

Special Report

Race, Ethnicity and
Alzheimer's in America



Despite decades of research and calls to action to ensure that health care is accessible and equal for all regardless of gender, race, ethnicity, geography and socioeconomic status, this aim is still far from reality for too many Americans.

Disparities Still Impacting Health and Health Care

Reducing or eliminating disparity has been part of the national conversation as a key goal of the U.S. Department of Health and Human Services' Healthy People initiative for more than 20 years.⁶⁶³⁻⁶⁶⁴ Yet disparity is still evident in health and health care.

While *health disparities* and *health care disparities* are often used interchangeably, there are important distinctions between the two terms. A health disparity exists when there is a higher burden of illness, injury, disability or mortality in one group relative to another, whereas a health care disparity is used to describe differences between groups in health insurance coverage, access to and use of health care, and quality of health care.⁶⁶⁵

The existence and adverse effects of health disparities are well documented. For example, Blacks and Native Americans are more likely than Whites to report a range of health conditions, including asthma and diabetes. Native Americans also have higher rates of heart disease compared with Whites.⁶⁶⁶

The existence of health care disparities is similarly well documented. Non-White racial/ethnic populations and low-income individuals have historically faced greater barriers to accessing care. One reason for this is that they are more likely to be uninsured than Whites and people with higher incomes.⁶⁶⁷

Health and health care disparities are intertwined with social, economic and environmental factors that perpetuate disadvantage. Both health and health care disparities are influenced by socioeconomic status, age, geographic location, gender, disability status and sexual orientation.⁶⁶⁵ Race and ethnicity are also important factors contributing to health and health care disparities.⁶⁶⁵

Health care system factors that contribute to disparity should also be acknowledged. These include implicit bias on the part of health care providers, as well as cultural and language barriers that impede patient-provider relationships.⁶⁶⁵

Understanding how different racial and ethnic groups view, access and experience health care is critical to informing improvements to the health care system and helping health providers care for an increasingly diverse population. The need to do so is urgent. It is projected that people of color will account for over half (52%) of the population in 2050.⁶⁶⁵

Pandemic Sparks New Discussions About Disparities

In 2020, the COVID-19 pandemic and social justice movements sparked new conversations about endemic and long-standing health and health care disparities faced by non-White racial/ethnic populations, especially when it comes to access, discrimination and trust in the health care system.⁶⁶⁸⁻⁶⁶⁹ These populations were disproportionately affected by the environmental, societal and economic impact of the pandemic — facing greater risk of losing a job or income, being more likely to be frontline workers with greater risk of exposure to the SARS-CoV-2 virus that causes COVID-19, and having a higher likelihood of housing uncertainty and food insecurity due to the pandemic.⁶⁷⁰⁻⁶⁷⁴ The effects of these social, economic and environmental factors, known as social determinants of health, can put a population's current and future health in jeopardy. For example, they have created stark contrasts in COVID-19 infection rates and outcomes. Black, Native American and Hispanic communities have seen COVID-19 cases, hospitalizations and deaths at rates greater than Whites, and these events far exceed their share of the U.S. population.⁶⁷⁵⁻⁶⁷⁸

Health Disparity vs. Health Care Disparity⁶⁶⁵

Health disparity: a higher burden of illness, injury, disability or mortality experienced by one group relative to another.

Health care disparity: differences between groups in health insurance coverage, access to and use of care, and quality of care.

Both: differences that are not explained by variations in health needs, patient preferences or treatment recommendations and are closely linked with social, economic and/or environmental disadvantage.

In seeking care for COVID-19, Black Americans nationwide report on social media and in news stories that they experienced bias and discrimination.⁶⁷⁹⁻⁶⁸⁰ One study found that Hispanics were prevented from accessing testing and care for COVID-19 because they lacked insurance and there were shortages of interpreters in local health systems.⁶⁸¹ Language barriers and low health literacy also contributed to misunderstanding of COVID-19–related health information and the spread of misinformation in some Hispanic communities.⁶⁸¹ A separate survey found that Asian and White individuals were more knowledgeable about COVID-19 than Hispanic and non-Hispanic Black individuals; this difference in awareness and understanding could exacerbate existing disparities in health care.⁶⁸²

Racial and Ethnic Disparities Exist in Alzheimer’s and Dementia Care

Racial and ethnic disparities in health and health care, such as those observed during the pandemic, extend to dementia care. Stigma, cultural differences, awareness and understanding, and the ability to obtain a diagnosis, manage the disease, and access care and support services for dementia vary widely depending on race, ethnicity, geography and socioeconomic status. These disparities reach beyond clinical care to include uneven representation of Black, Hispanic, Asian and Native Americans in Alzheimer’s research in clinical trials.

As discussed in the Prevalence section (see page 18), health and socioeconomic disparities and systemic racism contribute to increased Alzheimer’s and dementia risk in underrepresented racial and ethnic groups.^{85,140,217,284,287-289,292-293} Older Black and Hispanic Americans are also disproportionately more likely to have Alzheimer’s and other dementias, as well as more likely to have missed diagnoses, than older White Americans.^{271-277,294-296}

Caregiving for individuals with Alzheimer’s or other dementias differs between racial and ethnic groups too. These differences include the availability of support services, the time spent on caregiving, cultural perceptions of the burden of caregiving, whether social networks provide support, and the psychological well-being of the caregiver.^{384-388, 390}

The State of Disparity in Alzheimer’s and Dementia Health Care: Adult and Caregiver Surveys

To better understand racial and ethnic attitudes and experiences regarding Alzheimer’s and dementia care in the United States, the Alzheimer’s Association commissioned Versta Research to conduct surveys of (1) U.S. adults and (2) current or recent caregivers of adults age 50 or older with cognitive issues. Respondents were asked about access to care and support services, trust in providers and the health care system, participation in clinical trials and research, and caregiver experiences. This is the first Alzheimer’s Association survey to ask and report the views of Asian Americans and Native Americans on these issues. It is also one of the few reports to investigate the experiences of diverse caregivers.³⁸⁷

Key Findings

The Alzheimer’s Association surveys revealed:

Discrimination is a barrier to Alzheimer’s and dementia care.

- More than one-third of Black Americans (36%), and nearly one-fifth of Hispanic Americans (18%) and Asian Americans (19%), believe discrimination would be a barrier to receiving Alzheimer’s care.
- Half of Black Americans (50%) report they have experienced health care discrimination; more than 2 in 5 Native Americans (42%) and one-third of Asian Americans (34%) and Hispanic Americans (33%) likewise report having experienced discrimination when seeking health care.
- Among non-White caregivers, half or more say they have faced discrimination when navigating health care settings for their care recipient, with the top concern being that providers or staff do not listen to what they are saying because of their race, color or ethnicity. This concern was especially high among Black caregivers (42%), followed by Native American (31%), Asian American (30%) and Hispanic (28%) caregivers. Fewer than 1 in 5 White caregivers (17%) expressed this view.
- Two in 5 caregivers (41%) who provide unpaid care to a Black person say that race makes it harder for them to get excellent health care. Nearly 1 in 3 caregivers of Hispanic people (32%) say the same.

People of color want health care providers who understand their unique experiences and backgrounds, but many doubt they would have access to culturally competent providers.

