

SPECIAL REPORT

## **MORE THAN NORMAL AGING: UNDERSTANDING MILD COGNITIVE IMPAIRMENT**



**Fewer than 1 in 5 Americans  
(18%) are familiar with mild  
cognitive impairment (MCI).**

## Subtle cognitive changes, such as those in memory and thinking, are often a feature of aging.

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What does one do if these changes are not a result of normal aging, but caused by disease — offering a potential indicator of future cognitive decline and premature death? As the size of the United States’ older population grows dramatically over the next 30 years, more individuals and their physicians will confront this question.

### Confronting MCI and Why It Matters

Mild cognitive impairment (MCI) causes cognitive changes that are serious enough to be noticed by the person affected and by family members and friends, but may not affect the individual’s ability to carry out everyday activities. Approximately 12% to 18% of people age 60 or older are living with MCI.<sup>738</sup> The population of Americans age 60 and older has grown more than 30% over the past decade,<sup>739</sup> and the number of older individuals in the United States is expected to increase significantly by 2050 (see Prevalence section, page 19).<sup>218,220-221</sup> These aging individuals are potentially at higher risk of developing MCI.<sup>48</sup>

*“Mild cognitive impairment (MCI) is an early stage of memory loss or other cognitive ability loss (such as language or visual/spatial perception) in individuals who maintain the ability to independently perform most activities of daily living.”<sup>738</sup>*

MCI is characterized by subtle changes in memory and thinking. MCI is sometimes confused with normal aging, but it is not part of the typical aging process. A variety of factors can cause MCI, so it is viewed as a broad set of symptoms; this can make the diagnosis of MCI challenging for affected individuals and physicians. When a person exhibits symptoms of MCI and has biomarker evidence of the brain changes characteristic of Alzheimer’s disease, they are described as having MCI due to Alzheimer’s disease — a subtype of MCI.<sup>738</sup>

For the purposes of this Special Report, the term *MCI* refers to “syndromic” MCI of unknown cause or due to causes other than the brain changes associated with Alzheimer’s disease. The term *MCI due to Alzheimer’s disease* is used to describe MCI with the presence of Alzheimer’s disease-related biomarkers.

Individuals with MCI may have a higher risk of developing dementia. Studies estimate that 10% to 15% of individuals with MCI go on to develop dementia each year.<sup>48,740-741</sup> About one-third of people with MCI develop dementia due to Alzheimer’s disease within five years.<sup>49</sup> However, some individuals with MCI revert to normal cognition or do not have additional cognitive decline.<sup>738,740</sup>

Identifying which individuals with MCI are more likely to develop dementia is a major goal of current research. Distinguishing between cognitive issues resulting from normal aging, those associated with the broad syndrome of MCI, and those related to MCI due to Alzheimer’s disease is critical in helping individuals, their families and physicians prepare for future treatment and care.

### MCI Diagnosis and Treatment

MCI is classified as one of two types based on a person’s symptoms: *amnesic* (memory issues predominate) or *nonamnesic* (other cognitive issues, such as impaired language, visuospatial abilities, or executive function, predominate).<sup>48,738</sup> For example, a person with amnesic MCI could forget conversations or misplace items in their

### Prevalence of Mild Cognitive Impairment in Older Adults by Age

Age	Prevalence
60-64	6.7%
65-69	8.4%
70-74	10.1%
75-79	14.8%
80-84	25.2%

Created from data from Petersen et al.<sup>48</sup>

home, whereas a person with nonamnesic MCI could have difficulty keeping their train of thought during a conversation, finding their way around a once familiar place, or finishing everyday tasks, such as paying a bill.<sup>742</sup>

The number of people living with MCI increases with age (Table 22).<sup>48</sup> One in four individuals age 80 to 84 experience symptoms of MCI (Table 22).<sup>48</sup>

MCI can be caused by a variety of factors, such as medication side effects, sleep deprivation or anxiety.<sup>740</sup> MCI may also develop as part of neurologic, neurodegenerative, systemic or psychiatric disorders, as well as stroke or other vascular disease and traumatic brain injury.<sup>48,742</sup> MCI can also arise from the brain changes that occur in Alzheimer's disease.

To diagnose MCI, physicians conduct a review of the patient's medical history and use patient questionnaires, clinical exams and brief assessments to evaluate thinking and memory function. Cognitive assessment tools evaluate cognitive impairment by testing memory (the ability to learn and recall new information) and measuring changes in reasoning, problem-solving, planning, naming, comprehension and other cognitive skills.<sup>38</sup>

Sometimes, diagnosis of MCI requires ruling out other systemic or brain diseases, such as Alzheimer's disease, Parkinson's disease, dementia with Lewy bodies (associated with rapid eye movement sleep abnormalities), cerebrovascular disease in the blood vessels that support the brain, or prion disease or cancer (characterized by more rapid cognitive decline).<sup>38</sup>

Although patient-reported symptoms and the results from screening tools and clinical exams provide clues about whether a person has MCI, there is no test that can give a definitive diagnosis.<sup>738,740</sup>

### Strongest risk factors for MCI<sup>740</sup>

- Increasing age.
- Having a specific form of the Apolipoprotein E gene (APOE-e4) that has been linked to Alzheimer's disease.
- Some medical conditions and other factors, such as:
  - Diabetes
  - Smoking
  - High blood pressure
  - High cholesterol
  - Obesity
  - Depression
  - Sedentary lifestyle
  - Infrequent participation in mentally or socially stimulating activities

Currently there is no specific treatment for MCI.<sup>48,743</sup>

In some cases, physicians may be able to identify reversible causes of cognitive impairment, such as depression, medication side effects or sleep apnea. They may also recommend exercise and healthy lifestyle interventions to help improve cognitive function and quality of life.<sup>48</sup>

Once someone is diagnosed with MCI, the outcome can vary depending on the underlying cause and other factors. For some individuals, MCI may be a transitional state between normal cognitive aging and dementia.<sup>738,744</sup> In some cases, however, MCI will revert to normal cognition or remain stable. For example, MCI that is linked to use of a medication may resolve when the medication is changed or discontinued. According to new research, nearly half of people diagnosed with MCI did not progress to dementia and were cognitively normal when they were evaluated 2.4 years after their MCI diagnosis.<sup>745</sup>

### MCI Due to Alzheimer's Disease: A Distinct Condition

Although the symptoms of MCI due to Alzheimer's disease are no different than syndromic MCI, MCI due to Alzheimer's disease has a very specific underlying cause. MCI due to Alzheimer's disease is caused by distinct biological changes that lead to the damage and death of nerve cells in the brain.<sup>38,738</sup> MCI due to Alzheimer's disease is the symptomatic precursor to Alzheimer's dementia (see Alzheimer's Disease Continuum and Figure 1, page 9).

In fact, today, physicians can use biomarkers of Alzheimer's disease to diagnose MCI due to Alzheimer's disease. Biomarker tests measure beta-amyloid (A $\beta$ ) deposits, pathologic tau and other hallmarks of Alzheimer's disease-related neurodegeneration; these biomarkers can be detected in brain images or measured in cerebrospinal fluid (CSF).<sup>746</sup> Some biomarker tests, such as positron emission tomography (PET) imaging to look for beta-amyloid deposits or pathologic tau in the brain and measurement of a type of beta-amyloid called A $\beta$ <sub>42</sub> in CSF are readily available to physicians, whereas others are currently limited to clinical research.<sup>746-747</sup>

Unfortunately, not all physicians and patients have access to biomarker testing methods, and not all patients are referred for a more thorough evaluation after MCI is diagnosed based on the symptoms. New blood tests are under development that provide simple, accurate, non-invasive detection of Alzheimer's disease biomarkers — sometimes even before symptoms appear. For now, these blood-based biomarker tests are for research use only and not available in everyday medical practice, but they hold promise for identifying patients at risk of MCI due to Alzheimer's disease earlier in the disease process.<sup>747</sup>

Estimates suggest that roughly 5 million Americans have MCI due to Alzheimer's disease (see Prevalence section, pages 20-21). Because MCI develops years before dementia and potentially affects individuals younger than 65, there are likely far more than 5 million Americans — of any age — with MCI due to Alzheimer's disease (see Prevalence section, pages 20 and 21). Blood-based biomarkers are expected to make it easier to identify individuals with MCI due to Alzheimer's disease as part of routine clinical practice. Until then, the true number of individuals living with MCI due to Alzheimer's disease remains unknown.

### Progression to Alzheimer's Dementia Is Not Certain

Evidence suggests that over a 5- to 10-year period after a diagnosis of MCI due to Alzheimer's disease, 30% to 50% of people progress to Alzheimer's dementia.<sup>49,586</sup> Up to 3 in 20 (15%) people who have amnesic MCI are estimated to progress to Alzheimer's dementia in that period, and research indicates that progression to dementia may be more likely for people with this subtype of MCI due to Alzheimer's disease.<sup>586,744</sup>

*Not everyone who has MCI due to Alzheimer's disease will go on to develop Alzheimer's dementia.*

### MCI Due to Alzheimer's Disease Represents a Critical Turning Point in the Alzheimer's Disease Continuum

A key consideration for managing Alzheimer's disease is determining when to intervene. Researchers have long posited that pharmacologic treatments, or medications, aimed at slowing or stopping the progression of Alzheimer's disease to dementia and preserving brain function are most effective when administered early in the disease process.

