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Milken Institute Alliance to Improve Dementia Care

Improving Early Detection of Cognitive Impairment and Dementia

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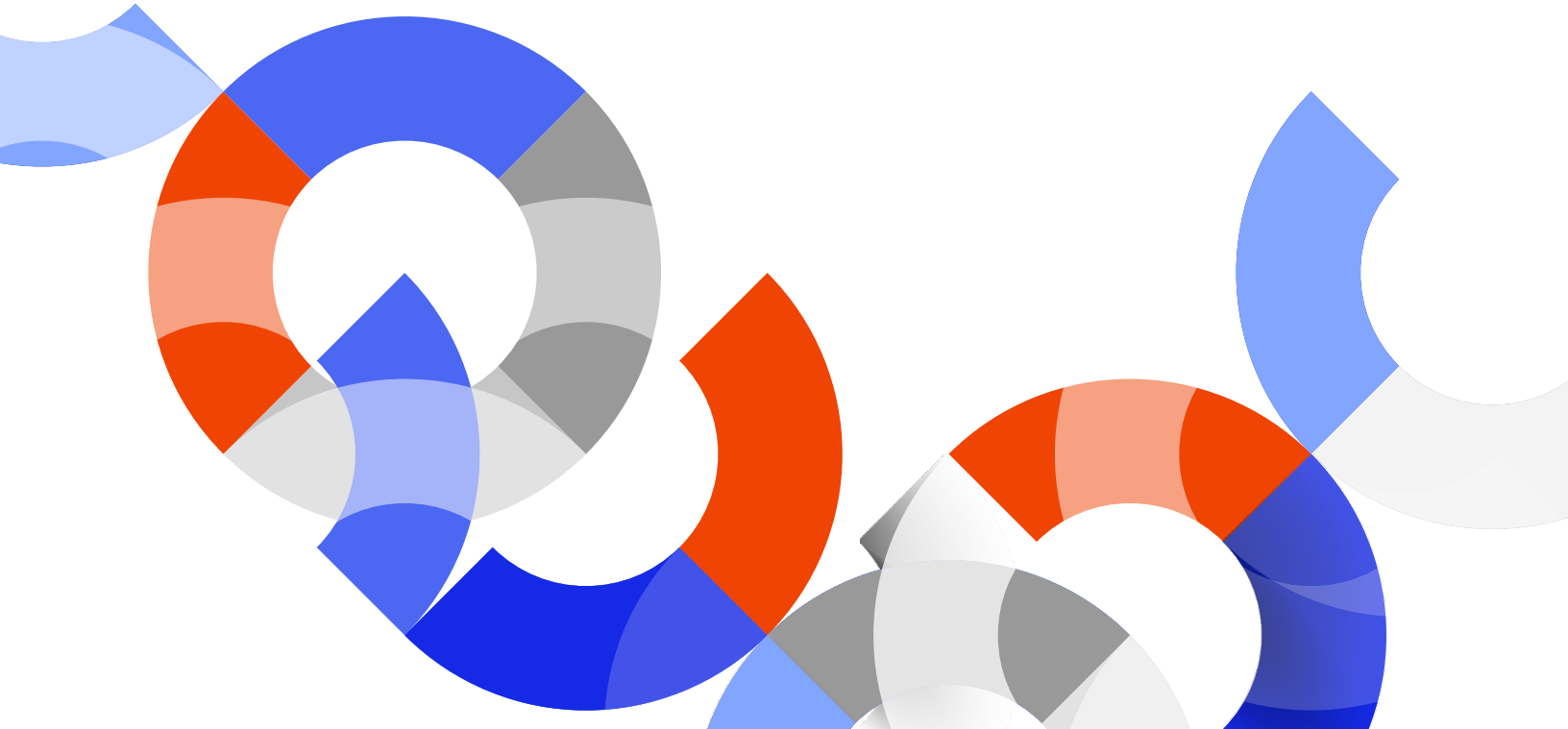

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About the Alliance to Improve Dementia Care

The Milken Institute Alliance to Improve Dementia Care (the "Alliance"), a signature program of the Future of Aging, brings together a multisector coalition of leaders committed to advancing early detection, access to treatment and coordinated care, and health equity for people at risk for or living with dementia and their caregivers. Through expert workshops, convenings, and collaborative initiatives, the Alliance amplifies and promotes the adoption of proven solutions and promising innovations. This report is informed by a consensus-building approach but may not reflect the views of all Alliance members.

Acknowledgments

This report was made possible by the Steering Committee members of the Alliance to Improve Dementia Care with additional support from Biogen, Eisai, and Eli Lilly & Company. We are grateful to those who participated in our working group and roundtable and provided feedback as key opinion leaders. Alliance members and participants contributed ideas and recommendations summarized in this report.

Contents

Executive Summary

The prevalence of mild cognitive impairment (MCI) and dementia is increasing as advancements in medicine, public health, and living standards extend human lifespans. Approximately 12–18 percent of Americans aged 60 and older have MCI, and nearly 7 million older adults (aged 65 and older) currently live with Alzheimer's disease (AD). By 2060, dementia is expected to affect one in five older adults, increasing the already substantial impact of dementia care, currently costing $360 billion annually, excluding the substantial contributions of unpaid caregivers.

Early detection of MCI and dementia can improve outcomes for people living with dementia and their families, offering critical benefits such as identifying addressable causes, enabling lifestyle interventions, facilitating access to treatment, clinical trials, and community-based services, and preparing for care while people living with dementia can still participate in future planning. Recent advancements in dementia care related to cognitive assessments, risk reduction strategies, biomarker testing, and new treatments and management approaches drive the need for early detection. However, MCI and dementia are often underdiagnosed or detected at later stages because of complex factors such as stigma, primary care capacity and access constraints, and limited health system engagement.

In response to these challenges, the Alliance to Improve Dementia Care is releasing this updated report, building on its May 2021 publication, *Building Workforce Capacity to Improve Detection and Diagnosis of Dementia*. This update identifies current solutions, showcases scalable case studies, and highlights emerging innovations to advance the early detection of MCI and dementia. The report offers five key recommendations to improve early detection practices across the health-care system and in community settings, developed through input from Alliance members, expert interviews, insights from an August 2024 expert roundtable, and extensive research.

These recommendations aim to enhance primary care's capacity for early detection by suggesting ways to improve clinical workflows for cognitive assessment and evaluation, expand training for brain health conversations, and standardize assessment procedures for primary care teams. They propose methods to improve financial incentives that support cognitive testing, encourage the use of advances in digital health, and consider how new diagnostic methods can streamline processes and enhance care. Additionally, the recommendations provide opportunities to expand detection efforts beyond primary care by leveraging non-primary care health professionals and providers and community settings to broaden access and raise awareness, showcasing the innovative work being done to advance these initiatives. The following five recommendations are centered around two overarching themes to improve early detection in primary care and beyond:

Theme 1: Enhancing Primary Care Capacity and Cognitive Assessment Workflows

1. Normalize brain health discussions, expand education, and tailor training for primary care providers.
2. Integrate cognitive assessment tools into clinical workflows at the health system level.
3. Establish appropriate reimbursement policies to encourage cognitive assessments.

Theme 2: Expanding Detection beyond Primary Care

4. Expand training and support to specialty physicians and allied health professionals.
5. Expand and support early detection in community settings.

Introduction

The prevalence of MCI and dementia is rising as advancements in medicine, public health, and living standards extend the human lifespan. Approximately 12–18 percent of Americans aged 60 and older have MCI, and about one-third of those affected will develop dementia within five years of symptom onset.[1] Nearly 7 million older adults (aged 65 and older) are living with AD, the most common cause of dementia, accounting for 60–80 percent of all affected individuals. This figure is expected to double over the next 35 years.[2] By 2060, it is estimated that one in five older adults will be living with dementia.[3]

Dementia imposes a staggering financial burden on individuals, families, health systems, and society. In the US, dementia care accounts for an estimated one in six Medicare dollars and costs $360 billion annually, excluding the $347 billion in unpaid caregiving.[4] For people living with dementia, monthly out-of-pocket expenses range from $420 to $903, depending on the severity of the disease, with additional indirect costs for family caregivers ranging from $72 to $1,298 per month.[5] These costs are expected to increase fivefold over the next 25 years.[6]

Despite the rising prevalence and escalating costs of MCI and dementia, these conditions often go undiagnosed for complex reasons. A significant contributor is avoidance due to stigma associated with dementia, which, combined with low demand for early detection from patients, clinicians, and insurance providers, leads to missed opportunities for diagnosis. Additionally, there are major gaps in the adoption of scalable and sustainable tools, processes, and strategies within health-care systems, including primary and specialty care. Limited engagement from health systems further complicates efforts to improve early detection.[7]

Only 8–11 percent of individuals with MCI, often a precursor to dementia, receive a timely diagnosis,[8] and a recent study revealed that 40 percent of older adults with dementia symptoms either receive a late diagnosis or no diagnosis at all.[9] These delays are exacerbated among minoritized populations and other underserved groups, who often experience an additional 3- to 12-month delay in diagnosis,[10] compounded by a higher prevalence of cognitive impairment and dementia in some of these groups.[11]

For patients and families, early detection of MCI and dementia provides several benefits. It enables the identification of addressable causes, such as hearing loss; implementation of lifestyle modifications to reduce complicating factors and potentially delay progression; and access to appropriate treatment and management, clinical trials, home and community-based services, and educational opportunities in support of people living with dementia and their caregivers. Early detection also helps reduce health inequities by improving access to timely diagnosis and care, enhances adherence to treatment plans, and encourages individuals to actively participate in their care planning.[12] The advancements in digital cognitive assessments (DCAs), expanded biomarker testing, and enhanced care management strategies— along with the Food and Drug Administration's (FDA's) approval of lecanemab (Leqembi®) and donanemab (Kisunla™) for MCI due to AD and mild AD dementia, and the Centers for Medicare & Medicaid Services' (CMS') introduction of the GUIDE model for improved dementia care navigation—collectively highlight the substantial progress achieved in both the biomedical and psychosocial aspects of care and underscore the critical importance of early detection to facilitate a timely diagnosis and intervention.[13]

The Alliance to Improve Dementia Care

The Alliance to Improve Dementia Care ("Alliance"), a signature program of the Milken Institute Future of Aging, engages more than 130 experts in the public, private, and nonprofit sectors and utilizes a multi-sector approach to develop recommendations to improve care for individuals living with dementia and their caregivers across all stages. Building a dementia-capable workforce across the care continuum is a primary goal of the Alliance as we seek to close gaps in care through the coordination of individualized and integrated medical and social care.

