SPECIAL REPORT
ALZHEIMER’S DETECTION IN THE PRIMARY CARE SETTING:
CONNECTING PATIENTS WITH PHYSICIANS

16 PERCENT
of seniors receive regular cognitive assessments during routine health check-ups.
Early detection of Alzheimer’s and other dementias provides a number of medical, social, emotional and planning benefits for affected individuals and their caregivers. According to a recent Alzheimer’s Association study, it also has financial benefits for both affected individuals and the country as a whole. A cornerstone of early detection of cognitive impairment is the routine assessment. Primary care providers may be especially well-suited to perform this evaluation and ensure timely follow-up. Through the use of physician and consumer surveys, this Special Report explores the state of cognitive assessment—termed “brief cognitive assessment” here—in the primary care setting and identifies potential solutions for existing barriers to widespread adoption of assessment in primary care settings.

Brief Cognitive Assessment in Primary Care

Overview of the Primary Care Setting
The goals of primary care include providing the first point of contact for medical care, as well as care that is continuous over time, is comprehensive and coordinates with other parts of the health system. Primary care providers who treat older adults include family physicians, general internists, geriatricians, nurse practitioners and physician assistants, and they practice in a variety of settings: private practices, hospital outpatient departments, community health centers and integrated care systems. In 2017, primary care physicians (PCPs) comprised one-third of the total physician workforce, and family and general internal medicine physicians combined comprised 75 percent of office-based PCPs. Estimates of non-physician primary care providers in 2016 indicate that 52 percent of nurse practitioners and 43 percent of physician assistants work in the primary care setting.

Primary Care Utilization
In 2017, there were 217 physicians per 100,000 people nationwide, 69 of whom were PCPs, which translates to one PCP for every 1,450 Americans. There is significant variation in the number of PCPs per 100,000 individuals across states, ranging from 48 in Mississippi to 102 in Maine. In general, the Northeast, Northwest and northern Midwest have the highest ratios of PCPs per 100,000 people. Including nurse practitioners and physician assistants, there are 101 primary care providers per 100,000 people, or about 1 for every 1,000 Americans.

According to the 2015 National Ambulatory Medical Care Survey, 51 percent of office visits were to primary care physicians. In the 2017 National Health Interview Survey, 86 percent of respondents reported having a “usual place of health care.” In an analysis of 2015-2017 data from the U.S. Centers for Disease Control and Prevention (CDC) Behavioral Risk Factor Surveillance System survey, 17 percent of women and 28 percent of men in the United States report not having a personal health care provider.

Benefits of Primary Care for First-Line Cognitive Assessment
Compared with neurology, psychiatry or other specialist care settings, the primary care setting may be better suited for brief cognitive assessment of seniors for several reasons. As the health care professionals likely to have the longest relationship with patients, and the practitioners whom patients tend to see most frequently, primary care providers may be in the best position to spot the earliest signs of cognitive decline. Continuity of care in a primary care setting is associated with lower mortality in older adults, as well as fewer hospitalizations and emergency department visits and improved patient satisfaction in the general adult population.

In addition, patients are more likely to discuss sensitive issues such as cognitive concerns with a provider they know and trust. Data from the 2016 Health Reform Monitoring Survey revealed that 74 percent of adults younger than 65 rated their trust in their usual provider as above a 7 on a scale from 0 to 10, and 90 percent would be comfortable talking to their usual provider about a potentially sensitive issue. In a 2006 telephone survey of 1,000 adults, more than 74 percent would advise a close friend or family member to check with a health professional about cognitive concerns, and 69 percent think a general physician is the best place to start.

Medicare Annual Wellness Visit
Overview
One opportunity for early identification of cognitive decline in the primary care setting is the Medicare Annual Wellness Visit (AWV), a benefit that began in 2011 as part of the 2010 Patient Protection and Affordable Care Act. A required component of the AWV is an assessment of cognitive function.

Any Medicare beneficiary who has received Medicare Part B benefits for at least 12 months and has not had an Initial Preventive Physical Exam or AWV within the last 12 months is eligible for the AWV.

Utilization
Use of the AWV among eligible Medicare beneficiaries has grown over time but is still generally low. According to a 2012 private survey of 1,028 adults age 65 and older, only one-third of respondents had heard of the AWV, and only 17 percent had had an AWV. According to the Centers for Medicare & Medicaid Services (CMS), in 2016,
What is a "Brief Cognitive Assessment"?

For the purposes of this report, a brief cognitive assessment is a short medical evaluation for cognitive impairment performed by a primary care practitioner that can take several forms. The practitioner may do one or more of the following:

- ask the patient directly about cognitive concerns
- observe patient interactions and cognitive function directly during the visit
- seek input about cognitive function from a patient’s family or friends
- take physical exams, medical history, and family history into account
- use one or more brief structured assessment tools to obtain objective measures of cognitive function

This Special Report uses the term “brief cognitive assessment” to avoid confusion with a longer, more comprehensive cognitive evaluation and to avoid confusion with an informal, nonmedical cognitive screening that might be performed online or at a health fair.

just 19 percent of the 55.3 million eligible Medicare Part B and Medicare Advantage beneficiaries utilized the AWV. This was up from 17 percent in 2015, 16 percent in 2014, and 8 percent in 2011.

