IMPROVING EARLY DETECTION AND CARE OF DEMENTIA IN LOS ANGELES COUNTY

Pathways to early detection and care for people living with dementia and their care partners

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ACKNOWLEDGMENTS

We thank the many individuals who generously shared their time, expertise, and passion for improving the lives of people living with dementia and their family caregivers in Los Angeles County. Their valuable insights, experiences, and recommendations broadened our understanding of what is needed to deliver on the promise of comprehensive, culturally relevant, equitable care and services.

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Executive Summary

In 2021, the Los Angeles County Department of Public Health, with the support of an award from the Centers for Disease Control and Prevention (CDC), launched a three-year strategic planning process for a countywide plan to address Alzheimer's disease and related dementias (ADRD). The LA BOLD initiative tasked the University of Southern California (USC) Keck School of Medicine with conducting a healthcare landscape analysis to identify leverage points for sustainably integrating early detection of dementia and developing a set of actionable recommendations.

Early detection is the gateway to a true population-based approach to care delivery, yet across the United States, only about half of all affected individuals receive a diagnosis.[1] The diagnosis of dementia is often made in late stages, especially in minoritized communities, or under crisis conditions such as hospitalization for advanced illness.[2,3] Many healthcare leaders recognize that siloed health and social care threatens the care of people living with dementia and their caregivers, but few have taken steps toward the necessary redesign to accommodate their needs. Most healthcare providers and systems have adopted no structured approach to early dementia detection or care, nor is it prioritized as a quality improvement goal.

Early recognition of dementia need not be limited to health care settings – the Dementia Friendly America movement has highlighted many opportunities for detection in the community. Expert community service providers focused on ADRD, such as Alzheimer's LA and the Alzheimer's Association, are highly skilled in recognizing dementia, responding to caregivers' needs, and providing education and support. Many others that serve broader groups of older adults can be trained to detect undiagnosed dementia and make appropriate triage decisions. Yet while formal assessment, diagnosis, and medical management of dementia are reserved for clinical settings, access is often difficult and the range of services offered is too narrow for optimal outcomes.

Our team summarized existing national public health guidance, opportunities for early detection of dementia, and relevant findings from a review of California state policies and initiatives that informed a current-state analysis in Los Angeles County. Based on results of a targeted survey and interviews with key stakeholders from four interacting sectors: public health, aging services, social services, and health services, we provide broad and specific recommendations that leverage public health's moral authority, messaging capabilities, and convening power for sustained improvement.

We make 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 expert working groups in communications, to create public awareness and demand for brain health services, utilizing learnings from successful public health campaigns, and (3) engage key stakeholders and agencies responsible for healthcare policy and reimbursement, to address care for persons with dementia and their families, by working to expand eligibility for public funding for persons 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. Lastly, (4) we recommend establishing 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. This learning collaborative can engage the strengths of academic partnerships in data infrastructure, research, and analytic strategy to assure comprehensiveness and usability.

The Research Team

The project lead, **Soo Borson, MD, FAPA, FGSA** co-leads the national BOLD Public Health Center of Excellence on Early Detection of Dementia and a member of the Clinical Advisory Board for Dementia Care Aware. She is a Professor in the Department of Family Medicine at the Keck School of Medicine at USC and Professor Emerita of Psychiatry at the University of Washington. She is board certified in Psychiatry and Neurology. Her research has made significant contributions to the science and practice of early detection of dementia and chronic disease care. She collaborates with researchers at several academic and health care institutions and has consulted widely with health care systems seeking to become dementia capable. She contributes to many national and international working groups dedicated to implementing better dementia care.

Carolyn Kaloostian, MD, MPH, FAAFP is an Associate Clinical Professor in the Department of Family Medicine at the Keck School of Medicine at USC. She is board certified in Family Medicine and is a Fellow of the American Academy of Family Physicians. She completed medical school and her geriatric fellowship at the UCLA David Geffen School of Medicine. She completed her palliative medicine fellowship at the VA/Cedar-Sinai Palliative Medicine Fellowship and her Transforming Primary Care Fellowship at Harbor UCLA. She received both her Executive Masters in Public Health in Health Policy and Management and a Global Health Certificate from UCLA's Fielding School of Public Health. She directs a Geriatric Interprofessional medical school course educating graduating physicians on geriatric principles and team-based care. She is also the Assistant Director of the Keck Signature Care Concierge Medicine Program at USC. She helped establish Keck USC's Perioperative Brain Health Initiative to screen and assess cognitive impairment preoperatively. She has also participated in Keck USC's Age-Friendly Health System implementation and certification.

Sonali Saluja, MD, MPH, FACP is an Assistant Professor of Clinical Medicine in the Department of Medicine at the Keck School of Medicine at USC. She is the Director of the USC Gehr Family Center for Health Systems Science and Innovation, a health services researcher, and is board certified in Internal Medicine. She completed her residency at Providence Portland Medical Center and a fellowship in General Internal Medicine at Harvard Medical School. Her research aims to uncover systemic causes of health inequities and provide plausible strategies that lead to a more equitable healthcare delivery system. Dr. Saluja also developed and co-directs the Health Justice and Systems of Care curriculum at the Keck School of Medicine. Dr. Saluja currently sees patients at LAC+USC hospital where she teaches and supervises residents and medical students.

Matthew Phan, MSG has extensive experience working with older adults in a myriad of capacities. Having served as a Leadership Fellow for Wallis Annenberg GenSpace, a community center in Koreatown, he supported the development and implementation of evidence-based programs for older adults. In addition, he convened with thought leaders in the aging space to find resolutions to social

issues related to ageism and equitable aging. Matthew has also interned with the Geriatric Assessment Program at Keck Medicine of USC, working alongside an interdisciplinary care team to provide comprehensive assessments and develop care plans for older adults. In his current capacity, Matthew works with the Center for Health Care Strategies where he provides project management for developing integrative care for dually eligible individuals and coordinating person-centered long-term services and supports.