Accurate diagnosis of MCI due to Alzheimer's disease, prior to the development of dementia, is thus crucial in identifying individuals who might benefit from early treatment. Initiation of treatment earlier in the disease process may also be associated with lower overall health care costs, as progression to dementia and the need for costly assisted living, nursing home and other types of residential care is postponed (see Use and Costs of Health Care, Long-Term Care and Hospice section, page 60).

Intervening earlier also offers significant benefits for diagnosed individuals, potentially allowing them more time to live independently while enjoying a higher quality of life.

The last 20 years has marked an acceleration in the development of a new class of treatments that target the underlying biology and aim to slow the progression of Alzheimer's disease. As of the writing of this report, 104 disease-modifying treatments are being evaluated in clinical trials or are at various stages of regulatory approval, including monoclonal antibodies, such as aducanumab, donanemab, lecanemab, gantenerumab and others.<sup>748-749</sup> The recent accelerated approval of aducanumab by the U.S. Food and Drug Administration is generating momentum and spurring progress for the development and approval of potential therapies aimed at slowing the progression of MCI due to Alzheimer's disease and mild Alzheimer's dementia.

## Understanding MCI and MCI Due to Alzheimer's Disease Today: Adult and Primary Care Physician Surveys

To better understand real-world awareness, diagnosis and treatment of MCI and MCI due to Alzheimer's disease in the United States, the Alzheimer's Association commissioned Versta Research to conduct surveys of U.S. adults and primary care physicians (PCPs). Surveys across both groups explored wide-ranging issues related to MCI and MCI due to Alzheimer's disease, including concern and awareness of MCI, attitudes about diagnosis, challenges in diagnosis, clinical management and treatment of MCI, including MCI due to Alzheimer's disease, and views on future disease-related treatments. Attitudinal differences among racial and ethnic groups were also investigated.

### Key Findings

The Alzheimer's Association surveys revealed:

Americans' awareness of MCI is low.

- Fewer than 1 in 5 Americans (18%) are familiar with MCI. Familiarity with MCI is low across all racial and ethnic groups surveyed: White Americans (18%), Asian Americans (18%), Native Americans (18%), Black Americans (18%) and Hispanic Americans (17%).
- More than 2 in 5 Americans (43%) report they have never heard of MCI.
- When prompted with a description of MCI more than half of all Americans (55%) say MCI sounds like "normal aging."

When MCI and MCI due to Alzheimer's disease are described, Americans express concern, but also reluctance to see their doctor.

- Nearly one-half of Americans (47%) say they worry about developing MCI in the future. More than 4 in 10 Americans (42%) say they worry about developing MCI due to Alzheimer's disease.
- A large majority of Americans (85%) say they would want to know if they had Alzheimer's disease early, including during the MCI stage (54%) and mild Alzheimer's disease stage (31%). Reasons cited most often for wanting to know early include planning for the future (70%), allowing for earlier treatment of symptoms (70%), taking steps to preserve existing cognitive function (67%) and to understand what is happening (66%).
- Yet only 4 in 10 Americans (40%) say they would talk to their doctor right away when experiencing symptoms of MCI. More than half of Americans (57%) say they would wait until they had symptoms for a while (33%), wait until symptoms worsened (12%) or wait until others expressed concern (12%).

- Overall, almost 8 in 10 Americans (78%) express concerns about seeing a doctor in the wake of MCI symptoms. Concerns cited most often include receiving an incorrect diagnosis (28%), learning of a serious health problem (27%), receiving unnecessary treatment (26%) and believing symptoms might go away (23%).

PCPs believe it is important to diagnose MCI, including MCI due to Alzheimer's disease, but challenges in diagnosis persist.

- An overwhelming majority of PCPs surveyed say it is important to diagnose MCI (98%) and MCI due to Alzheimer's disease (90%). One-third of PCPs (35%), however, are not fully comfortable diagnosing MCI and more than one-half of PCPs (51%) say they are not fully comfortable diagnosing MCI due to Alzheimer's disease.
- Nearly all PCPs (96%) say it is important to assess patients age 60 and older for cognitive impairment, but report that they conduct assessments for just half (48%) of their patients age 60 and older.
- When making an MCI diagnosis, the most frequently cited challenges by PCPs include difficulty in differentiating MCI from normal aging (72%) and difficulty in interpreting patient reports of daily functioning (51%).
- When diagnosing MCI due to Alzheimer's disease, top challenges cited by PCPs include lack of specialists/facilities to perform diagnostic testing (51%), patient reluctance to pursue follow-up testing (49%) and PCP reluctance to diagnose a condition that has limited treatment options (47%).
- Nine in 10 PCPs (90%) say it is hard to know where MCI ends and dementia begins.

PCPs say early intervention can slow progression of cognitive decline, but many are unfamiliar with clinical trials and research advances that may help diagnose and manage MCI and MCI due to Alzheimer's disease now and in the future.

- The vast majority of PCPs (86%) say that early intervention can slow progression of cognitive decline. When MCI is detected in patients, PCPs most often recommend lifestyle changes (73%), perform laboratory testing for reversible causes of MCI (70%) and/or refer patients to a specialist (53%).
- Only 4 in 10 PCPs (40%) say they are familiar (7% very familiar and 33% somewhat familiar) with current biomarker tests to aid in the diagnosis of Alzheimer's disease, and they refer fewer than 1 in 5 patients (18%) for biomarker testing for Alzheimer's disease when MCI is detected.
- One in 5 PCPs (20%) report being familiar with clinical trials available to their patients with MCI.
- Only 1 in 4 PCPs (23%) say they are familiar with new therapies in the pipeline to address MCI due to Alzheimer's disease.



Consumers and PCPs express optimism for future Alzheimer's disease treatments.

- More than 7 in 10 Americans (73%) expect new treatments to delay the progression of Alzheimer's disease to be available within the next decade. Six in 10 Americans (60%) anticipate new treatments to stop the progression of Alzheimer's disease. More than one-half of all Americans (53%) believe there will be new treatments to prevent Alzheimer's disease.
- PCPs also expressed optimism for future Alzheimer's disease treatments. More than 4 in 5 PCPs (82%) expect there will be new treatments to delay the progression of Alzheimer's disease during the next decade. More than half of PCPs (54%) anticipate there will soon be treatments to stop Alzheimer's disease progression. Less than half (42%) anticipate new treatments to prevent Alzheimer's disease.

## Survey Results

### Public Awareness of MCI

The Alzheimer's Association survey of U.S. adults found that fewer than 1 in 5 Americans (18%) are familiar with MCI (Figure 18 Left, page 86). Awareness and understanding of MCI is low across all racial and ethnic groups surveyed: White Americans (18%), Asian Americans (18%), Native Americans (18%), Black Americans (18%) and Hispanic Americans (17%). More than 2 in 5 Americans (43%) report they have never heard of MCI (Figure 18 Left, page 86). Americans aged 60 and older indicated no greater awareness of MCI despite being the most likely age group to develop the disease.

When prompted with a description of MCI, more than half of Americans (55%) say it sounds like normal aging (Figure 18 Right, page 86). Black and Asian Americans (58%) were most likely to associate symptoms of MCI with normal aging, followed by Hispanic (55%), White (53%) and Native Americans (47%).

The PCP survey echoes these findings, with only 1 in 8 PCPs (13%) saying they believe that patients with whom they have discussed MCI have a strong understanding of the disease, and 8 in 10 PCPs (81%) reporting that their patients believe MCI is a part of normal aging.

### Patient Concern for MCI and MCI Due to Alzheimer's Disease

Even though awareness and understanding of MCI and MCI due to Alzheimer's disease among Americans is low, they express concern when prompted with a description of both conditions.

Nearly one-half of Americans (47%) say they worry about developing MCI in the future, with 13% indicating they worry "a lot." Asian (54%) and Hispanic (52%) Americans are more likely to worry about developing MCI compared with Native (47%), White (45%) and Black Americans (44%).

## Survey Design and Research Methods

### Survey of U.S. Adults

A survey of 2,434 U.S. adults age 18 and older was conducted from November 5, 2021, to December 5, 2021. Respondents included 662 who were age 60 or older, and 1,772 who were age 18 to 59. The survey included a probability sample of 2,099 Americans fielded by NORC at the University of Chicago via the AmeriSpeak® panel. It was offered online or as a phone survey in English or Spanish. Hispanic (n=328), Black (n=342), and Asian Americans (n=318) were oversampled and weighted back to their true population proportions for analysis and reporting. The probability sample of all Americans was additionally supplemented with an oversample of Native Americans (n=335) using non-probability online research methods. The Native American oversample was stratified and weighted by gender, age, income and education to match U.S. Census Bureau data.

