

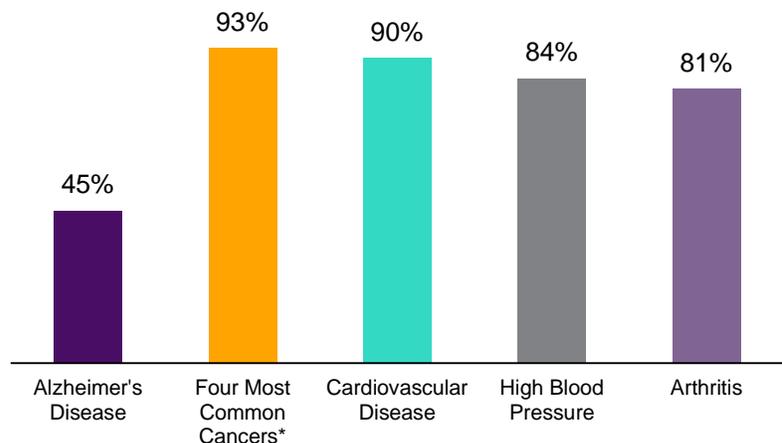
## Early Detection and Diagnosis of Alzheimer's Dementia

Quality care for people with Alzheimer's disease and other dementias starts with an early, documented diagnosis, including disclosure of the diagnosis. However, most people who have been diagnosed with Alzheimer's dementia are not aware of their diagnosis. Evidence indicates that only about *half* of those with Alzheimer's dementia have been diagnosed.<sup>1</sup> Among those seniors who have been diagnosed with Alzheimer's dementia, only 33 percent are even aware that they have the disease. Even when including caregivers, 45 percent of those diagnosed with Alzheimer's or their caregivers are aware of the diagnosis. These data are comparable to baseline data from *Healthy People 2020*, the nation's 10-year public health agenda, that indicate approximately 35 percent of Medicare beneficiaries age 65 and older diagnosed with dementia, or their caregivers, were aware of the diagnosis.<sup>1</sup>

To address this challenge, *Healthy People 2020* includes the objective to "increase the proportion of persons with diagnosed Alzheimer's disease and other dementias, or their caregiver, who are aware of the diagnosis."<sup>2</sup> To achieve progress towards this, actions include ensuring that both the public and health care providers are aware of the early warning signs of Alzheimer's dementia; educating health care providers on early detection and diagnosis, including patient/family communications and documentation in medical records; and assessing cognition during the Medicare Annual Wellness Visit (AWV). These actions, among others, provide a foundation for the delivery of quality dementia care.

### Disclosure of Diagnoses

Percentage of Seniors Diagnosed with Specified Condition or Their Caregivers Who Are Aware of the Diagnosis



\*Breast, Lung, Prostate and Colorectal

Source: Alzheimer's Association, 2015 Alzheimer's Disease Facts and Figures

### Basics of Alzheimer's dementia

Alzheimer's disease, the most common cause of dementia, is a disabling chronic condition characterized by symptoms such as increased confusion, memory loss and impaired judgment.<sup>1</sup> These symptoms impede daily activities and the management of comorbid conditions and can lead to functional decline, significant caregiver

burden and long-term disability. Although Alzheimer's dementia is not a normal part of aging, age is the biggest risk factor: only an estimated 4 percent of Alzheimer's cases occur among those under the age of 65; of those 85 years and older, 38 percent have the disease.<sup>2</sup> With the aging of the baby boom generation, an increasing number of Americans will move into the age range where they will be at a higher risk of developing Alzheimer's dementia and would benefit from increased efforts aimed at promoting early detection and diagnosis.

### Benefits of early detection and diagnosis

Early detection and diagnosis offers a number of benefits to help individuals who have Alzheimer's dementia and their families. Due to the progressive nature of Alzheimer's and other dementias, the best opportunity for individuals to benefit from available treatments, enroll in clinical trials, build a care team, and express their wishes, is in the early stages of the disease. People who are aware of their diagnosis and their caregivers can plan for the future by creating advance health directives and making financial and legal arrangements before cognition significantly declines. They can also address safety issues and seek counseling on how to cope with behavioral changes associated with disease progression.<sup>1</sup>