- An overwhelming majority of non-White Americans say it is important for Alzheimer's and dementia care providers to understand their ethnic or racial background and experiences, including Native Americans (92%), Blacks (89%), Hispanics (85%) and Asian Americans (84%).
- But fewer than half of Black (48%) and Native Americans (47%) feel confident there is access to providers who are culturally competent, and only about 3 in 5 Asian Americans (63%) and Hispanics (59%) likewise feel confident.

Black Americans lack trust in research clinical trials, and half doubt that advances in Alzheimer's treatments will be shared.

- Nearly two-thirds of Black Americans (62%) believe medical research is biased against people of color, and Black Americans are less interested in participating in clinical trials for Alzheimer's than all other groups surveyed.
- Only half of Black Americans (53%) trust a future cure for Alzheimer's will be shared equally regardless of race, color or ethnicity.

Knowledge, concern and stigma about Alzheimer's varies widely across racial and ethnic groups.

- Concern about developing Alzheimer's is lower among Native Americans (25%), Blacks (35%) and Hispanics (41%), especially when compared with Whites (48%).
- More than one-third of Native Americans (35%) and nearly 3 in 10 Hispanics (28%) do not believe they will live long enough to develop Alzheimer's or another dementia.
- More than half of non-White Americans believe significant loss of memory or cognitive abilities is "a normal part of aging."
- Hispanic, Black and Native Americans are twice as likely as Whites to say they would not see a doctor if experiencing thinking or memory problems.
- One in 5 Black (21%) and Hispanic Americans (20%) say they would feel insulted if a doctor suggested a cognitive assessment.
- Hispanic and Black Americans worry less than other groups about being a burden on family if they develop Alzheimer's disease.
- Nearly 2 in 3 caregivers (64%) across all groups say that caregiving is stressful, but nearly all (92%) say caregiving is rewarding as well.

Overall, the results of the Alzheimer's Association surveys indicate that despite ongoing efforts to address health

and health care disparities in Alzheimer's and other dementias, there is still much work to do. Non-White racial/ethnic populations face more challenges in accessing and receiving high quality dementia care and support services in the current environment. The data suggest that discrimination and lack of diversity in the health care profession are significant barriers that demand attention.

Survey Design and Research Methods

Surveys across both groups explored wide-ranging issues related to Alzheimer's and dementia care, including:

- Knowledge and understanding of the disease.
- Access to care and support services.
- Trust in health care, providers and disease research.
- Interest in clinical trials.
- Existence of discrimination and how that impacts care.

Survey of U.S. Adults

A survey of 2,491 U.S. adults age 18 and older was conducted from October 26, 2020, to November 11, 2020. Data was collected by NORC at the University of Chicago via the AmeriSpeak® panel. AmeriSpeak is a probability-based panel of all U.S. households. The survey included 945 White respondents. Oversamples of Hispanic (n=541), Black (n=515) and Asian Americans (n=412) were weighted back to their true population proportions for statistical analysis and reporting. For full inclusion of Native Americans, the same survey was administered to an additional sample of 406 Native Americans recruited through online (non-probability) panels with sampling stratified and data weighted on gender, age, income and education to match U.S. Census Bureau data. The survey was offered in both English and Spanish.

Survey of Caregivers

A survey of 1,392 U.S. adults who were current or recent unpaid caregivers for an adult relative or friend age 50 or older experiencing problems with thinking, understanding or remembering things was conducted from October 21, 2020, through November 22, 2020. The sample included White (n=313), Hispanic (n=309), Black (n=305), Asian (n=301) and Native American caregivers (n=154), and caregivers who identified as belonging to another ethnic or racial group (n=10). Respondents were recruited via non-probability online panels used exclusively for research, with full population screening and respondent data weighted to match U.S. Census data on age, gender, income, education and race/ethnicity to ensure accurate representation of the caregiving population, and to correct for demographic oversamples. The survey was offered in both English and Spanish.

For both surveys, differences noted in the report between racial and ethnic groups were tested and found to be statistically significant at the p<.05 level.

TABLE 20

Perceived Barriers to Getting Excellent Health Care and Support for Alzheimer's or Another Dementia Among U.S. Adults

	White Americans	Hispanic Americans	Black Americans	Asian Americans	Native Americans
Affordability of care	61%	55%	52%	70%	61%
Lack of good health care insurance coverage	31%	41%	31%	39%	36%
Lack of good health care services in my community	20%	24%	27%	27%	24%
Lack of family and social support to help me	20%	21%	20%	25%	20%
Being treated differently because of my race, color or ethnicity	1%	18%	36%	19%	12%
Not being able to communicate easily in English	4%	9%	9%	8%	5%
Other barriers	2%	1%	1%	1%	2%
There would be no barriers	21%	17%	20%	12%	14%

TABLE 21

Types of Discrimination Based on Race, Color or Ethnicity Among Alzheimer's and Dementia Caregivers

	White Americans	Hispanic Americans	Black Americans	Asian Americans	Native Americans
Felt not listened to	17%	28%	42%	30%	31%
Provider acted like you were not smart	11%	26%	28%	28%	43%
Treated with less courtesy than others	11%	26%	26%	23%	22%
Treated with less respect than others	8%	24%	26%	20%	27%
Received poorer service than others	7%	21%	19%	10%	18%
Provider acted afraid of you	7%	11%	13%	7%	4%

Survey Results

Discrimination Continues to be a Barrier to Dementia Care

The Alzheimer's Association survey of U.S. adults found that more than one-third of Black Americans (36%) and one-fifth of Hispanic (18%) and Asian (19%) Americans see discrimination as a barrier to receiving Alzheimer's and dementia care (Table 20). Specifically, they expect to be treated differently because of their race, color or ethnicity.

Other perceived barriers to care cited by survey respondents include affordability (especially among Asian Americans), followed by lack of good health insurance coverage, lack of good local health care (especially among Black Americans and Asian Americans), and lack of family and social support. Fewer respondents saw language as a barrier to receiving dementia care, but among current

caregivers, almost 1 in 4 Asian Americans (23%) and nearly 1 in 5 Hispanic caregivers (17%) cited language as a barrier to care.

When asked more directly about the impact of race or ethnicity on the quality of care, two-thirds of Black Americans (66%) believe it is harder for Black Americans to get excellent care for Alzheimer's disease or other dementias. Likewise, 2 in 5 Native Americans (40%) and Hispanic Americans (39%) believe their own race or ethnicity makes it harder to get care, as do one-third of Asian Americans (34%).

Caregivers, too, see discrimination as a top barrier, with 1 in 4 Black caregivers (25%) citing discrimination as a barrier, followed by Native American (19%), Asian American (17%) and Hispanic (8%) caregivers. In fact, more than half of Native American (63%), Black (61%) and Hispanic (56%)

caregivers report having *experienced* racial discrimination when navigating health care settings for their care recipient. The same is true for nearly half of those who are Asian American (47%). Two in 5 caregivers (41%) who provide unpaid care to a Black person say that race makes it harder for them to get excellent health care. Nearly 1 in 3 caregivers of Hispanic people (32%) say the same.

What specifically have caregivers experienced? The top problem cited was that providers or staff do not listen to them because of their race, color or ethnicity (Table 21). This was especially high among Black caregivers (42%), followed by Native American (31%), Asian American (30%) and Hispanic (28%) caregivers. Fewer than 1 in 5 White caregivers (17%) expressed this same view. More than 1 in 4 non-White caregivers report health care providers treating them as if they were “not smart” (Native American, 43%; Asian American, 28%; Black, 28%; and Hispanic, 26%) compared with about 1 in 10 White (11%) caregivers. In addition, at least one-fifth of non-White caregivers report being treated with less courtesy and/or less respect.