In May 2021, the Alliance published a report titled *Building Workforce Capacity to Improve Detection and Diagnosis of Dementia* that presented consensus-based recommendations to advance timely detection and diagnosis in dementia care.

Given the rapidly evolving landscape of innovation in dementia care—from more accurate and scalable detection tools to new therapeutics to new payment models—the Alliance is providing this report update to improve early detection practices and emphasize the importance of early detection as a critical upstream activity, ensuring that these advancements can be fully leveraged to improve clinical outcomes and more effective use of health-care resources.

This update presents actionable recommendations to improve early detection in primary care and beyond. Recommendations were derived from members of the Alliance and other experts within its extended network and center around two themes: (1) Enhancing Primary Care Capacity and Cognitive Assessment Workflows and (2) Expanding Detection beyond Primary Care. The report also discusses persistent barriers to early detection and ongoing efforts to overcome them.

Barriers to Early Detection

To fully realize the benefits of early detection for individuals living with dementia, families, health systems, health and social service systems, and society, it is crucial for policymakers, health system leaders, clinicians, community-based organizations, and other stakeholders to address persistent barriers to the adoption of early cognitive assessment. The 2021 report *Building Workforce Capacity to Improve Detection and Diagnosis of Dementia* discusses various barriers in detail, such as stigma, limited time during primary care visits, the lack of trained staff, the US Preventive Services Task Force's conclusion that evidence is insufficient to support routine screening, and physicians' hesitancy due to perceived minimal benefits of early detection. Here, we review new insights and nuances learned since the original report and from efforts such as the Davos Alzheimer's Collaborative (DAC) to improve health system readiness.

What New Insights Have We Gained?

Routine cognitive assessments and clinician-initiated discussions about brain health, including strategies to reduce risk or slow cognitive decline, help reduce the stigma associated with dementia, educate individuals on the importance of brain health and its contribution to their overall health, and encourage individuals to seek help for memory concerns. These practices also emphasize the importance of brain health for overall well-being. Stigma, rooted in fear, ageism, and mental health biases, contributes to underdiagnosis or delays in diagnosis.[14] This issue can be particularly pronounced among people underrepresented in research; for example, an early report found a widespread misconception among Black older adults that dementia symptoms are a normal part of aging.[15]

The urgency of addressing inaccurate information and stigma has grown with recent developments, including the CMS-approved alternative payment model (GUIDE model) for individuals and families living with dementia, the FDA-approved disease-modifying treatments for individuals with MCI due to AD or mild AD dementia (lecanemab [Leqembi®] and donanemab [Kisunla™]), and the proliferation of clinical trials investigating novel therapies for Alzheimer's disease and related dementias (ADRD).[16] While detection of dementia at any stage of the disease is important for providing optimal patient care, late diagnosis denies individuals the opportunity to participate in clinical trials, receive treatments aimed at slowing progression to disabling cognitive impairment, and engage in care management planning.

The stigma surrounding MCI and dementia has been compared to the past stigma around cancer. However, it is important to recognize that stigma related to the brain and dementia differs from that of other chronic diseases or conditions. During an interview for this report, Malaz Boustani, MD, of Indiana School of Medicine, aptly described the unique stigma associated with dementia: "I think the main barrier for the early detection of AD and other related cognitive disorders is that there is no demand for early detection from the patient. Such a low demand is driven by dementia stigma. Patients worry that they will be perceived by their family, their neighborhood, and even their clinicians to have lost their brain, their identity, and their privilege of living independently in their homes, and even lose their driving privilege."

The deep fear older adults have of "losing who you are," "losing your dignity," and "losing your place" contributes to a lack of consumer demand for early detection. A detailed discussion of early detection protocols to help normalize cognitive assessment and promote brain health can be found in Recommendation 1 below.

Simple, systematic workflows, along with proper training, could streamline cognitive evaluations and make assessment and follow-up more efficient and accessible for both clinicians and patients. Whether conducting a cognitive screening program in community settings or administering structured cognitive assessment tests during routine primary care visits, any result indicating cognitive impairment necessitates a follow-up evaluation. This often becomes a bottleneck within health systems, which face numerous challenges related to resources and operational capacity that hinder the feasibility of widespread, consistent cognitive assessments.[17]

These challenges are compounded by the limited time primary care providers (PCPs) have during routine visits to address broader health maintenance goals, as well as immediate concerns that are more top of mind for patients and providers than brain health. Although the Medicare Annual Wellness Visit (AWV) is reimbursable and requires checking for cognitive impairment for reimbursement, implementation of validated approaches is not currently required. Additionally, most PCPs are employed by hospitals, health systems, or corporate entities that establish care protocols that may limit what individual clinicians might value or wish to do.

To overcome these barriers, effective change management, quality improvement practices, and updated reimbursement policies, including appropriate reimbursement rates, are essential to drive the adoption of cognitive assessments in primary care, as detailed below in Theme 1. Leadership support and advocacy are critical to ensuring the successful implementation and sustainability of new processes, as is involving other health-care professionals in brain health screenings to reduce the burden on primary care. Detailed recommendations on interprofessional collaboration for early detection are outlined in Theme 2.

Leveraging primary care practice values could strengthen critical pathways for early detection of MCI and dementia. Recent surveys show that PCPs recognize their role in identifying cognitive issues and conducting initial assessments. Most consider dementia care an integral part of their responsibility to provide comprehensive care.[18] However, early detection in primary care has been hindered by doubts about the benefits of an early diagnosis, limited treatment options, a shortage of accessible dementia support services (including a lack of knowledge of community-based resources to which they can refer their patients), and a lack of confidence and resources in diagnosing and managing dementia. A recent clinical trial showed that screening patients did not induce depression or anxiety, even if they screened positive, and a recent AARP survey revealed that providers tend to overestimate the level of worry patients have about dementia and underestimate their desire to know their diagnosis.[19]

These encouraging findings support new efforts to educate and train providers on how to discuss brain health and address patients' concerns in ways that are appropriate to primary care, while leveraging direct-to-consumer initiatives to complement these efforts. Recommendation 1 offers a discussion of this opportunity.

Clarifying the purpose of detecting cognitive impairment in the Medicare Annual Wellness Visit could improve its scalability for early detection and make routine cognitive assessment part of an individual's health risk assessment (HRA). Although the Alliance's previous report and other literature advocate a focus on the AWV as the principal vehicle to conduct routine cognitive assessments, the uptake and impact of cognitive outcomes remain relatively low despite over a decade of efforts to increase the detection of cognitive impairment during this visit.[20] In 2019, 55 percent of beneficiaries reported having an AWV, and among those, only 26 percent received a structured cognitive test. Updated data from 2023 indicate that while AWV uptake has increased,

the rise in structured cognitive testing has been more modest, with 81 percent of beneficiaries reporting having an AWV and only 31 percent undergoing a structured cognitive assessment.[21]

Experts agree that the AWV remains a valuable, convenient, and important touchpoint if appropriately designed. A strength of the AWV is its focus on detecting signals of possible cognitive impairment, not making a cognitive disorder diagnosis. Jeff Williamson, MD, chief of gerontology and geriatric medicine and director for the Center for Healthcare Innovation at Wake Forest University School of Medicine, reminded us during an interview for the report that "[t]he annual wellness visit was never meant to diagnose new and more subtle complex diseases like MCI or to start a referral process. It is more aligned with ensuring preventive practices for known conditions or to update documents like your advanced care plan or living will, and to make sure your vaccinations are up to date."

Medicare Advantage (MA) plans could be designed to promote early detection of dementia. More than half of Medicare beneficiaries are currently enrolled in a managed Medicare ("Medicare Advantage") insurance plan.[22] These privately administered plans negotiate a fixed monthly payment from the federal government for each enrollee, based on their expected health-care costs. The payments are adjusted using a "risk adjustment" model, which assigns an HRA score to each enrollee based on their diagnosed medical conditions. MA plans often pay licensed health-care professionals (usually registered nurses, nurse practitioners, or physician assistants) to meet with patients, conduct an HRA (sometimes as part of a Medicare AVW), and document all medical conditions affecting each patient.

However, these providers may not have longitudinal relationships with patients or close working relationships with PCPs and are not positioned to pursue a complex and nuanced diagnosis such as dementia. It is more likely that they would refer a patient to their PCP if they were concerned about cognition.

