

# The Los Angeles County Strategic Plan for Alzheimer's Disease and Related Dementias

2023-2028

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# **EXECUTIVE SUMMARY**

In 2020, the Los Angeles County Department of Public Health (Public Health) established the Los Angeles County BOLD Initiative (LA BOLD), with the purpose of convening a coalition to develop a strategic plan for improving dementia care and support in Los Angeles County. With assistance from the Los Angeles County Aging and Disabilities Department, Public Health launched the Healthy Brain LA Coalition in the Summer of 2021. The Coalition comprises representation from local area agencies on aging, health care organizations, health plans, institutions of higher learning, and community-based organizations that support older adults with dementia and their caregivers. Together, the Coalition developed the Los Angeles County Strategic Plan for Alzheimer's Disease and Related Dementias, 2023-2028 (Strategic Plan). The Strategic Plan and its recommended actions were designed to align with the priorities of the Centers for Disease Control and Prevention's *Healthy Brain Initiative Road Map Series*.

The Strategic Plan addresses three focus areas that were identified as both high priority and ripe for action:

- Hypertension Prevention and Management
- Early Detection
- Advance Care Planning

Each focus area includes a range of strategies and activities addressing the following four domains:

- Policy and Systems
- Education
- Health Care Workforce Capacity
- Caregiver Services and Supports

The Strategic Plan serves as a practical guide for addressing the complex issue of dementia in Los Angeles County, using a health equity lens to shape and plan the next steps for this effort. The following report presents an overview of the local dementia landscape, describes the strategic planning process, and the Strategic Plan.

# ACKNOWLEDGEMENTS

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# A. INTRODUCTION

# 1. Background

Dementia, which includes Alzheimer's disease and other types of dementia, has a profound physical, psychological, social, and economic impact on those living with the condition, as well as on their caregivers, families, and society at large.<sup>1</sup> As the population ages, the impact of dementia is expected to grow. An estimated 6.5 million Americans aged 65 years and older have dementia caused by Alzheimer's disease alone.<sup>2</sup> While increasing age remains the strongest risk factor for this condition, it is not exclusive to older adults. An additional 200,000 people under the age of 65 are thought to have younger-onset dementia.

Dementia does not affect all communities equally. Certain populations including women and racial/ethnic minorities such as African American and Latino communities, are disproportionally impacted by this condition. For example, African American people are twice as likely, and Latino people are one and a half times more likely than White people to have dementia. While the causes of these disparities are complex, there have been many advancements in research related to risk factors that can be modified to reduce the risk of this condition. Notably, undermanaged comorbidities, such as high blood pressure and diabetes, and unmet social needs prevalent in many communities of color, have been shown to contribute to an increased risk for dementia.<sup>2,3,4</sup> Nonetheless, there remains an overall lack of awareness and understanding of dementia that can lead to stigmatization and barriers to diagnosis and early care.<sup>1</sup>

# DEMENTIA

Dementia is a term that describes the loss of cognitive abilities like thinking, remembering, and reasoning to the extent that it interferes with daily life.<sup>5</sup>

Although Alzheimer's disease is thought to be the most common type of dementia, there are many others including vascular dementia, frontotemporal degeneration, dementia with Lewy bodies, Creutzfeldt-Jacob disease, and mixed dementia, to name a few.

This strategic plan aims to support people with any type of dementia as well as their caregivers and families.

# 2. Building Our Largest Dementia (BOLD) Infrastructure

In an effort to address the growing burden of dementia, the Building Our Largest Dementia Infrastructure for Alzheimer's Act (BOLD Act) was passed into law by the United States Congress on December 31, 2018.<sup>6</sup> The BOLD Act was designed to support the development of a uniform national public health infrastructure that could effectively implement the Centers for Disease Control and Prevention's (CDC's) *Healthy Brain Initiative State and Local Public Health Partnerships to Address Dementia: The 2018-2023 Road Map* and the *Healthy Brain Initiative Road Map for Indian Country.* In accordance with this legislation, CDC established the *BOLD Public Health Program to Address Alzheimer's Disease and Related Dementias* which provides funding to 18 recipient communities to help develop or update a local dementia-focused strategic plan using the Road Map series as a guide (Core Capacity). The program also provides 5 recipients with funding to implement dementiarelated activities (Enhanced). In 2020, the Los Angeles County Department of Public Health (DPH) was selected for a Core Capacity award and established *the Los Angeles County BOLD Initiative* (LA BOLD).

# 3. The Healthy Brain LA Coalition

As part of LA BOLD, DPH established the Healthy Brain LA (HBLA) Coalition. Through the development of a dementia-focused strategic plan, the Coalition aims to drive forward a cohesive agenda that positions dementia as a top public health issue in Los Angeles County. The Coalition is led by DPH and the Los Angeles County Aging and Disabilities Department (previously known as the Los Angeles County Department of Workforce Development, Aging and Community Services) and brings together a group of diverse stakeholders committed to promoting brain health and improving the lives of people living with dementia, their caregivers, and their families.

# VISION

A Los Angeles County that prioritizes dementia risk reduction and ensures equitable care for people living with dementia and their caregivers.

# MISSION

The Healthy Brain LA Coalition serves as a unified voice in providing meaningful support to people living with dementia and their caregivers by increasing awareness, promoting dementia risk reduction behaviors, and advancing early detection strategies. Coalition membership includes representatives from multiple sectors with expertise in areas such as dementia care, geriatrics, mental health, health services delivery, policy development and adoption, and research. The Coalition comprises a Steering Group and an Advisory Council, with the former serving as the core group that guides the Coalition's efforts and provides logistics support. The Advisory Council serves as the subject matter experts tasked with developing actionable strategies and activities.

# 4. Dementia in Los Angeles County

Los Angeles County is the most populous county in California. It is home to approximately 10 million residents, spanning more than 4,000 square miles of urban, suburban, and rural areas. In 2019, more than 166,000 Los Angeles County adults aged 65 and older were living with Alzheimer's disease – the most common type of dementia; this number is expected to rise by 150% in 2040, likely affecting over 405,000 people in the region.<sup>7</sup> Similar to national trends, Alzheimer's disease, does not affect all communities equally in the county of Los Angeles. When examined by race and ethnicity, it is estimated that 47,422 Latino people and 13,962 Black people are living with Alzheimer's disease in the region (**see Table 1**).<sup>7</sup> Between 2019 and 2040, these numbers are expected to increase by 223% and 153%, respectively.

