

## FEDERAL EFFORTS TO ADDRESS RACIAL AND ETHNIC DISPARITIES IN ALZHEIMER'S DISEASE AND RELATED DEMENTIAS

### DIRECTIVE

The National Alzheimer's Project Act (NAPA) requires "the inclusion of ethnic and racial populations at higher risk for Alzheimer's or least likely to receive care, in clinical, research, and service efforts with the purpose of decreasing health disparities in Alzheimer's".<sup>1</sup> To meet this requirement, in 2020 the Advisory Council on Alzheimer's Research, Care, and Services recommended that in order to advance health equity, work must be done to address racial and ethnic disparities in Alzheimer's disease and related dementias (ADRD). As a starting point, the Advisory Council tasked the U.S. Department of Health and Human Services (HHS) to develop a report on federal initiatives taken to address such disparities. The Office of the Assistant Secretary for Planning and Evaluation (ASPE), which coordinates the implementation of NAPA, developed the following issue brief and inventory of federal efforts to address racial and ethnic disparities in dementia research, care, and services.

### BACKGROUND

In the United States, racial and ethnic minority groups such as Black, Hispanic, Native American, and Asian adults have greater difficulty accessing ADRD services and supports than White adults. Black and Hispanic older adults are burdened by a disproportionately high prevalence of ADRD, while Native American and Asian adults have a lower likelihood of receiving a timely ADRD diagnosis.<sup>2-10</sup> Older Black adults are twice as likely, and Hispanic adults are one and one-half times as likely, to have Alzheimer's disease (AD) compared to older White adults.<sup>2-6</sup> Some of these challenges may be attributable to disparities in the prevalence of risk factors and chronic health conditions, and differences in health-related behaviors and socioeconomic status.<sup>8</sup> Native American and Asian adults have lower rates of AD diagnosis; however, this may be due to underdiagnosis, which is also common among Hispanic and Black adults.<sup>9,10</sup> While the reasons for disparities in ADRD and health care more broadly are manifold and complex, some factors addressed in this brief include bias and discrimination within the health care system, the lack of culturally competent care, and underrepresentation of people from minority racial and ethnic groups in clinical trials.

Bias within the health care system can both create and amplify racial and ethnic disparities in ADRD.<sup>11</sup> The negative impact of biases may be felt across the spectrum of care, but for ADRD bias can especially impede the proper diagnosis of patients from minority racial and ethnic backgrounds, such as those who are Black or Hispanic. Many of the common diagnostic tools currently in use may be less accurate for patients who are not White, even after controlling for age, education, and socioeconomic status.<sup>12</sup> One example is the Mini-Mental State Exam (MMSE), a brief paper-based test of cognitive function in older adults that evaluates orientation, attention, memory, language, and visual-spatial skills.<sup>13</sup> Studies have found measurement bias and differential item functioning (DIF) in the MMSE, and higher false-positive ratios of cognitive impairment have been observed for Black and Hispanic respondents compared to White respondents.<sup>14</sup> DIF occurs when people from different groups, such as people of different educational attainments, genders, or races or ethnicities, are not

equally likely to get questions and tasks correct despite having equal underlying ability.<sup>15</sup> Discrimination refers to differences in treatment due to bias, prejudice, stereotyping, and uncertain communication.<sup>16</sup>

Discrimination and bias in health care have implications beyond diagnosing ADRD. Black, Hispanic, Asian, and Native American older adults tend to report experiencing racial discrimination from dementia care providers at a higher rate than White older adults; and they commonly report feeling like their provider does not listen to them, acts as if they are unintelligent, or treats them with less courtesy or respect than others.<sup>10</sup>

Discrimination in health care is linked to worse health outcomes among racial and ethnic minorities for conditions that may increase risk of ADRD.<sup>17,18</sup> For example, among patients with hypertension, a modifiable risk factor for ADRD, Black individuals are less likely than White individuals to have their blood pressure controlled.<sup>19</sup>

People of color often lack access to culturally competent care, which can affect the quality and quantity of care they receive. The vast majority of Black, Hispanic, Native American, and Asian adults reported that having a provider who could provide culturally competent care for ADRD was important, but they were not confident such care was available.<sup>10</sup> In addition, a recent survey found that Hispanic, Black, and Native Americans are twice as likely as White Americans to report they would not see a doctor for thinking or memory problems, further delaying or inhibiting a dementia diagnosis.<sup>10</sup> Both Hispanic and Black Americans are more likely than White Americans to perceive that ADRD symptoms are a normal part of aging.<sup>20,21</sup> Because of the lack of culturally competent care, providers are not typically taught to recognize cultural differences in how patients perceive and report symptoms of ADRD and the need to screen more proactively for ADRD among these populations.

Racial and ethnic minority populations are also often underrepresented in clinical trials and research studies, which in turn inform the approaches used to diagnose and treat ADRD. In some instances, it is the study design that leads to underrepresentation. For example, racial and ethnic minority populations may in some cases be excluded because they have higher rates of comorbid conditions that are exclusionary criteria from clinical trials; those who are also non-native English speakers may be excluded if there are English fluency requirements.<sup>22</sup> Clinical trials may not be located in diverse communities and may not offer compensation even though they require individuals to take time off of work in order to participate. In other instances, people of color may choose not to participate in research trials because of distrust stemming from the long history of unethical experimentation and abuse of clinical trial participants from racial and ethnic minority groups, particularly Black Americans.<sup>10</sup> Lack of access to timely and adequate health care is thought to also contribute to lower rates of participation in research by Black and Hispanic people: as a result of broader barriers to health care access, both groups are typically diagnosed later in their dementia progression than non-Hispanic White adults, making them ineligible for many clinical trials.<sup>22</sup>

## METHODS

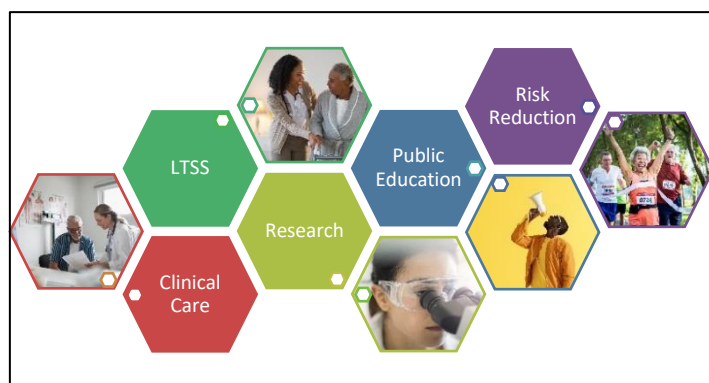
To identify initiatives addressing racial and ethnic disparities in ADRD, ASPE requested that partner federal agencies provide a summary of their efforts from 2011 to Spring 2021, aligning with the implementation of NAPA. Agencies submitted examples of their work, including databases, research grants, direct service provision, and public education opportunities. ASPE categorized these efforts into five topics that roughly align with the Goals of the National Plan to Address Alzheimer's Disease: research, clinical care, long-term services and supports (LTSS), public awareness, and risk reduction. The following agencies submitted responses:

- Administration for Community Living (ACL)
- Agency for Healthcare Research and Quality (AHRQ)
- Centers for Disease Control and Prevention (CDC)
- Centers for Medicare & Medicaid Services (CMS)

- Indian Health Services (IHS)
- Health Resources and Services Administration (HRSA)
- National Institutes of Health (NIH)
  - National Institute on Aging (NIA)
  - National Institute of Neurological Disorders and Stroke (NINDS)
- U.S. Department of Veterans Affairs (VA)

## SUMMARY OF FINDINGS

This section summarizes the items agencies submitted based on category (research, clinical care, LTSS, public awareness, and risk reduction). Though strictly delineated in this document, these categories and the programs and interventions within them often overlap in the real world. For example, to better include diverse



populations in **research**, NIA and NINDS must create and disseminate materials that **educate the public** on the importance of clinical research and how to participate in it. **Public education** is also a key component of **risk reduction** efforts, since people, communities, and systems need to understand the connection between ADRD and risk factors such as hypertension in order to best modify their actions and interventions. In such cases where overlap exists, ASPE included the agency submission in the category that seemed most relevant to the intervention or program.

For additional details about the following initiatives please see the [Appendix](#) of Agency Work to Address Disparities, which is organized first by category and then by agency.

Federal agencies' work on racial and ethnic disparities in ADRD **research** falls into three main categories: intramural research identifying disparities within the populations they serve, work on improving recruitment of racial and ethnic minorities in research, and funding of external research on disparities in ADRD. VA, CMS, NIA, and NINDS all reported intramural research. For example, CMS has designed an interactive map, the Mapping Medicare Disparities Tool, to identify geographic areas with greater health disparities between subgroups of Medicare beneficiaries. VA Geriatric Research, Education, and Clinical Centers (GRECCs) explore race and ethnicity in a variety of dementia-specific or dementia-relevant research, education, and/or clinical demonstration projects. NIA has developed a National Strategy for Recruitment and Participation in Alzheimer's and Related Dementias Clinical Research, which aims to improve recruitment of racial and ethnic minorities in both intramural and external research. VA has also prioritized increasing recruitment of minority populations in research studies. AHRQ, NIA, and NINDS are also funding multiple research grants related to addressing disparities in ADRD care and services. For example, an ongoing AHRQ-funded project is examining help-seeking intentions for AD among Korean American older adults. The focal points of NIH research grants are wide-ranging and include topics such as prevalence of and social and biological drivers of ADRD disparities, methods to improve recruitment of a diverse geriatric research workforce, and interventions to facilitate healthy aging of older racial and ethnic minorities.