AWV Cognitive Assessment

CMS provides limited guidelines concerning the exact nature of the brief cognitive assessment: “Assess the beneficiary’s cognitive function by direct observation, while considering information from beneficiary reports and concerns raised by family members, friends, caregivers, and others. If appropriate, use a brief validated structured cognitive assessment tool. For more information, refer to the National Institute on Aging’s Alzheimer’s and Dementia Resources for Professionals website.”

A number of professional organizations provide additional information to help primary care providers perform brief cognitive assessments. The Alzheimer’s Association Cognitive Assessment Toolkit includes the Medicare Annual Wellness Visit Algorithm for Assessment of Cognition as well as recommendations for operationalizing the detection of cognitive impairment during the AWV (alz.org/professionals/healthcare-professionals/cognitive-assessment). The Gerontological Society of America Kickstart Assess Evaluate Refer (KAER) Toolkit, the American Academy of Family Physicians Cognitive Care Kit and Minnesota’s Act on Alzheimer’s® Provider Practice Tools also provide recommendations for identifying cognitive impairment.

The State of Brief Cognitive Assessment in Primary Care: PCP and Consumer Surveys

How many seniors are receiving brief cognitive assessments, how often, and what do they entail? How important do PCPs and seniors think these assessments are, and do PCPs feel adequately trained to perform them? Are seniors aware that an AWV should include a brief cognitive assessment? What barriers to brief cognitive assessments exist, and how might they be overcome?

Knowledge of the overall usage, procedures and outcomes of brief cognitive assessment in older adults is quite sparse, and most of the limited data that does exist is at least a decade old. Therefore, the Alzheimer’s Association commissioned Versta Research to conduct surveys of PCPs and seniors to explore awareness and utilization of brief cognitive assessments in the primary care setting.

Alzheimer’s Association Surveys

Physicians included in the Alzheimer’s Association Primary Care Physician Cognitive Assessment Survey were recruited through WebMD’s Medscape Physician Panel, which includes 68 percent of all practicing PCPs in the United States. To qualify for the survey, physicians
were required to have practiced for at least 2 years, spend at least half of their time in direct patient care, and have a practice in which at least 10 percent of their patients are age 65 and older. A total of 1,000 PCPs, balanced by region, practice type and years in practice, completed the survey by phone or online.

The Alzheimer’s Association Consumer Cognitive Assessment Survey polled consumers aged 65 and older via the research organization NORC at the University of Chicago’s AmeriSpeak panel, a probability sample of the full U.S. population. A total of 1,954 individuals completed the survey by phone or online. Fifty-five percent were female and 45 percent male. Forty-one percent were age 75 and older, 33 percent were age 65-69, and 26 percent were age 70-74. Forty-two percent had an annual household income below $40,000, 30 percent had an income between $40,000 and $74,999, and 28 percent had an income above $75,000. Seventy-seven percent of respondents identified as white and non-Hispanic, 9 percent as black and non-Hispanic, and 8 percent as Hispanic.

The Alzheimer’s Association surveys revealed that, although nearly all PCPs and four of five seniors think brief cognitive assessments are beneficial, only half of seniors are being assessed and just one in seven is getting regular brief cognitive assessments. This number is in sharp contrast to the high percentages of seniors who receive routine assessments of other aspects of their health such as blood pressure and cholesterol levels. The surveys also found a disconnect between patient and PCP expectations: a large majority of seniors expect their physicians to recommend brief cognitive assessments, but physicians are waiting for patients or family members to report symptoms or request an assessment before doing so. In addition, most seniors are aware of the AWV provided by Medicare, but just one-third know that an AWV should include a brief cognitive assessment and only one-third are aware that Medicare will pay for testing and care planning for individuals with dementia. Nine of 10 PCPs want more guidance on nearly all aspects of the brief cognitive assessment process, including which assessment tools to use and how to use them, which patients to assess, and what to do when an assessment indicates possible cognitive impairment.

Overall, the survey results highlight significant underusage of this important health assessment and identify several areas where both PCP and senior education could be improved.
### Survey Results

#### Usage of Brief Cognitive Assessments in Primary Care

The results of the consumer survey show that nearly all seniors (94 percent) have seen a PCP for routine exams in the last year, but fewer than half (47 percent) have ever discussed their thinking or memory abilities with a health care provider. Less than a third (28 percent) have ever been assessed for cognitive problems.

In fact, just one in seven seniors (16 percent) receives regular cognitive assessments for problems with memory or thinking during routine health checkups, which stands in sharp contrast to regular screening or preventive services for other health factors: blood pressure (91 percent); cholesterol (83 percent); vaccinations (80 percent); hearing or vision (73 percent); diabetes (66 percent) and cancer (61 percent) (Figure 14, see page 61).

The results of the PCP survey show that PCPs perform brief cognitive assessments for an average of 50 percent of their patients age 65 or older, and roughly half of PCPs (47 percent) report that performing brief cognitive assessments for all patients age 65 or older is their standard protocol. Of those who report performing brief cognitive assessments as part of their standard protocol, 72 percent do so annually, 22 percent do so at least every 2 years, and 6 percent do so less frequently.

There are limited older data on how often cognitive assessments were performed in primary care. An analysis of 2000-2002 data from the Aging, Demographics, and Memory Study (ADAMS) of 845 community-based seniors over age 70 found that only 8 percent had ever received a cognitive evaluation by a physician. More generally, a 2008 survey of 1,000 PCPs showed that 40 percent reported discussing cognitive impairment risk with adults who did not have a diagnosis of dementia “often” or “very often” in the last 6 months, and another 39 percent reported having this discussion “sometimes.”