Davis Lee is a student intern studying Human Development and Aging, and Senior Living Hospitality at The USC Leonard Davis School of Gerontology. Davis serves as the President of the Student Gerontology Association and worked on projects such as the Intergenerational Phone Chain that sought to combat loneliness amongst older adults during the COVID-19 lockdown. He uses his diverse passions in health, business, and community service to advocate for older adults.

Alissa Maier, MPH is the project manager for Quality and Population Health at the Gehr Family Center for Health Systems Science and Innovation in the Department of Medicine at the Keck School of Medicine of USC. She holds a BS in Psychology from the University of Dayton and an MPH with an emphasis on health Education and Promotion from the University of Cincinnati. She has spent much of her career working on chronic disease prevention and has experience working at national nonprofit organizations. Her passion and interest in quality improvement and public health inspired her to join the Gehr Center team.

Background

Comprehensive medical and psychosocial support can have powerful, sustaining benefits for people living with dementia and their care partners at home. Though models vary in their details, four principles define high quality dementia care:

- early detection and diagnosis;
- an accountable dementia care team, with engaged patients, care partners, and knowledgeable professionals;
- a unified, proactive, and trackable medical and psychosocial care plan;
- longitudinal follow up throughout the remaining life course.

Few of us would want less for ourselves or our families – but too few people living with dementia today can expect to receive such care.

The BOLD Act of 2018 established a national framework to address ADRD – the term now generally used to refer to all forms of progressive cognitive impairment in older adults – as a public health imperative. Improving detection and diagnosis of ADRD is one of three core priorities, along with dementia risk reduction through lifespan brain health initiatives and support and assistance for caregivers. The BOLD Act aims to embed ADRD in a durable, comprehensive, and dynamic public health approach that reaches communities via multiple interacting sectors of health care delivery systems, social service networks, and aging services.

THE NATIONAL CONTEXT FOR DEMENTIA DETECTION, DIAGNOSIS, AND CARE

THE GROWING CHALLENGE The proportion of adults providing care to an adult with functional limitations, including those caused by ADRD, has reached unprecedented levels across the country. In 2015, family caregivers comprised 16.6% of the adult population in the United States, and today it is 19.2%.[6] In 2017, approximately 41 million family caregivers in the United States provided an estimated 34 billion hours of uncompensated care to an adult with functional limitations, with an estimated economic value of $470 billion.[7]

BROAD DEMOGRAPHIC INEQUITIES In 2020, 5.8 million Americans aged 65 and older were living with ADRD.[4] Racial, ethnic, economic, and other disparities are widespread:
- Older African Americans are 2 times and older Latino/Hispanic Americans are 1.5 times more likely than older non-Hispanic Whites to develop ADRD.[4]
- Dementia cases and mortality rates are increasing disproportionately in communities of color.
- Among the various racial and ethnic minority groups in the United States, the prevalence of ADRD is highest among African Americans aged 65 and older (13.8%), followed by Latino/Hispanic Americans aged 65 and older (12.2%).[5] As their life expectancy continues to increase, American Indian groups are also experiencing rising rates of ADRD.
- Among those 85 and older, African Americans and Latino/Hispanic Americans have the highest rates of ADRD (43.1% and 40.2% of the respective populations).[5]

THE PUBLIC HEALTH RESPONSE The Healthy Brain Initiative (HBI), created by the CDC and the national Alzheimer's Association, began in 2005 to raise awareness of brain health and ADRD. This effort was joined by other critical national initiatives that created a national plan for ADRD (the National Alzheimer's Project Act), workforce training opportunities (Geriatrics Workforce Enhancement Project, GWEP, funded by the Health Resources and Services Administration), new evidence around long- term services and supports (e.g. through the Older Americans Act and Administration for Community Living), and reimbursement mechanisms for dementia detection and care under the Centers for Medicare and Medicaid Services (CMS). These and other efforts culminated in passage of the BOLD Act – Building Our Largest Dementia Infrastructure – in 2018. BOLD commissioned the CDC to fund:

- Development of public health infrastructure, through [the National Healthy Brain Initiative Road Map](#) (update expected in 2023)
- BOLD Public Health Centers of Excellence, three national centers to collate and disseminate evidence-based approaches and best practices for supporting early detection, prevention, and caregiving. These centers collaborate with CDC, national partners and state, local, and tribal health entities to ensure maximum effect and reach.
- BOLD and HBI program awards to public health departments in nearly two dozen states and counties, including Los Angeles County, and other selected national entities. Public health departments choose the ADRD efforts they will undertake, guided by the HBI Roadmap, and the division they assign for accountability.

US AGING/AREA AGENCIES ON AGING (AAA) AAAs are public or private non-profit agencies, designated by the state to address the needs and concerns of all older persons at the regional and local levels. They provide services to many people living with dementia and their families, and some make basic training in dementia available to their staff. In a new development, consortia of AAAs have initiated novel contractual relationships with healthcare payer groups, aimed at aligning social and medical aspects of care.

CENTERS FOR MEDICARE AND MEDICAID SERVICES (CMS) CMS provides three benefits under traditional Medicare that enable improvements in dementia detection and care: 1) the Annual Wellness Visit, a no-copay preventive visit that requires detection of any cognitive impairment as part of a health risk assessment and prevention plan; 2) a reimbursable Cognitive Assessment and Care Plan process that brings caregivers into the care team for the first time, and calls for assessment of psychosocial and behavioral as well as general medical needs; and 3) a range of Chronic Care Management services that support ongoing care. Uptake of all three benefits has been disappointing to date, with barriers identified at all levels of health care delivery. CMS also offers a set of quality measures for voluntary reporting of dementia care components by physicians; these are underutilized and largely employed by specialists, who care for a small fraction of patients. More recently, CMS has adjusted payment formulas for Medicare Advantage plans to account for the added costs of caring for individuals with dementia. There is no evidence to date that these adjustments translate into efforts to improve dementia care in practice.

