

Policy Forum

Report on milestones for care and support under the U.S. National Plan to Address Alzheimer's Disease

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Abstract

Introduction: Under the U.S. national Alzheimer's plan, the National Institutes of Health identified milestones required to meet the plan's biomedical research goal (Goal 1). However, similar milestones have not been created for the goals on care (Goal 2) and support (Goal 3).

Methods: The Alzheimer's Association convened a workgroup with expertise in clinical care, long-term services and supports, dementia care and support research, and public policy. The workgroup reviewed the literature on Alzheimer's care and support; reviewed how other countries are addressing the issue; and identified public policies needed over the next 10 years to achieve a more ideal care and support system.

Results: The workgroup developed and recommended 73 milestones for Goal 2 and 56 milestones for Goal 3.

Discussion: To advance the implementation of the U.S. national Alzheimer's plan, the U.S. government should adopt these recommended milestones, or develop similar milestones, to be incorporated into the national plan.

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Keywords:

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1. Introduction

Alzheimer's disease and other dementias are progressive, debilitating conditions that affect millions of Americans, their families, and federal and state governments. Total payments for the care of people with Alzheimer's and other dementias was an estimated \$226 billion in 2015, of which nearly 70 percent was paid by Medicare and Medicaid [1]. Barring a method of prevention or treatment, total costs of care will grow to an estimated \$1 trillion in 2050 [1]. The high costs of caring for Alzheimer's and other dementias make them among the most costly conditions in the United States [2,3].

Perhaps even more daunting than the costs of care is the burden on individuals and families. Over time, affected individuals become completely dependent on others. Underscoring this, about 15 million unpaid family members and friends provided over 17 billion hours of unpaid care in 2014 [1]. As more baby boomers reach the age of greater risk of developing Alzheimer's, it can be expected that millions of them will spend their retirement years either living with the disease or caring for someone who has it.

Recognizing the significance of this growing crisis, the U.S. Department of Health and Human Services (HHS), under the auspices of the National Alzheimer's Project Act [4] (NAPA), created the National Plan to Address Alzheimer's Disease. Released in 2012 [5] and updated annually [6], the National Plan aims to assist individuals and families affected by Alzheimer's and other dementias by advancing research, enhancing care and support, and increasing collaboration across federal, state, and tribal governments.

Among the National Plan's five goals, two goals specifically relate to care and support: goal 2, "Enhance care quality and efficiency" and goal 3, "Expand supports for people living with Alzheimer's disease and their families." Although the federal government has established a series of milestones required to meet the National Plan's first goal on research [7], which have been reviewed by independent experts [8], it has yet to establish similar milestones on care and support. Appendix 2 of the most recent iteration of the National Plan [6] lists "implementation milestones"—actions that have been completed or are currently underway by various federal agencies—across all five goals of the National Plan. However, these are a listing of actions that have been completed or are currently underway and are not analogous to the milestones created by the National Institutes of Health (NIH) to indicate what must be accomplished by 2025 to successfully attain the Plan's first goal regarding research on prevention and treatments.

To assist with the establishment of analogous milestones for goals 2 and 3, the Alzheimer's Association convened an expert workgroup to develop recommendations on a comprehensive set of milestones and timelines. The workgroup consisted of experts in the fields of clinical care and long-term

services and supports, dementia care and support research, and public policy. In addition, external advisors, including representatives from various federal agencies and experts specializing in the fields of elder justice, dementia care, and public and private health systems, served as peer reviewers on the workgroup's recommendations, providing input and making suggestions for improvement.

This report outlines the workgroup's activities and recommended milestones for adoption by HHS as part of the National Plan. Table 1 summarizes milestones to meet goal 2; Table 2 summarizes milestones to meet goal 3. Within each table, milestones are listed according to existing strategies in the National Plan. Except for one recommendation under goal 3 and discussed below, the workgroup did not change the existing strategies but focused instead on developing milestones for each of the existing strategies. In the tables, under each of these strategies, milestones are grouped by sections and include a detailed description of each milestone, its success criteria and an estimated timeline to meet those criteria. Although the number of milestones for each goal appears extensive (73 milestones under goal 2 and 56 milestones under goal 3), each set of milestones is comparable in volume to the 86 milestones established to meet goal 1. They are also indicative of the substantial effort that the workgroup believes is necessary to achieve goals 2 and 3.

2. Key activities

From October to December 2015, the workgroup participated in four phone meetings and one in-person meeting to formulate and review the milestones. In addition, select members of the workgroup also participated in topic-specific calls on select strategies the workgroup felt required further discussion. Each workgroup member also provided input through one-on-one interviews and in written comments on the numerous drafts of the recommendations.

2.1. Establishing objectives

Goals 2 and 3, and their strategies, had been previously identified in the National Plan. The workgroup did not seek to change that existing structure or what had been previously identified but instead focused on developing milestones for each of the existing strategies. The workgroup used the milestones established by the NIH for goal 1 as a guide [7]. That effort sets as milestones all steps and activities that need to be undertaken by 2025 to reach the overarching goal. However, unlike for goal 1, the language of goals 2 and 3 is fairly general, and the workgroup believed it needed to begin by more specifically articulating the 2025 "endpoint" in the areas of care and support. Thus, more specific objectives were established. For both goals, the objectives are consistent with the ideal care and support systems for all individuals with chronic conditions. For goal 2, "Enhance care quality and efficiency," the

Table 1
Proposed milestones for goal 2

Milestone	Implementation detail	Success criteria
Strategy 2A: Build a workforce with the skills to provide high-quality care		
Milestone section: Build and retain a diverse dementia-capable workforce with the skills and capacity to provide high-quality care		
Identify and set targets for dementia-capable workforce needs at the state and county level*	Collect data on current dementia-capable workforce capacity and training needs at a state and county level, project growth in workforce demand, and estimate future shortages. Dementia-capable workforce should include primary care physicians, geriatricians, hospitalists, neurologists, psychiatrists, psychologists, nurses, social workers, health care administrators, and related disciplines, including physician assistants, nurse practitioners, direct-care workers, nursing home workers, and home health aides. Collect information on current and projected levels of dementia-capable workforce diversity by location, race, ethnicity, and sexual orientation and set targets to increase representation of each underrepresented group over time. Timeline: Short term	Outline county and state 2025 targets for dementia-capable workforce needs by setting and provider type, published by 2017
Increase dementia-capable workforce through financial incentives and competitive income	Create financial incentives (through tuition assistance, loan forgiveness, housing subsidies, and stipends) and ensure competitive income to increase the number of health care providers, including professionals and direct-care workers, who pursue education and training to become dementia capable, particularly those who make a commitment to work in underserved communities or underserved provider settings in otherwise served communities. Timeline: Long term	Achieve dementia-capable workforce targets across settings and providers in 80% of states and counties by 2025
Increase dementia-specific technical education for direct-care roles	Provide funding for dementia-specific direct-care education for workforce positions that do not require a 4-year college degree for: (1) students pursuing education for direct-care roles and (2) community or technical colleges, high school allied health career or technical programs, and online courses to provide the necessary education. Timeline: Long term	Dementia-capable direct-care workforce targets met in 80% of states and counties by 2025
Expand efforts to retain direct-care workforce by building career pathways with supervisory and administrative support	Consult with national and state groups already devoted to developing direct-care workforce career pathways and form a coalition of public-private partnerships to develop and implement career pathways that provide career ladders for direct-care workers, offer employers a professional pipeline to aid in job recruitment and retention and have supervisory and administrative commitment, especially in for-profit facilities. Link workforce incentives (financial and not) to tenure in career pathway. Timeline: Long term	Formal direct-care career pathway established by 2020; dementia-capable direct-care workforce targets met in 80% of states and counties by 2025
Increase diverse dementia-capable workforce through financial incentives	Create financial incentives for health care providers from diverse communities to pursue dementia-specific practice in those communities. Focus efforts on diverse groups, including tribal populations, African Americans, Hispanics, and lesbian, gay,	Incentives in place to increase diversity of the ADRD workforce by 2025

<p>Milestone section: Ensure health care providers across settings are skilled and credentialed in dementia-specific care</p>	<p>bisexual, and transgendered (LGBT) individuals, which are underrepresented in the dementia-capable workforce relative to the Alzheimer's disease and related dementias (ADRD) population. Examine whether the loss of state and federal benefits when an individual returns to the workforce creates a barrier to attracting workers from diverse communities. Timeline: Long term</p>	
<p>Create and gain endorsement of national professional dementia-specific training curricula tailored to clinical specialties</p>	<p>Create national dementia-specific curricula, incorporating best of existing programs, for higher education, tailored to primary care, geriatrics, hospital care, neurology, psychiatry, psychology, nursing, social work, health care administration, and related disciplines. The curricula should include how and when to use cognitive assessments, ADRD progression, communication skills (with diagnosed individual and key family and friend caregivers), role of key family and friend caregivers (as part of care team and caregiver health), care planning in the context of other comorbidities including postdiagnosis and end of life, daily life skills for person with ADRD, importance of person-centered care, challenging behaviors and nonpharmacologic interventions to address, and medication management. Include training on identifying the root cause of behavioral expression and addressing through an individualized approach focusing on the strengths and preferences of the individual. Incorporate dementia-specific components into School of Public Health or other notable curricula for use with undergraduate public health students. Ensure that cultural competency is a key component of all curricula. Seek endorsement by key health professional, trade, and accreditation associations, incorporate curricula components in relevant educational textbooks, and encourage adoption of curricula by schools. Timeline: Short term</p>	<p>National curricula endorsed by key associations tailored to all relevant providers by 2019; primary care by late 2016; geriatrics and hospitalists curricula by 2017, health care administration, social work, and nursing curricula by 2018, neurology, psychiatry, and psychology curricula by 2019; incorporation into undergraduate Public Health curricula by 2019.</p>
<p>Provide Centers for Medicare and Medicaid Services (CMS) Direct Graduate Medical Education (DGME) funds only to hospitals that incorporate the national dementia-specific curricula within the broader context of geriatric medicine</p>	<p>Tie Medicare Direct Graduate Medical Education (DGME) funds to the implementation of the national professional dementia-specific training curricula, within the broader context of geriatric medicine, for all medical and residency programs focused on primary care, geriatrics, hospital care, neurology, psychiatry, and related disciplines with exceptions granted for non-relevant specialties such as pediatrics. Timeline: Short term/Medium term</p>	<p>DGME funds tied to all relevant medical training curricula by 2020; tied to primary care by 2017; tied to geriatrics and hospitalists curricula by 2018; tied to neurology psychiatry and psychology curricula by 2020</p>
<p>Expand dementia specialization in universities</p>	<p>Support universities in the development and expansion of dementia-specific track for residents, physician assistants, nurse practitioners, and psychology students and raise awareness of availability of such programs to promote enrollment. Timeline: Long term</p>	<p>>50% of residency, physician assistant, nurse practitioner, and professional psychology programs adopted a dementia-specific medical specialization by 2025</p>

(Continued)

Table 1. Proposed milestones for goal 2 (Continued)