Not surprisingly, the belief among non-White Americans (not just caregivers) that discrimination is a barrier to Alzheimer’s and dementia care is rooted in their own experiences with the health care system. Half of Black Americans (50%), more than 2 in 5 Native Americans (42%) and a third of all Asian (34%) and Hispanic (33%) Americans report having *experienced* discrimination when seeking health care (see Figure 18, page 76). In contrast, fewer than 1 in 10 White Americans (9%) report having experienced discrimination because of their race, color or ethnicity.

Desire for Providers Who Understand Ethnic or Racial Background

Given their own experiences with discrimination, it is not surprising that non-White racial/ethnic populations feel it is important for Alzheimer’s and dementia care providers to be more culturally competent. Responses from both surveys indicate a strong desire for dementia care providers who understand different racial and ethnic backgrounds, but many survey respondents say access to these providers is lacking.

Figure 19 (see page 77) shows responses to two questions that were tailored to a respondent’s race or ethnicity. For example, Black respondents were asked: “How important do you feel it is for Black people with Alzheimer’s or other dementias to have health care providers who understand their background and experiences as Black people?” And then: “How confident are you that Black people with Alzheimer’s or other dementias have access to health care providers who understand their background and experiences as Black people?”

An overwhelming majority of non-White respondents said it was important for Alzheimer’s and dementia care providers to understand their ethnic or racial background and experiences, including Native Americans (92%), Black Americans (89%), Hispanic Americans (85%) and Asian Americans (84%). However, fewer than half of Black respondents (48%) and Native American respondents (47%) felt confident that people in their communities with Alzheimer’s or other dementias currently have access to such providers, and fewer than two-thirds of Asian Americans (63%) and Hispanic Americans (59%) felt the same.

The survey of caregivers mirrored these results. Among those caring for a non-White person, most felt it was important for health care providers to understand the ethnic or racial background and experiences of the person they are caring for, including 96% of those caring for Native Americans, 94% of those caring for Asian Americans, 91% of those caring for Black Americans and 89% of those caring for Hispanic Americans.

Far fewer caregivers rated their current health care providers as being “excellent” or “good” when it comes to understanding the ethnic or racial background and experiences of the person they are caring for (Native Americans, 67%; Hispanic Americans, 65%; Black Americans, 61%; and Asian Americans, 53%).

Belief That Research Is Biased Is More Common Among Non-Whites; Blacks Do Not Believe a Cure Will Be Shared Equally

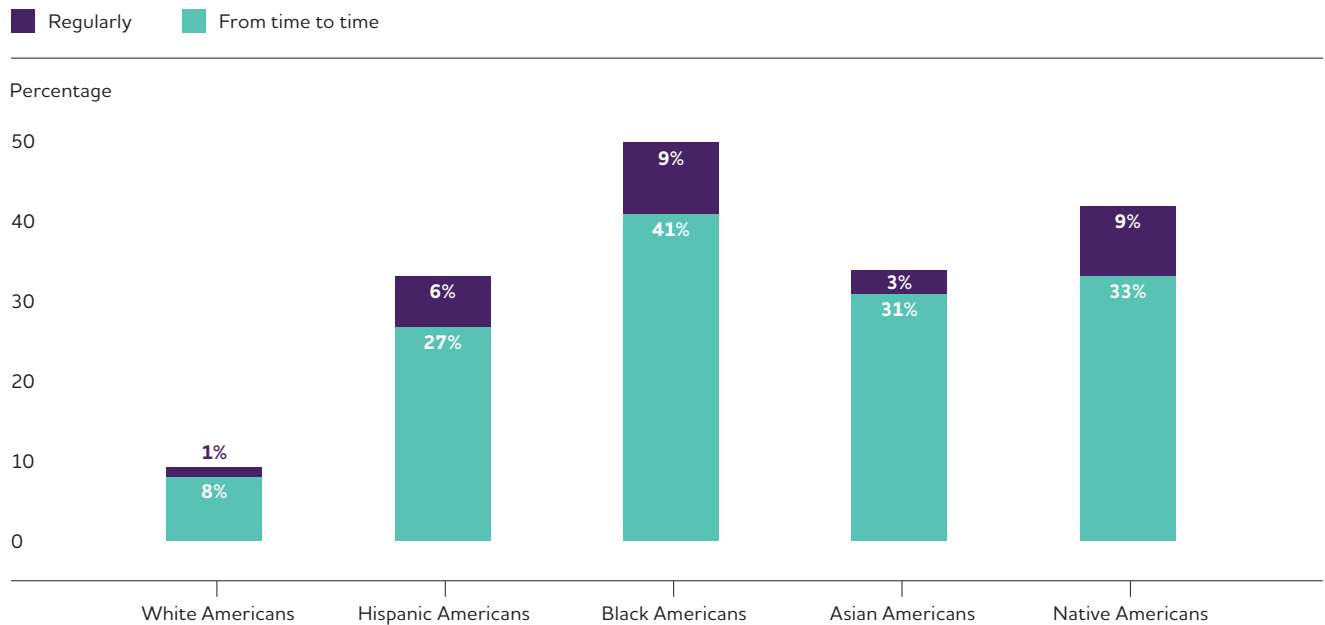
The experiences and views of discrimination expressed by respondents in both surveys are reflected in their views on clinical trials, research and potential treatment for Alzheimer’s and other dementias.

A majority of Black Americans (62%) believe that medical research is biased against people of color — a view shared by substantial numbers of Asian Americans (45%), Native Americans (40%) and Hispanic Americans (36%) as well. Notably, even a third of White Americans (31%) see medical research as being biased against people of color (see Figure 20, page 78).

It’s not surprising, then, that among Americans as a whole, Blacks have less interest in clinical research trials to prevent or slow the progression of Alzheimer’s disease. White Americans are most likely to express interest (82%), followed by Native Americans (81%), Hispanic Americans (78%), Asian Americans (73%) and lastly, Black Americans (67%).

FIGURE 18

Percentage of U.S. Adults Who Have Experienced Racial or Ethnic Discrimination When Seeking Health Care



Responses from caregivers present a somewhat different picture. Compared with other groups, Black caregivers and Hispanic caregivers are somewhat more interested in clinical trials for their care recipient (Black caregivers, 73%; Hispanic caregivers, 70%), while Asian American caregivers are least interested in having their care recipient be involved in clinical research (57%). Overall, interest in clinical trial participation was higher in both Alzheimer’s Association surveys than is reflected in current trial participation, particularly for non-White racial/ethnic populations.⁶⁸³ Follow-up research is needed to better understand mitigating factors that may prevent interested individuals from actual trial participation.

Among U.S. adults who are not interested in clinical trial participation, the most common reason cited regardless of race or ethnic group is not wanting to be a “guinea pig” (see Table 22, page 79). This sentiment is especially strong among Black Americans (69%), for whom other differences stand out as well. For example, almost half of Black Americans (45%) worry that treatments might cause sickness. They are twice as likely as other groups to say they “don’t trust medical research.” And they are more than twice as likely than other racial or ethnic groups to say they “might not be treated fairly.”

A noteworthy difference for Asian Americans is that the potential time and cost of clinical trials ranks second among

their reasons for not wanting to participate; this reason was cited by 43% of respondents.