AGE-FRIENDLY HEALTH SYSTEMS (AFHS) The Institute for Healthcare Improvement and the John A. Hartford Foundation have partnered to develop the "age-friendly health systems" movement, with the aim of spreading geriatric care principles of geriatrics broadly throughout the healthcare sector. AFHS provides voluntary training and certification for systems willing to implement improvements in the quality of patient-centered care for older adults, based on the 4Ms: what Matters most, Mentation (delirium, dementia, and depression), Mobility, and Medications – a framework for patient-centered care that enacts core principles of geriatrics. Participating health systems can qualify for certification by choosing one or more clinical settings for implementation and specifying how they operationalize

the 4Ms. A related initiative is the Geriatric Emergency Department certification movement that has been growing rapidly around the world.

THE CARE ACT Family caregivers make multiple essential contributions to the health and wellbeing of older adults. However, federal law and policy do not require that they be identified in medical records where they can be readily recognized and invited into the health care team. The CARE (Caregiver Advise, Record, and Enable) Act, initiated and widely promoted by AARP, has been enacted by California and many other states and territories. The CARE Act requires hospital staff to identify and document caregivers of hospitalized individuals, to involve them in care decisions, and to instruct them on providing care for a patient at home after discharge from the hospital. Outcomes beyond endorsement by states as of 2019 have not been reported thus far.[8] The CARE Act does not require identification of caregivers in ambulatory care settings, but a broader, primarily nurse-led ongoing initiative, the Home Alone Alliance, seeks their inclusion in all aspects of health care.

THE STATE CONTEXT

California's first state plan for ADRD was released in 2011, but as with plans in other states, implementation of its goals required new funding, development of broad coalitions, and creation of extensive, multi-stakeholder collaborations. These have now produced important new aging initiatives with ADRD impact:

GOVERNOR'S MASTER PLAN FOR AGING The updated local playbook shares tools and resources to guide communities to create their own master plans, but does not address early dementia detection.

CALIFORNIA ADVANCING AND INNOVATING MEDI-CAL (CALAIM) This Medi-Cal innovation effort seeks to leverage successful pilots (Whole Person Care, Health Homes Program, Pharmacy Executive Order) to support new state infrastructure for implementing Managed Long-Term Services and Supports (MLTSS) statewide by 2026. MLTSS will provide appropriate services and infrastructure for home and community-based services to meet the needs of aging beneficiaries and individuals at risk of institutionalization. The Enhanced Care Management benefit developed for CalAIM is intended to better serve individuals with complex care needs, and though not specifically targeted to individuals living with dementia, its relevance is clear: dementia is the most disabling condition of older adults and a major contributor to the need for complex care.

DEMENTIA CARE AWARE AND THE CALIFORNIA DEPARTMENT OF PUBLIC HEALTH DEMENTIA STANDARD OF CARE Dementia Care Aware is a new online clinician education program specially designed for professionals caring for Medi-Cal recipients aged 65+, offering continuing education credits for training and a unique Medi-Cal billing code that pays for cognitive assessment and

components of diagnosis not otherwise covered by Medi-Cal. The training, open to all healthcare providers, incorporates the five elements of the California Department of Public Health (CDPH) Dementia Standard of Care:

- Detect and diagnose
- Provide post-diagnosis support and disease education
- Provide care planning and coordination
- Manage medications and treat co-morbidities
- Refer to community-based organizations for additional supports

Realizing the impact of these bold principles requires buy-in, planning, and implementation within healthcare systems that have heretofore been slow to adopt dementia care innovations. Moreover, no readily available data sources exist to make evaluation of new programs possible; a Dementia Care Aware workgroup is now in the process of determining how such data might be accessed.

THE LOS ANGELES COUNTY CONTEXT

Several local efforts in ADRD are led by the Office of Senior Health, a County of Los Angeles Board of Supervisors-mandated Office housed in the Division of Chronic Disease and Injury Prevention in the Los Angeles County Department of Public Health. The Office maintains a website including links to resources, including information for caregivers, information about nursing homes, and other relevant topics, as well as a link to local *Healthy Brain LA* activities. The website remains under active development, with links to ADRD programs geared mainly toward public health and other professionals. Not yet available are links directing lay people to topics such as how to know when a cognitive change is not 'just aging,' how to find a clinician to evaluate someone with concerns about their own or a loved one's cognitive functioning, or how to look for training in dementia detection or care. Other topics not featured 'front and center' are materials focused on disproportionately affected populations within Los Angeles County, such as Latinx, Native American, and Black communities. There are links to other websites reporting county data, but the Department of Public Health does not typically collect or publish primary data about dementia diagnoses, including rates, stages, or types. The agency historically does not deliver primary care services and has limited access to patient level data, as these data are protected health information and access is governed by HIPAA regulations.

FACTS AND FIGURES

Aging, ADRD, and Health Disparities Los Angeles County is one of the largest, most populous, and ethnically diverse counties in the nation. An estimated 166,857 Los Angeles County residents over age 65 years old are currently living with ADRD, with numbers expected to double by 2040.[9] These increases are due in large part to the growth in the County's older adult population, expected to rise from 9.7% in 2000 to 18.2% in 2030.[10] Estimated ADRD prevalence among Los Angeles County's Medicare beneficiaries is about 14%, higher than at the state (11%) and national (11%) levels. ADRD is the second leading cause of death, accounting for nearly 6,000 in Los Angeles County and almost 23% of all ADRD related deaths statewide.[4] From 2009 to 2019, the ADRD mortality rate in the county increased by 68%,

by far the largest increase seen in any disease during that time span, though figures are likely influenced by changing trends in attribution.[4] Los Angeles County is among the most diverse counties in the US: there are an estimated 43,870 Latino/Hispanic individuals and 12,727 African American individuals living with AD in Los Angeles. Between 2015 and 2030, this number is expected to increase by 90% and 48% respectively as these populations continue to age.[4] The prevalence of dementia among minoritized populations – especially Latino/Hispanic, African American, and Native American and other indigenous persons, and others experiencing prolonged and persistent marginalization – is well known to exceed that among non-Hispanic Whites of European ancestry; a newly vigorous and more inclusive research community is making important new discoveries about the basis for these discrepancies – and their importance for planning dementia risk reduction efforts.

