymptomatic Alzheimer's [A4] study Trial and Dominantly Inherited Alzheimer Network Trial Unit [DIAN-TU]).

Data-sharing under the AMP-AD program includes making the screening data and biosamples available after enrollment completion and making post-randomization data and biosamples available as soon as possible after completion without compromising trial integrity.

For more information see:

- <https://www.nia.nih.gov/research/amp-ad>

In February 2022, NIA-supported scientists developed a blood test that was found to effectively predict the presence of beta-amyloid in the brain; and the test became even more accurate when the research team considered the version of APOE (a gene linked to AD risk) that each person had. An NIH-funded study led to the development of the next-generation version of the PrecivityAD blood test 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 cerebrospinal fluid tests. 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 Alzheimer's disease 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 relevant NOFOs 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. An additional benefit of HABLE and HABLE-AT(N) is now in its fourth 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>

At Columbia University, investigators recruit students from underrepresented groups to conduct research projects with neuroimaging data for their NIA-funded Summer of Translational Aging Research for Undergraduates. The trainees are helping to develop brain images as biomarkers of dementia through NIA's Advancing Diversity in Aging Research Through Undergraduate Education program. For a full list of relevant NOFOs and their links, please see [Appendix 3](#).

For more information see:

- <https://www.columbianeurology.org/education-and-training/summer-translational-aging-research-undergraduates-star-u>

NIA is developing a challenge prize competition to discover the best data, methods, and strategies for the early prediction of AD/ADRD. The Pioneering Research for Early Prediction of Alzheimer's Disease and Related Dementias (PREPARE) challenge encourages solvers to build diverse teams and solutions that generalize to groups that historically have been excluded from participation in AD/ADRD research, despite being disproportionately impacted by these conditions.

For more information see:

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

NIH continues to support the development of AD/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 supports 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 demonstrated in 2022 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. Amyloid and tau PET imaging have already proven useful in the clinic to detect Alzheimer's pathologies. Similarly, several research teams are working to develop PET imaging approaches for pathologies more specific to LBD and FTD. In 2022, NIH-supported scientists produced the first complete and exquisitely detailed pictures of abnormally clumped alpha-synuclein, which is a primary component of Lewy bodies. This represents 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, NINDS plans to renew its CWOW for PET Ligand Development for ADRDs and is also inviting applications for researchers to develop multimodal 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 subjects have been enrolled and continue to be followed as part of the PDBP effort. Additionally, investigators through the AMP-PD 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. For a full list of relevant NOFOs 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/lewy-body-data>

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 2, 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. For a full list of relevant NOFOs and their links, please see [Appendix 3](#).

For more information see:

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

**(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 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.

Leveraging the power of real-world data (RWD) -- including EHRs, diagnostic test results, medical images, insurance claims, patient-generated data collected in the home, through mobile devices and wearables, and more -- has great potential to advance AD/ADRD research. Improved access to and use of RWD can lower research costs, reduce participant burden, and help researchers rapidly evaluate treatments and interventions across large and more representative groups of people living with dementia and their care partners. NIH issued a funding opportunity to establish a RWD platform via a cooperative agreement in March 2023, with an anticipated start date -- if an outstanding application is received and is recommended for funding after thorough vetting by a high level and interdisciplinary review panel -- in April 2024. This transformative effort will provide a data and recruitment infrastructure while protecting the privacy of the study participants as a service to the research community. It will help a broad range of researchers access and analyze health data in a secure cloud computing environment and may also help recruit research participants from a more diverse pool of individuals. It will also support collaboration among health care and community health providers to develop and facilitate innovative methods for scalable clinical trials that take place in a variety of settings, including decentralized trials. For a full list of relevant NOFOs and their links, please see [Appendix 3](#).

For more information see:

- <https://impactcollaboratory.org/building-infrastructure/>
- <https://www.nia.nih.gov/research/dbsr/nia-impact-collaboratory>
- <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/gaps-opportunities-stakeholder-workshop>

Another example is the Collaboration for Alzheimer's Prevention (CAP). CAP is a public-private partnership that brings together research groups to harmonize biomarker, clinical, and cognitive measures and align data-sharing and sample-sharing approaches used in certain trials so that findings can inform the entire research community. CAP includes researchers from three trials co-funded by NIH, industry, and foundations: the Alzheimer's Prevention Initiative, the A4 study, and the DIAN-TU. Collaborative efforts like CAP provide an effective platform for implementation of AD/ADRD research standards and advancing AD/ADRD prevention research with rigor, care, and maximal 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/>

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

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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**

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**Lead Agency:** NIA

IADRP, a free, searchable database providing a global overview of AD/ADRD research and funding, is an invaluable tool for assessing and planning AD/ADRD research projects. Funding organizations, researchers, and advocates are discovering IADRP's merits to help them 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 2021, reflecting more than \$8 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.

In 2018, the IADRP database was relaunched with several changes to the Common Alzheimer's Disease Research Ontology, including greater specificity in the coding of FTD, LBD, and VCID. Additionally, users can now link research to related clinical trials, patents, and data repositories, as well as visualize search results with dynamic charts and graphs. NIA awarded a new contract in November 2022 for the continued maintenance and development of the IADRP knowledge base.

For more information see:

- <https://iadrp.nia.nih.gov/>
- <https://iadrp.nia.nih.gov/about/cadro>

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:

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

The 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 participates 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>

The NIA-supported HCAP project, implemented in the HRS and similar sister studies in other countries, is an innovative approach to assessing trends in cognitive function and aging in the United States and worldwide. The primary aim of the HRS, funded by NIA and the Social Security Administration, is to collect and distribute longitudinal multi-disciplinary data on a nationally representative sample of over 20,000 Americans over the age of 50 for research on aging. To provide the research community with new and richer data to study the prevalence, predictors, and outcomes of cognitive impairment and dementia, NIH first supported HCAP during the HRS's 2016 field period. In this field period, investigators administered a supplemental in-home, 1-hour battery of cognitive tests to 3,496 randomly selected HRS respondents aged 65 and older, along with a 20-minute informant interview. Many of the HCAP participants also participated in the HRS venous blood study, which is producing plasma and serum AD biomarkers including Aβ<sub>42/40</sub>, pTau180, neurofilament light chain, and glial fibrillary acidic protein in approximately 4,200 HRS participants. Genotype information are already available for those HCAP (and HRS) participants who consented to being genotyped. The data from that 2016 assessment have now been made publicly available to the scientific community and analyses are underway. A second wave of HCAP assessment was scheduled for 2020 but was postponed to 2022 due to the COVID-19 pandemic. The field period of the 2022 HCAP substudy is about to end and the updated HCAP data is tentatively scheduled for public availability in CY 2024. To further facilitate 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 will be able to design studies that provide insights into potential racial/ethnic differences in the incidence, prevalence, and impact of AD/ADRD. Additionally, NIA released a RFA for the renewal of the HRS and HCAP in FY 2024 that calls for improved overall response/retention rates to maintain representativeness and additional content on social factors to study racial disparities and minority health via life histories. For a full list of relevant NOFOs and their links, please see [Appendix 3](#).

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For more information see:

- <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://hrsdata.isr.umich.edu/data-products/2016-harmonized-cognitive-assessment-protocol-hcap?_ga=2.202519186.2017360935.1670277481-1021185182.1670277481)
- <https://reporter.nih.gov/project-details/10003934>
- <https://reporter.nih.gov/project-details/10017122>
- <https://reporter.nih.gov/project-details/9618704>
- <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/>

The HCAP has been administered in a diverse range of countries, where HRS-like representative population surveys are conducted. HCAP data collected in China, England, India, Mexico, South Africa, and Chile has been publicly released. In addition, HCAP data have been collected in Denmark, Czech Republic, Germany, France, and Italy in the European Union and will be collected in Ireland, Northern Ireland, the Dominican Republic, Nepal, and Lebanon.

For more information see:

- <https://charls.pku.edu.cn/en/index.htm>
- <https://haalsi.org/projects-cores>
- <https://hcap.isr.umich.edu/>
- <https://hrs.isr.umich.edu/data-products/hcap>
- <https://lasi-dad.org/>
- <https://www.mhasweb.org/DataProducts/AncillaryStudies.aspx>

In 2019, NIA funded 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 (WHO). NIA has also approved a concept to renew the HCAP Network and continue to support harmonization and collaboration across international studies conducting the Harmonized Cognized Assessment Protocol.

For more information see:

- <https://hcap.isr.umich.edu/>
- <https://www.nia.nih.gov/approved-concepts#BSRNetworks>

NIA collaborates with the NIH's Fogarty International Center (FIC) to support global research for AD/ADRD in low and middle income countries (LMICs). Research in LMICs will not only help to mitigate AD/ADRD in the developing world 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 also 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 LMICs. To support

training efforts, NIA is working to support the development of early-stage investigators who have begun to establish research programs and who will be ready to assume leadership roles in their field of expertise and will be poised to change theory, practice, and health outcomes related to the health of older individuals in LMICs through partnership in the Emerging Global Leader Award (K43) and Institutional Training Program (D43). NIA also supports the development of institutional training programs by LMIC institutions through the Chronic, Noncommunicable Diseases and Disorders Across the Lifespan (NCD-LIFESPAN): Fogarty International Research 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 also participates in the Global Alliance for Chronic Diseases Implementation Research to Reduce NCD Burden in LMICs program, through which NIA will support implementation research addressing risk factors associated with non-communicable diseases in LMICs. For a full list of relevant NOFOs and their links, please see [Appendix 3](#).

For more information see:

- <https://www.fic.nih.gov/Programs/Pages/brain-disorders.aspx>
- <https://www.nia.nih.gov/research/blog/2021/04/addressing-global-challenges-aging-and-dementia>

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

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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**

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**Lead Agency:** NIA

**Partners:** FDA, ACL, CDC, partner organizations

NIA continues to expand its efforts to educate clinicians about recent research findings, clinical practice tools for assessment, diagnosis and management of cognitive impairment, training materials, and a patient checklist handout in English and Spanish, and other resources available online in a mini-portal of resources for professionals.

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

In 2020, NIA and partner federal agencies led efforts to update and enhance the [Alzheimers.gov](https://www.alzheimers.gov) website. NIA launched this new portal to Federal Government AD/ADRD information and resources in February 2021. The site features:

- Information about AD/ADRD.
- Tips and resources for caregivers and people living with dementia.
- Updates on Federal Government activities to address AD/ADRD.
- How to take part in clinical research and how to find studies.
- Resources for health care providers, community and public health workers, and researchers.

NIA launched a Spanish version of the site in October 2021.

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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=PLmk21KJuZUM5en04!9gF08T74EMmFSkY5>

In June 2022, the Building Our Largest Dementia (BOLD) Infrastructure for Alzheimer's Act Public Health Center of Excellence (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 people living with dementia. 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/dementia-caregiving-as-a-public-health-priority-national-conference/>

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**(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 13 print publications, including four in Spanish. NIA disseminates ADEAR's resources through outreach to the general public, conferences and events in the research and care communities and through media and advocacy organizations. NIA, via weekly e-alerts, reaches more than 145,000 subscribers, and social media accounts reach more than 50,000 followers. In addition, ADEAR is promoted on all Alzheimers.gov educational pages. From September 16, 2021, to September 15, 2022, the ADEAR Center responded to more than 2,000 inquiries, distributed more than 250,000 publications, and received roughly one million website pageviews.

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 are currently funded are encouraged to work with nearby Alzheimer's Disease Centers.

For more information see:

- <https://www.nia.nih.gov/about/bypass-budget-proposal-archive>
  - <https://www.nia.nih.gov/alzheimers>
  - <https://www.nia.nih.gov/health/about-adear-center>
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**(ONGOING) Action 1.E.3: Facilitate translation of findings into public health practice**

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**Lead Agency:** CDC**Partners:** private partners

CDC provided funds to the Alzheimer's Association through a cooperative agreement to co-develop the fourth edition in the series of Healthy Brain Initiative (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. 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, and Engage and Educate the Public.

In 2022, the Alzheimer's Disease Team collected evaluation information from 23 BOLD program awardees on the status of their efforts to implement Road Map Activities from the third Edition. Preliminary analyses of this data indicated that:

- 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.
- Road Map activities were balanced across the four traditional domains of public health.
- As expected, the largest number of awardees are engaged with the required actions P-1 and M-3.
- The next most actively engaged actions are E-1 and W-3.
- 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 2019, the first Road Map for Indian Country was released identifying eight priority actions for Indian Country. This document is being revised and launched in November 2024.

For more information see:

- <https://www.cdc.gov/aging/healthybrain/Indian-country-roadmap.html>
- <https://www.cdc.gov/aging/pdf/roadmap/HBI-State-and-Local-Road-Map-for-Public-Health-2023-2027-508-compliant.pdf>

In late FY 2020, CDC made the first awards for the BOLD Infrastructure for Alzheimer's Act to three BOLD PHCOEs and 16 BOLD Public Health Programs. 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." CDC awarded the second round of recipients of the BOLD Public Health Programs awards in late FY 2021.

In 2023, CDC implemented a new 5-year funding opportunity to increase 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 provides dedicated funding for STLT public health staff to communicate risk reduction strategies and risk factors.

For more information see:

- <https://www.cdc.gov/aging/bold/index.html>
  - <https://www.cdc.gov/aging/funding/phc/index.html>
  - <https://www.cdc.gov/aging/funding/php/index.html>
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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 (NBNA), the National Association of Hispanic Nurses (NAHN), and members of Alzheimer's Los Angeles.

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. One example of the Brain Health Equity Center's success in the past year is the fact that they met and exceeded their outreach goal by 687% (goal 90,000 vs. reached 709,369) with tailored messaging related to cognitive impairment, COVID-19, brain health, and AD/ADRD for Hispanic and African American people and their caregivers.

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

- Completed the development of its practical guide for tailoring brain health messaging after an extensive review process with external experts from BOLD and HBI awardees and CDC staff.
- Successfully executed a logo licensing agreement with the CDC to co-brand its practical message guide, enabling wider dissemination of the guides in the current and future years.
- Partnered with HBI and BOLD awardees on several occasions to raise awareness of brain health among Latino and African American people.
- Reached more than 5,000 nurses with tailored brain health educational messaging through digital communications strategies, direct educational events, and presentations with its partners NAHN and NBNA in the past year.

For more information see:

- <https://www.usagainstalzheimer.org/center-brain-health-equity>

CDC is partnering with the National Indian Health Board (NIHB) to expand knowledge of public health practice within AI/AN communities. NIHB is expanding website content aimed at health practitioners, as well as conducting a virtual Brain Health Action Institute for Tribal Nations. This institute, facilitated by NIHB, will support tribes and Tribal organizations in using the HBI *Road Map for Indian Country* to start conversations, as well as develop and plan strategies for improving brain health in their own communities. The *Road Map for Indian Country* is the first-ever public health guide focused on dementia in AI/AN communities.

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. The state infographics for 2022 data will be available in late 2023. 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/aging/healthybrain/brfss-faq.htm>
- <https://www.cdc.gov/aging/publications/briefs.htm>

The infographics have all been translated to Spanish.

For more information see:

- <https://www.cdc.gov/aging/data/index.htm>

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.

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

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**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 translate and implement at least one evidence-based or evidence-informed program or intervention as part of funded programs. In order to be included in funded projects they must meet the ACL definitions of which are:

- **Evidence-based programs or 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 people living with dementia 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 people living with dementia 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.
- **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 evidence-based interventions including, but not limited to, BRI Care Consultations, Care of Persons with Dementia in their Environments (COPE), Powerful Tools for Caregivers, Resources for Enhancing Alzheimer's Caregivers Health (REACH) Community, and most recently Cognitive Stimulation Therapy are being made available at the community level. These grant-funded activities support ACL's commitment to making research-based interventions available to support people living with dementia and their caregivers, including robust evaluation to demonstrate the interventions impact in the community. The National Alzheimer's and Dementia Resource Center (NADRC) each year updates the *Grantee-Implemented Evidence-Based and Evidence-Informed*

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*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 aid service providers in the selection of interventions to meet the needs of their communities, as well as a compendium of evaluation instruments to support demonstration of program impact.

For more information see:

- <https://acl.gov/programs/support-people-alzheimers-disease/support-people-dementia-including-alzheimers-disease>
- <https://nadrc.acl.gov/details?search1=20221214043701>
- <https://nadrc.acl.gov/details?search1=20210126080816>
- <https://nadrc.acl.gov/details?search1=70>

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### **(NEW) Action 1.E.5: Review and Approve Disease-Modifying Therapies that Slow Cognitive Decline**

**Lead Agency:** FDA

The 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 substantial evidence of 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, there must be substantial evidence of effectiveness demonstrated based on a validated measure of clinical benefit. Aducanumab and lecanemab both received accelerated approval from the FDA in 2021 and 2023, respectively.

In July 2023, the 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. The drug works by reducing amyloid plaques that form in the brain, a defining pathophysiological feature of the disease. Leqembi was originally approved in January under the Accelerated Approval pathway. As a post-marketing requirement of the accelerated approval, the FDA required the applicant to conduct a clinical trial, often referred to as a confirmatory study, to verify the anticipated clinical benefit of Leqembi. Efficacy of Leqembi was evaluated using the results of Study 301 (Clarity AD), a Phase 3 randomized, controlled clinical trial. Leqembi is the first amyloid beta-directed antibody to be converted from an accelerated approval to a traditional approval for the treatment of AD.

For more information see:

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

**Lead Agency:** CMS

On July 6, 2023, FDA converted Leqembi (lecanemab-irmb) to traditional approval, and CMS announced the opening of a CMS-facilitated registry that is available nationwide for clinicians to use. Additional registries have been approved by other organizations and other registries may also become available in the future. With respect to the CMS-facilitated registry, clinicians across

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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 will only need to complete a short, easy-to-use data submission that should be readily available from the patient's medical record, such as a clinical diagnosis. The study criteria can be found in the NCD and any study that is approved will be listed on the CMS website. Physicians will be able to choose the registry or study that works for them and are not required to use the CMS-facilitated registry.

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**(NEW) 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 (NCD) 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 NCD 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>
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## Goal 2: Enhance Care Quality and Efficiency

Providing all people with AD/DRD 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 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.<sup>20</sup> 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/DRD 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/DRD 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/DRD 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/DRD. In addition, work is needed to expand the capacity of the primary care community to serve people with AD/DRD. 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/DRD.

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

**Lead Agencies:** HRSA, VA

**Partners:** CMS, NIA, CDC, ACL

In FY 2022, 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 \$40.3 million GWEP budget, \$8.68 million was for dementia education and training activities. In academic year 2021-2022 (latest available data), GWEP grants provided 673 AD/DRD courses and trained 130,012 health care providers in AD/DRD. In FY 2022 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 another 12 GWEPs (a total of 24 GWEPs participated) assisted in the development of the modules. The modules will be placed on the HRSA dementia website page in November 2023. Also, in FY 2022 an administrative supplement funded 48 GWEP awardees to develop or enhance nursing curricula on nursing home care using

<sup>20</sup> 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>.

an age-friendly health systems 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.

In FY 2022, HRSA funded 24 non-competing continuation Geriatrics Academic Career Award (GACA) program awards totaling \$1.71 million. GACA grant recipients are encouraged to provide dementia education to the workforce.

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 relevant NOFOs and their links, please see [Appendix 3](#).

For more information see:

- <https://impact-ad.org/about/>

ACL, through its ADPI program, continues to expand efforts to educate professionals (at all levels) engaged in providing care and services to persons living with AD/ADRD and their caregivers. ACL-funded programs are developing and translating tools to educate and support clinicians ranging from micro-learning modules for primary care providers and doctors to training programs tailored to CHWs. Several funded programs partner with GWEP grantees to maximize the impact that both funding streams can have in the communities they support. In 2017, ACL secured approval to collect 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 2022, ACL grantees report having trained in excess of 118,000 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, with sample training links below.

For more information see:

- <https://nadrc.acl.gov/>
- <https://nadrc.acl.gov/details?search1=169>
- <https://nadrc.acl.gov/details?search1=20230113010454>
- <https://nadrc.acl.gov/resources?search3=professionals%20%20%20%20#result>
- <https://vda.virginia.gov/dementiacapableVA.htm>

The VA's Geriatric Scholars 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 Geriatric Scholars 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” 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 supported the American College of Preventive Medicine (ACPM) to develop Continuing Education Courses regarding brain health and dementia risk reduction 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 (NACHC) to complete a three-part webinar series on provider awareness and brain health. Resources, materials, and reimbursement strategies were demonstrated and discussed. The sessions also included multiple national partners representing diverse populations, including racial and ethnic minority groups with materials adapted for specific populations.

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### **(ONGOING) 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, the Indian Health Service (IHS) established the Alzheimer’s Grant 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 Health (UIH) programs as a major priority. In response, the 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. These efforts will 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), the VA (in the Geriatric Scholars Program, the RITT, and education resources on the TRAIN Learning Network), and the CDC (in the BOLD Centers of Excellence). Education and training efforts will 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.

