NEHI Network for Excellence in Health Innovation

***Discussion Summary***

**The Alzheimer's Disease Patient Journey: Pathways to Early-Stage Screening and Detection**

**NEHI Roundtable – Washington DC**

**May 23, 2024**

The May 23 roundtable discussion focused on the wide range of innovative tests and tools emerging for dementia assessment as well as the implications and challenges such innovations present for primary care and other dementia-related services. We provide a summary of the discussion below.

***There is a need for better and more scalable dementia screening of aging Americans.*** For many individuals, the patient journey toward appropriate care for Alzheimer's disease or other serious neurological conditions begins in earnest with screening for Mild Cognitive Impairment (MCI) and dementia. Screening and assessment are essential to rule in additional testing for neurological disorders, and to rule out conditions that may present as dementia, but are treatable as byproducts of other conditions, including chronic conditions such as heart disease or diabetes.

As many as 10% of U.S. adults 65 years or older are estimated to suffer some form of dementia, and the incidence of dementia rises with age. Despite this, relatively few older patients are routinely screened.[1] As the U.S. population ages and the medical and social burden of dementia-related conditions rises, innovations that accurately detect these conditions—and do so at greater scale—take on increasing importance.

***Innovations, now emerging or in development, are enabling more nuanced and comprehensive brain health assessment.*** AI-enabled digital devices, novel biomarker analysis conducted through lab-based tests, and new applications of predictive analytics are creating the ability for comprehensive assessment at earlier stages of a patient's susceptibility to disease and disease progression. This includes the assessment of Alzheimer's disease, dementia-related conditions, movement disorders, and other serious neurological conditions.

***Innovations for screening and brain health assessment could change clinical practice in at least two ways.*** First, innovative screening and comprehensive brain health assessments could lead to earlier and more accurate detection of dementia and related disorders. This could enable clinicians to rule in or out appropriate follow-up action to monitor troubling signs and symptoms or proceed to formal diagnosis.

Second, many emerging innovations enable more convenient and patient-friendly screening (i.e., minimally- or non-intrusive methods). For example, clinical decision support (CDS) provided by predictive analysis of patient health data is non-intrusive, as is comprehensive brain health assessment by digital device. Lab-based testing of novel biomarkers is a minimally intrusive form of testing that may spare patients the need for more complex, costly, and intrusive testing such as cerebrospinal fluid (CSF) analysis or PET imaging.

[1] See Manly et al, "Estimating the prevalence of dementia and Mild Cognitive Impairment in the U.S: The 2016 Health and Retirement Study Harmonized Cognitive Assessment Protocol Project," JAMA Neurology, December 2022, and Jacobson et al, "Cognitive assessment at Medicare's annual wellness visit in fee-for-service and Medicare Advantage plans," Health Affairs, November 2020

The convenience of emerging innovations such as smartphone- or tablet-based digital health assessments and lab-based biomarker testing also means that screening might occur on a scale more commensurate with the high—and now largely unscreened—level of dementia found among U.S. adults.

***High-value use of these emerging innovations could relieve serious bottlenecks and flaws in a patient's journey to appropriate care.*** Comprehensive brain health assessment could create a new impetus for preventive measures known to reduce brain disorders and for better treatment of chronic conditions known to exacerbate dementia. This could also create tools that enable safer, more efficient, and clinically appropriate pathways to formal diagnosis of serious neurological conditions such as Alzheimer's disease. At present, patients throughout the U.S. are faced with limited access to formal diagnosis due to long wait times at overburdened neurology practices, an uneven distribution of neurology practices that fosters racial-ethnic and urban-rural disparities, and out-of-pocket costs that vary with the quality of the patient's insurance coverage.

***The ideal end result: more rational, clinically appropriate pathways of care for patients.*** High-value use of emerging innovations for MCI and dementia screening could shift neurological assessment of patients "upstream" toward primary care and community-based services that are more convenient and less costly to patients, caregivers, and the health care system. This essentially moves the neurological assessment burden away from "downstream" services, such as neurology specialist medicine, and more complex and intrusive testing that is often unnecessary. This could result in more equitable access and case-by-case referrals to specialty downstream services that are more clinically appropriate.