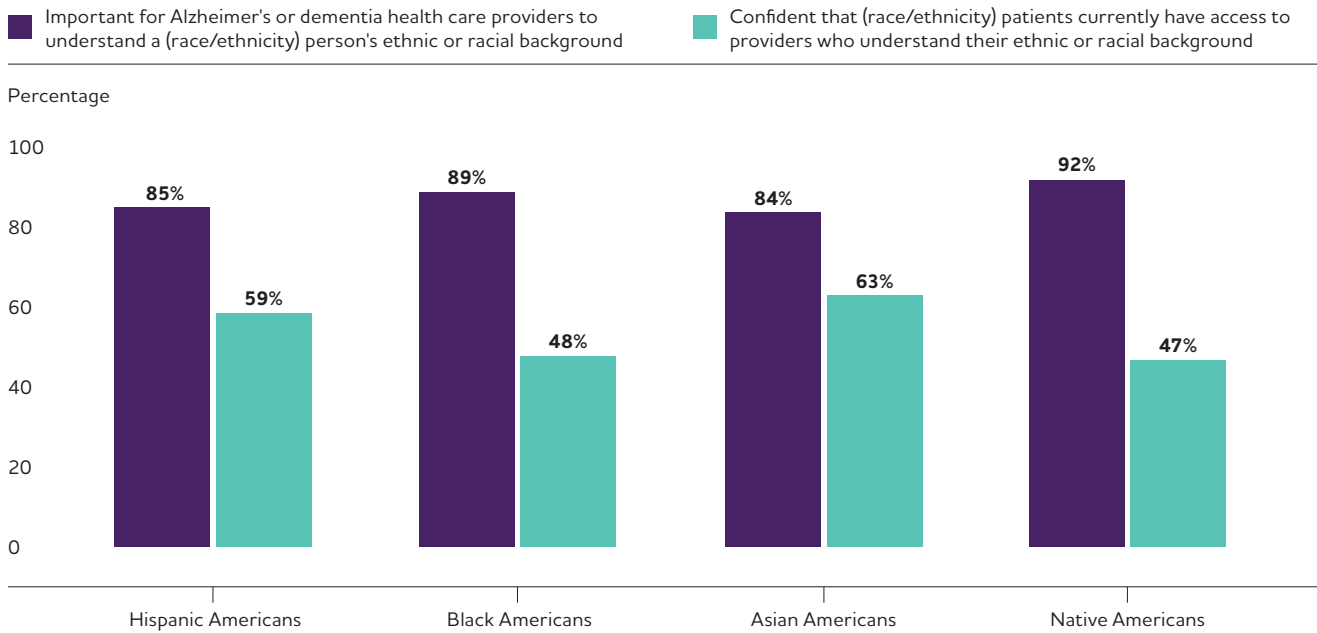
For caregivers, reasons for lack of interest were more varied. Black caregivers were most focused on lack of perceived benefit (35%) and not wanting the person to be a guinea pig (32%). Hispanic caregivers were most focused on not wanting a placebo treatment (28%). Asian American caregivers were twice as likely as others to say the person might not be treated fairly (20%). Native American caregivers were more focused on not wanting the person to be a guinea pig (40%) and potential lack of support among family and community (39%).

The impact of discrimination and bias is also apparent in respondents’ views on treatment access. Should clinical trials identify a treatment or “cure” for Alzheimer’s disease, only half of Black Americans (53%) trust that this cure will be shared equally regardless of race, color or ethnicity (see Figure 21, page 78). This is in sharp contrast to White Americans (75% of whom believe it will be shared) and lower than other racial and ethnic groups as well, including Asian Americans (69%), Hispanic Americans (66%) and Native Americans (65%).

While the majority of both White and non-White Americans trust health care providers generally, trust is somewhat weaker among Hispanic, Black and Native Americans. Asian Americans are most likely to say

FIGURE 19

Access to Health Care Providers Who Understand Racial and Ethnic Backgrounds Among U.S. Adults



they trust health care providers (93%), followed by White Americans (88%), with lower numbers for Black Americans (82%), Hispanic Americans (81%) and Native Americans (79%).

Perhaps related to this, Hispanic, Black and Native Americans are twice as likely as White Americans to say they would not see a doctor if they were experiencing thinking or memory problems. Almost 1 in 10 Hispanics (9%), Blacks (8%) and Native Americans (9%) say they would not see a health care provider, versus 1 in 25 White Americans (4%). Six percent of Asian Americans say they would not see a health care provider.

One in 5 Black Americans (21%) and Hispanic Americans (20%) say they would feel insulted if a doctor suggested an assessment for their thinking or memory, versus half as many White Americans who would feel insulted (10%). About 1 in 6 Asian Americans (16%) would feel insulted, as would 1 in 7 Native Americans (14%).

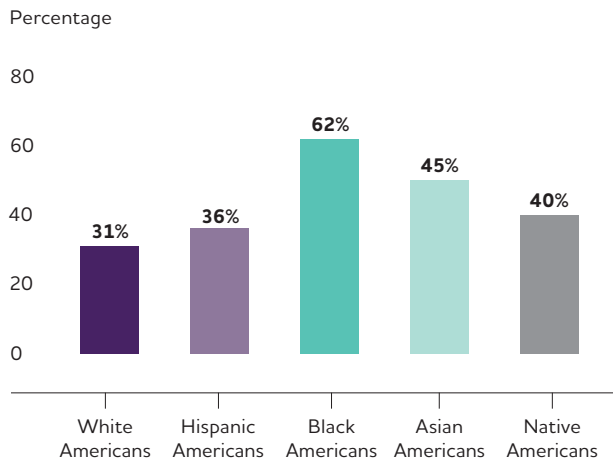
Hispanics are also least confident they would be able to access quality health care for Alzheimer's disease or other dementias if they needed it, especially compared with White Americans. In particular, fewer Hispanic Americans express confidence in being able to get excellent health care for specialist testing and diagnosis (69% versus 79% of White Americans) and health care and support to manage the disease (67% versus 74% of White Americans).

Knowledge and Understanding of Alzheimer's Disease Varies

The Alzheimer's Association survey of U.S. adults also revealed that fewer non-White Americans report knowing someone with Alzheimer's. Four in 5 White Americans (80%) report having known somebody with Alzheimer's or another type of dementia. The numbers among all other groups are 15 to 20 percentage points lower (Hispanic Americans, 64%; Black Americans, 65%; Asian Americans, 59%; and Native Americans, 65%).

Native Americans are least worried about developing Alzheimer's disease, with 1 in 4 (25%) expressing concern, followed by 1 in 3 Black Americans (35%) and 2 in 5 Hispanic Americans (41%). In contrast, almost half of White Americans (48%) worry about it, as do nearly as many Asian Americans (46%). Hispanic and Native Americans are also more likely than other groups to believe they will not live long enough to get Alzheimer's or another dementia. More than a third of Native Americans (35%) and one-quarter of Hispanic Americans (28%) believe they will not live long enough, versus fewer than 1 in 4 Asian Americans (19%), Black Americans (20%) and White Americans (23%).

Additionally, more than half of non-White Americans believe that significant loss of memory or cognitive abilities is a "normal part of aging" rather than being an indicator of disease (Hispanic Americans, 57%; Asian Americans, 56%; Black Americans, 55%; and Native Americans, 53%).

FIGURE 20**Percentage of U.S. Adults Who Believe Medical Research Is Biased Against People of Color**

This is in contrast to White Americans, among whom fewer than half (48%) believe that memory loss or cognitive decline is normal.

