

LA BOLD:

Perspectives of Older Adults and Caregivers
on Strategies to Improve Brain Health and the
Lives of People Living with Alzheimer's
Disease and Related Dementias

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Table of Contents

Executive Summary	1
Introduction	5
The Los Angeles County BOLD Initiative (LA BOLD)	6
Listening Session Overview and Methodology	7
Key Findings	9
Hypertension Prevention & Management	9
Understanding & Terminology	9
Reactions to Proposed Strategies in the Draft ADRD Strategic Plan	10
Early Detection	13
Understanding & Terminology	13
Reactions to Proposed Strategies in the ADRD Draft Strategic Plan	14
Advance Care Planning	17
Understanding & Terminology	17
Reactions to Proposed Strategies in the Draft ADRD Strategic Plan	17
Recommendations	21
Conclusions	22
Appendix	23

This project and report were made possible with funding from the Centers for Disease Control and Prevention through the Los Angeles County Department of Public Health Division of Chronic Disease and Injury Prevention, Award No. NU58DP006920.

The findings included in this report do not represent the opinions nor the positions of the Los Angeles County Department of Public Health or any organizations mentioned in the text; they capture themes that emerged from listening sessions conducted with older adult and caregiver participants.

The project team would like to thank the listening session host organizations and participants who generously shared their time and experience for the purposes of this project.

Executive Summary

Introduction

As the proportion of the US population aged 65 and older grows, health care providers and public health practitioners are increasingly focused on strategies to ensure older adults maintain good health, a healthy brain, and an overall quality of life. The challenge is to overcome older adults' risk of and impacts from multiple chronic conditions, often compounded by memory issues that may be an early symptom of more advanced brain health issues such as Alzheimer's Disease and related dementias (ADRD).¹ Brain health and caregiving data point to a need for greater collaboration among public health professionals and a variety of partners to generate solutions and maximize health and wellbeing for older adults.

In 2020, the Los Angeles County Department of Public Health Division of Chronic Disease and Injury Prevention (DPH-CDIP) launched Healthy Brain LA, which is guided by the National Healthy Brain Initiative Roadmap.² The three main components of this effort are the *Healthy Brain Initiative: Los Angeles*, the *Los Angeles County BOLD Initiative* (LA BOLD), and the *Healthy Brain LA Coalition*. LA BOLD, a three-year initiative funded by the Centers for Disease Control and Prevention's *Building Our Largest Dementia Public Health Programs*, seeks to facilitate the development of a strategic plan to address ADRD in the county. DPH-CDIP leads this initiative in collaboration with the Los Angeles County Aging and Disabilities Department (formerly the Department of Workforce Development, Aging, and Community Services).

Methods

During the summer of 2022, Ad Lucem Consulting was asked by DPH-CDIP to conduct a series of listening sessions with older adults and caregivers to better understand how the actions proposed in the draft ADRD strategic plan developed through LA BOLD by the Healthy Brain LA Coalition may affect or align with their concerns and priorities as they related to ADRD. In response, Ad Lucem conducted ten listening sessions in September and October 2022 with 92 older adults and caregivers from Los Angeles County's five supervisorial districts (SDs). Community organizations partnered with Ad Lucem to recruit these listening session participants.

Listening sessions were designed with an equity lens to engage county residents from a variety of racial/ethnic and cultural communities with the goal of learning from Los Angeles County subpopulations with the highest risk for and/or who are disproportionately impacted by ADRD. Listening sessions focused on understanding community members' perceptions of and opinions about ADRD related health issues, familiarity with ADRD resources, reactions to the proposed strategic plan actions, and key barriers and facilitators to ADRD care. Each listening session was assigned to explore one of the three focus areas in the draft strategic plan: Hypertension Prevention & Management, Early Detection, and Advance Care Planning. Key findings and themes for each focus area emerged from the qualitative analysis of the listening session transcripts.

Key Findings

Participants across the ten listening sessions were enthusiastic about the invitation to discuss ADRD and related health issues. Overall, they perceived the proposed actions in the draft

¹ Centers for Disease Control and Prevention. (2020). [Chronic Diseases and Cognitive Decline](#).

² Centers for Disease Control and Prevention. (2021). [National Healthy Brain Initiative Road Map Series](#).

ADRD strategic plan as important. The key findings point to ADRD related disparities and suggest solutions to facilitate equity in prevention and management.

Hypertension Prevention & Management

Education Strategy

- Basic familiarity with existing hypertension-related information and culturally relevant resources varied across the listening sessions and between the different language groups represented.
- A history of health care bias and medical mistrust present barriers to hypertension treatment and adherence.
- Concerns about the need for a potential lifetime of hypertension medication are common, and if unaddressed, these concerns hamper adherence to hypertension medications.

Health Services Strategy

- Doctors may not spend enough time discussing hypertension prevention and treatment with patients and caregivers.
- When health care and public health professionals have cultural alignment with, or at minimum deep knowledge of, the populations served and use culturally/linguistically appropriate hypertension education materials, patient understanding of hypertension management/health issues is greatly improved.

Caregiving Strategy

- Caregivers need information on and access to financial and wellness supports to help with all aspects of caregiving, including hypertension management.
- More support is needed to build capacity for individuals and caregivers to monitor blood pressure and manage hypertension/health effectively at home.
- Experiences with paid caregivers and non-culturally relevant care impact hypertension management.

Early Detection

Education Strategy

- Although resources exist, many individuals have challenges finding quality resources when they/their loved ones first experience ADRD symptoms or are newly diagnosed.
- Culturally responsive and linguistically tailored early detection strategies are important for reaching diverse populations of older adults and caregivers across LA to promote early detection and reduce stigma associated with ADRD.

Health Services Strategy

- Insufficient health insurance coverage and limited income to pay out-of-pocket costs are substantial barriers to accessing early detection services.
- Perceptions of insufficient ADRD screening tools and health care providers' lack of attention to reports of memory problems negatively impact early detection and build mistrust among individuals and caregivers.

Caregiving Strategy

- Caregivers need training and support to provide high quality care and monitor the need for early detection screening.

Advance Care Planning

Education Strategy

- Navigating advance care planning resources can be “daunting” and information on advance care planning is often hard for patients and caregivers to understand.
- The lack of readily accessible and quality information on ADRD and advance care planning means that many individuals are unprepared when the time comes.
- Many partners in addition to doctors can play an important role in advance care planning efforts: public health departments, medical schools, nursing schools, as well as financial institutions, can provide different types of advance care planning support.

Health Services Strategy

- Health care providers are not providing sufficient assistance and input on advance care planning as conversations about advance care planning are difficult and require adequate time.
- Social service providers and support groups can be important advance care planning resources.

Caregiving Strategy

- Caregivers need more information and training to support advance care planning efforts outside of their regular care duties.
- Caregivers need support to provide those in their care with high quality advance care planning information and support.

Recommendations

The following recommendations synthesize and build upon ideas and suggestions that emerged primarily from the listening session participants, with input and nuance added from the Healthy Brain LA Coalition members.

The recommendations support the proposed ADRD strategic plan actions. Although not all recommendations will be feasible within the context of LA BOLD’s call for action, they do provide a concrete direction for addressing the priorities expressed by the Los Angeles County older adults and caregivers who participated in the listening sessions. These recommendations serve as a guide to refining and prioritizing many of these actions so they will meet the needs of county residents who are or will be affected by ADRD.