Early detection can also help health care providers deliver better care. A diagnosis can help physicians better manage an individual's comorbid conditions and avoid prescribing medications that may worsen cognition or function.<sup>3</sup> Since early warning signs such as memory problems, confusion, personality changes, and trouble with judgment<sup>4,5</sup> may be attributable to other sources, early detection of cognitive changes allows physicians to identify and treat reversible conditions that mimic cognitive impairment and dementia such as depression or vitamin deficiency.<sup>1</sup>

The G0505 Cognitive Impairment Care Planning billing code (on January 1, 2018, the permanent code will be 99XX3) that was issued by the Centers for Medicare & Medicaid Services will also aid early detection efforts through increased opportunities for care planning. Historically, one reason that physicians have not diagnosed Alzheimer's dementia or have not disclosed

### U.S. Preventive Services Task Force

The U.S. Preventive Services Task Force, a group of national experts who develop recommendations on clinical preventive services and evidence-based medicine, concluded that the current evidence is "insufficient" to recommend routine screening for cognitive impairment in asymptomatic older adults. The benefits and harms of screening could not be determined. However, the Task Force stated that "clinicians should remain alert to early signs or symptoms of cognitive impairment and evaluate as appropriate." The Task Force also recognized cognitive impairment as a serious public health issue and encouraged consumers experiencing memory problems to speak with their health care providers.

*Final Recommendation Statement: Cognitive Impairment in Older Adults:  
Screening. U.S. Preventive Services Task Force. 2014*

a diagnosis is a lack of time and resources to engage in care planning.<sup>6</sup> Under this billing code, Medicare pays for care planning services for individuals who are cognitively impaired, including people with Alzheimer's dementia.<sup>7</sup>

Eligible services under the G0505 Cognitive Impairment Care Planning billing code include: medical decision-making, functional assessment, cognition evaluation, medication reconciliation, advance care planning and care plan creation. Also, the G0505 code includes the identification of a specific caregiver and an assessment of the caregiver's knowledge, needs and ability to provide care.

Additionally, care assessment and planning may help to reduce unmet needs of individuals with Alzheimer's dementia who are more likely to experience disability. Among Medicare beneficiaries who report being aware of their diagnosis, 57 percent required assistance with three or more activities of daily living (ADLs) and 59 percent required assistance with three or more instrumental activities of daily living (IADLs).<sup>1</sup> Data from the 2015 Behavioral Risk Factor Surveillance System (BRFSS) found over half of adults with subjective cognitive decline reported that their memory problems create functional difficulties that interfere with work or social activities.<sup>8</sup>

## Barriers to early detection and diagnosis

For early detection to occur — and subsequent diagnosis and disclosure awareness — individuals and physicians must overcome several barriers. Persons with Alzheimer's dementia face significant barriers such as low public awareness of the early signs of Alzheimer's; emotional distress of Alzheimer's and other dementias on family members;<sup>9</sup> and misperceptions about Alzheimer's and other dementias.<sup>10,11</sup> For example, a recent survey of 12 countries found 59 percent of respondents incorrectly believed that Alzheimer's is a typical part of aging, and 40 percent believed that Alzheimer's is not fatal.<sup>12</sup> These barriers can lead to stigma, delays in seeking medical assistance or reluctance to communicate with health care providers. Data from the 2015 BRFSS showed that 55 percent of adults age 45 and older who reported subjective cognitive decline in the previous 12 months had not discussed this matter with a health care provider.<sup>13</sup> Also, even among those whose memory problems were creating functional difficulties, 42 percent had not discussed these issues with a health care provider.<sup>14</sup>

Physicians face barriers such as low recognition of the signs of cognitive impairment; a lack of education or training on dementia care; concerns about stigma and the usefulness of an early diagnosis; lack of time; and difficulty talking about dementia or disclosing a diagnosis.<sup>1,15,16,17</sup> Contributing to these challenges are low rates of documentation of diagnoses in individuals' medical records. Less than half of those with Alzheimer's and other dementias have these diagnoses documented in their medical records.<sup>14,18,19</sup> Research also indicates low rates of documentation for mild cognitive impairment, even if doctors recognize and diagnose it.<sup>15</sup>

## Detection/assessment of cognitive change

Experts agree establishing a cognitive baseline in a medical setting can assist health care providers with identifying changes in cognition that merit further evaluation.<sup>20</sup> Consistent with this, the detection of possible cognitive impairment is a mandatory element

of the Medicare Annual Wellness Visit (AWV).<sup>21</sup> As previously noted, because early signs and symptoms of cognitive impairment and dementia may be characteristic of other health conditions, these routine, brief cognitive assessments are an important way for physicians to detect notable changes over time that could indicate underlying pathology.

