



The Shared Fight to Stop Dementias by 2025

Improving Detection and Diagnosis of Alzheimer's Disease and Related Dementias

An Urgent Call to Action for Health Care Systems Worldwide

The first in a series of white papers from the Global CEO Initiative on Alzheimer's Disease: a patient-led, private-sector coalition, and respectfully submitted to the World Health Organization.

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Executive Summary

"The best time to plant a tree was 20 years ago. The second-best time is now." — Chinese proverb

ementia is a progressive neurodegenerative disease and Alzheimer's disease is its most common form, representing between 60 and 80 percent of the total dementia burden.¹ Dementia has no survivors-it destroys brain cells, causes memory changes, and ultimately robs those affected of the ability to do basic things, like eat, swallow, and cough.² The condition has largely confounded scientists and clinicians for more than a century, as the global scientific community has struggled to identify dementia triggers and has frequently been frustrated in their attempts to develop reliable diagnostic and treatment technologies for detecting the disease or halting its progression. While progress in the fight against dementia has been slow at times, its prevalence has only continued to grow as populations age and life expectancies increase. Today, there are 50 million people living with dementia, globally,³ and a new case of dementia occurs somewhere in the world every 3.2 seconds.⁴ Dementia is increasingly prevalent in low- and middle-income countries as well—in fact, 72 percent of the global burden of dementia will take place in these settings by 2050.⁵ In sub-Saharan Africa alone the number of people living with dementia is expected to nearly double every 20 years.⁶

The costs of care associated with dementia are unsustainable for patients, families, and national health systems. In 2015, the worldwide cost of dementia including lost patient productivity, formal, and informal care—was estimated at \$818 billion; up 35 percent since 2010.⁷ Costs are only projected to continue rising, with estimates indicating that the global cost of dementia will exceed \$1 trillion by the end of 2018.⁸ Family caregivers and health systems alike are feeling stretched to the limit, and shortages are forecasted among both informal caregivers and clinicians.

These considerations have led the Health Ministers of the G8 to commit to globally prioritizing dementia with the aim of identifying a means of prevention and a cure by

2025.⁹ Following this landmark commitment, countries like the United Kingdom, France, and the United States have devoted substantial additional resources towards dementia research; and, the World Health Organization has adopted its own Global Action Plan to advance progress on dementia across all nations.¹⁰

Scientific advances have progressed alongside global political commitments, resulting in new causes for optimism and guideposts to action. Advances in science and imaging technology now allow us to visualize and evaluate the living brain, unveiling the early footprints of dementia that may materialize up to twenty years before symptoms emerge.¹¹ New technologies in imaging and genetic testing can, in essence, grant clinicians a twentyyear "head start" in treating dementia, and, as a result, new treatment strategies aimed at slowing the progression of cognitive impairment or preventing dementia symptoms are under development.

Two primary, complementary strategies have emerged. First, innovative drugs aimed at those people demonstrating the earliest signs of dementia are now poised to come onto the market in the next few years.¹² Ultimately, these drugs may also be relevant for people with a high-risk of developing dementia, even if they are not yet exhibiting early symptoms. If successful, these drugs have the potential to slow or prevent worsening cognitive symptoms and defer the disability, cost, and family hardships associated with dementia.¹³

Second, new research has demonstrated that lifestyle changes, management of risk factors, and other medical care strategies may be able to defer or prevent the development of dementia symptoms. The *Lancet Commission* suggests that effective prevention of cognitive impairment is possible and within our reach¹⁴—in fact, one study suggests that 35 percent of dementia cases may be prevented by modifying nine risk factors: low



education, midlife hearing loss, obesity and hypertension, late-life depression, smoking, physical inactivity, diabetes, and social isolation.¹⁵ Primary care providers have the opportunity to integrate risk reduction strategies informed by these risk factors—consistent with those risk reduction strategies used to mitigate the risk of developing other non-communicable diseases—into today's care plans to prevent cases of Alzheimer's disease, dementia, and cognitive decline tomorrow. The power of these nonmedical interventions is now under evaluation, with leading studies suggesting that these prevention strategies have the potential for far-reaching positive benefits, even before any drug becomes available.¹⁶

Both of these complementary strategies rely upon the "head start" afforded by new imaging and diagnostic technologies—that is, our ability to detect dementia prior to the onset of symptoms is central to the efficacy of emerging treatment and prevention strategies, alike. In the near future, less expensive and more readily available blood or cerebrospinal fluid tests will allow clinicians to identify patients who should be referred for further imaging tests or can be diagnosed outright with dementia.¹⁷

Taken together, these scientific advances point to the transformative value of earlier detection of cognitive impairment and the use of clinical interventions today to alter the trajectory of dementia at a global level. Early detection and diagnosis will allow us to treat those conditions that are treatable today, mitigate cognitive decline that is currently non-preventable, and identify patients to participate in clinical trials for pharmacological treatments set to come to the market within the next five years. New strategies and tools are unlocking the opportunity for countries to make national commitments and preparations that will both improve and safeguard the brain health of today's populations, while simultaneously preparing health systems for the time when treatments become available.