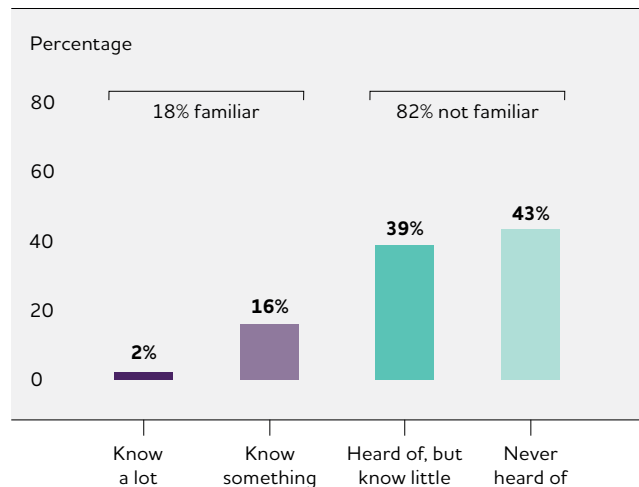
### Survey of U.S. Primary Care Physicians (PCPs)

A survey of 801 primary care physicians (M.D. or D.O.) was conducted from November 1, 2021, to November 22, 2021. Physicians were recruited via WebMD's Medscape physician network, which includes 70% of all practicing primary care physicians in the United States. Sampling was stratified and weighted by type of practice, specialty, years in practice and region using benchmarks from the American Medical Association Masterfile of all practicing physicians in the U.S. To be included in the survey, physicians had to have been in practice for at least two years and spend at least 50% of their time in direct patient care, with at least 10% of their patients being age 60 or older. Physicians included in the survey reported spending an average (mean) of 93% of their time in direct patient care, and reported that 45% of their patients were age 60 years or older. Years in practice ranged from 2 years to 54 years, with a mean of 20 years. Primary medical specialties represented were internal medicine (49%), family medicine (48%) and general practitioner (3%).

figure 18

Familiarity and Perceptions of MCI Among U.S. Adults

Familiarity of MCI Among U.S. Adults



Percentage of U.S. Adults Who Say MCI Sounds Like Normal Aging

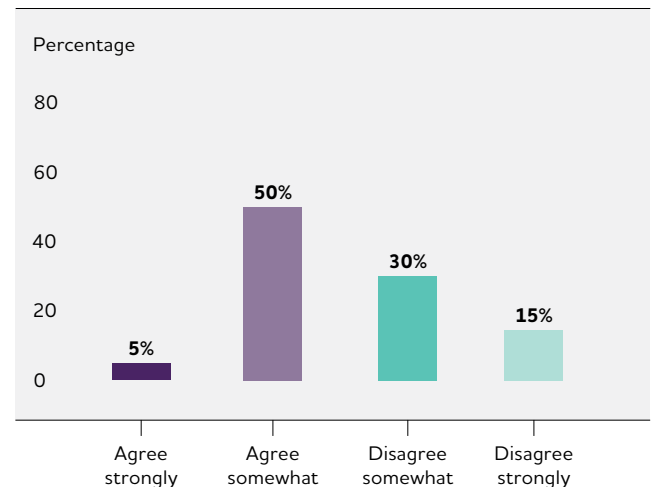
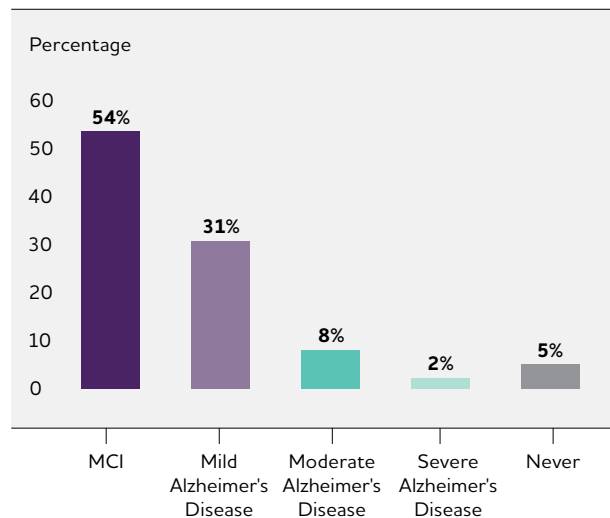


figure 19

Stage at Which U.S. Adults Would Want to Know If They Have Alzheimer's Disease



Overall, 42% of Americans say they worry about developing MCI due to Alzheimer's disease, with 14% of individuals indicating they worry "a lot." Asian (50%), Hispanic (49%), and Black (47%) Americans are most likely to worry about developing MCI due to Alzheimer's disease, followed by Native (41%) and White Americans (39%).

Despite these concerns, a majority of Americans (85%) say they would want to know if they had Alzheimer's disease early, including during the MCI stage (54%) and mild Alzheimer's disease stage (31%) (Figure 19).

Reasons Americans cited most often for wanting to know early if they have Alzheimer's disease include planning for the future (70%), allowing for earlier treatment of symptoms (70%), taking steps to preserve existing cognitive function (67%) and being able to understand what is happening (66%) (Figure 20).

Overall, 43% of Americans cited clinical trial participation as a reason for early diagnosis of Alzheimer's disease (Figure 20). White Americans (50%) were twice as likely as Hispanic Americans (25%) to cite clinical trial participation as a reason for early diagnosis, followed by Asian (40%), Native (35%) and Black Americans (32%).

Hispanic (79%) and Black (80%) Americans are least likely to want to know if they had Alzheimer's during an earlier stage (MCI or mild Alzheimer's dementia), especially when compared with White Americans (88%). Among Asian and Native Americans, 84% say they would want to know if they had the disease during an earlier stage.

Only 15% of Americans say they would want to know if they had Alzheimer's disease during later stages of the disease (moderate/severe stage) or not at all (Figure 19). The most cited reasons for not wanting to know include: a diagnosis would be difficult to accept (34%), treatment options are limited (31%), there is no cure so it doesn't matter (28%) and people might treat me differently (26%) (Figure 21). Difficulty in accepting an Alzheimer's disease diagnosis was the most often cited reason across all racial and ethnic groups.