The National Institute on Aging (NIA),<sup>22</sup> the Gerontological Society of America (GSA)<sup>23</sup> and the Alzheimer's Association<sup>19</sup> have developed evidence-based guidelines to advise health care providers on how to detect cognitive impairment in primary care settings, including during the Medicare AWV. Although expert groups have not recommended a single preferred instrument, there is consensus that tools for the detection of cognitive impairment should be short, easy to administer, and validated for use in primary care settings.<sup>19,21,22</sup> If cognitive impairment is detected, health care providers can then refer individuals for comprehensive diagnostic evaluations.

In addition to employing a brief assessment tool for detection, these guidelines recommend physicians incorporate informant interviews and self-reports. A growing body of evidence suggests subjective cognitive decline (SCD) may be a harbinger of subsequent cognitive impairment or dementia, including Alzheimer's. Studies have shown SCD to be associated with increased risk of mild cognitive impairment or dementia,<sup>24</sup> significant decline in episodic memory,<sup>25</sup> early Alzheimer's pathology such as the accumulation of beta-amyloid plaque,<sup>26</sup> and memory decline in people who carry the apolipoprotein E (APOE)-e4 gene,<sup>27</sup> a genetic risk factor for Alzheimer's disease. As research continues, health care providers may be able to employ SCD as a clinical complement to other cognitive detection tools.

## What can be done?

Early detection and diagnosis of Alzheimer's and other dementias helps those with the disease achieve better quality care by identifying cognitive impairment as early as possible. As with other chronic conditions, early identification and management of Alzheimer's

and other dementias helps individuals better understand and anticipate care needs as they arise. The following public policies can help promote early detection and diagnosis, and ultimately support the health outcomes of those with Alzheimer's dementia.

- **Raise public awareness about the signs and symptoms of Alzheimer's disease and other dementias — and the importance of early detection and diagnosis.** The Arizona Department of Health, the Bangor (Maine) Public Health Department, and the South Carolina Department of Health and Environmental Control are among the public health agencies that have educated the public about Alzheimer's and other dementias and early detection. These public health agencies have provided educational materials regarding the early warning signs and the importance of talking with a health care provider when experiencing memory problems. When developing a public education campaign, outreach efforts should include faith-based groups and diverse communities. Materials should be provided in languages appropriate for local audiences. Large employers and governmental agencies can be encouraged to participate in the Alzheimer's Workplace Alliance<sup>®</sup> (AWA), which aims to raise awareness about Alzheimer's disease and the importance of early detection while providing help to those who are balancing work and caregiving responsibilities.<sup>28</sup>
- **Promote use of the Medicare Annual Wellness Visit (AWV).** The Medicare AWV provides an excellent opportunity for physicians to discuss healthy aging with individuals, regardless of their health status. Discussion topics in the Medicare AWV can include risk factors for cognitive decline and guidance on lifestyle and behavioral changes that can support brain health.<sup>29</sup> Public health, aging, and health professionals' organizations can educate the public on the importance of this annual health visit by providing information on the advantages in easy-to-read, culturally appropriate materials. Public health can also educate physicians on how to detect cognitive impairment and use validated cognitive assessment tools and quick references such as the Alzheimer's Association Cognitive Assessment Toolkit,<sup>30</sup> a guide for detecting cognitive impairment during the Medicare AWV.
- In addition, the Gerontological Society of America has also developed a cognitive impairment toolkit that helps providers to conduct the Medicare AWV. The toolkit is based on the four-step KAER model (Kickstart the cognition conversation; Assess for cognitive impairment; Evaluate for dementia; and Refer for community resources). Each step in the KAER model is designed to allow primary care physicians to achieve greater awareness of cognitive impairment in older adults; increase detection of cognitive impairment and earlier diagnostic evaluation; and increase referrals for education and community services for persons with dementia and their caregivers.
- **Raise provider awareness concerning the new G0505 Cognitive Impairment Care Planning billing code.** Even though the new G0505 Cognitive Impairment Care Planning billing code has been in effect since January 2017, many health care providers are not aware of it.<sup>31</sup> State public health agencies, together with provider groups, can raise provider awareness concerning this new code in a number of ways. These organizations can utilize newsletters and conferences to inform providers about the new code; educate them on the advantages and importance of care planning; and can provide practitioners with toolkits and other sources of guidance. The Alzheimer's Association developed a Cognitive Impairment Care Planning Toolkit that provides an introduction to the G0505 billing code, clinician requirements for participation, beneficiary eligibility for comprehensive planning services, as well as tools and suggested measures to support the care planning process.
- **Educate health care providers.** State public health agencies and provider groups can share information with physicians about early detection and diagnosis, including the importance of disclosing a diagnosis and medical record

