



January 17, 2019

The Honorable Alex Azar
Secretary
U.S. Department of Health and Human Services
200 Independence Avenue, S.W.
Washington, D.C. 20201

via electronic submission to HP2030@hhs.gov

Dear Secretary Azar:

Thank you for the opportunity to comment on the proposed Healthy People 2030 (HP2030) national objectives for improving the health of all Americans. The measurable objectives established by the decades-long Healthy People initiative are serving to empower individuals, communities, and providers to improve health and health care systems. **We strongly support the three dementia specific objectives (DIA-2030-01, DIA-2030-02, and DIA-2030-03) and objectives highly relevant to reducing dementia risk (OA-2030-01) or improving health and safety among people living with dementia (OA-2030-02, OA-2030-03, OA-2030-04, OA-2030-05, OA-2030-06, OA-2030-07, and AHS-2030-R02). We propose two new objectives to improve quality of life among people living with dementia and their caregivers. We request that the Healthy People 2020 objective supporting geriatric certification, omitted from HP2030, be restored (OA-7).**

Taken together, these objectives would be consistent with the strategic plan of the Department of Health and Human Services (HHS),ⁱ in particular the Center for Medicare & Medicaid Services (CMS) vision, the Centers for Disease Control and Prevention (CDC) Healthy Brain Initiative Road Map, the Administration of Community Living (ACL) Alzheimer's Disease Supportive Services Program's grant funding prioritiesⁱⁱ, the National Institute on Aging (NIA) goals,ⁱⁱⁱ and the Office of the Assistant Secretary for Planning and Evaluation (ASPE) National Plan to Address Alzheimer's Disease.^{iv} In addition, these capitalize on recent updates to the Medicare Physician Fee Schedule that encourage dementia diagnosis and care planning (HCPCS 99483), the 2017 NIH "National Research Summit on Care, Services, Supports for Persons with Dementia and

Their Caregivers”ⁱ and the 2017 CMS “Behavioral Health Payment and Care Delivery Innovation Summit.”^v

Landscape

There are few more compelling or complex issues to confront our aging society, now and over the coming decades, than Alzheimer’s disease and other forms of dementia. These conditions impose enormous costs to our nation’s health, prosperity, and social fabric, costs that are skyrocketing. Based on the National Institute on Aging’s Health and Retirement Study (HRS), we know that the health system costs of caring for people with dementia in the United States are comparable to, and perhaps greater than, those for heart disease and cancer.^{vi} A recent analysis of HRS data revealed that average per-person health care spending in the last five years of life for people with dementia was more than a \$250 thousand dollars, 57 percent greater than costs associated with death from other diseases including cancer and heart disease.^{vii}

Today, more than 5.7 million Americans have dementia at an annual cost to our economy exceeding \$277 billion.^{viii} Alzheimer’s disease contributes to the deaths of at least 500,000 Americans each year, and it is the only leading cause of death in the United States for which there is no proven means of prevention, disease modification or cure.^{ix} If the current trajectory persists, 13.8 million Americans will have dementia in 2050 and total costs of care are projected to exceed \$1 trillion annually (inflation adjusted).^x The federal government, through Medicare and Medicaid payments, shoulders an estimated 70 percent of all such direct care costs.

The choice before our nation is not whether to pay for dementia; already, we are paying dearly. The question is how to best invest funds and capacity to maximize value for the American people. Fortunately, the federal response has been strong, wise and growing commensurate with the challenge. The National Institutes of Health will invest more than \$2.3 billion this year in research to prevent, treat and ultimately cure Alzheimer’s disease and other forms of dementia. The Food and Drug Administration is moving with alacrity to implement the 21st Century Cures Act to accelerate Patient Focused Drug Development, while clarifying the regulatory pathway for innovative disease modifying therapies aimed at Alzheimer’s disease.^{xi} CMS continues to encourage dementia detection, diagnosis and care planning, through pathways such as the Medicare Annual Wellness Visit’s cognitive assessment benefit and HCPCS 99483. CDC and the Alzheimer’s Association have developed the third in a series of Healthy Brain Initiative Road Maps to advance cognitive health as an integral component of public health. CDC is applying these public health tools to reduce the incidence of dementia while seeking to ensure that all Americans facing dementia have the most accurate and actionable information at the earliest appropriate opportunity to optimize use of evidence-based care and support programs.^{xii} Now, **HP2030 builds on that strong 2018 foundation with its vision of the coming decade.**

Given that some forms of dementia such as frontotemporal degeneration typically affect people younger than 65 and that as many as 200,000 people younger than 65 have Alzheimer's disease in particular (including many people with Down Syndrome and other forms of intellectual and developmental disabilities), it would be beneficial for the dementia objectives to apply across the age spectrum.