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These efforts include:

- Case-based learning and mentoring using the Extension for Community Healthcare Outcomes (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 Geriatric Scholars (GeriScholars) pilot (see [Action 2.A.6](#) and [Action 2.A.7](#)).
- Development of a Nurse Geriatric Fellowship pilot offering nursing professionals in a variety of roles in IHS, Tribal, and Urban Indian Organization (UIO) health programs an opportunity to acquire additional skills and training in care for older patients and those living with dementia and apply those new skills in the setting in which they work to improve care (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 and recognition of cognitive impairment 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 UIH 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.
- Redesign of the Education and Training pages of the new IHS AD and Dementia website to provide links for health care providers to the available educational, training, and workforce development resources (see [Action 2.A.9](#)).
- Collaboration with the Alzheimer's Association in the development of decision support for diagnosis of dementia in primary care (see [Action 2.A.10](#)).
- Collaboration with the VA in the delivery of RITT and the Addressing Behavioral Challenges in Dementia (ABCD) training (see [Action 2.A.11](#)).

For more information see:

- <https://www.ihs.gov/alzheimers>
- <https://www.ihs.gov/alzheimers/alztraining>
- <https://www.ihs.gov/dccs/alzheimers/alztraining/>

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### **(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*

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*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.

In 2023, the NADRC continued to highlight and make grantee-developed resources and tools available through the resource center website. *Highlights of Administration on Aging Alzheimer's and Dementia Program Grantee Developed Resources* was published in July 2023, this 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/>
- <https://nadrc.acl.gov/details?search1=153>
- <https://nadrc.acl.gov/details?search1=169>
- <https://nadrc.acl.gov/details?search1=20230719035406>
- <https://nadrc.acl.gov/details?search1=232>

Cross-agency collaborations have enhanced workforce dementia training and expertise. In FY 2022, the 48 HRSA GWEP grantees collaborated with 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).

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

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**Lead Agency:** HRSA

**Partners:** ACL, CDC, CMS, OWH, NIA, VA

From FY 2015 through FY 2017, HRSA partnered with federal staff at ACL, CDC, CMS, HHS Office on Women's Health, 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 the website below.

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 people living with dementia.

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/](https://www.resourcesforintegratedcare.com/2022_ric_webinar_innovations_alzheimers_disease_related_dementias_adrd_caregiver_support_programs_building_leveraging_support_systems/)

The VHA National Geriatrics and Extended Care Program Office, as well as its individual programs, have provided guidance and trainings to support field staff and caregivers in a variety of settings to ensure the safety of both veterans and caregivers during this unprecedented time of COVID-19 pandemic. These efforts support all VA patients, including those living with dementia. For example, guidance on limiting face-to-face visits between VA providers and veterans in Home-Based Primary Care, Geriatric Patient Aligned Care Teams, and Medical Foster Homes (MFHs) was provided early on and has been updated to reflect the varying stages of re-opening on a regional level. Guidance for increased virtual visits was provided, which allowed multiple commercial applications to be used for communication with veterans and their caregivers. Community Adult Day Health Care (CADHC) Service Plans were amended to enable, with state approval, supportive services for veterans in their homes in lieu of attendance at CADHC Centers. Personal Protective Equipment use recommendations for in-home care was created for veteran caregivers based on general guidance from the CDC. MFH facilitated monthly calls to provide education on creating COVID-Specific Emergency Plans, admission planning, and COVID-19 testing in Community Residential Care settings. Additionally, all programs have held regular virtual meetings with local and VA Veterans Integrated Service Network program coordinators to provide an avenue for discussion of successes and challenges as well as sharing best practices. SharePoint sites were quickly created to allow sharing of documents, online links, and other guidance to VA staff at all levels to ensure the continued safe care of our veterans.

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**(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 people living with dementia 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 relevant NOFOs and their links, please see [Appendix 3](#).

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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.

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>

In 2021, NIA, ACL, CDC, and HRSA revived and expanded the annual Focus on Aging: Federal Partners' Webinar Series. The webinar series, which addresses important topics for public health and health care professionals, aging services organizations, the research community, and other stakeholders in aging, now features approximately three webinars per year and encompasses new federal partners. 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. Recent webinars focused on resilience in dementia caregiving, COVID-19, and dementia risk reduction. All webinars are recorded and made available to the public on the Focus on Aging: Federal Partners' Webinar Series website.

For more information see:

- <https://effectivehealthcare.ahrq.gov/>
  - <https://www.acpm.org/page/brainhealth>
  - <https://www.nia.nih.gov/focus-aging-federal-partners-webinar-series>
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**(UPDATED) Action 2.A.6: Strengthen the ability of primary care teams in Indian Country to meet the needs of people with Alzheimer’s disease and related dementias and their caregivers**

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**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 Geriatric Scholars 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 health 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.
- A clinical practicum or mentorship in geriatric practice.
- Ongoing education, training, and peer support as an Indian Health GeriScholar.

In the first year of the pilot, IHS anticipated recruiting at least eight physicians, nurse practitioners, physician assistants, or pharmacists sponsored by their IHS, Tribal, or UIO health program but demand exceeded expectations, and by June 2023, 15 Indian Health GeriScholars at ten sites had attended training and completed projects focusing on detection and diagnosis of dementia, medication safety, and fall prevention. These Indian Health GeriScholars will be further supported in the coming year to deepen their skills and expertise in care for older adults and those living with dementia.

The 2023 cohort of Indian Health GeriScholars will include up to 14 physicians, nurse practitioners, physician assistants, and pharmacists from 14 sites, including seven IHS clinics and hospitals, six Tribal health programs, and one UIO health program representing seven IHS Areas.

The Indian Health GeriScholars can participate in the educational offerings available to the VA Geriatric Scholars.

In November 2023, the IHS will launch a Geriatric Nurse Fellowship pilot program patterned after the GeriScholars pilot. This fellowship will offer nursing professionals in a variety of roles in IHS, Tribal, and UIO health programs protected time and an opportunity to acquire additional skills and training in care for older patients and those living with dementia and apply those new skills in the setting in which they work to improve care.

In 2023, the IHS partnered with the NPAIHB Indian Country ECHO Program to develop two monthly ECHO series specific for Indian Country. In May 2023, IHS and NPAIHB initiated a monthly Dementia Clinical ECHO series to strengthen knowledge and confidence to detect, diagnose, manage, and provide holistic, culturally-appropriate care locally for AI/AN people living with dementia. In June 2023, IHS and NPAIHB initiated a monthly Caregiver Support ECHO to provide information, resources and tools and mentoring for IHS, Tribal, and UIO staff who provide support and coaching for caregivers of AI/AN people living with dementia. Each of these sessions is recorded for asynchronous viewing.

In 2023, the IHS Division of Oral Health conducted a pilot project at five sites (IHS and Tribal) aimed at increasing recognition of cognitive impairment in dental settings using a brief screening tool (Mini-Cog). In conjunction with this pilot, web-based education addressing core concepts in dementia and detection of cognitive impairment reached over 100 oral health professionals and training in the use of the Mini-Cog was a component of the biennial Dental Updates Conference. The IHS Division of Oral Health will integrate resources training and resources to support

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dementia recognition and optimal oral health care for those living with dementia into ongoing continuing dental education and support.

In 2023, the IHS collaborated 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 will recruit and support new sites with interest in seeking Bronze Level GEDA and one site intends to advance to the Silver Level GEDA.

In 2023, the IHS commenced planning for a CHR multi-site pilot that will include dementia training and use of the Mini-Cog in Tribal and UIO community settings. Recruitment of up to ten sites is planned for fall of 2023.

In 2023, the IHS conducted an environmental scan of existing dementia caregiver interventions and reviewed the experience of IHS and Tribal programs in the REACH into Indian Country pilot of caregiver support services. In 2024, the IHS will facilitate a review and assessment of existing interventions by IHS, Tribal, and UIO staff to assess potential interventions for relevance, adaptation, fitness for use, and likelihood of success in IHS, Tribal, and UIO health programs and solicit feedback training and support needs.

In 2023, the IHS completed an environmental scan of available federal and non-federal dementia training and certification programs to inform future discipline-specific training and education efforts. As part of this effort, 28 Advanced Practice Nurses and 32 RNs were recruited to evaluate a 28 module Dementia Care Specialist Course for relevance in the care of the population they serve and value as a training resource.

See [Action 1.E.3](#) for information on CDC's partnership with NIHB to expand knowledge of public health within AI/AN communities.

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**(COMPLETED) Action 2.A.7: Develop a baseline understanding of self-reported competence and confidence of Indian Health Service, Tribal and Urban Indian Health nursing staff in care of individuals with Alzheimer's disease and related dementias**

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**Lead Agency:** IHS

IHS created a survey to assess nursing in IHS, Tribal, and UIH programs on self-reported competence, confidence, and recent training specific to care for individuals with AD/ADRD. The survey was pilot tested at one Tribal site.

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**(ONGOING) Action 2.A.8: Improve educational resources for primary care staff in Tribal communities caring for individuals with Alzheimer's disease and related dementias and their families**

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**Lead Agency:** IHS

**Partners:** HRSA, ACL

IHS, in conjunction with HRSA, worked to pilot-test the HRSA curriculum for care of AD/ADRD in IHS, Tribal, and UIH Programs. The HRSA Dementia Curriculum and selected VA geriatric training materials are now available as a resource for Indian Health clinical staff through the IHS Alzheimer's Grant Program Education and Training page.

In 2023, the IHS, ACL, and CDC brought together grantees funded through the IHS Alzheimer's Grant program, the ACL ADPI and Dementia Capability in Indian Country grants, and the CDC BOLD AI/AN-focused grants for a one-day meeting at the ACL National Title VI Training to share

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their programs and experience with each other and identify additional resources to support their efforts.

The Education and Training pages of the newly designed 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 be added in the coming year.

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/DRD training and education and dementia-specific evidence-based interventions 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 a Tribal health system, have developed and are providing 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.ihs.gov/alzheimers/alztraining/>

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#### **(ONGOING) Action 2.A.9: Provide decision support for clinicians in Tribal communities**

**Lead Agency:** IHS

IHS worked to develop and pilot-test decision support tools for clinicians using the IHS EHR. The IHS has developed templates to support the Annual Wellness Visit (AWV), including cognitive assessments and chronic care management. The IHS is now focusing on the opportunities to improve support for geriatric care in the IHS HIT modernization effort underway.

In 2024 the IHS will 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 tailored to systems and cultural environments of care in Indian Country.

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#### **(ONGOING) Action 2.A.10: 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/DRD 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.

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#### **(COMPLETED) Action 2.A.11: 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 multifaceted approach to determine the minimum level and type of staffing needed to help enable safe and quality care in nursing homes, including a RFI, a mixed-methods Nursing Home Staffing Study, a stakeholder listening session, and a proposed rule.

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Using the information gathered from these actions, on September 1, 2023, CMS issued the Minimum Staffing Standards for Long-Term Care (LTC) Facilities and Medicaid Institutional Payment Transparency Reporting proposed rule, which seeks to establish comprehensive nurse staffing requirements to 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 long-term care 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/2023/09/06/2023-18781/medicare-and-medicaid-programs-minimum-staffing-standards-for-long-term-care-facilities-and-medicaid>

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## Strategy 2.B: Ensure Timely and Accurate Diagnosis

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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 long-term care 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**

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**Lead Agency:** NIA

**Partner:** CDC

NIA-supported scientists are making important progress toward the development of 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.

NIA has also funded applications to pursue development and validation studies of cognitive screening instruments or assessments in clinical settings and to translate these screening and assessment tools into EHR systems that can assist physicians in making clinically meaningful care recommendations for patients experiencing cognitive decline. Moreover, NIH-funded researchers recently developed and validated a tool called 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, more accurate diagnoses of dementia in older adults.

In addition, researchers are expanding the NIH Toolbox for the Assessment of Neurological and Behavioral Functions, a dynamic set of health assessments for all ages. Now available in English and Spanish, more than 200 clinical studies are using the NIH Toolbox, and more than 400 peer-

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reviewed articles have been published. The NIH-supported Advancing Reliable Measurement in Alzheimer's Disease and Cognitive Aging study is investigating the use of the NIH Toolbox measures for people with AD/ABDR. Through this effort, researchers are expanding the toolbox so that it will be valid to use with ethnically and racially diverse adults and 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://www.clinicaltrials.gov/ct2/show/NCT02814526>
- <https://www.healthmeasures.net/explore-measurement-systems/nih-toolbox>
- <https://www.healthmeasures.net/explore-measurement-systems/nih-toolbox/measure-development-and-research/publications-by-year/197-nih-toolbox-publications-by-year>
- <https://www.nia.nih.gov/health/alzheimers-dementia-resources-for-professionals>
- <https://www.nihtoolbox.org/publication-finder/>

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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 FOA 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 will go into widespread release to a greater number of researchers in 2023. 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) is calling 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 relevant NOFOs 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](#).

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

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**Lead Agency:** NINDS

**Partner:** NIA

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. To this end, in 2022, NINDS launched the second phase of the Consortium for Detecting Cognitive Impairment, Including Dementia (DetectCID; RFA-NS-22-009) -- a collaborative research network to develop and validate approaches to detect dementia in primary care or other everyday clinical settings. The detection approaches are designed to be simple to use, standardized, 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 2022, DetectCID investigators published lessons learned through the first phase of the program, including the importance of: (1) engaging primary care teams in research and helping them to both diagnose cognitive conditions as well as provide ongoing care support; (2) integrating newly developed screening tests with EHRs; and (3) ensuring that detection approaches address the needs of diverse populations. In Phase 2, the DetectCID research teams are now validating the most promising approaches from Phase 1 in larger pragmatic clinical trials and currently enrolling study participants with the goal of having half of the study population from underrepresented racial or ethnic groups. For a full list of relevant NOFOs and their links, please see [Appendix 3](#).

For more information see:

- <https://pubmed.ncbi.nlm.nih.gov/35124639/>
- <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**

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**Lead Agency:** CDC

In 2020, CDC funded the BOLD PHCOE to focus on early detection and diagnosis of AD/ADRD. The NYU 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 Center created a comprehensive three-part strategy to ensure a thorough scoping review of materials for early detection and diagnosis of AD/ADRD including: (1) collate public facing educational materials from websites including those of CDC, Alzheimer's Association, and NIA; (2) conduct a series of web-based searches for educational materials, tools, checklists, protocols, and resources designed to facilitate detection and early diagnosis of dementia; and (3) search the peer-reviewed literature using primarily PubMed to identify articles providing evidence of successful tools and strategies for early detection. As of April 2021, the Center has initiated this first strategy by gathering 13 pages of weblinks to resources with descriptions. The Center recently launched a website specific to its PHCOE on Early Detection of Dementia and is publishing all educational materials and peer-reviewed literature on the evidence of successful tools and strategies for early detection and diagnosis of AD/ADRD for public access and use.

In the past year, the PHCOE on Early Detection and Diagnosis of Dementia (EDD) has completing the following activities.

1. Launched the NYU PHCOE website on April 22, 2022.
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2. Created Executive Committee (seven people) who solicit feedback from their Advisory Council workgroup members on materials developed by the BOLD team and developed actions plans for developing, refining, and disseminating early detection toolkits for health care systems, state/local/Tribal departments of health, and community-based organizations (CBOs).
3. Identified common barriers and facilitators to dementia detection across CBOs, departments of health, and health system sectors.
4. Developed a list of cognitive screeners recommended by American Gerontology Society KAER model for primary care within a health care system and the U.S. Preventative Task Force. The list of cognitive screeners is being made into a searchable tool for use on the NYU PHCOE website. The public can use this tool to identify and gain a detailed understanding of the different types of cognitive screens health care providers use to assess people for AD/ADRD.
5. Wrote a manuscript including a timeline of key national policy initiatives that support dementia detection and dementia care planning to be featured in state AD/ADRD analysis paper that was submitted for peer review in May 2022.
6. Created infographics for the PHCOE-EDD website that provide guidance on approaching conversations around dementia detection and brain health.
7. Wrote “Why Detect Dementia” pieces that highlighted the importance of early detection of dementia featured on the website.
8. Began building relationships with new CBOs to develop a deeper understanding of this highly heterogeneous sector.
9. Pilot-tested the health systems dementia detection toolkit in IHS.
10. Provided technical assistance and guidance to the Maine BOLD program on their dementia detection program.

PHCOE-EDD is planning a national meeting on early detection and diagnosis of AD/ADRD entitled *Public Health Action to Advance Early Detection of Dementia National Virtual Symposium* on October 25-27, 2022. A total of 312 people registered for the virtual meeting with 179 individuals attending. This meeting was free, and the content will be available to all registrants via the meeting website through December 1, 2022, and available for the general public afterwards. Early evaluation data shows, 71% were extremely satisfied with symposium content and 25% were satisfied, providing them with 96% positive feedback.

For more information see:

- <https://bolddementiadetection.org/>

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

**Lead Agency:** FDA

In June 2023, FDA cleared for marketing the Elecsys Total-Tau Cerebral Spinal Fluid (CSF) and Elecsys  $\beta$ -Amyloid (1-42) CSF II tests for the detection of amyloid plaques in patients aged 55 years and older being evaluated for AD. The test is intended to be used in conjunction with other clinical diagnostic assessments to help health care providers determine whether a patient 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. The Elecsys CSF tests add to the increasing arsenal of clinical laboratory tests available to assist in the evaluation of patients with cognitive conditions such as AD.

In May 2022, FDA permitted marketing for the first in vitro diagnostic test for early detection of amyloid plaques associated with AD/ADRD. The Lumipulse G  $\beta$ -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,

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to detect/visualize amyloid plaques in a patient's brain, often years before clinical symptom onset, to aid in diagnosing AD/ADRD.

For more information see:

- <https://www.fda.gov/news-events/press-announcements/fda-roundup-june-9-2023>
- <https://www.prnewswire.com/news-releases/roche-receives-fda-clearance-for-additional-alzheimers-disease-cerebrospinal-fluid-csf-assays-supporting-timely-diagnosis-and-treatment-decision-making-301863708.html>
- <https://www.fda.gov/news-events/press-announcements/fda-permits-marketing-new-test-improve-diagnosis-alzheimers-disease>

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**(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**

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**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=169>
- <https://nadrc.acl.gov/details?search1=20210225025851&result>
- <https://nadrc.acl.gov/details?search1=20230113125636>
- <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/funding/hbi/index.html>
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**(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**

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**Lead Agencies:** IHS, CDC, NIA

**Partners:** ACL, VA

The IHS, with ACL and VA, pilot-tested AD/ADRD awareness strategies in communities in which 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 provide local resources for community-based education and training.

In Spring 2023, the IHS offered the Models of Care Webinar Series (five sessions) to increase awareness of funding opportunities and stimulate interest in adapting existing models of care for Tribal and Urban communities. Over 200 individuals representing all 12 IHS areas participated.

In April 2023, the IHS, ACL, and CDC brought together grantees funded through the IHS Alzheimer’s Grant program, the ACL ADPI and Dementia Capability in Indian Country grants, and the CDC BOLD AI/AN-focused grants for a preconference meeting at the ACL National Title VI Training to share their programs and experience with each other and identify additional resources to support their efforts.

Subscription to the IHS Elder Care Listserv, a vehicle for communication with stakeholders in aging services across Indian Country, has increased by 140% since September 2022, indicating a broadening of awareness and engagement in AD/ADRD and aging issues.

In 2023, the 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.

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 evidence-based interventions 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 Alzheimer’s and dementia 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 ADRD in Indian Country. As a result of the April meeting, new collaborative opportunities were identified, as well as the sharing of resources.

CDC, in partnership with National Council of Urban Indian Health (NCUIH), 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://www.cdc.gov/aging/healthybrain/videos/index.html>
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A number of NIA's ADRCs are working in Native Communities and have developed brochures and videos 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. Additional resources include information about AD/ADRD, caregiver resources, and research education. NIA is also currently holding focus groups and stakeholder interviews to develop tailored materials for AI/AN. Materials developed are made available to the public in both ADORE and Outreach Pro. Other notable projects to increase awareness of AD and ADRD include the *Native Alzheimer's Disease Resource Center for Minority Aging Research* and *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/research/adore>
- <https://www.nia.nih.gov/research/alzheimers-dementia-outreach-recruitment-engagement-resources/indigenous-aging-resources>

CDC funds a special interest project at the University of Washington School of Medicine through CDC's Prevention Research Centers that aims to improve cognitive impairment detection and referral to resources among older adults by applying the Gerontological Society of America's KAER Model to primary care within a health care system. The project will increase awareness of early signs, detection of cognitive impairment, and support of providers, patients, and caregivers to ultimately improve outcomes for care of dementia. The project will implement an education intervention for primary care providers and clinical staff to increase skills for evaluation and management of dementia. Working with the university clinic managers and information technology, the project will streamline operations and document care utilizing newly developed interdisciplinary workflows and EHR order sets. A Community Advisory Board will assist in the development of a web-based resource directory to be used in-clinic and at home to support providers, staff, patients, families, and caregivers. It is anticipated that by the end of the 2-year project, strategies developed and implemented will help other health care systems initiate steps to integrate the KAER Model and other tools for improving detection and management of dementia through support of primary care.

For more information see:

- <https://familymedicine.uw.edu/cpc/>
- <https://www.acpm.org/page/brainhealth>
- <https://www.cdc.gov/aging/bold/index.html>
- <https://www.cdc.gov/aging/healthybrain/issue-maps/early-detection.html>
- <https://www.geron.org/images/gsa/kaer/gsa-kaer-toolkit.pdf>

Also see [Action 2.A.5](#) for an update on the work of the CDC with support from the BOLD Infrastructure for Alzheimer's Act to create a uniform national public health infrastructure.