documentation. For example, the New York State Department of Health sent a “Dear Colleague” letter to all primary care providers in the state<sup>32</sup> to convey the importance of early detection, validated cognitive assessment tools, and the importance of referral for further evaluation. The department then conducted a free online training, which allowed participants to earn continuing medical education units. State agencies can also partner with medical associations to develop or link to an online resource page that includes information about Alzheimer’s and other dementias, community resources and continuing education courses that can help health care professionals improve their ability to recognize the early warning signs and provide appropriate care for individuals with the disease.

- Collect data on early detection and cognition.** While the Medicare AWV requires “detection of cognitive impairment,” there is currently no way to readily track if physicians are conducting these assessments in these visits. Medical associations, consumer health groups, and public health entities can form partnerships to periodically survey health care providers in their states to find out how often physicians discuss cognitive health during the AWV and what tools they use with individuals who have symptoms suggestive of cognitive impairment. For example, the Utah Department of Health surveyed health care providers on this issue and discussed the survey results in a physician’s summit. The survey results were also used in a “Dear Colleague” communication as well as in a tip sheet to enhance providers’ use of the AWV to support early detection. State public health agencies can also periodically field the Cognitive Module in their BRFSS surveys to capture state-specific data on cognitive decline (including discussions with health care providers) and use this information to inform interventions.
- Support research on outcomes of early detection.** Additional research is needed to

evaluate outcomes of early detection for cognitive impairment, specifically the impact detection has on individual and caregiver decision-making and societal outcomes.

## Conclusion

Detecting cognitive impairment, diagnosing Alzheimer’s and other dementias, and disclosing that diagnosis to the individual are necessary elements to ensuring that people with dementia, together with their families, have the opportunity to access available treatments, build a care team, participate in support services, enroll in clinical trials, and plan for the future. Policies to promote early detection and diagnosis — among the public and health care providers — can ensure that these opportunities are available when they will be most effective and beneficial.

### Free Resources to Promote Early Detection and Diagnosis

#### Provider Resources

Alzheimer’s Association:

- Information for Health Care Professionals
- Challenging Conversations about Dementia
- Care Planning Resources

Gerontological Society of America:

- Cognitive Impairment Detection Report
- Webinar on the Medicare Annual Wellness Visit
- KAER Toolkit: 4-Step Process to Detecting Cognitive Impairment and Earlier Diagnosis of Dementia

National Institute on Aging:

- Assessing Cognitive Impairment in Older Patients: A Quick Guide for Primary Care Physicians
- Talking with Your Older Patient: A Clinician’s Handbook

University at Albany, SUNY, School of Public Health:

- Webinars for Primary Care Providers and Health Professionals

#### Consumer Resources

Alzheimer’s Association:

- 10 Early Signs and Symptoms of Alzheimer’s
- Forgetfulness: Normal or Not?

National Institute on Aging:

- Understanding Memory Loss: What to Do When You Have Trouble Remembering

- <sup>1</sup> Healthy People 2020. Dementias, Including Alzheimer's Disease. Available at <https://www.healthypeople.gov/2020/topics-objectives/topic/dementias-including-alzheimers-disease/objectives>.
- <sup>2</sup> Alzheimer's Association. 2017 Alzheimer's Disease Facts and Figures. 2017. [alz.org/facts](http://alz.org/facts).
- <sup>3</sup> Dubois B, Padovani A, Schletens P, Rossi A, Dell'Agnello G. Timely Diagnosis for Alzheimer's Disease: A Literature Review on Benefits and Challenges. *J Alzheimer's Dis* 2016;49(3):617-631.
- <sup>4</sup> Alzheimer's Disease Education and Referral Center. About Alzheimer's Disease: Symptoms. National Institute on Aging n.d. Available at <http://www.nia.nih.gov/alzheimers/topics/symptoms>.
- <sup>5</sup> Alzheimer's Association. 10 Early Signs and Symptoms of Alzheimer's. Alzheimer's Association n.d. Available at [http://www.alz.org/alzheimers\\_disease\\_10\\_signs\\_of\\_alzheimers.as.p](http://www.alz.org/alzheimers_disease_10_signs_of_alzheimers.as.p).
- <sup>6</sup> Phillips J, Pond CD, Paterson NE, Howell C, Shell A, Stocks NP, et al. Difficulties in Disclosing the Diagnosis of Dementia: A Qualitative Study in General Practice. *Br J Gen Pract* 2012;62(601):e546-53.
- <sup>7</sup> Centers for Medicare and Medicaid Services, "Final Rule, CY 2017 Revisions to Payment Policies under the Physician Fee Schedule and Other Revisions to Part B." CMS-1654-F. November 15, 2016. <https://www.cms.gov/Medicare/Medicare-Fee-For-Service-Payment/PhysicianFeeSched/PFS-Federal-REGulation-Notices-Items/CMS-1654-f.html>.
- <sup>8</sup> Centers for Disease Control. [https://nccd.cdc.gov/aging\\_data/rdPage.aspx?rdReport=DPH\\_HAP\\_ExploreByTopic&isIClass=C06&isYear=2015](https://nccd.cdc.gov/aging_data/rdPage.aspx?rdReport=DPH_HAP_ExploreByTopic&isIClass=C06&isYear=2015)
- <sup>9</sup> Boustani MA, Justiss MD, Frame A, Austrom MG, Perkins AJ, Cai X, Sachs GA, Torke AM, Monahan P, Hendrie HC. Caregivers and Non-Caregivers Attitudes Toward Dementia Screening. *J Am Geriatr Soc* 2011;59(4):681-686.
- <sup>10</sup> World Health Organization and Alzheimer's Disease International. Dementia: A Public Health Priority. 2012.
- <sup>11</sup> Blendon RJ, Benson JM, Wikler EM, Weldon KJ, Georges J, Baumgart M, Kallmyer BA. The Impact of Experience with a Family Member with Alzheimer's Disease on Views about the Disease across Five Countries. *Int J Alzheimers Dis* 2012;2012:903645.
- <sup>12</sup> Alzheimer's Association. Press release on the Alzheimer's & Brain Awareness Month International Survey. 2014. Available at [http://www.alz.org/documents\\_custom/abam\\_intl\\_survey\\_release.pdf](http://www.alz.org/documents_custom/abam_intl_survey_release.pdf).
- <sup>13</sup> Centers for Disease Control and Prevention. Self-Reported Increased Confusion or Memory Loss (ICML) and Discussions with Health Care Providers Among Adults Aged 45 or Older: BRFSS 2015 Data Reported by 21 States. CDC 2015. [https://nccd.cdc.gov/aging\\_data/rdPage.aspx?rdReport=DPH\\_HAP\\_ExploreByTopic&isIClass=C06&isYear=2015](https://nccd.cdc.gov/aging_data/rdPage.aspx?rdReport=DPH_HAP_ExploreByTopic&isIClass=C06&isYear=2015)
- <sup>14</sup> Centers for Disease Control and Prevention, [https://nccd.cdc.gov/aging\\_data/rdPage.aspx?rdReport=DPH\\_HAP\\_ExploreByTopic&isIClass=C06&isYear=2015](https://nccd.cdc.gov/aging_data/rdPage.aspx?rdReport=DPH_HAP_ExploreByTopic&isIClass=C06&isYear=2015)
- <sup>15</sup> Bradford A, Kunik ME, Schulz P, Williams SP, Singh H. Missed and Delayed Diagnosis of Dementia in Primary Care: Prevalence and Contributing Factors. *Alzheimer Dis Assoc Disord* 2009;23(4):306-314.
- <sup>16</sup> Chodosh J, Petitti DB, Elliott M, Hays RD, Crooks VC, Reuben DB, Galen Buckwalter J, Wenger N. Physician Recognition of Cognitive Impairment: Evaluating the Need for Improvement. *J Am Geriatr Soc* 2004;52(7):1051-1059.