#### Brief Cognitive Assessment Procedures

Of the 28 percent of seniors who report ever having had a cognitive assessment, 89 percent say they were administered a test to measure their thinking and memory abilities; 59 percent were asked questions about cognitive symptoms; 28 percent were asked questions about symptoms that family, friends or caregivers had noticed; and 19 percent say their friends, family or caregivers were asked directly about the patient’s symptoms.

More than 95 percent of PCPs report that they use their own observations during visits, ask the patient questions about his or her cognition, and ask caregivers, family and friends about the patient’s cognition during a brief cognitive assessment. Nine of 10 also report using one or more structured assessments. The assessments PCPs most commonly report using are the Mini-Mental State Examination (MMSE; 80 percent), Clock Drawing Test (CDT; 64 percent) and the Mini-Cog (52 percent). Among those PCPs who use structured assessments, a large majority (77 percent) consider their structured testing not definitive enough to make a diagnosis, instead favoring more testing. This view is consistent with recent data indicating that brief structured assessment instruments are imperfect tools and comprise just one aspect of the diagnostic process.

PCPs report relying mostly on continuing medical education (CME) (92 percent), professional journals (85 percent), colleagues (77 percent) and scientific meetings (58 percent) for information about brief cognitive assessment best practices. However, their familiarity with resources designed to assist PCPs with brief cognitive assessments offered by specific professional groups is relatively low. Less than 40 percent of PCPs are familiar with, and less than one-third report using, the Alzheimer’s Association Medicare AWV Algorithm, the Alzheimer’s Association Cognitive Assessment Toolkit or the American Academy of Family Physicians Cognitive Care Kit.

A 2008 PCP survey found that 42 percent obtain cognitive health information from professional journals, 17 percent from CME sources and 17 percent from professional websites or listservs. In a focus group of primary care providers collected in 2007-2008 as part of the Healthy Brain Study, online information and CME were the major sources of information about cognitive health.

Nearly all respondents in the Alzheimer’s Association Primary Care Physician Cognitive Assessment Survey say that more information about several aspects of the brief cognitive assessment and follow-up process would be useful to them (Figure 15), consistent with earlier studies suggesting that PCPs could benefit from, and desire, more information about how to conduct brief cognitive assessments. For example, structured cognitive assessment tools are incorrectly scored or reported in one-quarter to one-third of cases.

#### Decision Whether or Not to Assess

Nearly all PCPs say the decision to assess patients for cognitive impairment is driven, in part, by reports of symptoms and/or requests. This includes reports of symptoms from family, caregivers or friends (98 percent) or patients themselves (97 percent), or requests for an assessment from family or caregivers (98 percent) or patients (94 percent). Ninety-six percent assess a patient for cognitive impairment if their own subjective assessment during an office visit indicates potential impairment. Three-quarters or more assess patients...
refusal rates, ranging from 48 percent to 67 percent. Nearly half of PCPs sometimes choose not to assess a patient because treatment options are limited. Additional concerns about the impact of a diagnosis on the patient, lack of confidence in assessing, business concerns and difficulties with patients were also cited.

Next Steps Following a Brief Cognitive Assessment

Medical Follow-up

When PCPs detect cognitive impairment, 97 percent recommend laboratory testing for reversible causes of cognitive impairment, and 99 percent make referrals to specialists. However, only 56 percent of PCPs recommend laboratory testing for all patients with a detected impairment, and only 17 percent make specialist referrals for all patients with a detected impairment.

Disclosure of Diagnosis

When cognitive impairment is detected, PCPs say they inform their patients 92 percent of the time (on average), and 64 percent report that they always inform patients. Nearly all seniors (95 percent) would want their health care provider to tell them if they were showing signs of thinking and memory problems, and 99 percent believe they have refusal rates, ranging from 48 percent to 67 percent. Nearly half of PCPs sometimes choose not to assess a patient because treatment options are limited. Additional concerns about the impact of a diagnosis on the patient, lack of confidence in assessing, business concerns and difficulties with patients were also cited.

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a right to know this information. Nine of 10 seniors would also want to undergo further testing to learn more about the problem and how it might be treated.

Among the 36 percent of surveyed PCPs who inform less than 100 percent of their patients, 73 percent say it’s because early disclosure before a full diagnostic workup is premature, and 41 percent say that brief cognitive assessments have high rates of false positives or false negatives. Fifty-four percent also note that treatment options are limited. Additional reasons PCPs decide not to disclose are similar to reasons cited for not assessing all patients, and include concerns about the impact of a diagnosis on the patient, a lack of confidence or expertise, business concerns and difficulties with patients, including refusal of follow-up testing.425

Seniors’ Concerns About Cognition

Half of all seniors (51 percent) report sometimes or frequently noticing changes in their ability to think, understand or remember things, and nearly one-quarter (22 percent) worry about such changes. Furthermore, one in nine seniors (11 percent) say that these changes interfere with their ability to function in activities such as cooking, getting dressed and grocery shopping. Forty-eight percent of seniors report doing activities or hobbies specifically because they hope it will help them with memory or thinking. This contrasts with the 84 percent who reported spending time doing activities that are beneficial for brain health in a 2006 telephone survey conducted by the American Society on Aging and the MetLife Foundation of attitudes and awareness of brain health involving 1,000 adults age 42 and older.545

Discussion of Cognitive Concerns with Health Care Providers

Of the 51 percent of seniors who sometimes or frequently notice changes in their cognition, most discuss these changes with family (67 percent) and friends (54 percent), but only 40 percent have talked to a health care provider about the changes. Among those who have, 37 percent talked to their primary health care provider and 12 percent talked to a specialist. Among the entire population of seniors surveyed, 47 percent have ever discussed their thinking and memory abilities with a health care provider, and 34 percent have done so in the last year.