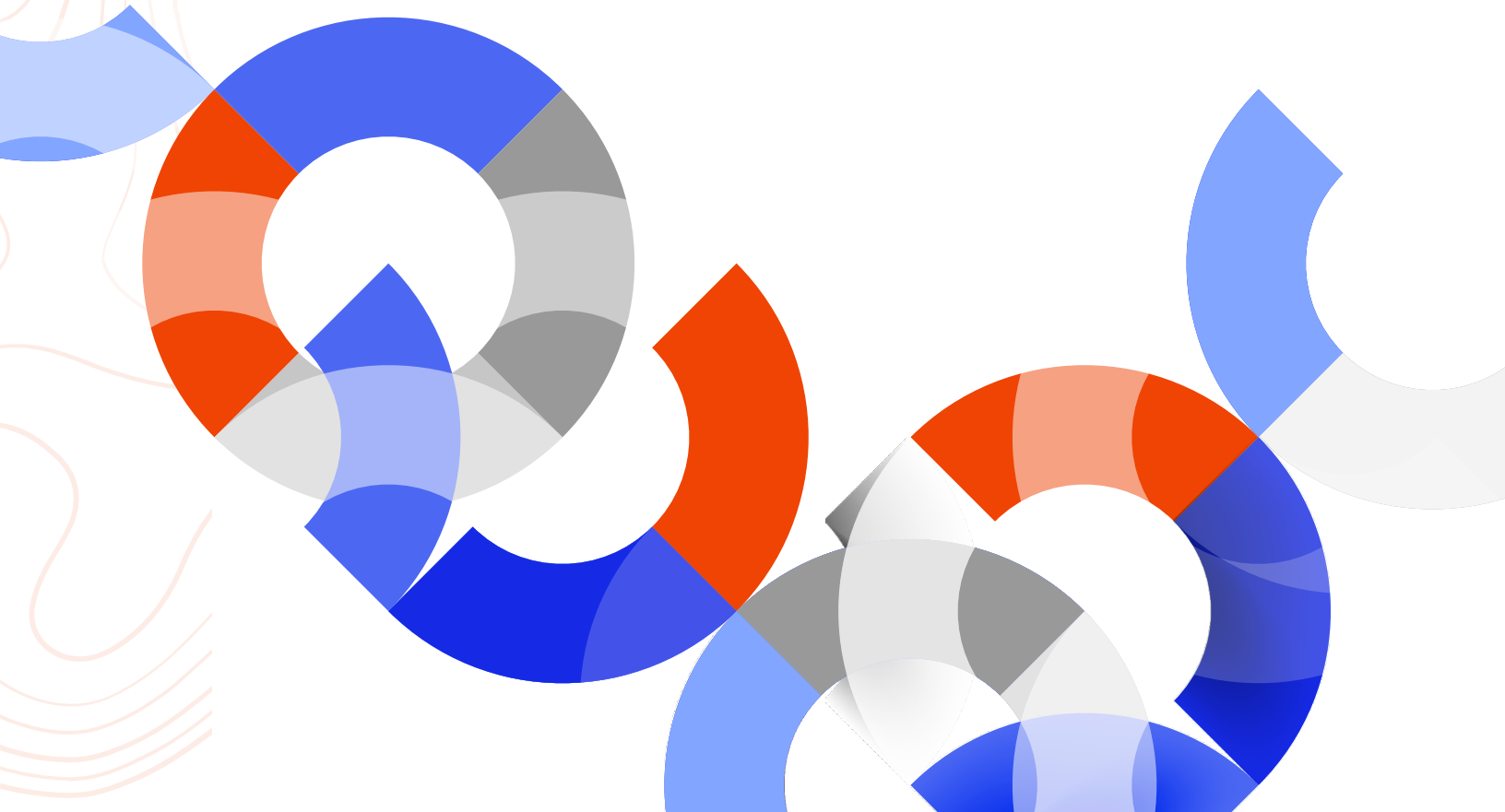
Payments linked to Hierarchical Condition Category (HCC) codes—HCC51 (dementia with complications) and HCC52 (dementia without complications)—are only realized after a diagnosis is made. Meanwhile, if cognitive impairment is detected through routine screening, the MA plan incurs costs for provider time and testing, including evaluations for addressable conditions that may contribute to impairment such as vitamin B12 deficiency, abnormal thyroid function, sleep apnea, depression, hearing loss, or polypharmacy interactions. MA plans may be reluctant to absorb these costs because the evidence shows that individuals diagnosed with ADRD are more likely to disenroll from MA plans or leave their existing MA contracts.[23]

Furthermore, the introduction of the GUIDE model—designed for and limited to traditional fee-for-service Medicare—may create additional reasons for patients to leave MA plans. CMS' implementation of the HCC V28 model, which introduces new categories for dementia—HCC 125 (severe dementia), HCC 126 (moderate dementia), and HCC 127 (mild or unspecified dementia)—may help to address this potential barrier. This substantial increase in payment associated with HCC dementia diagnoses presents a financial incentive to identify dementia. It is likely that the increased payment could outweigh the costs incurred for evaluating addressable conditions. Overall health may improve by addressing these conditions, leading to healthier beneficiaries and potentially lower costs.[24]

New tests, treatments, and models of care could stimulate earlier detection. The landscape of dementia care has shifted with the availability of high-performing blood biomarkers and

new treatments, requiring a change in how primary care approaches cognitive impairment.[25] Blood tests for AD have the potential to make biologically-based diagnoses easier, more widely accessible, and better integrated into primary care workflows for appropriate patients, helping to reduce misdiagnosis and health disparities in timely diagnosis.[26]

The recently launched GUIDE model, offered nationwide (to qualified beneficiaries by approved GUIDE providers), provides comprehensive dementia care resources aimed at enhancing the quality of life for people living with dementia, supporting caregivers, and promoting community-based living.[27] In addition, monoclonal antibody therapies targeting amyloid pathology showed positive results in Phase 3 clinical trials, resulting in the FDA approval of two such therapies, Leqembi® and Kisunla™.[28] The emergence of novel diagnostic tests and treatments, which are currently focused mainly on AD as the biological cause of cognitive decline, is likely to have a net positive impact on detection rates, if appropriate education is provided to both people living with dementia and clinicians about their appropriate use.



Recommendations to Improve Early Detection of Cognitive Impairment and Dementia

The following themes and recommendations for improving the early detection of cognitive impairment and dementia were shaped by insights from a series of interviews with key opinion leaders, a subset of Alliance members serving as a working group, an August 2024 expert roundtable, desktop research, and an expert review of the synthesized findings and recommendations. These recommendations focus on promising solutions for today, showcase scalable case studies, and highlight innovations on the horizon that can significantly change the course for early detection of MCI and dementia.

THEME 1:

Enhancing Primary Care Capacity and Cognitive Assessment Workflows

THEME 2:

Expanding Detection beyond Primary Care

Theme 1: Enhancing Primary Care Capacity and Cognitive Assessment Workflows

Primary care serves as the front line in health-care delivery, making it a pivotal setting for the early detection, diagnosis, and care of MCI and dementia. Moreover, as the shortage of dementia specialists, including geriatricians, neurologists, geriatric psychiatrists, and neuropsychologists, continues, primary care will play an increasingly essential role in caring for cognitive issues.[29]

To strengthen primary care's capacity to perform these services, cost-effective and validated cognitive assessment tests need to be integrated into clinical workflows along with clear guidelines for the next steps following the assessment. Additionally, expanded training, effective incentives, and robust quality measures will be critical to the successful implementation of new processes. The recommendations that follow are tailored to primary care's strengths and values. By addressing operational and financial barriers, leveraging technology, and standardizing procedures, primary care teams can significantly improve the early detection of cognitive impairment.

RECOMMENDATION 1

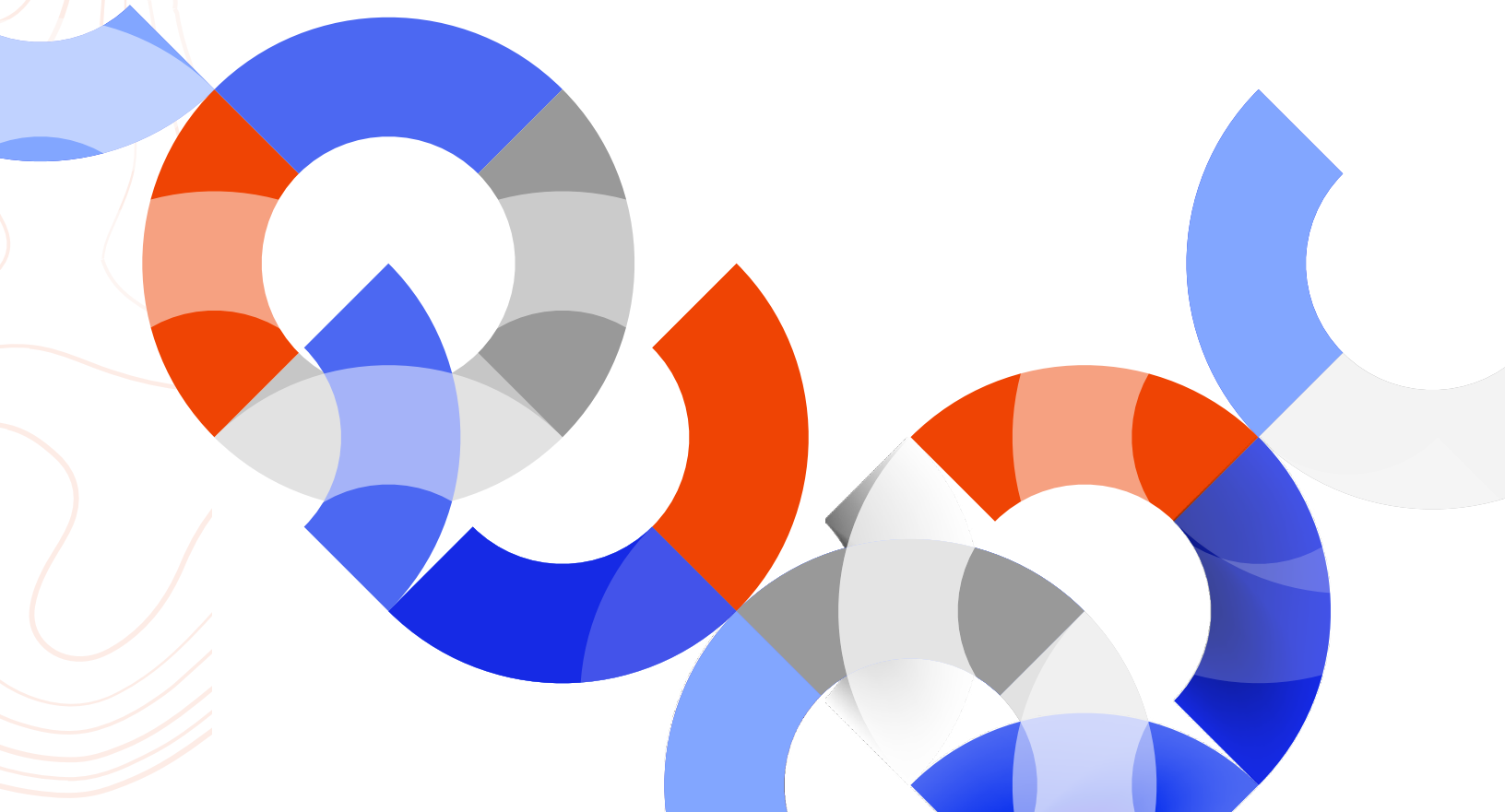
Normalize Brain Health Discussions, Expand Education, and Tailor Training to Primary Care Providers

Primary care teams need **comprehensive, scalable training** that can be tailored to their practice organization to effectively initiate general discussions of brain health, conduct cognitive assessments, evaluate and treat addressable causes of cognitive impairment, diagnose MCI and dementia, and manage dementia.