Now is the time for governments to take action and develop national plans and strategies for tackling dementia. While further investments in dementia care and research are certainly necessary, there are a lot of things that governments and health systems can do today that do not require a major uptick in dementia-related care expenditure. For example, educating primary care providers to look for and recognize early signs of cognitive impairment can begin to shift dementia diagnoses to less expensive, more readily accessible primary care settings. And, with new digitally-based screening tools on the horizon, self-diagnosis of dementia is on its way to becoming a reality.¹⁸ Amplifying our new findings on the non-medical tactics for preventing the worsening of dementia symptoms will almost certainly increase the public's appetite for seeking out early detection services. However, the uptake of this sort of innovation will hinge upon our ability to improve health care provider's awareness of dementia and empower communities with an understanding of the benefits of early diagnosis and links to appropriate care.



Alzheimer's and Related Dementias: The Growing, Global Impact

ementia is a progressive neurodegenerative disease and Alzheimer's disease is its most common form. Dementia has no survivorsit destroys brain cells, causes memory changes, and ultimately robs those affected of the ability to do basic things, like eat, swallow, and cough.¹⁹ Even in its early stages, dementia symptoms are noticeable and affect day-to-day life: people experiencing the early stages of dementia may have difficulty recalling things that happened recently or struggle to find the right word in conversation.²⁰ The progressive nature of the disease means that the average Alzheimer's disease dementia patient will only live for six to eight years after the onset of their symptoms.²¹ Nearly one in three people over the age of 85 will develop dementia, meaning that a growing portion of the population will spend their later years either living with dementia or caring for a loved one with the condition.22

A person's risk of developing dementia depends upon a combination of age, genetic, medical, and lifestyle risk factors—for example, smoking increases a person's risk of developing dementia.²³ However, one of the strongest factors in determining a person's dementia risk is age.²⁴ So, as we celebrate gains in life expectancy of nearly three-and-a-half months every year, we must also prepare our health systems for the realities of aging populations—in countries across the world.²⁵

Across geographies, the financial burden of dementia is difficult to overstate. In 2015, the worldwide cost of dementia—including lost patient productivity, formal, and informal care—was estimated at \$818 billion; up 35 percent since 2010.²⁶ Costs are only projected to continue rising, with estimates indicating that the global cost of dementia will exceed \$1 trillion by the end of 2018.²⁷ If the total costs of dementia were a country's economy, it would costs

The Burden of Alzheimer's Disease & Related Dementias

"I first became interested in Alzheimer's because of its costsboth emotional and economic-to families and healthcare systems. These costs represent one of the fastest growing burdens on healthcare systems in developed countries. This is something that governments all over the world need to be thinking about, including in lowand middle-income countries where life expectancies are catching up to the global average and the number of people with dementia is on the rise." -Bill Gates, Co-Chair, Bill & Melinda Gates Foundation^A

"We are facing **one of the biggest global health and social care challenges**—a challenge as big as those posed by cancer, heart disease, and HIV/AIDS."

—**David Cameron**, Former Prime Minister of the United Kingdom^B



be the world's 17th largest, ranking between Turkey and Indonesia.²⁸ If dementia costs were a company's annual revenue, it would be the largest in the world, exceeding Walmart and Exxon Mobil—combined.²⁹

The inconvenient truth of the 21st century is that our health systems, governments, families, and communities are ill-equipped to care for aging populations and a continuously rising tide of people living with dementia. Unfortunately, unlike the "original" inconvenient truth of climate change, the world has been slow to address aging and dementia with a true sense of urgency. Thus far, the United States and the United Kingdom have taken the lead in dementia research,³⁰ resulting in recommendations and data that are heavily United States- and United Kingdomcentric. Dementia advocacy and research efforts are crippled by a lack of data from low- and middle-income countries and regions, and any global advances in fighting the disease must include the collection of more and better data from diverse geographies and contexts.

Understanding Families' and Caregivers' Burdens

The "inconvenient truth" of aging and dementia are compounded when you consider the families behind the patient statistics. The number of people whose lives are impacted by dementia is exponentially higher than the number of people living with the disease itself. The families of people living with dementia are faced with watching a loved one's decline, and they are often devastated by the emotional and financial hardship that can follow a dementia diagnosis. Family caregiving is an increasingly important and common component in caring for people living with dementia³¹—in developing countries, family caregiving is even more common.³² In the United States alone, an estimated 34.2 million people provide unpaid care to seniors.³³ To give context, there are more unpaid caregivers than employees at the world's 90 largest companies, combined.³⁴ Reliance on family caregiving in the dementia care landscape could become unsustainable as modern family dynamics change-couples are having fewer children and adult children often live far from their aging parents, making day-to-day caretaking activities burdensome and oftentimes logistically impossible.³⁵ We know that a caregiver shortage is coming, as the ratio of caregivers to care recipients peaked in 2010 and has been falling ever since.36

The Caregiver Experience

In the United States, the "typical" Alzheimer's caregiver is a married, employed woman, 50 years or older, caring for her widowed mother who does not live with her.^c These caregivers are also very likely overwhelmed by their caregiving role. Caregiving exacts a physical, emotional, and financial toll, with **nine out of ten** caregivers in midlife reporting that family caregiving was harder than they anticipated, requiring more emotional strength, patience, and time than initially expected.^D Further, the majority of Alzheimer's caregivers report they had no choice in taking on their caregiving role.^E