Only one-quarter of seniors report that a health care provider has ever asked them if they have concerns about their thinking and memory without the seniors bringing it up first, and just 15 percent report having ever brought up concerns on their own, without a health care provider raising the topic first. Of those who haven’t talked to a health care provider about their concerns, a large majority say it’s because the changes seem like a normal part of aging (93 percent) and are not severe (80 percent). A number of other reasons were also provided.

When asked whether they agree or disagree with the statement “I trust that my doctor will recommend testing for thinking and memory problems if it is needed,” 93 percent of seniors reported that they strongly (54 percent) or somewhat agree (39 percent).

Attitudes Toward Cognitive Assessment

Seniors’ Attitudes Toward Cognitive Testing

Despite widespread lack of cognitive assessment, four of five seniors believe it is important to have their thinking and memory checked, similar to how they might have other routine physical check-ups and assessments, findings that are broadly consistent with earlier data (Figure 16).545,563

Eighty-nine percent of participants in the consumer survey think every senior should ask his or her doctor to check for thinking or memory problems, and 94 percent believe that early detection of cognitive decline is mostly beneficial.425 Only 2 percent of seniors believe that early detection of cognitive impairment is mostly harmful, and the top reasons focus on the negative psychological impact it may have.

Although most seniors believe in the value of assessment and early detection, a substantial minority (up to one-third) also express concerns about assessment and testing. 29 percent believe that tests for thinking or memory problems are unreliable; 24 percent agree that the idea of all seniors being tested for thinking or memory problems is insulting; and 19 percent believe there is no cure or treatment for thinking or memory problems, so why bother testing for them.

PCP Attitudes Toward Early Detection of Cognitive Impairment

Nearly all PCPs (94 percent) say they consider it important to assess all patients age 65 and older for cognitive impairment, and 58 percent say it is very important (Figure 16). Ninety-nine percent of PCPs consider it important to assess high-risk patients for cognitive impairment, and 87 percent consider it very important. High-risk patients were defined as those with a family history of dementia, personality changes, depression, unexplained deterioration of a chronic disease, or falls and balance issues. Taken together, these statistics demonstrate to PCPs that their colleagues do indeed value brief cognitive assessments.

PCPs are generally well aware of the importance of early detection, and see value in the opportunities for planning, support and potential treatment that early detection affords.529,531-532 Early detection of cognitive impairment is
While most PCPs say potential treatment and prevention are important, fewer than half (45 percent) believe there is strong scientific evidence supporting strategies to slow the rate of cognitive decline, including strategies such as smoking cessation, regular exercise, and control of hypertension and other cardiovascular risk factors. The remaining PCPs believe there is moderate (39 percent) or weak (16 percent) evidence.

Awareness and Utilization of Medicare Benefits

Annual Wellness Visit

Seventy-eight percent of seniors say they are knowledgeable about what their Medicare benefits cover, and 63 percent say they pay close attention to changes in Medicare laws and the benefits that are covered. Most (54 percent) also say they try to make full use of their benefits, getting all the tests, assessments and doctor visits available to them. Conversely, 46 percent say they use their Medicare benefits only when they are having a problem or need medical care.

Seventy-six percent of seniors are aware that Medicare specifically provides for a free AWV, and 64 percent report ever having seen a health care provider for an AWV (Figure 17, see page 66). However, only half as many (32 percent) are aware that an AWV includes a review of memory or thinking problems they might have, and only one-third (32 percent) recall a health care provider asking them about memory or thinking problems at an AWV (Figure 17).

Eighty-seven percent of PCPs are aware that Medicare provides free AWVs, and 72 percent, are aware that AWVs specifically provide for services to help detect cognitive impairment (Figure 17). On average, those who are aware that AWVs provide services to help detect cognitive impairments report performing an assessment at four of five AWVs. However, PCPs report, on average, that just four in 10 of their patients are coming in for AWVs.

Care Planning Benefits

Roughly one-third of seniors are aware that Medicare will pay for testing and care planning for people who have Alzheimer’s disease, other dementia or cognitive impairment. Just under one-third of PCPs (30 percent) are aware that Medicare provides reimbursement for a clinical visit that results in a comprehensive care plan, including cognition-focused evaluation (CPT® code 99483) and fewer than one in four (22 percent) report having billed under CPT® code 99483.

Differences Among PCPs Based on Years in Practice

PCPs who have been in practice fewer than 25 years (n=622) are more focused on assessing patients for cognitive impairment than those who have been in practice for seen as beneficial for two-thirds of patients, as it allows for planning and potential intervention. In all, PCPs estimate that 64 percent of patients benefit from early detection of cognitive impairment, while 7 percent are harmed, and 29 percent are neither benefited nor harmed.