Education and Messaging

- 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.
 - Partner with trusted, culturally fluent community-based organizations (such as the listening session host organizations) to develop maximally effective and culturally responsive education and outreach materials.
 - A priority topic for culturally/linguistically appropriate educational campaigns is vascular dementia awareness and prevention.
- 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.

- Distribute educational messaging to and engage with older adults and caregivers where they regularly congregate and feel comfortable, which may include faith organizations, community centers, barber shops, beauty salons, and grocery stores.
- Expand access to support groups for communities of color and monolingual communities to facilitate the sharing of culturally relevant information and advice.

Expand Access to ADRD Services

- Develop a strategy and identify the infrastructure needed to decentralize ADRD-related services (e.g., dementia screening) beyond the healthcare 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.
- Expand advance care planning resources by building relationships with financial institutions to provide financial advance care planning services to older adult and caregiver customers.

Engaging Health Care Providers

- Improve health care provider attention to patient and caregiver reports of changes in memory or behavior to ensure the earliest possible interventions.
- 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.
 - Ensure that caregivers are included in developing care plans and next steps.

Caregiving

- Develop strategies and identify needed infrastructure to:
 - 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.
 - 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.

Sustaining Community Input

- 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.
 - Ensure that listening session participants and participating community organizations are adequately and appropriately compensated for their time and expertise.

Introduction

As the proportion of the US population aged 65 and older continues to grow, health care providers and public health practitioners are increasingly focused on strategies to ensure older adults can maintain good health, a healthy brain, and an overall quality of life. Unfortunately, many older adults are impacted by or at risk for multiple chronic conditions, which are often compounded by memory issues that may be an early symptom of more advanced brain health issues such as Alzheimer’s Disease and related dementias (ADRD).³

In Los Angeles County, public health data show that ADRD was the third leading cause of death in 2020 and remains a growing public health concern. As the Los Angeles County population continues to age, it is anticipated that rates of ADRD will increase by 150% by 2040 and will impact more than 405,000 individuals, with Latino and Black/African American communities most disparately impacted.⁴

The increase in rates of ADRD coincides with an increased need for well trained and supported caregivers, both paid and unpaid. Nationally, the number of unpaid caregivers for adults aged 50 and over increased between 2015 and 2020, from 34.2 million to 41.8 million caregivers.⁵ Caregiver demographics reflect the US population broadly—including a range of diverse racial/ethnic groups, income levels, family types and gender identities. Recent Los Angeles County data identified almost 323,000 adults reporting providing care to persons with dementia or cognitive impairment.⁶ Recent trends indicate that, although older adults need increasingly complex care, many of their caregivers lack the adequate training, services, and financial supports needed to do this work.⁷ Many caregivers reported greater stress and worsening health in 2020, compared to 2015, which indicates the importance of strategies that address ADRD care both for older adults and for those responsible for their care.⁸

Given the significant challenges illuminated by the brain health and caregiving data, public health professionals and their partners across the US are working together to generate solutions and maximize health and wellbeing for older adults. Maintaining brain health, by managing high blood pressure, exercising, and eating a healthy diet allows older adults to “think, learn, remember, play, and communicate” and reduces risk of ADRD.⁹ In 2020, the Los Angeles County Department of Public Health Division of Chronic Disease and Injury Prevention (DPH-CDIP) launched Healthy Brain LA, an effort guided by the National Healthy Brain Initiative Roadmap.¹⁰ The three main components of this effort are the *Healthy Brain Initiative: Los Angeles*, the *Los Angeles County BOLD Initiative* (LA BOLD), and the *Healthy Brain LA Coalition*.¹¹

³ Centers for Disease Control and Prevention. (2020). [Chronic Diseases and Cognitive Decline](#).

⁴ Healthy Brain LA. (May 2022). [Snapshot of Alzheimer’s Disease and Related Dementias in Los Angeles County](#).

⁵ National Alliance for Caregiving and AARP Family Caregiving. (May 2020). [Caregiving in the US](#).

⁶ Healthy Brain LA. (May 2022). [Snapshot of Alzheimer’s Disease and Related Dementias in Los Angeles County](#).

⁷ National Alliance for Caregiving and AARP Family Caregiving. (May 2020). [Caregiving in the US](#).

⁸ Ibid

⁹ County of Los Angeles Public Health. (n.d.) [Brain Health Website](#).

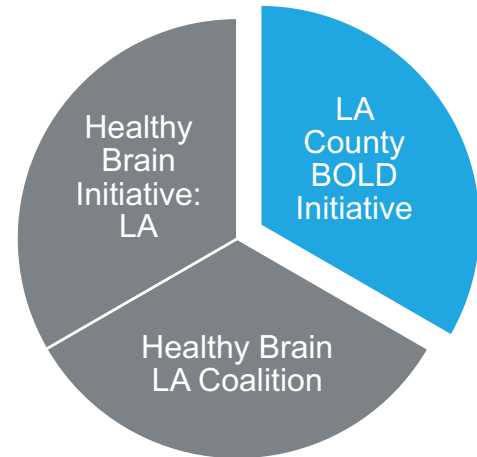
¹⁰ Centers for Disease Control and Prevention. (2021). [National Healthy Brain Initiative Road Map Series](#).

¹¹ County of Los Angeles Public Health. (n.d.) [Healthy Brain LA: About Us](#).

The Los Angeles County BOLD Initiative (LA BOLD)

LA BOLD works in tandem with the Healthy Brain Initiative: Los Angeles and the Healthy Brain LA Coalition (Figure 1). The initiative is a three-year project, funded by the Centers for Disease Control and Prevention’s *Building Our Largest Dementia Public Health Programs*. LA BOLD seeks to facilitate the development of a strategic plan to address ADRD in the county. DPH-CDIP leads this work in collaboration with the Los Angeles County Aging and Disabilities Department (formerly the Department of Workforce Development, Aging, and Community Services).

Figure 1: Healthy Brain LA



The Healthy Brain LA Coalition was launched in 2021 with a primary focus on “developing a cohesive agenda that positions ADRD as a top public health issue in Los Angeles County.”¹² The Coalition includes community-based organizations, government entities, health plans, and other partners dedicated to improving the lives of individuals with dementia and those who care for them.

The draft ADRD strategic plan developed through LA BOLD by the Healthy Brain LA Coalition elevates three focus areas (Table 1), with strategies and actions developed as part of four domains: policy and systems, education, health services, and caregiving. The listening sessions described in this report explored many of the strategies around education, health services and caregiving; policy and systems approaches were not addressed as these strategies would have been difficult for listening session participants to comment on without extensive orientation to them. Table 1 provides a summary of the three strategic plan focus areas and the proposed strategies discussed in the listening sessions.

Table 1: ADRD Strategic Plan Focus Areas

	Education:	Health Services:	Caregiving:
Hypertension Prevention & Management	Increase awareness of the importance of hypertension prevention and management across the lifespan.	Improve workforce capacity for accurate blood pressure measurement and effective management.	Increase caregiver capacity to manage their blood pressure and that of the person they care for.
Early Detection	Educate the general public and health care professionals about the benefits of early detection to address dementia stigma.	Increase health care professionals’ capacity to conduct cognitive assessments as part of routine care.	Strengthen programs and services across sectors to improve caregiver capacity to support early detection and enable them to prepare for the future.
Advance Care Planning	Reframe and normalize discussion of advance care planning to increase engagement in the process	Strengthen health care professionals’ capacity to support advance care planning for people living with dementia	Equip caregivers with support, training, resources and tools to play an active role in advance care planning

¹² County of Los Angeles Public Health. (n.d.) [Healthy Brain LA Coalition](#).