While family caregivers are an important piece of the dementia care ecosystem, the role exacts a physical, emotional, and financial toll, and also results in broader societal costs. For example, the physical health of a dementia caregiver is linked to the health of their loved one. According to a 2011 study, caregiver's health declines alongside the declining health of the dementia patient.³⁷ Caregivers also regularly report higher rates of insomnia, depression, and chronic illness than their non-caregiving peers,³⁸ with one European study showing that 60 percent of caregivers surveyed had either depressive or anxiety disorder.³⁹ Perhaps unsurprisingly, emergency department visits and hospital-based-service provision for Alzheimer's caregivers were twice that of the non-Alzheimer's caregivers evaluated in a recent study in the United States.⁴⁰ The demands of caregiving, coupled with an increased susceptibility of illness, result in a loss of workplace productivity for caregivers. Two-thirds of caregivers report having to go to work late, leave work early, or take time off to provide care.⁴¹ And, even if caregivers are making it into work, their careers are likely to suffer from "presenteeism," or working while ill.42



Improving Detection and Diagnosis of Alzheimer's Disease and Related Dementias: An Urgent Call to Action for Health Care Systems Worldwide



Laying the Foundation for Dementia Advances

Two complementary forces are at work in advancing the fight against dementia—first, researchers are identifying new technologies and strategies for evaluating and preserving brain health; and, second, there are promising new Alzheimer's disease and dementia treatments in the pipeline.

As new treatments for managing Alzheimer's disease and dementia symptoms and slowing the progression of the disease are on track to enter the market within the next five years,⁴³ it is important that health systems lay the groundwork for the adequate detection, diagnosis, and management of cognitive impairment to ensure maximum uptake of new innovations. Many of the new drugs under development are most appropriate for patients

with early-stage dementia, making early detection an imperative so that patients do not miss the window for securing effective treatment.⁴⁴ Innovative imaging and genetic testing technologies will boost the efficacy of new treatments by flagging early brain changes that precede the development of dementia symptoms, allowing for treatment to be administered as early as possible.

Advances in brain imaging technology have also unlocked the ability to evaluate different non-medical strategies for slowing cognitive decline, meaning that we now understand more about non-medical dementia prevention and risk reduction strategies than ever before. The *Lancet Commission* now states that dementia prevention that may have seemed unrealistic just a few years ago now seems feasible, giving patients reason for hope and clinicians reason to take the time to work with patients showing signs of cognitive impairment on lifestyle changes with the potential to slow cognitive decline.⁴⁵



Progress & Opportunities: Mounting a Global Response

he first case of Alzheimer's disease was diagnosed over 110 years ago—in the subsequent century of medical advances, the global community has made frustratingly little progress in developing treatments or cures for the disease and related dementia.⁴⁶ In fact, dementia is the only leading cause of death that is still on the rise, with global deaths due to dementia more than doubling between 2000 and 2016.⁴⁷

Historical lack of progress in the fight against dementia is due, in large part, to two primary challenges. First, the development of dementia was long thought to be a normal step in the aging process, and senility amongst seniors was accepted as unavoidable. Second, governments have fallen short in allocating resources towards dementia research. Despite the fact that dementia inflicts greater economic costs than cancer, and results in nearly as many deaths, it has received just a fraction of the government funding allocated for cancer research.⁴⁹

Rate of Disease-Related Deaths, 2000-2014^{48, F}



The Global Policy Community Grapples with Dementia's "Inconvenient Truth"

Today, the tide is turning. Governments, communities, and families are beginning to grapple with the realities of dementia within aging populations. As such, dementia research, awareness, and care have benefited from increasing focus and investments over the course of the past ten years. Dementia formally landed on the global policy agenda in 2013 when the UK government hosted the G8 Dementia Summit as part of its G8 presidency. Following the summit, the UK Prime Minister launched the "Prime Minister's Challenge on Dementia 2020," outlining the country's key aspirations to improve dementia care, support and research. Specifically, the challenge commits to doubling research funding for the disease by 2025.⁵⁰

The European Commission's initiative on Alzheimer's disease and other dementias has recognized the significant impact of dementia and of diseases linked to dementia on the financial sustainability of health and social security systems and has called for the need for early and timely dementia diagnosis, the further education of primary care providers, a reduction in dementia stigma, and improved public awareness of the disease.⁵¹

National Commitments to Fighting Dementia^G

32 countries and territories have adopted a plan on dementia, including **27 WHO Member States**.



There has also been progress on dementia and Alzheimer's disease commitments at national and regional levels. For example, the United States launched its National Plan to Address Alzheimer's Disease in 2012, with the aim of preventing and effectively treating Alzheimer's disease by 2025, amongst other objectives.⁵² Alzheimer's disease investments by the National Institutes of Health in the United States have more than doubled in the past four years, from \$704 million in 2014 to a projected \$2.34 billion allocated for 2019.53 The Pan American Health Organization adopted a Regional Plan of Action on Dementia in 2015, leading the Chilean government, among other countries in the region, to adopt a national plan on dementia in 2017.⁵⁴ The plan includes key targets for improving awareness, access to care, support and treatment, and risk reduction of dementia by 2025.55

Advances in Brain Health & Drug Development Illuminate the Path Forward

The past decade has brought about notable advances in our understanding of brain health, and of modifiable risk factors of cognitive impairment, dementia, and Alzheimer's disease. Emerging research suggests that diet, exercise, and engaging in activities such as reading may help to prevent dementia.⁵⁶ At the same time, the scientific community is collectively benefitting from advances in diagnostic imaging technologies that are allowing researchers to learn more about the mechanics of brain health than ever before. Predictive genetic testing can help identify whether a person has a high or low chance of developing dementia for example, blood tests that detect the presence of the Treatments Will Most Likely Address Early Stage Dementias

"By the time we see people with Alzheimer's disease, **it's organ failure for the brain**. In which field, when the organ has failed, have we been able to reverse stuff? None. We can't do it for the heart. We can't do it for the liver. The brain is a lot more complicated."