Interventions to address disparities in **clinical care** tend to focus on training providers. The VA Geriatric Scholars Program, for example, partners with IHS to offer Rural Interdisciplinary Team Training (RITT) to Tribal facilities in rural areas. The training is specifically focused on older adults with cognitive impairment and ADRD. IHS not only trains providers, but also directly cares for and supports Native Americans with dementia and their caregivers through Tribal and Urban Indian Health programs. HRSA trains providers nationwide on ADRD

care and treatment through its Geriatrics Workforce Enhancement Program (GWEP), which specifically educates participants in providing culturally competent care. HRSA also partnered with CDC to create a series of modules on ADRD care, including one entirely focused on racial and ethnic disparities. CMS works to improve cross-provider communication and quality of care for individuals living with dementia, including through the development of a common lexicon. CMS recently finalized the collection of Social Determinants of Health (SDOH) standardized patient assessment data elements (SPADEs), which include race, ethnicity, and preferred language/interpreter services. Through its Alzheimer's Disease Programs Initiative (ADPI), ACL grantees design and disseminate trainings to support the education of medical professionals in providing culturally competent dementia care, including bringing dementia education to federally qualified health centers. Specifically, in Hispanic communities, community health workers are being trained and deployed to support increased dementia screening and referrals to medical professionals for diagnosis.

As ADRD progresses, individuals often need to rely on **long-term services and supports (LTSS)** to help with daily living. LTSS include both institutional care and home and community-based services. Unfortunately, disparities also exist in the quantity and quality of the LTSS that individuals might receive. In order to address disparities in LTSS, federal agencies are also providing training on culturally competent ADRD care to paid and unpaid caregivers, and providers. HRSA training programs primarily target nursing home staff, and CMS also has a number of resources for nursing home providers, such as webinars and fact sheets on Tribal Nursing Home best practices. Both IHS and VA have initiatives that focus on providing caregiver support and training of caregiver coaches, which are available in person and virtually. VA initiatives include courses and materials in Spanish so as to better meet the needs of Hispanic caregivers. Additionally, agencies are enabling grantees to tailor federally funded ADRD supports and services interventions to best meet the needs of their diverse communities. ACL funds numerous interventions through ADPI that specifically focus on expanding health equity and cultural competence in ADRD care and services. For example, one ongoing grant funds a partnership between the State of South Carolina and the African Methodist Episcopal Church's Women's Missionary Society to train members as Caregiver Coaches for the Resources for Enhancing Alzheimer's Caregiver's Health (REACH) intervention, a strategy originally tested through funding from NIA.

**Public education and awareness** on ADRD have long been crucial goals for federal agencies and their partners. Ongoing efforts include webinars, issue briefs, infographics, and education of the public health workforce. CDC has played a particularly strong role in educating the public on ADRD, caregiving, and related racial and ethnic disparities. For example, CDC leads efforts on the Healthy People 2020 and 2030 Core Objectives on ADRD, which aim to increase awareness of ADRD diagnosis, reduce preventable hospitalizations, and increase discussions on subjective cognitive decline with health care professionals. Progress on these objectives is specifically being tracked for Hispanic, non-Hispanic Black, and non-Hispanic White individuals. IHS supported CDC in development of the Healthy Brain Initiative Road Map for Indian Country.

The burden of known **risk factors** for ADRD, such as hypertension, diet, smoking, obesity, and untreated hearing loss, is disproportionately high among racial and ethnic minorities. Direct federal efforts to reduce the burden of risk factors for ADRD focus not only on actions individuals can take to reduce their risks, but also on community and system-level investments needed to facilitate risk reduction and support healthy aging. For example, FDA is working to allow for over-the-counter (OTC) hearing aids to encourage innovation and accessibility. Hypertension is one of the most modifiable risk factors for brain health and potentially dementia. NINDS's Mind Your Risks campaign educates the public on the importance of reducing blood pressure, particularly in relation to dementia. NINDS is working to better target this campaign toward Black men in their early 20s-40s, who are at the highest risk for high blood pressure in midlife and dementia incidence in late-life. ACL enables states to provide home-delivered and congregate meals to help older adults meet their nutrition needs. Black older adults are more likely to be food insecure, so such efforts are crucial to enabling healthy aging among this population. CDC collaborated with the National Association of Chronic Disease Directors (NACDD) to create a series of customizable educational rack cards on factors related to risk reduction of

dementia and funded the first Building Our Largest Dementia (BOLD) Public Health Center of Excellence of Dementia Risk Reduction to serve as a national leader for public health on risk reduction of dementia. Through Medicare, CMS covers obesity screenings and behavioral counseling to help with weight loss as well as smoking and tobacco use cessation counseling. CMS, through the Medicaid program, partners with states to make an array of certain services available to eligible beneficiaries, which could include smoking and tobacco use cessation counseling, hearing aids, and home-delivered meals.

## CONCLUSION

Since the NAPA was implemented in 2011, the Federal Government has made significant progress in its efforts to reduce the impact of ADRD. Addressing racial and ethnic inequities across the dementia experience--from differential prevalence of risk factors to a lower likelihood of diagnosis to poorer quality LTSS--has been a core principle of the National Plan to Address Alzheimer's Disease since it was first released in 2012 and is reflected in work across the government. In 2021, HHS reaffirmed its commitment to addressing racial and ethnic disparities in ADRD by recognizing that:

*the burden of risk factors for 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 ADRD that are further amplified by disparities in ADRD diagnosis, treatment, and access to care and resources.*

Using NAPA as a foundation, HHS and its federal partners continue to work to identify these disparities and confront them with evidence-based practices designed to achieve equity in addressing ADRD.

## APPENDIX: FEDERAL AGENCY WORK TO ADDRESS DISPARITIES

The following appendix lists the initiatives and programs led by federal agencies and departments that aim to address racial and ethnic disparities in ADRD. These efforts are organized by topic (Research, Clinical Care, Long-Term Services and Supports, Public Awareness and Education, and Risk Reduction) and then by agency or department in alphabetical order.\*

### Research

#### **Agency for Healthcare Research and Quality (AHRQ)**

- AHRQ is funding three grants related to addressing disparities among older adults, particularly those with dementia.
  - [Language Barriers and Post-Acute Outcomes in Home Care: A Mixed Methods Analysis](#). The overall goal is to understand how language barriers impact 30-day rehospitalization and home health care resource utilization among limited English proficiency (LEP) patients recently discharged from the hospital, with a secondary aim of understanding the impact of language barriers on functional status. This is a mixed-methods study in partnership with the Visiting Nurse Service of New York, which documents the language skills and abilities of its employees and patients thereby allowing researchers to identify linguistically concordant visits in its extensive database of over a million LEP patient visits coming from 86,000 clients, with four language groups (Spanish, Korean, Russian, Chinese). Related Article:
    - [“Home Health Care Services to Persons with Dementia and Language Preference”](#)
  - [Help-Seeking Intentions for Alzheimer's Among Korean Americans](#). Using a community-based participatory research approach, this study examines potential barriers and facilitators to help-seeking for AD in Korean Americans, the fourth largest and fastest-growing Asian American subpopulation. Korean Americans are primarily foreign-born and non-English speaking and have higher rates of AD risk factors (e.g., stroke, hypertension, and diabetes) than their non-Hispanic White counterparts, making them a vulnerable group. Using a sequential mixed-method approach, this will conduct a cross-sectional survey of 220 middle-aged and older Korean American adults (Phase 1), followed by deliberative focus groups with 30 stakeholders in the Korean American community (Phase 2). It will examine behavioral intentions for help-seeking from each of the following areas: primary care physicians, AD specialists, care options, and advance health care planning. Related Article:
    - [“The Intention to Discuss Advance Care Planning in the Context of Alzheimer’s Disease Among Korean Americans”](#)

#### **Centers for Disease Control and Prevention (CDC)**

- [Racial and ethnic estimates of ADRD in the United States \(2015-2060\) in adults aged ≥65 years](#).
  - CDC authored a journal article in *Alzheimer’s & Dementia* that estimates the future burden of ADRD over the next several decades. It identified significant disparities by race and ethnicity, with projected increases in cases seven times higher than today’s estimates among Hispanics and four times higher than today’s estimates for African Americans.

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\* Note that within this appendix, the decision was made to defer to the submitting agencies on terminology for different races and ethnicities, as the agency terms selected are based on the specifics of the program in question. Therefore, some agencies and programs may use African American instead of Black American or Latin American or Latinx instead of Hispanic.

## **National Institute on Aging (NIA)**

- The [NIA Strategic Directions document](#), updated in June 2020, includes clear steps to be taken by NIA to better understand health disparities and develop additional strategies to improve the health status of older adults in diverse populations.
- In 2015, NIA's [Alzheimer's Disease Education and Referral \(ADEAR\) Center](#) developed an online mini-portal for encouraging participation in AD research. The portal features information on participating in AD research, an ADRD searchable clinical trial finder with user-friendly trial descriptions, and an infographic and social media messaging. This information also now appears on [Alzheimers.gov](#) (see below). NIA continues to promote participation in ADRD clinical trials and provide information and resources, including the [Focus on Aging](#) interagency webinar series, through ADEAR to specific populations, including racial and ethnic minorities.
- In 2021 NIA launched [OutreachPro](#), a web-based communication tool that enables researchers, community groups, and others working on clinical trial recruitment to more easily produce and brand tailored materials and strategies. The tool is designed to help the research community to access, adapt, and personalize materials that NIA has developed--and will continue to create--for underrepresented communities. OutreachPro currently includes a library of content developed for and tested with American/Black populations, Hispanics/Latinos, and Asian American and Pacific Islander communities. NIA is developing materials and content for specific American Indian and Alaska Native communities and plans to include that content in the tool in late 2022.
- NIA developed the [Together We Make the Difference: National Strategy for Recruitment and Participation in Alzheimer's and Related Dementias Clinical Research](#) to outline practical, proactive approaches to help study sites engage a wider, more diverse pool of volunteers. The National Strategy was the result of a multiyear public-private collaboration that involved convening several workshops and meetings designed to elicit feedback from a range of stakeholders, gathering feedback on recruitment strategies through the IdeaScale crowdsourcing platform, and issuing a Request for Information ([NOT-AG-12-017](#)). Recommendations of the National Strategy Group's Local, Diverse Working Group have been transformed into an [Alzheimer's Disease and Related Dementias Clinical Studies Recruitment Planning Guide](#).
- A pilot program, part of an ongoing collaboration between NIA and the VA Office of Research and Development, has so far resulted in successfully recruiting more than 60 veterans for ADRD research. As part of the program, VA and NIA are partnering with the NIA-funded Alzheimer's Disease Research Centers (ADRCs) to increase veteran participation in research on ADRD. Strategic priorities for the pilot include recruiting veterans, especially from diverse populations, and investigating unique risk factors for this population. [Recruitment materials](#), including a poster and an informational flyer for American Indian veterans, are already available.
- NIA recently launched the landing page [Scientific Workforce Diversity and Health Disparities Research Programs](#). It provides a one-stop shop of NIA's programs that aim to diversify the aging research workforce, both within NIA and through its grantees and eliminate health disparities in research, in part through novel recruitment initiatives to incorporate diverse participants in our clinical studies and trials.
- NIA's [Butler-Williams Scholars Program](#) aims to recruit and support new investigators into research, with a focus on ethnic and racial minorities and aging.
- One key component to improving enrollment of minorities into AD clinical studies is to ensure that active studies' actual recruitment can be tracked and monitored quickly and efficiently against their planned milestones. To do so, NIA has recently developed a unified [Clinical Research Operations and Management System](#) (CROMS) that will provide NIA the capability to track, report and manage NIA's clinical research enrollment data, activities, and portfolio in real time. CROMS will provide critical, timely information for ensuring that NIA's clinical studies are making appropriate progress toward reaching their inclusion recruitment goals related to multiple underrepresented groups, including

minorities. Using data from CROMS, NIA can then implement and enforce policies to address studies that perform poorly with respect to minority enrollment.