Caregiving In Los Angeles County in 2019-2020, approximately 1 in 5 adults reported providing care for a family member or friend in the last month, about 10% of whom reported providing care for someone with dementia.[11,12] A new Los Angeles County caregiver survey from the USC Family Caregiver Support Center, conducted as part of its work for Los Angeles County's BOLD projects, proved an important and unexpected source of evidence about local rates of under-diagnosis: this survey found a markedly lower prevalence of medically diagnosed ADRD (39%) than of functional disability attributable to cognitive impairment (over 80%).

PROGRAMS AND PARTNERSHIPS TO ADDRESS THE AGE BOOM AND ADRD

- *Purposeful Aging Los Angeles (PALA)* The partnership was formed to help the Los Angeles region prepare for the dramatic demographic shift in proportions of older adults in the population that will occur by 2030. PALA's ultimate goal is to make the Los Angeles region the most age-friendly in the world. PALA has begun to incorporate a dementia capable component into this effort.
- *Los Angeles Alliance for Community Health & Aging (LAACHA)* Part of PALA, this is a broad, multi-stakeholder strategic alliance. Its driving vision is a community in which all residents take action to improve their health and well-being and can access evidence-based community health programs through a cohesive, interdisciplinary, and culturally comprehensive network of organizations.
- *LA Found* quickly locates individuals with autism or ADRD who wander and go missing. It features a system of trackable bracelets that can be located using receivers carried in Los Angeles County Sheriff's Department helicopters and designated ground units. The program hosts a detailed, user-friendly website with links to key aging and dementia resources.
- *Los Angeles County BOLD Initiative (LA BOLD)* lays the foundation for enacting strategies to reduce the risk of brain failure in late life, increase early detection of dementia, prevent and manage comorbidities prevalent among individuals with ADRD, and include family caregivers as partners in care. The primary goal of this three-year initiative is to support the development of a countywide ADRD strategic plan that addresses policy, systems, and social/cultural environmental needs.
- *Healthy Brain Initiative: Los Angeles* seeks to promote brain health as a target to improve the wellbeing of minority communities already affected by ADRD in South Los Angeles.

- *Healthy Brain LA Coalition* is facilitated by the Division of Chronic Disease and Injury Prevention at the local health department. Launched in 2021, the Coalition aims to drive forward a cohesive agenda that positions ADRD as a top public health issue in Los Angeles County.

Tables 1 and 2 provide a fuller listing of state and countywide reports and programs with direct or potential relevance to ADRD.

Table 1: California and Los Angeles County Level Data Sources

Statewide
• California State Master Plan for Aging
• CHIS (California Health Interview Study, UCLA Center for Health Policy Research)
• Department of Health Care Services Comprehensive Quality Strategy 2022
• California Health and Human Services Advisory on Dementia Standard of Care Report
• CA Bold Ideas (Milken Foundation working group, 2022)
Countywide
• LA BOLD
• Our Path Forward: Alzheimer's Prevention and Preparedness Governor's Task Force Report 2020 (AARP/PALA)
• California Department of Health Care Access and Information (HCAI) (formerly OSHPD) healthcare utilization database
• Los Angeles County Caregiver Analysis Report 2022

Table 2: California and Los Angeles County Clinical and Community Programs Relevant to Dementia

Statewide
• Dementia Care Aware – clinician education/continuing education credits
• Comprehensive Alzheimer's Disease Centers – state-funded memory assessment and care clinics (10, all based in academic research institutions; 3 are in Los Angeles County: one at UCLA and two at USC, including Rancho Los Amigos (special focus on the Latinx population)
Countywide
• Healthy Brain LA Coalition (CDC funding to DPH)
• Los Angeles Alliance for Community Health and Aging (LAACHA)
• LA Found (Department of Aging and Disabilities)
• Purposeful Aging LA Initiative (City of Los Angeles/Los Angeles County/AARP/Private Sector/University)
• Independence at Home (SCAN)
• Wise & Healthy Aging
• Law Enforcement Training on Dementia (DA Office)
• Mental Evaluation Team (Los Angeles County Sheriff's Office)
• Alzheimer's Los Angeles
• Alzheimer's Association California Southland
• Geriatric Evaluation Networks Encompassing Services Intervention Support Program (GENESIS) (Los Angeles County Department of Mental Health)

- Workforce Development Aging and Community Services (WDACS)
- Los Angeles County Department of Health Services (Hospitals and Clinics)
- Federally Qualified Health Centers and Community Clinics
- Partners in Care Foundation
- Health Resources Services Administration- Geriatrics Workforce Enhancement Program Grants (Academic Centers)
- Clinical training programs in geriatrics (multiple disciplines)

California has been home to two nationally recognized, evidence-based innovations in dementia care with potential for population impact. Both were developed with national research and demonstration grant funding: the University of California Los Angeles' (UCLA) Alzheimer's and Dementia Care Program (ADC Program) led by Dr. David Reuben, and the University of California San Francisco's (UCSF) Care Ecosystem for caregivers, led by Dr. Katherine Possin.[13] Both programs have undergone significant expansion with implementation sites across the country. Though neither explicitly addresses dementia detection, both are examples of ways to build robust, clinically centered infrastructure for translating expanded detection efforts into high quality care in Los Angeles County.

Methods and Data Sources

We began our landscape analysis by first reviewing published materials related to the estimated prevalence of dementia, its detection and management, associated health disparities among traditionally marginalized communities, and culturally sensitive dementia care. We extracted state and Los Angeles County-specific current policies and practices related to dementia detection. We developed a key informant survey and interview guide centered on dementia detection, particularly on utilization of existing CMS benefits for dementia detection and the extent to which efficient cross-sector linkages have been developed.

Using our collective knowledge, local relationships, and a snowball recruitment approach, we successfully engaged 21 knowledgeable individuals working in health services, social services, aging services, and public health (see Appendix A). We chose individuals with administrative, dual clinical-administrative (and in some cases research), or leadership responsibilities in local programs and systems. We did not recruit individuals living with dementia or caregivers. We conducted 1- hour interviews with key informants and recorded them to capture detail. Lastly, we summarized survey data and extracted common interview themes.