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

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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-

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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/ADR and their families and caregivers and enhancing the ability of other networks to assist people living with AD/ADR 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**

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**Lead Agency:** HRSA

**Partners:** 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, and community organizations that provide LTSS to effectively educate physicians and other health care providers, direct service workers, and patients, families, and caregivers about support resources and services available to assist people with AD/ADR, as well as their caregivers. These activities will continue as part of the training in [Action 2.A.1](#).

Under Medicare, CMS 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://nadrc.acl.gov/details?search1=20230113110811>
  - <https://nadrc.acl.gov/details?search1=206>
  - <https://vda.virginia.gov/dementiacapableVA.htm>
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**(UPDATED) Action 2.C.2: Connect American Indians and Alaska Natives to Alzheimer's disease and related dementias resources**

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**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 2024, the IHS will partner with the CDC in the revision of the *Road Map for Indian Country*. Additionally, CDC developed an infographic describing SCD and related functional limitations, as well as caregiving, in AI/AN adults in order to educate stakeholders and policy makers on brain health in Indian Country. The International Association for Indigenous Aging (IA<sup>2</sup>), a recipient of HBI support, and the NPAIHB are developing, tailoring, and disseminating AD/ADRD materials and resources to AI/AN communities.

In 2022, IHS entered into a Memorandum of Understanding with the Alzheimer's Association to work together to address and improve the health and well-being of AI/AN living with dementia and their caregivers, and continues active collaboration and coordination, including linking Alzheimer's Association chapters with tribes, UIO health programs, and IHS services and increasing awareness among IHS, Tribal, and UIO health programs about technical assistance and resources available through the Alzheimer's Association. In 2023, the Alzheimer's Association engaged in support of the oral health pilot sites through training and development of customized dental patient education materials. The Indian Health Board of Minneapolis has collaborated with their local Alzheimer's chapter on an eight-session caregiver training and awareness series.

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. The University of Wyoming, in partnership with members of the Eastern Shoshone and Northern Arapaho Tribes, completed a culturally-relevant dementia training material for American Indian people on the Wind River Reservation by creating a pictorial version of the Alzheimer's Association's *Know the 10 Signs: Early Detection Matters*. This continues to be disseminated as a national resource. In 2023, the IHS began a collaboration with the University of Oklahoma (OU) Health Sciences' GWEP program on the OU CHW/CHR dementia training, developed in conjunction with local Tribal community health staff. The 2023 OU winter training reached maximum capacity shortly after national promotion by IHS to the Tribal and UIO health program community health workforce.

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 evidence-based interventions 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 Alzheimer's and dementia 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

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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://www.cdc.gov/aging/healthybrain/Indian-country-roadmap.html>
- <https://www.cdc.gov/aging/healthybrain/Indian-Country-resources.html>

CDC has partnered with the NCUIH to review, adapt, and disseminate existing culturally and linguistically appropriate flyers and posters on brain health for an urban AI/AN audience. To accompany the updated materials, NCUIH, with support and feedback from NCUIH staff, created three culturally-appropriate 1-minute videos on:

1. Preventing Alzheimer's.
2. Recognizing the signs of Alzheimer's in Loved Ones.
3. Healthy Living with Alzheimer's.

To ensure maximum exposure, NCUIH will develop and disseminate a healthy brain media kit for use by UIHs and others wanting to raise awareness on AD/ADRD and healthy aging. The media kit will include the updated flyers and posters, and links to the videos and social media campaign messaging information. Finally, NCUIH will launch a social media campaign with targeted outreach in cities with the largest AI/AN population (Los Angeles, Phoenix, Tulsa, Oklahoma City, and Anchorage) to disseminate all materials.

Additionally, CDC developed an infographic describing SCD and related functional limitations and caregiving on AI/AN adults in order to educate stakeholders and policy makers on brain health in Indian Country. These are available in both English and Spanish.

For more information see:

- <https://www.cdc.gov/aging/data/infographic/2018/american-indian-adults-caregiving.html>
- <https://www.cdc.gov/aging/data/infographic/2018/american-Indian-alaska-native-cognitive-decline.html>
- <https://www.cdc.gov/aging/data/infographic/2019-2020/ai-an-scd.html>
- <https://www.cdc.gov/aging/healthybrain/videos/index.html>
- <https://www.cdc.gov/aging/spanish/infographic/2018/ai-adults-caregiving.html>
- <https://www.cdc.gov/aging/spanish/infographic/2018/aian-cognitive-decline.html>

Also see [Action 1.E.3](#) for information on CDC's partnership with NIHB to expand knowledge of public health within AI/AN communities.

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

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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

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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.

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

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**Lead Agency:** CMS

**Partner:** ASPE

CMS has included dementia-related measures in the Merit-based Incentives Payment System for Medicare such as cognitive assessment, education and support of caregivers, and other measures that impact people with dementia. CMS has also released a voluntary 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. The agency maintains the CMS Measures Inventory Tool, which inventories 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.

For more information see:

- <https://cmit.cms.gov/cmit/#/>
  - <https://qpp.cms.gov/mips/quality-measures>
  - <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**

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**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.

For more information see:

- <https://mms-test.battelle.org/sites/default/files/Blueprint-CMS-CBE-Endorsement-Maintenance.pdf>
  - <https://www.cms.gov/blog/cms-national-quality-strategy-person-centered-approach-improving-quality>
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**(ONGOING) Action 2.D.3: Clarify and disseminate information on privacy, autonomy, and safety issues to physicians**

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**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.

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**(UPDATED) Action 2.D.4: Improve nursing home care and transparency during public health emergencies and disasters**

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**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 the 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.

In 2023, CMS began including ownership and operatorship affiliation on the Nursing Home Compare website, and publishing 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.

CMS is currently developing a proposed rule to revise and update national emergency preparedness requirements for Medicare and Medicaid-participating providers and suppliers to plan adequately for both natural and man-made disasters, including climate-related disasters, and coordinate with federal, state, Tribal, regional, and local emergency preparedness systems based on lessons learned during the COVID-19 PHE and other recent events.

For more information see:

- <https://nursinghomebehavioralhealth.org>
- <https://www.cms.gov/files/document/qso-22-19-nh-revised-long-term-care-surveyor-guidance.pdf>
- <https://www.cms.gov/files/document/qso-23-18-nh.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>

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

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

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

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**Lead Agency:** CMS**Partner:** NIA

In 2023, CMS announced the GUIDE Model which aims to improve the quality of life for people living with dementia, 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 will aim to define a standardized approach to dementia care delivery, provide a monthly per-beneficiary payment to support team-based collaborative care, provide caregiver training and respite care services, and 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 will launch in July 2024 and operate for 8 years.

For more information see:

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

NIA and the Patient-Centered Outcomes Research Institute (PCORI) funded a pragmatic trial as a follow-on to one of the Centers for Medicare and Medicaid 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.

For more information see:

- <https://innovation.cms.gov/innovation-models/guide>
- <https://pubmed.ncbi.nlm.nih.gov/32949145/>
- <https://pubmed.ncbi.nlm.nih.gov/35553424/>
- <https://reporter.nih.gov/search/s6vRgr3jpE2xSXQLAdNqjA/project-details/10665547>

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

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**Lead Agency:** CMS

The Independence at Home Demonstration tests a payment incentive and service delivery model that uses physicians and nurse practitioners to deliver services for Medicare beneficiaries with multiple chronic conditions. CMS released evaluation results from Year 7 of the demonstration in 2023.

For more information see:

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

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

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**Lead Agency:** ASPE

In April 2014, the Protecting Access to Medicare Act created the Certified Community Behavioral Health Clinic (CCBHC) demonstration. The demonstration establishes a standard definition for CCBHCs and allows states to develop new prospective payment systems (PPS) that reimburse CCBHCs for the total cost of providing comprehensive services to all individuals who seek care. ASPE is managing a multi-year evaluation of this demonstration to answer research questions on how the CCBHCs improve access to care, whether they implement a full scope of services, how

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they improve the quality of care, whether the PPS covers the full costs of care, and how the demonstration impacts costs and utilization in Medicaid. Reports to Congress are due annually, and both interim reports and a final report are posted on ASPE's website. The first Report to Congress was published in 2017; five additional Reports to Congress have been transmitted, and two interim reports were published in September 2020. Since the demonstration was extended and expanded several times, including most recently in the Safer Communities Act, ASPE is undertaking further evaluation of the extended and expanded demonstration.

For more information see:

- 2022: <https://aspe.hhs.gov/sites/default/files/documents/38dec5061e0270c39e571cde5f3d1c/ccbhc-report-congress-2022.pdf>
- 2021: <https://aspe.hhs.gov/sites/default/files/documents/105419805ccd240560bc8aff4be6e304/ccbhc-report-congress-2021.pdf>
- 2020: <https://aspe.hhs.gov/sites/default/files/documents/1faadf771e9567b0926e33739341cb50/ccbhc-report-congress-2020.pdf>
- 2019: [https://aspe.hhs.gov/sites/default/files/migrated\\_legacy\\_files/196036/CCBHCRptCong19.pdf](https://aspe.hhs.gov/sites/default/files/migrated_legacy_files/196036/CCBHCRptCong19.pdf)
- 2018: [https://aspe.hhs.gov/sites/default/files/migrated\\_legacy\\_files/191806/CCBHRptCong.pdf](https://aspe.hhs.gov/sites/default/files/migrated_legacy_files/191806/CCBHRptCong.pdf)
- 2017: [https://www.samhsa.gov/sites/default/files/ccbh\\_clinicdemonstrationprogram\\_071118.pdf](https://www.samhsa.gov/sites/default/files/ccbh_clinicdemonstrationprogram_071118.pdf)
- <https://aspe.hhs.gov/sites/default/files/documents/60f121a777ee63b20008e43ad45518bf/ccbhc-implementation-impacts-findings.pdf>
- <https://aspe.hhs.gov/sites/default/files/documents/90c1c4d1646109391a938b6e25395dc5/ccbhc-interim-cost-quality-findings.pdf>
- [https://aspe.hhs.gov/sites/default/files/migrated\\_legacy\\_files/196051/CCBHCImpFind.pdf](https://aspe.hhs.gov/sites/default/files/migrated_legacy_files/196051/CCBHCImpFind.pdf)
- [https://aspe.hhs.gov/sites/default/files/migrated\\_legacy\\_files/196041/CCBHCPreCost.pdf](https://aspe.hhs.gov/sites/default/files/migrated_legacy_files/196041/CCBHCPreCost.pdf)

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

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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: Implement and evaluate new care models to support effective care transitions for people with Alzheimer's disease and related dementias**

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**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>
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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.

For more information see:

- <https://www.medicaid.gov/sites/default/files/2023-01/smd23001.pdf>

CMS updated guidance for Medicare’s AWW 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](https://www.samhsa.gov/sites/default/files/a_practical_guide_to_psychiatric_advance_directives.pdf)

In 2023, CMS finalized new Medicare coding and payment for principal illness navigation services in the Physician Fee Schedule that begins in January 2024, which could be important for 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 access to community-based social services to address social determinants of health needs. PIN services can assist people with Medicare who are diagnosed with high-risk conditions like dementia identify and connect with appropriate clinical and support resources.

For more information, see

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

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=182>
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**(ONGOING) Action 2.F.2: National Center on Advancing Person-Centered Practices and Systems**

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**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/>

On September 13, 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/](https://www.resourcesforintegratedcare.com/2023_ric_webinar_promising-practices-for-promoting-person-centered-communication-and-care-coordination/)
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**Strategy 2.G: Advance Coordinated and Integrated Health and Long-Term Services and Supports for People Living with Alzheimer's Disease and Related Dementias**

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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.

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

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**Lead Agency:** CMS

CMS makes payment for care management and coordination services, including complex 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>
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**(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**

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**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* 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.

For more information see:

- <https://www.healthit.gov/isa/>

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

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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.

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

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**Lead Agency:** IHS**Partner:** ACL

Since May 2022, the IHS has awarded 12 cooperative agreements for the development of models of comprehensive and sustainable dementia care and services in Tribal and Urban Indian communities that are responsive to the needs of PLWD and their caregivers. In August 2022, the IHS awarded 2-year cooperative agreements to three tribes and one UIH program and in August 2023 the IHS awarded a second round of funding to eight additional tribes, Tribal organizations, and UIOs. The care and services developed through these 12 awards will improve care locally and serve as a model for Tribal and Urban Indian programs nationally.

The IHS will offer a new notice of funding opportunity in FY 2024 for tribes, Tribal organizations, and UIOs currently operating programs to support further expansion and sustainability of those programs.

The IHS also anticipates offering small program awards for IHS, Tribal and UIH programs for the development of specific services addressing care for those living with dementia and their caregivers.

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For more information see:

- <https://www.ihs.gov/alzheimers/fundingopps>
- <https://www.ihs.gov/dccs/alzheimers/alzfunding/>
- <https://www.ihs.gov/newsroom/ihs-blog/march-2023-blogs/1-8m-in-ihs-funding-provides-additional-resources-to-address-alzheimers-and-dementia/>
- <https://www.ihs.gov/newsroom/pressreleases/2022-press-releases/indian-health-service-announces-investment-to-address-alzheimers-disease-in-indian-country-on-world-alzheimers-day/>

As of 2023, ACL has funded a total of 180 AD/ADRD state and community-based projects, in support of people living with dementia and their caregivers, including training professional, since 2014 when funding was expanded beyond states. Included in the 180 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://acl.gov/news-and-events/announcements/alzheimers-disease-programs-initiative-adpi-dementia-capability-0>
- <https://nadrc.acl.gov/>
- <https://nadrc.acl.gov/details?search1=20210602113141#result>

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### **(COMPLETED) Action 2.H.2: Adapt care provision strategies for Tribal members during the COVID-19 pandemic**

**Lead Agency:** IHS

IHS's Tribal, and UIH programs rapidly shifted care from in-person to telephone and video-based visits to limit risk of exposing elders with dementia and other at-risk individuals to COVID-19. For example, the Chinle Service Unit deployed care coordinators with tablets to the homes of high-risk individuals in remote rural homes on the Navajo Nation to facilitate video-visits.

The UNITE collaborative of Tribal LTSS programs has been meeting regularly to share tactics and approaches to maintain the health of their residents and staff and to limit risk of exposure to COVID-19. The collaborative also presented on the CMS/ACL/IHS LTSS webinar series hosted by the CMS Tribal LTSS Technical Assistance website. IHS and Tribal contact tracers, public health nurses, and CHRs have worked with families to protect elders with dementia living in multi-generational homes from exposure.

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### **(UPDATED) Action 2.H.3: Improve detection, diagnosis, and care for Alzheimer's disease and related dementias in Tribal health systems**

**Lead Agency:** IHS

Initially funded in FY 2021, the IHS established the Alzheimer's Grants Program in May 2022 following Tribal Consultation and Urban Confer. Through the IHS Alzheimer's Grants Program, the IHS provides funding through cooperative agreements to tribes, Tribal organizations, and UIOs for the development of models of dementia care and services in Tribal and Urban Indian communities that are responsive to the needs of PLWD and their caregivers. Awardees will develop comprehensive and sustainable approaches to address AD/ADRD, including detection, diagnosis, assessment, management, and support for caregivers, and will create best practice models for replication by others. Additional funding in the form of program awards will support the development of specific care and services through IHS, Tribal, and UIH programs to improve outcomes for individuals living with dementia and their caregivers. The IHS Alzheimer's Grant

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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 communities, and development of data resources using the clinical data available through the IHS.

The programs and activities of the IHS Alzheimer's Grants Program are identified in this National Plan under [Action 2.A.2](#), [Action 2.A.6](#), [Action 2.A.9](#), [Action 2.A.10](#), [Action 2.A.11](#), [Action 2.B.7](#), [Action 2.C.2](#) and [Action 2.H.1](#).

For more information see:

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

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#### **(ONGOING) Action 2.H.4: 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.

Many ACL-funded programs use their resources to develop tools designed to support people living with IDD and dementia. Tools that demonstrate positive impact on the intended audience are made available to the public through the NADRC website.

In 2022, an ADPI grantee created the ONECaregiver website to provide a centralized location of resources that support caregivers and people living with IDD and at risk of developing ADRD which includes relevant 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. ACL continues to address the gap in services and supports for people living with IDD and dementia or at high risk of developing dementia. Since the inception of community programming, 111 grants received funding to include activities designed to close the gap in services for this population.

For more information see:

- <https://nadrc.acl.gov/>
- <https://nadrc.acl.gov/details?search1=169>
- <https://nadrc.acl.gov/details?search1=20210225025851&result>
- <https://nadrc.acl.gov/details?search1=20230113125636>
- <https://onecaregiverresourcecenter.org/>

Also see [Action 2.A.3](#) for information on CDC's funding of the PwIDD-HBI.

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## 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

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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**

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**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 specifically on caregiving issues, and social media. See [Action 1.E.2](#) for more information on ADEAR. NIA also operates several social media platforms and regularly conduct outreach efforts to share federally-developed educational materials on AD/ADRD. For example, in November 2021 during National Family Caregivers Month and June 2022 during Alzheimer’s & Brain Awareness Month, NIA showcased stories from Alzheimer’s caregivers as well as related resources through a highly popular social media storytelling series. In addition, the most visited Alzheimers.gov page *Tips for Caregivers and Families of People With Dementia* provides information on finding support and links to resources across the Federal Government.

For more information see:

- <https://twitter.com/NIHAging>
- <https://www.alzheimers.gov/life-with-dementia/tips-caregivers>
- <https://www.facebook.com/NIHAging>
- <https://www.nia.nih.gov/health/about-adear-center>
- <https://www.nia.nih.gov/health/alzheimers/caregiving>

ACL’s NADRC develops and makes available resources in support of both paid and unpaid caregivers. Examples of such resources include but are not limited to:

1. Advance Planning for People Living with Dementia.
  2. Dementia Training Resources for Professionals and Volunteers.
  3. Emergency Preparedness Toolkit for People Living with Dementia.
  4. Working Together: How Community Organizations and First Responders Can Better Serve People Living with Dementia.
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5. Intellectual and Developmental Disabilities and Dementia: Practical Strategies for Professionals.
6. Handbook for Helping People Living Alone with Dementia Who Have No Known Support.
7. Guide to Billing Codes for Dementia Services.

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=137>
- <https://nadrc.acl.gov/details?search1=151>
- <https://nadrc.acl.gov/details?search1=153>
- <https://nadrc.acl.gov/details?search1=155>
- <https://nadrc.acl.gov/details?search1=157>
- <https://nadrc.acl.gov/details?search1=169>
- <https://nadrc.acl.gov/details?search1=232>

IA<sup>2</sup>, a recipient of the HBI support, and NPAIHB are developing, tailoring, and disseminating AD/ADRD materials and resources to AI/AN communities.

For more information see:

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

Also see [Action 1.E.3](#) for updates on the Caregiving and SCD infographics, and [Action 1.E.3](#) for information on CDC's contribution to the Public Health Perspectives on the Family Care Gap textbook.

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

**Lead Agency:** AHRQ

**Partners:** NIA, VA

Reports from the National Research Council have reinforced the need for HIT applications for caregivers, as well as people with AD/ADRD and providers. Many opportunities exist for using technology to support people with AD/ADRD and their caregivers. Opportunities include assistance with reminders, communications, and monitoring. AHRQ has awarded three grants for integrating information and communication technology to facilitate aging in place.

One grant (1P50HS019917) was awarded and used to create Elder Tree, a suite of electronic services to support older adults and their caregivers and to conduct a study on the services. The study was a randomized control trial of adults aged 65 and older and their caregivers who had experienced challenges to aging in place. Control group participants were provided usual sources of information and communication, while the intervention group was given access to Elder Tree for 18 months. Findings suggested a positive effect for older adults who are heavy users of health services when they used Elder Tree. Analyses indicated that the system reduced the risk of falls and depression, and improved quality of life and social support for users. The Elder Tree tool is currently being evaluated. So far, 400 people have been recruited to use the suite, and participants were surveyed after use. An analysis is currently underway, and results will be available soon. Elder Tree has been successfully disseminated to 57 counties in Wisconsin and continues to expand.

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Another grant (5R18HS022836) was awarded to evaluate use of remote sensory technology to help manage persons with AD/ADRD, and to study the impact on ability of caregivers to manage a family member with AD/ADRD. So far, 60 caregivers have been recruited, out of a goal of 100, and systems are in the process of being installed and caregivers trained.

Finally, a grant (2R21HS026571) was awarded to evaluate the clinical integration of an AD/ADRD support application that provides education, supportive resources, and a platform to share real-time patient-related information with the care team from homes or community settings. The research team was modified based on feedback from stakeholders and is currently implementing the solution into the clinical environment.

For more information see:

- <https://digital.ahrq.gov/ahrq-funded-projects/bringing-communities-and-technology-together-healthy-aging>
- <https://digital.ahrq.gov/ahrq-funded-projects/examining-clinical-workflow-and-outcomes-integrating-health-information>

NIA has supported initiatives to advance progress toward NIA 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 (NOT-AG-20-017, NOT-AG-21-048) and 27 projects citing these NOSIs have been awarded. For a full list of relevant NOFOs and their links, please see [Appendix 3](#).

For more information see:

- <https://reporter.nih.gov/search/dCAsh6HZiEeIEK8OJ4SWpA/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 that have the potential to 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>

NIA collaborated with ACL to issue a SBIR FOA that addresses the fundamental need for the development of technologies that enhance caregiver training and address the financial and legal aspects of caregiving. NIA and ACL published this funding opportunity to encourage and fund research and development of technology and tools for the currently under-developed market serving caregivers and their family members suffering from AD/ADRD. Through their collaboration, NIA and ACL funded seven awards in FY 2021 to stimulate research and development of technology and tools that adapt to a range of levels of expertise/experience, specific care demands, and needs of family caregivers. For a full list of relevant NOFOs and their links, please see [Appendix 3](#).