- The NIA-funded [Alzheimer's Clinical Trials Consortium](#) (ACTC), a project established in 2017 that has developed the infrastructure needed to accelerate and expand studies for therapies in ADRD, continues to provide centralized resources and shared expertise to researchers nationwide to hasten the development of effective interventions for ADRD. The ACTC is investing in methods and strategies to enhance recruitment of racial and ethnic minority participants. The ACTC relies on community engagement using an innovative hub-and-spoke model to create a core of community-based minority and patient advocates who work closely with the recruitment units at ACTC sites. These advocates serve as liaisons between the community and the ACTC sites, and they communicate the concerns and perspectives of potential and enrolled study participants.
- In 2020, ACTC investigators successfully launched the Institute on Methods and Protocols for Advancement of Clinical Trials in ADRD (IMPACT-AD) course that aims to educate and promote diversity among research professionals and future researchers in the ADRD field. The inaugural class of IMPACT-AD was held in September 2020, with the second class held in 2021, fostering the training and career development of a diverse group of future ADRD clinical trialists.
- The NIA [Health Disparities Research Framework](#), developed and adopted in 2015, showcases priorities and investments in this important aging research area. The Framework outlines four key levels of analysis related to disparities research--environmental, sociocultural, behavioral, and biological--with priority focus areas in each level. Using the Framework as a guide, NIA has awarded over \$100 million in research awards between 2015 and 2020 to explore the determinants of health disparities related to aging, including improving recruitment and retention of underrepresented groups in research; understanding pathways that create and sustain ADRD health disparities; and addressing disparities within the context of both formal and informal caregiving.
- The NIA [IMbedded Pragmatic ADRD Clinical Trials \(IMPACT\) Collaboratory](#) was launched in 2019 to build the nation's capacity to conduct pragmatic clinical trials of interventions embedded within health care systems for people living with dementia and their care partners. The IMPACT Collaboratory was launched with a Health Equity Team that focuses on developing strategies to address diversity and inclusion for conducting pragmatic clinical trials.
- In 2019, NIA launched a funding opportunity ([RFA-AG-20-023](#)) for Exploratory ADRCs. NIA has since funded four exploratory ADRCs, which will broaden current ADRC research initiatives with additional underrepresented populations such as Black Americans, Native Americans, and those in rural communities. In addition, in 2021 NIA funded two new ADRCs in Texas and North Carolina, which bolster ADRD research specifically among Mexican American Hispanics and Black/African Americans.
- Through the funding opportunities Health Disparities and Alzheimer's Disease ([PAR-15-349](#)) and Emerging Directions for Addressing Health Disparities in Alzheimer's Disease ([PAR-15-350](#)), both originally launched in 2015, NIA--in collaboration with four other institutes--invited applications to study health disparities in ADRD, including biological, behavioral, sociocultural, and environmental factors that influence population-level health differences. Currently, [NOT-AG-21-033](#) encourages applications that examine mediators and moderators of disparities in ADRD, using diverse cohorts of subjects. To date, NIA has funded more than 115 projects in response to this initiative.
- NIA's Aging Research on Stress and Resilience to Address Health Disparities in the United States ([RFA-AG-16-022](#)), launched in 2015, was a funding opportunity designed to spur interdisciplinary health disparities research related to aging that considers the role that stress, including responses to stressors and stress resilience, plays in differential health outcomes among aging populations in the United States. NIA funded two projects via this funding opportunity.
- 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](#)), posted in 2017, was a funding opportunity to address the unmet need to detect cognitive impairment, including dementia, in large and diverse populations seen in primary care across the United States, including in



health disparities populations, when a patient, relative, or care provider indicates concern. The program is jointly supported by NINDS and NIA. NIA funded three projects in response to this funding opportunity.

- Geriatrics and Clinical Gerontology Research to Address Health Disparities in the United States ([PA-18-751](#)), offered by NIA in 2018, supported geriatrics and clinical gerontology research that addressed disparities in aging and health, with an emphasis on preclinical and clinical studies. The supplement program focused on mechanisms through which disparities influence age-related change; environmental, sociocultural, and biological influences on aging health disparities; and geriatric conditions where disparities emerge in diagnosis, prognosis, or treatment, including palliative and end-of-life care. NIA supported six projects through this funding opportunity.
- In 2018, NIA released the Small Research Grant Program for the Next Generation of Researchers in Basic ADRD Research opportunity ([RFA-AG-19-003](#)), aimed at producing trained clinical investigators pursuing careers in the field of ADRD research. One key objective is to enhance workforce diversity by encouraging individuals from nationally underrepresented groups to apply. NIA funded nearly 30 projects in response to this funding opportunity.
- In 2018, NIA released a funding opportunity called Examining Diversity, Recruitment, and Retention in Aging Research ([PAR-18-749](#)) for investigators who are focused on improving the research tools, methods, and recruitment practices used in clinical studies to produce a significant number of committed research participants in aging research. Through this funding opportunity, NIH is supporting a collaborative network comprised of 15 teams at research institutions nationwide to help inform scientists how to overcome barriers to enrolling research participants from underserved communities.
- In November 2018, NIA released [NOT-AG-18-047](#) to encourage grant applications for projects that examine health disparities related to AD, as well as strategies for recruitment and retention into clinical studies. NIA funded more than 60 projects in response to this initiative. Collectively, projects compared differences in risks for these conditions for men versus women, different racial and ethnic groups, rural communities, socioeconomically disadvantaged neighborhoods, and other societal and individual factors. NIA funded an initiative focused on Socioeconomic Disparities in Health and Mortality at Older Ages ([RFA-AG-18-011](#)), which resulted in funding of six projects by NIA.
- In 2019, NIA and National Institute on Minority Health and Health Disparities (NIMHD) released a funding opportunity announcement to establish collaborations to facilitate Building Resources for the Basic Biology of Aging in Health Disparities Research ([RFA-AG-20-035](#)). This initiative will provide a platform for discovery and pilot projects to establish feasibility of novel approaches to be used by these collaborations. Projects must include human participants and are expected to explore accelerated aging (i.e., earlier-than-expected physical changes typically associated with aging) as a driver of health disparities. Additionally, NIA utilizes administrative supplement programs to support research that addresses health disparities in ADRD, such as Aging Research to Address Health Disparities ([PA-17-164](#) and [PA-16-225](#) [the latter with NIMHD]). First launched in 2014 and 2015, respectively, these funding opportunities support research that addresses disparities in aging and health, with a specific focus on biological processes and mechanisms that are relevant to health disparities in aging. NIA has funded four projects under PA-17-164 and four projects under PA-16-225.
- In 2020, NIA issued two Request for Applications ([RFA-AG-20-050](#) and [RFA-AG-20-051](#)) for early detection of cognitive decline in older adults to pursue validation studies of cognitive screening instruments or assessments for diverse populations in clinical settings and to translate these screening and assessment tools into electronic health record systems that can assist physicians in making clinically meaningful care recommendations for patients experiencing cognitive decline.
- In 2022, NIA joined a funding opportunity announcement ([RFA-MD-22-004](#)) to support the development of innovations for healthy living that improve minority health and eliminate health disparities. NIA is soliciting a broad range of innovations focused on addressing health disparities in ADRD.