Training programs for early detection should cover rationale, workflow design, team-based strategies, and selection of cognitive assessment tests appropriate to the setting of use. They should also offer guidance on how to have a conversation about brain health, what to expect if additional testing is needed, and the opportunity to mitigate 14 modifiable factors identified by the Lancet Commission, linked to nearly 45 percent of dementia cases.[30]

In addition, **specialized training** is essential for equipping clinicians to meet **the specific needs of certain populations**, including individuals with Down syndrome, individuals with hearing and vision impairment, and individuals from socio-demographic marginalized groups.

Recent guidance from an expert workgroup, detailed in the journal *Alzheimer's & Dementia*, supports primary care in selecting cognitive assessment tools that align with their practice needs.[31] Additionally, the partnership between the American Academy of Physician Associates (AAPA), Physician Associate Foundation, and Cleveland Clinic provides a notable example of stakeholder collaboration to develop training resources that support task-shifting in cognitive care (see **Case Study 1**). This initiative, incentivized through Continuing Medical Education credits, offers a successful model for non-specialist provider training and support.



CASE

STUDY #1

OVERVIEW

The American Academy of Physician Associates (AAPA), the Physician Associate Foundation, and the Cleveland Clinic partnered to equip non-specialist providers with the education needed to screen and assess cognitive abilities.

APPROACH

A Cognitive Assessment Toolkit was developed and piloted at Cleveland Clinic locations and rural outpatient clinics. The pilot evaluated how providers used the toolkit and its short-term clinical impact and refined the program before its public launch in late 2023.

Toolkit Learning Objectives

- Understand and administer cognitive screening tests (AD8, Mini-Cog©, Montreal Cognitive Assessment [MoCA])
- Differentiate among normal aging, mild cognitive impairment, and dementia
- Discuss abnormal results with patients and their caregivers
- Promote lifestyle approaches to reduce dementia risk

IMPACT

- Screening rates for individuals aged 65 and older increased from 30.4 percent to 38.6 percent
- 82.4 percent of providers were "very to extremely satisfied"
- 93.5 percent would recommend the toolkit
- 80 percent of learners planned to implement practice changes, with improved provider confidence

Stigma around brain health remains a barrier to early detection. Normalization of brain health discussions can be advanced by incorporating standard cognitive screening questions into all exams. To facilitate these discussions, clinicians need education on the benefits of early detection and the addressable causes of cognitive impairment.

According to Williamson of Wake Forest University School of Medicine, "We need to overcome patient and provider inertia, thinking that 'there's nothing we can do' for cognitive impairment or its risks. The great need today is about getting PCPs to understand that there is an increasing amount of action we can take to slow the progression of MCI, AD, or reduce risk, just like we do when screening for cardiovascular disease or catching cancer early. We have not thought of cognitive decline and dementia like that. For example, there is a clinical trial showing a 15 percent drop in MCI or dementia risk for people who carefully control their blood pressure. There are other things like diet, exercise, alcohol reduction, and improving sleep."

Establishing a baseline cognitive assessment before age 65 can also help track potential changes over time and make testing a routine part of care.

Several resources are available to support primary care in addressing memory concerns or behavior changes raised by patients or family members and normalizing brain health conversations. Direct-to-consumer resources are also available to drive awareness about brain

health, normalize conversations around it, and help increase consumer demand for cognitive assessments. See examples in **Table 1**.

Other initiatives, such as Bank of America's work to raise awareness within corporate America about cognitive impairment in the workplace, may help normalize discussions around brain health. More information about available tools and selection criteria for PCPs to consider can be found in Recommendation 2, **Table 2,** and in this article in *Alzheimer's & Dementia*, co-authored by several members of the Alliance.

Table 1: Examples of Direct-to-Consumer Resources That Aim to Raise Awareness and Normalize Brain Health

Consumer-Focused Resources	Details
AARP's Brain Health Resource Center	Offers brain health tips, tools, and a free cognitive assessment to members
Alzheimer's Association's 10 Early Signs and Symptoms of Alzheimer's and Dementia	Provides 10 warning signs that indicate it's time to consult your doctor
Alzheimer's Los Angeles Telenovela	TV series to raise awareness of the Alzheimer's journey and the importance of brain health
USAgainstAlzheimer's Brain Health Best Practice Score from the Business Collaborative for Brain Health	A free, educational resource to help companies of all sizes assess their health and well-being and promote brain health among their employees
HFC Universe	Free, online resource leveraging the celebrity of Seth Rogen, primarily targeting young adults to raise awareness of dementia and the importance of brain health

Source: Milken Institute (2024)

Another opportunity to enhance sustainability and promote consistency in new workflows is to **create learning communities of practice** where clinicians and other health-care leaders can share peer-driven insights on common operational and clinical challenges. These communities would serve as collaborative platforms where participants can engage in discussions, share experiences, and exchange best practices. The Alzheimer's and Dementia Care ECHO® Program for Health Systems and Medical Professionals by the Alzheimer's Association is one such learning exchange opportunity.

Moreover, it is imperative that **the next-generation dementia workforce is well trained in early detection.** This requires integrating relevant materials into the curricula of medical schools and health professional programs for nurses, nurse practitioners, physician associates, physical and

occupational therapists, and social workers. Incorporating cultural competence in these programs will ensure future clinicians can provide care that is both culturally relevant and linguistically appropriate, preventing background from being a barrier to optimal care.

RECOMMENDATION 2:

Integrate Cognitive Assessment Tools into Clinical Workflows at the Health-System Level

To advance the adoption of best practices and cognitive assessment tools at the health system level, the Alliance and subject-matter experts identified the following opportunities.

Promote the implementation of clear clinical guidelines and evidence-based best practices for conducting cognitive assessment across primary care, recognizing the diversity in patient populations, workforce composition, available resources, and primary care settings.

Table 2 below lists toolkits that provide guidelines and recommendations for best practices for supporting the early detection of cognitive impairment and dementia in primary care. DAC has developed A Note on the Blueprint and US Toolkits, which provides on page 2 a more detailed overview of the toolkits.

Table 2: Toolkits and Programs to Support Early Detection in Primary Care

Toolkit/Program Developer	Name of Resource
American Academy of Physician Associates	Cognitive Assessment Toolkit
American Association of Family Physicians (AAFP)	Cognitive Care Kit
BOLD Public Health Center of Excellence on Early Detection of Dementia and Centers for Disease Control and Prevention	Early Detection of Dementia Toolkit—Health Systems
California Department of Health Care Services: Dementia Care Aware	Cognitive Health Assessment
Gerontological Society of America (GSA)	GSA KAER Toolkit for Brain Health Addressing Brain Health in Adults with Intellectual Disabilities and Developmental Disabilities
The University of Washington	The Cognition in Primary Care Program

Source: Milken Institute (2024)

One of these toolkits, the Cognition in Primary Care Program, was recently piloted in 14 clinics within the University of Washington health system, yielding promising results (see **Case Study 2**).[32] The University of Washington is now partnering with the American Academy of Family Physicians (AAFP) to expand this program to family practices nationwide.

CASE

STUDY #2

OVERVIEW

Barak Gaster, MD, and his team at the University of Washington developed a feasible cognitive assessment model for primary care settings based on the Gerontological Society of America's KAER toolkit. It is now packaged and ready to disseminate to other US health systems, including a partnership with the AAFP to allow its membership to access its integrated training and tools.

APPROACH

The Cognition in Primary Care Program is a package of integrated resources for quality improvement in primary care: (1) web-based training videos for continuing education, (2) tools and checklists within the electronic health record (EHR), and (3) a physical "Clinic Box Kit" mailed to clinic managers who open the box during a virtual training meeting. It includes the folders and other primary care practice tools mentioned in the training, providing PCPs not only with education but also with practice management tools that enable them to apply the training effectively.

The education series consists of three, 30-minute videos: (1) Evaluate cognition in primary care, (2) Set a plan for a newly diagnosed patient, and (3) Tips for managing dementia. The "Evaluate cognition" video highlights three components for evaluation: (1) a cognitive checklist (e.g., addressable causes), (2) cognitive function testing (e.g., MoCA), and (3) getting input from an observer (e.g., a family member, using the AD8).

IMPACT

The program was implemented in 14 clinics with 129 PCPs in a large health system. Six months post-training:

- Cognitive assessments documented in health records increased from 5.2 to 21.2 per month.
- New diagnoses of MCI increased from 23.5 to 32.2 per month.
- PCPs reported significantly increased knowledge and confidence in assessing cognitive concerns and managing dementia.

"Primary care loves these checklists. These are the concrete things they can do to improve a person's brain health right now. … When you give primary care that hook, we hear 'I want to diagnose this disease because there are things I can do about it.'"

—Barak Gaster, MD, Professor of Medicine, University of Washington at the Milken Institute virtual roundtable on early detection, August 2024

It is important to acknowledge that training programs and the adoption of toolkits alone are insufficient for driving practice change. To optimize adoption, health systems and primary care leaders need operational and change management resources. This includes access to tools and guidance on items such as billing codes for cognitive assessments (including baseline assessments), EHR integration, navigator roles, and implementation guides such as the Early Detection Blueprint from DAC.

These resources are pivotal for managing the operational aspects of early detection. However, because these activities are generally uncompensated, strategies to incentivize these efforts must be developed. **Case Study 3** illustrates the successful implementation of early detection across the Indiana University health system and shares its key learnings

CASE STUDY #3

The US Indiana Flagship site was located at Indiana University (IU) Health in partnership with the IU School of Medicine. IU conducted the study in a primary care setting, including physicians and nurse practitioners. It created a new primary care-based role called the brain health nurse navigator to bridge the handoff from primary to specialty care and help with diagnostic evaluation, post-diagnostic care, and patient support. It used Agile Implementation methodology[33] to run sprints to adapt digital cognitive assessment workflows to each local environment and measured the impact on clinical trial referrals.