Results

SURVEYS

Table 1. Survey Response Rate

Survey Response Rate	
Key Informants Invited	21
Survey Respondents	12
Response Rate	57%

From January 2022 to September 2022, a total of 21 key informant interviews were completed. Of the 21, 12 interviewees also completed the aforementioned survey (See Table 1). While clinicians and leaders of community-based organizations (including social and aging services) were highly receptive to our invitations, our efforts were less successful in engaging health plans and high-level administrative leaders.

Survey respondents represented a diverse background of professions and experiences. Table 2 shows the type of organization that survey respondents represented, while Table 3 demonstrates the individual's roles within their respective organizations.

Table 2. Organizations Represented

Represented Organizations	
Health Care Delivery	7
Academic Medical Center	3
Community Based Service Organization	1
Health Plan	1

Note: Community Based Service Organizations includes aging and social services.

Table 3. Organizational Roles Represented

Represented Roles Within Organizations	
Administration	11
Clinical Care	9
Education	5
Research	3
Advocacy	2

Note: Survey respondents could choose all roles that apply.

STRATEGIC PLANS AND GOALS FOR EARLY DEMENTIA DETECTION

Of the 12 respondents completing the survey, all were aware of potential opportunities for earlier dementia detection within their own scope of activity, but none of the organizations represented had a clear, measurable target goal, strategy (e.g. implementing early detection as a system priority) or accountability plan (e.g. making early detection a quality indicator), and none assessed their performance (e.g. by monitoring electronic medical record diagnoses or encounter data).

Does your organization have any strategic plans or goals to increase early detection of dementia?	*"Restarting annual wellness exams within clinic"* *"Incorporating Mini-Cog screening during annual wellness visits"* *"Increasing all team training, incorporating tools into the EHR, and implementing programs/supports when dementia is identified"* *"New diagnosis of dementia triggers a care manager follow-up"*

USE AND TRACKING OF COGNITIVE CARE BENEFITS UNDER MEDICARE: ANNUAL WELLNESS VISIT, COGNITIVE ASSESSMENT AND CARE PLANNING, AND CHRONIC CARE MANAGEMENT

Medicare benefits enable the establishment of a clinical pathway for dementia starting with proactive/early detection (via Annual Wellness Visits [AWV]), followed by reimbursable cognitive assessment and care planning that integrates a caregiver, and chronic care management. A system's use of each of these benefits can be tracked in administrative data through visit codes. Only two of the survey respondents reported that their respective organizations tracked use of these codes – both only tracked AWVs.

Table 4. Tracking Uptake of Dementia-Relevant Medicare Benefits

Does your organization promote or track the use of Medicare benefits that enable improvement in dementia care?	
No	6
Unsure	4
Yes	2

Note: The AWV can be utilized under all existing healthcare payment models, while the Cognitive Assessment and Care Plan code and the Chronic Care Management codes were designed for traditional (fee for service) Medicare. Medicare Advantage plans can now, under a recent update to Hierarchical Condition Coding (HCC risk stratification), receive additional dollars reflecting the 'value' of a dementia diagnosis; that change could, in principle, incentivize detection of dementia at earlier stages when the costs of healthcare for patients are lower than at late stages.

CAREGIVER IDENTIFICATION AND ENGAGEMENT

One key issue emerging from survey responses was the lack of a formal system for involving caregivers in the care of people diagnosed with dementia. Not only are caregivers 'invisible' in electronic health records, but integrating caregivers into processes of detection, diagnosis, and care for people with dementia is at best informal and unstandardized.

The majority of survey respondents noted that their respective organization did not identify people with cognitive impairment and/or dementia diagnosis as a population that requires caregiver

recognition and participation (Table 5). As shown in Table 6, most respondents also reported that their organization did not promote caregiver-inclusive discharge conferences, a key process for implementing the CARE Act and promoting continuity of care.

Table 5. Identifying Need for Caregiver Participation in Care

Does your organization flag people with a cognitive impairment and/or diagnosis of dementia as a population that requires caregiver participation in medical visits/decision making?	
No	9
Unsure	2
Yes	1

Table 6. Caregiver Participation in Discharge Conferences

Has your institution implemented the CARE Act requiring identification of a caregiver at the point of discharge?	
No	8
Unsure	4
Yes	0
Does your organization hold caregiver-participating discharge conferences?	
No	10
Yes	2
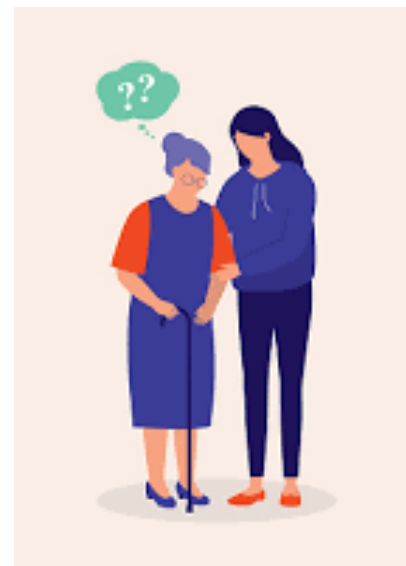
In addition, survey respondents were asked whether and how their respective organizations identified caregivers (family, friends, or other designated caregivers) in their electronic medical records. Examples are presented below. No organization had implemented caregiver identification within a searchable field; when a caregiver is identified that information resides in narrative notes that must be manually searched.

