

National Prevention Goal: Frequently Asked Questions

1. Why does the United States need a national prevention goal for Alzheimer's disease and related dementias?

- The U.S. needs a national prevention goal because the unique cognitive, physical, psychological, and economic burdens of Alzheimer's disease and related dementias (ADRD) on families and the healthcare system demands action that is long overdue.
- Alzheimer's disease is a public health crisis that is expanding as our nation ages, with a projected increase to nearly 14 million people living with the disease in the U.S. by 2050. Communities of color and women bear a disproportionate burden. Without early intervention and treatment, the cumulative care costs are projected to exceed \$20 trillion over the next 30 years.
- Emerging science points to the ability to reduce dementia risk and slow the rate of cognitive decline as people age through early detection and nonpharmacological and pharmacological interventions across the lifespan, particularly in midlife and at the earliest pre-dementia stages. Studies indicate more than a third of dementia cases are potentially preventable by addressing risk factors including treatment of hypertension, exercise, social engagement, education, smoking, hearing loss, depression, diabetes, and obesity. Addressing these social determinants of brain health is especially critical for Black Americans and Latinos who experience greater risk for Alzheimer's compared to non-Latino Whites.
- There are far-reaching benefits of this effort. Research shows dementia seems to be tightly connected to other chronic conditions. A national prevention strategy to reduce dementia risk offers a unique opportunity to mobilize clinical, policy, and public health efforts to reduce diabetes, hypertension, tobacco use, and depression, particularly among communities of color.
- Identifying clear, measurable targets can be an effective way to propel change and accountability, just as our nation has done for other health challenges such as tobacco, heart diseaseⁱ and kidney disease. These goals can spur advancements in clinical practice, public health, research, and health equity.
- It is time to show there are steps that our nation can take to reduce the risk of Alzheimer's and dementia, delay onset, and promote brain health. It is time to replace despair and disappointment with determination and hope. It is time to show there are steps that our nation can take to reduce the risk of Alzheimer's and dementia, delay onset, and promote brain health.
- Establishing a goal sends a strong message that there are things we can do, and cognitive decline is not an inevitable part of aging.

2. What difference would a national goal make?

- A clear prevention "north star" will benefit families, society, economy and our nation.

- For example, a 30 percent reduction in the prevalence of Alzheimer's disease and related dementias (ADRD) over 10 years would mean 2.5 million fewer people living with this terrible disease and its symptoms.
- Even a five-year delay would cut dementia prevalence in half. It would also reduce total healthcare payments 33 percent and out-of-pocket payments 44 percent in 2050 if achieved by 2025. For individuals age 70 and older, even a one-year delay would reduce total healthcare payments 14 percent in 2050; a three-year delay would reduce total healthcare payments 27 percent; and a five-year delay would reduce healthcare payments 39 percent.
- Preventing or delaying dementia will reduce financial pressure on the healthcare system and lower costs to public programs such as Medicare and Medicaid. It will also decrease the cognitive, physical, psychological, and economic burdens caused by Alzheimer's symptoms, which often last more than a decade, on those living with the disease and their families; improve quality of life for individuals of all ages; and increase the likelihood that adults can thrive and remain independent into their later years.

3. What evidence or examples exist that demonstrate setting a goal would be smart?

- Establishing dementia prevention as a clinical and research priority with measurable, time-bound targets will build on current efforts and drive changes in clinical practice, public health, research, and innovation – just as our nation has done for heart disease, kidney disease, and other health challenges, such as tobacco use.
- For example, the Million Hearts Campaign – led by the Centers for Disease Control and Prevention and the Centers for Medicare and Medicaid Services – set out to prevent 1 million heart attacks and strokes in the United States over the course of five years. Using a set of care delivery incentives such as quality measures, Electronic Health Record (EHR) incentive programs, public health strategies, and practice innovations, about 115,000 cardiovascular events were prevented during the first two years of the four-year initiative. It is estimated that up to half a million heart events may have been prevented from 2012 through 2016.
- While deaths from other major chronic diseases, such as heart disease, have decreased, the number of deaths from Alzheimer's disease have been increasing exponentially.
- The national prevention goal for Alzheimer's disease and related dementias (ADRD) should be ambitious but achievable. It should be timebound, and must include a roadmap to guide the efforts, metrics to measure progress along the way, and a focus on healthcare equity that recognizes the disproportionate impact of ADRD on communities of color and women.
- Setting this national prevention strategy to reduce dementia risk offers a unique opportunity to mobilize clinical, policy, and public health efforts to reduce diabetes, hypertension, tobacco use, and depression, particularly among communities of color.