The IU site exists in a multi-payer health-care model with various private insurance companies, government programs (e.g., Medicare, Medicaid), and self-pay patients. The involved primary care clinics included a large family medicine residency program, family medicine practices, general internal medicine practices, internal medicine–pediatrics practices, mixed specialty primary care practices, and enhanced primary care practices designed to meet the unique needs of older adult patients. Key learnings from this health system implementation included:

- **Engaging champions early and leveraging their support to scale the program.** The IU site engaged champions across different organizational stakeholders early in the planning stage and received continued support throughout implementation. Having champions in neurology, geriatrics, primary care, and at the executive level meant that it had a broad team that worked together to navigate challenges and find pathways forward.
- By starting with a committed team of champions, researchers, and providers, the IU site was able to take an incremental approach to gaining additional PCP buy-in and expanding the program's reach and sustainability.
- **Managing change effectively with an implementation coach.** The IU site used an implementation coach at the beginning of the project to ensure smooth planning and implementation of the program. The coach provided guidance, helped staff track toward goals, and managed the feedback loops between the staff and managerial teams. IU found having an implementation coach to be crucial for success, particularly in navigating personnel changes that occurred during the program.
- **Adhering to the standardized workflow.** To ensure adherence to the Early Detection Program's workflows, the IU site regularly performed check-ins to refine the program. This review started with staff self-audits, used reports of the process metrics, and moved to peer- or supervisor-led audits to identify any inconsistencies or deviations from the recommended workflow. Note that this type of process auditing should be built into the work culture and the monitoring procedures upfront.

Leverage novel digital tools, biomarkers, and AI-driven algorithms to streamline workflows. Innovations such as DCA software, blood tests for AD, and algorithms to calculate risk scores can potentially increase early detection and accelerate the pathway to diagnosis and care (see **Table 3** for additional commentary). These tools, along with innovative digital health platforms that provide an ecosystem of digital services, can be leveraged to streamline workflows, provide

valuable insights for early detection, and improve care frameworks after cognitive impairment is identified.

Research funded by the National Institutes of Health's National Institute on Aging is investigating how AI can be used to create and test passive digital markers, leveraging EHR data to inform better algorithms for risk assessment and early detection. DigiCare Realized is an example of an emerging AI technology firm that aims to commercialize this approach.

Table 3: Commentary on Recent Innovations to Improve Early Detection

Innovations to Improve Early Detection	Commentary
Digital Cognitive Assessments	• DCAs may offer advantages over paper-based cognitive assessment tools, such as greater user convenience and accessibility.[34] • Although there is a fee to use these tools, they may help address socioeconomic and cultural biases often present in traditional paper-based cognitive tests.[35] • The well-established Montreal Cognitive Assessment now has a digital version called XPressO by MoCA. • Several DCAs, such as the FDA-cleared Cognivue digital screening device, TabCAT-BHA, Cogstate's Cognigram, Braincheck, and Linus Health's DCR software[36] are showing promising performance for early detection, although more research is needed to better understand their performance in diverse and MCI populations. • Currently, these DCAs fall under the FDA's product code PTY, which classifies them as Computerized Cognitive Assessment Aids, indicated for use to determine the level of cognitive function and does not identify the presence or absence of clinical diagnosis and is not intended as a stand-alone or adjunctive diagnostic device.

Blood Tests for Alzheimer's Disease	• Blood-based biomarker advances may improve the scalability of the diagnostic pathway for individuals with cognitive impairment. • Blood tests for AD offer a less invasive, more accessible, and scalable tool to support primary care in identifying individuals with an increased likelihood of AD (but the AD tests do not evaluate other potential causes of dementia). • Blood tests such as C2N Diagnostics' PrecivityAD2, LucentAD's p-Tau 217, and Fujirebio Diagnostics' Lumipulse p-tau217 are beginning to show performance comparable to cerebrospinal fluid (CSF) biomarker tests and positron emission tomography (PET) scans in identifying AD pathology,[37] suggesting blood tests may soon displace more cumbersome and less accessible biomarker tests. • Additionally, these blood tests may be incorporated into the routine process of ordering a blood lab requisition, a practice both familiar and comfortable for PCPs. • Recommendations for test selection criteria, interpreting results, and integrating tests into diagnostic and care pathways, as well as the limitations of these tools, have been recently published by an expert workgroup convened by The Global CEO Initiative on Alzheimer's Disease.[38] • Researchers are working on developing blood-based biomarkers for other causes of dementia, such as frontotemporal dementia.
Risk Assessment Data Analytics	• Lifestyle for BRAin Health (LIBRA) and Brain Care Score are examples of brain risk assessment calculators/algorithms designed to identify, evaluate, and monitor patient risk factors, including dementia. • Risk assessment calculators/algorithms that analyze patients' EHRs offer clinicians efficient ways to understand individual risk profiles and tailor interventions to reduce risk or delay the onset of dementia. • Prior to deploying these tools for early detection, ethical considerations, such as ensuring the appropriate diagnostic, treatment, and psychosocial services are available to patients following detection, must be addressed.[39]

Note: The products cited in this table are examples of solutions and do not represent an endorsement by the Alliance.

Source: Milken Institute (2024).

"Partnerships to develop blood tests and other tools should continue alongside efforts to ensure coverage and accessibility in primary care settings."

—Maureen Japha, JD, Executive Director, Alzheimer's Environment Shaping, Eli Lilly and Company

Integrate cognitive assessment tools and risk assessment algorithms into the EHR. There are important opportunities to standardize the integration of cognitive assessment tools, workflows, and/or patient results into EHR software. EHRs can also help identify individuals at risk of cognitive decline by using algorithms to capture risk factors such as smoking or hypertension and prompt cognitive testing. Collaborations among health systems, digital health companies, and EHR vendors can streamline these integrations and establish consistent adoption protocols across health systems.

A CLOSER LOOK AT THE EHR INTEGRATION OPPORTUNITY

A leader at one of the top three EHR software systems explained that its current foundation (or base, out-of-the-box) software includes content and functionality reflecting best practices from many health systems. A steering board comprising elected clinicians meets regularly and is charged with recommending improvements and enhancements to the foundation EHR software's content to incorporate new workflows, tools, and best practices. EHRs can be leveraged to increase early detection by exploring these issues and opportunities.

Issues

- **Lack of standard tool**: When a standard assessment tool is defined and permission obtained, the tool can be available by default to all organizations. However, one of the major challenges to date has been the lack of standards about how to choose a paper-based, DCA, or risk analytics algorithm to include in the foundation. It is also important to note that once a health system has the foundation EHR software, it can customize and change it to incorporate validated cognitive assessment tools to meet organizational requirements.
- **Training**: Even if alignment is achieved on which tool(s) to use, licensors of the tools need assurance from a health system that proper training for the administration of the structured cognitive assessment tool and interpretation of the results is followed.
- **Licensing**: The EHR software company must secure a perpetual licensing agreement from the paper-based, DCA, or risk analytics algorithm owner to embed them in the foundation EHR software (an inhibitor to date because once a tool is part of the core foundation, it is difficult to remove, requiring manual intervention and follow-up).
- **Customization limits comparison and longitudinal tracking**: As different health systems build their own EHR tools, flow sheets, or templates, there is no way to compare and contrast patients' results across health-care organizations.
- **Ethical considerations**: The ethical considerations that arise with EHR integration of cognitive test results must be acknowledged. Individuals have the right to decide whether to undergo cognitive testing and whether to know the outcomes. Providing individuals with resources that outline the benefits of cognitive testing, along with confidentiality considerations and potential consequences (such as impacts on insurance premiums and employment), will support informed decision-making.

Opportunities

- **Data field for entering a test result:** Inclusion of a discrete data field to enter a standardized cognitive assessment result would be of significant value to PCPs because it would be easier for clinicians to find and track a score over time without searching through the free text of prior visit notes or previously scanned image of cognitive test results. Having data fields for cognitive assessment results and risk analytics scores is analogous to the PHQ9 for depression screening that is already embedded in EHR foundation software. Although embedding a cognitive assessment tool into the EHR is subject to the challenges described above, the Alliance recommends exploring the creation of these specific data fields in the foundation EHR.

- **CMS listed tools**: The new GUIDE model from CMS lists the Mini-Cog, MoCA, Saint Louis University Mental Status (SLUMS) Examination, and Mini Mental State Examination (MMSE) for structured cognitive assessments, which may present an opportunity to embed some or all of these tools as part of the foundation system.

- **Patient portals:** Brain health education, preventive measures, and a pre-visit questionnaire may be shared with patients via EHR patient portals, such as Epic MyChart or Oracle Health Patient Portal, to encourage discussion of brain health during upcoming appointments.

- **Workflow prompts:** A section in the EHR workflow for AWVs may be developed to include a reminder to perform a cognitive assessment (though it need not be a requirement). Similarly, workflow prompts and suggested cognitive assessment tools may be included within the EHRs of Age-Friendly Health Systems and the 4Ms Framework (What Matters, Mobility, Medication, and Mentation) Mentation section, which is defined as "Prevent, identify, treat, and manage dementia, depression, and delirium across settings of care."

RECOMMENDATION 3:

Establish Appropriate Reimbursement Policies and Practices to Encourage Cognitive Assessments

Billing and Procedural Codes

Billing and coding structures do not adequately support primary care in conducting brief, objective cognitive assessments. Introducing a dedicated reimbursement code for a brief cognitive assessment (BCA), alongside existing Medicare AWV and care planning codes, would align financial incentives with necessary workflow changes, making broad adoption of cognitive assessments more feasible**.** For example, this code could be used for a BCA following the identification of a concern by the patient, family, or clinician,[40] or for monitoring cognitive change in an individual with established impairment. **Improved billing and coding would also encourage using validated cognitive assessment tests** that support objective evaluation rather than relying solely on the clinician's general observations or subjective reports from the individual, family, or caregiver. **Table 4** illustrates the limitations of current codes and highlights the rationale for addressing the gaps.

"In our real-world implementation studies of early detection programs in primary care, incentive structures were a clear barrier to uptake in US health systems. A lack of dedicated codes for BCAs and DCAs means that the current reimbursement structure does not match the granularity of the workflow that is feasible in primary care."