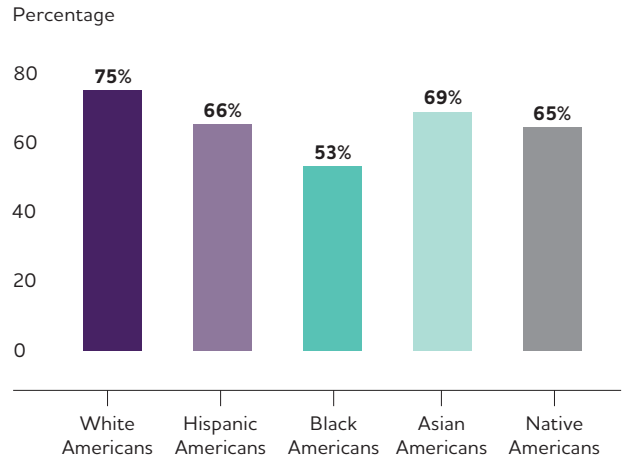
Caregiving Is Stressful But Rewarding

The Alzheimer's Association survey of caregivers provided additional insights, indicating that for many family and friends who provide care for a loved one, the rewards of providing care may help balance the stress.

Over half of unpaid caregivers surveyed report providing assistance with personal care, such as bathing, eating or dressing. The percentage providing this form of care is highest among Black caregivers (71%) and Hispanic caregivers (68%), followed by Asian American caregivers (59%), Native American caregivers (56%) and White caregivers (53%).

Fewer Black Americans (78%) and Hispanic Americans (83%) worry about being a burden on family if they develop Alzheimer's disease compared with other groups (White Americans, 93%; Asian Americans, 90%; Native Americans, 84%).

And while nearly 2 in 3 caregivers (64%) say that caregiving is stressful, nearly all (92%) say that caregiving is rewarding, as well.

FIGURE 21**Percentage of U.S. Adults Who Trust an Alzheimer's Cure Will Be Shared Equally Regardless of Race, Color or Ethnicity****Bridging Racial and Ethnic Barriers in Alzheimer's and Dementia Care: A Path Forward**

Findings from the Alzheimer's Association surveys indicate that despite ongoing efforts to address health and health care disparities in Alzheimer's and dementia care, there is still much work to do.

Current efforts to reduce health disparities, address social determinants of health, build diversity in the health care profession and train health care providers to meet the needs of a growing population of older adults from different racial and ethnic groups must be accelerated. Amid broader calls for social justice, greater strides must be made to eliminate discrimination and other forms of bias to ensure all Americans have access to high quality dementia care and support services, as well as opportunities to participate in — and benefit from — Alzheimer's research.

Based on the surveys' findings, paths forward include:

- Preparing the workforce to care for a racially and ethnically diverse population of older adults.
- Increasing diversity in dementia care.
- Engaging, recruiting and retaining diverse populations in Alzheimer's research and clinical trials.

TABLE 22

Reasons Cited By U.S. Adults for Not Being Interested in Clinical Trial Participation

	White Americans	Hispanic Americans	Black Americans	Asian Americans	Native Americans
Don't want to be a guinea pig	49%	51%	69%	54%	51%
Treatment might cause sickness	37%	36%	45%	32%	18%
Time and cost might be too much	33%	26%	24%	43%	31%
Don't trust pharmaceutical companies	28%	22%	29%	19%	26%
Doubt there would be any benefit	26%	26%	21%	28%	36%
Might get placebo	17%	12%	14%	20%	9%
Don't trust medical research	10%	10%	24%	6%	16%
Unable to travel or get transportation	11%	11%	16%	19%	23%
Might not be treated fairly	3%	8%	22%	12%	10%

Preparing the Workforce to Care for a Racially and Ethnically Diverse Population of Older Adults

As described in the Prevalence Section (see page 18), older Black and Hispanic Americans are more likely to have Alzheimer's or other dementias than Whites, and this is likely due in part to health and health care disparities.^{85,87,271-277, 284, 285,287-288} Coinciding with increasing diversity in the general population, the number of older Americans, particularly the oldest-old (those age 85 or older), is also expected to grow — with more than twice as many cases of Alzheimer's and other dementias anticipated by 2050.²¹⁶ Up to 39% of this older adult population in 2050 will be minorities.⁶⁸⁴⁻⁶⁸⁵

Current and future health care providers need to be prepared to screen, diagnose and treat Alzheimer's and dementia in this expanding racially and ethnically diverse population of older adults so that disparities are not perpetuated.

Earlier reports on racial and ethnic differences in Alzheimer's health care have proposed cultural competence education as one solution to address disparities. Training providers to recognize and overcome implicit bias is another method that organizations are using to tackle disparities.

Cultural Competence

At the organizational level, cultural competence helps build a diverse and inclusive workforce.⁶⁸⁶ At the provider level, cultural competence training equips professionals with the skills and resources needed to connect with dementia care recipients and caregivers across racial and ethnic groups in a way that is sensitive to culture and language.⁶⁸⁷

Elements of Cultural Competence⁶⁸⁷

- A culturally diverse staff that reflects the population served.
- Ability to overcome language barriers, either with bilingual staff or interpreters.
- Training for providers on the cultures and languages represented in the population.
- Patient materials and practice signage that are translated and sensitive to cultural norms.

There have been several efforts to instill cultural competence into dementia care. Stanford Health Care's Memory Support Program (MSP) is one such example. The model's efforts encompass culturally competent care in inpatient and outpatient settings to ensure continuity for patients and caregivers.⁶⁸⁸ A case study showed that MSP is a valuable way to provide culturally competent care to African Americans and posits this model could be implemented in other settings.⁶⁸⁸ Cultural competence

training has also been proposed as a component of Alzheimer's and dementia nursing and nursing assistant training curricula.⁶⁸⁹

Other organizations that engage health care providers who may screen and treat individuals with dementia are also committed to cultural competence. The U.S. Department of Health and Human Services' National Culturally and Linguistically Appropriate Services (CLAS) Standards offer information to improve communication with people from different ethnic groups in a way that is respectful and responsive to their culture.^{684,690} Recognizing the changing racial and ethnic demographics of Alzheimer's disease, the Alzheimer's Association began promoting cultural competence and cultural sensitivity in dementia care more than a decade ago and this effort remains a priority.⁶⁹¹ In 2016, the American Geriatrics Society (AGS) formed an Ethnogeriatrics Committee that issued a guidance stressing the importance of cultural competence in geriatric care.⁶⁸⁴ An Ethnogeriatrics Special Interest Group now convenes at the annual AGS meeting to discuss ongoing projects and new developments in the field.⁶⁹²

Implicit Bias

Implicit bias, or when people act unintentionally on prejudices or stereotypes, is a key contributor to health care disparities.⁶⁹³⁻⁶⁹⁴ Implicit bias clouds decision-making such that race, gender, ethnicity and other patient characteristics influence how physicians treat people. Medical schools are responding to the call to action to train future physicians to recognize and overcome implicit bias. Hospitals, clinics and health care systems are also working to address this issue among their employees.⁶⁹⁵

Although the Alzheimer's Association surveys did not explore how implicit bias is impacting dementia care, respondents did indicate that they faced discrimination. Discriminatory behaviors are often the result of implicit bias.⁶⁹⁶ A survey indicates that implicit bias held by the investigators and clinical trial recruiters in the field of cancer research may be a reason for the low recruitment and participation of racial and ethnic minorities in cancer clinical trials.⁶⁹⁷ Less has been reported on how implicit bias contributes to low participation rates in Alzheimer's and dementia research and suggests an area for future investigation.