More than nine of 10 PCPs say the benefits of early detection include allowing the patient and family to plan for the future; allowing testing and treatment for reversible causes; encouraging patients and families to seek support and education; and addressing potential safety issues ahead of time. The majority of PCPs also identified additional benefits, including allowing patients to understand what is happening to them and beginning health measures to preserve existing cognitive function for as long as possible. The majority of PCPs also identify additional benefits, including early treatment, more time to assemble medical and caregiving teams, and relieving patient concerns about other things that might be wrong. Surprisingly, just 35 percent of PCPs cite participation in clinical trials or other research as an important benefit of early detection.
PCPs believe regular assessments are important for all adults age 65 or older. It also indicates that PCPs are responsive to seniors bringing up cognitive symptoms. Important messages for seniors are that their doctors think cognitive assessments are valuable, and that they should speak to their doctor if they have concerns about their thinking or memory.

Despite nearly 80 percent of seniors reporting that they are knowledgeable about their Medicare coverage, only 32 percent are aware that AWVs include cognitive assessment. This represents an important opportunity to increase seniors’ knowledge of the benefits available to them.

While the Alzheimer’s Association senior survey showed that four of five older adults think brief cognitive assessments are beneficial and nine of 10 say they would want further testing if an impairment was detected, nearly 30 percent of seniors surveyed believe that tests for thinking or memory problems are unreliable. Furthermore, 57 percent of PCPs cite patient resistance to initial assessment, and 34 percent cite refusal of follow-up testing, as reasons they don’t always provide brief cognitive assessments, consistent with earlier studies documenting these two phenomena. Thus, seniors would benefit from increased awareness of the

Toward Better Cognitive Assessment: Challenges and Steps Forward

Taken together, the Alzheimer’s Association surveys provide a detailed view of the current state of brief cognitive assessments in the primary care setting and shed light on several opportunities for better education of both seniors and PCPs that have the potential to improve the quality and quantity of cognitive assessments.

Educational Opportunities for Seniors

The Alzheimer’s Association Primary Care Physician Cognitive Assessment Survey reveals that nine of 10

![Graph showing awareness of the Medicare Annual Wellness Visit (AWV) among primary care physicians and seniors.](image-url)
importance of brief cognitive assessments and of follow-up testing when cognitive impairment is detected.

Educational Opportunities for PCPs
In addition to highlighting key messages for older Americans, the Alzheimer’s Association surveys identified key trends for PCPs to understand. With four of five seniors indicating that brief cognitive assessments are beneficial and nine of 10 saying they trust their doctor to recommend cognitive testing, it is clear not only that seniors value cognitive assessments, but also that they are waiting for their doctor to ask about their thinking and memory symptoms.

Although PCPs are generally well aware of the many medical, financial and social/emotional benefits of early detection, fewer than four in 10 cite participation in clinical trials or other forms of research as an important benefit of early detection, suggesting an opportunity for increased education about the many ways that clinical trial participation can be helpful to their patients.

Resources on Brief Cognitive Assessment Best Practices
The Alzheimer’s Association PCP survey showed that nearly all PCPs desire more information about several aspects of brief cognitive assessments. In recognition of the lack of clear guidelines from CMS on how to perform cognitive assessment during an AWV, in 2017, the Alzheimer’s Association convened a Diagnostic Evaluation Clinical Practice Guideline Workgroup (the AADx-CPG Workgroup), composed of experts across disciplines in dementia care and research, that focuses on the evaluation, diagnosis and disclosure process in all care settings, particularly in primary care. When published, these clinical practice guidelines will be an important resource for PCPs.

Just four of 10 PCPs are aware of, and just three of 10 use, the existing resources for brief cognitive assessment best practices created by professional societies. The Alzheimer’s Association Medicare Annual Wellness Visit Algorithm for Assessment of Cognition and the Cognitive Assessment Toolkit provide guidance on review of patient health risk assessment information, patient observation, informal questioning about cognition, as well as the use of specific structured patient and informant cognitive assessment tools. The American Academy of Family Physicians Cognitive Care Kit contains resources on cognitive assessments, diagnosis and disclosure, and disease management, as well as prevention, long-term planning and caregiver resources. Increasing PCP awareness and use of these tools is an important step to empowering physicians to increase the quantity and quality of brief cognitive assessments.

The Healthy Brain Initiative State and Local Public Health Partnerships to Address Dementia: The 2018-2023 Road Map, published by the CDC and the Alzheimer’s Association, outlines 25 action agenda items to maximize cognitive health, including several strategies aimed at providing better education about brief cognitive assessments to PCPs. In addition, in 2018, the Alzheimer’s Association launched an innovative pilot program that is connecting dementia care experts with health care providers. The program includes information and resources relevant to clinical practice and is aimed at helping primary care providers not specialized in dementia care to better diagnose, care and support individuals with Alzheimer’s and other dementias.

A handful of primary care provider training programs have been developed to aid cognitive assessment in the primary care setting. Studies of these programs, which involved small sample sizes, had mixed results. Positive outcomes reported by these studies include increased cognitive assessment rates, improved ability to detect dementia, increased clinician confidence in diagnosis and dementia care overall, and higher patient satisfaction. More research is needed to further evaluate the utility of cognitive assessment training programs.

New Diagnostic Modalities
As research on additional ways to diagnose Alzheimer’s disease and other dementias moves forward, new tools for diagnosis are becoming available to clinicians. Three positron emission tomography (PET) radiotracers are currently approved by the U.S. Food and Drug Administration to assist clinicians in the diagnosis of Alzheimer’s disease, although they cannot yet be used to conclusively diagnose the disease in clinical practice. The Imaging Dementia—Evidence for Amyloid Scanning (IDEAS) Study, led by the Alzheimer’s Association, is currently assessing whether amyloid PET imaging can impact treatment decisions and medical outcomes in people with MCI or dementia of uncertain origin. Preliminary results indicate that amyloid PET imaging led to a change in patient management in more than 60 percent of participants.