- <sup>17</sup> Werner P, Karnieli-Miller O, Eidelman C. Current Knowledge and Future Directions about the Disclosure of Dementia: A Systematic Review of the First Decade of the 21st Century. *Alzheimers Dement* 2013;9(2):e74-88.
- <sup>18</sup> Löppönen M, Räihä I, Isoaho R, Vahlberg T, Kivelä SL. Diagnosing Cognitive Impairment and Dementia in Primary Health Care – A More Active Approach is Needed. *Age Ageing* 2003;32(6):606-612.
- <sup>19</sup> Valcour VG, Masaki KH, Curb JD, Blanchette PL. The Detection of Dementia in the Primary Care Setting. *Arch Intern Med* 2000;160(19):2964-2968.
- <sup>20</sup> Cordell CB, Borson S, Boustani M, Chodosh J, Reuben D, Verghese J, Thies W, Fried LB, Medicare Detection of Cognitive Impairment Workgroup. Alzheimer's Association Recommendations for Operationalizing the Detection of Cognitive Impairment During the Medicare Annual Wellness Visit in a Primary Care Setting. *Alzheimers Dement* 2013;9(2):141-150.
- <sup>21</sup> Patient Protection and Affordable Care Act, 42 CFR §410.15. 2010.
- <sup>22</sup> National Institute on Aging. Assessing Cognitive Impairment in Older Patients: A Quick Guide for Primary Care Physicians. National Institutes of Health 2014. Available at <http://www.nia.nih.gov/alzheimers/publication/assessing-cognitive-impairment-older-patients>.
- <sup>23</sup> The Gerontological Society of America. The Gerontological Society of America Workgroup on Cognitive Impairment and Earlier Diagnosis: Report and Recommendations. GSA 2015.
- <sup>24</sup> Kryscio RJ, Abner EL, Cooper GE, Fardo DW, Jicha GA, Nelson PT, Smith CD, Van Eldik LJ, Wan L, Schmitt FA. Self-Reported Memory Complaints: Implications from a Longitudinal Cohort with Autopsies. *Neurology* 2014;83(15):1359-1365.
- <sup>25</sup> Koppala A, Riedel-Heller S, Weyerer S, Bickel H, Pentzek M, Scherer M, Maier W, Jessen F, Wagner M. Subjective Memory Impairment in Healthy Elderly Specifically Predicts Decline in Episodic Memory over 8 Years. *Alzheimers Dement* 2013;9(4 Suppl): P782.
- <sup>26</sup> Amariglio RE, Becker JA, Carmasin J, Wadsworth LP, Lorus N, Sullivan C, Maye JE, Gidicsin C, Pepin LC, Sperling RA, Johnson KA, Rentz DM. Subjective Cognitive Complaints and Amyloid Burden in Cognitively Normal Older Individuals. *Neuropsychologia* 2012;50(12):2880-2886.
- <sup>27</sup> Samieri C, Proust-Lima C, Glymour MM, Okereke OI, Amariglio RE, Sperling RA, Rentz DM, Grodstein F. Subjective Cognitive Concerns, Episodic Memory, and the APOE ε4 Allele. *Alzheimers Dement*;10(6):752-759.
- <sup>28</sup> Alzheimer's Association. Alzheimer's Workplace Alliance<sup>®</sup>. Alzheimer's Association n.d. Available at <http://alz.org/AWA/AWA.asp>.
- <sup>29</sup> IOM (Institute of Medicine). Cognitive Aging: Progress in Understanding Opportunities for Action. Washington, DC: The National Academies Press. 2015.
- <sup>30</sup> Alzheimer's Association. Cognitive Assessment Toolkit. 2014. Available at [http://www.alz.org/documents\\_custom/141209-CognitiveAssessmentToo-kit-final.pdf](http://www.alz.org/documents_custom/141209-CognitiveAssessmentToo-kit-final.pdf).
- <sup>31</sup> Centers for Medicare and Medicaid Services, "Final Rule, CY 2017 Revisions to Payment Policies under the Physician Fee Schedule and Other Revisions to Part B." CMS-1654-F. November 15, 2016. <https://www.cms.gov/Medicare/Medicare-Fee-For-Service-Payment/PhysicianFeeSched/PFS-Federal-REGulation-Notices-Items/CMS-1654-f.html>.
- <sup>32</sup> New York State Department of Health. Dear Colleague Letter from Dr. Shah, NYS Health's Commissioner. 2013. Available at [https://www.health.ny.gov/diseases/conditions/dementia/alzheimer/docs/dcl\\_early\\_detection.pdf](https://www.health.ny.gov/diseases/conditions/dementia/alzheimer/docs/dcl_early_detection.pdf).