HP2030 Dementia-Specific Objectives

1. Objective DIA-2030-01, Increase the proportion of adults aged 65 years and older with diagnosed Alzheimer's disease and other dementias, or their caregiver, who are aware of the diagnosis

According to the CDC, "The earlier dementia is diagnosed, the sooner care can be provided. A formal diagnosis allows people living with dementia to have access to available symptomatic treatments and interventions, build a care team, participate in support services, and potentially enroll in clinical trials. They and their caregivers can set systems in place to better manage medications, receive counseling, and address the challenges of other chronic conditions. Additional advantages include planning for future financial and legal needs and end of life choices."^{xiii} Early and accurate diagnosis could save up to \$7.9 trillion in medical and care costs^{xiv} due to improved management of comorbid conditions and other costs of healthcare and caregiving.

It is not enough that the clinician records a diagnosis in the medical chart. The diagnosis must be conveyed in a timely, accurate, compassionate and actionable manner. The earlier in disease progression that the diagnosis is conveyed, the more cognitively able the individual will be to direct or participate in decision-making. Inclusion of the phrase "or their caregiver" in this objective should not be mistaken as endorsing clinical practices that withhold information from the patient, but rather to encourage caregivers to be included so they can better support the patient, particularly in cases where cognitive impairment has reached such an advanced stage as to make the patient unable to receive the diagnosis. To the greatest degree possible by medical training and advancement of diagnostic tools, it is important to have a differential diagnosis so that the individual, family, clinician and other decision-makers understand and can make choices tailored to the specific form of dementia. For example, care planning decisions may be influenced whether there are early stage Alzheimer's symptoms of memory impairment or early stage frontotemporal dementia symptoms of impaired interpersonal judgement. Clinical therapeutic decisions also benefit from a differential diagnosis since mistakenly prescribing Alzheimer's medications to a person with frontotemporal dementia poses substantial medical risk. When diagnosis is conveyed, all too often, it is done with neither compassion nor practical direction; many people report being ushered out of the exam room with only this information: "You have Alzheimer's. Here is a prescription that may help with some of the symptoms. Make an appointment to come back in six months for a check-up." Clinicians can and must be educated and supported to provide newly diagnosed patients and their families with a sense of hope, purpose and plan. As discussed in the ASPE National Plan to Address Alzheimer's Disease,

physicians often are not aware of resources available to patients for counseling, support, and information about next steps, so action is required to “educate physicians and other health care providers, direct services workers, and patients, families, and caregivers about support resources and services available to assist people with [Alzheimer’s Disease and related dementias], as well as their caregivers.”^{xv} CMS provides reimbursement for physicians to engage in meaningful care planning,^{xvi} the Health Resources Services Administration (HRSA) has fielded curriculum to educate clinicians on properly making and conveying diagnosis,^{xvii} and The Gerontology Society of America makes available a free online toolkit for clinicians to help them initiate conversations about brain health, detect and assess cognitive impairment, diagnose dementia, and provide post-diagnostic referrals for education and supportive community services for persons with dementia and their family caregivers.^{xviii}

A barrier to achieving HP2030 Objective DIA-2030-01 is the lack of uniformly accepted assessment and diagnostic tools for Alzheimer’s disease and other forms of dementia. The Medicare Annual Wellness Visit includes a cognitive assessment benefit,^{xix} but includes no standardized, evidence-based tools, or training for this exam. Instead, clinicians are asked to rely on their observations and on reports by patients and family. Objective DIA-2030-01 would be strengthened if CMS identified and adopted a uniform, reliable cognitive impairment detection tool or set of tools to incentivize clinicians to detect and diagnose Alzheimer’s disease and other forms of dementia in a timely, accurate, compassionate and actionable manner.