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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, 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 July 2022, over 800 caregivers of veterans have been enrolled.

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

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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.

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

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**Lead Agency:** NIA

**Partners:** AHRQ, CMS, CDC, ACL, DoD

In 2019, NIH funded a new effort called the IMPACT Collaboratory to meet the urgent public health need to deliver high-quality, evidence-based care to people living with dementias 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 general, a pragmatic clinical trial means that participants are enrolled as part of a real-world setting rather than selected from a broader community based on narrowly defined criteria. The IMPACT project will bolster the Nation's capacity to conduct pragmatic clinical trials of interventions, embedded within health care systems for people living with dementia and their caregivers. IMPACT supports pilot projects that have the potential to inform the design of larger scale pragmatic trials. To date, the IMPACT Collaboratory has supported 21 pilot grant projects, six health care system scholars, six demonstration projects, nine career development awards and one investigator diversity training award for researchers from varied disciplines. The IMPACT Collaboratory continues to expand in 2022 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.

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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 2023, NIA reissued the Notice of Funding Opportunity for the AD/ADRD-specific Roybal Centers to further the state-of-the-science in AD/ADRD care provider support. The purpose of the Roybal Centers is to develop behavioral interventions that improve the health, well-being and/or capacity of individuals and/or systems that provide care to persons with AD/ADRD. Current awards include:

- University of Pennsylvania Roybal: Supports the development of interventions to help persons with dementia receive much-needed palliative care services, as well as to help their family caregivers.
- University of Rochester Roybal: Seeks to develop behavioral interventions that promote social connectedness, particularly among family caregivers of persons with AD/ADRD.
- Emory University Roybal: Supports the development of interventions to improve the role-mastery of informal caregivers of persons living with AD/ADRD.
- Oregon Roybal: Seeks to leverage innovations in technology to improve dementia care provider support.

Key publications can be found on the Roybal publications website. For full list of relevant FOAs and their links, please see [Appendix 3](#).

For more information see:

- <https://reporter.nih.gov/search/m-zoWEyxzkOMTIkCABpxEw/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 AITCs for Aging Research: 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 were able to award 33 pilot projects in the first cohort. For a full list of relevant NOFOs 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/>

In addition to these activities, NIA released several FOAs that call 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 active FOAs that were 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. These include Dementia Care and Caregiver Support Interventions Research, to lay the groundwork for implementable interventions, and Pragmatic Trials for Dementia Care and Caregiver Support, which seeks phased award applications for dementia care pragmatic trials in multiple settings. Another example 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 relevant NOFOs and their links, please see [Appendix 3](#).

For more information see:

- <https://reporter.nih.gov/search/Ohb3vluOcU6IU1qXds2tDQ/projects?shared=true>
- <https://www.nia.nih.gov/health/alzheimers/caregiving>

ACL's ADPI and NADRC continue to support the translation, implementation, and evaluation of dementia-specific evidence-based interventions in states and communities across the Nation. ACL programs support the implementation of 20 evidence-based interventions, preparing some to be taken to scale across the Nation. For example, NIA funded the research behind interventions BRI Care Consultations, COPE, Powerful Tools for Caregivers, REACH Community, and most recently Cognitive Stimulation Therapy which are ACL-funded provider pilot programs that enable formal and informal caregivers and people living with dementia to benefit from the intervention. The NADRC has created a tool to support community decision making in the selection of the evidence-based intervention 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 evidence-based and evidence-informed interventions that meet ACL criteria and have been implemented by Alzheimer's Disease Supportive Services Program, Alzheimer's Disease Initiative-Specialized Supportive Services, and ADPI grantees between 2007-2022.

For more information see:

- <http://nadrc.acl.gov>
- <https://nadrc.acl.gov/details?search1=140#result>
- <https://nadrc.acl.gov/details?search1=20210126080816>
- <https://nadrc.acl.gov/details?search1=20210907025132>
- <https://nadrc.acl.gov/details?search1=20221214043701>
- <https://nadrc.acl.gov/details?search1=70>

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 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 AD/ADRD one-on-one in real-time. Recently, the study received a second award from CDMRP after submitting a proposal to expand the services focused on caregivers. 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>
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**(UPDATED) Action 3.B.2: Provide effective caregiver interventions through Alzheimer's disease and related dementias-capable systems**

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**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 180 AD/ADRD state and community-based projects, in support of people living with dementia and their caregivers, including training professional, since 2014 when funding was expanded beyond states. Included in the 180 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. Subject to appropriations, ACL anticipates continuing the programs to increase the availability of evidence-based interventions across the country.

For more information see:

- <http://nadrc.acl.gov>
- <https://nadrc.acl.gov/details?search1=20210907025132>
- <https://nadrc.acl.gov/details?search1=20221214043701>

Trainings for unpaid caregivers can be important in improving the lives of people living with dementia, 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 more information see:

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

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

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**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 conducts presentations on LTSS for people with AD/ADRD at Indian Country 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 and ACL host joint webinars on addressing the service and supports needs of persons with AD/ADRD. Dissemination of dementia-specific information through presentations occurs at Indian Country meetings and webinars.

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.

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**(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**

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**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. 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.

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

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**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: IIdentify the problem or challenging behavior, Explore the behavior, and Adjust your response. The training has tips sheets to support caregivers implement what they learn.

For more information see:

- <https://nadrc.acl.gov/>
- <https://nadrc.acl.gov/details?search1=178>
- <https://nadrc.acl.gov/details?search1=20210907025132>
- <https://nadrc.acl.gov/details?search1=222>
- [https://www.alzheimersla.org/wp-content/uploads/2018/06/CaregiverTipSheet\\_IDEA-strategy.pdf](https://www.alzheimersla.org/wp-content/uploads/2018/06/CaregiverTipSheet_IDEA-strategy.pdf)

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**(COMPLETED) Action 3.B.6: Adapt and implement Resources for Enhancing Alzheimer’s Caregivers’ Health in Tribal communities**

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**Lead Agency:** IHS

**Partners:** ACL, VA, University of Tennessee Health Sciences Center

The initial phase was completed with 80 REACH-certified caregiver support coaches in 56 Tribal communities, serving at least 55 caregivers as of February 2018. The second phase of the effort is focused on implementing strategies to increase penetration of REACH in the communities where there are certified coaches and building additional, sustainable options for evidence-based caregiver support services. IHS continues work developing the ECHO project model to support Caregiver Coaches in Tribal Communities and to identify additional training for caregiver support through public health nursing. IHS collaborated with the VA Greater Los Angeles GRECC in the development of the IHS ABCD training targeted at Public Health Nurses who provide support for caregivers of PLWD.

In 2020, ACL-funded grantees to train REACH-certified caregiver support coaches to deliver the intervention to Aleutian Pribilof Islands Association members. The grantee provides health

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services (primary care, behavioral health, community wellness, and prevention) in four communities (Atka, Nikolski, St. George, and Unalaska) across the Aleutian and Pribilof Islands.

For more information see:

- <https://www.apiai.org/>
- <https://www.cdc.gov/aging/healthybrain/Indian-Country-resources.html>

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**(ONGOING) Action 3.B.7: Develop and disseminate information to caregivers on Alzheimer’s disease and related dementias and caregiving**

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**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/aging/caregiving/pdf/Complete-Care-Plan-Form-508.pdf>
- <https://www.cdc.gov/aging/publications/podcasts.htm>
- <https://www.cdc.gov/features/caregivers-month/index.html>

Annually 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:

1. Handbook for Helping People Living Alone with Dementia Who Have No Known Support.
2. Disaster Planning Toolkit for People Living with Dementia.
3. Working Together: How Community Organizations and First Responders Can Better Serve People Living with Dementia.
4. Guide to Billing Codes for Dementia Services.

For more information see:

- <https://nadrc.acl.gov/>
- <https://www.nia.nih.gov/health/alzheimers/caregiving>

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**(ONGOING) Action 3.B.8: Support enhanced financial literacy and preparedness of family caregivers**

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**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.

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See [Action 3.A.2](#) for information on an NIA/ACL SBIR FOA that addresses the fundamental need for the development of technologies that enhance caregiver training and address the financial and legal aspects of caregiving.

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**(ONGOING) Action 3.B.9: Provide caregivers of veterans living with dementia with information about Department of Veterans Affairs Caregiver Support Program resources available to them**

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**Lead Agency:** VA

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/help_landing.asp)
  - [https://www.caregiver.va.gov/Publications\\_Resources\\_Topic.asp](https://www.caregiver.va.gov/Publications_Resources_Topic.asp)
  - [https://www.caregiver.va.gov/Publications\\_Resources\\_Topic.asp#Understanding%20Diagnoses](https://www.caregiver.va.gov/Publications_Resources_Topic.asp#Understanding%20Diagnoses)
  - [https://www.caregiver.va.gov/support/Communicating\\_Managing\\_Emotions.asp](https://www.caregiver.va.gov/support/Communicating_Managing_Emotions.asp)
  - <https://www.caregiver.va.gov/support-line/handouts.asp>
  - [https://www.caregiver.va.gov/support/New\\_CSC\\_Page.asp](https://www.caregiver.va.gov/support/New_CSC_Page.asp)
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### **Strategy 3.C: Assist Families in Planning for Future Care Needs**

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The vast majority of people do not think about or plan for the LTSS they will need until they experience a disability or AD/DRD. Many Americans incorrectly believe that Medicare will cover most of the costs of these supportive long-term care services like nursing home care and HCBS. Unfortunately, by the time care is needed, it is difficult to get coverage in the private long-term care 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/DRD 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**

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**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,

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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/>

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### **(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/aging/caregiving/pdf/Complete-Care-Plan-Form-508.pdf>

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### **(COMPLETED) Action 3.C.3: Model future expenditures on long-term services and supports and use of informal caregivers**

**Lead Agency:** ASPE

As the United States population ages, a larger proportion of individuals will likely need and use LTSS. Much of this support is provided by informal (i.e., unpaid) caregivers. For those that need paid LTSS, most Americans pay out-of-pocket. Some people may do so until their personal resources are completely exhausted, and then rely on the Medicaid program. Reliance on Medicaid for people with little income or limited assets may result in increased federal and state spending for LTSS. As such, there is a pressing need to understand the current cost of long-term care, national expenditures on LTSS, and future projections of the availability of unpaid caregivers. This project builds off previous ASPE work modeling LTSS needs and expenditures, as well as work that explores how key demographic changes will affect the supply of informal caregivers for older Americans. One of the primary goals of the project is to provide current and improved estimates of the value of informal caregiving and diversity in caregiving provision, as well as projections that show how changing demographics could affect older Americans' need for LTSS, the supply of future caregivers, and Medicaid utilization.

For more information see:

- <https://aspe.hhs.gov/reports/caregivers-ltss>

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## **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 long-term care 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 long-term care ombudsmen (LTCO) 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

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abuse, neglect, and exploitation. The Actions below will help ensure that people with AD/ADRD have their dignity, safety, and rights maintained.

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

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**Lead Agency:** CMS

**Partners:** ACL, NORC

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>

In 2023, 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. CMS started 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/gso-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**

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**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

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indicators that should raise concern, provided practical tips on when and how to intervene, and pay particular attention to the complicated issue of capacity.

For more information see:

- <https://nadrc.acl.gov/>
- <https://nadrc.acl.gov/details?search1=20210719034914&result>
- <https://ncea.acl.gov/>

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

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**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/ADR.

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 web page, to educate the public and disseminate information about identifying and addressing types of elder abuse and dealing with caregiver stress. In addition, the ADEAR Center responds to roughly 90 inquiries per year related to elder maltreatment and makes appropriate referrals.

For more information see:

- <https://www.nia.nih.gov/health/elder-abuse>
- <https://www.nia.nih.gov/health/infographics/spotting-signs-elder-abuse>

NIA is also currently supporting new research in this area. For example, NIA awarded grants from RFA-AG-22-024 (Primary Care-Based Screening and Intervention Development for Prevention of Abuse in Older and Vulnerable Adults in the Context of AD/ADR) and published a reissue (RFA-AG-24-048). These opportunities solicit research that can lead to the development of evidence-based primary care screening tools and behavioral interventions to prevent mistreatment in at-risk older and vulnerable adults with MCI and AD/ADR and their families. With RFA-AG-22-020 (Triadic Interactions in Clinical Encounters Involving People with AD/ADR, 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/ADR) invited research focused on social and other factors that render older adults vulnerable to financial exploitation and other forms of mistreatment and abuse. NIA is also soliciting research on risk, protective, and resilience factors related to elder mistreatment via NOT-AG-21-047 (Notice to Specify High Priority Research Topic for PAR-19-070 and PAR-19- 071).

NIA also 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

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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. The awardee will 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 relevant NOFOs and their links, please see [Appendix 3](#).

For more information see:

- [https://reporter.nih.gov/search/mRv4AX7TAkay\\_MZUE5zhUA/projects?shared=true](https://reporter.nih.gov/search/mRv4AX7TAkay_MZUE5zhUA/projects?shared=true)
- [https://reporter.nih.gov/search/RcQIAIM89U-n4oAd\\_2qKg/projects?shared=true](https://reporter.nih.gov/search/RcQIAIM89U-n4oAd_2qKg/projects?shared=true)
- [https://reporter.nih.gov/search/Srp1dhziWEi2j7vz\\_Wq3cg/projects?shared=true](https://reporter.nih.gov/search/Srp1dhziWEi2j7vz_Wq3cg/projects?shared=true)
- <https://reporter.nih.gov/project-details/10663728>
- <https://www.nia.nih.gov/health/elder-abuse>
- <https://www.nia.nih.gov/health/infographics/spotting-signs-elder-abuse>

DoJ launched a guardianship page on the Elder Justice Initiative (EJI) website in July 2021 for the general public, providing information and resources related to guardianship itself and to abuse perpetrated by guardians. The web page features four sections: an overview, least restrictive options, key concepts and resources, and mistreatment and abuse by guardians and other fiduciaries.

For more information see:

- <https://www.justice.gov/elderjustice/guardianship>

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 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>
- <https://www.justice.gov/elderjustice/foundational-articles>
- <https://www.justice.gov/elderjustice/research-related-literature>
- <https://www.justice.gov/elderjustice/roadmap>

In addition, EJI's renowned webinar series features several webinars on this topic presented by elder justice experts:

1. The Neuroscience Behind Financial Scams.
  2. Responding to Elder Abuse Victims with Alzheimer's Disease or Other Dementias.
  3. Increasing Access to Capacity Assessments via New Technologies.
  4. Digging Deeper: When Consent is Not Consent.
  5. Assessing Cognitive Capacity in Elder Abuse Cases.
  6. Innovations in Guardianship: Maximizing Autonomy and Ensuring Accountability.
  7. Identifying and Prosecuting Power of Attorney Abuse.
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8. Trauma Informed Counseling for Older Adults.
9. Innovations in Guardianship: Maximizing Autonomy and Ensuring Accountability.

For more information see:

- <https://ovcttac.adobeconnect.com/px6tzz3q5y94/>
- <https://www.justice.gov/elderjustice/video/assessing-cognitive-capacity-elder-abuse-cases>
- <https://www.justice.gov/elderjustice/video/digging-deeper-when-consent-not-consent>
- <https://www.justice.gov/elderjustice/video/identifying-and-prosecuting-power-attorney-abuse>
- <https://www.justice.gov/elderjustice/video/innovations-guardianship-maximizing-autonomy-and-ensuring-accountability>
- <https://www.justice.gov/elderjustice/video/neuroscience-behind-financial-scams>
- <https://www.justice.gov/elderjustice/video/responding-elder-abuse-victims-alzheimer-s-disease-or-other-dementias>
- <https://www.justice.gov/elderjustice/video/trauma-informed-counseling-older-adults>

The EJI supported the development of Finding the Right Fit: Decision-Making Supports and Guardianship in collaboration with the National Center for State Courts. This online training is designed to assist individuals in exploring ways to help someone who may need assistance in making decisions with informal supports, legal options, and/or adult guardianship. Finding the Right Fit provides a broad overview of decision making supports and guardianship that is not specific to state laws or rules.

For more information see:

- <https://www.eldersandcourts.org/training/finding-the-right-fit>

DoJ's Office for Victims of Crime launched the Elder Fraud Hotline in March 2020. This no-cost national resource is available to all older adults who may be victims of financial fraud. The hotline (1-833-FRAUD-11; 1-833-372-8311) is staffed with experienced case managers who provide personalized support to assist callers in reporting suspected fraud to the relevant agencies and offer resources and referrals to other appropriate services as-needed.

For more information see:

- <https://ovc.ojp.gov/program/stop-elder-fraud/providing-help-restoring-hope>

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**(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/DRD. 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/DRD 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

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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 *The Handbook for Helping People Living Alone with Dementia Who Have No Known Support*. Among other things it provides practical guidance as well as tools for helping a person living alone who does not have informal supports. 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://nadrc.acl.gov/>
- <https://nadrc.acl.gov/details?search1=137>
- <https://nadrc.acl.gov/details?search1=157>
- <https://ncler.acl.gov/>

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

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**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. One grantee created 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/details?search1=196>

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:

1. Safe Return: Alzheimer’s Disease Guide for Law Enforcement (Alzheimer’s Association).
  2. A Booming Problem: Alzheimer’s, Dementia, and Elder Abuse (DoJ Office of Community Oriented Policing Services).
  3. Approaching Alzheimer’s: First Responder Training Program (Alzheimer’s Association).
  4. Communicating with Someone with Dementia (Alzheimer’s Association).
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For more information see:

- [http://cops.usdoj.gov/html/dispatch/05-2015/alzheimers\\_dementia\\_elder\\_abuse.asp](http://cops.usdoj.gov/html/dispatch/05-2015/alzheimers_dementia_elder_abuse.asp)
- <http://www.alz.org/care/alzheimers-first-responder.asp>
- [http://www.alz.org/national/documents/SafeReturn\\_lawenforcement.pdf](http://www.alz.org/national/documents/SafeReturn_lawenforcement.pdf)
- <https://www.alz.org/help-support/caregiving/daily-care/communications>
- <https://www.justice.gov/elderjustice/law-enforcement-1>

In August 2022, EJI released Safe Accessible Interviewing for Older Adults (SAFE), developed to meet the growing need for victim-centered interview techniques for use with older adults in criminal contexts. SAFE is grounded in forensic interviewing best practices with considerations and adaptations to account for age-related changes, with particular attention to the nuance of interviewing individuals living with AD/ADRD. In 2023-2024, EJI will be supporting Modell Consulting Group in providing the 2-Day SAFE Training to ten law enforcement communities (including state and local law enforcement, Medicaid Fraud Control Unit investigators, APS, and many other elder justice professionals) across the country and the 4-Day SAFE Training to four communities.

For more information see:

- <https://www.justice.gov/elderjustice/safe-training>

In 2020, DoJ launched the National Nursing Home Initiative (NNHI), which was designed to coordinate and enhance civil and criminal enforcement related to nursing homes that provide grossly substandard care to their residents. The NNHI is actively engaged in training professionals (Medicaid Fraud Control Units, LTCO, state and local prosecutors, and others) to recognize and respond to these facilities housing vulnerable adults. This multi-disciplinary and coordinated approach to training and outreach ensures a swift and robust response when facilities are identified, holding facilities accountable and promoting the safety and recovery of residents.

Victim-Witness programs across the country assist law enforcement by providing support and resources for victims of and witnesses to crime. Last updated in 2011, in March 2023, DoJ released *The Attorney General Guidelines for Victim and Witness Assistance*. The “Guidelines” provide guidance to federal officers and employees of DoJ on the treatment of victims of and witnesses to crime, and for the first time, provide guidance on the treatment of older victims and witnesses.

For more information see:

- <https://www.justice.gov/ag/page/file/1546086/download>

On April 19-21, 2022, EJI convened a groundbreaking virtual symposium entitled *Elder Justice Decision-Making Capacity Symposium: The Role of Decision-Making Capacity in Elder Justice Cases that Reach Civil and Criminal Courts*, attended by over 1,500 individuals from every state in the Nation. The symposium was designed to raise awareness of how older adults are profoundly and negatively impacted in both the criminal and civil justice systems based on mistaken assumptions and inadequate assessments of their capacity to make decisions for themselves. The session recordings and relevant resources are available on the symposium web page. An article summarizing the symposium specifically for law enforcement entitled *Elder Justice Decision-Making Capacity Symposium: Capacity for What?* is also featured on the page.

For more information see:

- [https://cops.usdoj.gov/html/dispatch/06-2022/Elder\\_Justice\\_Symposium.html](https://cops.usdoj.gov/html/dispatch/06-2022/Elder_Justice_Symposium.html)
- <https://www.justice.gov/elderjustice/symposium>

In April 2022, EJI released the Judicial Guardianship Evaluation Worksheet, intended for judges and other court personnel. Probate judges are routinely required to make determinations



regarding an individual's capacity and where appropriate, to appoint a guardian to protect individuals who are unable to make decisions on their own behalf or are unable to manage their personal needs to support their welfare. Designed to assist judges in making these determinations, the Worksheet was developed over 2 years with input from and testing by judges. The Worksheet is an evidence-based two-page fillable and printable PDF that provides judges with an organizational framework of the relevant factors to consider in adjudicating guardianship cases. The tool also helps judges consider less-restrictive alternatives and weigh factors which can forewarn abuse in guardianship prior to appointment. In June 2022, the developer was featured on a webinar titled Judicial Guardianship Evaluation -- A New Tool for Judges describing the Worksheet's development and how to use it.