figure 20

Reasons for Seeking an Early-Stage Alzheimer’s Diagnosis Among U.S. Adults

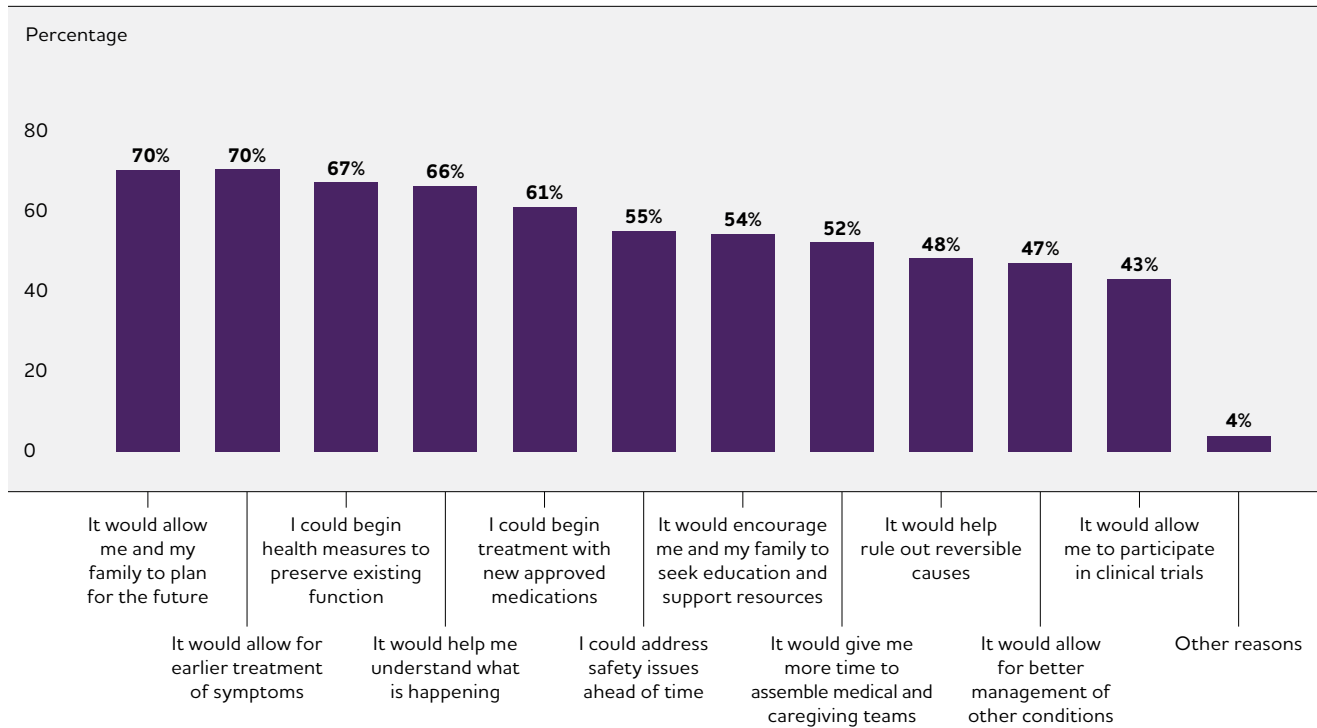


figure 21

Reasons for Not Seeking an Early-Stage Alzheimer’s Diagnosis Among U.S. Adults

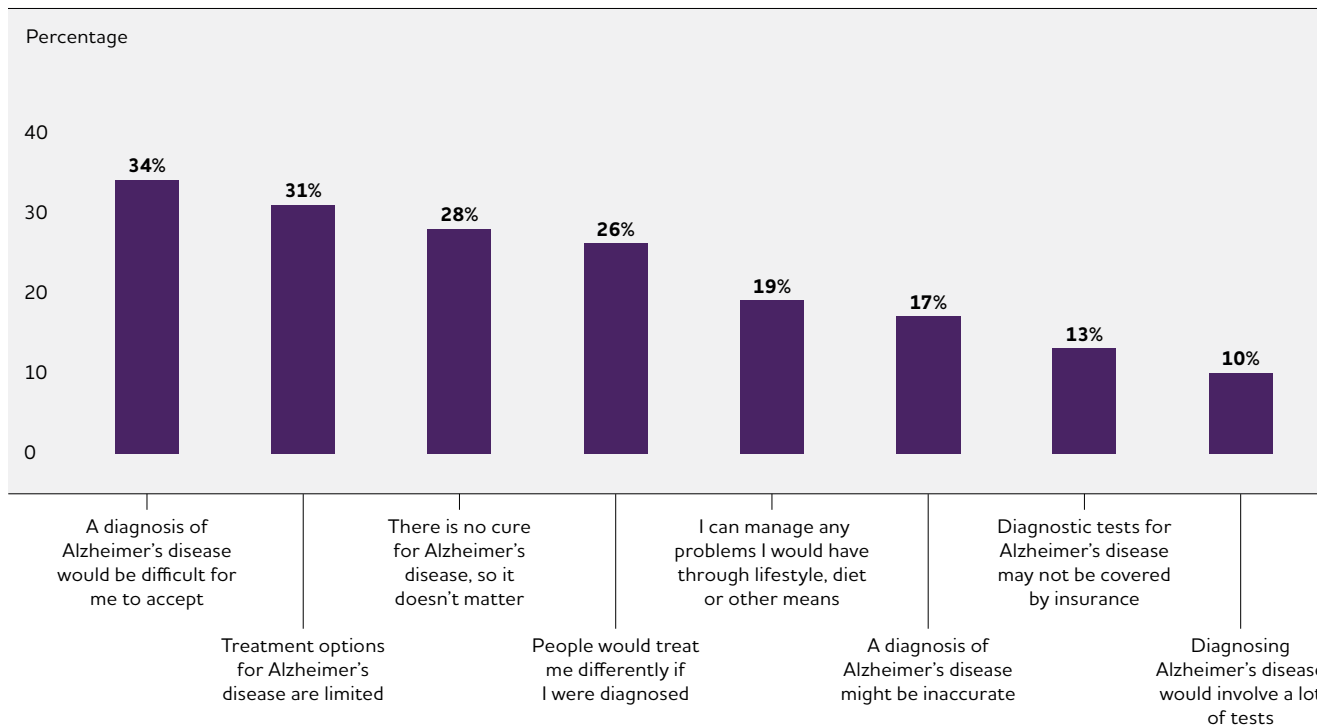
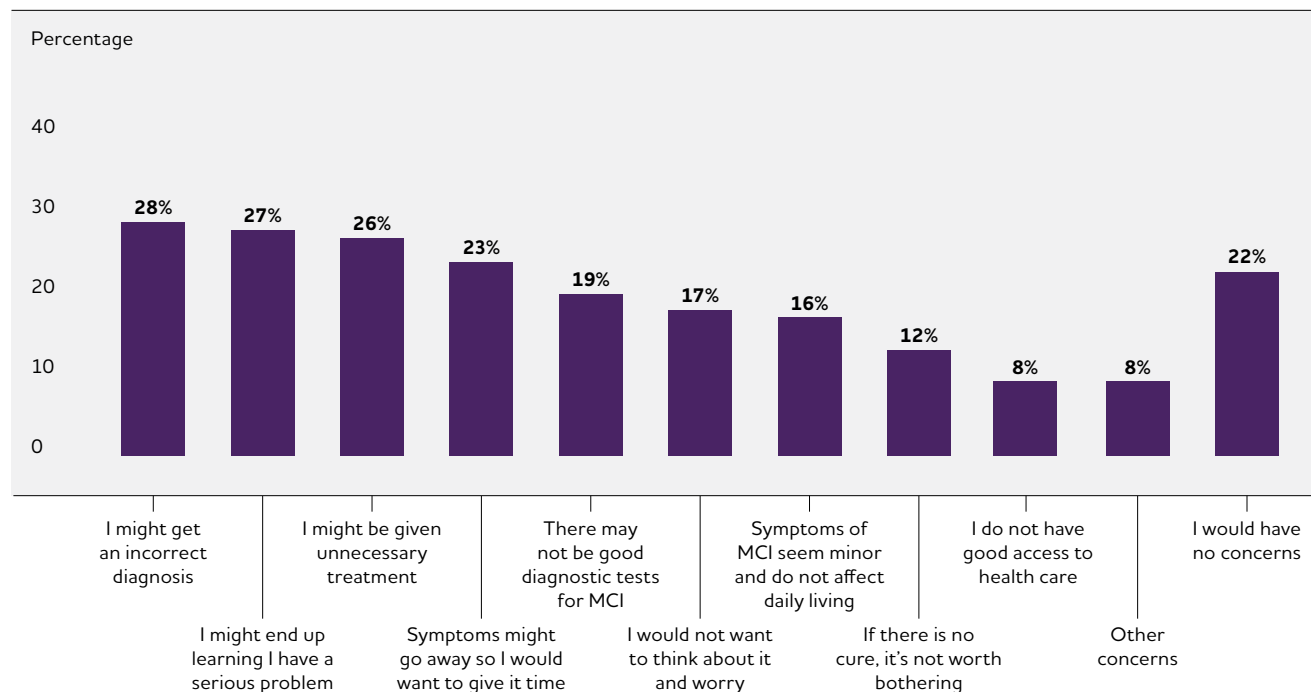




figure 22

Concerns About Seeing a Doctor for MCI Symptoms Among U.S. Adults



**Patient Reticence in Addressing Concerns About MCI and MCI Due to Alzheimer's**

Most Americans (70%) say they would talk to someone if they started noticing symptoms of MCI but only 4 in 10 Americans (40%) report that they would talk to their doctor right away. More than half of Americans (57%) say they would wait until they had symptoms for a while (33%) or their symptoms worsened (12%), or wait until others expressed concern (12%). Just 2% of Americans say they would never talk to their doctor about MCI symptoms.

The Alzheimer's Association survey revealed that the decision to see a doctor when experiencing MCI symptoms is not a foregone conclusion for many individuals. In fact, almost 8 in 10 Americans (78%) say they would have concerns about seeing a doctor in the wake of MCI symptoms. Reasons for not seeing a doctor include concerns about receiving an incorrect diagnosis (28%), learning of a serious health problem (27%), receiving an unnecessary treatment (26%) and believing symptoms might go away (23%) (Figure 22).

Receiving an incorrect diagnosis was the top concern for not seeing a doctor right away for MCI symptoms among Asian (38%), Black (31%) and White Americans (27%). The top reason cited by Hispanic (27%) and Native Americans (31%) was learning they might have a serious problem.

Native Americans (16%) were three times as likely as White Americans (5%) to cite having good access to health care as a concern for seeing a doctor. Hispanic (12%), Asian (11%) and Black Americans (10%) were twice as likely to cite this concern as White Americans. Surveys reported by the Alzheimer's Association in 2021 found that affordability of care, lack of insurance coverage and lack of access to community health care services were significant barriers in accessing dementia care for Hispanic, Black, Asian and Native Americans.<sup>750</sup>

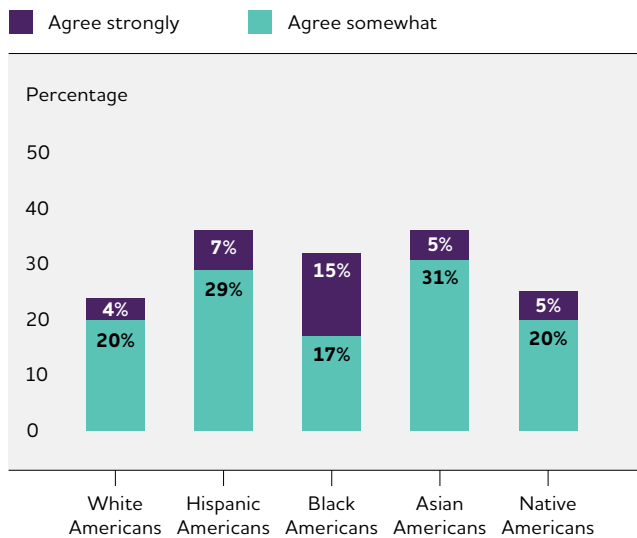
Despite their concerns and often with some delay, most Americans see value in having MCI (73%) and MCI due to Alzheimer's disease diagnosed (70%). Still, more than 1 in 4 Americans (27%) report seeing little value in having MCI formally diagnosed, while nearly 1 in 3 Americans (30%) say there is little value in having MCI due to Alzheimer's disease diagnosed. Hispanic, Black and Asian Americans expressed this view most often for both diagnoses (Figure 23).