Listening Session Overview and Methodology

During the summer of 2022, Ad Lucem Consulting was asked by DPH-CDIP to conduct listening sessions with older adults and caregivers to better understand how the actions proposed in the draft ADRD strategic plan may affect these groups, and in particular, how they may align with their concerns and priorities. The listening sessions were designed with an equity lens to engage county residents from a variety of racial/ethnic and cultural backgrounds with the goal of learning from these subpopulations who often have the highest risk for and/or are disproportionately impacted by ADRD.

This listening session project focused on the following research questions:

- What is the understanding level of community members around discussing hypertension, early detection and advance care planning as they relate to ADRD?
- How familiar are older adults and caregivers with available dementia resources? (E.g., prevention measures, screening, support groups, hypertension, and advance care planning.)
- Which barriers do older adults/caregivers face around hypertension prevention and management? Around screening for ADRD? Around advance care planning?
- What are the facilitators to maximize uptake of the proposed activities for hypertension prevention and management, ADRD screening and advance care planning?
- Which terminology has the most saliency with older adults and caregivers, and why?

Ad Lucem conducted ten listening sessions in September and October 2022 with 92 older adults and caregivers in Los Angeles County's five supervisorial districts (SDs), engaging residents throughout the County (Figure 2). Demographic data from a variety of sources informed the (a) number of listening sessions per SD and (b) identification of organizations serving older adults/caregivers/persons with ADRD that represent the largest racial/ethnic groups in the districts as well as the highest need populations.

Table 2 shows the ten organizations that agreed to host listening sessions. An orientation session was held with each host organization. The host organizations utilized materials developed by Ad Lucem to recruit 10-12 participants per listening session through in person, email and text communications, and by drawing participants from groups regularly convened by the host organization.

Ad Lucem developed listening session guides and accompanying slides/handouts for the three focus areas included in the draft ADRD strategic plan (Figure 3), tailored language to low reading levels, and translated guides into Spanish and Korean, with additional translation of handouts into Samoan. The listening sessions were facilitated by culturally/linguistically appropriate facilitators and lasted from 60-75 minutes. Listening sessions were recorded and professionally translated and transcribed.

Listening session transcripts were entered into and analyzed using ATLAS.ti to identify themes and illustrative quotes and capture diverse opinions.

Figure 2: Listening Session Breakdown by Supervisorial District and Focus Area

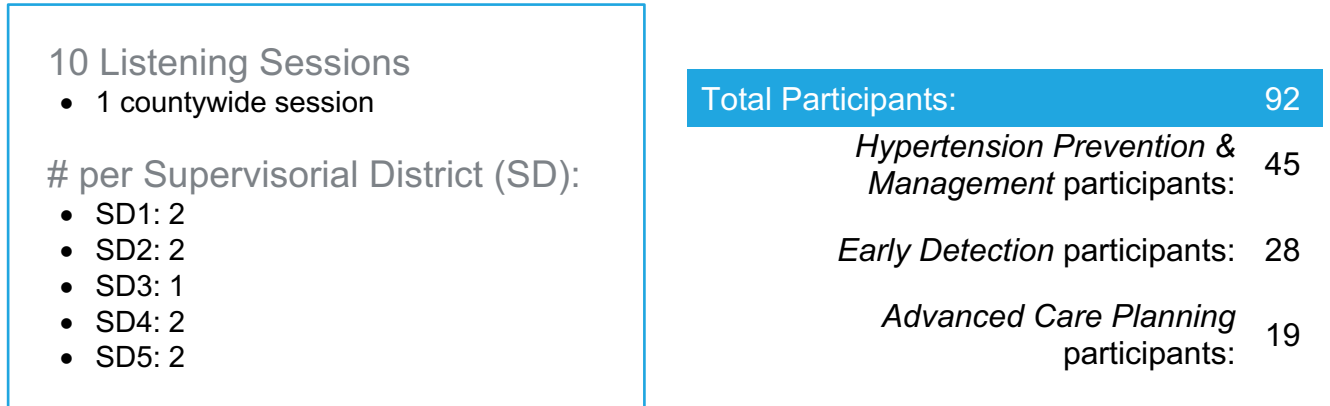


Table 2: Listening Session Host Organizations

Host Organization	Focus Area	Supervisorial District (SD)	Language	Primary ethnic/racial groups served by Host Organization
St. Barnabas		SD 1	Spanish	Asian, Hispanic/Latino, White
Koreatown Senior and Community Center	Hypertension Prevention & Management	SD 1	Korean	Korean
Stephen Sorensen Park		SD 5	English	White, Hispanic/Latino, Black/African-American
GREYvillage		SD 2	English	Black/African-American
Wise and Healthy Aging		SD 3	English	General population
USC Family Caregiver Support Center	Early Detection	SD 2	English	General Population
Office of Samoan Affairs		SD 4	English/Samoan	Asian Pacific Islander
Alzheimer's Los Angeles (early stage/caregivers)		Countywide	English	General population
Alzheimer's Los Angeles	Advance Care Planning	SD 5	English	General population
Humans Services Association of Bell Gardens		SD 4	Spanish	Hispanic/Latino

Key Findings

Participants across the ten listening sessions were enthusiastic about being invited to comment on the proposed actions included in the draft ADRD strategic plan. They were eager to communicate their life circumstances and discuss aging and ADRD. Many participants enthusiastically stated that they would like to meet again to discuss these focus areas. Overall, listening session participants perceived all the proposed actions in the draft strategic plan to be important.

The **key findings** presented in this report are organized around the three focus areas in the draft ADRD strategic plan (Figure 3). Listening session participants reflected on both their **understanding of the focus area** and basic terminology, and **provided reactions to the education, health services, and caregiving strategies and actions** presented.

Figure 3: ADRD Strategic Plan Focus Areas



Hypertension Prevention & Management

The objective of this focus area is to **expand and improve accessibility and use of effective hypertension prevention and management practices to support overall brain health and dementia risk reduction**. The following themes emerged from 45 listening session participants representing SDs 1, 2, and 5, who discussed their understanding of hypertension and associated terms, and provided reactions to the proposed actions to address this focus area.

Understanding & Terminology

Most of the listening session participants indicated an understanding of what high blood pressure is and how it can affect long term health.¹³ In an English-speaking group in SD 5, participants described their understanding of the term high blood pressure, using specific words such as “heart,” “overweight,” “salt,” “stroke,” “tension,” “possible death,” “eat right,” “silent killer” and “Alzheimer’s”. Although most participants in the groups had a general understanding of high blood pressure, others were less clear about exact definitions, how to correctly measure blood pressure, and the link between high blood pressure and ADRD.

Participants discussed differences among racial/ethnic and cultural groups’ beliefs about what causes high blood pressure, how to talk about it, and how to treat it. In the SD 1 Korean-

¹³ To ensure participants’ understanding of the listening session topic, facilitators used the term *high blood pressure*.

speaking session, participants had a detailed discussion of their understanding of high blood pressure, as well as the fears and misconceptions they have encountered in their community. They described the impact of diet and exercise, how genetics impact high blood pressure, and the concerns that some of them have about taking antihypertensive medication.