—Alireza Atri, Senior Scientist, Banner Sun Health Research Institute^H

ApoE4 gene can suggest a patient's susceptibility to developing dementia before any changes occur within the brain.⁵⁷ Brain-imaging tests, such as positron emission tomography (PET) scans, can identify clusters of plaques or twister insoluble fibers on the brain, called "amyloid proteins" and "neurofibrillary tangles,"⁵⁸ associated with dementia.⁵⁹ These plaques are known as "biomarkers," and they have been enormously valuable in advancing the field of dementia research. Today's amyloid and tau PET scans can identify and define patients earlier than ever before and assist in measuring the efficacy of new treatments.⁶⁰

Complementing advances in brain health research, drug development has also enjoyed significant advances. There is already exciting progress to report in the treatment

Barriers to Adequate Dementia Diagnosis

Lack of understanding among primary care providers on the signs and symptoms of early dementia and the benefits of early diagnosis

Physician reluctance to diagnose a disease that inflicts suffering and has no cure Inadequate patient access to neurology and geriatric specialists Existing health care infrastructure is insufficient to manage early detection activities at scale



pipeline. For only the second time, a drug has been developed that both decreases the presence of amyloid and reduces cognitive decline.⁶¹ This is a sign of hope.

These two types of scientific advances are closely related as early diagnosis technologies will be critical in identifying both those patients who are well-placed to engage in behavioral tactics for preventing the progression of diagnosed cognitive impairment to dementia, and those patients who are most likely to benefit from pharmacological treatment.

Researchers emphasize that early detection is the key to unlocking an effective treatment for dementia—it would be incredibly challenging to develop a single-drug treatment for patients with advanced dementia.⁶² It is much more likely that the treatments on the horizon will tackle the disease in its invisible, biological stages. Ultimately, progress in research and drug development, coupled with our growing ability to detect cognitive decline and then mitigate the risk that decline progressing to dementia, will result in better outcomes for patients.

Early, Accurate Detection and Diagnosis is Challenging, but Critically Important

Despite growing progress, persistent and complex challenges remain, with negative repercussions for people at risk of developing dementia, patients, and their caregivers. Underdiagnosis remains common. Dementia patients continue to be subject to care pathways that are inefficient or suboptimal with a risky over-reliance on informal care, especially in developing countries. Across the globe, access to specialists and expensive diagnostic technologies is severely limited, and the overall health care infrastructure has, for the most part, not yet responded to the rising demands of dementia care. Opportunities for improvement begin with optimizing the detection and diagnosis of dementia at a patient's first point-of-care and potentially employing widely-available mobile technologies to extend health system reach.

Globally, three-quarters of all dementia cases go undiagnosed,⁶³ and a recent study in the United Kingdom revealed that hospitals fail to diagnose dementia nearly 65 percent of the time in patients who have already received a dementia diagnosis in the past.⁶⁴ Health care providers



To diagnose dementia, physicians conduct tests to assess memory and other cognitive impairments, functional abilities, and behavior changes. To complement and verify diagnoses, physicians can also utilize brain-imaging diagnostic tests or other, less expensive and more widely available tests that examine cerebrospinal fluid.⁶⁷ In the future, it may be possible to diagnose dementia with a simple blood test.⁶⁸ The presence of amyloid plaques, among other biomarkers, is a key piece of the dementia diagnostic process⁶⁹—and detecting their presence is only possible through the use of sophisticated diagnostic technologies. A 2017 study showed that PET scans lead to more precise diagnoses and more appropriate use of dementia medications-for example, a positive PET-scan increased Alzheimer's disease diagnosis rates from 79 percent pre-scan to 95 percent post-scan.⁷⁰ Health care systems in low- and middle-income countries are unlikely to have access to these technologies, amplifying diagnostic challenges.

Encouragingly, innovations are coming and promise to offer people living in low- and middle-income countries, in particular, with the opportunity to benefit from an early diagnosis. New retinal imaging technologies could potentially scan a patient's eye to detect whether amyloid is present—ultimately, this could mean that an eye doctor could perform cognitive screenings during regular check-ups in just fifteen minutes.⁷¹ An even simpler new technology relies on a verbal test administered via tablet or smartphone.⁷² Someday, patients may even be able to take this type of verbal smartphone test in their homes, streamlining and democratizing the diagnostic process even further.

Cognitive impairment diagnoses are stymied because of behavioral challenges, as well, both on the supply and demand—that is, some people are reluctant to see a physician about their memory symptoms, and many physicians need to be better equipped to disclose a dementia diagnosis.⁷³ Physicians who fail to disclose a dementia diagnosis state that by withholding the



diagnosis, they hope to minimize emotional distress. Other commonly cited reasons include a lack of support services, inadequate time to discuss treatment options, and stigma surrounding the disease.⁷⁴ Survey results show that, despite physician's fears, over 85 percent of respondents say, if they were exhibiting confusion and memory loss, they would want to see a doctor to determine if their symptoms were related to dementia.⁷⁵ The impact of these missed and delayed diagnoses are multifold and will be addressed in detail later within this paper.