**Primary Care Physicians: On the Front Lines of Caring for Individuals With MCI**

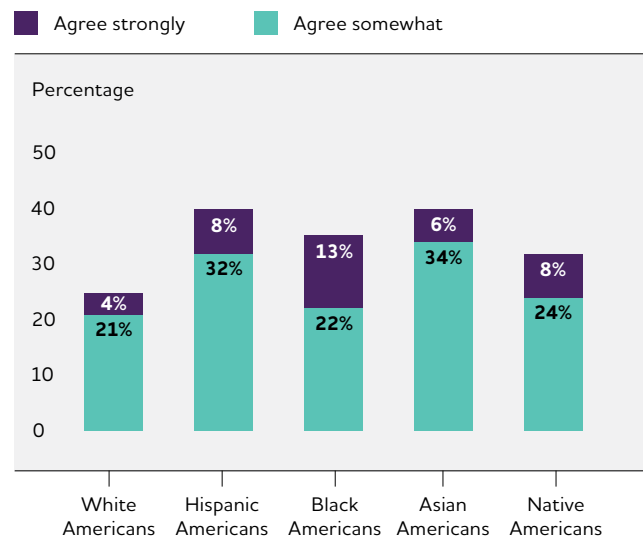
PCPs play an integral role in providing dementia care (see Workforce section, page 52). According to the Alzheimer's Association survey, 3 in 4 PCPs (75%) say they are on the front lines of providing care to patients with MCI, with two-thirds (62%) of PCPs reporting they receive questions

Percentage of U.S. Adults Who Question the Benefit of an MCI and MCI Due to Alzheimer's Disease Diagnosis

Percentage of U.S. Adults Who Question Benefit of Diagnosing MCI, by Race or Ethnicity



Percentage of U.S. Adults Who Question Benefit of Diagnosing MCI Due to Alzheimer's Disease, by Race or Ethnicity



at least weekly from their patients about symptoms consistent with MCI. These findings parallel those from a 2020 Alzheimer's Association report in which 82% of PCPs said they were on the front lines providing dementia care.<sup>589</sup>

Almost all PCPs (93%) surveyed are familiar with MCI and a majority of PCPs (65%) say they are "always comfortable" or "usually comfortable" answering patient questions about MCI. Nearly as many PCPs (85%) are familiar with MCI due to Alzheimer's disease, and the majority of them (60%) are comfortable discussing with their patients how MCI can be related to Alzheimer's disease.

More than 8 in 10 PCPs (82%) report having sought information on MCI due to Alzheimer's disease during the past year. Nearly 4 in 10 (39%) have done so during the past month, with almost 1 in 10 (9%) reporting they have done so within the past week.

Patients view PCPs as a trusted source for information on MCI, with 55% of Americans reporting they would discuss MCI symptoms with their PCP before others, including their spouse (42%) or physician specialists (29%).

**Primary Care Physicians: Diagnosis of MCI and MCI Due to Alzheimer's disease**

Almost all PCPs surveyed say it is important to diagnose MCI (98%) and MCI due to Alzheimer's disease (90%). Nearly two-thirds of PCPs (65%) say they are comfortable diagnosing MCI, while less than half (49%) report being comfortable diagnosing MCI due to Alzheimer's disease (Table 23).

Challenges cited most frequently when making an MCI diagnosis include difficulty differentiating MCI from normal aging (72%) and difficulty interpreting patient reports of daily functioning (51%) (Figure 24, page 91).

Top challenges in making an MCI due to Alzheimer's disease diagnosis include lack of specialists/facilities to perform diagnostic testing (51%), patient reluctance to pursue follow-up testing (49%) and PCP reluctance to diagnose a condition that has limited treatment options (47%) (Figure 25, page 91).

The Alzheimer's Association survey found that fewer than 1 in 10 PCPs (7%) are "very familiar" with current biomarker tests that aid in detecting Alzheimer's disease. This finding could partially explain why it is difficult for PCPs to diagnose MCI due to Alzheimer's disease.

table 23

### Primary Care Physicians' Perceptions on Diagnosing MCI and MCI Due to Alzheimer's Disease

PCP Perceptions	MCI	MCI Due to Alzheimer's Disease
It is important to diagnose	98%	90%
It is difficult to diagnose	57%	77%
PCP is comfortable diagnosing	65%	49%

One-third of PCPs (33%) report being “somewhat familiar” with biomarker testing. Not surprisingly, fewer than 1 in 5 patients (18%) are referred for biomarker testing when MCI is detected (Figure 26, page 92).

The Alzheimer's Association survey found that nearly all PCPs (96%) say it is important to assess patients 60 and older for cognitive impairment, but they report conducting assessments for just half their patients (48%). This finding is consistent with previous Alzheimer's Association reports published in 2019 and 2020 indicating PCPs provide cognitive assessments for less than half their patients age 65 and older.<sup>247,589</sup>

The current challenges PCPs face when diagnosing MCI and MCI due to Alzheimer's disease are underscored by the finding that 9 in 10 PCPs (90%) say “it is hard to know where MCI ends and dementia begins.”

#### Primary Care Physicians: Management and Treatment of MCI

The vast majority of PCPs (86%) say early intervention can slow progression of cognitive decline. When MCI is detected in patients, PCPs most often recommend lifestyle changes (73%), perform laboratory testing for reversible causes of MCI (70%) and/or refer patients to a specialist (53%) (Figure 26, page 92).

As indicated in Figure 26 (page 92), PCPs infrequently recommend testing for Alzheimer's disease biomarkers (18%). In addition, fewer than 1 in 4 PCPs (20%) report being familiar with clinical trials in MCI due to Alzheimer's disease and recommend trial participation when MCI is detected just 8% of the time. PCP referral of patients to clinical trials is much lower than the 43% of Americans who cite the potential for clinical trial participation as a reason for early diagnosis (see Figure 20, page 87).

Finally, as referenced earlier in this report, there are more than 100 disease-modifying treatments for Alzheimer's disease, including those aimed at addressing MCI due to Alzheimer's disease, under investigation in clinical trials and at various stages of regulatory

table 24

### U.S. Adults and Primary Care Physicians' Expectations for New Alzheimer's Disease Treatments During the Next Decade

Treatment type that...	U.S. Adults	Primary Care Physicians
Delays progression of Alzheimer's Disease	73%	82%
Stops progression of Alzheimer's Disease	60%	54%
Prevents Alzheimer's Disease	53%	42%

approval.<sup>748-749</sup> Yet fewer than 1 in 4 PCPs (23%) say they are familiar with these emerging treatments to address MCI due to Alzheimer's.

#### Optimism for Future Treatments

Despite the devastating toll Alzheimer's disease continues to have on individuals and families across the country, both patients and PCPs express optimism that new treatments to combat Alzheimer's disease are on the horizon.

More than 7 in 10 Americans (73%) expect new treatments to delay the progression of Alzheimer's disease to be available within the next decade (Table 24). Six in 10 Americans (60%) anticipate new treatments to stop the progression of Alzheimer's disease. More than one-half of all Americans (53%) believe there will be new treatments to prevent Alzheimer's disease.

PCPs also expressed optimism for future Alzheimer's disease treatments (Table 24). More than 4 in 5 PCPs (82%) expect there will be new treatments to delay the progression of Alzheimer's disease during the next decade. More than half of PCPs (54%) anticipate there will be treatments to stop Alzheimer's disease progression, and more than 4 in 10 (42%) anticipate new treatments to prevent Alzheimer's disease.

#### A Path Forward: Increasing Awareness and Diagnosis of MCI and MCI Due to Alzheimer's Disease

Taken together, the Alzheimer's Association surveys provide important insights and perspectives from the American public and primary care physicians on the current state of understanding, awareness, diagnosis, and management of MCI and MCI due to Alzheimer's disease. The findings indicate improvements are needed to increase public awareness of MCI, including MCI due to Alzheimer's, and that enhanced support is needed for primary care physicians on the front lines tasked with diagnosis,