***Nonetheless, most primary care practices are not well-positioned to absorb new and more comprehensive brain health assessments.*** Many physicians, patients, and policymakers view the U.S. primary health care system as in crisis, primarily characterized by a shortage of primary care physicians (PCPs), including geriatricians trained to provide primary care specifically for older patients. Relatively low reimbursement for primary care services discourages the training and recruitment of PCPs and primary care teams, compounding the nationwide phenomenon of PCP and staff burnout.
Primary care is also characterized by relatively quick appointments and multiple tasks as required by clinical guidelines and payment performance incentives. Integrating brain health assessment into primary care workflows remains a major challenge.

***Brain health assessment has not yet become a standard of care or a reportable and measurable subject of quality and performance measurement and payment incentives.*** Best practices for MCI and dementia screening and follow-up are actively researched, and examples of innovative physician teams that employ best practices can be found throughout the country. These include best practices currently employed by virtual care teams. Even so, such best practices have not evolved into widely adopted standards of care. Standards of care for other highly prevalent chronic conditions (e.g., heart disease and diabetes) have prompted reportable metrics that are now incorporated within value-based payment models, however, brain health care has yet to catch up.

***At a fundamental level, doubts among patients, caregivers, and clinicians are a barrier to action on preventing and treating dementia and other brain disorders, and thus on overall brain health assessment.*** Patients and caregivers are known to hesitate or deny the need for clinical attention due to the stigmas of dementia and a belief that little can be done to address it. Clinicians often share a similar belief that the detection of dementia has limited clinical utility. Opinion among the most highly specialized clinicians (i.e., neurologists) is split between those calling for urgent action on Alzheimer's

disease and dementia-related conditions, and those who believe that large-scale action is still premature. Innovative screening and assessment tests now on the market are still relatively new and unfamiliar to clinicians, while other promising tools still require clinical validation.

***Little has been done thus far to generate consensus on the detection of MCI and dementia among asymptomatic individuals.*** Advances in PET imaging, CSF analysis, and blood-based biomarker testing have generated findings suggesting that pathological biomarkers of Alzheimer's disease may appear in some patients well before symptoms of the disease appear. In some patients, the disease may not progress despite the presence of disease biomarkers. Advances in other technologies (e.g., AI-enabled digital devices, genetic testing, predictive analytics, and others) may yield similar findings within asymptomatic individuals. These findings could eventually expand the patient population addressable by preventive health measures and by Alzheimer's disease treatment, given the consensus that prevention measures and treatment of the disease at its earliest stages are likely to be more effective than at later stages (which often prove to be the stages at which patients are finally diagnosed). However, there has been little organized effort in the healthcare system to date to promote consensus on the ethics, cost, and health impact of expanding dementia detection to asymptomatic individuals, or to establish patient preferences regarding early detection of biomarkers of dementia-related conditions.

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***What are the most important actions stakeholders should take at this point?*** There is little disagreement that patients who are at identifiable risk or showing troubling signs of dementia should be screened and directed toward pathways of appropriate assessment, diagnosis, and care.

Meaningful steps forward at this time include:

- **Continue efforts to raise awareness and educate qualified professionals on standard screening and assessment techniques and tools** (e.g., the Gerontological Society of America's KAER toolkit), including awareness and adoption of screening practices among non-physician professionals whose efforts can supplement those of physician teams.
- **Continue efforts to raise awareness of the emerging capabilities of innovative screening and brain health assessment tests, tools, and protocols, including integration of information from multiple tests and tools**. Specifically, advanced data analysis and predictive analytics could generate information on patients most at risk for dementia (as demonstrated by the Kaiser Permanente-UCSF eRADAR trial). These non-intrusive CDS functions could enable clinical practices and health care delivery systems to prioritize patients for screening and minimize impacts on clinician workflows.
- **Promote policy changes that will standardize the use of validated cognitive assessment tools and provide training for their use** (e.g., enactment of the CHANGE Act and the ADAPT Act).
- **Monitor roll-out and implementation of the GUIDE model**, the CMS Innovation Center model for dementia care that includes caregiver support, for opportunities to expand its scope to screening and assessment for dementia.
- **Promote further development and subsequent validation of healthcare quality and performance metrics for dementia screening and assessment** for their eventual incorporation in existing reporting programs (e.g., Medicare STARS), elective or mandatory reporting requirements for Medicare, and adoption among other health insurance programs.
- **Initiate a more focused effort to include dementia screening, assessment, and follow-up into benefits offered under Medicare Advantage plans**.