Cerebrospinal fluid (CSF) biomarkers are another promising diagnostic tool for Alzheimer’s disease currently under development. In preparation for the inclusion of CSF biomarkers in the diagnostic process of Alzheimer’s disease, the Alzheimer’s Association convened a multidisciplinary workgroup that developed appropriate use criteria for lumbar puncture and CSF testing to guide clinicians.

It is important to note that these tools are likely to be utilized in tertiary care rather than primary care. They are not needed to diagnose the presence of cognitive decline or dementia, but rather may be used to determine the specific
cause or causes of a person's cognitive symptoms. As new diagnostic tools become available for clinical practice, physician and consumer attitudes and practices with respect to brief cognitive assessments may also evolve.

Trends of Hope
Despite significant challenges to improving brief cognitive assessments in the primary care setting, there are a number of encouraging signs that the United States is moving toward better and more numerous assessments, and better awareness of cognitive decline. Both seniors and PCPs think cognitive assessments are important, indicating that there is a strong foundation of knowledge on which to build going forward. PCPs are asking for information about how to better conduct assessments, demonstrating a desire for improvement. The fact that PCPs who have been in practice for fewer than 25 years are conducting more brief cognitive assessments and placing more importance on them than their older counterparts also suggests that the future will see improved early detection of cognitive decline. Finally, as awareness and usage of the Medicare AWVs, and the new care planning benefit grows, it will become progressively more common to regularly assess the cognition of older adults.

Conclusions
The Alzheimer’s Association Primary Care Physician and Consumer Cognitive Assessment Surveys provide a clear picture of the state of cognitive assessment in the primary care setting. Despite seniors’ and PCPs’ widespread awareness of the benefits of early detection and widely held beliefs that regular cognitive assessments are important, just half of seniors are being assessed, and only one in seven is receiving regular assessments.

The surveys highlight a number of educational opportunities for seniors and PCPs alike that have the potential to lead to the better utilization of brief cognitive assessments and the greater detection and diagnosis of cognitive impairment and dementia that are so urgently needed.
A1. Number of Americans age 65 and older with Alzheimer’s dementia for 2019: These state-by-state prevalence numbers are based on an analysis of incidence data from CHAP, projected to each state’s population, with adjustments for state-specific age, gender, years of education, race and mortality. Specific prevalence numbers for 2019 were derived from this analysis and provided to the Alzheimer’s Association by a team led by Liesi Hebert, Sc.D., from Rush University Institute on Healthy Aging.

A2. Percentage of total Alzheimer’s dementia cases by age groups: These 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 6 months’ duration were used, lifetime risks of Alzheimer’s and other dementias would be higher than those estimated by this study.

A3. Proportion of Americans age 65 and older with Alzheimer’s dementia: The 10 percent for the age 65 and older population is calculated by dividing the estimated number of people age 65 and older with Alzheimer’s dementia (5.6 million) by the U.S. population age 65 and older in 2019, as projected by the U.S. Census Bureau (54.6 million) = approximately 10 percent. Please note that the proportion of Americans age 65 and older with Alzheimer’s dementia has gone down slightly in recent years despite the number of Americans with Alzheimer’s dementia in this age range going up, this is because of the large number of baby boomers who have started to enter this age range and increased the overall number of seniors, but at the early low risk years in this range.

A4. Differences between CHAP and ADAMS estimates for Alzheimer’s dementia prevalence: ADAMS estimated the prevalence of Alzheimer’s dementia to be lower than CHAP, at 2.3 million Americans age 71 and older in 2002, while the CHAP estimate for 2000 was 4.5 million. At a 2009 conference convened by the National Institute on Aging and the Alzheimer’s Association, researchers determined that this discrepancy was 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. 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, 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.

A5. Number of new cases of Alzheimer’s dementia in 2019: The East Boston Established Populations for Epidemiologic Study of the Elderly (EPPESE) estimated that there would be 454,000 new cases in 2010 and 491,000 new cases in 2020 (see Hebert et al). The Alzheimer’s Association calculated the incidence of new cases in 2019 by multiplying the 10-year change from 454,000 to 491,000 (37,000) by 0.9 (for the number of years from 2010 to 2019 divided by the number of years from 2010 to 2020), adding that result (33,300) to the Hebert et al. estimate for 2010 (454,000) = 487,300. Rounded to the nearest thousand, this is 487,000 new cases of Alzheimer’s dementia in 2019.

A6. Criteria for identifying people with Alzheimer’s or other dementias in the Framingham 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. 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 6 months’ duration were used, lifetime risks of Alzheimer’s and other dementias would be higher than those estimated by this study.

A7. State-by-state prevalence of Alzheimer’s dementia: The estimates for the number of U.S. women (1.5 million) and men (2.1 million) age 65 and older with Alzheimer’s in 2019 is from unpublished data from CHAP. For analytic methods, see Hebert et al.

A8. Number of women and men age 65 and older with Alzheimer’s dementia in the United States: These estimates for the number of U.S. women (1.5 million) and men (2.1 million) age 65 and older with Alzheimer’s in 2019 is from unpublished data from CHAP. For analytic methods, see Hebert et al.