Reactions to Proposed Strategies in the Draft ADRD Strategic Plan

The following section presents the themes that emerged from participant reactions to the proposed actions to address, prevent, and manage hypertension.

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

Key Theme: Basic familiarity with existing hypertension-related information and culturally relevant resources varies.

- Participants in all listening sessions reported differing levels of familiarity with high blood pressure resources. Even among those who felt well-acquainted with available resources, the prevailing message was the need for more information.
- English-speaking participants in SD 5 and Korean-speaking participants in SD 1 identified the different sources of information they utilize, including YouTube, the internet, doctors, friends and family, and community gathering spaces (e.g., grocery stores or churches for English speakers, the Korean community center for Korean-speaking participants).
- Participants from SDs 1 and 5 mentioned the importance of relying on trusted sources in communities as an effective way to deliver information.
- Participants expressed a desire for clear information in multiple languages relaying hypertension-related services to support patients and caregivers in managing health.
- Participants from SDs 1 and 5 described experiences that underscore distinct barriers to understanding medical materials and medication instructions.

A Korean-speaking participant from SD 1 talked about the limited usefulness of materials received from their doctor:

“When I found out I had high blood pressure, my primary doctor at [my clinic], he gave me a packet. Then I got phone calls...It’s all about food, what foods to eat and stuff. Of course, I didn’t look at it.”

A Spanish-speaking participant in SD 1 identified challenges related to understanding their medications:

“I take 18 pills a day that I don’t even know what they are for. When I go to the doctor, they ask me which pills I take, and I just take out my list and show them.”

Key Theme: A history of health care bias and medical mistrust present barriers to hypertension treatment and adherence.

- Participants stated that when patients and caregivers do not believe health care professionals have their best interests in mind, they may be less likely to follow instructions.
- Participants of sessions in SDs 2 and 5 discussed the disparities, biases, and stresses that communities of color disproportionately experience in the healthcare system.

An English-speaking participant from SD 2 reflected on racial bias impact on health care treatment:

“When African Americans are diagnosed, they use a different set of rules or policies, or terminology. I just feel that it’s just not balanced. Why is the Caucasian or even the Hispanic culture, why do all of these cultures have to be scaled differently or diagnosed differently?”

An English-speaking participant from SD 2 shared perceptions of care and differences between men, women, and older populations, asking:

“[How] will the county have a different approach that’s more focused for how men perceive [hypertension] versus how a woman perceives it versus how a senior over the age of 80 [perceives hypertension]?”

Key theme: Concerns about the need for a potential lifetime of hypertension medication are common, and if unaddressed, these concerns hamper adherence to hypertension medications.

- English-, Spanish- and Korean-speaking participants from SDs 1 and 2 discussed their concerns about the emphasis on medication for hypertension, which several participants described as “synthetic” and “not natural;” other participants highlighted preventive practices such as “eating right and exercising” as “very important.”
- A number of participants from each listening session pointed to community preferences for medicines rooted in their cultural heritage (e.g., Latino, Chinese, Korean and southern US medicinal practices).

Participants from SDs 1 and 2 raised concerns about their lack of trust in the medical system and pharmaceutical industry. One Spanish-speaking participant in SD 1 stated:

“With all the things that I have gone through with my family, I am convinced that doctors and medicine are a business. Due to this, many of us have resorted to natural medicine, and we only go to the doctor’s office just to fulfill an obligation.”

Other SD 1 and 2 participants described being directed to take medication without a full understanding of why the medication is needed. One Korean-speaking participant reported:

“It is really shocking when we are told to take the medication for the rest of our lives. If you are injured, we can take medicine until it heals. But for this one [high blood pressure], we have to remain on the medication simply to prevent making it worse, even though we don’t have any symptoms, for the rest of our lives. It was very difficult for me. That’s why prevention is important.”

Proposed Hypertension Health Services Strategy: Improve workforce capacity for accurate blood pressure measurement and effective management.

Key Theme: Doctors may not spend enough time discussing hypertension prevention and treatment with patients and caregivers.

- Listening session participants expressed a desire for effective and consistent communication with their health care providers and more consistent integration of ADRD messaging or advice into health care visits to support overall health and wellbeing.
- Almost half of participants in the SD 5 English-speaking session reported that their health care providers never discussed the connection between managing blood pressure and ADRD. One person from that group stated:

“Stop rushing us out of the doctor’s office and explain to us more about what’s going on with our bodies and our blood pressures.”

Key Theme: When health care and public health professionals have cultural alignment with, or at minimum deep knowledge of, the populations served and use culturally/linguistically appropriate hypertension education materials, patient understanding of hypertension management/health issues is greatly improved.

- Participants across all the listening sessions expressed a need for hypertension information in simple, accessible language and culturally/linguistically appropriate terminology that they and their caregivers can understand.
- An SD 2 English-speaking participant pointed out that improving health care workforce practices may require providers to address their own biases when it comes to providing high-quality care:

“What I’d like to know is what does the County plan on doing regarding working with health care providers when it comes to health care disparities? If you don’t address that, it doesn’t matter what the program is, because those biases that providers bring in are still going to be present in the care that they provide.”

Proposed Hypertension Caregiving Strategy: Increase caregiver capacity to manage their blood pressure and that of the person they care for.

Key Theme: Caregivers need information on and access to financial and wellness supports to help with all aspects of caregiving, including hypertension management.

- Caregiver participants across all listening sessions discussed difficulties managing their own health while providing care for another. As one SD 2 English-speaking participant asked, “If you’re not taking care of yourself, how are you going to take care of somebody else?”
- Many listening session participants in SDs 1, 2 and 5 resonated with strategies to “educate healthcare providers to talk to and work with caregivers on accessing services in the community”.
- The SD 1 Korean-speaking listening session discussed the misinformation and lack of information related to programs and benefits that provide payment to family caregivers. A few expressed frustrations that they had not heard of financial support for caregivers when they were caring for loved ones:

“I was not aware of this information at that time, and I also had to work. We hired a maid, paying \$2,300 and giving her a private room with a TV.... After we moved into the Korea town and learned this information, I was like, what on earth? I sacrificed so much when those [family caregiver] benefits were out there.”

Key Theme: More support is needed to build capacity for individuals and caregivers to monitor blood pressure and manage hypertension/health effectively at home.

- A few participants in the English- and Korean-speaking listening sessions (SDs 1 and 2) mentioned needing blood pressure monitoring equipment or not knowing how to use the blood pressure monitors they have at home.
- One English-speaking participant suggested that Medi-Cal send everyone, regardless of their health status, a home blood pressure monitor, similar to COVID-19 home testing kit distribution by the federal government.

- Several SD 1 Spanish- and Korean-speaking participants confirmed the importance of blood pressure self-monitoring, indicating that they would like to know 1) how to monitor their own blood pressure and 2) what numbers define high blood pressure.

Key Theme: Experiences with paid caregivers and non-culturally relevant care impacts hypertension management.