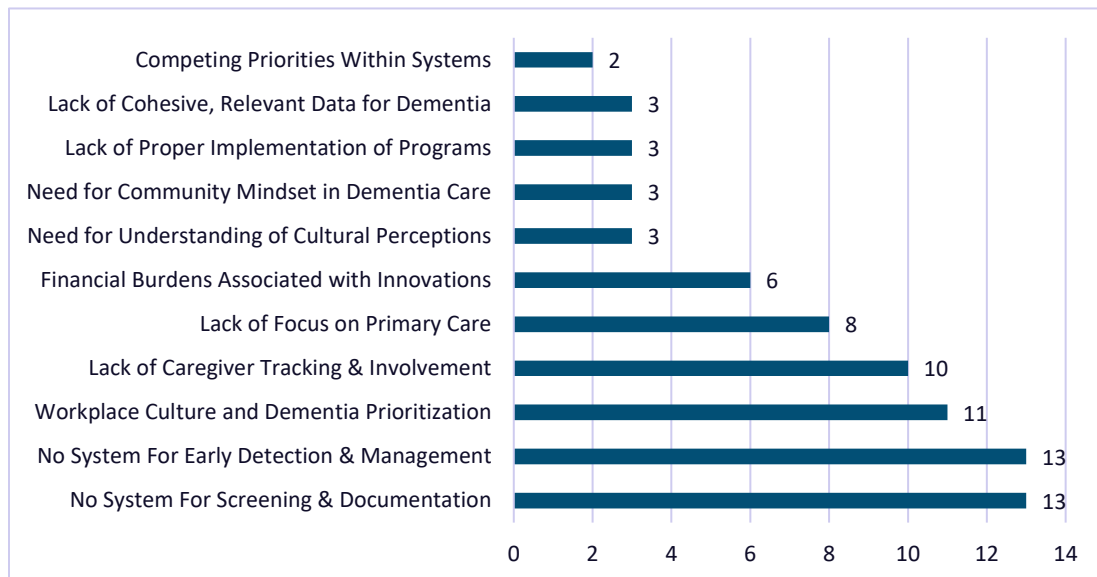| How does your organization identify family/friend/employed caregivers in the medical/other record system?	*"Each provider has to document it in their own clinical notes."* *"Adherence to this varies greatly from clinician to clinician."* *"Free text in either their history of present illness or treatment plans."* *"Patients with dementia are asked if they have a caregiver/who helps them, and the caregiver is routinely requested to attend visits with the patient."* *(Health Plan Respondent) "Caregiver is named within the care management documentation system [which is held within the health plan and is separate from clinicians' records], and while the care plan is shared with providers, the care manager and provider systems exist independently and do not directly interact."*

Note: Caregivers may or may not be legal next of kin or hold durable power of attorney (DPOA), which along with parties responsible for paying the patient's medical bills, are documented within searchable medical record fields.

KEY INFORMANT INTERVIEWS

IDENTIFYING ROOT CAUSES OF LOW IMPLEMENTATION OF DEMENTIA CARE PRINCIPLES: SYSTEM BARRIERS

Figure 1. Barriers to Improving Detection and Diagnosis: Themes from Key Informant Interviews

Barrier	Count
Competing Priorities Within Systems	2
Lack of Cohesive, Relevant Data for Dementia	3
Lack of Proper Implementation of Programs	3
Need for Community Mindset in Dementia Care	3
Need for Understanding of Cultural Perceptions	3
Financial Burdens Associated with Innovations	6
Lack of Focus on Primary Care	8
Lack of Caregiver Tracking & Involvement	10
Workplace Culture and Dementia Prioritization	11
No System For Early Detection & Management	13
No System For Screening & Documentation	13

Note: Multiple themes were common throughout each key informant interview.

Throughout all 21 key informant interviews, we identified recurring themes centered around root causes – attitudinal and systemic barriers to improving detection and diagnosis (Figure 1) – that, if overcome, could fill the practice gaps identified in the surveys. The most prevalent barrier, noted by

13 of 21 key informants, was a lack of systems in place for conducting, documenting, and retrieving information about early detection activities and specific management steps. Also important, but not specifically mentioned except as a subject for research, was the lack of attention to utilization or other outcomes associated with dementia care (e.g., hospitalizations, ED visits, ambulatory care) within health care systems.

Qualitative themes from these interviews highlight some of the root causes of under-detection of dementia within Los Angeles County across all four sectors – health services, public health, aging services, and social services. For all, a leading contributor to under-detection of dementia was the lack of a workplace culture that promotes early detection and absence of systems for doing so.

Within health care systems, several barriers were identified. Despite strong evidence that most dementia is first diagnosed by primary care clinicians in the United States, interviews with health care providers indicated that workplace culture does not prioritize primary care, dementia detection and care more broadly, or formal caregiver identification and involvement in that care. Another cause for poor dementia detection and care within health care systems is the lack of optimal use of available Medicare benefits designed to improve them. We found no evidence that the COVID-19 pandemic played a role in the state of dementia detection today, despite having consumed both the attention and many of the resources of Los Angeles County health systems for the past two or more years –one recent peer-reviewed publication from a local healthcare system found that the pandemic-related transition to virtual visits did not reduce dementia detection as captured by diagnosis codes.[14]

The other three sectors (public health, social services, and aging services) have not taken the initiative to include formal mechanisms for detecting cognitive impairment as part of their work. However, organizational staff are often aware that a client likely is living with dementia and may not have been diagnosed; in such instances, interviewees commonly commented that despite wanting to link such clients to a clinician for formal evaluation, the pathway is often unclear or progress stalls.

Importantly, interviewees from all four sectors agreed that dementia detection needs to increase and should happen outside of, as well as within, health care delivery. In a notable demonstration project, a community-based organization, Alzheimer's LA, collaborated with a health plan serving dual-eligible individuals to implement telephonic cognitive impairment screening for beneficiaries.[15] We learned, however, that the results of screening may not make their way into clinical hands due to parallel information systems that do not communicate. It is clear that there is both insight and enthusiasm for collaboration across all four sectors to achieve sustained improvement in early detection.

LIMITATIONS

Survey focused mainly on healthcare.

- The survey content was created principally for healthcare; future efforts should include surveys developed with and tailored for specific organization types in order to fully represent the spectrum of attitudes, practices, and activities relevant to dementia detection.
- We did not interview people living with dementia or their caregivers; their perspective on improving early detection of dementia and their engagement in reform are crucial.

Lack of input from payers and senior healthcare decision makers.

- We were unable to secure interviews with the majority of health plan providers in Los Angeles County, and as a result, could not determine what they might be doing in regard to early detection and diagnosis. This may hint at a lack of interest on the payer part in elevating early detection of dementia as a priority.
- We were unsuccessful in engaging high-level administrators within healthcare provider organizations that serve large populations. Because these institutions care for a large older population, their perspectives would have enriched our understanding of the landscape of dementia detection from a systems point of view.