The LEAD Coalition recommends strengthening Objective DIA-2030-01 by amending it to read “Increase the proportion of adults aged 65 years and older with diagnosed Alzheimer’s disease and other dementias, or their caregiver, who are aware of the diagnosis *based on an increase in the number of providers using a uniform, reliable cognitive impairment tool or set of tools identified and adopted by CMS.*”

2. Objective DIA-2030-02, Reduce the proportion of preventable hospitalizations in adults aged 65 years and older with diagnosed Alzheimer’s disease and other dementias

People with Alzheimer’s disease and other forms of dementia have twice as many hospital admissions as those without dementia and at least a quarter of these admissions are preventable.^{xx} This is unsurprising given that diabetes, heart disease and other frequently occurring comorbid and complicating medical conditions require strict medication adherence, and lifestyle improvements made more challenging by dementia (such as exercise, diet and sleep). Guidelines for managing chronic conditions often fail to consider that patients may have dementia, and untrained family members and other informal caregivers are ill-prepared to recognize or address signs of deteriorating health from multiple conditions. Guidelines also rarely consider that “Dementia is one of the major causes of disability and dependency among older people worldwide.”^{xxi} nor that providing disability supports promote more enduring

independence and reduce personal and public costs associated with dementia. CMS is well positioned to advance Objective DIA-2030-02 by establishing continuum of care guidelines and tools to reduce preventable and costly hospital admissions. This is also consistent with the CDC's Healthy Brain Initiative Roadmap strategic objectives to improve professional care for people living with dementia.^{xxii}

The LEAD Coalition recommends that HHS use its authority to test comprehensive continuum of care guidelines to address care needs of people living with Alzheimer's disease and other forms of dementia modeled on the Programs of All-Inclusive Care for the Elderly (the PACE Program).^{xxiii} The PACE program long has been recognized for dramatically reducing preventable hospitalizations. This care continuum would be significantly less costly than the roughly \$3 billion per year that Medicare pays for preventable hospitalizations among people with dementia.^{xxiv}

The LEAD Coalition also recommends that HHS create a coverage and payment model that offers family caregivers evidence-based training and certification specific to dementia care, qualifying them to provide certain medically necessary services to reduce the proportion of preventable hospitalizations in adults aged 65 years and older with diagnosed Alzheimer's disease and other dementias. Our nation expects too much from dementia family caregivers and, notwithstanding excellent HRSA caregiver training initiatives,^{xxv} does too little to offer them the tools to meet these responsibilities: "Dementia caregivers shoulder more caregiving responsibilities than do other caregivers: they help with a wider variety of activities and spend more hours per week providing care. On average, dementia caregivers provide care for 28 hours per week. They assist in significantly more tasks than do other caregivers, including more Activities of Daily Living (ADLs) and more Instrumental Activities of Daily Living (IADLs). In addition, most dementia caregivers play an important role in guiding their loved one through the healthcare system and ensuring that they receive needed treatments. Moreover, two out of three dementia caregivers (67 percent) say they themselves perform medical/nursing tasks for their care recipient, and more than half of all dementia caregivers do these medical/nursing tasks with no prior training or preparation."^{xxvi}

3. Objective DIA-2030-03, Increase the proportion of adults aged 65 years and older with Subjective Cognitive Decline (SCD) who have discussed their confusion or memory loss with a health care professional

The LEAD Coalition is pleased that HP2030 includes a new third objective under the dementia category. This expansion clearly demonstrates increasing urgency, determination and effort to tackle this exceptionally challenging national health crisis.

It is likely that early therapeutic intervention will be the most promising avenue for slowing or arresting the progression of Alzheimer's disease and other forms of dementia. With proper training and tools (including validated clinical assessment tools,

guidance, and online training such as HRSA’s Alzheimer’s Disease and Related Dementias Curriculum and Caregiving Curriculum), health care professionals can detect when self-reported subjective cognitive decline (SCD) merits additional monitoring and testing, referral for early intervention clinical trials, and other health care planning. Clinicians adept at interpreting self-reports will serve as the frontline for detecting and referring participants for early intervention clinical trials. Criteria and training for this expertise could be highly beneficial for making Objective DIA-2030-03 more effective and measurable using the Behavioral Risk Factor Surveillance System (BRFSS). As explained in the CDC Healthy Brain Initiative 2018-2023 Roadmap on page 36: “The BRFSS is an established data collection tool used in every state, the District of Columbia, and the U.S. Territories. The BRFSS Cognitive Decline Module asks about subjective cognitive decline, the potential difficulties it may cause with everyday activities, and whether people have discussed their memory challenges with a healthcare professional. The companion Caregiver Module includes questions about caregiving status and the caregiving situation, care recipient’s health issues, and prospects for future caregiving needs. These two BRFSS modules offer states an efficient mechanism for collecting data that affords comparisons with other states. Past use of the data indicate they can be instrumental in communicating the impact of cognitive problems and caregiving to state leaders, and facilitate understanding of their relationship with other chronic health conditions and health behaviors.”