- Listening session participants suggested that paid caregivers need education and support from health care professionals to overcome patient concerns related to the quality of caregiving.
- A number of SD 1 Spanish- and Korean-speaking participants described negative experiences with paid caregivers that provided low quality services. SD 1 session participants reported controlling, indifferent, abusive behaviors, theft, and neglect from their paid caregivers.
- One SD 2 English-speaking participant expressed that clear and culturally-relevant caregiver information from health care professionals is critical:

“Culture plays a very big part [in caregiving]... [A lot of caregivers] still do things that are not necessarily in the best interest of what they need to do [for their patient] in a healthy way, because they can’t relate to the information or they can’t understand the information from the person giving it to them. Making sure that it’s spoken in language, but also culturally speaking in a way that they can understand.”



Early Detection

Normalize and expand early detection of dementia in home, community, and health care settings is the objective of this focus area. Twenty eight participants discussed early detection during listening sessions in SDs 2, 3, and 4 that explored understanding of this issue and associated terms, and opinions of the proposed actions to address early detection.

Understanding & Terminology

Participants in the early detection sessions had varying familiarity with the terms associated with, and the importance of, early detection, screening, and memory and brain health checks.¹⁴ Although a few participants indicated a clear understanding of early detection terminology and the connection between AD/DRD and brain health, many participants did not understand that memory/brain health screening is an important strategy for maintaining a healthy brain and preventing or slowing future cognitive decline. Samoan-speaking participants from SD 4 spoke to the challenges their community experiences distinguishing AD/DRD from mental illness, which can lead to shame, stigma, and a reluctance to access dementia screening or services.

An SD 4 Samoan-speaking participant highlighted the different ways that people think about brain health:

“Samoan people, they don’t know. They say it is sickness of the brain. You can be crazy, right? We just don’t have the information and I feel like our Samoan people, they’re reluctant to share [when they have] this illness because, for starters, they don’t understand.”

¹⁴ To ensure participants’ understanding of the listening session topic, facilitators used the term *memory and brain health checks*.

An SD 3 English-speaking participant described confusion about brain health:

“Even with myself being a nurse, I’ve never really heard of brain health, so with his diagnosis...we’ve always separated our mind from our bodies, so we’ve never really looked at that being an issue.”

Reactions to Proposed Strategies in the ADRD Draft Strategic Plan

The following section presents the themes that emerged from participant reactions to the proposed actions to enhance education on and expand access to early detection.

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

Key Theme: Although resources exist, many individuals have challenges finding quality resources when they/their loved ones first experience ADRD symptoms or are newly diagnosed.

- All listening sessions (SDs 2, 3, and 4) listed ADRD and screening resources they were familiar with or from which they have personally benefitted.
- Participants across all listening sessions agreed that early screening and detection education is critical.
- SD 4 Samoan-speaking participants specified that education on brain health and memory issues should be a priority, and start as early as feasible.
- Listening session participants suggested outreach methods to reach broad segments of their communities, including public service announcements on varied media platforms, door hangers, and outreach in trusted community spaces such as “church circles.”

Participant-Identified ADRD Resources

- Alzheimer’s Association
- Johns Hopkins University (medical research)
- Personal Assistance Services Council (IHSS)
- UCLA Health’s Division of Geriatric Medicine
- Independence at Home
- Meals on Wheels
- OPICA Adult Day Care and Counseling Center
- USC Leonard Davis School of Gerontology
- AARP
- Los Angeles County Department of Mental Health
- Hilarity for Charity
- Alzheimer’s Los Angeles

An SD 2 English-speaking participant observed a lack of ADRD public education campaigns:

“There are those PSAs for mental health everywhere, but for this [ADRD], there’s nothing.”

One SD 3 English-speaking participant described challenges finding information:

“I felt totally on my own during the early phases. Even now, it’s still difficult to find resources, you’ve got to do it on your own.”

Key Theme: Culturally responsive and linguistically tailored early detection strategies are important for reaching diverse populations of older adults and caregivers across LA to promote early detection and reduce stigma associated with ADRD.

- SD 4 Samoan-speaking participants reported that the significant stigma associated with mental decline can be a barrier to screening and treatment. Accurate and relevant information, on the other hand, can motivate memory loss and brain health discussion among friends and family.

One SD 2 English-speaking participant reflected on the importance of culturally responsive care, stating:

“I feel like healthcare providers, especially those in Spanish-speaking neighborhoods need to be informed about what it [memory loss] means to culturally different groups, what it means to have memory problems.”

Highlighting the importance of clear, culturally relevant language, an SD 4 Samoan-speaking participant reflected:

“In our Samoan language, we don’t have the words to explain what... dementia is...but we have words that make fun of Alzheimer’s or forgetting... the most important thing to me, after our discussion here, is to go back to our families and share what we learned today, and to reinforce [screening] and encourage it in a positive way.”

Proposed Early Detection Health Services Strategy: Increase health care professionals’ capacity to conduct cognitive assessments as part of routine care.

Key Theme: Insufficient health insurance coverage and limited income to pay out-of-pocket costs are substantial barriers to accessing early detection services.

- SD 2 and 3 English-speaking participants detailed barriers related to healthcare and caregiving costs, including inconsistent health care due to poverty or lack of insurance, and specific services not being covered by insurance including non-traditional or alternative services, such as yoga.
- One SD 3 English-speaking participant talked about the need for expanded access to ADRD screening for individuals under age 65, and many SD 3 participants noted that insurance may not cover early screening.
- One English-speaking participant in SD 3 described how inadequate insurance coverage disincentivizes people from seeking appropriate care:

“We’re all here trying to find the right support, but if it’s not covered by insurance, doctors won’t push for it, and then people will be reticent to ask for it.”

Key Theme: Perceptions of insufficient ADRD screening tools and health care providers’ lack of attention to reports of memory problems negatively impact early detection and build mistrust among individuals and caregivers.

- Several SD 2 English-speaking participants expressed concern that the medical community is not directing sufficient attention to ADRD and early detection screening given the increasing proportion of older adults in the population.
- English-speaking participants in SD 2 and 3 claimed that the testing done by primary health care providers was not thorough enough to detect mild symptoms, thus delaying critical diagnosis and potential treatments.
- One SD 4 Samoan-speaking participant suggested allowing a variety of health care professionals to provide ADRD screening, including nurses, community health workers, and social workers who may be more accessible to and trusted by individuals and caregivers.

One SD 2 English-speaking participant expressed frustration with the lack of attention paid to ADRD:

“I don’t know how much focus there is right now from the healthcare providers on [ADRD]. It disappoints me because this is an increasing problem because people are living longer, and all you can see is more of this to come statistically. I don’t know what it would take, unless things have to get so much worse before they put more emphasis, education, and money behind it.”

An SD 2 English-speaking participant described how inadequate screening delayed care:

“We probably could have gotten her to the neurologist sooner if the test that the primary physician gave was similar to what the neurologist asked for. I kept advocating, saying, ‘This is not my mother.’ [W]e would go to the primary care physician, and she kept passing the test...But then when she went to the neurologist, she failed completely.”

Proposed Early Detection Caregiving Strategy: Strengthen programs and services across sectors to improve caregiver capacity to support early detection and enable them to prepare for the future.

Key Theme: Caregivers need training and support to provide high quality care and monitor the need for early detection screening.