figure 24

Primary Care Physician Challenges in Diagnosing MCI

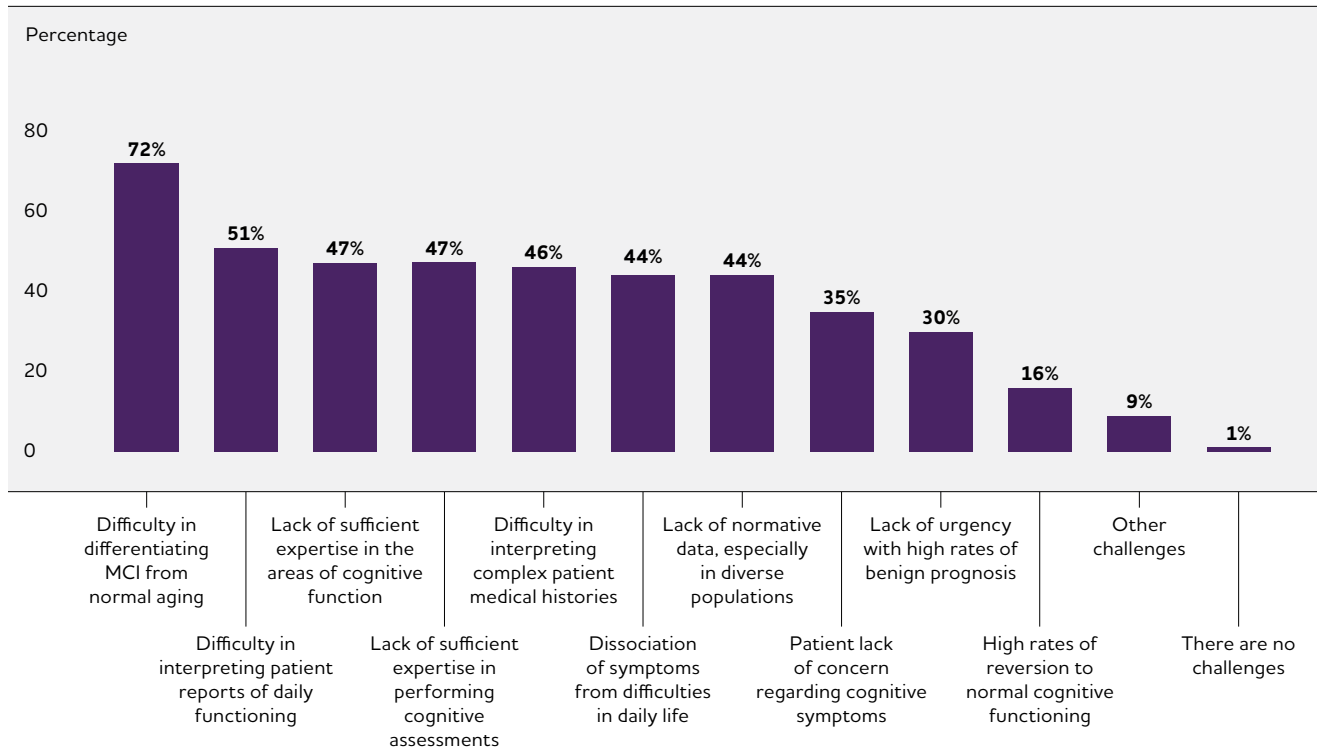


figure 25

Primary Care Physician Challenges in Diagnosing MCI Due to Alzheimer's Disease

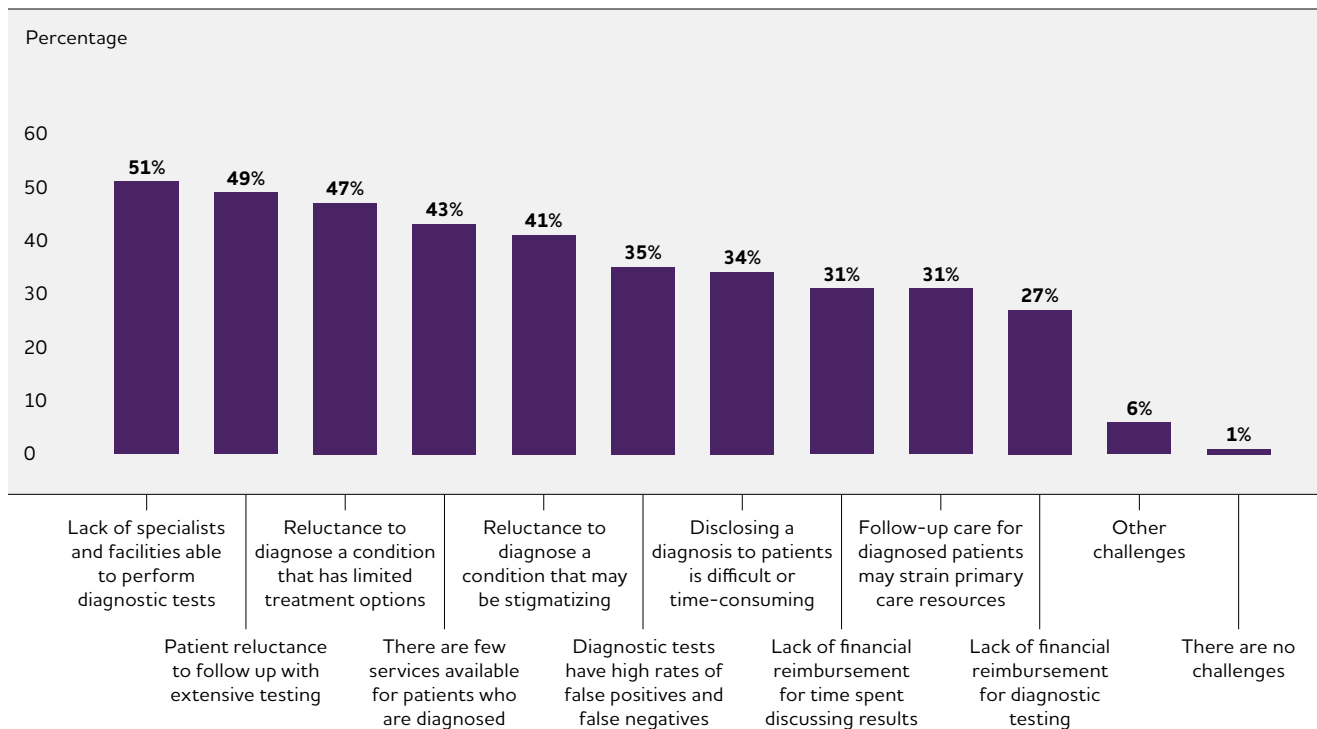
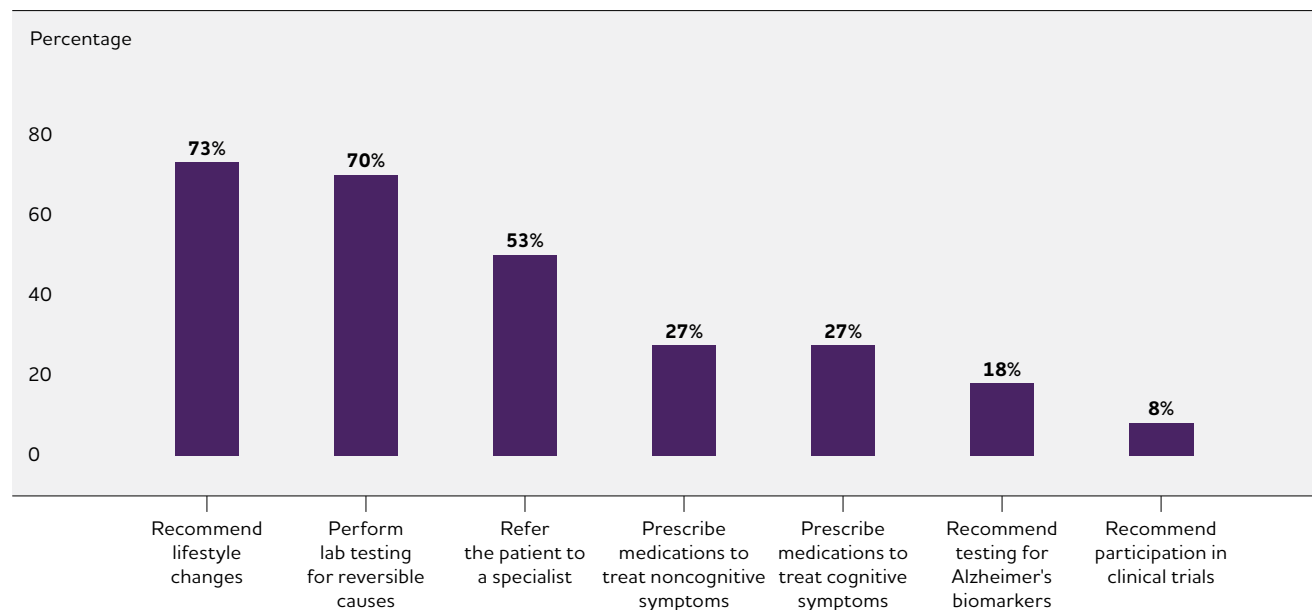


figure 26

### Steps Recommended by Primary Care Physicians When MCI Is Detected



management and treatment of MCI, including MCI due to Alzheimer's disease, and other dementias. The Alzheimer's Association proposes four broad efforts to improve the current situation:

- Promote greater public awareness by leveraging awareness campaigns and community-based disease education programs.
- Improve ease of use and uptake of cognitive assessments in the primary care setting.
- Expand primary care physicians' ability to diagnose cognitive impairment, including MCI and MCI due to Alzheimer's disease.
- Bolster public and primary care physician awareness of and patient participation in Alzheimer's disease-related clinical trials and research.

#### Leveraging Public Awareness Campaigns and Community-Based Disease Education Programs

Findings from the Alzheimer's Association surveys reveal that Americans have a concerning lack of awareness of MCI, MCI due to Alzheimer's disease, and the distinction between these conditions and normal aging. When Americans do have concerns about their cognitive functioning, they are often slow to act — potentially delaying or impeding diagnosis and potential intervention for MCI or MCI due to Alzheimer's disease.