Normalizing conversations between healthcare professionals and their patients about baseline brain health and possible cognitive decline is important for driving adoption of dementia risk reduction public health strategies. It is equally important for developing and bringing to market for patients the disease-modifying therapies that could stop Alzheimer’s disease and other forms of dementia at the earliest stages, and for readying the clinician-patient relationship for any needed care planning discussions required by onset or progression of dementia.

HP2030 Dementia-Related Objectives

Healthy lifestyle. The diseases, such as Alzheimer’s, that eventually cause dementia begin to appear in the brain well before symptoms manifest. There is strong evidence that lifestyle changes can reduce risk and delay onset of symptoms.^{xxvii} Consequently, **the LEAD Coalition strongly supports HP2030 objectives related to nutrition and weight status, and physical activity, particularly the objective to increase the proportion of older adults with reduced physical or cognitive function who engage in light, moderate, or vigorous leisure-time physical activities (Objective OA-2030-01).** For objectives relating to healthy aging generally, as well as for objectives related to cognitive and physical disabilities, **(OA-2030-03, PA-2030-01, PA-2030-02, PA-2030-03, PA-2030-04)** it may be appropriate to highlight the value of aerobic and muscle strengthening activities.

Disease- and falls-related acute events and medication adherence. Additional objectives specific to older adults include reducing the rate of hospital admissions and emergency department visits for diabetes, pressure ulcers, pneumonia, urinary tract infections, and falls; and use of inappropriate medications.^{xxviii} Achieving each of these objectives becomes dramatically more challenging when the older adult has dementia. **The LEAD Coalition recommends that the cohort of older adults with dementia be considered separately, if possible, when measuring the progress of HP2030 objectives OA-2030-02, OA-2030-03, OA-2030-04, OA-2030-05, OA-2030-06, and OA-2030-07.** Because the healthcare system depends heavily on family and other informal dementia caregivers to prevent these harmful and costly events and assure correct medication adherence, we reiterate our earlier recommendation that CMS create a coverage and payment model that offers family caregivers evidence-based training and certification specific to dementia care, qualifying them to provide certain medically necessary services.

Telehealth. **The LEAD Coalition strongly supports inclusion of Objective AHS-2030-R02 to increase the use of telehealth to improve access to health services.** Care planning, psychotherapy and health risk assessment via telemedicine helps to improve quality of life for people with dementia, supports family caregivers, strengthens clinical practice, and reduces costs to federal and state health programs. People with dementia face additional challenges related to travel from home to medical offices, including difficulty driving and using public transportation. These challenges are all the more acute for people living in medically underserved rural and urban communities. Telehealth, while not a panacea, is a vital lifeline worthy of increased availability, utilization, quality of dementia-appropriate specialization.

Hearing Loss. **The LEAD coalition recommends that HP2020 Objective ENT-VSL-3.4 be restored in HP2030: “Increase the proportion of adults aged 70 years and older with hearing loss who use assistive listening devices.”** There is growing evidence that “Hearing aids may have a mitigating effect on trajectories of cognitive decline in later life. Providing hearing aids or other rehabilitative services for hearing impairment much earlier in the course of hearing impairment may stem the worldwide rise of dementia.”^{xxix}

HP2030 Proposed Additional Objectives

Quality of life for those with dementia: The LEAD Coalition is grateful for the strong consideration of Alzheimer’s disease and other forms of dementia in HP2030. National goals combined with commensurate plans, resources and evaluation are essential for strengthening systems of care to improve quality of life among individuals with dementia and their caregivers. Most people living with dementia spend only a fraction of their time in traditional healthcare settings or systems, in the functional role of being a patient. Most people with dementia live in community settings, often in their own homes. Their quality of life is influenced significantly by interactions with the healthcare system but even more dominantly by interactions with other individuals and institutions in their

community – neighbors and strangers they encounter in libraries, parks, banks and local shops, and places of worship. **The LEAD Coalition strongly recommends adding an objective to expand dementia friendly communities nationwide and evaluate their impact.**^{xxx}

Quality of life for caregivers: As noted throughout these comments, caregivers are essential to assure high quality, affordable support for individuals living with dementia. About 15.7 million family caregivers support Americans living with dementia, and many family caregivers experience dramatic negative physical and psychological health consequences.^{xxxii} **The LEAD Coalition recommends addition of a HP2030 objective to target improvements in the quality of life for dementia caregivers, specifically addressing detection of and reduction in rates of depression, injury and self-neglect.**