Disparities Between Alzheimer's Diagnosis Demands and Actual Diagnoses

85% of patients would like to receive a diagnosis if they develop Alzheimer's



Only 45% are actually receiving diagnoses from their physicians^J

The Growing Care Gap and Potential Solutions

Once a patient receives a diagnosis of dementia, they are likely to face obstacles in obtaining efficient and optimal care. Dementia care, at the later stages of the disease, is currently palliative in nature and requires ongoing counseling and social support—unfortunately, hospitals have historically struggled to effectively provide efficient links to this type of care. Effective support for patients and caregivers after the receipt of a diagnosis is a documented challenge—19 percent of caregivers and 30 percent of



Specialist Shortages Create Barriers for Dementia Diagnosis & Care

100 / 58,000

There are less than 100 geriatricians among 58,000 registered physicians in Hyderabad, India^k

-6,250

The shortfall of geriatricians in the United States to meet forecasted patient demand $^{\rm L}$

people living with dementia interviewed as part of a study on dementia diagnosis across five countries in Europe reported receiving no information on the disease or further care resource at the time of diagnosis.⁷⁶ Despite evidence proving that home visits and care assessments can enable patients to remain at home—rather than in a nursing home or assisted living center—for nearly 10 months longer than patients who do not receive those visits, many people living with dementia do not have access to this type of coordinated and home-based care.⁷⁷

However, progressive health systems are embracing robust care coordination tactics for people affected by dementia, utilizing a dedicated care coordination professional to connect patients and families to a network of different care resources to meet their needs efficiently and comprehensively. This coordinated approach has been proven to decrease the unnecessary use of medical services, delay institutionalization, decrease the costof-care burden for hospitals and payers, and, most importantly, improve quality of life for people living with dementia, their families, and caregivers.⁷⁸

One example of this is a new program at a leading US hospital, Rowan University-Rutgers, that provides a formal training program to certify "journey coordinators" who assist patients and families to secure the medical and social resources they need. In the absence of a dedicated care coordinator with an expertise in linking people affected by dementia with the relevant care resources, primary care providers are increasingly expected to play a central role in the diagnosis and management of dementia, effectively acting as case managers for people living with dementia and their caregivers. This type of approach and trend is likely to continue—the World Health Organization's Global Action Plan on the Public Health Response to Dementia 2017-2025 recommends increased dementiarelated task-shifting from specialists to primary care providers and other health care professionals.⁷⁹ This recommendation is grounded in necessity: there is a global shortage of both neurologists and geriatricians, hindering patients' access to specialty care.⁸⁰

The shortage is forecasted to worsen in the coming years. There are about 7,000 geriatricians in practice today in the United States—the American Geriatrics Society estimates that to meet growing demand, medical schools would have to train at least 6,250 additional geriatricians between now and 2030, or about 450 more a year than the current rate.⁸¹ In Mexico, there are only 400 geriatricians in the entire country,⁸² while in Hyderabad, India, of the 58,000 doctors registered with AP State Medical Council, less than 100 are trained in geriatrics.⁸³ The health care policy need is clear—in the face of a shortage of neurologists and geriatricians to diagnose and manage dementia, primary care providers will be asked to step in to fill the gap.

Clinical training and practice have yet to catch-up to these needs, leaving patients to fall through the cracks between political aspirations and the practical reality of today's health systems. Primary care providers and public health systems simply have not been developed to effectively identify and manage people living dementia; and, these issues are significantly exacerbated in low- and middle-income countries where health care systems are often under-resourced. Even in high-income countries, the Global Coalition on Aging's Dementia Readiness Index reports that governments are consistently not equipping health care providers with elder-care training, nor consistently including dementia in public health surveillance activities.⁸⁴

Opportunities for Educating Primary Care Providers on Dementia

A 2015 survey of family physicians in Canada revealed that while more than 86% of Canadian primary care doctors are "often" or "sometimes" providing medical care for people living with dementia, just 41% of all surveyed doctors felt they were well-prepared and equipped to manage this care.^M

Estimated Wait Times in 2020 for Alzheimer's Treatments^{85, 86, N, O}



Boosting Early Detection with Incentives & Training

The CHANGE Act was introduced with bipartisan support in the United States Congress in 2018 the bill introduces a new payment model that would incentivize clinicians to detect, refer, and diagnose dementias in their earliest stages.^P

The state of Massachusetts has enacted a law requiring content on dementia to be incorporated into clinician training and continuing medical education programs.⁹



The Need to Strengthen Health Care Infrastructure

All of this adds up to a health care infrastructure that is illequipped to effectively manage or treat dementia. A 2017 study by the RAND Corporation determined that health care systems in the United States are unprepared to deliver Alzheimer's disease treatment—the study utilizes health care provider capacity projections to calculate anticipated future wait times for patients, with alarming results.

Health care infrastructure capacity constraints impact patients all along the care spectrum—for example, access to imaging services that confirm dementia diagnoses is constrained, along with access to infusion centers that deliver treatments.⁸⁷ In Europe, treatment delivery capacity is a key access issue; and, in France, the United Kingdom, and Spain, specialist capacity is the key ratelimiting factor for patient access.⁸⁸ Building an adequate pipeline of health care providers to meet these capacity challenges will be critical to strengthening health care infrastructure in the face of a growing population of people affected by dementia, an imperative that has informed the WHO's recommendation to increasingly shift responsibility for dementia diagnosis and management to primary health care settings.