There is little information about the implementation and outcomes of implicit bias training specifically in Alzheimer's and dementia care. However, specialties that play a role in dementia care, such as primary care/family medicine and geriatric medicine, do have materials to train providers. For example, the National Institute on Aging (NIA) offers resources on implicit bias for those who care for older adults, and The EveryONE Project from the American Academy of Family Physicians recently introduced the

comprehensive Implicit Bias Training Guide for primary care physicians.⁶⁹⁸⁻⁷⁰⁰

Increasing Diversity in Dementia Care

Trust in health care and perceptions of health care quality are eroded when individuals experience racial and ethnic discrimination in clinical settings. An analysis of data from the 2015 to 2016 Adult California Health Interview Survey found that discrimination in a clinical setting "make[s] a person less likely to have a future interaction with health care," such as by not receiving medical care when necessary or not filling prescriptions.⁷⁰¹

The Alzheimer's Association surveys uncovered weaker trust in the health care system among Hispanics, Blacks and Native Americans. The same groups were also less likely to see a health care provider for diagnosis or treatment of Alzheimer's disease. This could exacerbate existing health disparities. Non-Whites surveyed already face discrimination and anticipate encountering future discrimination when seeking Alzheimer's care, and as a result want to see their racial and ethnic backgrounds reflected in their Alzheimer's and dementia health care providers.

Currently, only 1 in 3 U.S. physicians are Black, American Indian or Alaska Native, Hispanic or Asian.⁷⁰² Primary care is more diverse, which is encouraging. Approximately 40% of primary care physicians are Black, Hispanic, American Indian or Alaska Native.⁷⁰³ As discussed in the Alzheimer's Association *2020 Alzheimer's Disease Facts and Figures Special Report*,⁵³¹ primary care physicians play an important role in diagnosing and caring for people with Alzheimer's and other dementias. The survey results presented earlier indicate that Hispanic Americans may rely on their primary care providers more than other groups to test for and diagnose Alzheimer's disease because they face barriers to accessing specialists. Ensuring diversity in these frontline providers may help reduce future disparities in dementia care. Diversity in other related specialties, such as neurology and geriatric medicine, however, remains low.⁷⁰⁴⁻⁷⁰⁵

Shortages of physicians and other health care professionals in underserved areas contribute to health disparities. The racial and ethnic diversity of medical school applicants is not keeping pace with shifting demographics of the U.S. population. Half of applicants are White and almost one-quarter are Asian.⁷⁰⁶ Together, Blacks, Hispanics, individuals who are Latino or of Spanish origin, and American Indians or Alaska Natives make up only 15% of applicants.⁷⁰⁴ Since Blacks and American Indians or Alaska Natives enrolled in medical school are two to three times more likely than their White or Asian American counterparts to practice in an underserved area, it is important to support programs that recruit diverse students to medical schools in greater numbers.⁷⁰⁷

Developing a workforce that reflects the demographics of individuals with Alzheimer's or other dementias should begin during outreach and recruitment to training programs, continue with programming designed to support racially and ethnically diverse students during their training years, and extend to offering residency opportunities in health care settings that treat diverse populations. In addition, hiring practices should consider diversity and inclusion to meet the needs of local patient populations.

Future Alzheimer's and dementia research can be strengthened by increasing the diversity of investigators and professionals who conduct clinical trial and population health research. Doing so introduces varied perspectives, lived experiences and cultural nuances vital to culturally accountable research. For example, one study found that Black community liaisons were able to successfully recruit Black participants to a dementia clinical trial when they were the ones to explain and manage trial procedures.⁷⁰⁸

The innovative Institute on Methods and Protocols for Advancement of Clinical Trials in Alzheimer's disease and related dementias (IMPACT-AD) program launched in fall of 2020 is a step toward this goal.⁷⁰⁹ A major emphasis of this intensive training course is to enhance future Alzheimer's and dementia research, especially clinical trials. IMPACT-AD includes efforts to ensure program participants reflect diversity across the spectrum. Its inaugural class included physicians, nurses, public health professionals, scientists and study coordinators, as well as postdoctoral researchers and research fellows from universities and health care systems across the country. Participants included both early-career and established professionals. Seventy percent were women and more than half self-identified as people of color.

Engaging, Recruiting and Retaining Diverse Populations in Alzheimer's Research and Clinical Trials

There is a large body of evidence demonstrating low diversity in clinical trials and research, and in Alzheimer's research the participants are mostly older non-Hispanic Whites.⁷¹⁰⁻⁷¹² Efforts to ensure greater diversity in Alzheimer's disease research and clinical trials must be accelerated. Without appropriate participation by Black, Hispanic, Asian and Native Americans in Alzheimer's clinical trials and research, it is impossible to get a complete understanding of how racial and ethnic differences may affect the efficacy and safety of potential new treatments. Future clinical trials must do more to reflect the entire population so everyone benefits from advances in Alzheimer's research.

A critical first step to increasing diverse participation and representation in clinical research is building and restoring trust in underrepresented communities. One way to do so

is through community-based organizations (CBOs) and other respected local partners.⁷¹⁰ These efforts are gaining traction but should be expanded to more groups and more communities. The Healthy Brain Initiative *State and Local Public Health Partnerships to Address Dementia: 2018-2023 Road Map*, launched in partnership with the Alzheimer's Association and the Centers for Disease Control and Prevention (CDC), is organized around a core principle of "eliminating disparities and collaborating across multiple sectors." In addition, the Alzheimer's Association and CDC collaborated to develop the first-ever *Healthy Brain Initiative Road Map for Indian Country*. The Association has used this guidebook to build relationships with American Indian/Alaska Native communities, raise awareness about Alzheimer's and collaborate with national partners on communications tailored to the unique tribal traditions present in American Indian/Alaska Native communities.⁷¹³⁻⁷¹⁴

To succeed, relationships with CBOs must demonstrate that they are sustainable, transparent and integrated with other public health efforts. Strong community relationships can serve to address misconceptions and mistrust about research because the community has a sense of ownership in the research initiative.⁷¹⁵⁻⁷¹⁶ Participants are stakeholders rather than bystanders or subjects in the endeavor. This could make a difference in reinstating trust that Alzheimer's treatments or cures will be shared equitably. For example, a recent report suggests that strong commitment to earning the trust of the Black community is essential to encourage their participation in research.⁷¹⁷

The Alzheimer's Association is working with several CBOs and other groups to educate and engage diverse communities about Alzheimer's disease and care and support services the Association provides. National partnerships include those with the African Methodist Episcopal Church, the National Hispanic Council on Aging and SAGE (Advocacy & Services for LGBTQ Elders). In early 2021, the Association announced new partnerships with the Thurgood Marshall College Fund and Tzu Chi USA. Local Association chapters are also working with various nearby groups to engage diverse communities. In addition, several chapters are working with *promotoras de salud* (community health workers) to provide Alzheimer's education and resources to Spanish-speaking communities.