- A number of English- and Samoan-speaking caregivers in SDs 2 and 4 described feeling isolated and overwhelmed by the responsibility of vetting and connecting with the appropriate services (by extension, cognitive assessments) for their care recipient—even after receiving information from providers or other sources.
- English- and Samoan-speaking participants from SDs 2 and 4 appreciated the benefits received from caregiver and family support groups but noted that it is difficult to find the time to attend support groups.

An SD 2 English-speaking participant noted that caregivers are contending with a range of challenges, including limited time and competing life responsibilities:

“When you say training, I don’t think there’s time for [caregiver] training. You all of a sudden are—pow!—a caregiver. It’s on the job, trial by fire.”

One SD 2 English-speaking participant reported that important early detection and ADRD needs beyond clinical information and medication are not being met:

“I would have thought there would be more social work involved, or some other entity within the HMO to help navigate and give you other resources to connect with. I found that almost non-existent. I had to do that on my own. I did it extensively, over and over and over.”



Advance Care Planning

The objective of this focus area is to **strengthen knowledge about, and greater use of, advance care planning and related tools for supporting people in all stages of dementia**. Listening sessions in SDs 4, 5 and countywide discussed their understanding of advance care planning and related terminology, and provided reactions to the draft ADRD strategic plan actions to address advance care planning. Nineteen older adults and caregivers participated in the advance care planning sessions.

Understanding & Terminology

Many advance care planning listening session participants had a clear understanding of advance care planning and what it entailed. English-speaking participants in the SD 5 and countywide groups identified aspects of advance care planning, such as investigating health care options available as ADRD progresses, end-of-life care, insurance coverage, and financial and legal arrangements for patients and caregivers. Other English-speaking participants in the SD 5 and countywide sessions and SD 4 Spanish-speaking participants had a less precise understanding of advance care planning. SD 4 Spanish-speaking participants described a general “life plan” for their loved ones and/or themselves; a few participants in this session described the legal and financial steps needed, but did not connect these activities to advance care planning.

Most participants across all listening sessions stated that advance care planning is a priority, for themselves and their care recipients, perceiving advance care planning as essential to documenting end-of-life wishes while individuals can still express their preferences and to ensuring fidelity to end of life requests.

Reactions to Proposed Strategies in the Draft ADRD Strategic Plan

The following section presents the themes that emerged from participant reactions to the proposed actions to support expanded advance care planning.

Proposed Advance Care Planning Education Strategy: Reframe and normalize discussion of advance care planning to increase engagement in the process.

Key Theme: Navigating advance care planning resources can be “daunting” and information on advance care planning is often hard for patients and caregivers to understand.

- A number of participants from the English-speaking SD 5 and countywide sessions reported that information on advance care planning is available, but it is not always obvious where to find it.
- A few English-speaking SD 5 participants described older adults’ difficulties using computers and technology as a barrier to accessing advance care planning information and tools.
- English-speaking participants from the SD 5 and countywide listening sessions perceive physicians as providing inadequate answers to advance care planning questions beyond providing referrals to other health care providers, social workers, or pamphlets/websites with general information.

Even when advance care planning information is available, it can be difficult to interpret, as stated by an English-speaking countywide participant:

“I had to search, unfortunately, an awful lot on my own trying to understand all of this in the past two and a half years.”

An English-speaking participant from the countywide session expressed their difficulties with advance care planning:

“It 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.”

Key Theme: The lack of readily accessible and quality information on ADRD and advance care planning means that many individuals are unprepared when the time comes.

- Participants across all listening sessions offered suggestions for better preparing communities for advance care planning; public education campaigns were suggested as a tactic to reduce the stigma surrounding ADRD related health issues to facilitate advance care planning.
- One English-speaking countywide participant reflected that ADRD education needs to take place before discussion of advance care planning takes place:

“There is a lot of education that needs to happen before we even talk about ‘What is advance care planning?’”

Key Theme: Many partners in addition to doctors can play an important role in advance care planning efforts: public health departments, medical schools, nursing schools, as well as financial institutions, can provide different types of advance care planning support.

- Participants across the listening sessions described the importance of speaking with a knowledgeable professional to guide advance care planning and answer detailed and specific questions.
- A number of English-speaking participants from the countywide group expressed concerns about paying for long-term care, worrying that they lack the information needed to make the best financial decisions and suggesting that financial experts could provide accurate information and planning assistance:

“I never purchased long-term healthcare. My concern right now is financially, how it would impact me? And perhaps getting someone who would be able to help me from this point forward, to make sure that financially I’m able to take care of my husband.”

Proposed Advance Care Planning Health Services Strategy: Strengthen health care professionals’ capacity to support advance care planning for people living with dementia.

Key Theme: Health care providers are not providing sufficient assistance and input on advance care planning as conversations about advance care planning are difficult and require adequate time.

- While participants across all listening sessions (SD 4, 5 and countywide) agreed that advance care planning should be a required part of their health care and treatment plans, many reported a lack of assistance from both primary and specialty health care providers.
- Participants across all listening sessions described that office visits tend to be short, precluding questions or in depth conversation on advance care planning.
- One English-speaking participant from the countywide group was frustrated with being redirected from one provider to another in their quest for advance care planning help:

“We had a neurologist and I asked him for information because we were under his care. He recommended I go to the gerontologist to get information. I went to the gerontologist at our hospital. He said, ‘Well, we only take care of the physical.’ I said, ‘Where do I go? What do I do?’ He gave me some paperwork that had ‘Alzheimer’s Association’ on it. Again, I had to do the leg work of researching... It wasn’t helpful.”

Key Theme: Social service providers and support groups can be important advance care planning resources.

- A number of English-speaking participants from the SD 5 and countywide sessions perceived case managers and social workers as more reliable sources of information and advice on advance care planning than primary care and specialist providers.
- Countywide and SD 5 session participants pointed to the value of advance care planning advice and guidance from peers and support groups for patients and caregivers. Participants suggested that peer to peer connections and resources be widely available and better advertised.
- One SD 5 English-speaking participant described the importance of intentionally training allied health professionals to address advance care planning:

“I think it’s more so the case managers and the social workers that really need to be trained...when the loved one is hospitalized and upon discharge they’re supposed to sit with the family and really go through these things in great detail. I think additional training for them would be very vital.”

Proposed Advance Care Planning Caregiving Strategy: Equip caregivers with support, training, resources, and tools to play an active role in advance care planning.

Key Theme: Caregivers need more information and training to support advance care planning efforts outside of their regular care duties.

- Participants in the listening sessions perceived that caregivers’ lack of understanding of the importance of advance care planning diminishes the ability to provide comprehensive, quality care.
- One SD 5 English-speaking participant stated that most caregivers have no knowledge of advance care planning.
- A number of participants in the advance care planning sessions expressed fears that caregivers outside of their own home lack the necessary skills to take care of their loved ones.
- SD 4 Spanish-speaking participants relayed concerns about poor treatment their loved ones might receive from paid caregivers in long-term care facilities, leading these session participants to prioritize keeping their loved ones at home, despite the difficulties and challenges experienced as caregivers.

“I can’t just leave him somewhere. I don’t dare to do it yet. I have been told that when they go somewhere, they are treated very badly. At home, he is very well cared for in every way. It is a difficult situation for me.”

Key Theme: Caregivers need support to provide those in their care with high quality advance care planning information and support.