A9. Prevalence of Alzheimer’s and other dementias in older whites, black/African Americans and Hispanics: The statement that black/African Americans are twice as likely and Hispanics one and one-half times as likely as whites to have Alzheimer’s or other dementias is the conclusion of an expert review of a number of multiracial and multietnic data sources, as reported in detail in the Special Report of the Alzheimer’s Association’s 2010 Alzheimer’s Disease Facts and Figures.

A10. Projected number of people with Alzheimer’s dementia: This figure comes from the CHAP study. Other projections are somewhat lower (see, for example, Brookmeyer et al.) because they relied on more conservative methods for counting people who currently have Alzheimer’s dementia. 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.

A11. Projected number of people age 65 and older with Alzheimer’s dementia in 2025: The number 7.1 million is based on a linear extrapolation from the projections of prevalence of Alzheimer’s for the years 2020 (5.8 million) and 2030 (8.4 million) from CHAP.

A12. 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 true 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.

A13. 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 BRFSS survey. In 2009, the BRFSS survey asked respondents age 18 and over whether they 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. To determine the number of family and other unpaid caregivers nationally and by state, we applied the proportion of caregivers nationally and for each state from the 2009 BRFSS (as provided by the CDC, Healthy Aging Program, unpublished data) to the number of people age 18 and older nationally and in each state from the U.S. Census Bureau report for July 2018. Available at: https://www.census.gov/data/tables/time-series/demo/popest/2010s-state-detail.html. Accessed on Jan. 3, 2019. To calculate the proportion of family and other unpaid caregivers who provide care for a person with Alzheimer’s or another dementia, the Alzheimer’s Association used data from the results of a national telephone survey also conducted in 2009 for the National Alliance for Caregiving (NAC/AARP). 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. In response, 26 percent of caregivers said that (1) Alzheimer’s...
or another dementia was the main problem of the person for whom they provided care, or (2) the person had Alzheimer's or other mental confusion in addition to his or her main problem. The 26 percent figure was applied to the total number of caregivers nationally and in each state, resulting in a total of 16,249.5 million Alzheimer's and dementia caregivers.

A14 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, selected from U.S. Census tracts with higher than an 8 percent 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.

A15 Number of hours of unpaid care: To calculate this number, the Alzheimer’s Association used data from a follow-up analysis of results from the 2009 NACC/AARP national telephone survey (data provided under contract by Matthew Greenwald and Associates, Nov 11, 2009). These data show that caregivers of people with Alzheimer’s or other dementias provided an average of 21.9 hours a week of care, or 1,139 hours per year. The number of family and other unpaid caregivers (16,249.5 million)\(^{11}\) was multiplied by the average hours of care per year, which totals 18,505 billion hours of care. This is slightly lower than the total resulting from multiplying 1,139 by 16,249.5 million because of rounding.

A16 Value of unpaid caregiving: To calculate this number, the Alzheimer’s Association used the method of Amo and colleagues.\(^{572}\) This method uses the average of the federal minimum hourly wage ($7.25 in 2018) and the mean hourly wage of home health aides ($18.02 in July 2018).\(^{567}\) The average is $12.64, which was multiplied by the number of hours of unpaid care (18,505 billion) to derive the total value of unpaid care ($233,903 billion; this is slightly higher than the total resulting from multiplying $12.64 by 18,505 billion because 18,505 is a rounded number for the hours of unpaid care).

A17 Higher health care costs of Alzheimer’s caregivers: This figure is based on a methodology originally developed by Brent Fulton, Ph.D., for The Shriner Report: A Woman’s Nation Takes on Alzheimer’s. A survey of 17,000 employees of a multinational firm based in the United States estimated that caregivers’ health care costs were 8 percent higher than non caregivers.\(^{573}\) To determine the dollar amount represented by that 8 percent figure nationally and in each state, the 8 percent figure and the proportion of caregivers from the 2009 BRFSS\(^{574}\) were used to weight each state’s caregiver and non-caregiver per capita personal health care spending in 2014,\(^{586}\) inflated to 2018 dollars. The dollar amount difference between the weighted per capita personal health care spending of caregivers and non-caregivers in each state (reflecting the 8 percent higher costs for caregivers) produced the average additional health care costs for caregivers in each state. Nationally, this translated into an average of $72.77. The amount of the additional cost in each state, which varied by state from a low of $540 in Utah to a high of $1,084 in the District of Columbia, was multiplied by the total number of unpaid Alzheimer’s and dementia caregivers in that state\(^{581}\) to arrive at that state’s total additional health care costs of Alzheimer’s and other dementia caregivers as a result of being a caregiver. The combined total for all states was $11,785 billion. Fulton concluded that this is “likely to be a conservative estimate because caregiving for people with Alzheimer’s is more stressful than caregiving for most people who don’t have the disease.”\(^{583}\)

A18 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 (previous version 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 Hebert and colleagues\(^{575}\) and included in this report (5.8 million in 2019),\(^{576}\) 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 (the 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.

A19 All cost estimates were inflated to year 2018 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.

A20 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.\(^{577}\) 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 2019 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 2018 dollars.

A21. Differences in estimated costs reported by Hurd and colleagues: Hurd and colleagues estimated per-person costs using data from participants in ADAMS, a cohort in which all individuals underwent diagnostic assessments for dementia. 2019 Alzheimer’s Disease Facts and Figures estimated per-person costs using data from the Medicare Current Beneficiary Survey (MCBS). 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 2019 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).