Milestone	Implementation detail	Success criteria
Develop and implement dementia-specific continuing education curricula	Collaborate with professional associations and accrediting bodies, such as the Accreditation Council for Graduate Medical Education, to develop and improve competency-based, dementia-specific continuing education curricula for primary care physicians, geriatricians, hospitalists, neurologists, psychiatrists, psychologists, nurses, social workers, nursing home and assisted living administrators, and other related disciplines. Encourage uptake by health care continuing education programs. Timeline: Short term	Dementia-specific continuing education curricula endorsed by key associations tailored to relevant providers by 2019; primary care by late 2016; geriatrics and hospitalists by 2017, health care administration, social work and nursing by 2018, neurology, psychiatry, and psychology by 2019.
Promote dementia-specific continuing education as condition of license renewal*	Partner with state licensing boards to promote competency-based, dementia-specific continuing education as a condition of license renewal for primary care physicians, geriatricians, hospitalists, neurologists, psychiatrists, psychologists, nurses, social workers, nursing home and assisted living administrators, and other related disciplines, with exceptions granted for nonrelevant specialists, such as pediatricians. Timeline: Long term	Integration into at least ~40 state licensing boards by 2023; 50 state licensing boards by 2025
Require dementia-specific continuing education for all emergency room health care professionals as a CMS condition of participation	Require mandatory competency-based dementia-specific continuing education for all emergency room staff including hospitalists, specialists, and nurses, as a CMS condition of participation for hospitals. Timeline: Long term	Dementia-specific continuing education completion by emergency room staff integrated as a CMS condition of participation for hospitals by 2024
Milestone section: Ensure all direct-care workers have proper training to effectively care for persons with ADRD and support their key family and friend caregivers in home, community, and institutional settings		
Establish minimal standards for person-centered dementia-specific training for direct-care workers by provider type and by setting**	Ensure all home, community, and institutional settings (including but not limited to home health agencies, adult day care centers, assisted living facilities, hospitals, and nursing homes) meet minimum standards for ensuring competency-based, person-centered dementia-specific training to all direct-care staff, including supportive therapists (physical, occupational, speech), on hire and annually thereafter. Develop criteria for evaluating the quality and evidence base behind trainings provided, including online based. Provide grants to states and technical assistance to fund the achievement of these minimum standards. Seek endorsement by key direct-care worker, trade, and accreditation associations. Timeline: Short term	100% of states require demonstrated competency as a condition of employment as a direct-care worker in home, community-based, and institutional settings nationally by 2019
Adopt dementia-specific direct-care competency as a quality measure in Medicare compare	Integrate dementia-specific skills and competency among the direct-care workforce and facility administrators as a quality measure for nursing homes and home health services in Medicare Compare. Timeline: Medium term	Measured and disseminated in Medicare Compare by 2020

<p>Provide funding to states for demonstrations in developing, incentivizing, and implementing direct-care dementia-capable certifications</p>	<p>Provide federal funding to states for demonstrations to develop direct-care worker dementia-capable certifications with competency-based, person-centered evaluation requirements for long-term care (LTC) facility workforce, personal care attendants, home health aides, care navigators, hospital workers, and others who are direct-care workers. Ensure certifications meet minimum standards for dementia-specific training and require recertification at specified intervals. Work to incentivize and encourage adoption of dementia-capable direct-care worker certifications nationwide. Evaluate the feasibility of making direct-care worker certifications transferrable across states and creating a national direct-care worker registry to centralize and track certifications. Timeline: Medium term</p>	<p>Five state demonstrations in developing certifications for direct-care workers by 2020; 90% of states with direct-care worker certifications by 2023</p>
<hr/> <p>Strategy 2B: Ensure timely and accurate diagnosis</p>		
<p>Milestone section: Develop consensus on ADRD prevalence measurements and report ADRD diagnosis levels</p>		
<p>Gather and report ADRD diagnostic data</p>	<p>Measure and publicly report data on ADRD diagnostic levels nationally and by state, released within 6 months of year end. If feasible, report data on a substate level. Timeline: Short term</p>	<p>ADRD diagnostic levels publicly reported annually starting in 2017</p>
<p>Develop consensus on ADRD prevalence measurement</p>	<p>Develop consensus on how to measure ADRD prevalence at the population level and its variance across communities to enable diagnostic rate measurement, with the objective of increasing the safety and quality outcomes of persons with ADRD. Timeline: Short term</p>	<p>Consensus on how to measure ADRD prevalence disseminated by 2017</p>
<p>Milestone section: Raise public awareness of ADRD and encourage detection of cognitive impairment</p>		
<p>Support ADRD public awareness campaigns to increase understanding of ADRD among the public and encourage cognitive assessments among those at greater risk of ADRD</p>	<p>Provide funding to states and nonprofit advocacy groups to support multilingual and multicultural public awareness campaigns to raise awareness and understanding, reduce stigma, and encourage brain health among the general public, as well as encourage regular cognitive assessments and raise awareness of the Medicare Annual Wellness Visit among those at greater risk for developing ADRD. Timeline: Short term</p>	<p>80% people above 65 believe that ADRD is not a normal sign of aging by 2018; 80% of people above 65 are comfortable discussing memory problems with their health care provider by 2018</p>
<p>Activate faith- and community-based organizations to increase awareness and understanding of ADRD**</p>	<p>Provide and disseminate ADRD awareness materials, leveraging existing materials where possible, to faith-based and community-based organizations to help them reach higher risk populations within their constituencies. Promote brain health in the context of overall general health needs. Ensure reach to populations at risk across all locations, races, ethnicities, sexual orientations, and socioeconomic classes. Timeline: Short term</p>	<p>Materials created by 2018; updated and redistributed every 2 years 2020 onward; 80% of faith-based and community-based organizations using materials in each state by 2025</p>

(Continued)

Table 1. Proposed milestones for goal 2 (Continued)

Milestone	Implementation detail	Success criteria
<p>Milestone section: Raise physician awareness on importance of detection of cognitive impairment and equip physicians to detect impairment, make an appropriate diagnosis, and properly disclose information about cognitive status to individuals and their key family and friend caregivers</p> <p>Support education campaigns targeted toward all relevant health care providers on timely detection of cognitive impairment, including in the Medicare Annual Wellness Visit</p>	<p>Allocate funds to educate primary care physicians, other health providers, and community workers about the importance of timely detection of cognitive impairment, applying the appropriate diagnosis, and disclosing cognitive status to the patient and their key family and friend caregivers, where they exist and the patient or the Health Insurance Portability and Accountability Act (HIPAA) clinical judgment allows. Increase health care provider awareness and understanding of the Medicare Annual Wellness Visit and knowledge of validated cognitive assessment tools, through their local and state conferences.</p> <p>Timeline: Short term</p>	<p>>70% of physicians are knowledgeable on the importance of detection, appropriate diagnosis, and patient disclosure by 2018; >90% by 2022</p>
<p>Encourage providers to include cognitive conversations and assessments in annual routine visits for populations at greater risk for ADRD</p>	<p>Work with professional and trade associations, such as American Medical Association, American Neurological Association, American Academy of Family Physicians, American Association of Geriatric Psychiatry, and others to encourage cognitive conversations and assessments as a standard part of annual routine visits or check-ups regarding other conditions, for populations at greater risk for ADRD, including individuals >65 years and persons with Down Syndrome or other intellectual disabilities.</p> <p>Timeline: Short term</p>	<p>Regular cognitive assessments incorporated into professional guidelines by 2018</p>
<p>Modify reimbursement structure to ensure adequate clinician time to assess cognitive impairment during visits</p>	<p>Assess and modify the reimbursement structures of CMS, other insurers and health systems to ensure adequate time for primary care clinicians to assess, appropriately diagnosis and disclose to the patient and key family and friend caregivers (where exists and person with ADRD or HIPAA clinical judgment allows) their cognitive status, which may require multiple visits.</p> <p>Timeline: Long term</p>	<p>Reimbursement modified by 2024</p>
<p>Identify practices successful in implementing Medicare Annual Wellness Visits and evaluate approaches to increase participation, cognitive assessment tools used, and next steps taken when impairment is detected</p>	<p>Identify provider practices and organizations that have successfully implemented the Medicare Annual Wellness Visit above a certain threshold across the country by analyzing Medicare claims data. Evaluate methods that these successful providers used for increasing beneficiary participation, the cognitive assessment tools they used, and common next steps taken after cognitive impairment was detected, such as care planning.</p> <p>Timeline: Medium term</p>	<p>Data collected and published annually, starting in 2020.</p>
<p>Issue CMS sub-regulatory guidance on cognitive assessment tools to be used in the Medicare Annual Wellness Visit</p>	<p>Issue sub-regulatory guidance to clinical practitioners on the different cognitive assessment tools that would be most appropriate to use during the Medicare Annual Wellness Visit.</p>	<p>Sub-regulatory guidance in place by 2020; 80% practitioners report comfort using specified assessment tools by 2022</p>

<p>Evaluate and develop guidelines for populations more likely to require specialists to diagnose ADRD</p>	<p>Leverage criteria outlined by the National Institutes of Health, Alzheimer's Association, and Gerontological Society of America working groups. Timeline: Medium term Encourage research to identify guidelines for specified populations, such as individuals with Lewy body dementia, individuals with frontotemporal dementia, or persons with younger-onset AD, who may need a referral to a specialist for ADRD diagnosis and/or treatment. Reversely, specify other populations with ADRD who can generally be diagnosed and/or treated by primary care physicians. Publicly disseminate findings. Timeline: Medium term</p>	<p>Research performed by 2020; guidelines in place by 2021</p>
<p>Equip and require clinicians to disclose cognitive status to people with clinically consequential cognitive impairment that affects their independence in activities of daily living and increase the proportion of those diagnosed with ADRD, or their caregiver, who are aware of the diagnosis</p>	<p>Partner with key professional, trade, and accreditation associations to create, endorse, and disseminate cognitive status disclosure guidelines to clinicians through local, state, and national health care professional meetings. Guidelines should require cognitive status disclosure to all persons with clinically consequential cognitive impairment as a condition of Medicare or other payer billing at the time of ADRD diagnosis. Key family and friend caregivers, where they exist and person with ADRD or HIPAA clinical judgment allows, should be included in the cognitive status disclosure conversation. Clinicians should provide information on capacities affecting independence in activities of daily living, including traditional IADLs (Instrumental Activities of Daily Living) and financial and medical decision-making capacity that shows differing impairment and decline across the dementia continuum. Disclose cognitive impairment to patient, irrespective of whether the etiology is neurodegenerative or not (or not known), and follow-up at regular increments to track course and identify progression. Furthermore, increase the proportion of those diagnosed with ADRD, or their key family and friend caregivers, who are aware of the diagnosis, consistent with the Centers for Disease Control and Prevention (CDC) Healthy People 2020 (HP2020) Initiative. Provide a written copy of the cognitive status and/or ADRD diagnosis to the patient to ensure clear communication. Ensure follow through on postdiagnostic next steps (strategy 2C). Timeline: Medium term</p>	<p>Ensure disclosure guidelines adopted by key professional, trade, and accreditation associations by 2018; materials incorporated into at least 20 national and 100 state and local annual conferences by 2020; >38% of persons diagnosed with ADRD or their key family and friend caregivers are aware of the diagnosis by 2020 (consistent with HP2020); >80% of people diagnosed with ADRD or their key family and friend caregivers are aware of the diagnosis by 2025</p>
<p>Incorporate cognitive changes and ADRD diagnostic information, including documentation of key family and friend caregivers, into Meaningful Use</p>	<p>Ensure cognitive changes and documentation of any ADRD diagnosis, including stage and classification of ADRD, care plan, and name and contact information of key family and friend caregivers (where exists and person with ADRD or HIPAA clinical judgment allows), is incorporated into the certified electronic health record technology to enhance care coordination, while maintaining privacy and security. Where multiple caregivers exist, record each in all patient medical records, denoting one as the primary caregiver. Timeline: Short term</p>	<p>Incorporated into meaningful use by 2017</p>

(Continued)

Table 1. Proposed milestones for goal 2 (Continued)

Milestone	Implementation detail	Success criteria
Record all cognitive changes and ADRD diagnostic information, including documentation of key family and friend caregivers in all patient medical records	Ensure that cognitive changes, delirium, and depression be recorded in all patient medical records. Require documentation of any ADRD diagnosis in the medical record, including stage and classification of ADRD, care plan, and name and contact information of key family and friend caregivers (where exists and person with ADRD or HIPAA clinical judgment allows). If not equipped to provide a stage or classification, include referral to a specialist equipped to do so and follow-up with patient to ensure consultation occurs. Where multiple caregivers exist, record each in all patient medical records, denoting one as the primary caregiver. Where lack of medical record integration across care settings exists, ensure each care provider, including primary care, specialists, hospitalists, and others, documents patient's ADRD diagnosis. Timeline: Short term	Incorporated in Medicare medical record systems by 2018
Strategy 2C: Educate and support people with Alzheimer's disease and their families on diagnosis		
Milestone section: Standardize and ensure basic information about ADRD and its management are provided immediately after an appropriate diagnosis is made		
Develop guidelines for provider response to ADRD diagnosis	Develop guidelines for minimal immediate next steps for clinician to take after diagnosing an individual with ADRD, including (1) inform individuals and their key family and friend caregivers or health proxy, where exists, of the diagnosis, including stage and classification; (2) discuss and provide individuals and their key family and friend caregivers or health proxy, where exists, a standard set of basic postdiagnosis information about ADRD, what to expect (including potential behavioral issues and how caregiving approaches may add to or minimize them), and treatment options, including the option to participate in clinical trials; (3) refer individuals and their key family and friend caregivers or health proxy, where exists, to available resources in the community, including those that can help provide immediate triage of needs; (4) for those without key family and friend caregivers or health proxy, assist individuals in identifying someone to be included in future visits and document that name and contact information in the medical record, and encourage the individual to name a health care and financial proxy; and (5) develop a care plan to be shared with individuals and their key family and friend caregivers or health proxy, where exists, and document this plan in the medical record. Define components of a comprehensive ADRD care plan, including a form to document the person with ADRD's preferences for everyday living. Incorporate these guidelines into any standards of care developed (Strategy 2D). Recognize that these guidelines represent principles for ideal situations, yet clinical judgment will require adaptation to each patient's heterogeneous circumstances. Timeline: Short term	Guidelines developed and disseminated by 2018