- The [Health and Retirement Study \(HRS\)](#), a critical investment of NIA and an example of a highly productive collaboration with the Social Security Administration, was designed to collect and distribute a wide range of multidisciplinary data to support research on aging. Launched in 1992, this longitudinal study surveys a population-representative sample of more than 20,000 Americans over the age of 50 every two years. To further facilitate health disparities research, the HRS added 2,000 additional African American and Hispanic respondents to the existing oversample of these populations. By continuing to diversify this cohort, researchers using HRS data will be better able to design studies that provide insights into potential racial/ethnic differences in the incidence, prevalence, and impact of ADRD. In most of these studies, important biomarker data, including DNA for genotyping and future sequencing, is also being collected. Sister studies of HRS include diverse audiences. For example, NIA supports the Mexican Health and Aging study, a national longitudinal study of adults 50 years and older in Mexico designed with protocols highly comparable to HRS. This sister study examines aging and disease burden in older Mexicans. The original survey was conducted in 2001, with new cohorts added in 2012 and 2018.
- NIA's Health and Retirement Study: [Harmonized Cognitive Assessment Protocol \(HCAP\)](#) initiative, started in 2016, is an innovative approach to assessing trends in cognitive function and aging in the United States and worldwide. HCAP currently includes approximately 3,500 HRS participants over the age of 65 randomly sampled from HRS. A translated and adapted version of the neuropsychological test battery employed in HCAP is being administered to population-representative samples in other developed and developing countries where HRS-like representative population surveys are conducted. These HRS "sister studies" include studies conducted in China, England, India, Mexico, South Africa, and parts of the European Union. For example, NIA supports Mexi-Cog (Mexican Health and Aging Study).
- NIA supports 15 [Edward R. Roybal Centers for Translational Research in the Behavioral and Social Sciences of Aging](#), as well as a coordinating center. The goal of the Roybal Center program, first authorized in 1993, is the translation and integration of basic behavioral and social research findings into interventions to improve the lives of older people and the capacity of institutions to adapt to societal aging. In September 2016, the Edward R. Roybal Institute on Aging at the University of Southern California, in collaboration with the Latinos Against Alzheimer's Network and Coalition, released a report to help understand the growing impact of AD on the Latinx community and the nation.
  - "[Latinos and Alzheimer's Disease: New Numbers Behind the Crisis](#)"
- NIA's [Resource Centers for Minority Aging Research \(RCMARs\) program](#), initially funded in 1997, serves as NIA's flagship mentoring program for scientists from historically underrepresented groups who conduct behavioral and social research focused on aging and health disparities in older adults. In 2018, NIA expanded the RCMAR program to fund eight new Centers focused on behavioral and social research related to ADRD. These new AD-RCMARs are providing mentorship to scientists conducting research on the epidemiology of dementia, preventive interventions, and formal and informal care challenges, among other topics.
- The need to understand the sources of persistent health disparities in overall longevity, cardiovascular disease, and cerebrovascular disease led NIA to develop the [Healthy Aging in Neighborhoods of Diversity across the Life Span \(HANDLS\)](#) study. The primary objective of HANDLS has been to conduct a 20-year longitudinal study, beginning in 2004, of minority health focused on investigating the relationship between race, socioeconomic status, and health outcomes--including those related to AD. The study is ongoing.
- Launched in 2021, the Neighborhoods Study: Contextual Disadvantage and Alzheimer's Disease and Related Dementias brings together 22 ADRC sites to examine the impact, mediators, and moderators of exposure to neighborhood disadvantage on cognitive decline and pathologic features. Detailed residential histories will be created to establish a dosage and timing of neighborhood disadvantage exposure across each life course.

- NIA funds the Vietnamese Insights into Cognitive Aging Program to explore the role of adversity and trauma on AD risk in Vietnamese Americans.
- The Accelerating Medicines Partnership® 2.0 program (AMP AD 2.0) was launched in March 2021. This NIA-led public-private partnership, managed by the Foundation for NIH, brings together five partner organizations from the pharmaceutical industry and the non-profit sector. Because the prevalence of this disease is greater among [Black and Latino Americans](#) than among White Americans, the central goal of AMP AD 2.0 is to expand the molecular characterization of AD in brain, blood and spinal fluid samples collected in these diverse populations. These datasets will allow the [AMP AD 2.0 research teams](#) to refine the characterization of new targets, discover new fluid biomarkers, define disease subtypes and increase the understanding of causative factors and steps in disease progression. The knowledge gained will inform the development of therapies that can be tailored to different stages of the disease and diverse disease risk profiles.
- The [Alzheimer’s Disease Sequencing Project](#) (ADSP) serves as an international resource of genetics data from multiple centers and studies. Launched in 2012 as a collaboration between NIA and the National Human Genome Research Institute, the ADSP is designed to promote innovative collaboration among scientists to provide genetic samples for sequencing, with the goal of identifying from multiethnic populations new genetic variants that influence risk and protection from AD. The NIA Genetics of Alzheimer’s Disease Data Storage Site serves as the ADSP Data Coordinating Center. In 2017, NIA launched the ADSP Follow-Up Study, which aims to pursue rare variants in a range of different populations, including those that have been underrepresented in sequencing studies. Leveraging the existing infrastructure of the ADSP, the Follow-Up Study aims to generate whole genome sequence data in African American, Hispanic, Native American, and Asian populations. The Follow-Up Study 2.0 was launched in 2021 to expand ADSP samples to increase diversity and be more representative of the United States population.
- The NIA-supported [Study of Latinos-Investigation of Neurocognitive Aging \(SOL-INCA\) project](#), initiated in 2015, is analyzing SOL-INCA’s wealth of data to examine how genetics and cardiovascular disease risk factors impact the prevalence of neurocognitive disorders among middle-aged and older participants. SOL-INCA scientists hope to find sociocultural risk and protective factors that may contribute to observed differences in dementia rates in the Latinx community. Its long-term goal is to identify targets that can be tested for actionable, culturally appropriate strategies for preventing or delaying the progression of dementia.
- The Health and Aging Brain among Latino Elders (HABLE) study, launched in 2017, investigates cognitive aging among Latinx elders, primarily Mexican Americans. In 2020, [NIA awarded new support](#) for an extension called the Health and Aging Brain Among Latino Elders-Amyloid, Tau, and Neurodegeneration (HABLE-AT(N)) Study. The extension will support more biomarker measures, including positron emission tomography (PET) imaging, to better understand health disparities of brain aging and ADRD between Mexican Americans and non-Hispanic Whites.
- The NIA-funded [ACTC](#), a clinical trials infrastructure established in 2017 to accelerate and expand studies for therapies in ADRD, is investing in methods and strategies to enhance recruitment of racial and ethnic minority participants. ACTC relies on community engagement using an innovative hub-and-spoke model to create a core of community-based minority and patient advocates who work closely with the recruitment units at ACTC sites.
- The nationwide [All of Us Research Program](#) is seeking to enroll one million participants by 2024 who will reflect the diversity of the United States to help build one of the most diverse health databases in history and to learn how our biology, lifestyle, and environment affect health. This is one example of NIH’s commitment to enrolling participants from diverse backgrounds to help identify the genetic variants and other risk and protective factors involved in health and disease. The diagnosis of dementia is captured through electronic health records and survey responses, and many of the participants who have already enrolled are living with ADRD. The scientific community, including dementia researchers, can access participant data via the All of Us Research Workbench, launched in

May 2020. Data currently available for analysis in the Workbench include information sourced from participant surveys, electronic health records, physical measurements, and wearables. As the program grows, additional data—including genomic data—will become available so that researchers can conduct analyses by a wide array of factors including lifestyle differences, socioeconomic factors, environment, and genes and other biologic characteristics. Program enrollment began in 2018.

- The [Diversity and Cognitive Aging: Progress and Future Challenges](#) meeting was held in March 2016, at the Latino Aging Research Resource Center, a former NIA-funded RCMAR (see above) focused on the future directions in aging and diversity research in the United States. The conference highlighted NIA-funded research in northern California and brought together nearly 100 leading national experts to discuss building a collaborative, nationwide framework for disparities research.
- In July 2020, NIA, in collaboration with the Alzheimer’s Association, held the [Developing Applied Science of Recruitment and Retention for ADRD Clinical Research Symposium](#) at the Alzheimer’s Association International Conference. This symposium provided a broad perspective that builds on existing scientific knowledge to support the goal of ultimately accelerating and expanding research efforts on recruitment strategies for clinical trials for ADRD. One specific goal of the symposium was to identify challenges and opportunities in enhancing clinical trial participant diversity.
- In July and August 2020, NIA held the second [National Research Summit on Care, Services, and Supports for Persons with Dementia and their Caregivers](#), during which multiple sessions discussed the importance not only of making research on dementia and dementia care more person-centered but also the need to address racial and ethnic disparities in dementia care and research.

#### ***National Institute of Neurological Disorders and Stroke (NINDS)***

- In March 2019, NINDS hosted the most recent Alzheimer’s Disease-Related Dementia Summit. Outcomes of the summit included identification of 47 research gaps and opportunities to help guide investment in dementia research. Among the highest priority recommendations were the creation and improvement of cognitive assessment tools that are culturally and linguistically optimized for populations facing ADRD health disparities. In addition, the Summit’s final report included the recommendation to increase policy-relevant research on disparities in access to care, awareness and stigma, and costs of care for persons living with ADRD, their families and caregivers.
- In 2019, NINDS launched a scholarship program to offset barriers to attend the ADRD Summit. Aggressively removing barriers to inclusion is critical for inclusion of diverse perspectives on health disparities. The goal of this program, which awarded 21 scholarships (including 12 to women and nine to self-declared diverse applicants), was to provide a positive and informative experience that add to ADRD knowledge for trainees across a wide spectrum of fields. Emphasis was placed on professionals in training roles related to ADRD so that their unique perspective would be represented and so that the information they learned would be incorporated into the training that they offer.
- The NINDS Human Genetics Resource Center, hosted by the Coriell Institute for Medical Research, receives blood samples and clinical data and prepares DNA and cell lines for distribution to promote neurogenetics research (including ADRDs). This resource now includes 1,000 African American DNA samples from the REasons for Geographic and Racial Differences in Stroke (REGARDS) study.
- The ongoing Research Supplements to Promote Diversity in Health-Related Research ([PA-20-222](#)) focuses on increasing the number of minority scientists focused on health disparities research. NIA has supported approximately 20 supplements via this funding opportunity. Likewise, NINDS issued the [Notice to Encourage Eligible NINDS Awardees to Apply](#) for PA-20-222 in 2020 and has made 15 awards so far in 2021.
- Several NIH institutes are participating, including NIA and NINDS, in an NIMHD sponsored research opportunity focused on addressing structural racism and discrimination (SRD) called “Understanding and Addressing the Impact of Structural Racism and Discrimination on Minority Health and Health Disparities” ([RFA-MD-21-004](#)). Under this funding opportunity, NINDS specially invites research

applications on the impact of SRD on mechanisms related to increased risk of cognitive impairment and ADRD.