A22. Alzheimer’s Association Consumer and Primary Care Physician, Cognitive Assessment Surveys: The consumer survey was conducted by Versta Research from December 13, 2018, through December 26, 2018. The survey was offered in English and Spanish and as either an online Web survey or a phone survey. The 1,954 respondents had the following demographics: 55 percent were female and 45 percent were male. Forty-one percent were age 75 and older, 33 percent were age 65-69, and 26 percent were age 70-74. Thirty-eight percent resided in the South, 22 percent in the West, 21 percent in the Midwest, and 19 percent in the Northeast. Forty-two percent had an annual household income below $40,000, 30 percent had an income between $40,000 and $74,999, and 28 percent had an income above $75,000. Seventy-seven percent of respondents identified as white and non-Hispanic, 9 percent as black and non-Hispanic, and 8 percent as Hispanic. Seventy-six percent were retired, and 17 percent were working. The primary care physician survey was conducted by Versta Research from December 10, 2018, through January 8, 2019. Of the 1,000 respondents, 68 percent spent less than 90 percent of their professional time in direct patient care, while 32 percent spent between 90 and 100 percent of their time in direct patient care. On average, 43 percent of their patients were age 65-74 and 42 percent were age 65 and older. Thirty-two percent had been in practice for 15-24 years, 31 percent for fewer than 15 years, 24 percent for 25-34 years, and 14 percent for 35 years or more. Eighty-four percent had office-based practices, and 14 percent had hospital-based practices. Fifty-one percent had a primary medical specialty of family medicine, 46 percent specialized in internal medicine, and 3 percent were general practitioners. Thirty-six percent of respondents resided in the South, 23 percent in the West, 22 percent in the Midwest, and 19 percent in the Northeast.

A23. Additional structured assessments used by primary care physicians: Additional responses, ranked by the percentage of participants who selected that choice, are shown below. Participants were allowed to select more than one answer, so percentages do not add up to 100.

- Montreal Cognitive Assessment (MoCA): 25 percent
- Memory Impairment Screen (MIS): 22 percent
- General Practitioner Assessment of Cognition (GPCog): 12 percent
- Cambridge Cognitive Examination (CAMCOG): 7 percent

A24. Other reasons primary care physicians choose not to assess: Additional responses, grouped by theme, are shown below. Participants were allowed to select more than one answer, so percentages do not add up to 100. Concerns about the patient:

- Few services are available for diagnosed patients (32 percent)
- Diagnosis of cognitive impairment may be stigmatizing (25 percent)
- Early diagnosis does not provide benefits (19 percent)
- Lack of confidence in assessing: Specialists are better equipped to assess and diagnose (38 percent)
- Cognitive assessments have high rates of false positive or negatives (28 percent)
- Lack of training or confidence in performing such assessments (25 percent)

Business concerns:

- Lack of financial reimbursement for time spent discussing results (22 percent)
- Lack of financial reimbursement for performing an assessment (21 percent)
- Follow-up care for diagnosed patients would strain primary care resources (17 percent)
- Difficulty with patients: Managing patients with cognitive impairment is difficult or time consuming (29 percent)
- Disclosing a diagnosis to patients is difficult or time consuming (24 percent)

A25. Other reasons primary care physicians choose not to disclose: Additional responses, grouped by theme, are shown below. Participants were allowed to select more than one answer, so percentages do not add up to 100. Concerns about the patient:

- Early disclosure of results may be stigmatizing (44 percent)
- Few services are available for diagnosed patients (40 percent)
- Early disclosure does not provide benefits to a patient (29 percent)
- Lack of confidence or expertise: Disclosing results is difficult (44 percent)
- Specialists are better equipped to discuss results (43 percent)

Business concerns:

- Lack of training or confidence in disclosing results (30 percent)
- Business concerns: Lack of time during visits (40 percent)
- Follow-up care for diagnosed patients would strain primary care resources (24 percent)
- Lack of financial reimbursement for time spent discussing results (23 percent)

Difficulties with Patients:

- The patient refusal rate for follow up testing is high (44 percent)
- Managing patients with cognitive impairment is difficult or time consuming (35 percent)

A26. Additional reasons seniors believe early diagnosis is important: Additional responses, ranked by the percentage of participants who selected that choice: It allows for earlier treatment of symptoms with medication or other interventions (93 percent)
- A person can begin health measures to preserve existing cognitive function for as long as possible (92 percent)
- It helps to understand what is happening (91 percent)
- It allows the person and their family to plan for the future (91 percent)
- It allows the person to be tested and treated for reversible causes of thinking or memory problems (91 percent)
- It helps a person address potential safety issues (76 percent)
- It allows the person to participate in clinical trials and other research (71 percent)

Participants were allowed to select more than one answer, so percentages do not add up to 100.

Appendices
References


https://www.medicare.gov/coverage/long-term-care.html


541. Chawarsngh OR, Henry Y, van de Ven PM, Deeg DJ. Continuity of care in primary care and association with survival in older

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The Alzheimer’s Association is the leading voluntary health organization in Alzheimer’s care, support and research. Our mission is to eliminate Alzheimer’s disease through the advancement of research; to provide and enhance care and support for all affected; and to reduce the risk of dementia through the promotion of brain health.

Our vision is a world without Alzheimer’s disease.