- English-speaking caregiver participants from the countywide session expressed concern about being the sole decision-maker on behalf of their loved one or themselves, sharing that this responsibility causes stress related to finances, healthcare decisions, long-term care plans, legal obligations and documents, and family relationships.

- Participants across all listening sessions agreed that caregivers need access to respite care and mental health services for their own mental wellbeing.

An English-speaking participant from the countywide group expressed concerns about serving as the decision maker for her loved one:

“My issue now is that because of my husband’s condition, that it’s not going to be conducive to us to make intelligent decisions together. It’s up to me to go in and do what I need to do for us.”

One SD 4 Spanish-speaking participant offered a concrete suggestion to provide caregivers space to maintain their own well-being:

“I think it is very important for caregivers to be able to say, ‘There is a list of caregivers who can assist me because today I need three or four hours off. I need time for myself.’

Healthy Brain LA Coalition Meeting

Guided by the vision of a **“Los Angeles County that prioritizes dementia risk reduction and ensures equitable care for people living with dementia and their caregivers,”** the Healthy Brain LA Coalition plays an important role in advancing the LA BOLD strategies and actions.¹⁵ Coalition members—including community-based organizations, government entities, health plans, and other partners—met on November 1, 2022 to review and discuss the listening session findings. As part of this meeting, they sought to identify how the findings could be used to revise recommendations included in the draft ADRD strategic plan.

¹⁵ County of Los Angeles Public Health. (n.d.) [Healthy Brain LA: About Us](#).

Recommendations

The following recommendations synthesize and build upon ideas and suggestions that emerged primarily from the listening session participants, with input and nuance added from the Healthy Brain LA Coalition members.

The recommendations support the proposed ADRD strategic plan actions. Although not all recommendations will be feasible within the context of LA BOLD's call to action, they do provide a concrete direction for addressing the priorities expressed by the Los Angeles County older adults and caregivers participating in the listening sessions. These recommendations serve as a guide to refining and prioritizing many of these actions so they will meet the needs of county residents who are or will be affected by ADRD.

Education and Messaging

- 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.
 - Partner with trusted, culturally fluent community-based organizations (such as the listening session host organizations) to develop maximally effective and culturally responsive education and outreach materials.
 - A priority topic for culturally/linguistically appropriate educational campaigns is vascular dementia awareness and prevention.
- 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.
 - Distribute educational messaging to and engage with older adults and caregivers where they regularly congregate and feel comfortable, which may include faith organizations, community centers, barber shops, beauty salons, and grocery stores.
- Expand access to support groups for communities of color and monolingual communities to facilitate the sharing of culturally relevant information and advice.

Expand Access to ADRD Services

- Develop a strategy and identify the infrastructure needed to decentralize ADRD-related services (e.g., dementia screening) beyond the healthcare 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.
- Expand advance care planning resources by building relationships with financial institutions to provide financial advance care planning services to older adult and caregiver customers.

Engaging Health Care Providers

- Improve health care provider attention to patient and caregiver reports of changes in memory or behavior to ensure the earliest possible interventions.
- 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.
 - Ensure that caregivers are included in developing care plans and next steps.

Caregiving

- Develop strategies and identify needed infrastructure to:
 - 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.
 - 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.

Sustaining Community Input

- 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.
 - Ensure that listening session participants and participating community organizations are adequately and appropriately compensated for their time and expertise.

Conclusions

Findings from the listening sessions reflect a diversity of perspectives from Los Angeles County older adults and their caregivers. Most participants found the proposed actions in the draft ADRD strategic plan relevant to their own lives and the lives of the persons they care for, and agreed that these actions are needed to improve the overall health and wellbeing of older adults and caregivers across the county. Listening session participants discussed barriers and challenges faced in accessing services and the needed supports for hypertension prevention and management, ADRD early detection, and advance care planning, but also offered several suggestions to facilitate the uptake of the strategies contained in the draft ADRD strategic plan.

The recommendations presented in this report are a call to action for Los Angeles County stakeholders to collaborate on building a more robust infrastructure that will be needed in order to accommodate and improve ADRD services in response to the expected rise of these conditions and the needs expressed and foreshadowed by the listening session participants.

LA BOLD Listening Session Guide

Hypertension Prevention & Management, Early Detection, Advance Care Planning

Introduction

Virtual: As participants get onto the Zoom say hello and tell them we are waiting for everyone to arrive.

In Person: As participants gather say hello and tell them we are waiting for everyone to arrive.

Welcome and Introductions (*Say each of these points*)

- Hello everyone, thank you for joining our discussion today.
- My name is (Leader).
 - a. **Leader Note:** *Let the group know your name and why you wanted to be a part of this discussion.*
- As the group leader, I'll be asking you questions, asking follow up questions and keeping track of time and keeping the discussion moving so we can get through all of the questions.
- This is (Notetaker) who will be taking notes during our conversation.
- Our discussion today will take about 1 hour.
- We want you to know that your participation is voluntary and you can leave the group at any time.
- We are recording the session today so we do not miss any of your thoughts. During the discussion, feel free to ask that we turn off the recording if you do not want to be recorded for a specific comment. Is anyone NOT OK to start recording?
 - a. **Leader Note: *START RECORDING***
IN PERSON – start recording.
VIRTUAL – press the Zoom record button.
- Now I'd like to have each of you introduce yourself. IN PERSON: Please introduce yourself by telling us your first name. VIRTUAL: I'll call on you by your first name and please wave and say hi so the group knows who you are.

Notetaker Note: *Write down the number of participants.*

- Thanks for these introductions, now we will talk about the purpose of today's discussion.

Purpose of Discussion (*Read to the group*)

The LA County Department of Public Health is talking with older adults and caregivers about issues related to memory, Alzheimer's Disease, dementia and what LA County organizations can do to help people prevent and manage these conditions.

Today's discussion will focus on (**TOPIC: High Blood Pressure, Memory/Brain Health Checks, Advance Care Planning**) so people have the information they need to make decisions about their health and their care. Your life experiences, such as age, gender, culture, race/ethnicity, primary language and sexual orientation, can all influence what you think about this topic.

We greatly value hearing your opinions and thoughts on these topics. It is really important to learn from older adults and caregivers throughout LA County and from different communities to understand their priorities and needs.

The information gathered during this discussion and others will be used to guide planning for essential dementia related services for LA County residents.

Ground Rules (Say each of these points)

Now I would like to share the ground rules we'll use to make sure our discussion is meaningful and comfortable for everyone. (*Read the list of ground rules to the group.*)

1. There are no right or wrong answers because we're interested in everyone's thoughts and opinions and people often have different opinions.
 - Please, feel free to share your opinions even though it's not what others have said.
 - If there are topics you don't know about or a question you are not comfortable answering, feel free to not answer.
 - All input will be welcomed and valued.
2. Next, we want to have a group discussion, but we'd like only one person to talk at a time because we want to make sure everyone has a chance to share their opinion.
 - Please speak loudly and clearly since we are recording, and we don't want to miss anything you say.
 - Let's also remember to turn off or silence our cell phones.
 - If you absolutely must take an urgent call, please step away from the discussion.
3. The last guideline is about protecting your privacy.
 - Your name will not be used in any reports, and your name will not be linked to comments you make.
 - Transcripts of this discussion will go to LA County Public Health, but won't include any identifiers.
 - When we are finished with all of the groups, the transcripts will be read by the consultants, who will then summarize the things we learn. Some quotes will be used to describe opinions in the voice of discussion participants. No names will be used when we use quotes.
 - I'd also like for all of us to agree that what is said in this group stays in this group.
4. VIRTUAL - Stay on video the whole time so you can fully participate.
5. Are there other ground rules you would like us to add?