—Tim MacLeod, PhD, Director, Davos Alzheimer's Collaborative Health Systems Preparedness

Table 4: Gaps in Codes/Reimbursement for Early Detection

Patient Encounter	Code(s)	Commentary
Medicare Prevention-Oriented Visits	G0402 Initial Preventive Physical Examination or "Welcome to Medicare" visit Annual Wellness Visit G0438 (one-time only for the first visit) G0439 (subsequent visits, eligible every 12 months)	Limitations • CMS does not require the use of a validated cognitive assessment tool when performing the cognitive assessment part of the AWV exam. Clinicians are instructed by CMS' Medicare Wellness Visits web page to use "direct patient observation or reported observations from the patient, family, friends, caregivers, and others" and "consider using brief cognitive test" to review a patient's functional ability and safety level. • The visit is designed to establish preventive practices (e.g., staying up to date with vaccinations) or update documents, such as an advance care plan or health care power of attorney, rather than diagnose a new disease or start a referral process. • Using paper-based tools requires an additional step: scanning results into a PDF and uploading them to the EHR. Opportunities (not limited to the AWV) • Integrate a prompt for cognitive assessment in EHRs, especially for patients with higher-risk indications. • Add a field to the foundation EHR software to capture the numeric score of a BCA for longitudinal tracking. • Provide a decision tree with questions to guide the clinician to the right cognitive assessment tools for the patient population and health system context.

Cognitive Assessment and Care Plan Service	99483	• This is a comprehensive clinical visit that results in a written care plan, requiring significant documentation and completion of nine elements. • The significant required documentation makes it onerous and difficult for primary care to utilize this code, which typically requires 50 minutes and can only be billed every 180 days.
Brief Cognitive Assessment (paper-based or digital)	GAP	• There is "no in-between" for the AWV and a Cognitive Assessment and Care Plan Service or a neurological workup for a BCA conducted in primary care. • For use whenever cognitive impairment is suspected or patients/family members express a concern in primary and specialty care or to establish a baseline measurement. • Preference is for an in-office procedural code to cover using a DCA versus a code for evaluation and management.
Brain Health Navigation	GAP	• Navigators are needed to counsel the patient and family during the evaluation stage if cognitive impairment is detected; can assist with all pre-diagnostic-related steps such as testing, scheduling, and pre-diagnostic workups. • There is an opportunity to get brain health navigation covered through Chronic Care Management codes, which should be discussed with a billing specialist within the health-care institution.
Neurocognitive Workup	96132-96146	• These codes are designed to be used in neuropsychology or psychology evaluations. • Some DCA tool providers recommended the use of some of these codes in primary care. • Utilization of these codes in primary care negates its use by a neuropsychologist for the next 12-month period. • Many MA plans require prior authorization for these codes, which can create a delay in assessment.

Source: Milken Institute (2024)

Cognitive Function Testing

As noted in Table 3, several FDA-cleared DCA tools on the market are accurate, sensitive in detecting MCI, modulate the influence of education, language, or cultural background of the test recipient, and leverage machine learning. Gaster, of the University of Washington, proposes that

the administration of these assessments be done using computers and/or tablet devices and the discussion with patients of the results may see greater market penetration and an increase in earlier detection of MCI and dementia if they are "taken out of the rough and tumble assembly line of the office visit" and are scheduled instead as separate tests performed in a standardized setting. From a policy perspective, evaluating whether CMS billing codes for computer-based assessments can be improved to better reflect their cost and complexity could significantly enhance their adoption by large health systems.

By decoupling the time spent performing the procedure from the time spent counseling patients about their results, a major obstacle to integrating testing such as this into primary care could be overcome. This would bring cognitive testing into a similar category used for the testing, evaluation, and management of other organ systems—pulmonary function testing (spirometry) for the lungs and echocardiography for the heart (recognizing that these tests are not exclusively performed in primary care).

Quality Measures

To further promote accountability from health plans and insurers, several members of the Alliance expert group recommend the institution of quality measures for early detection. This recommendation aligns with another expert workgroup, detailed in the journal *Alzheimer's & Dementia*, which advocates for CMS and the National Committee for Quality Assurance (NCQA) to **establish quality measures for BCAs and track detection rates of cognitive decline in the Healthcare Effectiveness Data and Information Set (HEDIS)**. Incorporating these measures in quality-reporting programs would increase incentives for primary care teams to adopt cognitive testing and support standardized guidelines for testing.

"There is too much fragmentation in our documentation and billing approaches. The complexity for users and multiplicity of relevant service codes are such that unless or until there is a required omnibus quality indicator or measure, significant change is unlikely."—*Soo Borson, MD, Co-Lead of the BOLD Public Health Center of Excellence on Early Detection of Dementia at the Milken Institute virtual roundtable on early detection, August 2024*

Theme 2: Expanding Detection beyond Primary Care

Early detection efforts beyond primary care can increase initial cognitive screenings with appropriate referral capacities, promote awareness of brain health and risk reduction behaviors, and improve access for underserved populations. Soeren Mattke, MD, DSc, director of the Center for Improving Chronic Illness Care at the University of Southern California, who has researched and written extensively on health systems readiness and capacity to detect, diagnose, and treat dementia, sums up the need and opportunity: "We need to go beyond institutions and into the community. There is a very, very, very large population that has never had their cognition screened or tested."

RECOMMENDATION 4

Expand Training and Support to Specialty Physicians and Allied Health Professionals

By leveraging specialty care practices (e.g., cardiologists, anesthesiologists, and OB/GYNs) and

allied health practices, more older adults can access cognitive screenings, and clinicians can better understand the role and influence of brain health and the impact of dementia within their overall practice areas.

Specialty Physicians

Specialty physicians should have a vested interest in dementia. From pre-anesthesia assessment visits for older adults planning surgery to routine gynecological care visits to cardiology consultations for cardiovascular issues, dementia can be a factor in care management.

- Cardiology: Knowing whether a patient is living with MCI or dementia should factor into the treatment of cardiovascular disease and hypertension. There is growing evidence of the links between cardiovascular disease and AD,[41] including evidence that intensive blood pressure control can reduce the risk of developing MCI, a precursor for dementia.[42] Hypertension is also one of the 14 modifiable risk factors for dementia, as identified by the Lancet Commission. Older adults with cognitive decline often struggle with medication adherence, have difficulty managing chronic conditions, experience increased hospital admissions, and frequently miss appointments.[43]

  To address the high prevalence of cognitive impairment in heart failure patients, researchers at Amsterdam University Medical Centers are piloting an innovative Heart-Brain Clinic. This interprofessional approach utilizes cardiology nurses to conduct screenings and facilitate appropriate referrals, which has been shown to alter cardiologist management, resulting in better outcomes for patients.[44]

- Anesthesiology: Cognitive impairment, such as delirium, is among the most serious postoperative complications, which can hinder recovery and elevate the long-term risk of dementia if left unaddressed.[45] These negative outcomes may incentivize clinicians to screen for cognitive impairment to better inform care and improve patient outcomes.

- Obstetrics and gynecology (OB/GYN): **Notably, OB/GYN care providers**, as specialists in women's health care, **have an opportunity to discuss brain health as changes to the brain occur during pregnancy, perimenopause, and menopause** with their patients. The effect of hormonal changes associated with menopause on the brain has been a recent topic of public discourse.[46] Significant changes to brain structure, connectivity, and energy metabolism are observed throughout the menopause transition, notably in brain regions involved in cognitive processing.[47] Although many of these changes stabilize and adapt postmenopause, **an increased deposition of amyloid, a pathological hallmark of AD, has been observed starting in perimenopause through postmenopause, particularly in those with genetic risk factors**.[48] Perimenopause aligns chronologically with the preclinical phase of AD, suggesting that earlier and prolonged exposure to amyloid pathology may explain, in part, the higher prevalence of AD in postmenopausal women, who comprise greater than 60 percent of all cases.[49] Given these insights, gynecological care providers play a critical role in initiating brain health and risk reduction conversations with patients entering menopause. Moreover, these providers must be **properly trained to implement cognitive screenings for individuals who may be at higher risk for dementia**.

Allied Health Professionals in Community Care Settings

To further support the growing number of older adults who may benefit from early detection of cognitive impairment, **training for many frontline allied health professionals should be a priority**. Technical assistance and continuous support for implementing screenings can be provided in **non-primary care settings such as retail health clinics, dental offices, hearing centers, optometry practices, and pharmacies,** if those settings are integrated into pathways for follow-up with a PCP or dementia specialist based on the screening results. Act on Alzheimer's offers training packages and resources specifically designed for dental providers.

An example of an initiative engaging pharmacies is the partnership between the Avant Institute and the Community Pharmacy Enhanced Services Network to implement routine cognitive screenings in diverse pharmacies across the US (see **Case Study 4**).

CASE STUDY #4

OVERVIEW

Avant Institute implemented a standardized assessment program in community pharmacies across the US to promote routine cognitive screenings outside of primary care.

APPROACH

Twenty-seven pharmacies from the Community Pharmacy Enhanced Services Network serving rural, urban, and underserved areas were trained to administer Cognivue Clarity, a self-administered 10-minute cognitive screening tool. Pharmacy staff contacted older adult customers (65+) and asked about their interest in participating in a cognitive screening study. Consenting volunteers were screened at the point of care with the DCA tool. A total of 425 individuals were screened, and those with abnormal results were referred to primary care for further evaluation.

IMPACT

- 73.4 percent had scores outside the normal range.
- 80.7 percent reported this was their first cognitive assessment.
- Success was attributed to three key factors:
  - well established patient-pharmacist relationship,
  - ease of the screening tool, and
  - simple training process.

Innovative tests, such as the AI-driven RetiSpec eye test for AD, have been developed to facilitate early detection outside of primary care. A recent implementation study using RetiSpec's technology leveraged the expertise of optometrists and social workers to identify individuals who would benefit from further evaluation in primary care (see **Case Study 5**).

CASE

STUDY #5

OVERVIEW

The Toronto Memory Program and RetiSpec partnered to train social workers to detect possible AD and optometrists to conduct retinal imaging to screen for the presence of AD biomarkers using RetiSpec's AI. The study aimed to identify individuals who would benefit from further assessment in primary care.