<p>Incorporate set of standard ADRD information into medical records postdiagnosis</p> <p>Milestone section: Ensure access to ADRD care planning services for every person diagnosed</p> <p>Reimburse for high-quality care planning immediately after ADRD diagnosis</p>	<p>Incorporate ADRD educational materials for patients and key family and friend caregivers into digital libraries to enable physicians to store and share information on diagnosis. Where electronic medical records exist, automate process so that when diagnosis is recorded in records, physician is automatically prompted to send information to patient electronically or print to provide a hard copy.</p> <p>Timeline: Short term</p>	<p>ADRD postdiagnostic educational materials for clinicians disseminated broadly and incorporated into medical record systems by 2017</p>
<p>Educate providers on HIPAA allowances that allow clinician to meet with key family and friend caregivers of persons with ADRD independently</p> <p>Milestone section: Ensure ADRD self-management education and skill building for persons with ADRD and their families across provider networks</p> <p>Reimburse for ADRD self-management education and skill building across provider networks</p>	<p>Modify reimbursement structure to allow clinicians, hospitalists, or members of their teams, including nurse practitioners, social workers, certified counselors, clinical psychologists, or other health care professionals, to work with persons with ADRD and their key family and friend caregivers, where exists, to outline an initial person-centered care plan immediately on diagnosis. Care plan should include care for person with ADRD in the context of overall health needs and other comorbidities and address minimal immediate next steps laid out in provider guidelines. Enforce quality feedback loops and measurement to ensure high-quality and effective care planning.</p> <p>Timeline: Long term</p> <p>Work with professional and trade associations to educate clinicians, hospitalists, and other members of their teams on current HIPAA allowances that allow for providers' discretion in certain circumstances to meet with key family and friend caregivers of persons with ADRD independently without he or she being present, especially as it pertains to topics difficult to discuss in front of the person with ADRD, such as advanced care planning and behavioral management. Leverage-existing HIPAA guidelines to educate clinicians and key family and friend caregivers.</p> <p>Timeline: Short term</p>	<p>Reimbursement tied to provider guidelines in place by 2020; 80% of health systems/physician practices have this in place by 2022; >90% of patients with ADRD receive care planning immediately after diagnosis by 2025</p> <p>Education disseminated through institutes of higher learning, continuing education, and health care professional meetings by 2018</p>
<p>Provide Medicare reimbursement for social workers, certified counselors, or dementia-qualified health care providers across health systems, to provide ADRD self-management education and skill building for people with ADRD and their key family and friend caregivers, similar to existing Medicare reimbursement for diabetes self-management educators.</p> <p>Timeline: Long term</p>	<p>Reimbursement available by 2024</p>	

Strategy 2D: Identify high-quality dementia care guidelines and measures across care settings

Milestone section: Identify, standardize, and gain endorsement of ADRD care guidelines across care settings from initial diagnosis to end of life that are explicitly tied to outcome measurements

(Continued)

Table 1. Proposed milestones for goal 2 (Continued)

Milestone	Implementation detail	Success criteria
Identify, standardize, and gain endorsement of national clinical ADRD standards of care across care settings	Identify key stakeholders in clinical ADRD care (including government representatives, key professional and trade associations, private stakeholders, and nonprofits) to (1) congregate, review, and vet the conceptual framework put forth by the National Quality Forum, most recent evidence on high-quality care, and existing ADRD care guidelines and standards, (2) outline comprehensive standards of dementia care across each care setting, including primary and geriatric care, specialties, hospital care, long term services and support, palliative and hospice care, and other relevant settings, explicitly tied to process and clinical outcome measurements. Include protocols around diagnosis and disclosure (strategy 2B), postdiagnostic care planning guidelines (Strategy 2C), hospital care for acute problems (Strategy 2D), care management guidelines across condition continuum (Strategy 2G), safety policies and measures (e.g. physical restraint) to avoid inappropriate use, prevention and management of behavioral complications management (including environmental design), and provision of long-term services and supports. Specifically provide guidance on addressing delirium in the broader context of cognitive impairment. Encourage inter-professional teaming necessary to provide high-quality ADRD care. Reconcile dementia guidelines in the context of other comorbidities to provide comprehensive guidelines for physicians treating ADRD patients with multiple chronic conditions. Timeline: Short term	Publish and disseminate translational documents on ADRD standards of care tailored to all relevant providers and endorsed by key health care professional, trade, and accreditation associations by 2019: primary care by late 2016; geriatric and hospital care by 2017, LTC by 2018, palliative and hospice care by 2019, specialties (including neurology, psychiatry, and psychology) by 2019
Identify, review, standardize, and test ADRD-specific quality measures for providers and facilities aligned to ADRD standards of care, and process and clinical patient/family centered outcomes	Establish ADRD as a condition with specific quality measures across the continuum of Accountable Care Organizations (ACOs), managed care plans, long term services and supports, and other payer/provider networks. Identify, review, standardize, and test quality measures consistent with standards of care and explicitly tied to process and clinical patient-centered and family-centered outcomes, including quality of care, care economics, and patient satisfaction measures. Support current development and testing of ADRD quality measures through state demonstrations. Timeline: Medium term	ADRD standards incorporated into relevant quality measures across payer and provider networks and publicized by 2022
Align reimbursements and regulations to reflect most up-to-date ADRD standards of care	Adjust CMS reimbursements and federal regulations to tie directly to ADRD standards of care. Measure and publicize provider adherence to standards of care on annual basis. Timeline: Long term	ADRD standards incorporated into relevant reimbursements and regulations and first compliance report publicized by 2025
Identify and collect population-level outcome measures for ADRD care, including health care and LTSS, leveraging community health needs assessments	Identify key outcome measures to be collected on an ADRD population basis at the national, state, and county level and disseminated on an annual basis to track progress in ADRD care. Ensure measurements cover ADRD process and clinical patient-	Outcome measurements identified by 2018; begin collection by 2020; disseminate by 2021 and onward

<p>Convene workgroup or workgroups annually to update ADRD standards of care</p>	<p>centered and family-centered outcomes spanning both health care settings and through long-term services and support (LTSS). Leverage community health needs assessments to collect and track data on ADRD populations. Timeline: Medium term</p> <p>Review new evidence around models of care across settings, refine standards to reflect the best and most cost-effective practice, and make recommendations for adjustments to ADRD-specific quality measures, dementia care reimbursement, and regulations that reflect updates to standards. Disseminate standards publicly, partnering with professional and trade associations and institutes for higher education for greater reach. Identify areas with low adherence to standards of care and develop recommendations on how to improve their observance. Timeline: Long term</p>	<p>Annual meetings held; annual report with updated standards of care released 2018 onward</p>
<p>Milestone section: Outline ADRD-specific guidelines for hospital, acute, palliative, and hospice care Specify the components of dementia-competent hospital care and encourage adoption</p>	<p>Specify guidelines for dementia-competent hospital care, which should include guidelines on assessing a hospitalized patient's cognitive condition at initial sign of impairment, evidence-based strategies for communicating with patients with cognitive impairment, guidance on using protocols to address delirium, and identifying a root cause of behavioral expression and addressing through a person-centered, nonpharmacologic approach. Guidelines should also include discharge guidelines, including identifying a postdischarge arrangement, establishing follow-up appointments before discharge, providing discharge instructions to minimize risk of readmission, and working with patient with ADRD and key family and friend caregivers, where exists, to align on medication management. Disseminate information and partner with universities and health care professional and trade associations to include in hospitalist training and continuing education. Timeline: Medium term</p>	<p>Guidelines created, endorsed by key professional, trade, and accreditation associations and disseminated by 2017; Incorporated into 80% of hospitalist education programs and 90% of continuing education credits for hospitalists by 2020;</p>
<p>Collate existing evidence to identify gaps in knowledge, practice, and funding for alternative acute care models for persons with ADRD</p>	<p>Collate existing evidence to identify gaps in knowledge, practice, and funding mechanisms for alternative support models that allow persons with ADRD to receive high-quality care for acute episodic illnesses at their residence, including nursing homes, assisted living facilities, or their home, as opposed to in a hospital. Ensure key family and friend caregivers are effectively integrated in acute care models that provide care in the home. Evaluate whether effective international models, such as Hospital at Home, might provide higher quality and more cost-effective care for patients with ADRD. Timeline: Medium term</p>	<p>Grant funding provided by 2017; at least 4 alternative acute care model studies by 2019; recommendations released by 2020</p>

(Continued)

Table 1. Proposed milestones for goal 2 (Continued)

Milestone	Implementation detail	Success criteria
Develop components of dementia-competent palliative care for persons with ADRD	Develop components of dementia-competent palliative care for persons with ADRD, recognizing that palliation should be included in all ADRD care throughout the condition trajectory and leveraging the Institute of Medicine (IOM) recommendations on palliative care for persons with advanced dementia. Specifically identify guidelines for those who lack advanced care plans that document their wishes or key family or friend caregivers or guardians to represent their wishes. Disseminate these guidelines broadly in the health and legal system. Timeline: Short term	Dementia-competent palliative care components developed by 2018
Modify hospice criterion from end of life estimate to disability severity for persons with ADRD	Modify hospice guidelines to remove 6 months until end of life prognosis criterion for persons with ADRD to allow those with severe disabilities and in their end of life stage to receive hospice support in their preferred setting, regardless of whether their end-stage dementia allows them to live longer than 6 months. Disseminate these guidelines broadly in the health and legal system. Timeline: Long term	Update hospice guidelines by 2025
Milestone section: Ensure dementia care guidelines are tied to facility accreditations, licensures, and certifications		
Increase dementia capabilities in hospitals and nursing homes through Joint Commission accreditations and certifications	Ensure Joint Commission accreditations of hospitals and accreditations and certifications of nursing homes include dementia-capable criteria informed by the ADRD standards of care. Ensure differential Medicaid reimbursement for nursing homes with Joint Commission dementia-specific certification. Disseminate these differential quality conditions to consumers to better inform their choice of LTC facility. Timeline: Medium term	Dementia capability incorporated into Joint Commission hospital accreditation by 2018; differential reimbursement for Joint Commission certified nursing homes by 2020
Ensure ADRD care standards incorporated into existing home, community, and institutional care licensures and certifications*	Incorporate ADRD care standards into requirements for home, community, and institutional care and integrate into existing state licensure and certification requirements. Timeline: Long term	Dementia-capable care requirements integrated into state licensures or certifications for home, community, and institutional care facilities in 40 states by 2022; 50 states by 2025
Provide supplementary funding to states to enforce home, community, and institutional facility dementia-specialized care claims and advertising	Outline federal standards for home, community, and institutional care settings to claim or advertise dementia-specialized care. Provide funding to help states ensure that those advertising dementia-specialized care capabilities are doing so accurately and honestly. Timeline: Long term	Federal dementia-specialized care claim standards in place by 2020, annual ADRD auditing in place in 40 states by 2022; 50 states by 2025

Strategy 2E: Explore the effectiveness of new models of care for people with Alzheimer's disease

Milestone section: Identify the state of science in ADRD Care and Support and develop a research road map to build consensus around best practices

Build a coalition of cross-disciplinary experts convened by appropriate agencies to a research summit on care and support for persons with ADRD and their key family and friend caregivers

Cross-disciplinary fields should include primary care, geriatrics, hospitalists, geriatric-psychiatry, psychology, social work, nursing, supportive therapy (physical, occupational, speech), administrators and medical directors of nursing homes and assisted living facilities, medical technology, public health, social science, quality management, health policy research, and others relevant to ADRD care and support to:

- (1) Review progress on national ADRD standards of care, in both medical settings and long-term supports and services (strategy 2D).
- (2) Agree on success and effectiveness metrics to measure ADRD care and support research on key family and friend caregivers and persons with ADRD, such as cost effectiveness, health care resource utilization, population-level and system-level process and clinical outcomes, depression scales, quality of life, and others.
- (3) Identify a typology of community-based pragmatic and adaptive research methods, including those that promote statistically sound quality improvement methods on a population-level and system-level. Outline principles for building intervention studies applicable and scalable to real-world populations, including those that are most at risk for ADRD to be complicated by circumstances or comorbidities, and designed for feasible and adaptive implementation in community settings. Include a dictionary of appropriate research applications.
- (4) Review effectiveness of existing intervention research to date in ADRD care and support in improving health and functional outcomes for persons with ADRD and their key family and friend caregivers.