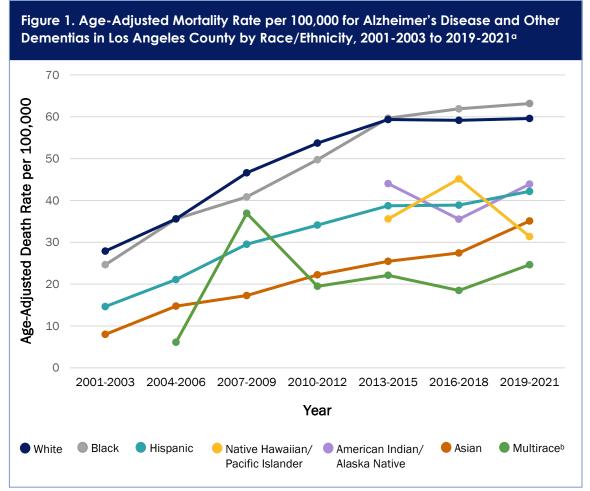
Disease by Race/Emnicity in Los Angeles County, 2019 and 2040"			
Race/Ethnicity	2019	2040	% Change
Non-Latino White/Caucasian	72,055	142,764	98%
Asian American/Pacific Islander	31,245	68,225	118%
Black/African American	13,962	35,341	153%
Other	2,173	6,072	179%
Latino	47,422	152,980	223%

Table 1. Estimated Number and Percent Change in People 65+ with Alzheimer's Disease by Race/Ethnicity in Los Angeles County, 2019 and 2040°

<sup>a</sup> Data Source: Alzheimer's Disease and Related Dementias Facts and Figures in California: Current Status and Future Projections Report.

In 2021, dementia was the third leading cause of death in Los Angeles County, accounting for over 6,200 deaths.<sup>8</sup> Based on national and local trends data, these numbers will continue to increase in the next decade.

For example, from 2008 to 2017, the Alzheimer's disease mortality rate in Los Angeles County increased by 71%, the largest increase of any disease during that time.<sup>9</sup> In Antelope Valley, the county's most rural region, the age-adjusted Alzheimer's disease mortality rate was 70 per 100,000, far higher than the overall county rate of 38.7 per 100,000. The mortality rate has also continued to climb across all racial and ethnic groups in Los Angeles County over the last two decades (**see Figure 1**). Between 2019 and 2021, the age-adjusted death rate for dementia was highest among African American/Black people (63.2 per 100,000), followed by White people (59.6 per 100,000), American Indian people (43.9 per 100,000) and Latino people (42.2 per 100,000).<sup>8</sup>



<sup>a</sup> Data Source: California Community Burden of Disease and Cost Engine Tool <sup>b</sup> Not reliable due to changing data collection practices

According to the California Health Interview Survey, in 2019-2020, an estimated 1 in 5 caregivers (322,800) provided care for people with dementia or cognitive impairment in Los Angeles County.<sup>10</sup> Although these caregivers were demographically diverse, the largest portion were women (59%), married or living with a partner (55%), Latino/Hispanic (44%), and between the ages of 50-64 years of age (32%).

Caregivers of people living with dementia often shoulder more responsibility and provide greater assistance with activities of daily living, such as eating, bathing, and dressing as compared to other caregivers. On average, caregivers of adults with dementia and cognitive impairment in Los Angeles County provided more hours of care per week (18.7) than caregivers of those without these conditions (13.2). Caregiving can also take an emotional and financial toll. Among caregivers of adults with dementia and cognitive impairment,61% reported extreme financial stress, 18% suffered physical and mental health problems, and 27% reported a change in job status as the result of caregiving.

# LOS ANGELES COUNTY CAREGIVER PROFILE **ADULTS PROVIDED CARE TO** 322,880 **PEOPLE WITH DEMENTIA AND** COGNITIVE IMPAIRMENT AMONG THESE CAREGIVERS: 32% **59**% were Latino/Hispanic were female were between ages 50-64 27% 18% 61% suffered physical experienced some reported a change level of financial in job status and/or mental health problems stress due to due to caregiving caregiving

# B. DESIGNING A PLAN FOR LOS ANGELES COUNTY

# 1. Goal and Guiding Principles

Using a public health approach, the HBLA Coalition set out to develop a 5-year strategic plan that would offer institutions across Los Angeles County (e.g., government entities, health systems, community organizations) a guide for implementing actionable changes to address the growing impact of dementia. In alignment with the *National Healthy Brain Initiative 2018-2023 Road Map*'s Conceptual Framework, the following core principles guided the strategic planning process.<sup>11</sup>

- Eliminate health disparities & promote health equity
- Collaborate across multiple sectors
- Leverage resources for sustained impact

Furthermore, an important consideration in the development of the strategic plan was the disproportionate impact of dementia across populations. These populations include, but are not limited to:

- African American
- Latino
- Asian/Pacific Islander
- People with Intellectual or Developmental Disabilities
- Rural Communities (e.g., Lancaster, Palmdale)

# 2. The Process

The strategic planning process was carried out in three phases. Each phase built upon one another and expanded the number of stakeholders engaged in the process. This approach was chosen to optimize project efficiency, while ensuring the Strategic Plan incorporated a diverse range of expertise and perspectives.

# Phase I: Establish Strategic Plan Framework

The first phase of the process began by convening the HBLA Coalition Steering Group in a series of monthly meetings between June 2021 – December 2021 to discuss key priorities and challenges related to dementia care in Los Angeles County. As part of these discussions, the Steering Group reviewed available data and literature, examined existing and complementary dementia and aging initiatives, and identified potential focus areas for implementation in the next five years. As a result, the Steering Group established a

framework that would be used to guide the development of the Strategic Plan. The framework includes three focus areas that address each of the three public health levels of prevention and were identified as both high priority and ripe for action – hypertension prevention and management, early detection, and advance care planning. Each focus area is addressed through four domains: policy and systems; education; health care workforce capacity; and caregiver services and supports. See section *B3. Strategic Plan Framework* for additional details regarding the framework, including selection rationale for the focus areas and domains.

# ALIGNING FOCUS AREAS TO PUBLIC HEALTH LEVELS OF PREVENTION

#### Primary Prevention – Hypertension Prevention and Management

Primary prevention aims to prevent disease before it happens. *Hypertension Prevention and Management* focuses on preventing and managing hypertension which is a risk factor that can contribute to dementia later in life.

#### Secondary Prevention – Early Detection

Secondary prevention aims to identify and manage disease before it progresses or becomes serious. *Early Detection* focuses on identifying dementia early and providing services that may slow the progression and can improve outcomes for persons with dementia, their caregivers, and families.