Other notable but relatively new efforts to increase recruitment and retention of diverse groups are also underway. In 2018, the NIA released its National Strategy for Recruitment and Participation in Alzheimer's and Related Dementias Research. The strategy outlines practical, proactive approaches to help dementia study sites engage a wider, more diverse group of volunteers.⁷¹⁸

New guidance released in late 2020 by the U.S. Food and Drug Administration aimed at enabling greater diversity in clinical trials through changes to eligibility criteria, enrollment practices and trial designs is a welcome development. This guidance offers new approaches to help Alzheimer's and dementia researchers navigate current barriers that hinder clinical trial recruitment of racial and ethnic minorities. These barriers include strict eligibility requirements, participant burden, and lack of culturally appropriate communication and outreach to build trust with these diverse populations.⁷¹⁹

In December 2020, the Alzheimer's Association and the American College of Radiology announced the opening of recruitment for the New IDEAS study with particular focus on outreach in Black and Hispanic communities. New IDEAS will enroll 7,000 participants, including 2,000 Hispanics/Latinos and 2,000 Blacks/African Americans. New IDEAS will build upon the original IDEAS study, which provided the strongest phase 4 data to date supporting the clinical value of brain amyloid positron emission tomography (PET) scans. The goal of New IDEAS is to determine if using a brain amyloid PET scan can help inform an individual's memory care plan and improve their health outcomes.⁷²⁰⁻⁷²²

Conclusion

The Alzheimer's Association surveys of U.S. adults and caregivers of individuals with cognitive issues are among the first to explore perspectives and experiences of different racial and ethnic groups as they relate to health care for Alzheimer's and other dementias. Collectively, the responses indicate that organizations must remain committed to addressing health and health care disparities for older adults. Disparities in Alzheimer's and dementia care are the result of deeply rooted issues in society and the health care system. The NIA Health Disparities Research Framework⁷²³ recommends responses that are multi-level and consider factors and risks over the lifecourse to address these disparities. Actions and solutions are needed to ensure that the already devastating burden of Alzheimer's disease and other dementias on disproportionately affected racial and ethnic groups is not made worse by discrimination and health inequities in the current health care system.

Appendices

End Notes

- A1. Estimated prevalence (number and proportion) of Americans age 65 and older with Alzheimer's dementia for 2021: The number 6.2 million is from updated prevalence estimates based on data from the Chicago Health and Aging Project (CHAP) and population projections from the U.S. Census.²¹⁶ The number is higher than previous estimates from CHAP data and the US census because it used more recently updated Census projections and incorporated information on the prevalence of Alzheimer's dementia for Hispanic/Latino Americans.
- A2. Differences between CHAP and ADAMS estimates for Alzheimer's dementia prevalence: The number of people in the U.S. living with Alzheimer's dementia is higher in CHAP than in the Aging, Demographics, and Memory Study (ADAMS).^{216,219} This discrepancy is mainly due to two differences in diagnostic criteria: (1) a diagnosis of dementia in ADAMS required impairments in daily functioning and (2) people determined to have vascular dementia in ADAMS were not also counted as having Alzheimer's, even if they exhibited clinical symptoms of Alzheimer's.²¹⁸ Because the more stringent threshold for dementia in ADAMS may miss people with mild Alzheimer's dementia and because clinical-pathologic studies have shown that mixed dementia due to both Alzheimer's and vascular pathology in the brain is very common,²² the Association believes that the larger CHAP estimates may be a more relevant estimate of the burden of Alzheimer's dementia in the United States.
- A3. State-by-state prevalence of Alzheimer's dementia: These state-by-state prevalence numbers are based on an analysis of incidence data from CHAP, projected to each state's population for 2020 and 2025, with adjustments for state-specific age, gender, years of education, race and mortality.²³⁹ These projections come from a previous analysis of CHAP data that is not the same as the analysis providing the total number for the United States in 2021. State-by-state projections are not available for 2021.
- A4. Criteria for identifying people with Alzheimer's or other dementias in the Framingham Heart Study: From 1975 to 2009, 7,901 people from the Framingham Study who had survived free of dementia to at least age 45, and 5,937 who had survived free of dementia until at least age 65 were followed for incidence of dementia.²⁴⁴ Diagnosis of dementia was made according to the *Diagnostic and Statistical Manual of Mental Disorders, 4th Edition (DSM-IV)* criteria and required that the participant survive for at least 6 months after onset of symptoms. Standard diagnostic criteria (the NINCDS-ADRDA criteria from 1984) were used to diagnose Alzheimer's dementia. The definition of Alzheimer's and other dementias used in the Framingham Study was very strict; if a definition that included milder disease and disease of less than six months' duration were used, lifetime risks of Alzheimer's and other dementias would be higher than those estimated by this study.
- A5. Projected number of people with Alzheimer's dementia, 2020-2060: This figure comes from the CHAP study.²¹⁶ Other projections are somewhat lower (see, for example, Brookmeyer et al.²²⁴) because they relied on more conservative methods for counting people who currently have Alzheimer's dementia.^{A2} Nonetheless, these estimates are statistically consistent with each other, and all projections suggest substantial growth in the number of people with Alzheimer's dementia over the coming decades.
- A6. Annual mortality rate due to Alzheimer's disease by state: Unadjusted death rates are presented rather than age-adjusted death rates in order to provide a clearer depiction of the burden of mortality for each state. States such as Florida with larger populations of older people will have a larger burden of mortality due to Alzheimer's — a burden that appears smaller relative to other states when the rates are adjusted for age.
- A7. Number of family and other unpaid caregivers of people with Alzheimer's or other dementias: To calculate this number, the Alzheimer's Association started with data from the Behavioral Risk Factor Surveillance System (BRFSS) survey. Between 2015 and 2019, 44 states and the District of Columbia utilized the BRFSS caregiver module. This module identified respondents age 18 and over who had provided any regular care or assistance during the past month to a family member or friend who had a health problem, long-term illness or disability. The module asks a series of follow-up questions, including asking the caregiver to identify what the main health problem, long-term illness, or disability that the person they care for has. One of the reported condition categories is Alzheimer's disease, dementia, or other cognitive impairment. This number does not include caregivers whose caregiving recipient has dementia, but is not their main condition. To calculate the total percentage of adults that are caregivers for individuals living with dementia, data collected in 2019 by the National Alliance for Caregiving (NAC)/AARP was also utilized. The NAC/AARP survey asked respondents age 18 and over whether they were providing unpaid care for a relative or friend age 18 or older or had provided such care during the past 12 months. Respondents who answered affirmatively were then asked about the health problems of the person for whom they provided care: 11% of respondents reported dementia as the main condition of their care recipient, while 26% of all respondents reported the presence of dementia. Using this ratio in combination with BRFSS data, the Alzheimer's Association was able to determine the percentage of adults in 44 states and the District of Columbia who are caregivers for individuals living with Alzheimer's or another dementia. For the 6 states without 2015-2019 BRFSS data, this percentage was estimated using state-specific BRFSS data from 2009 combined with the aggregated average of BRFSS data from 2015-2017. To determine the number of Alzheimer's and dementia caregivers in each state, the percentages were applied to the estimated number of people age 18 and older in each state in July 2020, using U.S. Census Bureau data available at: <https://www.census.gov/programs-surveys/popest/technical-documentation/research/evaluation-estimates.html>. This resulted in a total of 11.199 million Alzheimer's and dementia caregivers across all 50 states and the District of Columbia.
- A8. The 2014 Alzheimer's Association Women and Alzheimer's Poll: This poll questioned a nationally-representative sample of 3,102 American adults about their attitudes, knowledge and experiences related to Alzheimer's and dementia from Jan. 9, 2014, to Jan. 29, 2014. An additional 512 respondents who provided unpaid help to a relative or friend with Alzheimer's or a related dementia were asked questions about their care provision. Random selections of telephone numbers from landline and cell phone exchanges throughout the United States were conducted. One individual per household was selected from the landline sample, and cell phone respondents were selected if they were 18 years old or older. Interviews were administered in English and Spanish. The poll "oversampled" Hispanics/Latinos, selected from U.S. Census tracts with higher than an 8% concentration of this group. A list sample of Asian Americans was also utilized to oversample this group. A general population weight was used to adjust for number of adults in the household and telephone usage; the second stage of this weight balanced the sample to estimated U.S. population characteristics. A weight for the caregiver sample accounted for the increased likelihood of female and white respondents in the caregiver sample. Sampling weights were also created to account for the use of two supplemental list samples. The resulting interviews comprise a probability-based, nationally representative sample of U.S. adults. A caregiver was defined as an adult over age 18 who, in the past 12 months, provided unpaid care to a relative or friend age 50 or older with Alzheimer's or another dementia. Questionnaire design and interviewing were conducted by Abt SRBI of New York.