For more information see:

- <https://vimeo.com/722938044>
- <https://www.justice.gov/elderjustice/help-judges-hearing-guardianship-cases>

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

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Lead Agency: ACL

Partners: DoJ, CDC

ACL, NADRC, and dementia grantees continue to make the provision of dementia-specific education of first responders a priority in their funded programs. 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 people living with dementia, 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 people living with dementia. 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 people living with dementia and reminders about how to handle the interactions and any follow-up.

For more information see:

- <https://nadrc.acl.gov/details?search1=153>
- <https://nadrc.acl.gov/details?search1=155&result>
- <https://nadrc.acl.gov/details?search1=196>
- <https://nadrc.acl.gov/details?search1=197>

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>
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CDC recently launched the Healthy Brain Resource Center (HBRC), an easy-to-navigate website that helps users find credible public information and materials to support implementing the HBI Road Map actions. The CDC and its partners designed the HBRC to help state, local, Tribal, public health agencies and other organizations have easy access to resources and materials to help people with AD/ADRD better utilize the HBI Road Map Series. The HBRC will continue to be updated with new and additional resources over the next 2 years. It currently houses over 300 vetted resources and materials.

For more information see:

- <https://www.cdc.gov/aging/healthy-brain-resource-center/index.html>

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**(COMPLETED) Action 3.D.7: Understand the predictors and outcomes of inpatient psychiatric facility placement among people living with dementia**

**Lead Agency:** ASPE

Some people with dementia may have severe behavioral and psychological symptoms of dementia (BPSD) such as aggression, agitation, depression, or psychosis. These symptoms are associated with hospital admission and nursing home placement in addition to caregiver distress and poor health. In some cases, individuals with BPSD require intensive care and are admitted to an inpatient psychiatric facility (IPF).

An ASPE-sponsored analysis showed that dementia is a common diagnosis and in 2018, 41% of Medicare beneficiaries who used IPFs had a primary diagnosis of Alzheimer's disease or a related dementia. People living with dementia who used IPFs were older, had more co-morbidities, were frailer than IPF users without dementia. Emergency room visits and new antipsychotic medication use often preceded IPF stays for this population. In addition, people living with dementia were more likely to use a skilled nursing facility or have a hospitalization after being discharged from an IPF. The full report will be posted in 2024.

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**(ONGOING) Action 3.D.8: 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 at 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/>
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### **Strategy 3.E: Assess and Address the Long-Term Services and Supports Needs of People with Alzheimer’s Disease and Related Dementias**

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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.

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

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**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 long-term care services in some circumstances. This study will explore the incidence rate of nursing facility closures per year over the last decade and describe factors that may be contributing to those closures. The study will contribute to HHS’s general understanding of changes in the nursing facility industry and how recent closures may impact access for the aging population. ASPE identified a total of 1,220 closures and 1,168 openings from 2011 to 2019. Closures were relatively stable from 2011 to 2017, averaging 121 facilities or 0.82% per year. Closures increased to 172 facilities (1.15%) in 2018 and 200 facilities (1.36%) in 2019. Openings decreased from 2011 to 2019, averaging 135 facilities (0.91%) per year from 2011-2018 and then dropping to 87 facilities (0.59%) in 2019. The resulting impact on individual-level access to nursing homes is less clear. In the aggregate, the nursing home supply may be appropriately meeting demand; however, there may be cases where closures could cause immediate access problems. ASPE analyzed data from 2011 through 2021 and did not find persistent increases in the closure rates.

#### **(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**

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**Lead Agency:** ASPE

Through this project, launched in fall 2021, ASPE is assessing the extent to which states have “rebalanced” Medicaid-funded LTSS from institutional LTSS to HCBS between 2016 and 2019. Using the Transformed Medicaid Statistical Information System (T-MSIS) and Medicare data, ASPE is estimating rebalancing measures, nationally, by state, and by select subpopulations (e.g., older adults, younger adults with adult-onset disabilities, and individuals with IDD), as well as transition rates from the community to institutional LTSS for older adults, accounting for frailty severity. Analyses will involve identifying characteristics of state LTSS programs that correlate with greater rebalancing toward HCBS and calculating transition rates from the community to nursing facilities among older adults. This research is informed by a panel of federal and non-federal experts.

CMS’s Money Follows the Person (MFP) demonstration supports state efforts for rebalancing their LTSS system so that individuals have a choice of where they live and receive services. From the start of the program in 2008 through the end of 2020, states have transitioned over 107,000 people to community living under MFP.

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For more information see:

- <https://aspe.hhs.gov/reports/identifying-classifying-medicaid-hcbs-t-msis>
- <https://www.medicaid.gov/medicaid/long-term-services-supports/money-follows-person/index.html>

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**(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 Medicaid 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 long-term care 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 long-term care 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 long-term care 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). This project is currently underway with an expected completion date of March 2025.

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**(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/DRD and their caregivers in an effort to develop evidence for sustainability post-grant funding.

In 2017, ACL rolled out its dementia capability assessment tool for implementation through the ACL state and community grant program. The tool assesses program partners over the course of a grant to measure the improvement in dementia capability over time. The tool is available for non-grantees on the NADRC website.

For more information see:

- <https://nadrc.acl.gov/>
- <https://nadrc.acl.gov/details?search1=117#result>

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**(UPDATED) 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/DRD programs designed to fill service gaps at the community level. This program was initiated to supplement longstanding state managed programs. Target areas for the community programs were chosen to align with gaps identified by the NAPA

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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.

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 evidence-based interventions across the country.

For more information see:

- <https://nadrc.acl.gov/>
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### **(ONGOING) Action 3.E.6: Improve home and community-based services provided through state Medicaid waivers**

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**Lead Agency:** CMS

In 2022, CMS notified states they have an additional year -- through March 2025 -- to use funding from the American Rescue Plan 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.medicaid.gov/federal-policy-guidance/downloads/smd22002.pdf>
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### **(ONGOING) Action 3.E.7: Expand resources to support person-centered care**

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**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\\_Short\\_Comp508.pdf](https://ncapps.acl.gov/docs/Shorts/Culture_PCP_Short_Comp508.pdf)
  - <https://ncapps.acl.gov/home.html>
  - <https://ncapps.acl.gov/learning-collaboratives.html>
  - <https://ncapps.acl.gov/ncapps-shorts.html>
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## 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

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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.

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

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**Lead Agencies:** ACL, NIA, CDC, IHS

**Partners:** multiple cross-agency and funded partners

Through its grant and resource center programs, ACL continues to 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.

In 2020, NIA, working with other federal agencies, led efforts to update and enhance the [Alzheimers.gov](https://www.alzheimers.gov) website. NIA launched this new portal to Federal Government information and resources in February 2021. The site features:

Information about AD/ADRD.

- Tips and resources for caregivers and people living with dementia.
  - Updates on Federal Government activities to address AD/ADRD.
  - How to take part in clinical research and how to find studies.
  - Resources for health care providers, community and public health workers, and researchers.
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In October 2021, NIA also launched a Spanish version of the Alzheimers.gov website.

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. For example, in 2022 NIA held an #AlzScience Twitter Chat to highlight current and future progress in dementia research. NIA also created the Alzheimer's and Related Dementias Press Kit to help curate resources from across the institute that other organizations and stakeholders could use to raise awareness of AD/ADRD research.

For more information see:

- <https://www.alzheimers.gov/>
- <https://www.alzheimers.gov/es>
- <https://www.nia.nih.gov/aging-alzheimers-resources-multimedia/alzheimers-press-kit>
- <https://www.nia.nih.gov/news/alzheimers-gov-website-now-available-spanish>

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. Web features for 2021-2022 include the following, most of which are also available in Spanish:

#### 1. Web Features

- Lifestyle Factors Can Lower Your Risk of Dementia (June 2023)
- When to Talk to Your Doctor About Memory Loss (May 2023)
- Reducing Risk of Alzheimer's Disease (September 2022)
- Dementia Risk Reduction (June 2022)
- Memory Loss Among Caregivers (May 2022)
- Down Syndrome and Risk for Alzheimer's (September 2021)
- Barriers to Equity in Alzheimer's and Dementia Care
- Baby Boomers Who Are Caregivers Report Poor Health
- Healthy Body, Healthy Brain
- Loneliness and Social Isolation in Older Adults

#### 2. Podcasts (Aging and Health Matters Series)

- Modifiable Risk Factors for Alzheimer's Disease and Related Dementias
- Memory Loss Among Caregivers
- How Are You Feeling Right Now? Coping Strategies for Caregivers
- Social Isolation and Loneliness Among Older Adults and What You Can Do to Help
- Baby Boomers Who Are Caregivers Report Being in Poor Health
- Healthy Body, Healthy Brain
- Loneliness Puts Older Adults at Risk for Serious Medical Problems
- What About the Caregivers?
- The Importance of Physical Activity for Older Adults

For more information see:

- <https://podcasts.apple.com/us/podcast/ep38-cdc-highlights-social-isolation-loneliness-among/id1508046828?i=1000501704755>
  - <https://tools.cdc.gov/medialibrary/index.aspx#/media/id/405188>
  - <https://tools.cdc.gov/medialibrary/index.aspx#/media/id/406088>
  - <https://tools.cdc.gov/medialibrary/index.aspx#/media/id/407659>
  - <https://tools.cdc.gov/medialibrary/index.aspx#/media/id/408892>
  - <https://tools.cdc.gov/medialibrary/index.aspx#/media/id/412477>
  - <https://tools.cdc.gov/medialibrary/index.aspx#/media/id/594685>
  - <https://tools.cdc.gov/medialibrary/index.aspx#/media/id/730355>
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- <https://solesourcepodcast.buzzsprout.com/789140/8142833-ep55-caring-for-caregivers-with-the-cdc>
- <https://www.cdc.gov/aging/publications/features/barriers-to-equity-in-alzheimers-dementia-care/index.html>
- <https://www.cdc.gov/aging/publications/features/caregivers-baby-boomers-report-poor-health/index.html>
- <https://www.cdc.gov/aging/publications/features/dementia-risk-reduction-june-2022/index.html>
- <https://www.cdc.gov/aging/publications/features/healthy-body-brain.html>
- <https://www.cdc.gov/aging/publications/features/lonely-older-adults.html>
- <https://www.cdc.gov/aging/publications/features/memory-loss-among-caregivers/index.html>

Additionally, CDC provided communication guidance and technical assistance to all its funded partners.

CDC has participated in the Did You Know? feature offered by CDC's Center for State, Tribal, Local, and Territorial Support (now the Public Health Infrastructure Center) to promote prevention activities. Featured topics have included: baby boomers who are caregivers, brain health, memory loss, chronic conditions in relation to memory loss, and how dementia disproportionately affects minority populations and women.

For more information see:

- <https://www.cdc.gov/aging/covid19-guidance.html>

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-19 related services to older adults.

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/DRD 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>
- <https://www.nia.nih.gov/news/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 develop 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/aging/agingdata/index.html>
  - <https://www.cdc.gov/aging/data/index.htm>
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Additionally, CDC-developed infographics co-branded 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. These briefs are currently being updated.

For more information see:

- <https://www.cdc.gov/aging/publications/briefs.htm>

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.

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### **(NEW) Action 4.A.3: Develop internal and public outreach on Alzheimer's disease and related dementias tailored to Tribal and Urban Indian populations**

**Lead Agency:** IHS

In FY 2023, the IHS has initiated a small, targeted, awareness-building campaign that includes use of social media, recurring stories in the *IHS Week in Review* (for staff) and publicly distributed *IHS Updates for Tribes and Tribal and Urban Indian Organizations*, an IHS blog post, IHS Area Office newsletter stories, and an update to the IHS Alzheimer's and Dementia website. Twenty-two social media posts to the nearly 75,000 followers of IHS Facebook, LinkedIn, and Twitter accounts reached 167,691 people. Alzheimer's program website page views increased from just over 600 in the 6 months prior to content updates, to nearly 4,000 in the following 6 months. Subscription to the IHS Elder Care Listserv, a vehicle for communication with stakeholders in aging services across Indian Country, has increased by 140% since September 2022, indicating a broadening of awareness and engagement in AD/ADRD and aging issues. In FY 2024 this initiative will expand.

For more information see:

- <https://www.ihs.gov/alzheimers/>
  - <https://www.ihs.gov/newsroom/ihs-updates/>
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## 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

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State, Tribal, and local governments are working to help address challenges faced by people with AD/ADRD and their caregivers. Nineteen 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.

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### **(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.

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### **(COMPLETED) Action 4.B.2: Convene state and local partners**

**Lead Agency:** ASPE

ASPE convened the Cities and States in Action Roundtable in July 2022. The Roundtable convened representatives from Chicago, Illinois, Washington State, Tennessee, Georgia, and Massachusetts to discuss their state and local efforts to address AD/ADRD. Presenters highlighted successful programs and partnerships in their states, such as the Engage-IL, which is leading the development of age-friendly and dementia-friendly communities in Chicago, and the Georgia Memory Network, which connects primary care providers, Memory Assessment Clinics, and AAAs in order to link people with potential cognitive impairment to services. The report, *An HHS Roundtable on 10 Years of the National Plan to Address Alzheimer’s Disease: States in Action*, is available on the ASPE website and the NAPA Anniversary Page.

For more information see:

- <https://aspe.hhs.gov/collaborations-committees-advisory-groups/napa/napa-documents/napa-national-plan#np-10th-anniversary>
- <https://www.hhs.gov/aging/napa/index.html>

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### **(UPDATED) Action 4.B.3: Build upon lessons learned to improve the dementia-capacity of state and local service systems**

**Lead Agencies:** ACL, CDC

**Partner:** CMS

HHS will improve the dementia capability of state and community service systems through the ACL’s ADPI and 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.

ADPI grantees, partners and other collaborators work in peer-led groups on specific activities to make state and local-level improvements related to dementia capability. The peer-led groups develop practical tools to promote the adoption of dementia-capable practices at the state and

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local levels. HHS will help states and communities meet the needs of people with AD/ADRD through an expanded Dementia Capability Toolkit and other, related resources. Additional materials will result from similar program activities.

For more information see:

- <https://nadrc.acl.gov/>
- <https://nadrc.acl.gov/details?search1=117#result>

CDC BOLD program awardees are funded to create and maintain jurisdiction-wide coalitions to collaborate on setting AD/ADRD priorities informed by data for their area. The state and local jurisdictions of Colorado, Georgia, Los Angeles County, Maine, Mississippi, Nevada, Iowa, Oklahoma, Vermont, Wisconsin, and North Carolina have all created statewide AD/ADRD coalitions to guide strategic planning for people with AD/ADRD and their caregivers. The BOLD program awardees are all working on updating their statewide AD/ADRD plans to include a minimum of four actions from the *Healthy Brain Initiative: State and Local Road Map for Public Health, 2023-2027*. In the past year, Iowa, Los Angeles County, Maine, Mississippi, Nevada, Oklahoma, and Vermont worked with their coalitions to draft their updated state/local AD/ADRD strategic plans to include NIH Road Map Actions. All of these BOLD programs from the first cohort will have final updated AD/ADRD strategic plans by the end of 2023.

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>

In the past year, the North Carolina BOLD program successfully completed their update of their state strategic AD/ADRD plan and North Carolina's Institute of Medicine's report at the end of March 2022. Revisions to the state plan include background on the BOLD Initiative, a synopsis of current and planned BOLD activities, an explanation of the update process, and a new brain health chapter with recommendations and revisions to five existing recommendations from the 2016 plan. All four of the required HBI Road Map Actions were integrated into the new brain health chapter along with a fifth strategy related to brain health messaging. Each of these five overarching strategies includes a subset of additional strategies and recommendations for a total of 24 new HBI-guided recommendations. The updated plan has been published in an electronic format with plans to make print version available later in the year. Promotion and dissemination efforts have begun and will continue through the remainder 2022.

In the past year, BOLD program awardees have completed the following activities.

- The Iowa BOLD AD/ADRD program has partnered with local libraries across the state to promote AD/ADRD messaging via bookmarks, handouts, and posters with the catchphrase "Brains Love Bookworms!" that encourages people to keep their brain active through reading. The bookmarks, posters, and handouts were disseminated at the Iowa Library Conference and afterward Iowa AD/ADRD staff sent emails to every library in Iowa offering to send as many bookmarks, posters, and handouts as they requested to give to their community members. Additionally, the Iowa AD/ADRD program developed posters to address risk reduction and empowerment. Working with graphic designers, the posters are framed to encourage people of all ages to live a healthier lifestyle in order to decrease risk for dementia. The theme is "Alzheimer's prevention should always be on your brain" with a series of characters of different races and genders happily posing with items on their heads that represent activities they can do. They are intended to be displayed in doctors' offices, waiting rooms, senior centers, public gathering spaces, etc.

The posters were finalized in late March 2022 with final printing and distribution happening in April.

- The North Carolina BOLD program produced a data brief using the SCD Module data from the BRFSS. The data brief was reviewed by staff at the North Carolina Department of Public Health, North Carolina Department of Aging and Adult Services, and CDC. The data brief was disseminated to more than 20 partners and to many of their Listserv members. It was also posted on the North Carolina Center for Health and Wellness website and was included in a Healthy Aging North Carolina newsletter distributed to a network of over 300 professionals who care for people with aging-related health challenges.
  - The Maine BOLD program worked with their HBI Stakeholder group to produce over 200 recommendations for the State Plan by adopting a coordinated approach to accomplish the task of revising and updating the 2012 State Plan. The group met over the course of a 6-month period in five subcommittees that each addressed a key topic: access to care and family caregivers, legal and safety issues, public awareness, research and data collection, and workforce development. The overall success of the process was associated with the high level of engagement of the stakeholders as demonstrated by additional work performed by subcommittee leadership after the process ended to condense, re-organize, and prioritize recommendations. The Alzheimer's Program and its evaluator, Public Consulting Group, are currently working on the next step of creating a framework for the recommendations and anticipate a fall release of the Maine AD/ADRD State Plan.
  - In Vermont, the BOLD Public Health Analyst prepared their first data brief titled *Risk Factors for Subjective Cognitive Decline in Vermonters*. The data brief cross tabulates behavioral risk and demographic measures that assisted the program and stakeholders in gaining a deeper state-specific understanding of AD/ADRD, risk behaviors, brain injury and lifestyle behaviors. Development and release of this brief achieved two of their prioritized data goals -- communication of data to AD/ADRD partners and the public health workforce and to support data-driven decision making. Additionally, the brief lays the groundwork for forwarding AD/ADRD-related measures to the committee charged with honing the Healthy Vermonters 2030 State Plan, which will begin deliberating in late Spring 2022. Additionally, the Vermont BOLD program analyst produced and delivered several data presentations to the Alzheimer's and Healthy Aging Workgroup, followed by an interactive data presentation with the Governor's Commission on AD/ADRD. A Health Disparities and Aging data presentation was delivered to the Vermont Action Plan on Aging Well Advisory Council in January 2022 and to our Hub & Spoke workgroup in February. This data presentation included the rate of hospitalizations and emergency department visits among Vermonters 65 years and older diagnosed with AD/ADRD (2016-2019).
  - In Oklahoma, the BOLD program partnered with Oklahoma State Department of Health Communications for weekly social media content on Thursdays called Healthy Brain Tip of the Week. These posts began in November 2021 with the announcement of the Oklahoma Healthy Brain Program and National Caregivers Month. In November 2021 through February 2022, they reached 104,383 people on Facebook with their posts. In March, the focus of the month was the Caregiver Survey in which three posts were made. They saw an influx of survey responses immediately following these posts on Facebook, Instagram, and LinkedIn.
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**(UPDATED) Action 4.B.4: 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**

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**Lead Agencies:** IHS, ACL

**Partners:** ASPE, VA

HHS will solicit input from Tribal leaders on the impact of AD/ADRD on Indian Country during the annual Tribal Consultation process and through broader meetings and convenings. HHS will use these opportunities to convene leaders and solicit input on the needs related to recognition, diagnosis, and support for individuals with dementia and their families.

The Alzheimer’s Association, in collaboration with CDC, has started meetings with the United South and Eastern Tribes and with the NPAIHB. There has been increased Tribal representation on the CDC HBI *Road Map for Indian Country* work.

The IHS undertook Tribal Consultation and Urban Confer to gain insight into needs and opportunities to improve the care and services for AI/AN people living with dementia and their caregivers and guide the allocation of resources for the IHS Alzheimer’s Grant Program. The IHS will use meetings of the Direct Services and Contracting Tribes and Self-Governance Tribes and Urban Indian Organizations and other venues to update Tribal and UIO leaders on the work underway through the IHS Alzheimer’s Grants Program and solicit ongoing feedback.

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**(ONGOING) Action 4.B.5: Develop and update a public health road map for assisting state, Tribal, and local health departments in prioritizing actions**

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**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 collaboration with the Alzheimer’s Association and numerous partners, the was released in 2019 and disseminated to multiple stakeholders and Tribal leaders. This Road Map has been designed specifically for public health systems serving AI/AN and Native Hawaiians. This document is being revised and will be launched in late 2024.