APPROACH

A social worker screened older adults (55+) with memory concerns at their local Alzheimer Society chapters. Then, the participants completed the RetiSpec eye test with an optometrist. The results were shared with PCPs or nurse practitioners to be discussed with the participants.

IMPACT

Of the 916 individuals who were screened (60.2 percent of these in optometry settings), 124 underwent cognitive assessments with RetiSpec:

- 96.8 percent of individuals who received a cognitive assessment discussed their results with a clinician.
- 41.9 percent of those with memory concerns received an AD-related diagnosis.
- Participants rated RetiSpec scans positively and expressed willingness to undergo future scans, especially if financially covered.

Facilitators and Barriers to Implementation

Facilitators: Accessible settings, comfortable screening process, effective staff training

Barriers: Stigma, communication gaps, follow-up delays

RECOMMENDATION 5

Expand and Support Early Detection in Community Settings

Cognitive screenings in community settings, such as churches, senior centers, and health fairs, can broaden the scope of brain health education and early detection. To ensure the accuracy of results and because of the seriousness of the issue, cognitive screenings should ideally be done in a health-care context by health-care professionals who can follow up with an appointment or refer to a dementia care specialist. However, given the capacity limitations in primary care, early detection of cognitive impairment can and should be extended to community settings. These efforts must include appropriate referral pathways and follow-up care for individuals identified with possible cognitive impairment. To support community-based early detection, members of the Alliance to Improve Dementia Care and other subject-matter experts highlight several key opportunities.

Community Partnerships and Engagement

Roundtable participants discussed the opportunities to **engage community organizations with health-care professionals (including those from community clinics) and dementia-trained volunteers under supervision by a health-care professional** who can raise awareness about the importance of early detection, conduct initial cognitive screenings (often referred to as brain

health or memory screenings), and establish referral pathways for further testing and evaluation by PCPs or dementia specialists, as needed. Engaging communities is vital for improving health equity and ensuring diverse populations are included in these efforts.

"In our implementation studies of early detection in primary care, several sites successfully used community events as an engagement point for community members. These events tend to happen in spaces where older adults already congregate and around trusted organizations that are accessible to a diversity of community members."

—Tim MacLeod, PhD, Director, Davos Alzheimer's Collaborative Health Systems Preparedness

For community-based screenings in senior centers, in faith-based organizations, or at health fairs, these efforts must have clear referral pathways that facilitate timely access to primary care or dementia care specialists if further evaluation is needed. Otherwise, expectations and possibly fear might be raised for community members who run into a "bottleneck" long wait to be evaluated. Leaders working in faith-based communities acknowledge that health-care systems may not accept community referrals, and insurance coverage can also dictate the next steps. During the Alliance expert roundtable convening, Fayron Epps, PhD, expressed the challenge:

"Without clear community referral pathways, we are creating more barriers for families by not offering the timely and proper follow-up assessments that are needed.

—Fayron Epps, PhD, Professor, Karen and Ron Hermann Endowed Chair in Caregiving Research, School of Nursing, UT Health San Antonio

The Alzheimer's Association strongly believes that only health-care professionals—not trained laypersons—should conduct initial cognitive screenings. This belief is due to the importance of accurate interpretation, the potential stigma and emotional impact of a "positive" result (especially if it is a false positive), and the concerns that individuals may react strongly to the results. In addition, unless cognitive screenings are conducted under the watchful and experienced eye of a health-care professional, there is a risk of delays in receiving a follow-up visit with a PCP or dementia care specialist and/or of individuals failing to make a follow-up appointment where they can be helped to understand the seriousness of the screening result.

Opportunities for Engagement	**Community Examples**
• Senior Centers • Faith-Based Organizations • Health Fairs	Alter Dementia, founded by Fayron Epps, PhD, works with health professionals to address dementia-related disparities, providing support and resources and offering cognitive screenings and other dementia-friendly initiatives in African American faith communities. Reminiscent is a community in Valdosta, Georgia, led by Debra Tann, EdD, which offers virtual and in-person classes, cognitive screenings, and resources focused on raising awareness of dementia in this rural, predominantly Black community.

Community Health Workers

Support the essential role of community health workers and *promotores* in raising awareness, overcoming cultural and socioeconomic barriers, and helping individuals navigate dementia-related resources. These unlicensed care workers are a growing part of the expanded health-care workforce and a key component of interprofessional care teams, especially in underserved communities. To better serve these communities, community health workers and *promotores* (the Spanish term for community health workers and defined as "health promoters") should be trained on the importance of early detection, the warning signs of cognitive impairment, and how these symptoms differ from normal aging. They should also have access to culturally tailored outreach materials that support education and awareness of local resources. Frameworks, tools, and training materials to build their capacity are available, including the **Alzheimer's Association's** *Community Health Workers: A Resource for Healthy Aging and Addressing Dementia*.

An initiative spearheaded by the Chinese American Services League (CASL) illustrates how empowering community health workers can help facilitate a timely diagnosis and access to other dementia support services for individuals from communities with limited spoken English (see **Case Study 6**).

CASE

STUDY #6

OVERVIEW

Communities with limited spoken English often face barriers to early dementia detection and diagnosis due to stigma, lack of awareness, and difficulties accessing resources. To address these challenges, the Chinese American Services League, with funding from the Administration for Community Living, developed and implemented a structured, multi-component program to improve dementia detection among older adults and access to support services in a Chicago community.

APPROACH

CASL adopted a multipronged approach that included:

1. Comprehensive staff training on dementia services, including screening using the Mini-Cog
2. Dementia certification for staff
3. Multilingual community workshops
4. Outreach initiatives

Individuals who screened positive on the Mini-Cog were referred to a CASL social service provider, who followed up to discuss a more comprehensive cognitive test (MoCA) and behavioral health assessment by a licensed health-care professional. Based on assessment results, individuals were connected with appropriate resources and external referrals. CASL provided care coordination and referral support to ensure clients could access the necessary services, addressing common challenges such as language barriers and navigating health-care systems.

IMPACT

- 589/800 people were screened for dementia using the Mini-Cog.
- 142 of those screened agreed to undergo further testing.
- Many clients were linked to PCPs or specialists for diagnostic evaluations, while others received case management and support services.
- Survey results indicated a slight improvement in attitudes toward dementia, increased confidence in dementia knowledge, and greater ease in accessing services and resources.

Public Health Campaigns and Programs

Utilize public health programs and campaigns to raise awareness of dementia risk factors, how to reduce the risks of dementia, and the benefits of early detection. Increased funding will be required to support public health campaigns in targeting and disseminating education, as well as tailoring initiatives to be inclusive of different cultures and backgrounds. States can have a major role in funding public health campaigns and initiatives, accounting for around 85 percent of total public health spending. Local events provide ideal opportunities to extend the reach of these campaigns. Many organizations are advancing these efforts, with examples of current public health initiatives outlined in **Table 5**.

Table 5: Examples of Public Health Initiatives to Raise Awareness and Educate about Brain Health and Promote the Benefits of Early Detection

Initiative	Details
California's "Take on Alzheimer's" Campaign	• Targeted to the general public • Offers free resources on brain health and navigating the Alzheimer's journey, starting with early detection

Healthy Brain Initiative (HBI) Road Map championed by the Centers for Disease Control and Prevention and Alzheimer's Association	• Targeted to state and local public health leaders
	• Provides a road map for community leaders to implement strategies to address dementia and improve brain health within their communities
	• Select offerings include:
	  • Implementation guide
	  • Evaluation tool to track impact in their communities
	  • Topic-specific maps on early detection and risk reduction
	  • Road Map for Indian Country to support American Indian and Alaska Native leaders implementing culturally relevant public health strategies in their communities

Source: Milken Institute (2024)

What's on the Horizon

The pace of innovation in dementia care is rapidly advancing due to significant public and private investments, including

- The nine-fold increase in National Institutes of Health investment in research, increasing from $448 million in 2011 to nearly $4 billion in 2024, or a compound annual growth rate of 16.9 percent[50]
- The National Alzheimer's Project Act (NAPA) was signed into law in 2011, and the bipartisan NAPA Reauthorization Act and Alzheimer's Investment Act have been signed into law
- The BOLD Infrastructure for Alzheimer's Act authorization of the Public Health Centers of Excellence and grants to state, local, and tribal public health departments
- Massive investments in drug discovery, resulting in two FDA-approved disease-modifying therapies and one for AD-related agitation, plus a robust pipeline of new therapies
- Guidance from FDA and the Alzheimer's Association on AD staging[51]
- New biomarkers ranging from plasma to retinal scans to voice

Alliance roundtable participants and other experts recognize that these developments and more will continue to change the trajectory of detection for dementia, especially as several complementary efforts are underway to increase public awareness of the importance of brain health. "What's good for the heart is good for the brain," and one of the leading patient advocacy groups, the American Heart Association Ventures, announced its Go Red for Women Venture Fund that "invests in companies that focus first, or substantially, in improving women's cardiovascular health, brain health, and related conditions." Growing evidence of the brain-heart connection is driving new research and entrepreneurial activity, which promises to advance the field.