#### **Tertiary Prevention – Advance Care Planning**

Tertiary prevention aims to minimize disease-related complications. *Advance Care Planning* focuses on ensuring that persons living with dementia receive the care that aligns with their wishes and values, so that their quality of life is maximized as dementia progresses.

#### Phase II: Draft a Strategic Plan

The second phase of the process occurred between January 2022 – August 2022. During this time, HBLA Coalition members (Steering Group and Advisory Council) were assigned to one of three Work Groups – hypertension prevention and management, early detection, and advance care planning – based on their area of expertise.

Each Work Group, led by a subject matter expert, met three times to engage in targeted discussions that informed the development of the Strategic Plan objectives, strategies, and activities. The Work Group meeting sessions yielded a draft of the Strategic Plan, including strategies and activities related to surveillance and implementation. The draft was presented and discussed with HBLA Coalition membership for feedback and review.

#### Phase III: Gather External Input & Finalize Plan

The third phase of the process took place between August 2022-January 2023. During this phase, additional data was gathered on key topic areas and community feedback was solicited. In addition, the team received input from the Public Health Center of Excellence on Dementia Caregiving and the City of Pasadena Public Health Department. The information and feedback was then incorporated into the Strategic Plan, which was presented to HBLA Coalition membership for final review and approval.

#### Additional Data

To help identify leverage points for sustainably integrating early detection of dementia and care in Los Angeles County, a team from the University of Southern California Keck School of Medicine completed a two-part landscape analysis. The landscape analysis consisted of (a) an examination of existing national public health guidance, opportunities for early detection of dementia, and relevant findings from a review of California state policies and initiatives; and (b) surveys and interviews with key stakeholders from four interacting sectors: public health, aging services, social services, and health services. The analysis produced four specific recommendations:

- (1) Convene a series of working groups comprised of health system leaders and representatives to set policies, practices, and consensus data elements that prioritize early detection of dementia and enable quality assessment, improvement, and management.
- (2) Convene an expert working group in communications, to create public awareness and demand for brain health services, utilizing learning from successful public health campaigns.
- (3) Engage key stakeholders and agencies responsible for health care policy and reimbursement, to address care for people with dementia and their families, by working to expand eligibility for public funding for people with dementia and their caregivers, and enabling the Department of Aging and Disabilities to implement trainings and protocols for community service providers to recognize cognitive impairment and make triage decisions.
- (4) Establish a learning collaborative led by a core team to bring together representatives from four key sectors: health services, social services, aging services,

and public health to address the need for improving the quality, scope, and accessibility of data pertinent to dementia detection, care, and services, and create a repository for those data.

The full report can be accessed online.

To better understand the needs of caregivers in Los Angeles County, the University of Southern California Family Caregiver Support Center led a separate landscape analysis of caregiving in the region. The goal of the analysis was to identify, understand, and facilitate a thoughtful response to the diverse needs of caregivers of people with dementia in Los Angeles County. The analysis consisted of a series of semi-structured interviews with leading caregiver stakeholders, focus groups with caregivers, and an environmental scan of best practice models that could be used or expanded in Los Angeles County. Results were synthesized into three key recommendations:

- (1) Leverage existing infrastructure to strengthen and build family caregiver services and supports.
- (2) Promote health care payer, provider, and system recognition of and support for caregivers.
- (3) Increase respite services for caregivers.

The full report can be accessed online.

# Community Feedback

To provide an opportunity for community feedback and to understand how proposed strategies aligned with older adult and caregiver concerns and priorities, Ad Lucem Consulting conducted a series of 10 listening sessions held across the 5 Supervisorial Districts of Los Angeles County. A total of 92 people participated, including people with cognitive decline, adults aged 65 years and older, and caregivers. Sessions were either held in-person or virtually and were facilitated in English, Spanish, Korean, and English/Samoan. To minimize participant fatigue, each session concentrated on a single focus area. Each session was guided by a standard set of questions adapted to each focus area and included a discussion of key terminology and solicitation of feedback on strategies included in the drafted Strategic Plan. Questions were tailored to meet needs of older adults and a variety of literacy levels. Building upon ideas and suggestions that emerged from listening session participants, Ad Lucem developed the following recommendations for refining and prioritizing dementia-focused actions in Los Angeles County:

(1) Given the diversity of Los Angeles County, prioritize and ensure funding for the creation and dissemination of easy to understand educational and outreach messages and materials in more languages than currently available and use

culturally appropriate narratives and visuals.

- (2) Conduct outreach and disseminate educational messaging to a broader age range of older adults before they experience memory loss issues to reduce stigma, and increase readiness to protect brain health, seek preventive and screening services, and plan for future care.
- (3) Expand access to support groups for communities of color and monolingual communities to facilitate the sharing of culturally relevant information and advice.
- (4) Develop a strategy and identify the infrastructure needed to decentralize dementiarelated services (e.g., dementia screening) beyond the health care clinical setting to community institutions/organizations (e.g., pharmacies) – that may already have cultural and linguistic capacity -- to offset the burden on primary care providers and ensure that older adults and caregivers receive needed services and guidance.
- (5) Expand advance care planning resources by building relationships with financial institutions to provide financial advance care planning services to older adult and caregiver customers.
- (6) Improve health care provider attention to patient and caregiver reports of changes in memory or behavior to ensure the earliest possible interventions.
- (7) Expand adoption of gold standard practices for linking patients newly diagnosed with ADRD and their caregivers to information resources and community supports so they understand care plans and have confidence in immediate next steps.
- (8) Develop strategies and identify needed infrastructure to (i) expand access to social work and case management services to reduce the care management burden experienced by caregivers due to finding, organizing, scheduling, and paying for care recipients' services and treatments and (ii) activate peer mentoring networks to build supportive caregiver communities of practice around hypertension, early detection, and advance care planning to increase caregivers' sense of efficacy to act on these focus areas, particularly in low income and communities of color.
- (9) Regularly convene older adult/caregiver listening sessions to test messaging, vet approaches, and provide insights to professionals and providers on overcoming barriers to maximizing brain health.

The full report can be accessed <u>online</u>.

# 3. Strategic Plan Framework

Using a multi-pronged approach, the Strategic Plan addresses three focus areas (hypertension prevention and management, early detection, and advance care planning) across four domains (policy and systems, education, health care workforce capacity, and caregiver services and supports). Selection of focus areas and domains was informed by meetings with Steering Group members, CDC priorities, and various dementia and aging initiatives (e.g., *National Healthy Brain Initiative, BOLD Public Health Centers of Excellence on Dementia Caregiving, Early Detection, and Risk Reduction, National Healthy Brain Initiative Road Map Series, National Alzheimer's Project Act, California's Master Plan on Aging, Dementia Care Aware, Purposeful Aging Los Angeles*).