For more information see:

- <https://www.cdc.gov/aging/healthybrain/Indian-Country-resources.html>
  - <https://www.cdc.gov/aging/healthybrain/Indian-country-roadmap.html>
  - <https://www.cdc.gov/aging/healthybrain/roadmap.htm>
  - <https://www.cdc.gov/aging/pdf/roadmap/HBI-State-and-Local-Road-Map-for-Public-Health-2023-2027-508-compliant.pdf>
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## Strategy 4.C: Coordinate United States Efforts with Those of the Global Community

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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**

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Lead Agencies: ASPE, NIA

The United States participated in WHO's Global Dementia Observatory (GDO) in 2019. The GDO is an information exchange platform that collects information from countries on dementia policy, service delivery, and information and research. As of August 2019, 21 other countries had submitted information to the GDO.

See [Action 1.D.2](#) for information on the HRS HCAP initiative, an innovative approach to assessing trends in cognitive function and aging in the United States and worldwide.

Wave 2 HCAP fieldwork is ongoing through August 2023. Researchers will readminister the same in-home cognitive assessment to the same 2016 respondents and seek an informant report from all surviving members of the original HCAP sample and administer the assessment to a new random sample of those age 65-70. HCAP will provide extensive new data to better assess trajectories of cognitive decline. These data afford an unprecedented opportunity to describe trends more clearly in the incidence and prevalence of dementia around the world. In 2023, NIA issued funding opportunities to enhance use of HCAP data for secondary analyses (RFA-AG-24-032) and for renewal of the HRS and HCAP studies (RFA-AG-24-010).

See [Action 1.D.2](#) for information on administration of HCAP in other developed and developing countries. In most of these studies, important biomarker data, including DNA for genotyping and future sequencing, is also being collected; genotype information is already available for the United States, England, and Mexico studies.

See [Action 1.D.2](#) for information on the HCAP network, which aims 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. For a full list of relevant NOFOs and their links, please see [Appendix 3](#).

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://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>

NIA also supports an international team of researchers that has made more progress in explaining the genetic component of AD/ADRD. Their analysis, involving data from more than 39,000 individuals with AD, has identified variants in 42 novel AD/ADRD genes (75 AD/ADRD genes in total). Their recent analysis on an expanded data collection (>56,000 individuals with AD, >978,000 total participants) has newly identified variants in an additional 21 genes that put people at greater risk of AD/ADRD and offers further confirmation of the genes that had been implicated previously in AD/ADRD. The results of this largest-ever genomic study of AD/ADRD suggests key roles for genes involved in the processing of beta-amyloid peptides, which form plaques in the brain recognized as an important early indicator of AD/ADRD. They also offer the first evidence for a genetic link to proteins that bind tau, the protein responsible for telltale tangles

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in the AD/ADRD brain that track closely with a person's cognitive decline. The new findings are the latest from the International Genomics of Alzheimer's Project (IGAP) consortium. The effort, spanning four consortia focused on AD/ADRD in the United States and Europe, was launched in 2011 with the aim of discovering and mapping all the genes that contribute to AD/ADRD. IGAP has multiple ongoing projects including studies exploring differences by sex in genetic risk of AD/ADRD and studies exploring variability in genetic risk profiles between individuals diagnosed at earlier ages with AD/ADRD and those diagnosed at later ages.

For more information see:

- <https://pubmed.ncbi.nlm.nih.gov/35379992/>
  - <https://www.nih.gov/news-events/news-releases/data-sharing-uncovers-five-new-risk-genes-alzheimers-disease>
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## 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 long-term care 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

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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**

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**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, CDC is leading a project to cognitively test caregiving questions by the National Center for Health Statistics (NCHS) Collaborating Center for Questionnaire Design and Evaluation Research.

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 primary care providers, 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**

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**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, in partnership with the Alzheimer's Association, revised the cognitive decline module of the BRFSS with input from with topical and measurement experts on information that should be

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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.

CDC, in partnership with the Alzheimer's Association, revised the caregiver module of the BRFSS with expert input, 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.

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**(ONGOING) Action 5.A.3: Summarize data on cognitive impairment across states**

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**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.

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 are then being used to inform the development of use cases. Prioritized use cases will then inform future tasks of the project.

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**(ONGOING) Action 5.A.4: Summarize existing data on people with Alzheimer's disease and related dementias and their caregivers**

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**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 (CDI).

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.

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For more information see:

- <https://www.cdc.gov/aging/publications/healthy-people-2030/index.html>
- <https://www.prb.org/resources/fact-sheet-u-s-dementia-trends/>

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.

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**(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**

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**Lead Agency:** CDC

**Partner:** NACDD

CDC partnered with NACDD 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/aging/publications/briefs.htm>

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**(ONGOING) Action 5.A.6: Leverage data to better understand racial, ethnic, and other sociodemographic disparities in Alzheimer’s disease and related dementias**

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**Lead Agency:** CMS

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>

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## **Strategy 5.B: Monitor Progress on the National Plan**

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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.

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**(ONGOING) Action 5.B.1: Track National Plan progress**

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**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

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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 2020 and 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.

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**(ONGOING) Action 5.B.2: Update the National Plan annually**

**Lead Agency:** ASPE

Tracking progress will help HHS and the 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.

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## 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 racism and 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

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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**

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**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 LTSS. Gaps and opportunities identified by participants providing individual input at these summits are used to inform research planning at the NIH. In order to advance research on risk reduction, beginning with the next ADRD Research Summit in 2024, NIA and NINDS will ensure that risk reduction is integrated into the summits. An integral part of the 2024 Research Summit will be discussions on developing effective risk reduction strategies within a precision medicine research framework. As NIH develops plans for future summits, it will

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continue to engage a diverse mix of investigators, representatives from non-governmental organizations, industry, people living with dementia and their caregivers, and other communities in both organizing the meeting and in leading the individual meeting sessions. Consideration will be given to gender diversity, as well as ensuring diverse representation from underrepresented racial and ethnic groups, individuals with disabilities, and individuals from socially and economically disadvantaged backgrounds.

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.

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.

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**(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  $\geq 45$  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.

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. CDC has submitted a revised version of its Cognitive Decline Module which has been approved by BRFSS State Coordinators and is planned to enter the field in 2023.

For more information see:

- <https://www.cdc.gov/aging/agingdata/index.html>
  - <https://www.cdc.gov/aging/data/BRFSS-statistical-brief-cognitive-decline-508.pdf>
  - <https://www.cdc.gov/aging/data/index.htm>
-

- <https://www.cdc.gov/aging/healthybrain/brfss-faq-cognitive.htm>
- <https://www.cdc.gov/aging/publications/BRFSS-caregiver-brief-508.pdf>
- <https://www.cdc.gov/aging/publications/briefs.htm>
- <https://www.cdc.gov/brfss/>
- <https://www.cdc.gov/nchs/nhanes/>

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**(ONGOING) Action 6.A.3: Expand and diversify clinical research studies on promising interventions to reduce individual and community-level risk**

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**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. 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 relevant NOFOs and their links, please see [Appendix 3](#).

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**(UPDATED) Action 6.A.4: Enhance research to better understand the varying levels of or types of dementia risk across demographic groups**

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**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 its research (referenced above), both intramural and external. NIH continues to expand its portfolio of research on social and structural determinants of health across all conditions. In 2022, NINDS invited applications from existing AD/ADRD observational studies to examine the relationship between early life SDOH, including adverse childhood experiences (ACEs), and later risk for cognitive impairment and dementia (PAR-22-221). Additional funding will be provided to enable the collection of new biological measures and data, for example, AD/ADRD relevant biomarkers, assessments of cognition, or assessment of SDOH or ACEs in diverse cohort populations. 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 in regard to vascular risk factors. 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 now include understanding disparities in the risk for dementia and cognitive decline as well as stroke. In a 2022 publication, REGARDS investigators examined neighborhood characteristics, physical activity, and health status of study participants and their roles in promoting healthy cognitive aging. The researchers

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found several factors that correlated with higher cognitive function, including engaging in moderate physical activity, having better health status, and living in more walkable neighborhoods. Conversely, living in a socioeconomically disadvantaged neighborhood was negatively associated with cognitive function.

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 new 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. NIA also recently issued a funding opportunity to establish an AD/ADRD Exposome Coordinating Center in FY 2024 to facilitate and advance research on the roles of social, behavioral, psychological, and economic exposures in the causes of, and disparities in, dementia risk and resilience. The Coordinating Center will promote research development and the sharing and harmonizing of environmental and individual exposure data to support the scientific field. More research is needed to fully capture the impacts of the exposome on AD/ADRD risk and resilience, as well as the intermediate biological, psychosocial, economic, and behavioral mechanisms. For a full list of relevant NOFOs and their links, please see [Appendix 3](#).

For more information see:

- <https://pubmed.ncbi.nlm.nih.gov/32282019/>
- <https://pubmed.ncbi.nlm.nih.gov/35234529/>
- <https://reporter.nih.gov/project-details/10118228>
- <https://reporter.nih.gov/project-details/9918026>
- <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 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 chronic traumatic encephalopathy (CTE)-related progressive neurodegeneration and neurocognitive decline. In 2023, NINDS is inviting new research to develop and characterize experimental models of post-TBI dementia (PAR-23-218). 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. In FY 2023, the

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focus areas for the program include care support for the individual and family, prevention and risk reduction, and environmental/diagnostic/prognostic factors. Currently supported research investigates the etiology, epidemiology, and potential quality of life impacts related to AD/ADRD.

The VA ORD continues its multi-pronged approach for TBI-related AD/ADRD. Key initiatives include longitudinal epidemiological studies, intra-mural and extra-mural research consortia, and therapeutics.

The 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.

The 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.

The 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 Alzheimer-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 relevant NOFOs and their links, please see [Appendix 3](#).

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**(ONGOING) Action 6.A.6: Expand research on the impact of emerging potential risk factors such as COVID-19**

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**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-19 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.

For more information see:

- <https://recovercovid.org/>

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**(UPDATED) Action 6.A.7: Continue clinical trials on the most promising health promotion interventions**

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**Lead Agency:** NIA

**Partner:** VA

See [Action 1.B.5](#) for updates regarding the ACTC and ongoing clinical trials supported by NIA. Over 150 of the approximately 200 active trials of interventions to enhance cognitive health in older adults and to prevent, treat, or manage AD/ABDRD investigate non-pharmacological interventions, including testing lifestyle factors such as diet and exercise. NIA has also released FOAs specifically focused on clinical trials for AD/ABDRD, including most recently RFA-AG-23-034, Mechanism-Focused Research to Promote Adherence to Healthful Behaviors to Prevent Mild Cognitive Impairment and AD/ABDRD. For a full list of relevant NOFOs and their links, please see [Appendix 3](#).

For more information see:

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

A recent NIH-funded clinical study of more than 3,500 adults ages 60 and older examined how dietary supplements affect cognitive health in older adults. 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 multivitamin 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 multivitamins, the scores of those with cardiovascular disease improved significantly, becoming comparable to those without the disease. These findings were recently published in May 2023.

Additionally, NIA-funded research has shown that hearing loss may impact cognition and dementia risk in older adults. Through the Aging and Cognition Health Evaluation in Elders Study, NIH-funded investigators recently found that a hearing intervention may reduce cognitive change over 3 years in older adults at increased risk for cognitive decline but had no effect in those at decreased risk for cognitive decline. These findings suggest that older adults at increased risk for cognitive decline who also have hearing loss may benefit the most from hearing interventions.

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For more information see:

- <https://pubmed.ncbi.nlm.nih.gov/37244291/>
- <https://pubmed.ncbi.nlm.nih.gov/37478886/>
- <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. Recent 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. For a full list of relevant NOFOs 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>

NIA's HCAP Network aims to harmonize international data resources for the study of AD/ADRD that will expand research on key life-course factors that are thought to affect cognitive function and increase risk for AD/ADRD. This support for global research provides a broader data resource regarding health-related behaviors, diets, and environmental factors, expanding insight on potential risk and protective factors of AD/ADRD. See [Action 1.D.2](#) for more detail and resources.

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.

The 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.

For more information see:

- <https://pubmed.ncbi.nlm.nih.gov/34880498/>
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## Strategy 6.B: Facilitate Translation of Risk Reduction Research Findings into Clinical Practice

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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/ABDR, and resources available to support them.

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### **(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 AWW. In FY 2022, HRSA also required that the primary care partners of the geriatrics workforce development programs work to obtain/maintain Level 1 and Level 2 age-friendly health systems recognition, which includes addressing what matters, medication, mobility, and mentation for all older adults in their practices.

To increase providers awareness of brain health, CDC supported the ACPM to develop a Brain Health Continuing Education Courses regarding brain health and dementia risk reduction to increase physician and health care professionals’ knowledge and facilitate improvements in clinical practice.

In 2022-2023, CDC supported the NACHC to complete a three-part webinar series on provider awareness and brain health. Resources, materials, and reimbursement strategies were demonstrated and discussed. The sessions also included multiple national partners representing minority populations with materials adapted for specific populations.

The CDC’s BOLD Public Health Center of Excellence 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 Public Health Center of Excellence 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 is 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 deciding what strategies and actions to take.

For more information see:

- <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>

Through the ACL’s ADPI grantees are advancing educational initiative in their grant programs in community and public health entities. The funded programs educate on the intersection between

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brain health and dementia, build awareness of resources continue raising awareness in communities and health care systems around the importance of brain health.

For more information see:

- <https://nadrc.acl.gov/details?search1=20211015100133>
- <https://nadrc.acl.gov/details?search1=20211026041616>
- <https://nadrc.acl.gov/details?search1=228>

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### **(COMPLETED) Action 6.B.2: Increase access to hearing aids for individuals with hearing loss**

**Lead Agency:** FDA

Hearing loss has been identified as a risk factor for AD/ADRD, and recent research has demonstrated that hearing aid use is associated with reduced dementia risk. Hearing aids are often expensive, making them inaccessible to many individuals who could benefit.

In October 2022, FDA established a new regulatory category for over-the-counter (OTC) hearing aids and made related amendments to update the regulatory framework for hearing aids. Among other things, the Final Rule provides for reasonable assurance of safety and effectiveness of OTC hearing aids and aims to foster innovation in hearing aid technology. It also is expected to improve access to hearing aids, as OTC options are easier to obtain and less expensive.

For more information see:

- <https://pubmed.ncbi.nlm.nih.gov/33614893/>
- <https://www.fda.gov/medical-devices/hearing-aids/otc-hearing-aids-what-you-should-know>
- <https://www.federalregister.gov/documents/2022/08/17/2022-17230/medical-devices-ear-nose-and-throat-devices-establishing-over-the-counter-hearing-aids>

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### **(ONGOING) Action 6.B.3: 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 have been developed in 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<sup>2</sup>, 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://www.cdc.gov/aging/partnership/nacdd-partner-resources/index.html>
  - <https://www.cdc.gov/aging/partnership/partner-resources/index.html>
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**(ONGOING) Action 6.B.4: 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.<sup>21,22,23</sup> 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 evidence-based interventions 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 new 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://quality.allianthealth.org/topic/center-of-excellence-for-behavioral-health-in-nursing-facilities/>
- <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,

<sup>21</sup> 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.

<sup>22</sup> 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.

<sup>23</sup> Rehm J, Hasan OSM, Black SE, Shield KD, Schwarzingner M. "Alcohol use and dementia: A systematic scoping review." *Alzheimers Research Therapy*, 2019; 11(1). doi:10.1186/s13195-018-0453-0.

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 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/product/Get-Connected-Linking-Older-Adults-with-Resources-on-Medication-Alcohol-and-Mental-Health-2019-Edition/SMA03-3824>
- <https://store.samhsa.gov/product/Growing-Older-Providing-Integrated-Care-for-An-Aging-Population/SMA16-4982>
- <https://store.samhsa.gov/product/treatment-improvement-protocol-tip-26-treating-substance-use-disorder-in-older-adults/PEP20-02-01-011>

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## Strategy 6.C: Accelerate Public Health Action to Address the Risk Factors for Alzheimer's Disease and Related Dementias

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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**

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**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. A second Summit will be held in 2025.

### **(UPDATED) Action 6.C.2: Accelerate dissemination of information on risk reduction to public health entities**

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**Lead Agencies:** CDC, ODPHP

**Partners:** NACDD, ASTHO, NACCHO

CDC is partnering with 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

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Maps. Products designed to facilitate implementation of the HBI Road Maps include a series of HBI Action Institutes, health communication materials for AI/AN communities, healthy aging, and a series of recorded webinars to promote the importance of public health in addressing brain health. The communication materials for AI/AN communities are now customizable.

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, and in 2022 NACDD is working to integrate these messages within state and local public health departments. Three new rack cards are being developed for 2023.

Beginning in 2022, CDC is funding the Dementia Risk Reduction Research Thematic Network, a national network of academic, public health, and community partners that will improve interventions and management for people at increased risk for developing AD/ADRD with the ultimate goal of reducing the burden of AD/ADRD, especially for populations disproportionately impacted. Three Collaborating Centers are being funded to kick-start this Network.

In 2023, CDC implemented a new 5-year funding opportunity to increase funding for AD/ADRD through the BOLD Public Health Programs. Funding was awarded to 43 different STLT public health agencies. These awards support creating and updating AD/ADRD strategic plans and provides dedicated funding for STLT public health staff to communicate risk reduction strategies and risk factors.

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://astho.org/Healthy-Aging/>
- [https://learn.astho.org/p/hbi-action-plan#tab-product\\_tab\\_overview](https://learn.astho.org/p/hbi-action-plan#tab-product_tab_overview)
- <https://www.astho.org/topic/report/od2a-bpi-federal-award-spenddown-analysis/>
- <https://www.cdc.gov/aging/healthybrain/Indian-Country-resources.html>
- <https://www.cdc.gov/aging/partnership/partner-resources/index.html>

CDC's weekly newsletter, *Alzheimer's Disease and Healthy Aging*, disseminated information on brain health, risk reduction, caregiving, SCD, general health, emergencies, care planning, and COVID-19 guidance 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.

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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 has 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

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was updated in late 2019, with additional enhancements, including video modules, added in 2021.

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\\_Compencies.aspx](http://www.phf.org/resourcestools/Pages/Core_Public_Health_Compencies.aspx)
- <https://alz.org/risk-reduction-summit/overview.asp>
- <https://www.cdc.gov/aging/services/index.htm>

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/funding/phc/index.html>

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#### **(UPDATED) 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 by for people 14 years and older. The majority of sodium consumed comes from processed, packaged, and prepared foods, which makes it difficult to monitor and limit sodium intake.

To address this, the FDA is taking an iterative approach that includes establishing voluntary sodium 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 expects to issue revised subsequent targets throughout the process to facilitate a gradual, iterative process to reduce sodium intake.

Complementing the goals of this process, the FDA announced in March that it would propose 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.

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Also in March, the FDA issued draft guidance for industry on how and when to use Dietary Guidance Statements in food labeling, and to ensure that Dietary Guidance Statements promote good nutrition and nutritious dietary practices. The draft guidance recommends that foods with Dietary Guidance Statements contain a meaningful amount of the food or category of foods that is the subject of the statement and that they also not exceed certain amounts of saturated fat, sodium, and added sugars.

For more information see:

- <https://www.fda.gov/food/cfsan-constituent-updates/fda-issues-draft-guidance-dietary-guidance-statements-food-labels>
- <https://www.fda.gov/food/cfsan-constituent-updates/fda-propose-permit-salt-substitutes-reduce-sodium-standardized-foods>
- <https://www.fda.gov/food/food-additives-petitions/sodium-reduction>

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### **(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 Physical Activity Guidelines for Americans 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/2019-09/09_F-3_Brain_Health.pdf)
  - [https://health.gov/sites/default/files/2019-09/Physical\\_Activity\\_Guidelines\\_2nd\\_edition.pdf](https://health.gov/sites/default/files/2019-09/Physical_Activity_Guidelines_2nd_edition.pdf)
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## **Strategy 6.D: Expand Interventions to Reduce Risk Factors, Manage Chronic Conditions, and Improve Well-Being through the Aging Network**

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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.

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### **(ONGOING) Action 6.D.1: Ensure older adults have access to nutritious meals through home-delivered and congregate meal programs**

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**Lead Agency:** ACL

Through the OAA Nutrition Program, ACL's Administration on Aging 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 the health and well-being, promoting 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.

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### **(ONGOING) Action 6.D.2: Expand the delivery of health and wellness programs to older adults in every community**

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**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.

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### **(ONGOING) Action 6.D.3: Identify the most promising health promotion and disease prevention interventions for dissemination through the Aging Network**

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**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.

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**(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.

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**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/ADR. 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/ADR 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.

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**(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

The National Brain Health Center for African Americans (NBHCAA), supported by CDC, is raising awareness of the issues of cognitive health among Black Americans by working through networks of faith-based institutions, and by establishing partnerships with organizations and individuals dedicated to NBHCAA’s mission. NBHCAA is working on a training program geared towards Black American health professionals to raise awareness and diagnostic proficiency regarding cognitive health. CDC is collaborating with the Center to expand on the foundational work of NBHCAA to further education of health professionals about risk reduction as part of the HBI.