4. How and who would set this goal, and who would be accountable for achieving it?

- A national goal should be set by Congress, the White House, the Secretary of Health and Human Services, and other public health leaders with the input, expertise, and collaboration of a broad range of patient advocates and experts.
- A specific, time-bound national prevention goal should be directed in statute or by accountable executive action that drives public-private collaboration around an accountable process and measurable action steps to achieve it.

5. Why is health equity essential to achieving this national goal?

- Communities of color and women bear a disproportionate burden and are at the center of the Alzheimer's public health crisis. This is due to a range of factors, including comorbidities such as heart disease and diabetes, as well as social determinants of health, such as lagging educational attainment, exposure to air pollution, and income inequality.
- Black Americans are twice as likely as non-Hispanic whites to develop the disease, and Latinos are 1.5 times more likely. Women also are especially impacted, comprising two-thirds of those living with Alzheimer's and 60 percent of all caregivers.
- By 2030, if left unaddressed, nearly 40 percent of all Americans living with Alzheimer's will be Black or Latino. This disparity is compounded by other significant gaps in diagnosis rates and access to treatments, care, and cutting-edge research.
- In addition, women are twice as likely to develop Alzheimer's as men. Black and Latina women are further disproportionately affected.
- Women also pay the majority of the direct cost of Alzheimer's. It is estimated that women bear 80 percent of the disease's total economic burden, including medical costs, elder care, and assisted living.
- Driving equity must be at the center of this effort if we are to succeed, which means designing a national prevention goal that is built to address disparities and advance health equity and access to Alzheimer's health services, research, and prevention strategies.

6. Can we really “prevent” Alzheimer's and other dementias? What is the difference between “risk reduction” and “prevention”?

- Rapidly advancing science points to the ability to reduce dementia risk and slow the rate of cognitive decline as we age. Scientific evidence is promising, and there is real hope to reduce the risk of dementia and slow the progression towards cognitive impairment by making key lifestyle changes, such as consuming a healthy diet, participating in physical and cognitive activities, and maintaining overall good heart health by reducing blood pressure and managing blood lipids.
- An NIH-funded study led by Dr. Klodian Dhana of Rush University Medical Center reported that individuals who adhere to a healthy lifestyle have a 60 percent lower risk of Alzheimer's dementia compared with people who did not follow a healthy lifestyle. These lifestyle factors include exercising at least 150 minutes a week, engaging in cognitive

activities such as reading newspapers, writing letters, playing puzzles and games, consuming a brain-healthy diet, and not smoking.

- The results from a comprehensive randomized clinical trial, the FINGER study, indicate that rigorous lifestyle modifications, including diet, physical activity, cognitive training, social activities, and monitoring and management of metabolic vascular risk factors, can improve or maintain cognitive functioning in at-risk older adults.
- In addition, the SPRINT MIND study found that people with hypertension who received intensive treatment to lower systolic blood pressure were less likely to develop memory problems that often progress to dementia than those who were receiving standard blood pressure treatment.
- A growing number of government organizations and advisory groups are increasingly aligned in the position that it is possible to reduce the risk of dementia, including the World Health Organization, the Lancet Commission, the American Heart Association, and the Centers for Disease Control and Prevention.

7. Would adopting such a goal detract from efforts to find a cure?

- No. Research must continue into promising disease-modifying drug therapies to treat Alzheimer's and its symptoms for patients in the early and later stages of dementia. But to truly reduce the number of people impacted by this devastating disease, our nation must also build on concrete research findings demonstrating that public health interventions and lifestyle modifications may prevent or delay the onset of Alzheimer's and related dementias and disrupt progression of mild cognitive impairment.