# **HEALTH CARE PROFESSIONALS**

Throughout the Strategic Plan, health care professionals are broadly defined as professionals that provide essential services that promote health, prevent disease, and deliver health care services to individuals, families, and communities.<sup>12,13</sup>

Examples of health care professionals include physicians, nurses, dentists, pharmacists, social workers, direct care workers, community health workers, nursing home administrators, or paramedics.

# Focus Areas

Focus areas were selected based on local priorities and current research. Additional background information and evidence gathered to support the selection of these three focus areas are summarized below.

# Hypertension Prevention and Management

The 2020 Lancet Commission on dementia prevention, intervention, and care identified 12 modifiable risk factors as potentially contributing to 40% of worldwide dementias.<sup>3</sup> Hypertension in mid-life (aged 45-64) was among these risk factors. Studies have demonstrated an association between vascular conditions, such as hypertension, and cognitive health.<sup>14,15</sup> The prevention and management of hypertension has the potential to reduce the incidence of cognitive impairment, as well as reduce the risk of mild cognitive impairment (MCI) that may progress to dementia.<sup>16,17</sup> An analysis by the Public Health Center of Excellence on Dementia Risk Reduction, led by the Alzheimer's Association, identified hypertension as the modifiable dementia risk factor with the most stringent epidemiologic evidence available and, therefore, best suited for public health action.<sup>14</sup>

Hypertension has also been identified as a top priority for dementia risk reduction at the national level. In 2022, the National Alzheimer's Project Act (NAPA) Advisory Council added a sixth goal to the National Alzheimer's plan focused on addressing targeted risk factors of dementia, one of which is mid-life hypertension.<sup>18</sup>

In Los Angeles County, an estimated 1.7 million adults have hypertension and less than half have their condition under control.<sup>19</sup> Hypertension disproportionality impacts Black/African American and American Indian/Alaska Native adults aged 18 and older who have the highest rates of hypertension in Los Angeles County, approximately 42% and 35% respectively.<sup>20</sup> Despite the availability of effective tools for prevention and management of hypertension, there remain gaps in care and accessibility, especially among underrepresented populations. Findings from the Strategic Plan listening sessions conducted by Ad Lucem Consulting reflect these challenges at the local level. Community members expressed concerns about anti-hypertensive medication and the lack of culturally and linguistically relevant high blood pressure resources. Furthermore, many community, the prevention and management of hypertension was identified as an essential component of the population-level response to address dementia regionally.

# Early Detection

Early detection of dementia can increase opportunities to provide better care and support for people with dementia, their families, and caregivers.<sup>21</sup> Timely detection of dementia can help mitigate complications and security risks from a delayed or missed diagnosis and allows people to prepare for the future. An economic modeling study has even suggested that early diagnosis could significantly lower health care costs by reducing the risk of hospitalization and supporting improved management of chronic conditions.<sup>22</sup> However, despite its importance, it is estimated that only half of the people who would meet the diagnostic criteria for dementia are actually diagnosed. Furthermore, it is common for individuals to receive a diagnosis in the late stages of disease or under crisis conditions such as hospitalization for advanced illness.<sup>23</sup> A number of barriers to diagnosis and early diagnosis have been documented including: lack of support for patients, caregivers, and clinicians; clinician time constraints; inadequate reimbursement; stigma-related fear; clinician difficulties disclosing diagnosis to patients and their families; belief that diagnosis is not worthwhile due to lack of treatment; and missed symptoms or attribution of symptoms to old age.<sup>24</sup> Furthermore, it has also been noted that more attention should been given to addressing the critical and widespread lack of health care system support for implementing early detection protocols and detection-to-care pathways.

Increasing early detection of dementia has become a national priority and a strategic goal for several initiatives. For example, Healthy People 2030 includes a goal focused on improving the health and quality of life for people with dementia with objectives such as

increasing the proportion of adults discussing cognitive concerns with health care professionals.<sup>25</sup> Improving dementia detection is also embedded among the six major goals of the 2021 National Plan to Address Alzheimer's Disease.<sup>18</sup> Furthermore, early detection and diagnosis of dementia is a public health essential area in the *National Healthy Brain Initiative 2018-2023 Road Map*.<sup>11</sup>

Given its importance to supporting quality of life for people with dementia as well as their caregivers and families and its prominence as a national goal, the Coalition identified early detection as a priority, both within the clinical and community setting. The importance of including this focus area in the Strategic Plan was further emphasized in the recommendations outlined in the reports by the University of Southern California Keck School of Medicine and Ad Lucem Consulting. Recommendations highlighted opportunities to train service providers that frequently interact with older adults to screen for cognitive impairment and identify community institutions/organizations with the cultural and linguistic capacity to provide dementia screening services and ensure people access needed supports and services.

# Advance Care Planning

Advance care planning is an essential component to providing high-quality care for people living with dementia. It allows people the opportunity to engage in thoughtful discussions about serious illness and make informed decisions regarding their preferences for future care.<sup>26</sup> The process can also reduce decision-making demands among caregivers and families as dementia progresses.<sup>27</sup> Advance care planning is a shared decision-making process that can be challenging for people, caregivers, and providers to navigate effectively.<sup>28</sup> For example, among providers, barriers for initiating advance care planning discussions include: lack of knowledge, confidence, and skills related to this topic; lack of a formal structure in the health care system to address these discussions; and having no place on the electronic health record to indicate the patient has an advance care plan.<sup>29,30</sup>

# **ADVANCE CARE PLANNING**

Advance care planning is the culturally responsive process of exploring, identifying, documenting, and sharing individual preferences for care, appointing a health care proxy if applicable, and periodically reviewing and updating these plans with the health care proxy and care team.

Care may refer to programs and services addressing all aspects of a person's well-being – medical, physical, behavioral, legal, and financial needs.

In 2016, Medicare initiated reimbursement billing for advance care planning and while providers demonstrated support for the new benefit and agree that it is important to have conversations about advance care planning, only 14% billed Medicare and less than 29% reported any formal training in end- of-life conversations.<sup>29</sup> It is therefore unsurprising that studies have shown that fewer than half of older adults in the United States have completed at least one advance care planning legal document.<sup>31,32</sup>

Cognitive impairment and dementia can pose additional challenges to establishing an advance care plan. Failure to acknowledge dementia as a life-limiting illness, lack of knowledge regarding advance care planning, waiting for a health care professional to initiate the discussion are some of the barriers to initiating advance care planning among people with dementia.<sup>27</sup> The need to address the aforementioned challenges is reflected in the *National Plan to Address Alzheimer's Disease*, which outlines actions that focus on bolstering engagement with care planning services such as increasing provider awareness of the Medicare advance care planning reimbursement mechanism. By prioritizing advance care planning as a focus area, public health can improve the safety and quality of care, including prevention and management of comorbidities and avoidable hospitalizations, for those living with dementia.