CDC’s HBI is increasing tailored messaging related to cognitive impairment, COVID-19, brain health, and AD/ADR to Black and Hispanic populations across the United States. In 2021, three digital education events -- #SaludTues Twitter Chats -- amplified educational content, including CDC resources, about cognitive impairment and AD/ADR as public health issues among diverse audiences. These three events were held in partnership with more than ten community-partners, generating 19.7 million impressions. Relatedly, a virtual congressional briefing was held in July 2021 entitled Brain Health Equity and the Social Determinants of Health, Congressional Districts and Alzheimer’s Prevalence Among Communities of Color.

In 2020, CDC funded three organizations for 5 years to tailor brain health messaging for four populations disproportionately affected by dementia: persons with IDD and Hispanic, Black, and AI/AN individuals. In 2021, a virtual congressional briefing was held in July entitled Brain Health Equity and the Social Determinants of Health, Congressional Districts and Alzheimer’s Prevalence Among Communities of Color. There was also the virtual HealthMatters Webinar Series, which reached over 400 attendees, and authored two publications on persons with IDD

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and AD/ADRD. In 2022 and early 2023, a three-part series on AD/ADRD was given by multiple different agencies specifically for the Hispanic and Black communities as well as a separate series for AI/AN individuals.

For more information see:

- <http://brainhealthcenterforafricanamericans.org/>

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**(UPDATED) Action 6.E.2: Support the development of programs and materials designed to increase awareness of the importance of brain health for Tribal communities in culturally sensitive ways**

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**Lead Agencies:** CDC, IHS

**Partners:** private organizations, ASTHO

Through CDC's HBI, in 2021 IA<sup>2</sup>, which provides support to AI/AN adults, developed a new website, AI/AN Brain Health, which features a robust online brain health resource library. IA<sup>2</sup> has collaborated with the Dementia Friends Program to provide tribes, UIH organizations, and Alaska Native communities with training and content from this program. IA<sup>2</sup> 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 hosted at the American Indian Elders Conference hosted by NICOA.

CDC partnered with the ASTHO and the Alzheimer's Association to develop culturally sensitive materials to educate and empower tribes and Tribal populations about brain health and caregiving. In 2021, the materials were adapted to be customizable templates with logos, websites and images that focus on cardiovascular risk factors related to brain health and caregiving issues for Tribal communities.

In conjunction with the Alzheimer's Association and other partners, CDC is developing a special edition of the *Public Health Road Map for Tribal Communities*, the *HBI Road Map for Indian Country*. The original Road Map focuses on issues pertinent to state and local public health agencies and their partners. A companion *Road Map for Indian Country* has been designed specifically for public health systems serving AI/AN adults. Additionally, there are several companion materials to support brain health in Tribal communities developed by CDC in partnership with ASTHO and the Alzheimer's Association. IA<sup>2</sup>, a recipient of the HBI support, and the NPAIHB are developing, tailoring, and disseminating AD/ADRD materials and resources to AI/AN communities. CDC and the Alzheimer's Association, in collaboration with IHS, also produced infographics sharing data from the 2015-2018 BRFSS describing caregiving and SCD among AI/AN adults.

In 2023, the IHS began collaboration with the CDC BOLD PHCOE 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 September 2023, the IHS Alzheimer's and Health Promotion and Disease Prevention programs provided support to the Oklahoma City Area Office for an elder-focused community event promoting physical activity incorporating brain health and dementia content and resources based on the national *Just Move It* campaign, an indigenous program that promotes physical activity, diabetes risk reduction, and healthy living.

In 2023, IHS Alzheimer's grantees have implemented or planned brain health and risk reduction-focused activities. The Indian Health Council, Inc. reported a shift in community outreach promotion and engagement away from stigmatized terminology, including "dementia" and

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“Alzheimer’s” as a result of community feedback. Promotional language and resources use brain health and health promotion messaging and they have revised their project manager position as “Cognitive Wellness” nurse manager.

For more information see:

- <http://www.aianbrainhealth.org/>
- <https://iasquared.org/brain-health/resource-library/>
- <https://www.astho.org/healthy-aging/healthy-heart-healthy-brain/>
- <https://www.cdc.gov/aging/healthybrain/Indian-Country-resources.html>
- <https://www.cdc.gov/aging/partnership/partner-resources/index.html>
- <https://www.dfamerica.org/>

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### **(COMPLETED) Action 6.E.3: Reduce financial barriers to hearing aids for individuals with hearing loss**

**Lead Agency:** FDA

As described in further detail under [Action 6.B.2](#) above, the FDA recently issued a Final Rule, effective October 2022 that established a new regulatory category for OTC hearing aids and made related amendments to update the regulatory framework for hearing aids. This Final Rule is expected to increase the availability of less costly, OTC options for hearing aids, and therefore promote broader and more equitable access to these devices.

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## **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.

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### **(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 educational materials around dementia risk reduction and AD prevention, 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.

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For more information see:

- <https://www.alzheimers.gov/life-with-dementia/can-i-prevent-dementia>
- <https://order.nia.nih.gov/publication/reducing-your-risk-of-dementia>
- <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>

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**(UPDATED) 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 recently launched a series of podcasts titled Aging and Health Matters that includes short discussions on issues in older adult health, including AD/ADRD and caregiving. Topics include: Healthy Body, Healthy Brain, Alzheimer's Disease-Genes do not equal Destiny, and Memory Problems? Talk to your Doctor among others. 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 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://www.astho.org/Healthy-Aging/>
- <https://tools.cdc.gov/medialibrary/index.aspx#/media/id/397843>
- <https://tools.cdc.gov/medialibrary/index.aspx#/media/id/402234>
- <https://tools.cdc.gov/medialibrary/index.aspx#/media/id/408892>
- <https://tools.cdc.gov/medialibrary/index.aspx#/podcastseries/id/302101>

Grant recipients of HRSA's GWEP are expanding their social media footprint by developing Tweets, Threads, public service announcements, videos, podcasts, and public radio and television spots. In 2022, 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.

The campaign, "What is Brain Health?" formerly managed by ACL was transferred to NIA in 2017 and retired in 2020. NIA maintains online materials on Cognitive Health. Also, in 2022, NIA published 19 lay-friendly stories that highlight recent research results in brain and cognitive health.

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.

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In 2012, ACL, in partnership with NIH/NIA 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 was updated and simplified in 2018 and 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 people living with dementia.

For more information see:

- <https://nadrc.acl.gov/details?search1=20211015100133>

In 2022, all of the 48 HRSA-funded GWEPs are 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](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/data/index.htm>
- <https://www.cdc.gov/aging/healthybrain/Indian-Country-resources.html>
- <https://www.cdc.gov/aging/publications/briefs.htm>

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### **(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 emphasizes the link between uncontrolled blood pressure in midlife and increased risk for dementia. NINDS launched a "reboot" of Mind Your Risks in May 2021, which now includes an even stronger focus on health equity: the primary audience is Black men ages 28-45, who are at particularly high risk of hypertension, stroke, and dementia over the long term. Campaign materials include an updated website, videos, graphics, social media content, and educational resources including a 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.

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For more information see:

- <https://www.mindyourrisks.nih.gov/>
  - <https://www.mindyourrisks.nih.gov/resources.html>
  - <https://www.youtube.com/watch?v=mJi9srnvI3Q>
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## 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)

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## Appendix 2: National Plan to Address Alzheimer's Disease Milestones and Achievements Timeline

### 2012

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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>
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### 2013

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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/hgVMKEkvHo>

HRSA and ASPE developed the continuing education course Case Challenges in Early Alzheimer's Disease.

- [https://www.medscape.org/viewarticle/806464\\_4](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>
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### 2014

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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>
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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>
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## 2015

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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](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 website, making a broad range of grantee and center-developed resources available to the general public.

- <https://nadrc.acl.gov/>
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## 2016

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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/>
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## 2017

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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.

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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](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>
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## 2018

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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*.

- <https://www.cdc.gov/aging/pdf/2018-2023-Road-Map-508.pdf>

CDC released four State of Aging and Health in America Data Briefs.

- <https://www.cdc.gov/aging/publications/healthy-brain-issue-maps.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>
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## 2019

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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 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>
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## 2020

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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/combo-healthy-lifestyle-traits-may-substantially-reduce-alzheimers-disease-risk>

ACL expanded ADPI programming to dedicate resources to expanding dementia capability in Indian Country, launching grant and education programs in tribes and Tribal consortiums.

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## 2021

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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 Project ECHO (Extension for Community Healthcare Outcomes) 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>

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## 2022

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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 within Tribal communities.

- <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.

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IHS created a collaborative to support Geriatric Emergency Department Accreditation (GEDA) for IHS and Tribal entities.

CDC established the Healthy Brain Resource Center (HBRC).

- <https://www.cdc.gov/aging/healthy-brain-resource-center/index.html>

The DoD CDMRP required community collaboration (inclusion of persons with dementia, their care partners and/or family members) in all clinical research projects proposed to next PRARP.

NIH renewed the DetectCID consortium to conduct clinical trial testing on early dementia detection approaches in primary care.

- <https://www.detectcid.org/>
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## 2023

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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>

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 people living with dementia, 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/gso-23-05-nh-adjusting-quality-measure-ratings-based-erroneous-schizophrenia-coding-and-posting.pdf>

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 cerebrospinal fluid tests.

- <https://pubmed.ncbi.nlm.nih.gov/37932961/>
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An NIH-funded clinical study found that participants taking a multivitamin 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>
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## 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

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Notice to specify a high-priority topic of interest for PAR-19-070 "Research on Current Topics in Alzheimer's Disease and Its Related Dementias" and PAR-19-071 "Research on Current Topics in Alzheimer's Disease and Its Related Dementias" (NOT-AG-18-046)

- <https://grants.nih.gov/grants/guide/notice-files/NOT-AG-18-046.html>

Notice to specify two high-priority topics of interest for PAR-19-070 "Research on Current Topics in Alzheimer's Disease and Its Related Dementias" and PAR-19-071 "Research on Current Topics in Alzheimer's Disease and Its Related Dementias" (NOT-AG-18-048)

- <https://grants.nih.gov/grants/guide/notice-files/NOT-AG-18-048.html>

Notice to specify a high-priority topic of interest for PAR-19-070 "Research on Current Topics in Alzheimer's Disease and Its Related Dementias" (NOT-AG-18-051)

- <https://grants.nih.gov/grants/guide/notice-files/NOT-AG-18-051.html>

Notice to specify two high-priority topics of interest for PAR-19-070 "Research on Current Topics in Alzheimer's Disease and Its Related Dementias" (NOT-AG-18-052)

- <https://grants.nih.gov/grants/guide/notice-files/NOT-AG-18-052.html>

Notice to specify two high-priority topics of interest for PAR-19-071 "Research on Current Topics in Alzheimer's Disease and Its Related Dementias" (NOT-AG-19-007)

- <https://grants.nih.gov/grants/guide/notice-files/NOT-AG-19-007.html>

Notice of Special Interest: Neurological and Neurocognitive Sequelae from SARS-CoV-2 Infection and COVID-19 in Aging and Age-Related Neurodegeneration (NOT-AG-21-016)

- <https://grants.nih.gov/grants/guide/notice-files/NOT-AG-21-016.html>

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: 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>

Multi-Disciplinary Collaborations to Understand Mechanisms of Systemic Immune Signaling and Inflammation in AD/ADRD and its Progression (PAR-22-023)

- <https://grants.nih.gov/grants/guide/pa-files/PAR-22-023.html>
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Selectively Target Technology Development to Understand How Changes or Dysfunction at the Capillary, Arterioles, and Small Lymphatic Vessels Level Can Have Long-term Impact on AD/ADRD (PAR-22-026)

- <https://grants.nih.gov/grants/guide/pa-files/PAR-22-026.html>

Longitudinal Single Cell Characterization of ADRD Postmortem Tissue (PAR-22-029)

- <https://grants.nih.gov/grants/guide/pa-files/PAR-22-029.html>

Role of Astrocytes in Degeneration of the Neurovascular Unit in AD/ADRDs (PAR-22-037)

- <https://grants.nih.gov/grants/guide/pa-files/PAR-22-037.html>

Prodromal Synaptic and Circuit Changes that Contribute to AD/ADRD Onset and Progression (PAR-22-059)

- <https://grants.nih.gov/grants/guide/pa-files/PAR-22-059.html>

Cellular and Molecular Mechanisms of Prion-Like Aggregate Seeding, Propagation, and Neurotoxicity in AD/ADRD (PAR-23-023)

- <https://grants.nih.gov/grants/guide/pa-files/PAR-23-023.html>

Blood Barrier Response to Antibodies Targeting Beta-Amyloid (PAR-22-235)

- <https://grants.nih.gov/grants/guide/pa-files/PAR-22-235.html>

Alzheimer's Drug-Development Program (PAR-18-820)

- <https://grants.nih.gov/grants/guide/pa-files/par-18-820.html>

Drug Discovery For Nervous System Disorders (PAR-19-146)

- <https://grants.nih.gov/grants/guide/pa-files/par-19-146.html>

Drug Discovery For Nervous System Disorders (PAR-19-147)

- <https://grants.nih.gov/grants/guide/pa-files/par-19-147.html>

National Institute on Aging Genetics of Alzheimer's Disease Data Storage Site (PAR-20-110)

- <https://grants.nih.gov/grants/guide/pa-files/PAR-20-110.html>

Blueprint Neurotherapeutics Network (BPN): Small Molecule Drug Discovery and Development of Disorders of the Nervous System (PAR-20-122)

- <https://grants.nih.gov/grants/guide/pa-files/PAR-20-122.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-22-022)

- <https://grants.nih.gov/grants/guide/pa-files/PAR-22-022.html>
-

Impact of the Microbiome-Gut-Brain Axis on Alzheimer's Disease and Alzheimer's Disease-Related Dementias (PAR-22-211)

- <https://grants.nih.gov/grants/guide/pa-files/PAR-22-211.html>

Early-Stage Therapy Development for ADRD (RFA-NS-22-059)

- <https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-22-059.html>

Optimization of Genome Editing Therapeutics for Alzheimer's Disease and Alzheimer's Disease-Related Dementias (RFA-NS-23-017)

- <https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-23-017.html>

Alzheimer's Drug-Development Program (PAR-18-820)

- <https://grants.nih.gov/grants/guide/pa-files/par-18-820.html>

Alzheimer's Drug-Development Program (PAR-22-047)

- <https://grants.nih.gov/grants/guide/pa-files/PAR-22-047.html>

Translational Bioinformatics Approaches to Advance Drug Repositioning and Combination Therapy Development for Alzheimer's Disease (PAR-20-156)

- <https://grants.nih.gov/grants/guide/pa-files/PAR-20-156.html>

Small Research Grant Program for the Next Generation of Researchers in AD/ADRD Research: Area of Focus Archiving and Leveraging Existing Data Sets for Analyses (PAS-19-391)

- <https://grants.nih.gov/grants/guide/pa-files/PAS-19-391.html>

Small Research Grant Program for the Next Generation of Researchers in AD/ADRD Research: Area of Focus Basic Science (PAS-19-392)

- <https://grants.nih.gov/grants/guide/pa-files/PAS-19-392.html>

Small Research Grant Program for the Next Generation of Researchers in AD/ADRD Research: Area of Focus Systems Biology (PAS-19-393)

- <https://grants.nih.gov/grants/guide/pa-files/PAS-19-393.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**

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Notice to Extend the Expiration Date for PAR-17-214 "Limited Competition: Analysis of Data from NIA's Alzheimer's Disease Sequencing Project Follow-Up Study" (NOT-AG-20-021)

- <https://grants.nih.gov/grants/guide/notice-files/NOT-AG-20-021.html>

Limited Competition: Additional Sequencing for the Alzheimer's Disease Sequencing Project (PAR-19-234)

- <https://grants.nih.gov/grants/guide/pa-files/PAR-19-234.html>

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>

Limited Competition: NIA Genome Center for Alzheimer's Disease (PAR-19-288)

- <https://grants.nih.gov/grants/guide/pa-files/PAR-19-288.html>

Harmonization of Alzheimer's Disease and Related Dementias (AD/ADRD) Genetic, Epidemiologic, and Clinical Data to Enhance Therapeutic Target Discovery (PAR-20-099)

- <https://grants.nih.gov/grants/guide/pa-files/par-20-099.html>
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National Institute on Aging Genetics of Alzheimer's Disease Data Storage Site (PAR-20-110)

- <https://grants.nih.gov/grants/guide/pa-files/PAR-20-110.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>

Limited Competition: National Centralized Repository for Alzheimer's Disease and Related Dementias (NCRAD) (RFA-AG-21-005)

- <https://grants.nih.gov/grants/guide/rfa-files/rfa-ag-21-005.html>

Alzheimer's Disease Sequencing Project Functional Genomics Consortium (RFA-AG-21-006)

- <https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-21-006.html>

Limited Competition: National Institute on Aging (NIA) Late Onset of Alzheimer's Disease (LOAD) Family-Based Study (FBS) (RFA-AG-22-001)

- <https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-22-001.html>

Elucidating the Roles of Transposable Elements in AD/ADRD and Aging (RFA-AG-22-021)

- <https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-22-021.html>

Notice specifies a high-priority topic of interest for PAR-19-070 "Research on Current Topics in Alzheimer's Disease and Its Related Dementias" and PAR-19-071 "Research on Current Topics in Alzheimer's Disease and Its Related Dementias" (NOT-AG-18-046)

- <https://grants.nih.gov/grants/guide/notice-files/NOT-AG-18-046.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>

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>

Notice of Change to PAR-17-054, "Leveraging Existing Cohort Studies to Clarify Risk and Protective Factors for Alzheimer's Disease and Related Dementias" (NOT-AG-19-015)

- <https://grants.nih.gov/grants/guide/notice-files/NOT-AG-19-015.html>

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

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Examining Diversity, Recruitment and Retention in Aging Research (PAR-18-749)

- <https://grants.nih.gov/grants/guide/pa-files/PAR-18-749.html>

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>

Detecting Cognitive Impairment, Including Dementia, in Primary Care and Other Everyday Clinical Settings for the General Public and in Health Disparities Populations (RFA-NS-17-012)

- <https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-17-012.html>
-

Post-Stroke Vascular Contributions to Cognitive Impairment and Dementia (VCID) in the United States Including in Disparities Populations (RFA-NS-19-012)

- <https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-19-012.html>

White Matter Lesion Etiology of Dementia in the U.S. Including in Health Disparity Populations (RFA-NS-20-013)

- <https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-20-013.html>

Building Infrastructure for Precision Medicine Research on Minority Health and Disparities in Alzheimer's Disease (AD) and AD-Related Dementias (ADRD) (RFA-AG-23-020)

- <https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-23-020.html>

Alzheimer's Disease Research Centers (RFA-AG-24-001)

- <https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-24-001.html>

Request for Information (RFI) on Capacity and Support Needed to Increase Community-Based Research Networks Participation in Alzheimer's Disease and Related Dementias (AD/ADRD) Clinical Trials (NOT-AG-22-018)

- <https://grants.nih.gov/grants/guide/notice-files/NOT-AG-22-018.html>

Examining Diversity, Recruitment and Retention in Aging Research (PAR-18-749)

- <https://www.grants.nih.gov/grants/guide/pa-files/PAR-18-749.html>

Limited Competition: The Health and Retirement Study (HRS) and Harmonized Cognitive Assessment Protocol (HCAP) (RFA-AG-24-010)

- <https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-24-010.html>

Limited Competition: National Health and Aging Trends (NHATS) and National Study of Caregiving (NSOC) (RFA-AG-24-037)

- <https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-24-037.html>

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### **Action 1.B.5: Conduct clinical trials on the most promising interventions**

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Alzheimer's Clinical Trials Consortium (ACTC) Clinical Trials (PAR-20-309)

- <https://grants.nih.gov/grants/guide/pa-files/PAR-20-309.html>

Early Stage Clinical Trials for the Spectrum of Alzheimer's Disease and Age-related Cognitive Decline (PAR-18-877)

- <https://grants.nih.gov/grants/guide/pa-files/par-18-877.html>

Late Stage Clinical Trials for the Spectrum of Alzheimer's Disease and Age-related Cognitive Decline (PAR-18-878)

- <https://grants.nih.gov/grants/guide/pa-files/PAR-18-878.html>

Pragmatic Trials of Managing Multimorbidity in Alzheimer's Disease (RFA-AG-20-029)

- <https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-20-029.html>

Mechanism-Focused Research to Promote Adherence to Healthful Behaviors to Prevent Mild Cognitive Impairment (MCI) and Alzheimer's Disease and Related Dementias (AD/ADRD) (RFA-AG-22-016)

- <https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-22-016.html>

Dementia Care and Caregiver Support Intervention Research (PAR-21-307)

- <https://grants.nih.gov/grants/guide/pa-files/PAR-21-307.html>
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Pragmatic Trials for Dementia Care and Caregiver Support (PAR-21-308)

- <https://grants.nih.gov/grants/guide/pa-files/PAR-21-308.html>

Roystone 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>
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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**

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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>
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### **Action 1.B.8: Research the impacts of COVID-19 and Post-COVID Conditions on risk of AD/ADRD, cognition, and brain health**

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Notice of Special Interest (NOSI): NIA Availability of Administrative Supplements and Revision Supplements on Coronavirus Disease 2019 (COVID-19) (NOT-AG-20-022)

- <https://grants.nih.gov/grants/guide/notice-files/NOT-AG-20-022.html>

NIA Late Application Policy for NIA-Specific FOAs with Application Due Dates in May, June, and July 2020 (NOT-AG-20-033)