8. What actions can individuals take to achieve the goal?

- The fact that cognitive decline is not inevitable means there are steps that people can take to reduce the risk of Alzheimer's and dementia, possibly delay onset, and promote brain health.
- Emerging science points to the ability to reduce dementia risk and slow the rate of cognitive decline as people age through early detection and nonpharmacological and pharmacological interventions across the lifespan, particularly in midlife and at the earliest pre-dementia stages.
- Promising scientific evidence shows that people can reduce the risk of dementia and slow the progression towards cognitive impairment by making key lifestyle changes. These include steps such as consuming a healthy diet, participating in physical and cognitive activities, and maintaining overall good heart health by reducing blood pressure and managing blood lipids.
- We understand from market research that most Americans don't know the steps they can take to care for their brains but want to learn more. We also know that the topic of cognition is largely absent from our conversations with providers and loved ones and it is time to change that. Having national attention around a prevention goal can help bring about those conversations.

9. What actions can government and non-governmental organizations take to achieve a goal?

- Federal resources -- including funding, regulation, innovation, and information -- can all be marshaled more effectively toward a national goal of preventing Alzheimer's disease and related dementias (ADRD). A national goal also could help to drive additional resources and accountability.
- In terms of federal funding, the National Institutes of Health should include significantly higher budgets for prevention and translational research at the National Institute on Aging (NIA), the National Center for Advancing Translational Science (NCATS), and other institutes such as the National Institute of Neurological Disorders and Stroke (NINDS) and the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK). In addition, the Centers for Disease Control and Prevention Healthy Brain Initiative offers a national framework for public health action, charting a course for state and local public health agencies and partners. The Healthy Brain Road Map, which is currently underfunded, could be an essential component of any national strategy to reach a collective destination – reducing the number of people living with ADRD. Funding for improved surveillance and epidemiology, in coordination with efforts underway at NIH and opportunities for improved data collection via the Centers for Medicare and Medicaid Services, such as the Medicare Current Beneficiary Survey, would be important to improve our ability to measure and track progress, particularly for communities of color.
- Federal regulations can be revised to put more focus on prevention and expand strategies that leverage risk-reduction. For example, a concerted national dementia prevention and detection strategy is needed at CMS. Harnessing the financing power of Medicare and Medicaid is essential to incentivizing risk-reduction within the healthcare delivery system. The Department of Health and Human Services has within its authorities at CMS significant opportunity to encourage providers and payers to proactively address brain health among non-symptomatic, healthy older adults and to strengthen early detection and interventions that delay disease progression. For example, CMS could implement quality measures and incentives for providers and plans.
- The Annual Wellness Visit was added as a preventive Medicare benefit in 2010 under the Affordable Care Act, but CMS continues to allow providers to rely on subjective assessment measures. Several studies have been conducted that demonstrate physicians often miss the diagnosis of dementia until it is too advanced to do anything about it: estimates range from a low of 26 percent missed to a high of nearly 79 percent. CMS should specifically reference the use of standardized assessment tools.
- We must invest in community health centers to increase their capacity to respond to Alzheimer's and related dementias in underserved communities, building out the capillaries of Alzheimer's related health services and research.
- Health providers and consumers lack the information and resources they need to support brain health. Nine in 10 primary care physicians say they want more guidance on nearly all aspects of the brief cognitive assessment process. This knowledge gap

adds to a common misperception among providers and the public that there is nothing that can be done. Setting a national prevention goal would change this narrative.

- At the same time, efforts should be made to eliminate barriers to existing cognitive health benefits for underrepresented beneficiaries by addressing access gaps to tailored communications and health provider education. In addition, federal agencies have opportunities to integrate brain health information into existing chronic disease efforts such as Million Hearts, the Diabetes Prevention Program, CMS' MedLearn, and Health Resources and Services Administration training initiatives.