Summary and Broad Recommendations

Dementia is a chronic medical condition with behavioral and social manifestations; its growing prevalence and its personal, systemic, and societal costs call for a unified approach that engages four sectors: health care delivery, public health, social services, and aging services. To improve early detection and care, all sectors must play a role in recognizing cognitive change. With passage of the BOLD Act, strategies for improving early detection across all sectors should consolidate under the leadership of public health agencies responsible for chronic disease prevention and control.

The leadership role of public health centers on accountability for setting the vision, goals, strategic plan, road map, and policy directions for ADRD activities, but their powers lie in public health's moral authority, messaging capabilities, and convening functions. Public health has **moral authority** to set the vision and goals for dementia detection, including responsibility for recognition across sectors, and transitions from recognition to formal evaluation and diagnosis. Also, departments of public health can set all-sector goals for reducing risks to brain health through the lifespan and do so in a way that reduces health disparities. One promising opportunity leverages the planned redesign and new leadership of the Los Angeles County Department of Aging and Disabilities to establish simple, plain-

language tools and materials that facilitate recognition of dementia outside the health care sector (e.g., within senior centers, home based case management programs, home delivered meal providers, first responders, and community health workers). An important application of such tools would be to improve detection of dementia among individuals experiencing financial, psychological, and physical abuse and neglect, and connecting them with health care providers and systems.

Public health's **messaging capabilities** include crafting and disseminating culturally congruent brain health and dementia information to the public through diverse channels, and to promote partnerships with existing collaboratives such as LACCHA; publicizing standards for dementia detection as operationalized in Dementia Care Aware; and disseminating standards for dementia care established under the CDPH and enacted through training for implementation of evidence-based care models (e.g. UCLA's ADC Program, UCSF Ecosystem, and USC Keck Preoperative Brain Health Assessment).

Public health has the **convening power** to influence the course and quality of dementia detection across sectors by bringing together key stakeholders in aging services, social services, and healthcare services. Stakeholders also include health plans, information specialists, leaders of first responder services, and philanthropic sponsors to secure a shared population health vision, publicize standards for dementia-friendly care delivery, develop the business case for better dementia care, and establish the data systems and repositories needed for cross-sector collaboration and program evaluation.

Recommendations for Public Health Action

*Recommendation #1: **Convene small working groups to set health care policies and practices that prioritize early detection of dementia in their own organizations. Working group participants should include representatives from high level Los Angeles County healthcare systems, health plan administrators, and representatives from relevant professional organizations (such as the Hospital Association of Southern California). Working groups should address the following priorities:***

- Initiate agreement on core data elements required for assessing and managing quality, including identifying caregivers in a searchable field in electronic medical records.
- Prioritize uptake of Annual Wellness Visit, adoption of cognitive screening, and the use of available Medicare benefits, and teach providers to utilize and set measurable performance targets.
- Endorse and create a local implementation plan for California Department of Health Care Services and CDPH dementia care standards.
- Completion of Dementia Care Aware training for all providers who care for older adults.

Recommendation #2: **Convene an expert communications working group to develop public health messaging to heighten awareness of brain health and promote early detection of dementia among key providers and stakeholders. Strategies could include:**

- Leveraging important messaging successes developed by other BOLD-funded programs and centers around the country.
- Using learnings from successful public health campaigns in other fields of practice (e.g., in sexually transmitted infections, HIV, smoking, tele-mental health). Showing how to seek evaluation of cognitive concerns for oneself or a loved one.
- Developing plain-language messaging that explains California's core components of ADRD care.
- Assuring that messages reflect the diversity of the population and are disseminated across multiple media platforms (traditional, non-traditional, social media).

Recommendation #3: **Engage key stakeholders and agencies responsible for health care policy and reimbursement to plan and address care for persons with dementia and their families. Strategies should include:**

- Expanding eligibility for Enhanced Care Management under CalAIM to include dementia as a qualifying disability and source of complex care needs. Include individuals with a dementia diagnosis at any level of disability.
- Enabling the Los Angeles County Aging and Disabilities Department and other local government aging services agencies to implement training and protocols for community health workers and other service providers to recognize possible dementia and make appropriate, responsible, and protocolized handoffs. Such service providers could include Adult Protective Services, first responders, and senior center staff, among others.

Recommendation #4: **Establish a multi-sector learning collaborative with public health support, led by a core team that brings together representatives from healthcare delivery, aging services, and social services to address data needs, including a cross-sector data repository and analytic strategy.**

- Incorporate the essential data elements (see Recommendation #1) needed for a comprehensive approach to detection, care, monitoring, quality improvement, and planning. Consider processes such as those used to develop the California Controlled Substance Utilization Review and Evaluation System (CURES) database and Georgia's statewide dementia registry under their BOLD program, developed with academic partners at Emory University.
- Expand public health-academic partnerships to bring the research, policy, and information infrastructure skills and resources of local universities more fully to bear on dementia as a population health problem – including some that are already doing so, e.g., the Alzheimer's program within the Shaeffer Center at USC.

Appendix A

LIST OF INFORMANTS AND THEIR RESPECTIVE ROLES

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Laura Trejo, PhD, Executive Director of Aging and Community Services, WDACS