Public awareness campaigns and community-based disease education programs offer two important avenues for building public awareness nationally and locally.<sup>751</sup> Given low consumer awareness of MCI, core messaging

to public audiences within these efforts should be broad, encouraging more Americans to be proactive in recognizing early symptoms of cognitive impairment and addressing concerns with their physician.

These efforts should engage not only individuals at risk for cognitive decline, but family members as well. Close family members are typically the first to notice memory concerns or cognitive problems, yet many are reluctant to initiate a conversation with the affected individual or their physician. Touting the value and benefits of early diagnosis in messaging can help overcome reticence and rectify concerns identified in the current Alzheimer's Association survey.

Since 2019, the Alzheimer's Association has partnered with the Ad Council on a national communications campaign aimed at encouraging families to discuss cognitive concerns with each other and their doctor sooner to enable early diagnosis of Alzheimer's disease and related dementias.

The campaign features real stories of people who noticed cognitive changes in a close family member and took the first, difficult step to initiate a conversation about those changes. The campaign offers tools and resources to help families recognize early warning signs of Alzheimer's disease, provides tips for facilitating conversations about cognition, and explains benefits of early detection and diagnosis.<sup>752</sup> The campaign resources also include a collection of disease-related information and a discussion guide for use with doctors and health care professionals.<sup>753</sup>

Community-based disease education programs provide another important avenue to raise awareness about MCI, including MCI due to Alzheimer's, with the advantage that they can be tailored to reach diverse communities. As indicated in the current Alzheimer's Association survey, there are differences in how racial and ethnic groups view and respond to concerns about cognitive impairment. Creating disease-related materials and messaging that resonates with diverse communities is essential.

### Improving Cognitive Assessment in Primary Care Practice

Studies indicate that detection and diagnosis of cognitive impairment or dementia can be increased two- to three-fold with routine use of brief cognitive assessments.<sup>586</sup> Yet findings from the current Alzheimer's Association survey indicate that primary care physicians are evaluating just under half of their patients for cognitive impairment. These findings parallel those from Alzheimer's Association surveys of primary care physicians published in 2019 and 2020.<sup>247,589</sup>

In recent years, the Centers for Medicare and Medicaid Services (CMS) has attempted to increase utilization of cognitive assessments in routine care by making it a requirement of the Medicare Annual Wellness Visit (AWV), reimbursing the cognitive assessment and care plan as a separate visit and at a higher dollar amount, and making the option of reimbursable telehealth evaluation permanent.<sup>754</sup> Three other approaches arising from this year's Alzheimer's Association survey findings that could complement these efforts to increase uptake of cognitive assessments in primary care are:

1. Implementing new assessment approaches that do not detract from the physician portion of a visit.
2. Supporting physicians with resources to equip them to more confidently perform and interpret cognitive assessments.
3. Developing and disseminating culturally appropriate assessment tools for use in diverse populations.

### Rethinking Assessment Approaches

Currently, many physicians administer cognitive assessments themselves — asking patients questions, recording the answers, then interpreting the results and formulating next steps. This takes time, and not only do physicians have limited time with patients, but the cognitive assessment may also not be the priority during the visit. Time is a barrier to uptake without an easy solution. Using computerized or digital screening assessments outside of exam room time is one approach to overcome time constraints, as is using remote assessment through telehealth technology.<sup>638</sup> Other approaches include limiting the time it takes to conduct an assessment and involving other members of the care team to administer cognitive screenings (see Workforce section, page 52).<sup>586,755</sup>

### Resources

Limited expertise is a frequently cited barrier to performing cognitive assessments in the literature and was raised by PCPs in the current Alzheimer's Association survey, with PCPs citing lack of expertise in areas of cognitive function (47%) and lack of sufficient expertise in performing cognitive assessments (47%) as significant challenges (Figure 24, page 91).<sup>589,755</sup>

Increasing PCP awareness of self-directed training resources is an important first step to help them gain confidence and comfort using cognitive assessments more regularly. Resources and information on performing cognitive assessments are available to primary care practices from numerous government and professional organizations, including:

- [Centers for Medicare and Medicaid Services](#)
- [The National Institute on Aging](#)
- [The Alzheimer's Association Cognitive Assessment Toolkit](#)
- [The Alzheimer's Association Medicare Annual Wellness Visit Algorithm for Assessment of Cognition](#)
- [The Gerontological Society of America Kickstart, Assess, Evaluate, Refer \(KAER\) Toolkit](#)
- [The American Academy of Family Physicians Cognitive Care Kit](#)
- [Minnesota's Act on Alzheimer's® Provider Practice Tools](#)

The Alzheimer's Association and others, including a working group of international experts on MCI and Alzheimer's disease, have published recommendations and descriptions of operationalizing cognitive assessments, including the AWV, in primary care practice to guide this process.<sup>586,755-757</sup>

### Culturally Appropriate Assessment

Clinicians need more cognitive assessment tools for diverse and underserved populations. Studies show sensitivity to differences in age, literacy levels and cultural variation are key limitations of many cognitive tests in use today.<sup>755,758-761</sup>

Evidence suggests that age, number of chronic conditions and socioeconomic status may influence screening rates with cognitive assessments, and that race, ethnicity, educational level and language barriers may negatively impact the utility of cognitive assessments in discriminating between normal aging and MCI or dementia.<sup>755,758-759</sup> Adapting existing cognitive assessments or developing new cognitive assessments for an increasingly diverse aging population is an avenue to explore to improve early diagnosis rates among groups that are disproportionately affected by Alzheimer's disease and related dementias (see Prevalence section, page 18).<sup>762</sup> An example of this is a best practices guide developed by CMS to help



physicians adapt cognitive assessments based on cultural considerations for screening Native Americans.<sup>763</sup> Having cognitive assessments that are designed specifically for historically underrepresented groups may also improve uptake in primary care practices, as these assessments could generate the normative data in diverse populations that physicians surveyed as part of this year's Special Report say they are lacking to diagnose MCI.<sup>755</sup>

### **Expand Primary Care Physicians' Ability to Diagnose Cognitive Impairment Early**

Ensuring that primary care physicians and care teams are equipped to diagnose and manage MCI and MCI due to Alzheimer's disease now and in a growing aging population is imperative, especially in light of a worsening shortage of other specialists, such as geriatricians (see Workforce section). Possible future directions informed specifically by the Alzheimer's Association survey findings are described below. They include adopting new diagnostic tools as they become available, continuing to enhance primary care capacity for dementia care, and ongoing efforts to deliver more culturally-competent care (for additional recommendations, see the Workforce section, page 52).

#### **Simplify Adoption of Future Diagnostic Tools**

Low diagnosis rates for MCI due to Alzheimer's disease can be partially explained by the challenges primary care physicians report in administering diagnostic tests. The Alzheimer's Association survey found that physicians report barriers in referring their patients to specialists for diagnostic tests, must overcome patient reluctance to pursue further testing and believe existing diagnostic tests can be inaccurate (Figure 25, page 91). Some of these barriers could be overcome with research advancements that bring new diagnostic tools, such as blood-based biomarker tests, to the primary care setting. Although not yet widely available in clinical practice, eventually blood-based biomarker tests could be ordered through the primary care practice and offer another way to help detect disease early so that a patient could be referred to a specialist or monitored more closely for cognitive decline by their primary care physician.

As reported in the 2017 Special Report, *"Alzheimer's Disease: The Next Frontier,"* "Alzheimer's disease exists as a continuum beginning with a phase that may only be detectable through biomarkers, moving through the dementia stage."<sup>764</sup> Research funded by the Alzheimer's Association and other institutions is underway to discover new biomarkers and evaluate this approach.<sup>747,765-768</sup> Advances in biomarker science will also help PCPs perform

a differential diagnosis to rule out modifiable causes of symptoms, and ascertain when it may be appropriate to refer patients to clinical trials of new treatment options.

The Alzheimer's Association survey found that very few PCPs are familiar with current biomarker tests that aid in detecting Alzheimer's disease. Therefore, when new blood-based biomarker tests are ready for adoption in routine primary care practice, it will be important to educate physicians about appropriate use. Education can be accomplished with implementation toolkits or stepwise diagnostic algorithms that clearly explain which patients to test and when, how biomarker tests complement other tools, such as cognitive assessments and clinical exams, and how to put the results into context with other clinical findings to create a care plan.<sup>747,755</sup>

### **Continue to Enhance Primary Care Capacity for Dementia Care**

Although less frequently cited than other challenges in this year's Special Report, physicians did acknowledge that they have difficulty diagnosing MCI due to Alzheimer's disease because there are few services for patients who are diagnosed, and they believe that follow-up care may strain primary care resources (Figure 25, page 91).

The Alzheimer's Association is partnering with primary care clinicians and practices to increase equitable access to timely detection, accurate diagnosis, and quality, person-centered care. In 2018, the Association launched a [Project ECHO](#)<sup>®</sup> — a highly successful telementoring program — that has connected more than 50 primary care practices with dementia care experts to enhance dementia care in underserved areas. University of Washington and West Virginia University have also launched Project Dementia and Memory Health to support primary care practices.<sup>769-770</sup>

In addition to work through Project ECHO, the Alzheimer's Association is partnering directly with more than 300 health systems in the United States, from community health centers to large integrated delivery networks, and offers guidance and resources for them at: [alz.org/professionals/health-systems-clinicians](http://alz.org/professionals/health-systems-clinicians).