Timeline: Short term

Nominate a governing committee, select working group members, and organize first summit by mid-2017

Release public report on ADRD care and support evidence-based interventions

Disseminate a report that identifies best practices in pragmatic and adaptive evidence-based interventions, including those tied to statistically sound quality improvements at the population-level and system-level for both persons with ADRD and their key family and friend caregivers. Identify current gaps in research to direct future funding. For interventions leading to quality improvements, applicable to real-world populations, and feasible for implementation in community settings, report should outline next steps to scale them up, including funding requirements and where possible, who should be funded. Prioritize funding needs to short- and long-term priorities. Incorporate the output of a summit into other dissemination and implementation initiatives, such as the Hartford Change Agents Initiative, to encourage and support translation and adoption of evidence-based programs.

Timeline: Short term

Completion of report summarizing best practices by year end 2017; funding and resources allocated to address needs by 2018

(Continued)

Table 1. Proposed milestones for goal 2 (Continued)

Milestone	Implementation detail	Success criteria
Convene working group annually to review most current ADRD care and support research	Review updates to national ADRD standards of care (strategy 2D), review and refine metrics for success and effectiveness, and review and refine typology of research approaches and principles for applicability, feasibility, and adaptability. Review new ADRD care and support intervention research, update recommendations for best practices, and refine research road map and translational efforts to encourage implementation. Identify potential new and innovative practices that should be researched. Review and report progress in scaling up evidence-based interventions in community settings and track quality improvement on population and system levels. Timeline: Long term	Annual meetings held; annual report released 2017 onward
Ensure geriatric research on general medical conditions incorporates persons with ADRD	Ensure general geriatric research on medical conditions not directly related to ADRD includes persons with cognitive impairment to enhance clinical applicability. Identify gaps in current geriatric research areas and outline steps to address. Timeline: Long term	150 non-AD related geriatric studies including persons with ADRD by 2025
Milestone section: Provide ADRD Care and Support research funding directed toward person-centered care and support interventions, informed by Annual Research Summit		
Identify and evaluate quality outcomes and cost effectiveness of interventions and social services to inform clinical decision making and social supports	Identify evidence and evaluate care and support interventions for persons with ADRD and their key family and friend caregivers, to understand program effect on system process, clinical outcomes, and cost effectiveness. Leverage findings to inform care decisions for people with ADRD by condition stage, comorbidities, and other demographic factors. Explore the feasibility of evaluating social services provided to persons with ADRD and their caregivers, such as nutrition, social contact, and respite, for overall system cost and outcome effects. Use findings to inform standards of care and make the case for program reimbursement or funding by mandates such as the Older American Act. Prioritize research to establish methods that address factors complicating quality measures, including but not limited to surrogate responses, interactions with decisions about treatment and cultural issues. Timeline: Medium term	Targeted request for applications with earmarked funds established by 2020
Provide funding for community-based pragmatic and adaptive research methods in ADRD care and support interventions	Provide direct funding for community-based pragmatic and adaptive studies on ADRD care and support for both key family and friend caregivers and persons with ADRD, including those that promote statistically sound quality improvement on a population and system level. Prioritize studies that are built for applicability and scalability to real-world populations, including those that are	Targeted request for applications with earmarked funds established by 2020

	<p>most at risk for complications of ADRD due to social circumstances or comorbidities and those designed for feasible and adaptive implementation in community settings. Include studies related to behaviors and behavioral management that seek to identify and address the root causes of behavioral issues, including use of environmental design and training in interpersonal care practices, at home and in residential settings that affect behavior. Include studies that seek to develop innovative services and service-delivery systems for those who live in rural areas.</p> <p>Timeline: Medium term</p>	
<p>Provide funding to stimulate and support innovative learning for new models of care for persons with ADRD</p>	<p>Promote funding for innovative learning organizations and communities to develop community-based participatory designs to implement and evaluate new models of care for persons with ADRD that lead to improved population-level economics and quality improvements, recognizing the heterogeneity of research methods. Include research on the role of technology in innovative supports for persons with ADRD and their caregivers across settings.</p> <p>Timeline: Medium term</p>	<p>Targeted request for applications with earmarked funds established by 2020</p>
<p>Provide funding for ADRD care and support translation studies</p>	<p>Fund ADRD care and support translation studies to adapt effective randomized control trials (RCTs) for pragmatic and adaptive use in community settings for persons with ADRD and their key family and friend caregivers.</p> <p>Timeline: Medium term</p>	<p>Targeted request for applications with earmarked funds established by 2020</p>
<p>Provide funding for comparative effectiveness studies to identify most effective supportive ADRD interventions</p>	<p>Promote funding of comparative effectiveness studies to assess which ADRD supportive interventions are more effective for different sub-groups of patient-caregiver dyads.</p> <p>Timeline: Medium term</p>	<p>Targeted request for applications with earmarked funds established by 2020</p>
<p>Provide funding to roll out ADRD care and support interventions proven effective and adaptive throughout community settings</p>	<p>Scale up effective, pragmatic, and adaptive ADRD care and support interventions in community settings for both persons with ADRD and their key family and friend caregivers, including those that promote statistically sound quality improvement on a population-level and system-level, with the goal of providing the most effective interventions to the greatest number of persons with ADRD and their key family and friend caregivers.</p> <p>Timeline: Long term</p>	<p>80% of people diagnosed with ADRD and 80% of their key family and friend caregivers report having access to an effective evidence-based intervention by 2025</p>

Strategy 2F: Ensure that people with Alzheimer's disease experience safe and effective transitions between care settings and systems

Milestone section: Standardize ADRD patient medical records and advanced care planning forms to ensure provider access through care transitions

(Continued)

Table 1. Proposed milestones for goal 2 (Continued)

Milestone	Implementation detail	Success criteria
Incorporate ADRD expertise in efforts to standardize medical records across care settings	Ensure the inclusion of dementia as a key focus area in efforts to standardize patient medical records across care settings. Incorporate mechanisms of communication through medical records between downstream and upstream providers and identify best approaches for identifying key family and friend caregivers in electronic medical records. Timeline: Short term	Inclusion of ADRD as a key focus area for standardized medical records by 2018
Define components of process for clinicians to discuss end of life planning and standardize comprehensive end of life planning forms for persons with ADRD	Define process components for clinicians to discuss end of life planning with persons with ADRD and their key family and friends, where relevant. Develop comprehensive standard end of life planning forms, endorsed by leading patient advocacy and health care professional and trade associations and require integration into medical records to follow patients between transitions, particularly between nursing homes, hospice care settings, and hospitals. Include medical provider orders as part of standardized forms for patients with ADRD. Timeline: Short term	Develop components of process for clinicians to discuss end of life planning and require standardized form, endorsed by leading patient advocacy and health care professional and trade associations by 2018
Milestone section: Ensure people with ADRD and their key family and friend caregivers are supported by effective transition models between care settings		
Identify, encourage, and incentivize the use of evidence-based ADRD care transition models	Identify, encourage, and incentivize evidence-based ADRD care transition models that have been shown to improve system function and quality by improving hospital to home, community, and institutional transitions and reducing preventable re-hospitalizations. Use models that incorporate recommended dementia-competent hospital guidelines, specifically around effective transitions (strategy 2D). Timeline: Medium term	Data collected to show cost and quality effectiveness to managed care payers and providers by 2020
Define unnecessary and preventable transitions, and minimize transitions, for persons with ADRD	Develop guidelines to define unnecessary and preventable transitions between settings, including preventable hospitalizations, for persons with ADRD, make recommendations to reduce and minimize transitions, and create a system to collect data and track progress. Incorporate into tracking of ADRD population level outcome measurements (Strategy 2D). Align efforts with the CDC HP2020 initiative. Timeline: Long term	Guidelines outlined by 2018; recommendations, tracking, and baseline measures in place by 2019; preventable hospitalizations for persons with ADRD reduced to 22.8% by 2020 (consistent with HP2020) and reduced by an additional 20% by 2025; all preventable transitions reduced from baseline by 30% by 2025
Strategy 2G: Advance coordinated and integrated health and long-term services and supports for individuals living with Alzheimer's disease		
Milestone section: Improve care coordination structures for persons with ADRD		
Reform CMS payment structures to include ADRD in risk adjustment to account for increased services	Adjust risk reimbursement in managed care models for persons with ADRD to account for their enhanced care needs and the	Reformed payment structures for persons with ADRD by 2024

	correspondingly more complex coordination of necessary services to meet those needs. Timeline: Long term	
Provide differential reimbursement for CMS Bundled Payments for episodes of care experienced by persons with ADRD	Provide differential reimbursement for Medicare Bundled Payments for episodes of care experienced by persons with ADRD to account for enhanced care needs and coordination as a result of ADRD. Timeline: Long term	Differential reimbursement for bundled payments for episodes of care for persons with ADRD by 2024
Develop ADRD care coordination guidelines for case or care managers for people with ADRD	Strengthen care management for ADRD patients by outlining key principles necessary to coordinate care for this patient group, especially between the medical system and long-term services and supports. Ensure care manager for person with ADRD manages the patient's ADRD in the context of other comorbid conditions, including improving communication across multiple physicians, providing education on self-management for the person with ADRD and their key family and friend caregiver, where exists, and overseeing all aspects of condition management. Ensure all providers are informed when a patient transitions between settings. Timeline: Medium term	Guidelines developed by 2020
Identify and remove barriers to chronic care coordination	Identify barriers to practitioners performing chronic care coordination, outline a comprehensive plan to address and ensure high-quality delivery through quality assurance and performance improvement measures. Timeline: Short term	Barriers identified and plan outlined by 2018; plan to address and quality measures implementation by 2019
Milestone section: Assess and ensure adequate staffing levels across care settings		
Develop a framework for assessing adequate staffing levels across care settings that care for persons with ADRD	Develop a framework for assessing adequacy of staffing ratios (including turnover and retention) tied to outcomes across relevant health care settings and long-term services and supports that care for persons with ADRD, recognizing that persons with ADRD have differing care needs. Document findings. Timeline: Medium term	Framework of adequate staffing levels by care setting identified by 2020
Allow for sufficient staffing levels across care settings to ensure quality measures are met for persons with ADRD	Ensure relevant health care settings and long-term services and supports that care for persons with ADRD has sufficient staffing levels (taking into account turnover and retention) to ensure that quality measures are met for persons with ADRD. Ensure staff is equipped with the requisite ADRD knowledge and skills. Reimburse for appropriate staff levels. Timeline: Long term	Reimbursement updated by 2022; implemented in 70% of facilities in each state by 2025

(Continued)

Table 1. Proposed milestones for goal 2 (Continued)