- NINDS's [Northern Manhattan Study](#) (NOMAS) is an ongoing population-based study in Northern Manhattan, based in the Neurological Institute at Columbia Presbyterian Medical Center. It began in 1990. It has enrolled over 4,400 people from the surrounding community. NOMAS is the first study of its kind to focus on stroke risk factors in Whites, Blacks, and Hispanics living in the same community. It is helping to fill gaps in our knowledge of stroke epidemiology and complications like dementia in minority populations.
- NINDS's [REGARDS](#) has followed its participants for nearly two decades to understand why Southerners and Black Americans have higher rates of stroke and related cerebrovascular diseases that affect brain health. In its most recent renewal, an emphasis on cognitive decline and dementia outcomes was added. Data from this cohort have had a significant impact on our understanding of disparities in stroke and dementia risk and outcomes among Black Americans compared to Whites. REGARDS findings underscore the high need for community-based, primary prevention interventions, especially for hypertension control.
- Launched in 2020, the NINDS' "[Diverse VCID: White Matter Lesion Etiology of Dementia in Diverse Populations](#)" is a prospective clinical research study of patients, particularly those from underrepresented groups who are at risk for cognitive decline in that they present with cognitive complaints and exhibit incidental white matter lesions found on neuroimaging scans. This project will use advanced brain imaging and blood-based techniques to understand how vascular changes in late life cause brain injury and cognitive decline.
- Launched in 2020, the [Determinants of Incident Stroke Cognitive Outcomes and Vascular Effects on Recovery](#) (DISCOVERY) study, funded by NIA and NINDS, aims to determine the specific subsets of stroke-related events that cause cognitive impairment and dementia in people who have had a stroke, especially within racial and ethnic minorities who are at higher risk of stroke, cognitive impairment, and dementia. The long-term goal of this study is to identify potential targets for personalized medicine and dramatically reduce the rates of cognitive and functional disability following stroke in high-risk United States populations.
- Launched in 2017, the Consortium for Detecting Cognitive Impairment, Including Dementia ([DetectCID](#)) is a collaborative network of research programs that are developing and validating dementia screening tools that are simple to use, standardized, and take ten minutes or less to administer in a primary care setting or other everyday clinical settings. The ultimate goal is to increase early detection of cognitive impairment and dementia and lessen cultural and logistic barriers that currently impede both clinical care and research efforts. Up to half of the funded research focuses on approaches that are specifically designed to address barriers to detecting cognitive impairment in underserved populations. Now in Phase 2, the DetectCID research teams are scaling up their research by enrolling a larger number of research participants, including at least 50% from racial and ethnic minority groups.
- NINDS recently renewed the [MarkVCID consortium](#), a collection of nine research sites and a coordinating center devoted to developing biomarkers for the small vessel diseases of the brain that lead to vascular cognitive impairment/dementia. The consortium has developed 11 different biomarker kits, which include several types of vascular imaging and fluid-based biomarkers. Now in Phase 2, the focus of the next five years will be clinical validation in longitudinal studies in diverse populations. It is expected that MarkVCID will determine the respective effectiveness of several biomarker kits in Hispanic, Black/African American, and White populations.

### ***Department of Veterans Affairs (VA)***

- VA GRECCs explore race and ethnicity in a variety of dementia-specific or dementia-relevant research, education, and/or clinical demonstration projects. Examples of topics in 2020 include race and socioeconomic status-related disparities in magnetic resonance imaging markers of dementia risk and brain aging; ADRD in Older African American and White veterans; an agenda for addressing

multimorbidity and racial and ethnic disparities in ADRD; dementia and falls management in underserved populations; payment for care services to individuals living in the community with dementia; Medicaid contribution to costs of dementia care in an ethnically diverse community; and developing a research participation enhancement and advocacy training program for diverse seniors. In 2019, topics included dementia caregiver interventions in Chinese people; and Medicare expenditures and health care utilization from incident to death in a multiethnic community-based population with Dementia.

- VA and U.S. Department of Defense nationwide, multisite [Long-term Impact of Military-relevant Brain Injury Consortium](#) (LIMBIC) is applying “big data” and longitudinal prospective research methodologies to investigate the risk of combat concussions and comorbid conditions in later life dementia. The LIMBIC research program has been successful in recruiting a higher percent of ethnic minorities into its research study than in the general United States population, in order to be reflective of the military population they are studying. Key contributors to the representativeness and diversity of the cohort are the geographic and population diversity across the study enrollment sites, a wide range of recruitment approaches (in-person at VA medical facilities and military treatment facilities, radio ads, print ads, social media groups), and attempts to hire diverse and veteran/military-centric recruitment staff.
- The VA Office of Research and Development issued a fiscal year 2021 funding announcement to support health services research on racial and ethnic disparities and SDOH. Although this Request for Proposals is not dementia-specific, the results of research that it funds may benefit individuals with dementia, among others. This solicitation seeks applications that will identify, develop, evaluate, and/or implement evidence-based practices to mitigate unmet social needs of veterans; examine structural factors within VA Health Care that may contribute to disparities; and reduce racial and ethnic disparities in health outcomes and quality of care among veterans.
- The [Elizabeth Dole Center of Excellence for Veteran and Caregiver Research](#) (EDCoE) is part of the VA Choose Home Initiative. The purpose of the EDCoE is to expand VA capacity to deliver integrated, veteran and caregiver-partnered, data-driven approaches to care through a set of complimentary projects whose results will inform VA operational leaders in expanding VA caregiver programs. The EDCoE conducts a set of complementary research projects, two of which can inform our understanding of racial and ethnic health equities in veterans, including those with ADRD.
  - The EDCoE is conducting analyses using VA administrative data to assess which types of home-based care services are most effective for different veteran populations in terms of preventing institutionalization and hospitalization. As part of this analysis, race and ethnicity data are included as covariates, allowing the EDCoE to assess their roles as factors influencing outcomes. Similarly, the EDCoE can focus these analyses on veterans living with ADRD.
  - As part of a study of the impact of COVID-19 on veteran caregivers, the EDCoE is surveying and interviewing caregivers with regard to how COVID-19 has impacted their roles. The EDCoE is collecting data regarding caregiver race and ethnicity and will be examining their association with other caregiver outcomes. While the EDCoE is not collecting data regarding specific veteran conditions, it is collecting data regarding the types of supports that caregivers are providing. These data will provide some insights regarding the role of race and ethnicity for Veterans who receive services typical of those with ADRD.
  - Finally, the EDCoE is conducting a longitudinal study of high-need, high-risk veterans and their caregivers, using survey and administrative data to assess evolving needs of this group over time. Veterans living with ADRD are highly represented in this high-need, high-risk group. We will be collecting veteran race and ethnicity data and can make assessments regarding their association with changing veteran and caregiver needs over time.
- The Veterans Health Administration Office of Health Equity (OHE) has established a COVID-19 database that includes information on veterans’ testing history, demographics, and comorbidities including

dementia. OHE is actively conducting analyses of COVID-19 and mortality outcomes for racial and ethnic minority veterans with dementia.

## Clinical Care

### *Centers for Medicare & Medicaid Services (CMS)*

- In response to the IMPACT Act of 2014, CMS finalized the collection of SDOH SPADEs in our post-acute care quality reporting programs (QRPs), including: Race, Ethnicity, Preferred Language/Interpreter Services, Health Literacy, Transportation, Social Isolation.
  - The [SDOH SPADEs](#) are standardized, interoperable, and support provider exchange of electronic health information (are mapped to Health Information Technology vocabularies and exchange standards).
  - These data elements have been added to the assessment instruments of skilled nursing facilities, inpatient rehabilitation facilities, long-term care hospitals and home health agencies. The onset of collection of this data in our post-acute care assessment instruments has however been delayed due to the COVID-19 public health emergency.
  - Although the Hospice QRP (HQRP) does not fall under the IMPACT Act, CMS is aligning the HQRP program with the other QRPs, where practicable. Currently, race, ethnicity and preferred language/interpreter services are being tested in the HQRP.
- The Social Security Act (Section 1139B) requires the Secretary of HHS to identify and publish a core set of health care quality measures for adult Medicaid enrollees. The [2022 Adult Core Set](#) was released in a December [2021 Informational Bulletin](#). For fiscal year 2020 reporting, 33 states report with a median of 59% of adult with hypertension have their blood pressure adequately controlled.

### *Health Resources and Services Administration (HRSA)*

- HRSA, in collaboration with CDC, has created a 16-module ADRD curriculum which has continuing education accreditation for continuing education units, continuing education contact hours, continuing nursing education and continuing medical education. These modules are accessible through the HRSA [Train Health Care Workers About Dementia page](#). Module 3 is dedicated to diversity and equity.
- HRSA's GWEP is providing education and training about ADRD to the health care workforce, which includes practicing health professionals, students, residents, fellows, faculty, patients and their families and caregivers, in 35 states and two United States territories. This work is done in collaboration with academic institutions that provide the geriatrics expertise, primary care practices where the patients are cared for, and community-based organizations that provide services, supports and resources that ensure that the health care offered can be accessed. All of the 48 funded GWEPs are training the primary care workforce to provide culturally competent health care and address the SDOH for patients, families, and caregivers in underserved and rural areas.
- HRSA's GWEP program received \$4.35 million for one-time supplemental funding for COVID-19 workforce training in telehealth and tele-education for 12 months. Forty-eight GWEPs used the funds to train students and clinicians currently involved in health professions training on:
  - How to provide telehealth-enabled COVID-19 referral for screening and testing, case management and outpatient care.
  - Maintaining primary care functionality away from physical sites, especially for COVID-19 positive, quarantined older adults and individuals at a higher risk of severe illness.
  - To address the digital divide and digital literacy, funds could also be used to purchase needed telehealth equipment for use by patients, and their caregivers and families in order to promote access and health equity.
- HRSA made 12 competitive supplemental GWEP awards in September 2021 to provide COVID-19 specific education and training to the nursing home workforce and nursing home residents and their

families and caregivers, within the context of the age-friendly health systems framework. This training must address best practices regarding the management and treatment of frail older adults living in nursing homes, including those living with dementia, who are at risk of contracting COVID-19 or who are currently ill with COVID-19, their families and caregivers who have been impacted by COVID-19, and families and caregivers of persons who have died of COVID-19. Successful applicants will collaborate to develop and disseminate a curriculum of COVID-19 management and treatment in nursing homes. This curriculum will include modules that address how Inclusion, Diversity, Equity, and Access are impacted by race, ethnicity, rural and urban environments, and sex/gender identity of populations of nursing home residents in each of the ten HHS geographical regions.