Appendix B

ENCYCLOPEDIA OF GAPS IN DEMENTIA DETECTION

1. Low awareness of standards of dementia detection and care.
2. Lack of consensus/core set of basic skills for dementia detection and care coordination that can be applied across different settings and agencies.
3. Lack of workflow for closed loop linkage between clinical and community-based organizations serving individuals with dementia and caregivers.
4. Limited eligibility for publicly funded disability services, overdependence on basic activities of daily living (ADL) deficits and physical disability; dementia itself is disabling condition from diagnosis onward.
5. Lack of mandatory workforce training on how to utilize public-facing programs, clinicians, and service providers, e.g.:
   - First responders, such as law enforcement and fire-fighters, can learn to suspect dementia in elderly or high-risk patients (e.g., frail older adults) and determine next steps.
   - Staff from social services (governmental agencies such as Adult Protective Services and community-based organizations such as housing services) that frequently interact with the elderly can learn to screen for cognitive impairment and refer individuals appropriately for additional care and support.
   - Emergency department and acute care providers on who and how to screen for and cognitive impairment and dementia,
   - Emergency department and acute care providers on how to diagnose cognitive impairment and dementia, arrange for a meaningful discharge plan that reflects patient needs and vulnerabilities and provide continuity for dementia care in the outpatient and community setting.
   - Primary care clinicians on how to screen and diagnose patients with cognitive impairment and dementia.
   - Trainees in all clinical and ancillary disciplines caring for people living with disabilities and families in basic understanding of cognitive disorders of aging, e.g., through the ECHO mechanism, already utilized by Alzheimer's LA, Alzheimer's Association of LA, Rancho Los Amigos, and others.
   - Next-generation clinicians, who will need skills for team-based care and dementia care
   - Residency training in dementia content, importance of diagnosis, next steps in referrals and management and team-based care
   - Interprofessional dementia training to collectively educate health professional students (Physical Therapy, Occupational Therapy, Medical, Pharmacy) about the interdisciplinary and team-based nature of dementia care

6. Lack of incentives for early detection.
7. Lack of agreement on protocols and methods for implementing care pathways once cognitive impairment is detected within and across sectors.
8. Lack of data resources, access to existing data, and reporting within and across sectors.
9. Unclear leadership authority and accountability for dementia related services in all sectors.

Appendix C

POTENTIAL ACTION TARGETS FOR DEMENTIA DETECTION

1. **Action targets for multistakeholder convening.** Based on critical identified gaps in existing data, infrastructure, clinical and administrative values and practices, and cross-sector linkages, we identify a range of goals for such convening:
   a. Formally adopt CDPH dementia care goals as an organizing framework for county-wide improvement. This sets a uniform benchmark.
   b. Build a unified, cross-sector "total cost" model that combines social and health care for people living with dementia and their caregivers. This better reflects true dementia-related care needs and costs, creates a basis for cross-sector planning, budgeting, cost-sharing, and fundraising. It also aligns in principle with alternative payment models for dementia care that are likely to emerge from CMS/CMMI.
   c. Make necessary improvements in use of clinical information technology:
      i. Increase specificity of data fields to capture data about dementia detection and care (e.g., cognitive assessments not searchable, care plan action steps not identified, systems don't track).
      ii. Require identification of caregivers in electronic medical records regardless of site of care; foster implementation of California's CARE Act that already requires caregiver identification and inclusion in discharge plan for all hospitalized patients.
   d. Stimulate uptake of Medicare benefits that enable dementia detection (e.g., Annual Wellness Visits) and care (e.g., care planning and chronic care management).
   e. Set benchmarks for including caregivers in detection, diagnosis, care planning, and follow up – as called for in the California Master Plan on Aging and the Los Angeles Caregiver Landscape Analysis Report.
   f. Engage Los Angeles County research institutions in developing evidence regarding needs for medical specialty care for dementia and define appropriate staffing densities for memory clinics in Los Angeles County. This creates a basis for long-term improvement in access.
   g. Engage the same institutions in identifying best practices for efficiently linking health and social care services, both in urgent/emergent situations (e.g., lost older adult; first responder emergency calls; essential cross-referrals for providing essential services as called for in the CDPH ADRD standard of care).
   h. Define dementia as a "dominant disability" that qualifies individuals for publicly supported services (e.g., Expanded Care Management under CalAIM).

2. We also identified a large group of potential advisors experienced in establishing organizational standards and taking practical steps to implement effective programs:

Primarily healthcare focused

- Health system specialists within AlzLA and Alzheimer's Association of LA; AlzOC also has expertise in bringing health systems and providers to the table.
- Hospital Association of Southern California
- Primary care, specialty, and nursing professional organizations
- UCLA's Alzheimer's and Dementia Care program (ADC program)
- Keck USC's Preoperative Brain Health Initiative
- Rancho Los Amigos physician education program (GWEP)
- Cedars Sinai inpatient dementia detection, management and post-hospital transition program.
- Potential new specialist Behavioral Neurology training program – Cedars
- Geriatrics-certified Emergency Departments in Los Angeles County
- Age Friendly-Certified Health Systems in Los Angeles County
- Geriatrics and dementia expertise within Los Angeles County's academic medical institutions: LAC+USC and Harbor-UCLA
- SCAN and other health plans
- FQHCs and Community Clinics

Primarily community and aging services focused

- Department of Aging and Disabilities
- ADRD-specific community services (AlzLA, Alz Association)
- Social work professional organizations
- CA Caregiver Support Program at USC

Primarily training and research focused

- USC Schools of Social Work and Gerontology; Keck School of Medicine
- Specialized USC Centers, e.g., Schaeffer Center for Health Policy and Economics (Alzheimer's Disease Resource Center for Minority Aging Research; Center for Advancing Sociodemographic and Economic Study of Alzheimer's Disease and Related Dementias; Roybal Center for Behavioral Interventions in Aging)

Appendix D

GLOSSARY OF TERMS/COMMONLY USED ACRONYMS

AAA	Area Agencies on Aging
AARP	The American Association of Retired Persons
ADC Program	Alzheimer's and Dementia Care Program
ADRD	Alzheimer's Disease and Related Dementia
AFHS	Age-Friendly Health Systems
CalAIM	California Advancing and Innovating Medi-Cal
CARE Act	Caregiver Advise, Record, and Enable Act
CBO	Community Based Organization
CDC	Centers for Disease Control and Prevention
CMS	Center for Medicare and Medicaid Services
CMMI	Center for Medicare and Medicaid Integration
GWEP	Geriatrics Workforce Enhancement Program
HBI	Health Brain Initiative
HCAI	California Department of Health Care Access and Information
LAACHA	Los Angeles Alliance for Community Health & Aging
LA BOLD	Los Angeles County BOLD Initiative
PALA	Purposeful Aging Los Angeles

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