Milestone	Implementation detail	Success criteria
Milestone section: Test creative alternatives for care delivery and reimbursement that are specifically adapted to the challenges of ADRD and associated disabilities		
Enhance ADRD-specific preparedness of care coordination models	Develop add-on dementia certification for National Committee for Quality Assurance (NCQA) Patient-centered Medical Home Recognition care coordination model. Timeline: Short term	Incorporate by 2018
Evaluate alternative ADRD care delivery models	Collect and report evidence on models of care delivery outside traditional clinical settings (e.g., home-based primary care and telehealth) and their unique impact on people with ADRD. Adjust Medicare reimbursement structure accordingly. Timeline: Long term	Five alternative models evaluated by 2020; reimbursement reformed by 2025
Implement home-based primary care*	Implement home-based primary care models under Medicaid's state plan option. Timeline: Long term	Implemented by 2024
Milestone section: Provide post-acute support for persons with ADRD		
Provide coverage for post-acute support in the appropriate care setting for Medicare beneficiaries with ADRD, regardless of length of hospital stay, and set guidelines to identify the appropriate setting	Ensure that persons with ADRD are covered by Medicare to transition to a post-acute care setting appropriate to their needs for some intermittent period of time immediately after an inpatient or outpatient hospital stay, regardless of the current 3 day length of stay in the hospital requirement, to prevent an unnecessary hospital readmittance. Set guidelines to help identify the appropriate post-acute setting. Ensure that post-acute services and supports are not limited for other comorbid conditions due to a person having ADRD. Timeline: Long term	Medicare reimbursement criteria modified by 2025.
Strategy 2H: Improve care for populations disproportionately affected by Alzheimer's disease and for populations facing care challenges		
Milestone section: Provide for the unique needs of persons with ADRD disproportionately affected or challenged		
Prioritize and fund the Office of the Assistant Secretary for Planning and Evaluation (ASPE) taskforce recommendations on persons with ADRD disproportionately affected	Prioritize recommendations made in 2013 ASPE (Office of the Assistant Secretary for Planning and Evaluation) report on younger-onset dementia, racial and ethnic minorities, and persons with Down Syndrome and other intellectual disabilities, identifying quick wins and longer term goals. Outline timeline needed to address each recommendation and suggest and provide funding where needed. Timeline: Long term	Create timeline with short-term and long-term priorities and related funding needs by 2018 to meet all recommendations by 2025.
Provide comprehensive brain health and ADRD training and resources in the context of overall health needs to Federally Qualified Health Centers (FQHCs), disproportionate share hospitals, and other public institutions to do proactive outreach	Improve the care of diverse populations with ADRD or at higher risk of ADRD in FQHCs, disproportionate share hospitals and other public institutions that tend to serve more diverse communities by providing training and resources to do proactive outreach around comprehensive brain health and ADRD care in the context of	Supplemental training and resources provided by 2018

<p>Improve awareness and access to clinical trials for those disproportionately affected</p>	<p>overall health needs. Timeline: Short term</p> <p>Increase awareness and outreach efforts for ongoing clinical trials to people with ADRD who have historically been underrepresented, including ethnically and socioeconomically diverse individuals and those living in rural areas. Perform outreach to tribal populations to expand participation in ADRD clinical trials. Raise awareness and encourage clinical trial enrollment annually during open enrollment. Timeline: Long term</p>	<p>>35% of ADRD clinical trial participants are ethnically diverse by 2023; >15% of ADRD clinical trial participants are socioeconomically diverse by 2023; >4% of clinical trial participants are LGBT by 2023</p>
<p>Milestone section: Expand medical access to underserved populations with ADRD through telehealth Expand and track telehealth</p>	<p>Develop guidelines for expanding telehealth to increase people with ADRD's access to dementia-competent health professionals, including for diagnostic services, especially in rural areas. Disseminate toolkit through partnership with professional and trade associations and local health agencies. Track telehealth reach and quality in providing care to people with ADRD. Timeline: Long term</p>	<p>Toolkit developed by 2018; data tracking metrics measured and publicized by 2020; 80% of rural communities reached by dementia-qualified physicians via telehealth by 2025</p>
<p>Modify CMS reimbursement for telehealth</p>	<p>Modify telehealth licensure restrictions to allow physician reimbursement for ADRD telehealth care provided across state lines. Loosen restrictions on requirements that currently require telehealth to be received within Medicare certified facilities, to allow patient to receive telehealth care services within their home. Timeline: Long term</p>	<p>Modified in 40 states by 2020; Modified in 50 states by 2025</p>

*Indicates milestone is primarily the responsibility of state governments.

**Indicates milestone is a joint federal-state responsibility.

Table 2
Proposed milestones for goal 3

Milestone	Implementation detail	Success criteria
Strategy 3A: Ensure receipt of culturally sensitive education, training, support materials		
Milestone section: Ensure all persons with Alzheimer's disease and related dementias (ADRD) and their key family and friend caregivers receive culturally competent support regardless of location, race, ethnicity, sexual orientation, or socioeconomic class		
Identify and develop scalable culturally competent and linguistically appropriate ADRD support resources	Build a coalition of public, private, and nonprofit entities to provide the resources, including grant funding, educational materials, and training. Coalitions should identify, and create where needed, highly scalable culturally competent and linguistically appropriate, evidence-based healthy aging, brain health, and ADRD program resources. Target healthy aging and brain health programs to people at risk of developing ADRD in the community and ADRD-specific programs for people with ADRD and their key family and friend caregivers. Translate programs into different languages, tailor materials to be accessible online, by phone, or in person across a variety of settings, and test materials to ensure comprehension and effectiveness for target audiences. Collaborate with Office of Minority Health to ensure Alzheimers.gov includes these materials. Timeline: Medium term	>35% programs targeted toward ethnically diverse persons with ADRD or their key family and friend caregivers by 2020; >15% targeted toward socioeconomically diverse persons with ADRD or their key family and friend caregivers by 2020; >4% targeted toward lesbian, gay, bisexual, and transgendered (LGBT) individuals with ADRD or their key family and friend caregivers by 2020; 80% of those at risk of ADRD are educated on healthy aging and brain health by 2020
Expand outreach to people with ADRD and their key family and friend caregivers to scale delivery of culturally competent support programs	Increase participation of culturally diverse populations by investing in efforts to raise awareness of support programs among these groups and diversify program delivery to increase access, including program delivery by native language speakers. Scale program delivery through online or phone resource portals, community-based organizations, residential facilities, senior centers, and other relevant settings. Educate and enlist the faith community and community health workers as local resources that can help reach out to and support key family and friend caregivers. Timeline: Long term	>90% of key family and friend caregivers/people with ADRD dyads have access to a community-based education or support program by 2025
Aggregate information on ADRD-related community services offered at the national, state, and local level**	Work with private and public partners to produce multilingual and multicultural information describing the availability and eligibility criteria for all ADRD-related national, state, local, and localized private support services, where applicable. Where needed, provide access to personnel who can assist families with obtaining this support. Provide this information to clinicians to include in postdiagnostic care planning for newly diagnosed individuals and their key family and friend caregivers and make accessible online. Timeline: Medium term	Information collected and materials developed by 2018; revisited biannually starting in 2020 to ensure up-to-date information on community services
Develop a system for collecting and tracking data on the supply, use, unmet needs, and outcomes of support services received by	Develop a system for collecting and tracking data on the supply, use, unmet needs, and outcome on quality and cost of care and support	Data collection system in place and annual results published in at least 40 states by 2020; 50 states by 2023

persons with ADRD and their key family and friend caregivers as a population management tool at the state level**

services available and accessed by all persons with ADRD and their key family and friend caregivers, where exists, by location, race, ethnicity, sexual orientation, and socioeconomic class. Use data collection and tracking system as a population management tool at the state level for persons with ADRD. Learn from successful state models and disseminate broadly.

Timeline: Medium term

Strategy 3B: Enable family caregivers to continue to provide care while maintaining their own health and well-being

Milestone section: Provide financial and employer supports to allow key family and friend caregivers to provide care to loved ones with ADRD

Provide tax and social security credits for key family and friend caregivers**

Provide federal/state tax credits or deductions and social security credits to key family and friend caregivers for providing in-home care, regardless of whether the caregiver and care recipient reside in the same home, to dependent (informal designation) relatives or friends with ADRD. Where primary caregiving responsibilities for dependent relative or friend with ADRD are shared across multiple key family and friend caregivers, allow tax credits to be split proportional to time spent providing care. Ensure verifications in place to confirm caregiver status to prevent fraud.

Timeline: Long term

Tax and social security credits in place by 2020; 25% of eligible key family and friend caregivers taking advantage of tax credits by 2025

Expand funding for Cash & Counseling and similar consumer-directed programs that pay key family and friend caregivers to provide care*

Expand funding for Cash & Counseling and similar consumer-directed programs that allow payment to key family and friend caregivers for care provided to person with ADRD, in place of paying a professional caregiver when the person with ADRD is eligible for such Home and Community Based services. Provide sufficient funding to eliminate waiting lists for these consumer-directed programs.

Timeline: Medium term

Double funding for consumer-directed programs such as Cash & Counseling by 2020

Increase funding for National Family Caregiver Support Program

Improve federal funding to the states as part of the National Family Caregiver Support Program of the Older Americans Act (OAA Title III) to ensure key family and friend caregivers of persons with ADRD are supported in caring for their loved ones at home as long as needed.

Timeline: Medium term

Double funding for National Caregiver Support Program by 2020

Amend Family and Medical Leave Act (FMLA) and related state laws**

Expand benefits coverage under FMLA and related state laws for key family and friend caregivers to include aunts/uncles, siblings, in-laws, grandparents, and nonrelatives with ADRD.

Timeline: Medium term

Integrate into law by 2020

Support paid family leave to key family and friend caregivers of people with ADRD**

Investigate the feasibility and work to expand paid or partially paid family leave for key family and friend caregivers of people with ADRD to all those currently covered under FMLA or similar state laws, as well as aunts/uncles, siblings, in-laws, grandparents, and nonrelatives with ADRD.

Timeline: Long term

Integrate into law by 2025

(Continued)

Table 2. Proposed milestones for goal 3 (Continued)

Milestone	Implementation detail	Success criteria
Identify best practices and incentivize employer supports for key family and friend caregivers of persons with ADRD**	Identify best practices for businesses and other workplace sites to offer key family and friend caregivers support services such as flexible work hours, telecommuting, on-site adult day care services, referrals to community-based support services, counseling, and others through Employee Assistance Programs and other employee initiatives and disseminate findings. Provide incentives to encourage employer uptake of identified best practices in supports for key family and friend caregivers of persons with ADRD. Timeline: Long term	Best practices identified and disseminated by 2017; incentive programs in place for public employers by 2022; for private sector by 2025
Milestone section: Facilitate access to supplementary care supports for persons with ADRD		
Expand state assessment to consistently identify key family and friend caregiver-related needs and coordinate access to evidence-based programs**	Expand state assessments to consistently identify key family and friend caregiver-related needs and connect them with the necessary resources to resolve those needs, through online self-assessment resources or financial support for in-person assessments, recognizing that caregiver services and supports are a key public health initiative. Create a pilot program to provide assessments for key family and friend caregivers <65 years and provide CMS reimbursement for these assessments for key family and friend caregivers >65 years. Based on identified needs, connect caregivers with effective, pragmatic, and adaptive support programs that have been identified to best meet their specific needs. (See strategy 2E). Timeline: Medium term	Online resources for assessment in place by 2018; Pilot program in place for key family and friend caregivers under 65 years by 2020; CMS reimbursement policy in place for key family and friend caregivers >65 years by 2020
Help launch volunteer respite programs in local communities**	Develop strategies and provide grant funding to help recruit, screen, train, and launch volunteer respite programs, similar to those provided for parents of adopted/foster children, through a variety of sources: nursing and other allied health schools' intern programs, volunteer organizations, school volunteer placement offices, faith-based groups, community organizations, and others. Provide resources to support self-sustainability after grant funds run out. Ensure ADRD respite programs are included in community resource networks for key family and friend caregivers (Strategy 3A) and provide viable options for persons with the greatest demonstrated need (e.g., rural areas, tribal populations). Timeline: Long term	500 grantees by 2020; At least 25% of those programs sustained after grant funds run out by 2025
Evaluate state dual eligible demonstrations and recommend adoption of most successful models	Evaluate Medicare/Medicaid dual eligible beneficiary demonstrations on integration of care and alignment of financing and administration for persons with ADRD currently in progress across various states. Determine their relative cost and quality effectiveness and recommend the most successful models for adoption and expansion. Timeline: Short term	Evaluation and recommendations completed by 2017; Implementation of successful models by 2019