Consent

By participating in this group, you are saying you consent to being part of this discussion. If you don't consent, please leave the group.

- Before we get started, do you have any questions for me?

Listening Session Questions

Introduction

Let's start off with talking about a few terms we will use during our discussion:

- First, tell me what the **(TOPIC)** means to you?

Topic specific definitions:

High Blood Pressure is when your blood pressure, the force of your blood pushing against the walls of your blood vessels, is consistently too high.

IF NEEDED: High blood pressure is blood pressure of 140/90 or higher. High blood pressure usually has no symptoms. It can harm the arteries and cause an increase in the risk of dementia/Alzheimer's, stroke, heart attack, kidney failure, and other conditions if untreated/managed. Also called hypertension.

Advance Care Planning is about putting a plan in writing about what matters most to you for care, identify the person that will make arrangements for you, state your religious or faith preference, and lets you update or change the plan at any time.

Leader Note (provide group definition if needed): care is defined as programs and services addressing all aspects of a person's well-being – medical, physical, behavioral, legal, and financial needs.

Thank you for those thoughts. We'll be talking about **(TOPIC)** related to brain health, memory issues, dementia and Alzheimer's disease.

Brain health is the ability to think, learn new things, remember, and allows you to function well in everyday life.

Memory issues means *unusual* forgetfulness. It is a normal part of aging but can sometimes be a sign of a brain disease like dementia.

Dementia is a general term for brain diseases that affect thinking, memory and behavior and are serious enough to interfere with daily life. There are different types of dementia.

Alzheimer's is a type of dementia. It is the most common type of dementia.

BOLD Strategies

We are going to review a list of the actions LA County organizations are thinking about taking to do something about **(TOPIC)**. For each of these actions, we will talk about why you think the action is or isn't an important one to help people.

Education Strategy: Let's start by talking about education actions.

In person: hand out education list

Virtual: put up education slide

High Blood Pressure	<ul style="list-style-type: none"> ○ Educate the public and health care providers about the link between high blood pressure and brain health and reducing risk for memory issues, Alzheimer's and dementia. ○ Ensure that information on preventing high blood pressure is specific to different cultural and ethnic communities and in the right language. ○ Ensure that public education on preventing high blood pressure includes information on diet and exercise, community resources, measuring your own blood pressure regularly, and taking medications as prescribed. ○ Partner with organizations in the community, like churches, to educate people about blood pressure.
Memory/Brain Health Checks	<ul style="list-style-type: none"> ○ Educate the public about how important it is to get memory and brain health checks regularly. ○ Educate the public about life habits to keep their brain healthy. ○ Educate health care professionals and other personnel on the importance of regular memory and brain health checks and how to better support patients with memory issues or dementia.

Advance Care Planning	<ul style="list-style-type: none"> o Educate people with memory issues, Alzheimer’s and dementia, their caregivers and family members on what Advance Care Planning is and how to talk about it to encourage more people to do Advance Care Planning.
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- What do you think about these ideas?
- Why do you think these are important or not important?
- **If more than one action, ask:** If you had to pick one action, which is the most important?

Health Care Strategy: Next we will talk about healthcare actions.

In person: hand out healthcare list

Virtual: put up healthcare slide

High Blood Pressure	<ul style="list-style-type: none"> o Train health care providers to improve their interactions with patients around high blood pressure to ensure accurate blood pressure measurements and clear communication about medication. o Make sure insurance pays for easy access high blood pressure screening and management, at the doctor’s office, the drug store or other locations in the community.
Memory/Brain Health Checks	<ul style="list-style-type: none"> o Include memory trouble and brain health checks at regular medical visits. o Train lots of different types of health care providers to check memory troubles and brain health. o Ensure health care providers have resources and services to refer patients to based on the results of their memory/brain health check. o Make sure insurance covers memory and brain health checks at regular visits.
Advance Care Planning	<ul style="list-style-type: none"> o Train health care providers working with people with memory issues, Alzheimer’s and dementia and their caregivers to help with Advance Care Planning.

- What do you think about these ideas?
- Why do you think these are important or not important?
- **If more than one action, ask:** If you had to pick one action, which is the most important?
- **For Memory/Brain Health Checks:** What do you think about someone other than a doctor – a community health worker, nurse or social worker - doing these memory and brain health checks?

Caregiving Strategy: Next, we will talk about caregiving.

In person: hand out caregiving care list

Virtual: put up caregiving slide

High Blood Pressure	<ul style="list-style-type: none"> o Train caregivers and provide them with tools to be able to help prevent and manage high blood pressure for the people they care for through blood pressure measuring, sticking to medication schedules and getting the help of health care providers if there is a problem. o Make sure that high blood pressure information and tools for caregivers are right for their culture and language. o Train health care and other providers talk to and work with caregivers on accessing services in the community.
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	<ul style="list-style-type: none"> ○ Reduce the financial, emotional, and physical challenges that come with caregiving so that the caregiver takes care of their own health and that of the person they care for.
Memory/Brain Health Checks	<ul style="list-style-type: none"> ○ Train caregivers and provide them with tools to be able to spot the early signs of memory problems and Alzheimer's/Dementia so that caregivers can get the person they care for to a care provider for a memory/brain health check. ○ Make sure that information and tools for caregivers are right for their culture and language. ○ Train health care and other professional to talk to and work with caregivers on accessing services in the community.
Advance Care Planning	<ul style="list-style-type: none"> ○ Give caregivers the tools and assistance they need to do Advance Care Planning for the person they care for; make this assistance easily available in communities. ○ Make sure caregivers know how to talk about Advance Care Planning with health care and other providers to ensure the care plan is developed and followed.

- What do you think about these ideas?
- Why do you think these are important or not important?
- If you had to pick one action, which is the most important?

Other Topics

High Blood Pressure	<ul style="list-style-type: none"> ○ What sorts of things make it hard for older adults to prevent or manage high blood pressure? ○ What needs to be available to make it easier for older adults to prevent or manage high blood pressure? <ul style="list-style-type: none"> ○ Probe: Where would you go to get help preventing or managing high blood pressure?
Memory/Brain Health Checks	<ul style="list-style-type: none"> ○ What sorts of things make it hard for older adults to get memory trouble and brain health checks? ○ What needs to be available to make it easier for older adults to get memory trouble and brain health checks? <ul style="list-style-type: none"> ○ Probe: Where would you go to get a memory trouble or brain health check? ○ What kind of information or resources do you need to understand Alzheimer's, dementia, and caregiving more?
Advance Care Planning	<ul style="list-style-type: none"> ○ What sorts of things make it hard for older adults and caregivers to do Advance Care Planning or talk about it? ○ What needs to be available to make it easier for older adults and caregivers to do Advance Care Planning? <ul style="list-style-type: none"> ○ Probe: Where would you go to get help with Advance Care Planning?

Question if time allows

- Thinking about your daily life, describe your comfort talking about (**TOPIC**). Who would you feel comfortable talking about this topic with?

Closing

Thank you for participating today. That was a really good discussion and gave us lots of information.