10. How can the nation measure progress towards this goal?

- A very specific, measure able goal should be set – for example, a 30 percent reduction in the prevalence of Alzheimer's disease and related dementias (ADRD) by 2030 to drive urgency, focus, and resources. Achieving this goal would spare an estimated 2.5 million people the tragedy of ADRD over the next decade.
- Accurate and frequent estimates of the number of people with ADRD at various stages and trends are essential to measure progress against a quantifiable goal. Population prevalence estimates are also critical for public policy development, evaluating the impact of risk reduction interventions, understanding and addressing health disparities, and preparing health and long-term care systems. In the absence of dementia tracking through a national screening program, the main sources for estimating dementia in the U.S. currently are nationally and regionally representative surveys and process of care data such as healthcare claims and health records.
- Increasing attention on basic public health surveillance should be a top priority and incorporated as a key component of a plan to reduce prevalence. Several areas of data collection and interpretation require strengthening: improvement of research methods used in data collection and interpretation; development of a consensus about valid coding of dementia for administrative databases; development of flexible approaches that take into account the variation in place and over time of health and social conditions that might lead to severe cognitive impairment; national samples of adults younger than 65; more accurate racial, ethnic, and gender epidemiological data; and more accurate measurements of the prevalence of all stages, including the earliest stages, of cognitive decline and dementia.
- It also would be useful to better understand how incidence and duration are contributing to prevalence, ideally at each stage.

11. Would pushing back the age of onset actually compress morbidity (i.e., reduce the number of years a person lives with illness) or would it be the same because people would live longer?

- Actuarial data show that a five-year delay would cut dementia prevalence in half. It would also reduce total healthcare payments 33 percent and out-of-pocket payments 44 percent in 2050 if achieved by 2025. For individuals age 70 and older, even a one-year delay would reduce total healthcare payments 14 percent in 2050; a three-year delay would reduce total healthcare payments 27 percent; and a five-year delay would reduce healthcare payments 39 percent.

12. How does a National Prevention Goal fit into other efforts currently underway to fight Alzheimer's disease and related dementias?

- Our nation cannot waver from its drive to find effective treatments and curing Alzheimer's disease and related dementias, and research must continue into promising disease-modifying drug therapies to treat Alzheimer's and its symptoms for patients in the early stages of dementia.
- This includes continued expanded federal spending for Alzheimer's research through the National Institutes of Health. Congress has increased this research spending from \$440 million a year a decade ago to \$2.8 billion in FY21, and additional funding is still needed for research on treatments and prevention.
- In addition to finding effective treatments, our nation must place greater emphasis on preventing it in the first place. To truly reduce the number of people impacted by this devastating disease, our nation must build on the concrete research findings showing that public health interventions and lifestyle modifications may prevent or delay the onset of ADRD and disrupt progression of mild cognitive impairment.

13. How does this effort for a new national prevention goal interplay with NAPA, which set a 2025 goal for preventing or effectively treating Alzheimer's?

- The National Alzheimer's Project Act (NAPA), signed into law in 2011, established a national goal to prevent and effectively treat Alzheimer's disease by 2025. The national advisory council for that effort has shepherded the national strategy to reach the 2025 goal, with yearly updates as required by law.
- The NAPA Council should include a specific national prevention goal in the plan update recommendations it sends to Congress and the Secretary of Health and Human Services (HHS) this year. This is consistent with the spirit and letter of the law and will help to ensure focus and accountability on strategies that both aim to cure and prevent Alzheimer's disease and related dementias (ADRD).
- At the same time, for a national goal to be effective, it must be supported by the White House, Congress, and a wide range of health, aging, and other public health organizations committed to preventing ADRD.

14. Would this national prevention goal have any additional benefits beyond Alzheimer's and dementias?

- Yes. There are far-reaching benefits that can result from this national prevention goal, given that research shows dementia seems to be tightly connected to other chronic conditions.
- A national prevention strategy to reduce dementia risk offers a unique opportunity to align clinical, policy, and public health efforts to reduce diabetes, hypertension, tobacco use, and depression, particularly among communities of color.

- That's one of the reasons supporters of this national prevention goal include organizations such as the National Kidney Foundation, YMCA of the USA, the American Public Health Association, Association of State and Territorial Health Officials, and the National Association of Chronic Disease Directors.

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¹ Benjamin, Regina M. "The million hearts™ initiative: progress in preventing heart attacks and strokes." *Public health reports (Washington, D.C. : 1974)* vol. 127,6 (2012): 558-60. doi:10.1177/003335491212700602<<https://millionhearts.hhs.gov/files/MH-meaningful-progress.pdf>>