Creating a Dementia-Friendly Regulatory and Payment Environment

The regulatory and payment environment surrounding the diagnosis and treatment of cognitive impairments can also constrain patients' access to care. Today's regulatory indications on the use of amyloid imaging agents are narrowly defined; in practice, this means that physicians can observe a positive PET scan but are barred from formally diagnosing the patient with Alzheimer's disease.⁸⁹ Instead, the physician can only suggest that the pathology for Alzheimer's disease is consistent with their test results.

Complications within the payment and reimbursement landscape for funding dementia management and treatment contribute to constraints within the health care ecosystem. Physicians feel time-constrained in managing patients with dementia because reimbursement and billing structures do not accurately reflect the time required to care for patients with the disease.⁹⁰ And, the role of reimbursement in supporting diagnostics and treatments for dementia is difficult to overstate. For example, challenges arise within the utilization of either cerebrospinal fluid or amyloid PET tests that confirm the presence of hallmark pathologies due to the fact that the clinical usefulness of these tests has not proven to be convincing to insurance providers.⁹¹

Payment and incentive challenges are inherent in bringing new diagnosis and treatment technologies to market, as well. For example, demonstrating cost-effectiveness for approved dementia drugs has also historically been difficult because of the need to model long-term outcomes for these new treatments on the basis of short-term data, and common valuation frameworks are inadequate, as they frequently do not include considerations of caregiver burdens, health, and costs.⁹² On the diagnostic side, health product suppliers report challenges in convincing global payers to evaluate the merits of diagnostic tools independently from their links to available or forthcoming therapies.



Improved Prevention, **Detection, and Diagnosis: The Starting Point for Changing** the Impact of Dementia

dvances in our understanding of brain health, coupled with new, forthcoming dementia treatments are poised to revolutionize the fight against dementia. However, in order to fully realize the benefits of these major scientific advances, the early detection of cognitive impairment must improve.

There is reason for optimism as we learn more about dementia prevention and risk modification. Emerging research suggests that diet, exercise, and engaging in activities such as reading and navigating new environments may stave off the onset of dementia symptoms. It is encouraging that many of the risk factors for dementia are influenceable—35 percent of dementia cases might, by one estimate, be prevented by modifying nine risk factors: low education, midlife hearing loss, obesity and hypertension, late-life depression, smoking, physical inactivity, diabetes, and social isolation.93 A study in rural Tanzania suggests that lower educational attainment is also significantly associated with dementia in low-income country contexts.⁹⁴ As with any disease prevention program, the earlier a patient can engage in preventative behaviors, the better for staving off cognitive decline, underlining the need for expanded access to screenings to identify cognitive impairment and the roots of dementia as soon as possible.

A growing body of evidence suggests people can take action in mid-life to prevent the onset of dementia. For example, aggressive blood pressure control may reduce the risk of mild cognitive impairment⁹⁵ and high cardiovascular fitness in mid-life is associated with a decreased risk of subsequent dementia.96 A comprehensive study on the topic, called the "FINGER" study, was conducted at Karolinksa Hospital in Sweden, and is the world's first large multidimensional study on lifestyle interventions. It



Modifiable Risk Factors^R



provides advice on diet, exercise, and "brain training" to prevent the onset of dementia.⁹⁷ Nearly all of the advice provided by the FINGER study is aligned with the WHO's recommendations on reducing major risk factors to prevent noncommunicable diseases.98

There are equally exciting scientific advancements to report within drug development. There are currently 25



Phase Three drugs that could reach the market in the next five years; and, of those, 12 are symptomatic drugs, and 19 are disease-modifying drugs.⁹⁹ Seven drugs are currently in Phase Three prevention trials.¹⁰⁰ Emerging treatments for dementia, as noted, will likely be most relevant for people with early-stage dementia, making early detection an imperative.

The Multi-faceted Benefits of Early Detection and Diagnosis

Together, detection and diagnosis represent one of the seven cross-cutting thematic areas that comprise the World Health Organization's Global Action Plan on the Public Health Response to Dementia (2017-2025) along with its Global Dementia Observatory.¹⁰¹ From a public health perspective, early detection is critical to reducing the costs to health systems associated with dementia and its common comorbidities. Early detection and diagnosis are even more important for people affected by dementia because it facilitates the development of a non-medical treatment plan and a long-term care plan, mitigates dementia-associated risks, opens the opportunity to participate in clinical trials, and provides people affected by dementia with the tools and lifestyle practices associated with slowing the progression of the disease.

At the most basic level, adequate detection and diagnosis is important in determining whether a patient is affected by dementia, or by one of the numerous other causes of cognitive impairment outside of dementia. Many of the causes of cognitive impairment are more easily treatable and can include: medication side effects, metabolic imbalances, thyroid disorders, vitamin deficiencies, psychiatric illness, and damage to brain neurons.¹⁰² If health care providers are not conducting cognition screenings, they may miss the opportunity to address some of these other easily treatable causes of impairment. In 2014, a group of dementia experts, convened by the Alzheimer's Foundation of America, met to discuss the value of standard population screenings for cognitive impairment. The group concluded that health systems should adopt a participatory cognitive screening model, facilitated by information technology.¹⁰³

The receipt of a dementia diagnosis also unlocks the opportunity for the patient's participation in clinical trials where innovative treatments are provided at no charge.¹⁰⁵

Skipping Cognitive Screenings Results in Unnecessary Suffering for Patients^{104, S}