[ADVANCE CARE PLANNING] WAS QUITE FRUSTRATING. THERE WERE A LOT OF TEARS. WE PERSEVERED, BUT I COULD SEE HOW SOME PEOPLE COULD JUST DECIDE NOT TO DO IT BECAUSE OF TIME AND NOT HAVING THE STRUCTURE AND SO ON.

- Community Member, Supervisorial District 5

#### **Domains**

To ensure that each focus area is comprehensively addressed, each includes activities across four domains.

#### Policy and Systems

This domain encompasses sustainable approaches to improve outcomes for people impacted by dementia by advancing policy, systems, and environmental changes across multiple sectors such as public health, aging services, social services, health services, academia, private and non-profit. Leveraging a wide range of resources through cross-sector partnerships provides opportunities to improve public health and address the underlying inequities that influence the social determinants of health.<sup>33</sup> Strategies and activities within

the policy and systems domain may refer to institutional, system-level practices or local and state legislation aimed at making systemic or structural changes.

# Education

Raising awareness about dementia is essential for public health action. Education strategies and activities offer opportunities to increase public knowledge regarding salient population health issues and mitigate stigma. This domain aims to promote reliable sources of information regarding brain health and normalize discussions about cognitive impairment and end-of-life planning.

Educational strategies and activities may target specific audiences, such as people living with dementia, their caregivers, or I FELT TOTALLY ON MY OWN DURING THE EARLY PHASES. EVEN NOW, IT'S STILL DIFFICULT TO FIND [INFORMATIONAL] RESOURCES, YOU'VE GOT TO DO IT ON YOUR OWN.

 Community Member, Supervisorial District 3

health care professionals that serve with these populations. When implemented, these strategies and activities should be tailored to meet the needs of the community by utilizing culturally appropriate narratives and visuals and dissemination through multiple channels (i.e., traditional, non-traditional, social media).

# Health Care Workforce Capacity

Including health care workforce capacity as a domain is important to address workforce challenges that exist across the dementia care continuum.<sup>34,35</sup> As the number of people with dementia increases, health care professionals must be well-trained to address the complex and highly variable needs of people living with dementia and their caregivers. This domain aims to increase individual professionals' capacity by strengthening the knowledge and skills of the dementia care workforce, such as physicians, community health workers, and clinical social workers.

I FEEL LIKE HEALTH CARE PROVIDERS, ESPECIALLY THOSE IN SPANISH-SPEAKING NEIGHBORHOODS NEED TO BE INFORMED ABOUT WHAT IT [MEMORY LOSS] MEANS TO CULTURALLY DIFFERENT GROUPS...

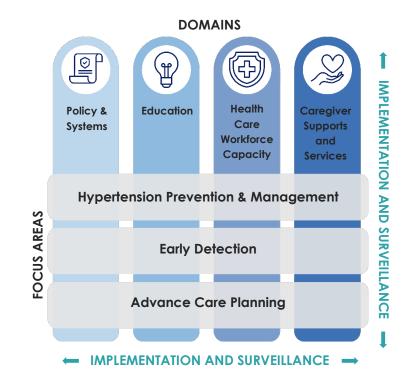
- Community Member, Supervisorial District 2

# Caregiver Services and Supports

Including caregiver services and supports as a domain across all three focus areas ensures that strategies and activities prioritize the needs of caregivers of people with dementia. Caregivers can play an essential role in promoting brain health, supporting early identification of dementia, and advancing care planning discussions.<sup>36</sup> Improving availability and streamlining accessibility of services and supports for caregivers is essential for both maintaining caregiver health and optimizing their capacity to care for people living with dementia. Strategies and activities within this domain aim to ensure equitable access to culturally relevant information and resources for caregivers, especially among communities of color.

# Surveillance and Implementation

Quality data and surveillance are key to driving effective policy and systems level decision making and informing effective public health practice. Throughout the strategic planning process, stakeholders noted the challenges accessing essential data elements needed for comprehensive dementia action. Challenges included inconsistent data collection, limited ability to extract and analyze existing data, lack of updated data, and a scarcity of Los Angeles County-specific data, to name a few. Thus, improving local data infrastructure was identified as a top priority to be included in the framework. Similarly, timely monitoring of Strategic Plan implementation was established as an essential priority to ensure the Strategic Plan drives meaningful change in the region.



# STRATEGIC PLAN FRAMEWORK

# C. COUNTYWIDE PLAN

The objectives, strategies, and activities set forth in the Strategic Plan aim to address three important areas of dementia prevention and management. They are meant to complement each other and may be implemented in tandem when appropriate. The order in which they are presented does not indicate any prioritization among them.

# Hypertension Prevention and Management

*Objective:* Expand and improve accessibility and use of effective hypertension prevention and management practices to support overall brain health and dementia risk reduction.

# **STRATEGIES**

Policy and Systems: Address barriers to quality hypertension prevention and management service delivery in health care and community settings.

**HPM.1:** Facilitate collaboration across health plans to develop and implement standards for home blood pressure monitor distribution, medication formularies, and prescription drug cost sharing.

**HPM.2:** Develop guidance for the use of team-based care to manage blood pressure in health care and community settings, including ways to leverage reimbursement opportunities for these services.

**HPM.3:** Identify and facilitate opportunities to expand the availability of community resources that can effectively prevent and manage hypertension such as lifestyle change programs, healthy food access, transportation, and safe living accommodations.

Education: Increase awareness of the importance of hypertension prevention and management across the lifespan.

**HPM.4:** Leverage existing health communication materials and messaging to educate the public and health care professionals about the connection between hypertension and dementia risk.

**HPM.5:** Develop culturally responsive and linguistically tailored messaging for the public promoting hypertension prevention and management, including the importance of lifestyle choices, the availability of supportive community resources, self-measured blood pressure monitoring, and medication adherence and management strategies.

**HPM.6:** Partner with faith-based organizations, local government entities, and community-based organizations to disseminate blood pressure messaging to people of all generations using multiple delivery methods.

Health Care Workforce Capacity: Improve workforce capacity for accurate blood pressure measurement and effective management.

**HPM.7:** Develop and disseminate practical resources to advance the use of standardized treatment approaches and guideline-recommended care, including best practices for optimizing medication therapy.