A9. **Number of hours of unpaid care:** The BRFSS survey asks caregivers to identify, within five time frames, the number of hours they provide care in an average week. Using the method developed by Rabarison and colleagues,⁷²⁵ the Alzheimer's Association assumed the midpoint of each time frame was the average number of hours for each caregiver within that time frame and then calculated the overall average number of hours of weekly care provided by dementia caregivers in each state. This number was then converted to a yearly average and multiplied by the number of caregivers in each state^{A7} to determine the total number of hours of care provided. For the 6 states without recent BRFSS data, their number of hours was calculated using the aggregated average of BRFSS data from 2015–2017. When added together, across all 50 states and the District of Columbia, the total number of hours provided by Alzheimer's and dementia caregivers is 15.338 billion hours.

A10. **Value of unpaid caregiving:** For each state, the hourly value of care was determined as the average of the state minimum hourly wage⁷²⁶ and the state median hourly cost of a home health aide.⁶¹⁶ The average for each state was then multiplied by the total number of hours of unpaid care in that state^{A9} to derive the total value of unpaid care. Adding the totals from all states and the District of Columbia resulted in an economic value of \$256,650 billion for dementia caregiving in the United States in 2020.

A11. **Lewin Model on Alzheimer's and dementia costs:** These numbers come from a model created for the Alzheimer's Association by the Lewin Group. The model estimates total payments for health care, long-term care and hospice — as well as state-by-state Medicaid spending — for people with Alzheimer's and other dementias. The model was updated by the Lewin Group in January 2015 (updating previous model) and June 2015 (addition of state-by-state Medicaid estimates). Detailed information on the model, its long-term projections and its methodology are available at alz.org/trajectory. For the purposes of the data presented in this report, the following parameters of the model were changed relative to the methodology outlined at alz.org/trajectory: (1) cost data from the 2011 Medicare Current Beneficiary Survey (MCBS) were used rather than data from the 2008 MCBS; (2) prevalence among older adults was assumed to equal the prevalence levels from Rajan and colleagues²¹⁶ and included in this report (6.2 million in 2021), rather than the prevalence estimates derived by the model itself; (3) estimates of inflation and excess cost growth reflect the most recent relevant estimates from the cited sources (Centers for Medicare & Medicaid Services [CMS] actuaries and the Congressional Budget Office); and (4) the most recent (2014) state-by-state data from CMS on the number of nursing home residents and percentage with moderate and severe cognitive impairment were used in lieu of 2012 data.

A12. **All cost estimates were inflated to year 2020 dollars using the Consumer Price Index (CPI):** All cost estimates were inflated using the seasonally adjusted average prices for medical care services from all urban consumers. The relevant item within medical care services was used for each cost element. For example, the medical care item within the CPI was used to inflate total health care payments; the hospital services item within the CPI was used to inflate hospital payments; and the nursing home and adult day services item within the CPI was used to inflate nursing home payments.

A13. **Medicare Current Beneficiary Survey Report:** These data come from an analysis of findings from the 2011 Medicare Current Beneficiary Survey (MCBS). The analysis was conducted for the Alzheimer's Association by Avalere Health.²⁴⁰ The MCBS, a continuous survey of a nationally representative sample of about 15,000 Medicare beneficiaries, is linked to Medicare claims. The survey is supported by the U.S. Centers for Medicare & Medicaid Services (CMS). For community-dwelling survey participants, MCBS interviews are conducted in person three times a year

with the Medicare beneficiary or a proxy respondent if the beneficiary is not able to respond. For survey participants who are living in a nursing home or another residential care facility, such as an assisted living residence, retirement home or a long-term care unit in a hospital or mental health facility, MCBS interviews are conducted with a staff member designated by the facility administrator as the most appropriate to answer the questions. Data from the MCBS analysis that are included in *2021 Alzheimer's Disease Facts and Figures* pertain only to Medicare beneficiaries age 65 and older. For this MCBS analysis, people with dementia are defined as:

- Community-dwelling survey participants who answered yes to the MCBS question, "Has a doctor ever told you that you had Alzheimer's disease or dementia?" Proxy responses to this question were accepted.
- Survey participants who were living in a nursing home or other residential care facility and had a diagnosis of Alzheimer's disease or dementia in their medical record.
- Survey participants who had at least one Medicare claim with a diagnostic code for Alzheimer's or other dementias in 2008. The claim could be for any Medicare service, including hospital, skilled nursing facility, outpatient medical care, home health care, hospice or physician, or other health care provider visit. The diagnostic codes used to identify survey participants with Alzheimer's or other dementias are 331.0, 331.1, 331.11, 331.19, 331.2, 331.7, 331.82, 290.0, 290.1, 290.10, 290.11, 290.12, 290.13, 290.20, 290.21, 290.3, 290.40, 290.41, 290.42, 290.43, 291.2, 294.0, 294.1, 294.10 and 294.11.

Costs from the MCBS analysis are based on responses from 2011 and reported in 2020 dollars.

A14. **Differences in estimated costs reported by Hurd and colleagues:** Hurd and colleagues⁵⁷⁷ estimated per-person costs using data from participants in ADAMS, a cohort in which all individuals underwent diagnostic assessments for dementia. *2021 Alzheimer's Disease Facts and Figures* estimated per-person costs using data from the Medicare Current Beneficiary Survey (MCBS) to be \$52,481. One reason that the per-person costs estimated by Hurd and colleagues are lower than those reported in *Facts and Figures* is that ADAMS, with its diagnostic evaluations of everyone in the study, is more likely than MCBS to have identified individuals with less severe or undiagnosed Alzheimer's. By contrast, the individuals with Alzheimer's registered by MCBS are likely to be those with more severe, and therefore more costly, illness. A second reason is that the Hurd et al. Estimated costs reflect an effort to isolate the incremental costs associated with Alzheimer's and other dementias (those costs attributed only to dementia), while the per-person costs in *2021 Alzheimer's Disease Facts and Figures* incorporate all costs of caring for people with the disease (regardless of whether the expenditure was related to dementia or a coexisting condition).

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Our mission: The Alzheimer's Association leads the way to end Alzheimer's and all other dementia — by accelerating global research, driving risk reduction and early detection, and maximizing quality care and support.

Our vision: A world without Alzheimer's and all other dementia.®

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