Benefits of Early Dementia Diagnosis

- 1. Treat or reverse causes of cognitive decline unrelated to dementia
- 2. Empower patients to participate in care plan development and make lifestyle changes to slow disease progression
- **3.** Protect people living with dementia from the physical, emotional, and financial risks associated with the disease
- 4. Decrease costs of care
- 5. Enhance the management of comorbidities
- **6.** Unlock the opportunity for patients to participate in clinical trials
- 7. Allow the person living with dementia and their family to attribute cognitive changes to the disease, rather than to personal failings, providing emotional solace



In fact, the underdiagnosis of dementia has implications for the development of new treatments—a 2016 study named the shortage of clinical trial participants as an impediment to expediting dementia drug development.¹⁰⁶ Even if a patient is not diagnosed with dementia, but exhibits cognitive changes associated with risk for dementia, a health care provider may elect to provide them with the opportunity to participate in clinical trials for preventative treatments. People diagnosed with mild cognitive impairment, or exhibiting pre-clinical signs of dementia, may also choose to consult with their health care providers on prevention options available to delay the cognitive advance to dementia—for example, there is early evidence that cholinesterase inhibitors may be beneficial, although they are not yet approved for this indication.¹⁰⁷

A positive diagnosis of dementia also allows health care providers, patients, and their caregivers to begin conversations on the development of a personalized long-term care plan beyond a personalized primary care intervention strategy. A robust care plan is critical to safeguard the well-being of both people living with dementia and their caregivers. For people living with dementia, the receipt of a care plan is proven to reduce the risk of future crisis and emergency department visits.¹⁰⁸ And, once patients and their caregivers are aware of the risks associated with dementia—such as an increased risk of falls-they can alter their lifestyle in ways that protect against these risks. People living with dementia are more likely to feel empowered and less likely to experience despair if they are equipped with practices for potentially slowing the progression of the disease. For example, adherence to the Mediterranean Diet appears to be a particularly promising lifestyle approach to reducing the risk of progression from mild cognitive impairment to dementia.¹⁰⁹ This dietary approach can be incorporated into care plans to empower patients to improve their well-being.110

Care plans are associated with improved health outcomes for caregivers, as well.¹¹¹ Dementia is called a "family disease" because the chronic stress of caring for a declining loved one impacts the whole family—an effective treatment plan must focus on the needs of the entire family.¹¹² A supportive and coordinated care plan can help to reduce caregivers' burden, and associated stress, leading to improved health outcomes.¹¹³ Specifically,

Italy's Interceptor Project

To capitalize on the benefits of early diagnosis, Italy has launched a project to identify patients with the highest risk of developing Alzheimer's disease to improve coordination and timeliness of care plan developing. Known as the "Interceptor Project," the initiative aims to develop strategies to identify patients with the highest risk of developing Alzheimer's and thus the greatest likelihood of benefiting from advanced care planning, and from new treatments, if they become available.^T

treatment plans that include caregiver training and access to caregiver support groups are proven to lower caregivers' stress and improve their health.¹¹⁴

Diagnosis and the development of a care plan can also have a positive emotional impact on people affected by dementia. The receipt of a diagnosis can help to protect a patient's social and emotional well-being by explaining the phenomenology that is causing cognitive changes—empowering patients and their families with this knowledge can reduce strains on social relationships brought about by misunderstood symptoms.¹¹⁵ Further, diagnosis knowledge can also help caregivers to protect people living with dementia from being taken advantage of—for example, people living with dementia are particularly vulnerable to financial exploitation.¹¹⁶

Finally, the early diagnosis of dementia can result in significant savings for health systems. In general, treatment costs are substantially higher for patients living with both dementia and comorbid diseases commonly targeted for disease management, such as cardiovascular disease and diabetes.¹¹⁷ 90 percent of dementia patients have at least one other chronic condition,¹¹⁸ and the costs of care associated with managing comorbid diseases in people living with dementia are 34 percent higher than that of managing comparable patients without dementia.¹¹⁹ This is in part because chronic conditions, like diabetes, require self-management and cognitive impairment hinders the individual's ability to follow disease management instructions.¹²⁰ An early diagnosis of dementia can guard against a patient's declining ability to manage their disease by alerting caregivers to the need for increased support.¹²¹



In 2018, the Alzheimer's Association commissioned a study on the potential cost savings associated with earlier diagnosis, utilizing data from the United States. The study revealed that a diagnosis rate of 88 percent during the mild cognitive impairment stage of Alzheimer's disease would result in cumulative savings of \$7 trillion.¹²² The cost savings to Medicare and Medicaid alone would be greater than the GDP of Japan.¹²³ These cost savings were yielded primarily from two sources: a smaller "spike" in health care costs immediately prior to and after a diagnosis, and lower medical and long-term care costs associated with people with diagnosed and managed dementia versus people with unmanaged dementia.¹²⁴ It is important to note that while detection via biomarkers is making the early detection of dementia progressively easier, the study showed that early diagnosis, even without biomarker confirmation, would yield significant cost savings for both governments and people diagnosed with dementia.¹²⁵ Once treatments come onto the market that are able to delay the onset of dementia symptoms, the potential for savings is even greater-one study estimated that a five-year delay in the onset of Alzheimer's disease would result in a 41 percent decrease in prevalence and a 40 percent decrease in Alzheimer's disease costs in 2050.126