**HPM.8:** Leverage professional networks to train health care professionals on hypertension-related topics such as techniques for accurate blood pressure measurement and strategies to encourage lifestyle modification and optimize medication therapy including improving medication adherence.

**HPM.9:** Provide technical assistance opportunities around key team-based care principles such as effective communication and role clarity to support blood pressure management.

Caregiver Services & Supports: Increase caregiver capacity to manage their blood pressure and that of the person they care for.

**HPM.10:** Develop tools and strategies for caregivers to effectively support hypertension management for people in all stages of dementia.

**HPM.11:** Identify and increase access to meaningful and culturally responsive and linguistically tailored information, services, and supports for hypertension prevention and management among caregivers.

**HPM.12:** Partner with organizations to identify and address service gaps and social risk factors of people living with dementia and their caregivers to support hypertension prevention and management.

**HPM.13:** Leverage existing local, state, and federal initiatives focused on reducing caregivers' financial, emotional, and physical challenges to enhance their ability to prioritize their health and that of the person they care for.

# **Early Detection**

*Objective:* Normalize and expand early detection of dementia in home, community, and health care settings.

# STRATEGIES

Policy and Systems: Improve early detection of dementia by building workforce and system capacity across health care and community settings.

**ED.1:** Identify and address gaps in early detection and referral pathways across health care, behavioral health services, local government entities, and community settings.

**ED.2:** Monitor and ensure state and federal policies and initiatives related to detection and management of dementia, including the California Department of Public Health's and the California Department of Health Care Services' dementia care standards and the *Caregiver Advise, Record, Enable Act,* are operationalized and implemented in Los Angeles County.

**ED.3** Partner with nonprofit hospitals to ensure that dementia and dementia caregiving is included in their Community Health Needs Assessment and, if appropriate, included as a priority area for their community benefit program.

Education: Educate the general public and health care professionals about the benefits of early detection to address dementia stigma.

**ED.4:** Develop culturally responsive and linguistically tailored messaging for the public promoting the benefits of early detection of dementia, including opportunities for lifestyle modifications that support quality of life for people with dementia and their caregivers.

**ED.5:** Leverage existing resources to educate the public on brain health, dementia, early signs of cognitive impairment versus normal aging, how to seek assessment opportunities such as the Annual Wellness Visit benefit, and their role in promoting early detection, including requesting a baseline assessment.

**ED.6:** Develop messaging for health care professionals on the benefits of conducting routine cognitive assessments and available resources to support the post-assessment process.

**ED.7:** Identify and partner with community leaders and existing local, state, and federal organizations such as <u>Dementia Friendly America</u> to promote the benefits of early detection.

**ED.8:** Pursue opportunities to develop training programs for direct care workers and other personnel to conduct screenings for cognitive impairment in home and community settings.

Health Care Workforce Capacity: Increase health care professionals' capacity to conduct cognitive assessments as part of routine care.

**ED.9:** Identify and disseminate effective practices and existing cognitive assessment resources and tools for health care professionals.

**ED.10:** Build the clinical case for medical specialty practices to conduct routine cognitive assessments as part of patient care with the goal of helping them understand their role, the benefits, and the steps needed for effective implementation of assessments and subsequent dementia care.

**ED.11:** Develop guidance for health care professionals on optimization of existing payment mechanisms to increase uptake of Annual Wellness Visits, adoption of cognitive assessments, and the use of available Medicare benefits.

**ED.12:** Partner with Federally Qualified Health Centers, pharmacies, and other health care organizations to train health care professionals on conducting cognitive assessments, including prioritizing completion of <u>Dementia Care Aware</u> training.

Caregiver Services & Supports: Strengthen programs and services across sectors to improve caregiver capacity to support early detection and enable them to prepare for the future.

**ED.13:** Identify and increase access to meaningful and culturally responsive and linguistically tailored information, services, and supports for caregivers related to screening for cognitive impairment and communicating concerns with the person they care for and health care professionals.

**ED.14:** Strengthen the training of health care professionals to identify caregivers, assess their needs, provide support, and increase engagement and referrals to home and community-based services.

**ED.15:** Identify and partner with institutions to build awareness of local dementia related resources and supports available to people in all stages of dementia and their caregivers.

# **Advance Care Planning**

*Objective:* Strengthen knowledge about, and greater use of, advance care planning and related tools for supporting people in all stages of dementia.

# **STRATEGIES**

Policy and Systems: Increase accessibility and sharing of advance care plans among health care teams, families, caregivers, and others to support dementia care coordination.

**ACP.1:** Develop or adapt protocols and incentives for health care system workflows to document and ensure advance care plans are accessible within electronic health record systems, in particular for patients diagnosed with dementia.

**ACP.2:** Identify strategies to increase advance care planning collaboration and alignment across relevant professions and organizations.

ACP.3: Leverage state policies and initiatives, such as the <u>California Advance Health</u> <u>Care Directive Registry</u>, to strengthen culturally responsive and linguistically tailored advance care planning efforts in Los Angeles County.

Education: Reframe and normalize the discussion of advance care planning to increase engagement in the process.

**ACP.4:** Develop and disseminate culturally responsive and linguistically tailored messaging for the public to increase understanding of advance care planning and promote its importance, even before signs of cognitive impairment.

**ACP.5:** Provide professionals and organizations across sectors with resources and support to facilitate the discussion of advance care planning in settings where people regularly congregate and feel comfortable, which may include faith-based organizations, senior centers, and libraries.

**ACP.6:** Collaborate with institutions of higher education, special interest organizations, and professional associations to augment curricula and professional continuing education about culturally responsive advance care planning particularly for people living with dementia.

Health Care Workforce Capacity: Strengthen health care professionals' capacity to support advance care planning for people living with dementia.

**ACP.7:** Develop practical and culturally responsive guidelines, tools, and metrics for health care professionals to actively engage in advance care planning with input from people living with dementia and their caregivers.

**ACP.8:** Train health care professionals on advance care planning topics such as engaging in advance care planning conversations, optimizing existing payment mechanisms for advance care planning, and including patients and caregivers in the process.

Caregiver Services & Supports: Equip caregivers with support, training, resources and tools to play an active role in advance care planning.

**ACP.9:** Partner with organizations to strengthen and increase access to affordable, reliable, and culturally responsive and linguistically tailored caregiver education and training resources that support advance care planning for people living with dementia.

**ACP.10:** Expand access to case management services, in- and out-of-home respite care, and support programs to foster caregiver health and wellbeing as they navigate the implementation of advance care plans.

**ACP.11:** Develop and promote resources to enhance caregiver's ability to engage as a key member of the care team and support effective communication of advance care plans with health care providers and other stakeholders.