We anticipate that during the next three to five years, we will see notable progress in the early detection of MCI and ADRD. While the Alliance will stay abreast of developments, these three specific areas warrant close following:

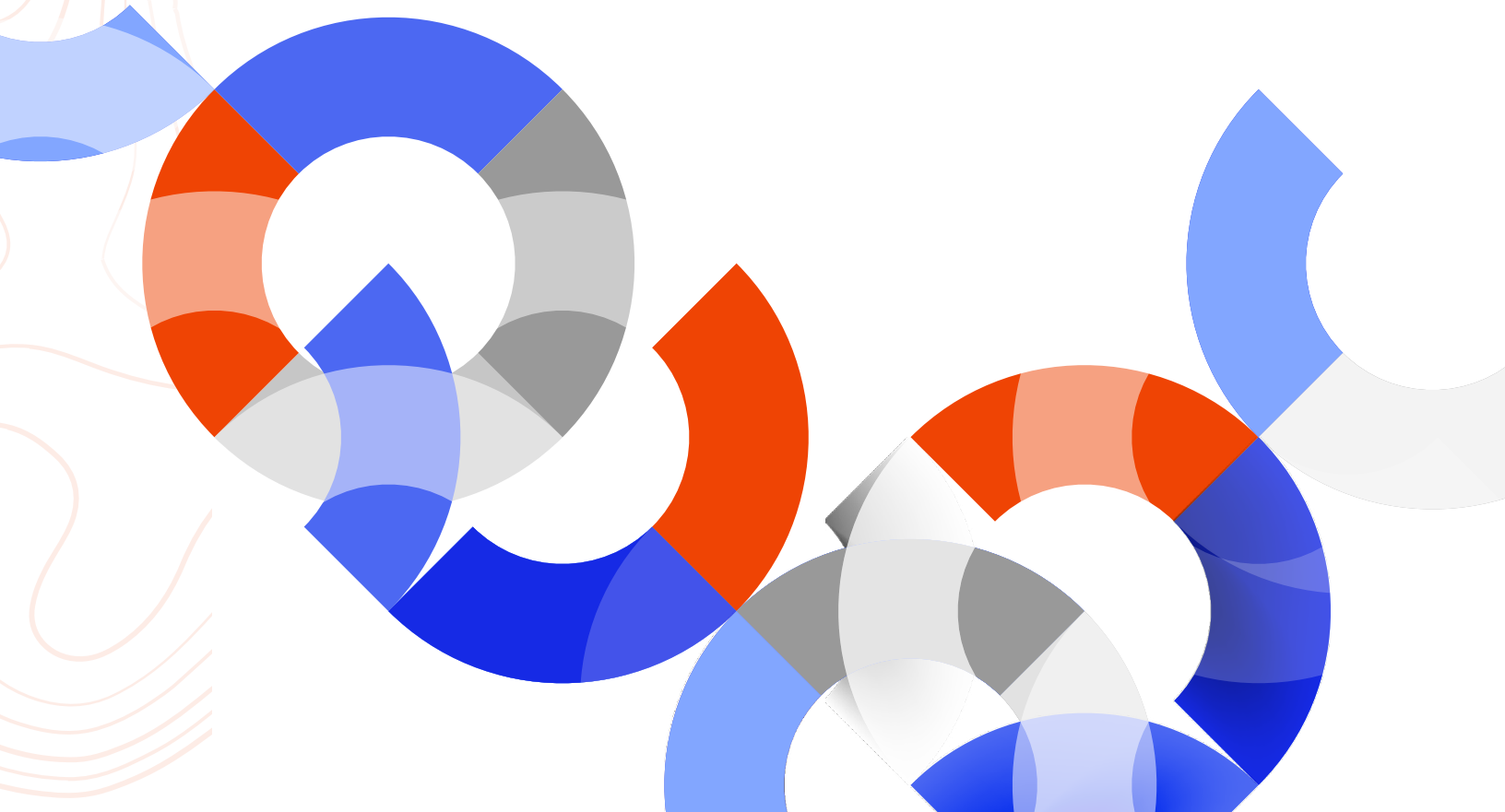
- **Blood-based biomarkers (BBMs)** have the potential to identify possible AD biology in a less invasive, less costly, and more accessible and scalable way than can lumbar punctures for CSF studies and brain PET scans. They have value in helping to separate AD from non-AD causes of cognitive decline and can be ordered alongside routine blood tests and used in the evaluation of cognitive impairment. Plasma p-Tau 217 can detect AD pathology with an accuracy of greater than 90 percent in research validation studies. Currently, these blood tests are not covered by Medicare or private insurance, though that will likely change. PCP education around appropriate use of these tests will be critical to ensure their proper application and interpretation. There are cautionary notes to consider because the diagnostic process performance of BBMs requires validation across population and clinical groups. More research is needed to fine-tune interpretation in the presence of possible confounding factors.[52] BBMs for other dementias, specifically frontotemporal dementia (FTD), are also showing promise with TDP-43, neurofilament light chain and progranulin all identified as possible BBMs of FTD, as reported in *Proceedings of the 1973 Laurentian Hormone Conference* and *Brain Research*.[53]

- **AI for dementia risk prediction** is being investigated as a way to uncover early indicators of cognitive impairment and search for data to connect dementia risk to chronic conditions such as hypertension, diabetes, high LDL cholesterol, osteoporosis (detailed in *Nature Aging*),[54] and more. Today, the experience and reporting of cognitive symptoms to a clinician is the usual trigger for cognitive evaluation, resulting in a shorter or closed window for meaningful preventive interventions or treatment. Researchers are harnessing AI to analyze massive amounts of data from patient EHRs, to develop algorithms that identify people who may be at elevated risk based on the presence of chronic conditions associated with a higher risk of eventual dementia. Better treatment and management of these chronic conditions can potentially protect or delay dementia.

- **Telehealth services and mobile memory clinics** offer a way for health-care systems and community leaders to scale cognitive screenings and create a more equitable, accessible framework for brain health care. These services make it easier for individuals in rural or underserved areas to access a cognitive screening without the need for travel and ensure the capacity to do further testing and evaluation, if needed. Developers of the Dementia Ideal Care Map[55] recommend establishing **Virtual Brain Health Clinics, staffed by trained and licensed clinicians, to improve access to timely cognitive care**. These clinics can leverage telehealth services to facilitate brain health awareness, risk reduction, early detection, and continuous monitoring of cognitive health.

Conclusion

Given the constraints in primary care and rising numbers of older adults at risk for MCI and dementia, the Alliance is committed to widening the multisector lens and leveraging the expertise of our members and extended stakeholder network to help drive increased early detection of MCI and dementia. The recommendations and discussions in this report are at varying stages of development and require leadership to accelerate change; some may be controversial for certain players or sectors and require further exploration to determine their feasibility, cost-effectiveness, and market acceptance. Our North Star will be to place individuals living with dementia and their families at the center of our work and to push new ideas and innovations to increase early detection and diagnosis that lead to improved care for people living with or at risk for dementia and their families.



Appendix: Alliance to Improve Dementia Care—Contributors to the Report

This list includes:

+ : Alliance to Improve Dementia Care Working Group Participant

! : Virtual Roundtable Participants and/or Key Opinion Leader Interviewee

@ : Expert Reviewer

Legend	Name	Title
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Katie Partrick, PhD, is a science communications specialist and writer with over a decade of experience collaborating with global leaders in academia and industry. She earned her undergraduate degree from The University of Georgia and her doctorate from Georgia State University, where she was both a William M. Suttles Fellow and a Brain & Behavior Fellow

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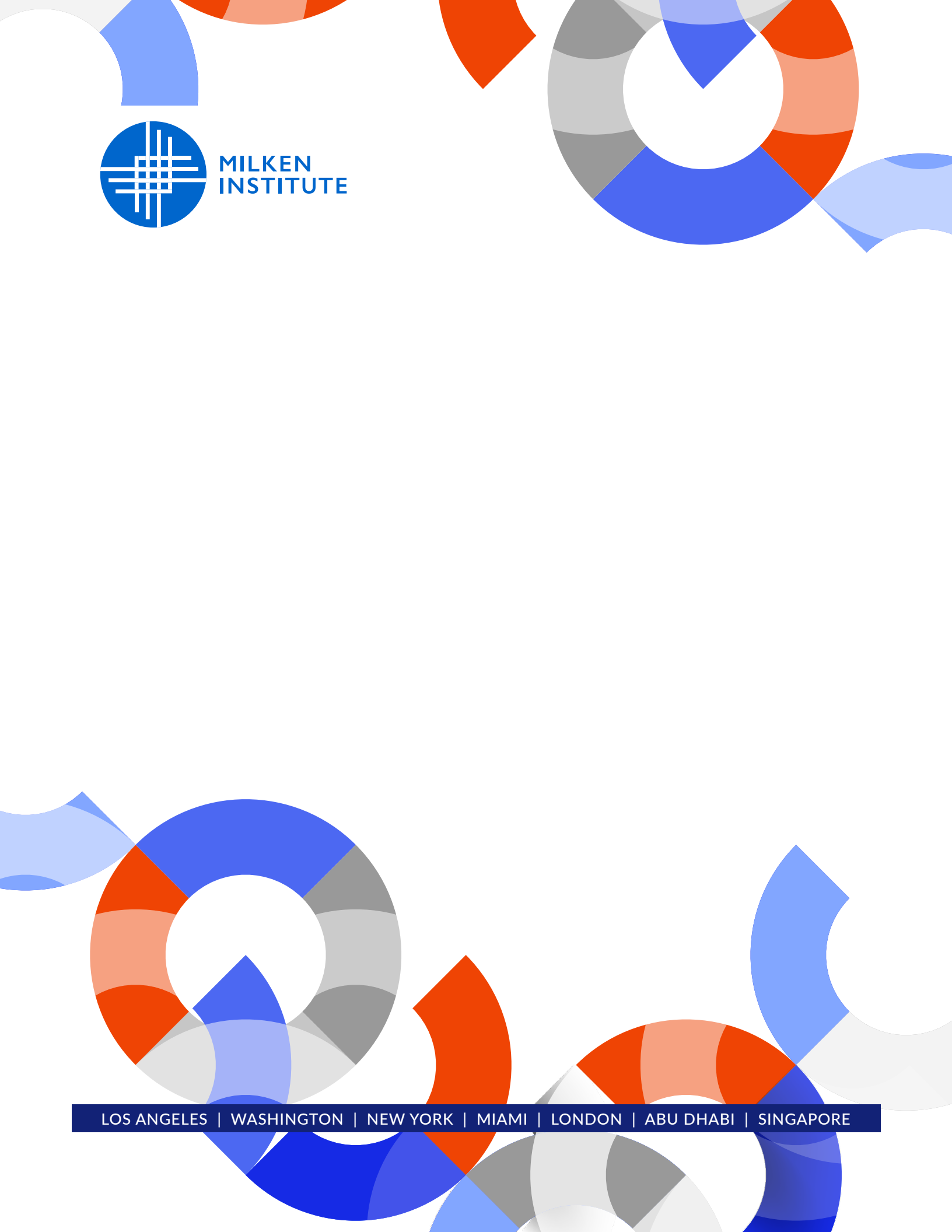
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