<p>Improve Home and Community Based Services (HCBS) waiver benefits and state plans to expand and improve key family and friend caregiver support services for those eligible*</p>	<p>Expand HCBS coverage benefits, both through waiver benefits and state managed care plans, to better meet the needs of persons with ADRD as the condition progresses and increased home support is required to keep the person with ADRD living safely at home. Ensure managed care organizations include statements about their ability to work with persons with ADRD. Provide sufficient funding to eliminate waiting lists for these programs. Timeline: Medium term</p>	<p>Increase funding by 25% per recipient for waiver benefits in at least 40 states for existing recipients by 2021; all 50 states by 2023</p>
<p>Modify short-term, in-home care covered by Medicare to include intermittent key family and friend caregiver support and skill building</p>	<p>Allow Medicare to cover key family and friend caregiver support and tailored skill building at home, by a certified home health aide, to help them care for the person with ADRD on an intermittent basis, either during a time of crisis or based on severe cognitive and functional disability. Provide sufficient funding to prevent waiting lists for these programs. Timeline: Long term</p>	<p>Program reimbursed under Medicare by 2025</p>
<p>Milestone section: Ensure key family and friend caregivers receive proper health care services, including counseling and mental health care</p>	<p>Identify key family and friend caregivers in their own medical records and update status regularly</p> <p>Include notes in key family and friend caregivers' medical record that identifies them as a "primary caregiver" similar to other recorded health behaviors such as exercise levels or alcohol consumption to ensure their physicians use that information to assess common issues such as sleep and stress and provide necessary preventative services to account for their higher health risks. Ensure designation is updated regularly to maintain accurate status. Timeline: Short term</p>	<p>Key family or friend caregiver designation in medical record systems by 2018</p>
<p>Build evidence-base around health impact of caregiving for persons with ADRD</p>	<p>Identify and collect existing evidence and provide funding for research to fill existing gaps in knowledge around the health impact and risks of caregiving, as well as successful health interventions for key family and friend caregivers of persons with ADRD to mitigate those risks. Use evidence base to make recommendations on improvements to the health system. Timeline: Medium term</p>	<p>Summary of health impacts of caregiving released by 2020; recommendations implemented by 2022</p>
<p>Provide proactive outreach to promote health and preventative services to key family and friend caregivers of persons with ADRD</p>	<p>Recognize caregiving as a health risk factor that warrants public health attention. Encourage health professionals to provide proactive outreach encouraging health assessments for key family and friend caregivers. Based on identified needs, outline a comprehensive action plan and referral to support services and primary care interventions targeted at their high-risk health areas, such as counseling and mental health care. Refine offerings to align with the newest evidence base around the health impact of caregiving. Timeline: Long term</p>	<p>Health professionals providing health assessments and preventative services for 50% of key family and friend caregivers by 2025</p>

(Continued)

Table 2. Proposed milestones for goal 3 (Continued)

Milestone	Implementation detail	Success criteria
Provide grant funding to organizations to provide support services for children of parents with younger-onset ADRD	Provide grant funding to community-based, faith-based, nonprofit, or governmental organizations to build the infrastructure and facilitate the provisions of support services to children of parents with younger-onset ADRD, separate from groups targeted at other conditions. Timeline: Long term	>90% of children of people with younger-onset ADRD have access to a community-based support program by 2025
Strategy 3C: Assist families in planning for future care needs		
Milestone section: Disseminate information on care providers and services to help families make care choices		
Create public recognition system to identify home, community, and institutional-based services based on high-quality ADRD care*	Create public recognition system to identify home, community, and institutional-based services based on high-quality ADRD care and verified dementia-specialized care, tied to state certifications, licensures, and nursing home Joint Commission accreditations and certifications (See Strategy 2D), as well as cultural competency, to help inform consumer choice. Make information accessible online and update regularly. Timeline: Long term	Recognition system in place and disseminated publicly by 2020; 40% of home-, community-, and institutional-based providers enrolled in at least 40 states by 2022; 60% enrolled in all 50 states by 2025
Create a public-private partnership to initiate a system for identification and consumer review of ADRD qualified physicians	Create a public-private partnership to outline criteria for identifying “dementia-qualified” practitioners, which may include some combination of minimum number of ADRD patients in practice; board certification in specialties such as neurology, geriatrics, geriatric psychiatry, or geriatric psychology; minimum ADRD training programs completed for primary care physicians such as the Harvard Dementia Care Program or others. Partnership should provide designation for all practitioners who meet such requirements as “dementia-qualified” and create a system to disseminate that list to the public and request consumer reviews for these physicians, enabling consumer choice based on quality. Partnership should align on objective rating criteria for reviews and ensure quality controls in place to verify reviewer authenticity. Timeline: Long term	Criteria for “dementia-qualified” outlined and endorsed by leading professional associations by 2018; consumer review forum launched by 2020; >80% of “dementia-qualified” physicians reviewed with quality controls in place by 2025
Incorporate ADRD quality care into Medicare Five-Star Rating systems	Ensure the Five-Star Rating Systems for Medicare Advantage, prescription drug part D plans, nursing homes, and other care facilities reflects quality coverage of care and support for persons with ADRD and their key family and friend caregivers to help inform patient choice of health payer and provider. Align rating system’s criteria to quality standards for dementia care (Strategy 2D). Timeline: Short term	Incorporated by 2018
Milestone section: Ensure families have the tools and opportunities to engage in advanced legal, financial, and care planning		
Evaluate and address barriers for persons with ADRD and their key family and friend caregivers to access and use available care and support services	Identify existing research completed to date and further evaluate barriers for persons with ADRD and their key family and friend caregivers to access and use available ADRD care and support	Report released on barriers to access and utilization of care and support services for persons with ADRD and their caregivers and recommendations to reduce by 2018; update released in 2022

<p>Provide funding and create triggers to encourage greater participation in advanced care, legal, and financial planning for persons with ADRD</p>	<p>services that could increase the care quality and reduce the cost of their health care resource utilization. Make recommendations to reduce those barriers to access. Timeline: Short term/Medium term</p> <p>Provide funding to hospitals/clinics to have nurse practitioners, social workers, certified counselors, or other nonphysician facilitators help families complete advance care directives as part of a care plan on ADRD diagnosis (Strategy 2C). Additionally, identify specific “trigger” points, such as when one is admitted to the hospital, fills out a life insurance policy, or signs up for social security to encourage comprehensive advanced care, legal, and financial planning, enabling persons with ADRD to make vital decisions while still cognitively aware. Provide guidance on how and when to address the conversation around limiting access to equipment that could endanger public safety as a result of cognitive impairment, including motor vehicles, guns, and others. Build a coalition of public, private, and nonprofit entities to ensure “trigger” points for advanced care directives using standardized forms (strategy 2F) are implemented into the appropriate health, legal, and financial systems to be completed by persons with ADRD and their key family and friend caregivers before a time of crisis. Timeline: Long term</p>	<p>Funding provided for facilitators of advanced care planning by 2018; Trigger points identified by 2019; advanced care, legal, and financial planning incorporated at trigger points by 2022; >90% of persons with ADRD completing advanced care directives at or before trigger points by 2025</p>
<p>Milestone section: Increase access to financial supports to pay for future care needs</p>		
<p>Incentivize employers to offer long-term care (LTC) insurance</p>	<p>Incentivize employers to offer LTC insurance policies as part of common benefit packages, alongside health, life, dental, and others, to encourage increased uptake by the workforce. Timeline: Long term</p>	<p>Incentives in place by 2024</p>
<p>Define standards and restructure LTC insurance to enhance affordability and coverage</p>	<p>Define standards for LTC insurance, including eliminating exclusions for persons with ADRD, introducing inflation protection, ensuring policy can be used at most facilities, and implementing a federal “backstop” for coverage of individuals with ADRD to constrain the risks being insured, enhancing the affordability, coverage, and reliability for people in need. Restructure LTC insurance to meet guidelines. Timeline: Long term</p>	<p>Standards defined and LTC insurance restructured by 2025</p>
<p>Explore the feasibility of new regulation that allows life insurance policies to convert to LTC insurance**</p>	<p>Partner with LTC insurance commissioners to explore the feasibility of new insurance regulations that allow an individual to convert life insurance to LTC insurance to fund long-term services and supports. Timeline: Long term</p>	<p>Feasibility investigated by 2023; Regulation enacted by 2025 if deemed feasible</p>
<p>[Revised] Strategy 3D: Maintain the dignity and rights of people with Alzheimer’s disease</p>		
<p>Milestone section: Ensure legal, financial, and social services are equipped to serve and protect persons with ADRD</p>		
<p>Require ADRD training for adult protective services (APS), LTC ombudsmen, judges, and court personnel*</p>	<p>Require mandatory ADRD-specific competency-based training for state APS workers, LTC ombudsmen, judges, court personnel, and others. Timeline: Long term</p>	<p>70% ADRD-competency rate by 2020; 100% ADRD-competency rate by 2025</p>

(Continued)

Table 2. Proposed milestones for goal 3 (Continued)

Milestone	Implementation detail	Success criteria
Identify quality measures for APS and create a system to collect data and track performance against those measures	Identify quality standards and measures for APS, such as average response times to calls, in working with persons with ADRD and their key family and friend caregivers to measure facility and worker performance. Create a system to collect data on performance against quality measures and track progress over time. Use child protective service system as a model. Timeline: Short term	Quality standards identified and data collection system created by 2018
Provide federal funding to APS to help facilities ramp up to meet quality measures and as incentives to maintain high-quality services	Provide increased overall federal funding to all APS facilities to help them ramp up service delivery to improve on identified quality measures over a 3-year horizon. After 3-year ramp up horizon, continue funding for facilities who meet minimum quality standards to incentivize high-quality services. Timeline: Medium term	Increased federal funding for all APS facilities by 2019–2021; Incentive funding for APS facilities meeting quality standards by 2022
Create a decision support assessment tool for APS workers	Develop decision support guidelines and a corresponding easy-to-use and methodologically sound assessment tool to help APS workers analyze problems in the field, most common for persons with ADRD and help them to determine next steps and what, if any, interventions should be taken. Timeline: Long term	Guidelines and assessment tool developed by 2020; Used by 80% of APS workers by 2023; 90% by 2025
Ensure cross-state adult guardianship framework*	Ensure Uniform Adult Guardianship and Protective Proceedings Jurisdiction Act is passed in all 50 states to ensure a framework is in place for courts in different states to communicate about adult guardianship cases and thus make the resolution of multistate jurisdictional issues easier for family members, and in many cases, alleviate the need for re-adjudication of guardianship issues. Timeline: Short term	In place in all 50 states by 2019
Create a public-private partnership to increase access and raise awareness of legal services equipped to counsel persons with ADRD and their key family and friend caregivers	Create a public-private partnership that includes key professional organizations representing attorneys, such as the American Bar Association, clinician professional organizations, and large universities to increase access and raise awareness of legal services in the community, including elder law clinics, to persons with ADRD and their key family and friend caregivers. Timeline: Long term	80% of people with ADRD and their key family and friend caregivers have access and are aware of legal services in their community by 2025
Provide training on legal guidelines, financial management, and basic ADRD education, for persons managing the legal and financial matters of people with ADRD**	Partner with attorneys to incorporate and disseminate educational materials regarding legal guidelines, financial management, and basic ADRD knowledge where needed, to conservators, guardians, power of attorneys, trustees, authorized persons, lay fiduciaries, and others managing the affairs of people with ADRD who no longer have the capacity to do so. Timeline: Long term	Programs and services linked to attorney services by 2022; 80% of attorney drafting processes include dissemination of legal guidelines and financial management training by 2025

Ensure states implement regulations to protect vulnerable adults from financial abuse resulting from exploitation or diminished capacity*