# Surveillance & Implementation

# Dementia Surveillance Infrastructure

**SI.1:** Develop standards for dementia-related data elements to be collected and monitored in Los Angeles County.

**SI.2:** Establish a cross-sector data inventory and analytic strategy for dementia in Los Angeles County.

**SI.3:** Collaborate with partners to implement the Behavioral Risk Factor Surveillance System optional module for Cognitive Decline or Caregiving in local surveillance data collection efforts.

# Strategic Plan Implementation & Monitoring

**SI.4:** Use data gleaned through available surveillance strategies and other sources to inform implementation of the Strategic Plan.

**SI.5:** Develop outcome measures to track progress and assess the impact of Strategic Plan activities.

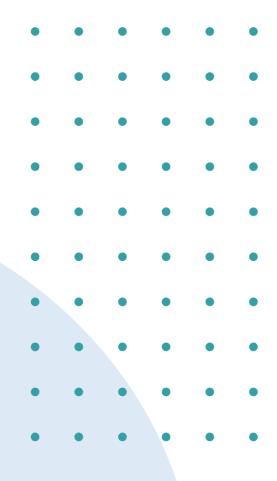
**SI.6:** Include evaluation and sustainability into Strategic Plan programming to determine program accessibility, effectiveness, and impact.

**SI.7:** Support analysis, translation, and dissemination of Strategic Plan surveillance efforts for sharing with multiple audiences.

# D. IMPLEMENTATION AND ACCOUNTABILITY

Meaningfully addressing dementia is an ongoing and long-term process that will require multi-sector collaboration at the policy, system, and environmental level. The development of this regional Strategic Plan serves as a first step for implementing coordinated actions that will target the areas of risk reduction, early detection, and prevention and management of comorbidities related to dementia in Los Angeles County. As a next step, the Coalition will develop an action plan that includes a timeline for implementation and identified key stakeholders who will "own" activities and ensure they are implemented using the same principles that were used to develop the plan – eliminate health disparities and promote health equity; collaborate across multiple sectors; and leverage resources for sustained impact.

Routine monitoring and reporting of metrics will also be critical to the success of this effort. Examining both reach and impact will offer concise, objective, and quantifiable measures of plan progress.<sup>37</sup> Identifying reliable and accessible data sources will be an important component of action plan development. **Table 2** provides sample key indicators of progress for the Strategic Plan evaluation that can be used to demonstrate results and accountability.



	Hypertension Prevention & Management	Early Detection	Advance Care Planning
Organizational Reach	<ul> <li>HPM.6) Number of faith-based organizations, local government entities, and community-based organizations disseminating blood pressure messaging.</li> <li>HPM.9) Number of health care organizations offered technical assistance around key team-based care principles such as effective communication and role clarity to support blood pressure management.</li> </ul>	<ul> <li>ED.8/ED.12) Number of organizations offered training for direct care workers and other personnel to conduct screenings for cognitive impairment in home and community settings.</li> <li>ED.15) Number of institutions disseminating information about local dementia related resources and supports available to people in all stages of dementia and their caregivers.</li> </ul>	<ul> <li>ACP.5) Number of organizations given resources and support to facilitate the discussion of advance care planning in community settings.</li> <li>ACP.7) Number of health care organizations provided with resources for actively engaging in advance care planning with input from people living with dementia and their caregivers.</li> </ul>
Individual Reach	<ul> <li>HPM.4-HPM.6) Number of people reached by educational messaging about the connection between hypertension and dementia risk.</li> <li>HPM.8) Number of health care professionals trained on hypertension- related topics such as techniques for accurate blood pressure measurement and strategies to improve medication adherence.</li> </ul>	<ul> <li>ED.5/ED.7) Number of people reached by education messaging about the benefits of early detection.</li> <li>ED.12) Number of health care professionals trained on conducting cognitive assessments.</li> </ul>	<ul> <li>ACP.4) Number of people reached by education messaging about advance care planning and its importance.</li> <li>ACP.8) Number of health care professionals trained on advance care planning topics.</li> </ul>
Impact	<ul> <li>HPM.1) Number of health plans adopting and implementing standards for home blood pressure monitor distribution, medication formularies, and prescription drug cost sharing.</li> <li>HPM.10-HPM.12) Number of caregivers who report having increased capacity to manage their blood pressure and that of the person they care for.</li> </ul>	<ul> <li>ED.5/ED.11) Number of people completing an Annual Wellness Visit.</li> <li>ED.3) Number of nonprofit hospitals including dementia and dementia caregiving in their Community Health Needs Assessment.</li> </ul>	<ul> <li>ACP.1) Number of health care systems with workflows to document and ensure advance care plans are accessible within electronic health record systems.</li> <li>ACP.9-ACP.11) Number of caregivers accessing support, training, resources, and tools to play an active role in advance care planning.</li> </ul>

# E. GLOSSARY

# Advance Care Planning<sup>38</sup>

A culturally responsive process of exploring, identifying, documenting, and sharing what matters most for a person's care, appointing a health care proxy if applicable, and periodically reviewing and updating these plans with the health care proxy and care team. Care in this definition is characterized as programs and services addressing all aspects of a person's well-being – health, social, physical, behavioral, legal, and financial.

# Alzheimer's Disease and Related Dementias<sup>39</sup>

Includes Alzheimer's disease as well as frontotemporal degeneration, Lewy body dementia, vascular contributions to cognitive impairment and dementia, and mixed etiology dementias.

# Annual Wellness Visit<sup>40,41</sup>

A Medicare benefit that consists of a yearly appointment where a health care provider performs a health risk assessment and develops or updates the patient's personalized prevention plan. Detecting cognitive impairment is an important component of the Annual Wellness Visit.

# Brain Health<sup>39</sup>

A concept that involves making the most of the brain's capacity and helping to reduce some risks that occur with aging. Brain health refers to the ability to draw on the strengths of the brain to remember, learn, play, concentrate, and maintain a clear, active mind.

# Caregiver<sup>39</sup>

Spouses, partners, adult children, other relatives, and friends providing unpaid support to persons living with dementia. Caregivers often assist with activities of daily living such as personal care, household management, medication and health care management, and coordination of financial matters.

# Cognitive Assessments<sup>42,43</sup>

Standardized tests used to evaluate a variety of cognitive processes such as reasoning, problem-solving, and language. These tests are often used by health care professionals to detect possible cognitive impairment and help determine if further evaluation is needed.

# Cognitive Impairment<sup>39</sup>

Trouble remembering, learning new things, concentrating, or making decisions that affect everyday life.