- <https://grants.nih.gov/grants/guide/notice-files/NOT-AG-20-033.html>

Notice of Special Interest (NOSI): Neurological and Neurocognitive Sequelae from SARS-CoV-2 Infection and COVID-19 in Aging and Age-Related Neurodegeneration (NOT-AG-21-016)

- <https://grants.nih.gov/grants/guide/notice-files/NOT-AG-21-016.html>

Notice of Special Interest: Impact of COVID-19 on Dementia Risk, Progression and Outcomes in ADRD Populations (NOT-NS-21-037)

- <https://grants.nih.gov/grants/guide/notice-files/NOT-NS-21-037.html>

NIA Multi-site COVID-19 Related Clinical Trial Implementation Grant on Aging-Related Topics in at-risk Older Adult Populations (PAR-20-234)

- <https://grants.nih.gov/grants/guide/pa-files/PAR-20-234.html>

Emergency Award: Social, Behavioral, and Economic Research on COVID-19 Consortium (PAR-21-213)

- <https://grants.nih.gov/grants/guide/pa-files/PAR-21-213.html>

Emergency Award: Social, Behavioral, and Economic Research on COVID-19 Consortium Coordinating Center (RFA-AG-21-035)

- <https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-21-035.html>

Neuropathological Interactions Between COVID-19 and ADRD (PAR-23-214)

- <https://grants.nih.gov/grants/guide/pa-files/PAR-23-214.html>
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Emergency Award: Social, Behavioral, and Economic Research on COVID-19 Consortium Coordinating Center (RFA-AG-21-035)

- <https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-21-035.html>

Emergency Award: Social, Behavioral, and Economic Research on COVID-19 Consortium (PAR-21-213)

- <https://grants.nih.gov/grants/guide/pa-files/PAR-21-213.html>
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### **Action 1.C.1: Identify imaging and biomarkers to monitor disease progression**

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Post-Stroke Vascular Contributions to Cognitive Impairment and Dementia (VCID) in the United States Including in Health Disparities Populations (RFA-NS-19-012)

- <https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-19-012.html>

NIA Medicine, Science, Technology, Engineering and Mathematics (MSTEM): Advancing Diversity in Aging Research through Undergraduate Education (PAR-17-290)

- <https://grants.nih.gov/grants/guide/pa-files/PAR-17-290.html>

Notice of Upcoming NIH Early Prediction of Alzheimer's Disease and Alzheimer's Disease Related Dementias (AD/ADRD) Open Innovation Challenge (NOT-AG-23-040)

- <https://grants.nih.gov/grants/guide/notice-files/NOT-AG-23-040.html>

Using Multimodal Biomarkers to Differentially Diagnose ADRDs for Clinical Trials (RFA-NS-24-001)

- <https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-24-001.html>

Center Without Walls for PET Ligand Development for Alzheimer's disease-related dementias (ADRDs) (RFA-NS-24-011)

- <https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-24-011.html>

Structural Biology of Alzheimer's Disease Related Dementias (ADRDs) Proteinopathies (PAR-22-208)

- <https://grants.nih.gov/grants/guide/pa-files/PAR-22-208.html>

Biomarkers for the Lewy Body Dementias (RFA-NS-22-001)

- <https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-22-001.html>

Leveraging Existing Data Resources for Computational Model and Tool Development to Discover Novel Candidate Mechanisms and Biomarkers for ADRD (RFA-NS-22-006)

- <https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-22-006.html>

Tools and resources to understand the vascular pathophysiology of in vivo neuroimaging findings in TBI-related dementia and/or VCID (RFA-NS-23-002)

- <https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-23-002.html>
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### **Action 1.C.2: Maximize collaboration among federal agencies and with the private sector**

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Alzheimer's Disease (AD) and AD-Related Dementias (ADRD) Real-World Data (RWD) Platform (RFA-AG-24-009)

- <https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-24-009.html>
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**Action 1.D.2: Expand international outreach to enhance collaboration**

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Limited Competition: The Health and Retirement Study (HRS) and Harmonized Cognitive Assessment Protocol (HCAP) (RFA-AG-24-010)

- <https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-24-010.html>

High-Priority Behavioral and Social Research Networks in Alzheimer's Disease and Alzheimer's Disease-Related Dementias (RFA-AG-22-012)

- <https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-22-012.html>

Notice of Participation of the National Institute on Aging (NIA) in PAR-21-230 "Chronic, Non-Communicable Diseases and Disorders Across the Lifespan: Fogarty International Research Training Award (NCD-LIFESPAN)" (NOT-AG-21-027)

- <https://grants.nih.gov/grants/guide/notice-files/NOT-AG-21-027.html>

Global Brain and Nervous System Disorders Research Across the Lifespan (PAR-18-835)

- <https://grants.nih.gov/grants/guide/pa-files/PAR-18-835.html>

Global Brain and Nervous System Disorders Research Across the Lifespan (PAR-18-836)

- <https://grants.nih.gov/grants/guide/pa-files/PAR-18-836.html>

Chronic, Non-Communicable Diseases and Disorders Across the Lifespan: Fogarty International Research Training Award (NCD-LIFESPAN) (PAR-18-901)

- <https://grants.nih.gov/grants/guide/pa-files/PAR-18-901.html>

Chronic, Non-Communicable Diseases and Disorders Across the Lifespan: Fogarty International Research Training Award (NCD-LIFESPAN) (PAR-21-230)

- <https://grants.nih.gov/grants/guide/pa-files/PAR-21-230.html>

Hubs of Interdisciplinary Research and Training in Global Environmental and Occupational Health (GEOHealth) -- Research (RFA-TW-21-001)

- <https://grants.nih.gov/grants/guide/rfa-files/RFA-TW-21-001.html>

Hubs of Interdisciplinary Research and Training in Global Environmental and Occupational Health (GEOHealth) -- Research Training (RFA-TW-21-002)

- <https://grants.nih.gov/grants/guide/rfa-files/RFA-TW-21-002.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>

Limited Competition: The Health and Retirement Study (HRS) and Harmonized Cognitive Assessment Protocol (HCAP) (RFA-AG-24-010)

- <https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-24-010.html>

High-Priority Behavioral and Social Research Networks in Alzheimer's Disease and Alzheimer's Disease-Related Dementias (RFA-AG-22-012)

- <https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-22-012.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>
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**Action 2.A.1: Educate health care providers**

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AD/ADRD Clinical Trials Short Course (PAR-21-141)

- <https://grants.nih.gov/grants/guide/pa-files/PAR-21-141.html>
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**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**

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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>
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**Action 2.B.2: Support Technology to Advance Mobile Monitoring of Cognitive Changes**

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Mobile Monitoring of Cognitive Change (RFA-AG-18-012)

- <https://grants.nih.gov/grants/guide/rfa-files/rfa-ag-18-012.html>

Low Cost Detection of Cognitive Decline in Clinical Settings (RFA-AG-20-050)

- <https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-20-050.html>

Low Cost Detection of Cognitive Decline in Clinical Settings (RFA-AG-20-051)

- <https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-20-051.html>

More Monitoring of Cognitive Change, Continued (M3C3) (RFA-AG-23-021)

- <https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-23-021.html>
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**Action 2.B.3: Identify and study effective approaches to increasing detection of cognitive impairment in clinical settings**

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Detecting Cognitive Impairment, Including Dementia, in Primary Care and Other Everyday Clinical Settings for the General Public and Health Equity, Pragmatic Clinical Trials (RFA-NS-22-009)

- <https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-22-009.html>
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**Action 3.A.2: Utilize health information technology for caregivers and persons with Alzheimer's disease and related dementias**

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Low Cost Detection of Cognitive Decline in Clinical Settings (RFA-AG-20-050)

- <https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-20-050.html>

Low Cost Detection of Cognitive Decline in Clinical Settings (RFA-AG-20-051)

- <https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-20-051.html>

Artificial Intelligence and Technology Collaboratories for Aging Research (RFA-AG-21-009)

- <https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-21-009.html>
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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>

Development of Cost-Effective and Customizable Training and Education Platforms for AD/ADRD Caregivers that Focus on Addressing Financial Management and Legal Planning (RFA-AG-21-025)

- <https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-21-025.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**

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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>

Artificial Intelligence and Technology Collaboratories for Aging Research (RFA-AG-21-009)

- <https://grants.nih.gov/grants/guide/rfa-files/rfa-ag-21-009.html>

Notice specifying a high-priority topic of interest for PAR-19-070 "Research on Current Topics in Alzheimer's Disease and Its Related Dementias" and PAR-19-071 "Research on Current Topics in Alzheimer's Disease and Its Related Dementias" (NOT-AG-18-056)

- <https://grants.nih.gov/grants/guide/notice-files/NOT-AG-18-056.html>

Notice specifying a high-priority topic of interest for PAR-19-070 "Research on Current Topics in Alzheimer's Disease and Its Related Dementias" and PAR-19-071 "Research on Current Topics in Alzheimer's Disease and Its Related Dementias" (NOT-AG-18-057)

- <https://grants.nih.gov/grants/guide/notice-files/NOT-AG-18-057.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-20-026)

- <https://grants.nih.gov/grants/guide/notice-files/NOT-AG-20-026.html>

Promoting Research on Music and Health: Phased Innovation Award for Music Interventions (PAR-20-266)

- <https://grants.nih.gov/grants/guide/pa-files/par-20-266.html>

Music and Health: Understanding And Developing Music Medicine (PAR-21-099)

- <https://grants.nih.gov/grants/guide/pa-files/par-21-099.html>

Music and Health: Understanding And Developing Music Medicine (PAR-21-100)

- <https://grants.nih.gov/grants/guide/pa-files/par-21-100.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>
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Dissemination and Implementation Research in Health (PAR-22-105)

- <https://grants.nih.gov/grants/guide/pa-files/par-22-105.html>

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)

- <https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-22-020.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**

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Notice specifying a high-priority topic of interest for PAR-19-070 "Research on Current Topics in Alzheimer's Disease and Its Related Dementias" and PAR-19-071 "Research on Current Topics in Alzheimer's Disease and Its Related Dementias" (NOT-AG-18-057)

- <https://grants.nih.gov/grants/guide/notice-files/NOT-AG-18-057.html>

Notice of Special Interest: Fundamental and Translational Research on Decision Making in Aging and/or Alzheimer's Disease and Alzheimer's Disease Related Dementias (AD/ADRD) (NOT-AG-20-039)

- <https://grants.nih.gov/grants/guide/notice-files/NOT-AG-20-039.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>

Interpersonal Processes in Alzheimer's Disease and Related Dementias Clinical Interactions and Care Partnerships (RFA-AG-20-006)

- <https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-20-006.html>

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)

- <https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-22-020.html>

Primary Care-Based Screening and Intervention Development for Prevention of Abuse in Older and Vulnerable Adults in the Context of Alzheimer's Disease and Related Dementias (RFA-AG-22-024)

- <https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-22-024.html>

Screening for Cognitive Impairment: Decision-Making (RFA-AG-23-007)

- <https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-23-007.html>

Primary Care-Based Screening Tool and Intervention Development for the Detection and Prevention of Abuse and Neglect in Older and Vulnerable Adults With, or at Risk for, Mild Cognitive Impairment and AD/ADRD (RFA-AG-24-048)

- <https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-24-048.html>
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**Action 4.C.1: Work with global partners to enhance collaboration**

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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>

Limited Competition: The Health and Retirement Study (HRS) and Harmonized Cognitive Assessment Protocol (HCAP) (RFA-AG-24-010)

- <https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-24-010.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**

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Pragmatic Clinical Trials in Community Settings to Decrease or Prevent VCID Outcomes, Including in Populations that Experience Health Disparities (RFA-NS-23-001)

- <https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-23-001.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**

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Research Coordinating Center on the Exposome and Alzheimer's Disease (AD) and AD-Related Dementias (ADRD): Elucidating the Role of Social and Behavioral Determinants of Health in AD/ADRD Etiology and Disparities (RFA-AG-24-011)

- <https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-24-011.html>

AD/ADRD, Adverse Childhood Experiences, and Social Determinants of Health Ancillary Studies of Existing Longitudinal Cohorts (PAR-22-221)

- <https://grants.nih.gov/grants/guide/pa-files/PAR-22-221.html>

Clinical Relevance of the Linkage between Environmental Toxicant Exposures and Alzheimer's Disease and Related Dementias (PAR-22-048)

- <https://grants.nih.gov/grants/guide/pa-files/PAR-22-048.html>

Post-Stroke Vascular Contributions to Cognitive Impairment and Dementia (VCID) in the United States Including in Health Disparities Populations (RFA-NS-19-012)

- <https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-19-012.html>
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**Action 6.A.5: Expand research on traumatic brain injury as a risk factor for neurodegeneration**

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Clinical and Biological Measures of TBI-related Dementia Including Chronic Traumatic Encephalopathy (PAR-22-024)

- <https://grants.nih.gov/grants/guide/pa-files/PAR-22-024.html>

Development and Characterization of Experimental models of post-TBI ADRD (PAR-23-218)

- <https://grants.nih.gov/grants/guide/pa-files/PAR-23-218.html>
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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) (RFA-NS-22-061)

- <https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-22-061.html>
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### **Action 6.A.7: Continue clinical trials on the most promising health promotion interventions**

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Alzheimer's Clinical Trials Consortium (ACTC) Clinical Trials (PAR-18-513)

- <https://grants.nih.gov/grants/guide/pa-files/PAR-18-513.html>

Mechanism-Focused Research to Promote Adherence to Healthful Behaviors to Prevent Mild Cognitive Impairment (MCI) and Alzheimer's Disease and Related Dementias (AD/ADRD) (PAR-21-207)

- <https://grants.nih.gov/grants/guide/pa-files/par-21-207.html>

Pragmatic Trials of Managing Multimorbidity in Alzheimer's Disease (RFA-AG-20-029)

- <https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-20-029.html>

Mechanism-Focused Research to Promote Adherence to Healthful Behaviors to Prevent Mild Cognitive Impairment (MCI) and Alzheimer's Disease and Related Dementias (AD/ADRD) (RFA-AG-22-016)

- <https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-22-016.html>

Mechanism-Focused Research to Promote Adherence to Healthful Behaviors to Prevent Mild Cognitive Impairment (MCI) and Alzheimer's Disease (AD) and AD-Related Dementias (ADRD) (RFA-AG-23-034)

- <https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-23-034.html>

Mechanism-Focused Research to Promote Adherence to Healthful Behaviors to Prevent Mild Cognitive Impairment (MCI) and Alzheimer's Disease and Related Dementias (AD/ADRD) (PAR-21-207)

- <https://grants.nih.gov/grants/guide/pa-files/PAR-21-207.html>

Mechanism-Focused Research to Promote Adherence to Healthful Behaviors to Prevent Mild Cognitive Impairment (MCI) and Alzheimer's Disease and Related Dementias (AD/ADRD) (RFA-AG-22-016)

- <https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-22-016.html>
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## List of Acronyms Used

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 Challenging Behaviors in Dementia
ACE	Adverse Childhood Experiences
ACL	Administration for Community Living
ACPM	American College of Preventive Medicine
ACTC	Alzheimer's Clinical Trials Consortium
AD	Alzheimer's disease
ADDP	Alzheimer's Drug Development Program
ADEAR	Alzheimer's Disease 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	Aging and Disability Resource Center
ADRD	Alzheimer's Disease and Related Dementias
ADSP	Alzheimer's Disease Sequencing Project
AHRQ	Agency for Healthcare Research and Quality
AI/AN	American Indian/Alaska Native
AITC	Artificial Intelligence and Technology Collaboratory
ALLFTD	ARTFL-LEFFTD Longitudinal Frontotemporal Lobar Degeneration research study
AlzPED	Alzheimer's Disease Preclinical Efficacy Database
AMP	Accelerating Medicines Partnerships
AMP-AD	Accelerating Medicines Partnerships-Alzheimer's Disease
AMP-PD	Accelerating Medicines Partnerships-Parkinson's Disease
APOE	Apolipoprotein E
APS	Adult Protective Services
ARTFL	Advancing Research and Treatment for Frontotemporal Lobar Degeneration
ASPE	HHS Office of the Assistant Secretary for Planning and Evaluation
ASTHO	Association of State and Territorial Health Officials
AtG	Alternatives to Guardianship
AT(N)	Amyloid/Tau/Neurodegeneration
BOLD	Building Our Largest Dementia (BOLD) Infrastructure for Alzheimer's Act
BPSD	Behavioral and Psychological Symptoms of Dementia
BRFSS	Behavioral Risk Factor Surveillance System
CADHC	Community Adult Day Health Care
CAP	Collaboration for Alzheimer's Prevention
CARD	Center for Alzheimer's and Related Dementias
CARE	Collaborative Approach for Asian Americans and Pacific Islanders Research and Education
CBO	Community-Based Organization
CBRN	Community-Based Research Network
CCBHC	Certified Community Behavioral Health Clinic
CDC	Centers for Disease Control and Prevention
CDMRP	Congressionally Directed Medical Research Program
CED	Coverage with Evidence Development
CHR	Community Health Representative

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CHW	Community Health Worker
CLC	Community Living Center
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 Persons with Dementia in their Environments
COVID-19	2019 Novel Coronavirus
CROMS	Clinical Research Operations and Management System
CSF	Cerebral Spinal Fluid
CSP	Cooperative Studies Program
CTE	Chronic Traumatic Encephalopathy
CWOW	Center Without Walls
CY	Calendar Year
DetectCID	Consortium for Detecting Cognitive Impairment, Including Dementia
DIAN-TU	Dominantly Inherited Alzheimer Network Trials Unit
DNA	Deoxyribonucleic Acid
DoD	U.S. Department of Defense
DoJ	U.S. Department of Justice
DREAM	Drug Repurposing for Effective Alzheimer's Medicines
EBP	Evidence-Based Practices
ECHO	Extension for Community Healthcare Outcomes project
EDD	Early Detection and Diagnosis of Dementia
EHR	Electronic Health Record
EJI	Elder Justice Initiative
ePCT	Embedded Pragmatic Clinical Trial
eRADAR	Electronic Health Record Risk of Alzheimer's and Dementia Assessment Rule
FDA	Food and Drug Administration
FIC	Fogarty International Center
FOA	Funding Opportunity Announcement
FTD	Frontotemporal Dementia
FY	Fiscal Year
GACA	Geriatrics Academic Career Award
GDO	Global Dementia Observatory
GEDA	Geriatric Emergency Department Accreditation
GeriScholars	(Indian Health) Geriatric Scholars
GRECC	Geriatric Research, Education, and Clinical Centers
GUIDE	Guiding an Improved Dementia Experience
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
HBRC	Healthy Brain Resource Center
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
IA <sup>2</sup>	International Association for Indigenous Aging
IADRP	International Alzheimer's Disease Research Portfolio

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IDD	Intellectual and Developmental Disability
IGAP	International Genomics of Alzheimer's Project
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
IPF	Inpatient Psychiatric Facility
IRP	Intramural Research Program
LBD	Lewy Body Dementia
LEFFTDS	Longitudinal Evaluation of Familial Frontotemporal Dementia Subjects
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
LTCO	Long-Term Care Ombudsman
LTSS	Long-Term Services and Supports
MCI	Mild Cognitive Impairment
MDT	Multidisciplinary Team
MFH	Medical Foster Home
MFP	Money Follows the Person
mg	milligrams
MODEL-AD	Model Organism Development and Evaluation for Late-onset Alzheimer's Disease
NACC	National Alzheimer's Coordinating Center
NACCHO	National Association of County and City Health Officials
NACDD	National Association of Chronic Disease Directors
NACHC	National Association of Community Health Centers
NADRC	National Alzheimer's and Dementia Resource Center
NAHN	National Association of Hispanic Nurses
NAPA	National Alzheimer's Project Act
NASEM	National Academics of Science, Engineering and Medicine
NBHCAA	National Brain Health Center for African Americans
NBNA	National Black Nurses Association
NCAPPS	National Center on Advancing Person-Centered Practices and Systems
NCD	National Coverage Determination
NCD	Non-communicable Disease
NCD-LIFESPAN	Chronic, Noncommunicable Diseases and Disorders Across the Lifespan
NCHS	National Center for Health Statistics
NCRAD	National Centralized Repository for Alzheimer's Disease and Related Dementias
NCUIH	National Council of Urban Indian Health
NHANES	National Health and Nutrition Examination Survey
NHATS	National Health and Aging Trends Study
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

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NLRC	National Legal Resource Center
NNHI	National Nursing Home Initiative
NOFO	Notices of Funding Opportunities
NORC	National Ombudsman Resource Center
NOSI	Notices 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
OTC	Over-The-Counter
OU	University of Oklahoma
OWH	HHS Office on Women's Health
PASC	Post-Acute Sequelae of COVID-19
PBRN	Practice-Based Research Network
PDBP	Parkinson's Disease Biomarkers Program
PDF	Portable Document Format
PET	Positron Emission Tomography
PHCOE	Public Health Center of Excellence
PHE	Public Health Emergency
PIN	Principal Illness Navigation
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
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
RNA	Ribonucleic Acid
RWD	Real-World Data
SAFE	Safe Accessible Interviewing for Older Adults
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
SES	Socioeconomic Status

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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
UIH	Urban Indian Health
UIO	Urban Indian Organization
UNITE	Uniting Tribal Nursing Homes in Excellence
VA	U.S. Department of Veterans Affairs
VCID	Vascular contributions to Cognitive Impairment and Dementia
VHA	Veterans Health Administration
WHO	World Health Organization

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