Create or strengthen financial industry regulations for bankers, financial advisers, brokers, investors, and other employees that manage funds and investments to protect vulnerable adults from financial exploitation or poor financial decisions due to the presence of ADRD. Recommendations should include protocols around identifying potential red flags that indicate suspicious activity around a person with ADRD’s finances and estate, who to notify if abuse or diminished capacity is suspected, instances that require delayed disbursements, mechanisms for contacting APS or requesting court intervention, and other relevant guidelines.
Timeline: Medium term

Regulations to protect against financial abuse implemented in 40 states by 2020; 50 states by 2022

Require ADRD training for bank employees, financial advisors, brokers, and investors**

Require bank employees, financial advisors, brokers, and investors to be trained on state regulations, protocols, and guidelines designed to protect persons with ADRD from financial abuse.
Timeline: Long term

70% of bank employees, financial advisors, brokers, investors receive ADRD financial awareness education by 2022; 100% by 2025

Milestone section: Reduce inappropriate use of antipsychotic and other psychotropic drugs for persons with ADRD in home-, community-, and institutional-based settings; and address root causes of behavioral issues

Develop consensus on “inappropriate use” of antipsychotic and other psychotropic drugs for persons with ADRD

Identify existing guidelines and develop consensus on the definition of “inappropriate use” of antipsychotic drugs and other psychotropic drugs among persons with ADRD across care settings. Use relevant quality improvement methodologies such as root cause analysis to evaluate the basis for inappropriate use of such medications, including but not limited to training and staffing issues, inter-professional dynamics, and weak accountability systems. Include that antipsychotic and other psychotropic drugs cannot, and must not, be used to substitute for high quality, person-centered care.
Timeline: Short term

Consensus developed for “inappropriate use” of antipsychotic and other psychotropic drugs in persons with ADRD by 2017; incorporated into ADRD Joint Commission certifications/accreditations by 2018; baseline set for “inappropriate use” across settings by 2019

Build on existing efforts to reduce inappropriate use of antipsychotics and other psychotropic drugs for persons with ADRD in nursing homes and hospitals**

Align with existing policy initiatives and build on those efforts to monitor, report, and reduce inappropriate use of antipsychotics and other psychotropic medications in nursing homes, hospitals, and the community. Levy financial penalties on facilities that continue to prescribe antipsychotics and other psychotropic medications inappropriately.
Timeline: Medium term

Reduce “inappropriate use” antipsychotic and other psychotropic drug use by 30% from established baseline in nursing home and hospitalized patients with ADRD nationwide by 2022

Expand outreach to reduce inappropriate use of antipsychotics and other psychotropic drugs for persons with ADRD across all care settings**

Expand education and outreach efforts beyond nursing home and hospital settings to include assisted living facilities and other care settings.
Timeline: Long term

Reduce “inappropriate use” antipsychotic and other psychotropic drug use for persons with ADRD across all care settings by 30% from established baseline by 2024

(Continued)

Table 2. Proposed milestones for goal 3 (Continued)

Milestone	Implementation detail	Success criteria
Address root causes of behavioral issues among persons with ADRD through research and development of measures	Provide funding for research, including translational research, related to nonpharmacologic methods of preventing care-disrupting behaviors as well as managing such behaviors when they occur. Include research to improve understanding the root causes of such behavior, including factors in both the physical and interpersonal environments of care. Embed this understanding in training programs for all care partners (professional and nonprofessional staff and key family and friend caregivers) aimed at prevention and mitigation of behavioral complications. Follow training with methods for measuring and sustaining improvement, ongoing assessment of treatment implementation, periodic feedback on care provider performance, and, in health care and residential settings, adopt a systems approach that involves all levels of staffing. Develop quality and outcome measures for various care settings on implementation of best practices regarding non-pharmacologic alternatives. Monitor effectiveness of quality and outcome measures, and adjust measures according to the findings and additional research. Timeline: Medium term	Targeted request for applications with earmarked funds established by 2018; quality and outcome measures established by 2020; measures adjusted based on effectiveness by 2023
Milestone section: Provide funding for community development and scale up of evidence-based meaningful activities for persons with ADRD Provide funding for community development and scale up of evidence-based meaningful activities for persons with ADRD	Provide grant funding and other resources to help community and institutional facilities, including adult day care, assisted living, nursing homes, and others, develop and scale-up innovative and low-cost evidence-based purposeful living activities for individuals with cognitive impairment that will also provide respite for key family and friend caregivers. Establish meaningful activities across the care continuum that are specifically adapted for the person with ADRD, including vocational, rehabilitative, social, and recreational activities and the use of memory/communication books in nursing homes. Provide resources to support self-sustainability after grant funds run out. Ensure ADRD meaningful activity programs are included in online and community-based key family and friend caregiver support resource locator services and provide viable options for persons not presently served, such as tribal groups and persons with ADRD in rural areas. Timeline: Long term	500 grantees by 2020; 200 of those programs sustained after grant funding runs out by 2025
Strategy 3E: Assess and address the housing needs of people with Alzheimer's disease Milestone section: Adapt community and institutional care settings and payment methods to better meet the unique needs of persons with ADRD and their key family and friend caregivers Provide funding to evaluate alternative long term care models, including for specific populations	Provide funding for pilot programs to evaluate alternative long term care models and care settings that may be more or less effective	Funding for pilot programs available by 2020; evaluations of pilot program effectiveness by 2022

	<p>for different populations. Ensure programs for persons with younger-onset ADRD who have unique care needs and those with related dementias, who can be refused by some community and institutional settings, are specifically evaluated. Models that may be considered for evaluation include continuing care retirement centers, the Green House Model, adult foster care, group homes, housing options that include the person's spouse without ADRD, and other models that may enhance quality and cost effectiveness. Timeline: Medium term</p>	
<p>Provide state specialty housing vouchers for low-income persons with ADRD*</p>	<p>Provide specialty housing vouchers that expand housing options for low-income persons with ADRD beyond institutional settings allowing use in a variety of community care settings, including assisted living and other residential care facilities. Timeline: Long term</p>	<p>Flexible voucher system for residential care in 40 states by 2024; 50 states by 2025</p>
<p>Promote use of universal design in facilities and products targeted at older adults</p>	<p>Partner with architectural, design, and engineering schools to promote the use of universal design in building architecture and products designed for older adults at greater risk of cognitive impairment, such as nursing homes, assisted living facilities, adult day centers, senior centers, and other retirement communities. Timeline: Long term</p>	<p>Universal design integrated in 80% of institutional and community-based settings by 2025</p>
<p>Milestone section: Support home care for persons with ADRD by providing financial and professional supports for key family and friend caregivers to make care at home sustainable</p>		
<p>Provide standard assessment guidelines and/or tools to help determine most suitable housing arrangements for persons with ADRD**</p>	<p>Assess an individual with ADRD's functional needs and key family and friend caregivers' input to determine the least restrictive environment that they can safely live in. Make assessment tool available online and work with health care professional and trade associations to disseminate to clinicians and care coordinators to help facilitate a person-centered conversation around housing arrangements for a person with ADRD. Timeline: Short term</p>	<p>Assessment tool in place by 2018</p>
<p>Provide guidelines that will enhance the safety of persons with ADRD remaining in their home as condition progresses, incorporating technology where relevant</p>	<p>Collaborate with health care professionals, including hospitalists, home health care professionals, and legal professionals to develop guidelines to permit persons with ADRD to safely remain in their current living environment, including interventions, based on the growing number of evidence-based models of care to support people with dementia at home, to reduce risks of fall, wandering, and poor nutrition. This would include providing safety checklists to key family and friend caregivers and conducting home assessments to ensure the safety of the living environment. Recommendations should be made to improve any problem areas flagged in the assessment, including the incorporation of technological solutions where relevant. Timeline: Short term</p>	<p>Home care guidelines endorsed by key stakeholder and advocacy groups by 2018</p>

(Continued)

Table 2. Proposed milestones for goal 3 (Continued)

Milestone	Implementation detail	Success criteria
Provide grants to develop programs to meet the needs of persons with ADRD who live alone	Develop a grant program for local or state entities to provide funds to better understand the prevalence and unique needs of people with ADRD who live alone and to develop programs to meet those needs, including care support when a person with ADRD living alone transitions out of a hospital or skilled nursing facility. Timeline: Medium term	Grant funding provided to 200 communities by 2020
[New] Strategy 3F: Support communities that are inclusive and safe for persons with Alzheimer's disease and related dementias		
Milestone section: Ensure persons with ADRD are safe and cared for in emergency situations		
Implement missing person protocol for adults with ADRD*	Ensure law enforcement agencies implement a missing persons protocol for adults with ADRD in all 50 states. Timeline: Medium term	All 50 states have adopted a Missing Persons protocol by 2020
Require ADRD training for first responders*	Require mandatory ADRD-specific competency-based training to first responders, including law enforcement, fire fighters, paramedics, EMTs, and others about medical and behavioral issues related to ADRD so they are prepared when responding to an emergency involving these individuals. Identify or develop training guidelines for these groups. Ensure law enforcement training includes Missing Person protocols for adults with cognitive impairment. Timeline: Short term	70% ADRD-competency rate of first responders by 2018; 100% ADRD-competency rate by 2020
Identify or develop guidelines for identifying elder abuse or neglect in patients with ADRD	Identify guidelines for health care providers to identify potential elder abuse in patients with ADRD in hospital emergency rooms, primary care settings, and first response situations and outline appropriate follow-up. Timeline: Medium term	Incorporated into Joint Commission hospital accreditation requirements, first-responder training, and ADRD standards of care by 2020
Convene a public-private group to identify and standardize emergency intervention health system protocols for persons with ADRD	Convene key public and private stakeholders to identify guidelines and outline protocols for health systems and law enforcement agencies when the following occur: (1) a primary family or friend caregiver is admitted to the hospital and there is no one else to care for the person with ADRD; (2) a primary family or friend caregiver passes away and there is no one readily available to care for the person with ADRD. Incorporate into state emergency preparedness plans, including natural and man-made disasters. Timeline: Medium term	Emergency interventions in place nationally by 2020
Identify and standardize emergency intervention protocols for persons with ADRD*	Implement emergency intervention in care facilities, hospitals, and the broader community for when the following occur: (1) a person with ADRD is found by public safety workers alone and in need of additional care and there is no one to provide care or time is needed in a court system to complete guardianship procedures; and (2) person with ADRD is found by Adult Protective Services to be in a dangerous situation. Incorporate into state emergency preparedness plans, including natural and man-made disasters. Timeline: Short term	Emergency interventions in place in 40 states by 2018; all 50 states by 2019

Milestone section: Ensure local community members who come in contact with persons with ADRD receive basic-dementia training

Create “dementia-sensitive” community-based qualification system

Outline federal guidelines for “dementia-sensitive” qualification, including cultural competency, of public and private community entities and businesses, such as movie theaters, restaurants, hotels, and other locations. Provide funding to create public and corporate awareness of the importance of dementia sensitivity and the unique needs of those with ADRD who live alone.
Timeline: Long term

Guidelines in place by 2017; 300 dementia-qualified businesses with over 50 employees by 2020; 1000 by 2025

Provide ADRD training for local governmental officials*

Provide basic ADRD education for Area Agency on Aging (AAA) employees, postal workers, transportation employees, and other community-based workers on how to interact with individuals with ADRD.
Timeline: Long term

70% of AAA employees, U.S. postal workers, transportation employees have basic ADRD education by 2020; 100% by 2025

Milestone section: Ensure safe transportation options for persons with ADRD

Fund public and social service transportation programs for persons with ADRD**

Provide additional funding for accessible and affordable transportation services that are dementia capable and improve the coordination of public and social service transportation. Offer incentives and training to local nonprofits to launch volunteer transportation programs in local communities. Give priority to providers familiar with this population, such as senior centers, faith-based programs, and adult day programs.
Timeline: Long term

40% of top 50 metropolitan areas have dementia-capable public transportation systems (where applicable) and/or community-based volunteer transportation programs by 2025

Provide referrals to community agencies for individuals with ADRD who no longer have driving privileges*

Ensure sufficient capacity in local communities and provide Department of Motor Vehicles, Secretary of State, and other relevant vehicle regulation agencies the necessary information to refer persons with ADRD to social and community agencies for assistance with transportation needs in the case of voluntary or involuntary surrender, expiration, or loss of driving privileges.
Timeline: Long term

Referral program incorporated into 40 states by 2024; 50 states by 2025

*Indicates milestone is primarily the responsibility of state governments.