### ***Indian Health Services (IHS)***

- The IHS mission is to raise the physical, mental, social, and spiritual health of American Indians and Alaska Natives to the highest level. IHS provides care through direct services and in support of Tribal and Urban Indian Health programs to persons living with dementia and their families.
- IHS has partnered with VA on the VA Greater Los Angeles, supported by the Office of Rural Health, to offer the RITT to IHS and Tribal facilities in rural settings who provide care to American Indian and Alaska Native elders, with a focus on elders with cognitive impairment. In March 2020, the VA Geriatric Scholars program added to the RITT a training specifically targeted to IHS and Tribal public health nurses providing support to caregivers of persons living with dementia: Addressing Behavioral Challenges with Dementia (ABCD).

### ***Department of Veterans Affairs (VA)***

- The VA Geriatric Scholars Program is a workforce development program to integrate geriatrics into VA primary care practices, through a collaboration among VA GRECCs.
  - The VA Geriatric Scholars Program has offered Rural Interdisciplinary Team Training in Care of Elders to IHS and Tribal Health Programs since 2016. This training includes recognition and assessment of ADRD among American Indians.
  - In 2020 the VA Geriatric Scholars Program began delivering a program to IHS that was targeted to Public Health Nurses and other clinicians. The ABCD program (see above) combines didactics and monthly telephone consultation on addressing behavioral and management issues around ADRD in American Indians.
  - In 2021, the VA Geriatric Scholars Program's mental health webinar series on clinical care of special populations discusses racial and ethnic equities. Although ADRD are not a specific focus of these webinars, the content may apply to those with ADRD. Examples of related webinar topics include Introducing Cultural Diversity Factors in Interdisciplinary Treatment Plans and Cultural Considerations in Care of American Indian Elders.

## **Long-Term Services and Supports**

### ***Administration for Community Living (ACL)***

- Through its ADPI, ACL and grantees demonstrate commitment to addressing the needs of those racial and ethnic communities disproportionately impacted by ADRD. ACL's ADPI grantees are awarded with the expectation that program funding aligns with the Older American's Act in that program efforts target those of greatest economic and social need. Programmatic efforts to expand health equity are demonstrated through calculated efforts to engage historically underserved populations with culturally competent resources that are designed with specific cultural traditions in mind and for delivery by members of their community. ACL funded programs and services are successfully reaching historically underserved racial and ethnic (e.g., African American, Asian and Pacific Islander, Latinx and Native American) and geographic (e.g., frontier, rural, and urban) communities and continue to expand



their reach. ACL funded programs that are dedicated to the provision of culturally competent dementia-capable home and community-based services include:

- In Los Angeles, California, through ACL's ADPI, ACL is working with leading health care system AltaMed to deliver culturally competent training, supports and services to Latino, multiethnic and underserved communities. ACL funds support AltaMed embedding much needed evidence-based and evidence informed caregiver trainings (SAVVY/SAVVY Express and Telenovela) and support groups in the communities they serve.
- In Chicago, Illinois, the Latino Alzheimer's and Memory Disorder Alliance (LAMDA) is providing dementia education, including SAVVY caregiver training, to their trusted community health worker network of Promotoras, to educate communities on ADRD as well as supporting and delivering supportive services for caregivers and people living with dementia.
- The State of South Carolina, through their 2020 ADPI, is working with the African Methodist Episcopal Church's Women's Missionary Society to train members as Caregiver Coaches for the REACH intervention. Through the program, trained coaches will support family caregivers from their faith community with culturally competent education designed to reduce their stress and burden, as well as resources for dementia-capable respite.
- In Chicago, Honolulu, Los Angeles and San Francisco ADPI grantees are bringing cultural competence to evidence-based interventions and dementia education to Asian Pacific Islanders (Chinese, Japanese, Korean, Vietnamese) in their communities. The communities are benefitting from culturally competent adaptations of supports and services, including SAVVY Caregiver, REACH Community, care navigation programs, memory cafés, and Dementia Friendly Community programs.
- In 2020, ACL released its first ADPI call for applications for its new Dementia Capability in Indian Country program. All applicants received funding. In 2020, the applicants funded were Aleutian Pribilof (Alaska), Absentee Shawnee Tribe (Oklahoma), Great Lakes Inter-Tribal Council (Wisconsin) and Spirit Lake Tribe (North Dakota); in 2021, applicants funded were Intertribal Council of Arizona and Wichita and Affiliated Tribes. Each program is different, designed to meet the needs of their community. Program activities include, but are not limited to, delivery of REACH into Indian Country, SAVVY Caregiver in Indian Country, community health worker programs to support caregivers and people living with dementia and culturally competent dementia education programs.

### ***Centers for Medicare & Medicaid Services (CMS)***

- The National Partnership to Improve Dementia Care in Nursing Homes (National Partnership) has been committed to finding new ways to implement practices that enhance the quality of life for people with dementia, protect them from substandard care and promote goal-directed, person-centered care for every nursing home resident. The inappropriate use of antipsychotic medications in nursing homes has a substantial impact on the quality of life and health outcomes of residents, in particular Medicaid residents. A recent study showed that nursing homes with higher proportions of Medicaid residents had higher rates of inappropriate antipsychotic use, whereas nursing homes with higher proportions of Medicare residents had lower rates of inappropriate antipsychotic use. The same study also found that nursing homes with a high proportion of Black residents had significantly lower rates of inappropriate antipsychotic use.<sup>23</sup> The actions of the National Partnership seek to provide additional information regarding antipsychotic medication use, which will improve the quality of care provided to residents in all Medicare and Medicaid certified long-term care facilities. Since the launch of the National Partnership, significant reductions in the prevalence of antipsychotic medication use in long-stay nursing home residents have been documented. In 2011 Q4, 23.9% of long-stay nursing home residents were receiving an antipsychotic medication; since then, there has been a decrease of 39.6% to a national prevalence of 14.4% in 2021 Q2. Success has varied by state and CMS region, with some states and regions having seen a reduction of greater than 45%. As a result of this reduction, there has

been an improvement in resident's quality of care and quality of life, in particular, Medicaid beneficiaries.

### ***Health Resources and Services Administration (HRSA)***

- HRSA's GWEP recipients are participating in the AHRQ Project ECHO nursing home project, which is reaching out to provide infectious disease and emergency preparedness training to all nursing homes in the United States. The GWEP faculty are providing geriatrics expertise to these trainings and are serving as resources for the nursing home staff, which includes health care professionals, administrators, direct care workers, certified nursing attendants, housekeeping staff, and food service staff. In 2016, 47.8% of nursing home residents had some form of dementia,<sup>21</sup> necessitating that the GWEPs provide education and training in ADRD and the impact of COVID-19 on that population. All of this training impacts the vulnerable nursing home population and is designed to promote access and health equity.

### ***Indian Health Services (IHS)***

- IHS has collaborated with ACL and CMS on a variety of efforts in support of Tribal LTSS, including the CMS technical assistance website, an ongoing webinar series, and periodic meetings to share best practices in Tribal LTSS.
- IHS has partnered with VA from 2015-2018 to train caregiver coaches in Tribal communities, in partnership with the VA REACH Training Center at the University of Tennessee Health Sciences Center. According to data provided by the REACH Training Center as of 2018, REACH into Indian Country trained and certified 80 caregiver coaches in 56 distinct Tribal communities. These caregiver coaches reported delivery of REACH services to 55 caregivers.

## **Public Awareness and Education**

### ***Centers for Disease Control and Prevention (CDC)***

- [Healthy People 2020 and 2030](#) Core Objectives on Dementias, including Alzheimer's (here referred to as ADRD).
  - CDC's Alzheimer's Disease and Healthy Aging Program leads, in coordination with NIA and ACL, 3 ADRD Healthy People 2030 objectives. The Program also led the Healthy People 2020 objectives. The focus of each of the three ADRD objectives are increasing awareness of ADRD diagnosis, reducing preventable hospitalizations, and increasing discussions related to subjective cognitive decline with health care professionals. For each objective, progress towards identified targets are tracked across the decade (2021-2030). Progress is specifically being tracked for Hispanics, non-Hispanic Blacks, and non-Hispanic Whites.
- [State of Aging and Health in America: Data Brief Series](#).
  - CDC collaborated with the NACDD to create four data briefs on public health issues related to older adults, with a focus on cognitive decline. Each brief provides data from the Behavioral Risk Factor Surveillance System (BRFSS) by gender and ethnicity and identifies disparities in prevalence among middle-aged and older adults.
- Web page on [Social Determinants of Health and Alzheimer's Disease and Related Dementias](#).
- The CDC's Alzheimer's Disease and Healthy Aging Program funds multiple organizations to implement strategies to reduce disparities. The National Healthy Brain Initiative (NHBI) activities include creating informational resources for the public, engaging state and local partners to adopt Road Map action items, developing training materials for current and future professionals about ADRD, and disseminating effective messages related to brain health. NHBI activities are expected to promote brain health, address cognitive impairment including ADRD, and support the needs of caregivers (unpaid persons providing care or assistance to someone with ADRD).