# Community Settings<sup>44</sup>

Settings in which the primary purpose is not medical care, for example, geographic communities, schools, churches, homeless shelters, worksites, or libraries.

# Culturally Responsive and Linguistically Tailored<sup>45,46</sup>

Ensuring information presented represents people in the communities for whom the information is intended and is respectful of their culturally beliefs, practices, preferred language, literacy levels, and communication needs.

# Dementia<sup>5</sup>

An umbrella term describing the loss of cognitive abilities like thinking, remembering, and reasoning to the extent that it interferes with daily life. Although Alzheimer's disease is thought to be the most common type of dementia, there are many others including vascular dementia, frontotemporal degeneration, Lewy body dementia, Creutzfeldt-Jacob disease, and mixed dementia, to name a few.

#### Direct Care Workers<sup>47</sup>

Assist individuals in daily living activities such as home care services. They may include certified nursing assistants, home health aides, and personal care aides.

# Health Care Professionals11,12

Professionals that provide essential services that promote health, prevent disease, and deliver health care services to individuals, families, and communities. Examples of health care professionals include physicians, nurses, dentists, pharmacists, social workers, direct care workers, community health workers, nursing home administrators, or paramedics.

#### Health Care Proxy<sup>38,48,49</sup>

Someone who is designated to make medical decisions for a person at times when the person is unable to do so. A health care proxy is also sometimes known as agent or surrogate.

#### Health Care Settings<sup>50</sup>

Places where a broad range of health care services can occur, including hospitals, urgent care centers, outpatient facilities and long-term care facilities.

#### Services and Supports<sup>51</sup>

Persons, agencies, and organizations that provide support in the form of physical (e.g., transportation) or emotional assistance and offer resource and information sharing.

#### Social Risk Factors<sup>52</sup>

Adverse social conditions that are associated with poor health such as food insecurity, social isolation, housing instability, and transportation needs.

#### Team-Based Care53

A strategy used in health care systems to enhance patient care by having health professionals across different disciplines work together with the patient and their primary care provider.

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# G. APPENDIX

# Prioritizing Road Map Actions for Los Angeles County

The table below presents Healthy Brain Initiative Road Map, 2018-2023 (RM) actions and the corresponding Los Angeles County Strategic Plan for Alzheimer's Disease and Related Dementias, 2023-2028 (Strategic Plan) activities that strongly align with these RM actions. Activities in **bold** indicate significant alignment between Strategic Plan activities and RM actions, while those that are not bolded are moderately aligned.

Heall	hy Brain Initiative Road Map, 2018-2023 Actions	Aligned Strategic Plan Activities			
Educ	Educate and Empower				
E-1	Educate the public about brain health and cognitive aging, changes that should be discussed with a health professional, and benefits of early detection and diagnosis.	ED.4, ED.5			
E-2	Integrate the best available evidence about brain health and cognitive decline risk factors into existing health communications that promote health and chronic condition management for people across the life span.	HPM.4, HPM.8, ED.5			
E-3	Increase messaging that emphasizes both the important role of caregivers in supporting people with dementia and the importance of maintaining caregivers' health and well-being.				
E-4	Promote prevention of abuse, neglect, and exploitation of people with dementia.				
E-5	Provide information and tools to help people with dementia and caregivers anticipate, avert, and respond to challenges that typically arise during the course of dementia.	HPM.10			
E-6	Strengthen knowledge about, and greater use of, care planning and related tools for people in all stages of dementia.	ACP.4			
E-7	Improve access to and use of evidence-informed interventions, services, and supports for people with dementia and their caregivers to enhance their health, well-being, and independence.	HPM.11, ACP.10			
Deve	lop Policies and Mobilize Partnerships				
P-1	Promote the use of effective interventions and best practices to protect brain health, address cognitive impairment, and help meet the needs of caregivers for people with dementia.	ED.14			
P-2	Assure academic programs, professional associations, and accreditation and certification entities incorporate the best available science about brain health, cognitive impairment, and dementia caregiving into training for the current and future public health workforces	ACP.6			
P-3	Support better informed decisions by educating policymakers on the basics of cognitive health and impairment, the impact of dementia on caregivers and communities, and the role of public health in addressing this priority problem.	ED.7			
P-4	Improve inclusion of healthcare quality measures that address cognitive assessments, the delivery of care planning to people with diagnosed dementia, and improved outcomes.	ACP.1			
P-5	Engage public and private partners in ongoing planning efforts to establish services and policies that promote supportive communities and workplaces for people with dementia and their caregivers.	ED.7			

P-6	Assure public health plans that guide emergency preparedness and emergency response address the special needs of people with dementia and their caregivers, support access to critical health information during crises, and prepare emergency professionals for situations involving people with dementia.	
Assure	A Competent Workforce	
W-1	Educate public health and healthcare professionals on sources of reliable information about brain health and ways to use the information to inform those they serve.	HPM.4
W-2	Ensure that health promotion and chronic disease interventions include messaging for healthcare providers that underscores the essential role of caregivers and the importance of maintaining their health and well-being.	ED.14
W-3	Educate public health professionals about the best available evidence on dementia (including detection) and dementia caregiving, the role of public health, and sources of information, tools, and assistance to support public health action.	ED.6
W-4	Foster continuing education to improve healthcare professionals' ability and willingness to support early diagnoses and disclosure of dementia, provide effective care planning at all stages of dementia, offer counseling and referral, and engage caregivers, as appropriate, in care management.	
W-5	Strengthen the competencies of professionals who deliver healthcare and other care services to people with dementia through interprofessional training and other strategies.	ED.12, ED.14, ACP.6
W-6	Educate healthcare professionals about the importance of treating co- morbidities, addressing injury risks, and attending to behavioral health needs among people at all stages of dementia.	
W-7	Educate healthcare professionals to be mindful of the health risks for caregivers, encourage caregivers' use of available information and tools, and make referrals to supportive programs and services.	ED.14
Monito	or and Evaluate	
M-1	Implement the Behavioral Risk Factor Surveillance System (BRFSS) optional module for Cognitive Decline in 2019 or 2020, and the BRFSS optional module for Caregiving in 2021 or 2022.	SI.3
M-2	Support national data collection on dementia and caregiving.	
M-3	Use data gleaned through available surveillance strategies and other sources to inform the public health program and policy response to cognitive health, impairment, and caregiving.	SI.4
M-4	Embed evaluation into training and caregiving support programs to determine program accessibility, effectiveness, and impact.	SI.6
M-5	Estimate the gap between workforce capacity and anticipated demand for services to support people with dementia and their caregivers.	

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