Geriatric training. The LEAD Coalition is disappointed by the omission from HP2030 of Healthy People 2020 (HP2020) Objective OA-7, Geriatric Certification, and its subobjectives to increase the proportion of the health care workforce with geriatric certification. As more Americans look toward living longer lives, healthcare workforce capacity must be expanded to provide high-quality, safe, and coordinated care to older adults. To address the acute and growing nationwide shortage of geriatricians and all geriatrics healthcare professionals,^{xxxii xxxiii} **the LEAD Coalition recommends that HP2020 Objective OA-7 be restored in HP2030 and that an additional objective be added to the Older Adults topic area as follows:**

Ensure that healthcare providers across all specialties have training that prepares them to meet the unique healthcare needs of older people. Data sources: the Geriatrics-for-Specialists Initiative (GSI) and the Grants for Early Medical/Surgical Specialists' Transition to Aging Research (GEMSSTAR) program,^{xxxiv} along with the American Geriatrics Society Geriatrics for Specialist Initiative "Geriatrics Education for Specialty Residents Program (GSR)."^{xxxv}

Conclusion

Healthy People 2030 is a thoughtfully constructed road map for achieving better health care for people of all ages and socioeconomic levels. We stand ready and eager to advise in our areas of expertise as this draft moves toward completion. Thank you for considering our views and for your commitment to better supporting people with dementia. Please contact Ian Kremer, executive director of Leaders Engaged on Alzheimer's Disease (LEAD Coalition)^{xxxvi} at ikremer@leadcoalition.org or 571-383-9916 with questions or for additional information.

Sincerely,

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ACT on Alzheimer's
ActivistsAgainstAlzheimer's Network
African American Network Against Alzheimer's
Aging Life Care Association®
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Alliance for Aging Research
Alliance for Patient Access
Alzheimer's & Dementia Alliance of Wisconsin
Alzheimer's Drug Discovery Foundation
Alzheimer's Foundation of America
Alzheimer's Los Angeles
Alzheimer's Mississippi
Alzheimer's New Jersey
Alzheimer's Orange County
Alzheimer's San Diego
Alzheimer's Tennessee
Alzheimer's Texas
American Association for Geriatric Psychiatry
American Brain Coalition
American Geriatrics Society
American Medical Women's Association
American Society of Consultant Pharmacists (ASCP)
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Caregiver Voices United
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Mount Sinai Center for Cognitive Health

National Alliance for Caregiving

National Asian Pacific Center on Aging

National Association of Activity Professionals

National Association of Area Agencies on Aging (n4a)

National Association of Chronic Disease Directors

National Association of Counties (NACo)

National Association of Nutrition and Aging Services Programs

National Association of State Long-Term Care Ombudsman Programs (NASOP)

National Association of States United for Aging and Disabilities

National Caucus and Center on Black Aged, Inc. (NCBA)

National Certification Council for Activity Professionals

National Committee to Preserve Social Security and Medicare

National Consumer Voice for Quality Long-Term Care

National Council for Behavioral Health

National Down Syndrome Society

National Hospice and Palliative Care Organization (NHPCO)

National Task Group on Intellectual Disabilities and Dementia Practices
NFL Neurological Center
Noah Homes
NYU Alzheimer's Disease Center
NYU Langone Center on Cognitive Neurology
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The Evangelical Lutheran Good Samaritan Society
The Michael J. Fox Foundation for Parkinson's Research
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WomenAgainstAlzheimer's
Women's Brain Health Initiative
Women's Brain Project

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- xxxv <https://onlinelibrary.wiley.com/doi/full/10.1111/jgs.14966>
- xxxvi <http://www.leadcoalition.org> Leaders Engaged on Alzheimer's Disease (the LEAD Coalition) is a diverse national coalition of member organizations including patient advocacy and voluntary health non-profits, philanthropies and foundations, trade and professional associations, academic research and clinical institutions, and home and residential care providers, and biotechnology and pharmaceutical companies. The LEAD Coalition works collaboratively to focus the nation's strategic attention on dementia in all its forms -- including Alzheimer's disease, vascular disease, Lewy body dementia, and frontotemporal degeneration -- and to accelerate transformational progress in detection and diagnosis, care and support, and research leading to prevention, effective treatment and eventual cure. One or more participants may have a financial interest in the subjects addressed.