- [National Healthy Brain Initiative \(NHBI\)--Component A Awardee.](#)
  - CDC, in partnership with the Alzheimer's Association created the Healthy Brain Initiative (HBI) Road Map series. The HBI Road Map series includes the "[Healthy Brain Initiative State and Local Public Health Partnerships to Address Dementia: The 2018-2023 Road Map](#)" and the "[Road Map for Indian Country](#)". HBI award recipients support populations with a high burden of ADRD, to develop and implement public health strategies guided by the HBI Road Map Series. The Road Map Series elevates ADRD, including caregiving, into high public health priorities by leveraging data, educating the public health workforce, and mobilizing adoption of impactful intervention by state and local public health departments and American Indian/Alaska Native communities.
  - Formed the HBI Collaborative to serve as a mechanism to foster collaboration among NHBI and the BOLD Public Health Centers of Excellence awardees.
  - In collaboration with National Association of County and City Health Officials, awarded the inaugural cohort of the HBI Road Map Strategists. The Road Map Strategist initiative is the first nationwide effort to build local health department capacity to address cognitive health and dementia. Eight local health departments were selected through a competitive application process for the cohort.
  - The Alzheimer's Association produces numerous newsletter articles to address SDOH or health equity.
- [National Healthy Brain Initiative \(NHBI\)--Component B Awardees.](#)
  - International Association for Indigenous Aging (IA<sup>2</sup>):
    - Focuses on health equity and disparities in work with American Indians, Alaska Native peoples, tribes, Tribal leadership, public health and health care staff, Urban Indian Health Centers and organizations, and Tribal elder services advocates across the country.
    - Advances community engagement and helps build capacity among tribes--who are recognized as sovereign entities--and Tribal member-serving organizations.
    - Promotes healthy cognitive aging strategies across the lifespan, and fosters dementia-capable Tribal communities
    - IA<sup>2</sup> is committed to gathering, creating, and distributing information and resources developed by and for American Indian and Alaska Native communities to improve the public health response to ADRD. These resources are available on their [brain health resource library](#).
    - IA<sup>2</sup> is a national sublicensee for the Dementia Friends program. This license allows tribes, urban Indian health organizations, and Alaska Native communities to receive training and affiliate with IA<sup>2</sup> versus working with a state-based entity or are in states with no Dementia Friends sublicense.
    - IA<sup>2</sup> hosted multiple sessions and trainings on ADRD at the American Indian Elders conference hosted by the National Indian Council on Aging.
  - UsAgainstAlzheimers. Increases visibility of the relationship of the SDOH, health disparities, and AD. Conducts digital events focusing on partnership development strategies. Digital events have been in partnership with minority-serving organizations and platforms, such as Latino Nurses Network, LatinaStrong Foundation, and Diverse Alzheimer's. Identifies resources and communications messages on brain health that are culturally tailored to Black and Latino Americans and that recognize the SDOH's role in shaping overall health. Held a virtual congressional briefing on July 20, 2021, titled "Brain Health Equity and the Social Determinants of Health, Congressional Districts and Alzheimer's Prevalence Among Communities of Color".
- The BOLD Infrastructure for Alzheimer's Act includes the creation of ADRD Public Health Centers of Excellence (The Centers). The Centers increase education of public health officials, health care

professionals, and the public on AD, brain health, and health disparities. The Centers provide technical assistance to public health departments across the country in implementing effective AD interventions. These interventions focus on priorities such as increasing early detection and diagnosis, reducing risk, preventing avoidable hospitalizations, reducing health disparities, supporting the needs of caregivers and supporting care planning for people living with the disease. The BOLD Centers and Programs received their initial funding in October 2020 and, despite delays due to COVID-19, have made significant progress. Sample of [BOLD Program Awardees' Activities](#):

- The Northwest Portland Area Indian Health Board has worked with their member Tribal health boards to create a first-ever draft of their comprehensive dementia plan.
- Colorado developed an ADRD Advisory Committee (ADRDAC) to begin collaborating on Colorado's long-term goals of enhancing access to and utilization of culturally relevant services that support individuals with ADRD and their caregivers. The ADRDAC focused on the development of the ADRD State Plan, including creating opportunities for expert review, inclusion of community voice, with particular emphasis on Black/African American, Hispanic/Latinx and American Indian/Alaska Native communities, and reflecting a cohesive approach to ADRD in the state.
- [BOLD Public Health Centers of Excellence Awardees](#).
  - Caregiving Public Health Center of Excellence (University of Minnesota): The BOLD Public Health Center of Excellence for Dementia Caregiving's (PHCOE-DC's) primary mission is to disseminate tools and promising practices to public health agencies (as well as other organizations) to best support unpaid family members, friends, or others who provide care to people living with dementia. The PHCOE-DC aims to support and provide technical assistance and information to local, Tribal, and state public health agencies (such as Core Capacity and Enhanced BOLD recipients) in their design, development, and implementation of supporting systems, environments, and policies that elevate and connect dementia caregiving programs, initiatives, and educational outreach. The PHCOE-DC supports and initiates new public health strategies for dementia caregivers via three activities: (1) provision of technical assistance to adopt dementia caregiving-related communication approaches; (2) dissemination of various resources, including webinar series, toolkits, and similar materials to educate and engage with public health agencies and elevate unpaid dementia caregiving as a public health priority; and (3) serve as a nexus to create connections and collaboration across the public health, aging service, and research networks to advance dementia caregiving initiatives. Hosted a three-part webinar series, Public Health Considerations and Models for Cultural Adaptations in Dementia Caregiving, illustrating that dementia support and services are not adequately tailored to meet the cultural needs of older adults and their caregivers, despite the projected rise in the diversity of caregivers in the United States.
  - Early Detection Public Health Center of Excellence (New York University): The [BOLD Center of Excellence on Early Detection and Diagnosis](#) brings together a broad coalition of stakeholders across the United States to assure widespread awareness of why early detection of dementia matters: Early detection is the first step on the pathway to high quality, effective diagnosis and health care for people living with ADRD and those who care for them. We assess and disseminate the best evidence supporting early detection and how to accomplish it. Our national advisory group represents key state and county departments of health, health care systems and primary care providers, community organizations, and professional societies. We identify optimally effective materials and marketing strategies for increasing awareness about cognitive impairment, the value of earlier detection, and ways to best enact detection strategies; and disseminate them through community-based and health care organizations and state, county, and Tribal

public health agencies. The Center works closely with public health agencies as key partners in dissemination and seeks to establish collaborative linkages with health care systems and their primary care providers to build strategies for post-detection diagnosis and care. The PHCOE will employ strategies to advance health equity that include expanding access to information by disseminating culturally relevant educational materials on ADRD and healthy aging; identifying barriers and facilitators to early detection of dementia across diverse stakeholders; generating solutions tailored to the needs of various communities; and promoting integration of early detection of dementia into state and regional public health initiatives, community service organizations, and health care systems with a focus on populations experiencing disparities.

### ***Centers for Medicare & Medicaid Services (CMS)***

- CMS has designed an interactive map, the [Mapping Medicare Disparities \(MMD\) Tool](#), to identify areas of disparities between subgroups of Medicare beneficiaries (e.g., racial and ethnic groups) in health outcomes, utilization, and spending. The MMD Tool includes an AD condition option that can be stratified by sex, race and ethnicity, and dual status at the county, state, and national levels.
- CMS also released a Data Snapshot, [Alzheimer’s Disease Disparities in Medicare Fee-for-Service Beneficiaries](#), which analyzes Medicare data on AD by race and ethnicity, age, sex, dual-eligibility for Medicare and Medicaid, and geographic area.

### ***Indian Health Services (IHS)***

- IHS collaborated with CDC in the development of infographics based on the BRFSS Data from American Indian and Alaska Native adults addressing Caregiving Among American Indian/Alaska Native Adults, Subjective Cognitive Decline Among American Indian/Alaska Native Adults and consulted on the development of the “Healthy Brain Initiative Road Map for Indian Country”.

### ***National Institute on Aging (NIA)***

- To complement and support the [National Strategy for Recruitment and Participation in Alzheimer’s and Related Dementias Clinical Research](#), NIA established the [Alzheimer’s and Dementia Outreach, Recruitment, and Engagement](#) platform in 2019. The platform is an online, searchable database of materials that facilitates resource sharing on topics related to the engagement, recruitment, and retention of participants in ADRD studies across diverse populations.
- To provide researchers with practical and proactive approaches for engaging a wider, more diverse range of research participants, NIA invests in a vast range of supportive resources, including the [Why I Participate in Alzheimer’s Research](#) video series, developed and released in 2019. This series is designed to motivate individuals to volunteer for research by enabling them to hear members of underrepresented communities describe their personal stories of why they chose to enroll in an AD study.
- NIA-supported [ADRCs](#) across the country provide important liaison and engagement between the Centers and people with dementia, their caregivers and both the professional and local lay community to augment participant and community engagement. For example, in collaboration with an ADRC Latinx interest group, NIA developed a [new landing page](#) in 2020 as a portal to aging-related health information content and information on participating in research in Spanish.
- NIA’s ADEAR Center educates the public about the latest research findings and provides evidence-based information online and in print, as well as through its information and referral helpline, a weekly email alert specifically on caregiving issues, and social media. ADEAR offers free information in English and Spanish.
- In 2020, NIA published and promoted the [Brain Donation Social Media Toolkit](#) to raise awareness about brain donation and the importance of donations from diverse populations. The toolkit includes flyers and social media messaging encouraging people to learn more about participating in a study that

involves donation or registering to donate through the NIH NeuroBioBank. Available in both English and Spanish, the toolkit is already being used by the NIA-supported ADRCs and others to spread the word about the importance of brain donation.

### ***National Institute of Neurological Disorders and Stroke (NINDS)***

- The fourth Alzheimer’s Disease-Related Dementia Summit, hosted by NINDS, took place in March 2022. As in previous years, one major area of focus was on health equity. Results from the Summit included eight recommendations to guide future research priorities and investments.
- In September 2021, NINDS hosted the [Health Disparities and Inequities in Neurological Disorders Workshop](#) (HEADWAY), which brought together a diverse array of subject matter experts in various disciplines from clinical and health services researchers, to implementation and behavioral scientists, along with community stakeholders and patient advocates. Findings and recommendations from the workshop will be placed on the NINDS website and used as resources for setting priorities and developing initiatives over the next 5-10 years, including in the ADRD research space.
- In February 2022, NINDS Director, Dr. Walter Koroshetz, and Director of the Office of Global Health and Health Disparities, Dr. Richard Benson, co-authored an article in the journal *Stroke* titled “[Health Disparities: Research that Matters](#)”. They propose a call to action and outline current NIH programs that aim to eliminate health disparities both broadly and in high priority areas, including the need to diversify the research workforce and ongoing efforts and struggles to establish trust with disadvantaged communities during the COVID-19 pandemic.
- Beginning in February 2020, NINDS and the American Heart Association/American Stroke Association annually host the “Health Equity and Actionable Disparities in Stroke: Understanding and Problem-solving (HEADS-UP) Symposium.” This multidisciplinary symposium focuses on cerebrovascular disease, with the overarching goal of reducing disparities in stroke and consequences like vascular cognitive impairment and dementia, and accelerating translation of research findings to improve outcomes for disadvantaged socioeconomic groups, along with mentoring the next generation of diverse health disparities investigators. The symposium also highlights an outstanding health disparities researcher, by conferring the Edgar J. Kenton award. The speakers and faculty for this symposium, present unique findings that are then written up and highlighted in the journal *Stroke*.