Another approach to enhancing primary care capacity for dementia care is through collaborative and coordinated care programs. The UCLA Alzheimer's and Dementia Care Program, for example, uses nurse practitioners and dementia care specialists to manage the care of people living with dementia. Since launching in 2011, the program has expanded to 18 sites across the country, reducing emergency department visits, days spent in the hospital, admissions to nursing homes for long-term care and overall Medicare costs.<sup>771</sup>

## Dedicate Sustained Effort to Improve Diversity and Inclusion in Primary Care

This year's Special Report uncovered some distinctions between racial and ethnic groups in understanding, diagnosis and management of MCI and MCI due to Alzheimer's disease. As we move forward, it is critical to recognize racial and cultural differences in how underserved and disproportionately affected populations respond to health concerns and work to eliminate barriers that may delay or prevent timely access to care and treatment.

Recommendations outlined in the Alzheimer's Association 2021 *Alzheimer's Disease Facts and Figures* Special Report still hold true this year. The Alzheimer's Association survey reported in 2021 found that individuals want health care providers who reflect their racial and ethnic backgrounds.<sup>750</sup> A diverse, representative, culturally-competent primary care workforce could strengthen trust with underserved populations, helping them to overcome some of their reticence to seek evaluation and diagnosis of cognitive impairment, potentially reducing future disparities in dementia care.<sup>750</sup>

## Bolstering Public Awareness and Physician and Public Participation in Clinical Trials

Low public awareness, difficulty recruiting and retaining clinical trial participants, and a lack of diversity in clinical trials are ongoing challenges that impede progress toward advancing new disease-related treatments and therapies.

Registries established at the local and national levels aim to help in the recruitment process by offering people the chance to be matched to current and future Alzheimer's disease clinical trials.<sup>772</sup> Examples include the [Alzheimer's Prevention Registry](#), which is trying to enlist large numbers of people for future disease prevention trials, [The Alzheimer's Association's TrialMatch](#), the [NIH-funded ResearchMatch](#) and the [Brain Health Registry](#). Rolling information about registries into public awareness campaigns and community outreach efforts could be a step towards educating the public.

Grassroots community outreach has also shown some success in recruiting Alzheimer's disease clinical trial participants from the community-at-large, and could be included as part of the public awareness campaigns described previously.<sup>772-773</sup> Online patient communities and support groups can also serve as an avenue to awareness and recruitment.<sup>773</sup>

The 2021 Alzheimer's Association Special report found that a majority of Americans feel that medical research is biased against Asian, Black, Hispanic and Native Americans, which leads these underrepresented groups to be less interested in participating in clinical trials.<sup>745</sup>

As outlined in the same report, building relationships with community-based organizations and trusted leaders from underrepresented groups can help facilitate education and the delivery of dementia-related information and resources to these communities, including the importance of these groups' participation in clinical trials and disease research.<sup>774</sup>

For PCPs, awareness may not be the only reason they are not recommending and referring patients for participation in clinical trials and disease research. Some studies have found that not all physicians see value in clinical trials.<sup>772-773</sup> Others are hesitant to refer due to potential risks to their patients, concerns from their patients and logistical obstacles that prevent easy referral if the physician is not affiliated with an academic research institution.<sup>772-773</sup>

The Alzheimer's Association survey of PCPs published in 2019 found that fewer than 4 in 10 believe participation in clinical trials or other research is an important benefit of early detection of Alzheimer's disease.<sup>247</sup> This finding appears to still hold true today, as PCPs recommend trial participation just 8% of the time when MCI is detected (Figure 26, page 92). Education that reinforces the value and benefits of clinical trial participation is warranted.

Finally, many clinical trials today seek to include patients with preclinical Alzheimer's disease or MCI due Alzheimer's disease, highlighting a heightened need for PCP referral. Findings from the current survey indicate many PCPs do not feel they have the diagnostic tools to accurately confirm MCI due to Alzheimer's disease without referral to a specialist and follow-up testing. As outlined previously, increasing use of cognitive assessments and the potential availability of blood-based biomarkers to aid in detection and diagnosis of MCI due to Alzheimer's disease may help overcome this particular challenge.

## Conclusion

The Alzheimer's Association surveys of U.S. adults and primary care physicians underscore the need for robust efforts to raise the public's awareness of MCI, including MCI due to Alzheimer's disease, while also better preparing primary care physicians to identify, diagnose and manage their patients' cognitive impairment at its earliest stages. As we wait for widespread use of biomarkers to be common practice in the clinical setting, patients and physicians share responsibility in recognizing and addressing symptoms of MCI sooner and more proactively.

Early intervention offers the best opportunity for management and treatment, allowing individuals with MCI or MCI due to Alzheimer's disease more time to plan for the future, adopt lifestyle changes that may help slow disease progression, participate in clinical trials and to live more fully, with a higher quality of life, for as long as possible.

## Appendices

### End Notes

- A1. Activities of daily living: Everyday activities a person typically performs without assistance, including getting into and out of a bed or chair, bathing, dressing, grooming, eating and using the toilet.
- A2. Estimated prevalence (number and proportion) of Americans age 65 and older with Alzheimer's dementia for 2022: The estimated 6.5 million persons ages 65 years and older with Alzheimer's dementia and the estimated numbers of persons with Alzheimer's in each age group were reported from a study that used data from the Chicago Health and Aging Project (CHAP) in combination with population projections from the U.S. Census.<sup>224</sup> The number, 6.5 million, is higher than estimated from previous study that also combined CHAP and U.S. Census data. This is because the more recent study used updated Census projections and incorporated information from Hispanic/Latino American persons. The proportion of the population with Alzheimer's dementia (among all persons age 65 and older and by age group) is calculated using as the numerators the numbers of persons with Alzheimer's dementia, as reported by the recent study in CHAP.<sup>224</sup> The denominators were the U.S. Census population projections for the specific age groups of interest.
- A3. 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).<sup>224,228</sup> 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.<sup>227</sup> 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,<sup>32</sup> 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.
- A4. 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.<sup>259</sup> 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 2022.
- A5. 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.<sup>263</sup> 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.
- A6. Projected number of people with Alzheimer's dementia, 2020-2060: This figure comes from the CHAP study.<sup>224</sup> Other projections are somewhat lower (see, for example, Brookmeyer et al.<sup>775</sup>) because they relied on more conservative methods for counting people who currently have Alzheimer's dementia.<sup>A3</sup> 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.
- A7. 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.
- A8. 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 2020, 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." In the 2019 and 2020 BRFSS, an additional follow-up question was included, asking if the caregiving recipient also had dementia in addition to their main condition. Prior to 2019, the survey did not include caregivers of recipients for whom dementia was not their main condition, so these numbers were imputed using data collected in 2019 by the National Alliance for Caregiving (NAC)/AARP survey. 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 six states without 2015-2020 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 2021, using U.S. Census Bureau data available at: <https://www.census.gov/programs-surveys/popest/data/tables.html>. This resulted in a total of 11.343 million Alzheimer's and dementia caregivers across all 50 states and the District of Columbia.
- A9. 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.

- A10. **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,<sup>395</sup> 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<sup>A8</sup> 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 16.023 billion hours.
- A11. **Value of unpaid caregiving:** For each state, the hourly value of care was determined as the average of the state minimum hourly wage<sup>776</sup> and the most recently available state median hourly cost of a home health aide. (For Nevada, the minimum wage used was the average of the minimum wage for those who are not provided health insurance and the minimum wage for those who are provided health insurance.)<sup>686</sup> The average for each state was then multiplied by the total number of hours of unpaid care in that state<sup>A10</sup> 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 \$271.598 billion for dementia caregiving in the United States in 2021.
- A12. **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](http://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](http://alz.org/trajectory): (1) cost data from the 2018 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 colleagues<sup>224</sup> and included in this report (6.5 million in 2022), 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. Because state-specific prevalence estimates do not exist for 2022, the state-specific Medicaid costs included in *Facts and Figures* are based on the 2020 prevalence estimates reported here.<sup>A4</sup>
- A13. **All cost estimates were inflated to year 2021 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.

- A14. **Average annual per-person payments for health care and long-term care services for Medicare beneficiaries age 65 and older with and without Alzheimer's or other dementias:** Payments are unadjusted, and therefore, do not account for differences in patient characteristics, such as age or sex.
- A15. **Medicare Current Beneficiary Survey Report:** These data come from an analysis of findings from the 2018 Medicare Current Beneficiary Survey (MCBS). The analysis was conducted for the Alzheimer's Association by Health Care Cost Institute.<sup>260</sup> 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 setting, 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 *2022 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 setting 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 2018 and reported in 2021 dollars.
- A16. **Differences in Estimated costs reported by Hurd and colleagues:** Hurd and colleagues<sup>644</sup> estimated per-person costs using data from participants in ADAMS, a cohort in which all individuals underwent diagnostic assessments for dementia. *2022 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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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 is a world without Alzheimer's and all other dementia.®

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