**Indicates milestone is a joint federal-state responsibility.

workgroup developed the objective: All persons living with Alzheimer's disease and related dementias, regardless of location, race, ethnicity, sexual orientation, or socioeconomic class, should receive high-quality person/family-centered care by well-trained practitioners and workers from detection and diagnosis through end-of-life, across all health care and long-term services and supports settings and systems. For goal 3, "Expand supports for people living with Alzheimer's disease and their families," the workgroup developed the objective: People with Alzheimer's disease and related dementias, their families, and their caregivers should have access to effective interventions and supports that expand their care giving skill sets, enhance the meaningfulness and quality of their lives, and reduce the burden of Alzheimer's disease and related dementias.

2.2. Building on existing efforts

The workgroup acknowledged ongoing efforts of key federal agencies toward the established goals and strategies in the National Plan. In addition to noting areas where material progress had been made—such as the dementia-specific primary care curriculum under development by the Health Resources and Services Administration; the Centers for Disease Control and Prevention's (CDC) *Healthy People 2020* dementia objectives; the Administration on Community Living's work in support of caregivers, including the Alzheimer's Disease Supportive Services Program and the creation of alzheimers.gov; and the Centers for Medicare and Medicaid Services' (CMS) efforts to support the detection of cognitive impairment during the Medicare Annual Wellness Visit—the workgroup sought to incorporate and expand on these efforts in its recommendations. In addition, the workgroup noted that in areas of common subject matter, the recommended milestones are consistent with the CMS Quality Strategy report [9].

2.3. Defining terms

The workgroup noted different interpretations for various terms used in NAPA, the National Plan and general Alzheimer's lexicon and sought to establish terms that were more explicit and inclusive. For example, although the workgroup acknowledged that NAPA and the National Plan explicitly use the term "Alzheimer's disease" to encompass all forms of dementia, the workgroup chose to adopt "Alzheimer's disease and related dementias," abbreviated ADRD, throughout the milestones.

Similarly, the workgroup believed that terms like "families" or "family caregivers" were not inclusive of unpaid assistance provided by individuals who are unrelated to their care recipients. Therefore, as the workgroup believed that these unrelated, unpaid caregivers were nevertheless meant to be included as beneficiaries of the supports

referred to in the National Plan—and often provide crucial support—the workgroup chose to adopt the term, "key family and friend caregivers." Although paid caregivers are not included in this designation, milestones addressing paid caregivers are included in the strategy on the workforce, consistent with the structure and approach of the National Plan. Furthermore, while using the term "caregivers" is consistent with the widely used lexicon, particularly in professional circles, the workgroup recognized that the term may not be similarly used among those family members and friends who are actually providing care.

Because the workgroup did not seek to amend the already existing strategies, the recommended use of "ADRD" and "key family and friend caregivers" is not reflected in the strategies in the Tables. However, the workgroup recommended incorporating these amended terms throughout the National Plan. For example, strategy 2C "Educate and support people with Alzheimer's disease and their families on diagnosis" could be broadened to also include ADRD and key family and friend caregivers. Likewise, key family and friend caregivers could be used in place of "family caregivers" in strategy 3B. Similar changes could be made to strategies 2E, 2F, 2G, 2H, 3C, 3D, and 3E.

The workgroup also spent time discussing the term "dementia-capable"—what it meant and how it differed from similar sounding terms such as "dementia-friendly." Within strategy 2A, the workgroup agreed the term "dementia-capable" should be used to describe the target skill level of the workforce caring for people with ADRD, but recognized that the term is multidimensional and that the agreed-on definition may be a limitation of this work.

The workgroup struggled to come to consensus on what populations were "disproportionately affected" by Alzheimer's disease and related dementias. Ultimately, the workgroup adopted the National Plan's definition, which identified three specific populations: persons with younger-onset dementia, racial and ethnic minorities, and persons with Down syndrome and other pre-existing intellectual disabilities. However, the workgroup believed that other specific subpopulations are underserved and present unique challenges beyond the challenges of ADRD in general. As noted in various milestones (e.g. milestones under strategies 2E, 2H, 3B, 3D, 3E, and 3F) of particular concern are individuals with ADRD who live alone and/or in rural areas. Viable service options and research and development on innovative service-delivery systems are needed for these populations.

The workgroup experienced similar challenges when interpreting what comprised an "accurate" diagnosis, as noted in strategy 2B, "Ensure timely and accurate diagnosis." The workgroup agreed the word "accurate" was imprecise, owing to current limitations of diagnostic tests and cognitive assessment for ADRD and suggested replacing it with the term "appropriate." It is possible,

however, that by 2025—the period covered by NAPA and these recommended milestones—technological and other advancements could occur that would add more precision to the term “accurate.”

2.4. *Recognizing the roles of federal and state governments*

As noted in the National Plan, the workgroup acknowledged that achievement of an ideal system of care and support by 2025 will require coordination across federal, state, and local entities—and, in some cases, by both health care and non-health care agencies. As a result, the workgroup recognized that certain of its recommended milestones would require efforts by both federal and state governments or would need to be largely addressed and accomplished at the state level. In [Tables 1 and 2](#), milestones are assumed to be the responsibility of the federal government unless denoted with an asterisk (*), indicating primarily state-level initiatives or two asterisks (**), indicating joint federal-led and state-led policies.

2.5. *Estimating timelines*

The workgroup provided guidance on the estimated amount of time required to achieve each milestone's success criteria. Milestones that should be expected to reach their success criteria between today and 2019 are designated as “short term;” between 2020 and 2023 as “medium term;” and between 2024 and 2025 as “long term.” The workgroup recognized that select milestones, such as those that require changes in regulations or statutes, may take longer to enact than others. However, with the rapid growth of an aging population, the workgroup stressed the urgent need to move forward with milestone implementation. In other words, the timeline designation should be interpreted as the recommended date of achievement, not the time-frame in which to begin addressing the milestones; the work related to many milestones designated “long term” must nonetheless begin immediately. Also, the timeline designation is not meant by the workgroup and should not be interpreted as reflecting relative importance of the milestones.

Furthermore, the workgroup noted that not all the milestones are linear in nature. Although it is tempting to think of milestones in the abstract as a sequential series of actions or intermediate targets on the way toward meeting an overarching goal—one action to follow another—that is neither possible nor always advisable in this case. Some of the recommended milestones do naturally follow other milestones. For example, ensuring that quality care standards are adopted and incorporated in practice settings necessarily first requires that quality care standards be established. But, as with the milestones established by the NIH for goal 1, not all steps that need to be taken necessarily need to follow specific earlier actions.

Numerous milestones can and need to be addressed simultaneously, and some milestones will naturally take longer to achieve given that they involve more complicated legislative and regulatory processes.

3. Discussion of specific milestones

[Tables 1 and 2](#) contain all the recommended milestones for goals 2 and 3 of the National Plan, including detail on the implementation of each milestone, most of which is self-explanatory. For a few strategies and milestones, however, the workgroup believed that it was necessary to make some specific clarifying comments.

3.1. *Strategy 2B on diagnosis*

During its discussion, the workgroup deliberated what was the best way to “ensure timely and accurate diagnosis” as noted by strategy 2B. Rather than focus on milestones that solely supported diagnosis of ADRD, the workgroup felt it was important to also consider milestones that would support the identification and disclosure of cognitive change over time. Consequently, the workgroup concluded that clinicians should assess the cognitive and functional skills of individuals at risk for ADRD and disclose clinically consequential cognitive impairment—that is, cognitive impairment that is accompanied by deficits in an individual's activities of daily living or instrumental activities of daily living. Furthermore, clinicians should ensure that diagnosed individuals and their key family and friend caregivers, where they exist, are aware of any ADRD diagnosis. The workgroup clarified that it is not the aim of the diagnosis-related milestone recommendations, given the current state of the science, to call for, at this time, the use of biomarkers for all individuals at risk of cognitive impairment.

3.2. *Strategy 2D on guidelines*

The milestones in Strategy 2D include the development of high-quality guidelines and measures on the clinical care of individuals with dementia across care settings. Although mentioned within the recommendations themselves, the workgroup wanted to underscore that all such quality measures should be explicitly tied to both processes and clinical person-centered and family-centered outcomes.

3.3. *Strategy 2E regarding research on care and support practices*

The workgroup spent considerable time discussing milestones to support research on new models of care for people with ADRD and their key family and friend caregivers (strategy 2E). The workgroup strongly supported additional research. But, although the workgroup endorsed the “gold standard” of randomized-controlled trials (RCTs) in studies of discrete biochemical interventions

(such as medications), it also noted that evaluating certain care and support models in RCTs is not always feasible and may be a poor method of learning from and monitoring complex, real-world system change. Methods drawn from management science and epidemiology will often be more appropriate and should be prioritized and funded in those settings. There was also consensus on the need to test innovations and use research methods that promote quality care for all affected by ADRD at a population level, not just for the individual with ADRD. It should become possible to compare quality over time in a particular city or county and to compare across geographical areas.

During discussion on the success criteria, the workgroup highlighted that some studies may address more than one milestone, such as translational studies that also evaluate cost effectiveness of a particular intervention, reducing the potential number of overall studies needed. The workgroup also noted that a particular care or support intervention may require multiple replications in separate studies to be considered evidence based. The workgroup further noted that variations in treatment and support across populations of interest would be expected to affect many measures of quality, either directly or by altering the proportion of persons living at different stages of ADRD. Methods should be developed to monitor and account for these variations.

3.4. Strategy 3D on safety, dignity, and inclusive communities

The workgroup made several observations as it developed milestones for Strategy 3D, "Maintain the dignity, safety, and rights of people with Alzheimer's disease." First, the workgroup felt the existing strategy was far reaching and encompassed too many topics under the rubric of a single strategy. The workgroup also noted that, although it is implicit in some of the recommended milestones on safety (such as recommendations on emergency preparedness and transportation), the idea of creating and expanding communities inclusive of people with ADRD appeared to be missing and did not naturally fall under any specific existing strategy. As a result, the workgroup recommended revising strategy 3D to focus on the dignity and rights of people with ADRD and recommended a new strategy, 3F, "Identify and support efforts to build communities that are more inclusive and safe for persons with ADRD." The workgroup agreed the term "inclusive" was meant to describe the aspiration of communities effectively adapting to the needs of persons with ADRD, yet recognized the lack of an agreed-upon consensus of what such an effort entails, thus potentially limiting the work.

Within the realm of dignity and rights for the ADRD population, the workgroup also noted the inherent ambiguity of safety and risk assessments for persons with ADRD. The workgroup suggested an overarching commitment to

ensure reasonable autonomy for persons with ADRD, recognizing that bearing responsibility for decision making differs by decision. For example, the choice of what clothing to wear could be respected for many persons with cognitive impairment who could not otherwise bear the responsibility for deciding whether to have an invasive surgery.

4. Conclusion

Although much work needs to be done to achieve goals 2 and 3 of the National Plan by 2025, the workgroup believed that the recommended milestones included in [Tables 1 and 2](#) are a significant step toward changing how care and supports are provided for people affected by ADRD, their families, and their key family and friend caregivers.

RESEARCH IN CONTEXT

1. Systematic review: Pubmed and other searches were conducted to identify best practices in the care of individuals with Alzheimer's and the support of unpaid caregivers. Published state Alzheimer's plans and dementia plans from other countries were mined for policy ideas.
2. Interpretation: For the first time, a set of comprehensive milestones have been identified to achieve goals 2 (care) and 3 (support) of the U.S. national Alzheimer's plan—providing a comprehensive listing of what is needed by 2025 to ensure a high-quality care and support system for people with Alzheimer's and their families.
3. Future directions: The milestones could be improved with the development of a consensus in the field as to what is meant by "dementia-capable" and what specifically is needed for communities to be "inclusive" of individuals with dementia. The milestones could be strengthened with further research that results in identification of ways to prevent Alzheimer's and of biomarkers that aid in diagnosis.

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