## **Risk Reduction**

### ***Administration for Community Living (ACL)***

- An important aspect of healthy aging is a healthy diet; however, many Americans of color experience food insecurity. Older adults who are Mexican, Hispanic, and Black all report being food insecure at much higher rates than White and Asian older adults.<sup>25</sup> 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 underserved individuals into the spotlight.

### ***Centers for Disease Control and Prevention (CDC)***

- BOLD Public Health Center of Excellence (PHCOE), Risk Reduction (Alzheimer’s Association): Alzheimer’s Association’s [Public Health Center of Excellence on Dementia Risk Reduction](#) provides guidance on how public health can address the risk factors for cognitive decline and dementia. With

recent advancements in the science on dementia risk factors, we can now identify targets for public health action. The PHCOE is convening a series of meetings review the state of the science and identify points of intervention through reviewing, synthesizing, and summarizing the latest scientific evidence on modifiable risk factors; identifying public health interventions and best practices that address the risk factors; creating actionable tools, materials, and messaging for public health agencies to use in addressing risk reduction; and working with public health agencies to implement risk reduction interventions and best practices in their communities. The PHCOE emphasizes health equity and SDOH-relevant factors to dementia risk reduction, for example by developing toolkits specific to the issue of how public health can engage diverse communities in dementia risk reduction; developing a plan on how public health can address SDOH related to dementia risk factors (first year) and begin implementing that plan (second year); and ensuring community stakeholders representing diverse communities participate in the Community Convenings and that health equity/social determinants of health are considered in community-developed actions.

- CDC collaborated with the NACDD to create a series of customizable [educational rack cards](#) on factors related to risk reduction of dementia.

### ***Centers for Medicare & Medicaid Services (CMS)***

- The Million Hearts® Cardiovascular Disease (CVD) Risk Reduction Model was a randomized controlled trial that sought to bridge a gap in cardiovascular care by providing targeted incentives for health care practitioners to engage in beneficiary CVD risk calculation and population-level risk management. Instead of focusing on the individual components of risk, participating organizations engaged in risk stratification across a beneficiary panel to identify those at highest risk for atherosclerotic cardiovascular disease. The model performance period was January 3, 2017-December 31, 2021.
- Effective for claims with dates of service on or after November 8, 2011, CMS began covering intensive behavioral therapy for CVD (referred to below as a CVD risk reduction visit), which consists of the following three components: encouraging aspirin use for the primary prevention of CVD when the benefits outweigh the risks for men age 45-79 years and women 55-79 years; screening for high blood pressure in adults age 18 years and older; and intensive behavioral counseling to promote a healthy diet for adults with hyperlipidemia, hypertension, advancing age, and other known risk factors for cardiovascular and diet-related chronic disease.
- CMS expanded coverage of ambulatory blood pressure monitoring (ABPM) in July 2019. ABPM is a non-invasive diagnostic test that uses a device to track blood pressure over 24-hour cycles, allowing a doctor to assess a patient's blood pressure during routine daily living, instead of when they are sitting nervously on an examination table. ABPM may measure blood pressure more accurately and lead to the diagnosis of high blood pressure in patients who would not otherwise have been identified as having the condition.
- By way of the Quality Innovation Network-Quality Improvement Network, CMS targeted at-risk beneficiaries to receive smoking cessation comprehensive education and resources including webinars, newsletters, case studies, change packages, and other technical assistance materials to support to support CVD prevention, improved health outcomes, and health care cost savings.
  - Smoking and tobacco use cessation is also a covered benefit under Medicare. States can also use Medicaid to cover tobacco use treatments.
- Obesity screenings and behavioral therapies are covered under Medicare, and states may choose to provide obesity-related services through Medicaid. States may also leverage Medicaid waivers to cover services that support healthy aging and risk reduction, such as home-delivered meals and hearing aids
- CMS continues to leverage expertise and access to valuable hypertension control resources including periodic webinars targeting the establishment of hypertension, CVD, and stroke prevention programs; community trainings on blood pressure control best practices to increase awareness and detection of hypertension particularly with racial and ethnic minorities. One such resource is the CMS Data Snapshot [Hypertension Disparities in Medicare Fee-for-Service Beneficiaries](#).

## **Food and Drug Administration (FDA)**

- Hearing loss has been identified as a modifiable risk factor for ADRD, and recent research has demonstrated that hearing aid use is associated with reduced dementia risk. Black and Hispanic individuals who experience hearing loss use hearing aids at a lower rate than White individuals.<sup>26,27</sup> While discriminatory health care practices may play a role in this disparity, the high cost of hearing aids may also contribute to making them inaccessible to many individuals who could benefit. To address this barrier, FDA recently issued a Proposed Rule to establish a new regulatory category for OTC hearing aids and to make related amendments to update the regulatory framework for hearing aids. Such action would entail defining OTC hearing aids and their requirements and amending existing rules to be consistent with the new category. The Proposed Rule aims to foster innovation in hearing aid technology. It would also improve access to hearing aids, as OTC options would likely be easier to obtain and less expensive.
- Hypertension has also been identified as a modifiable risk factor for ADRD. Research has found strong evidence that hypertension control can reduce the risk of developing cognitive impairment, commonly a precursor of ADRD. Hypertension is more common among Black, Hispanic, and Asian individuals than among White individuals.<sup>28,29</sup> Excess sodium intake can raise blood pressure and lead to hypertension. At present, people living in the United States consume nearly 50% more than the recommended amount of sodium per day. 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 gradually reduce sodium across the food supply, including processed and restaurant foods. The FDA issued the [final guidance](#) with voluntary short-term targets for reducing sodium in commercially processed, packaged, and prepared food over the next two and a half 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 in the next few years to facilitate a gradual, iterative process to reduce sodium intake.

## **National Institute of Neurological Disorders and Stroke (NINDS)**

- First launched in 2015, NINDS's [Mind Your Risks](#)<sup>®</sup> is a health campaign to educate the public about the importance of controlling blood pressure, especially during midlife, to help reduce the risk of having a stroke and developing dementia later in life. NINDS launched a “reboot” of Mind Your Risks in May 2021, which now includes an even stronger focus on health equity: the primary target audience is Black men ages 28-45, who are at particularly high risk of high blood pressure, stroke, and dementia over the long term. New materials include an updated website, [video](#), social media content, and downloadable flyers. Next steps include strengthening messaging partnerships, especially with community organizations and public stakeholders, and enhancing dissemination efforts.

## **Translations**

Finally, a number of agencies have translated resources related to ADRD into other languages to ensure that individuals with limited English proficiency can access information and programs they may need.

## **Centers for Disease Control and Prevention (CDC)**

- [BRFSS Infographics and Spanish translations](#).
  - CDC's Alzheimer's Disease and Healthy Aging Program created [easy-to-use infographics](#) in English and Spanish that highlight national data on Subjective Cognitive Decline and Caregiving. The data were compiled from CDC's BRFSS, 2015-2018 (combined).



- These infographics provide data for disproportionately affected populations: African Americans; American Indian/Alaska Natives; Asian/Pacific Islander; Hispanic Adults; Women; LGBT; veterans; and rural adults.

### ***National Institute on Aging (NIA)***

- Through the [Recruiting Older Adults into Research \(ROAR\) project](#), first launched in 2013, and in partnership with other federal agencies, NIA collaborated with researchers and private organizations to raise awareness, enhance knowledge, and connect gatekeepers and older adults with easy, actionable opportunities for research participation. The [ROAR toolkit](#) includes customizable materials for aging services and public health professionals to use in community settings and on social media in English, Spanish, and Chinese. Since January 2015, the ROAR toolkit has been viewed more than 14,000 times.
- In February 2021, NIA launched a re-designed [Alzheimers.gov](#) to serve as the federal portal for ADRD content in English and Spanish for an increasingly diverse public audience. The new website features easy-to-read, accessible information on dementias and living with dementia, including information for researchers and community and public health workers. The site also links to NIA's [online portal of resources for clinicians](#), which includes updates on recent research findings; clinical practice tools for assessment, diagnosis, and management of cognitive impairment; training materials; a patient checklist handout in English and Spanish, and other resources. The [Spanish version of the site](#) launched in October 2021.
- NIA uses formative research and communication activities to enhance outreach to underrepresented populations. In 2020, NIA used this approach to develop a set of materials, including videos, print ads, posters, social media, and other multimedia messages, tailored to the Latinx community, in both English and Spanish. A similar approach was used in 2019 to develop materials for African American audiences. Additional formative research and communication activities to enhance outreach to other underrepresented populations will continue to be conducted in subsequent years. Current plans include developing clinical study recruitment materials and messages for Chinese Americans, Filipino Americans, and Indian Americans in English and other languages.

### ***Department of Veterans Affairs (VA)***

- The VA Caregiver Support Program provides Spanish language services to caregivers of veterans, including those veterans with dementia, through a few avenues. The VA Caregiver Center located at the Memphis VA Medical Center offers four group classes on self-care, either in-person or virtually: Managing Stress, Problem Solving and Effective Communication, Taking Care of Yourself, and Utilizing Technology. All materials for caregivers are in Spanish, including a Workbook for each class and other materials, such as a relaxation CD. The Resources for Enhancing All Caregivers Health (REACH VA) provides dementia-specific individual and telephone support group and caregiver interventions offered at facilities in Spanish, with Spanish language Caregiver Notebooks. Additionally, the Peer Support Mentoring Program within the Caregiver Support Program offers a series of four quarterly telephone support group calls for Spanish-speaking caregivers, including those caring for veterans with dementia. Calls cover various topics, including general information about the Caregiver Support Program, Being a Caregiver During COVID-19, Dementia and Caregiving, and What It Means to be a Caregiver.

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