These benefits make early diagnosis a universal imperative regardless of a country's access to advanced diagnostic technologies.¹²⁷ Countries such as Nigeria are already making progress in increasing diagnosis rates in in the absence of sophisticated imaging technologies; thousands of health care workers in Nigeria are trained to spot the signs of dementia during door-to-door health screening exercises, resulting in a significant increase in dementia diagnoses.¹²⁸

Dementia & Non-Communicable Diseases

90%

of people living with dementia have at least one other chronic condition $^{\ensuremath{\text{u}}}$

34%

higher costs for managing comorbid noncommunicable diseases in people living with Alzheimer's disease than in people without Alzheimer's disease^v

For each comorbidity, the **mean annual cost for individuals was substantially higher** in the dementia group^w

Comorbidity	Non-ADOD Cost	ADOD Cost	Cost Difference
Ulcer & gastritis	\$4,294	\$11,087	\$6,793
UTI	\$4,678	\$13,181	\$8,503
Pneumonia	\$10,582	\$15,856	\$5,274
Diabetes uncomp	\$2,753	\$8,581	\$5,828
Fractures	\$5,895	\$13,155	\$7,260
Diabetes comp	\$3,793	\$12,066	\$8,092
CHF	\$8,645	\$14,106	\$5,461



Improving Detection and Diagnosis: Reaching the Sustainable Development Goals (SDG)

Improved detection, diagnosis, and care for cognitive impairment and dementia would also help to improve management of other non-communicable diseases-in line with the targets established in the World Health Organization's Sustainable Development Goals (SDGs). The effective management of dementia is the prerequisite for the effective management of other non-communicable diseases in people living with dementia.¹²⁹ Because of the close links between the management of other noncommunicable diseases and dementia, the effective diagnosis and management of the disease will have the halo effect of reducing premature mortality from noncommunicable diseases, as established in the SDGs. Further, dementia and non-communicable diseases are driven by many of the same shared risk factors, suggesting that prevention activities will prove mutually beneficial in stemming the overall burden of dementia, and other noncommunicable diseases such as cancer, heart disease, and diabetes.¹³⁰ Given the sheer costs associated with dementia care, adequately and efficiently addressing the future care needs of people living with dementia will be a critical component in meeting 2030 goals around the provision of universal health coverage and the provision of health services without risking financial hardship.131

Further, there are other, more nuanced links between dementia and SDG priorities. For example, in both highand low-income countries, women are far more likely to serve as the hands-on family caregivers for people living with dementia.¹³² In Sub-Saharan Africa, specifically, despite women spending their time at home providing care, men are still more likely to make the financial decisions related to caregiving.¹³³ Dementia exacerbates gender inequities by inflicting an outsized burden on women in caregiving roles. Further support for caregivers, coupled with the earlier detection and management—medical or otherwise—of cognitive decline has the potential to free women from caregiving roles that are often unwanted¹³⁴ and responsible for stripping away opportunities for seeking further education or employment.¹³⁵



Learning from Best Practices

round the world, leading organizations are developing novel solutions to support early and accurate detection and diagnosis. These pioneering efforts indicate opportunities and models to accelerate progress against the disease:

National Dementia Strategies: Scotland, United Kingdom

Throughout the past decade, Scotland has approached the challenges of dementia with a series of three "national dementia strategies" since naming dementia a national priority in 2007.¹³⁶ Each strategy is implemented for a three-year period, targeting slightly different aspects of the disease. The First National Dementia Strategy was published in 2010, focusing on improving the quality of dementia services with timely diagnosis and improved access to better care and treatment.¹³⁷ The Second National Dementia Strategy, spanning from 2013 to 2016, focused on improving post-diagnostic support and strengthening integrated and person-centered support.138 In 2017, Scotland introduced a Third National Dementia Strategy.¹³⁹ This strategy focuses on improving the quality of care for patients and families living with dementia and will expire in 2020.

The strategies target three main populations: caregivers, people living with dementia, and the increasingly large ageing population. *The Carers (Scotland) Act 2016* established that it is the duty of local authorities to provide support to unpaid caregivers. This act encourages caregivers to look after their own well-being.¹⁴⁰ In an effort to reduce anxiety around diagnosis, Scotland now guarantees that every newly diagnosed dementia patient will be entitled to a minimum of a year's worth of post-diagnostic support, including connections to community support networks, peer support, planning for future care, and planning for future decision-making.¹⁴¹ Scotland has also implemented a "Promoting Excellence Framework," which provides guidelines for health and social services

staff.¹⁴² The Self-Directed Support Act of 2013 aims to encourage patients and their families to make informed choices about their support. For the broader ageing population, Scotland initiated a "Health and Social Care Delivery Plan." This program improves health and social care services allowing the ageing population to live longer, healthier lives.

According to the Scottish Government, they have made significant progress since declaring dementia a national priority in 2007. Scotland has seen progress in diagnosis rates, post-diagnostic support, and in improving the experience of people with dementia. There have also been improvements in the experience of families and caregivers of dementia patients.¹⁴³ Through these national efforts, Scotland has increased its understanding of the dementia patient population, producing "Estimated and Projected Diagnosis Rates for Dementia 2014-2020."¹⁴⁴

In 2016, Scotland announced, "people are generally living longer, thanks to improvements in standards of living and healthcare support."¹⁴⁵ Scotland recognizes that there are returns on investing in and delivering these National Dementia Strategies. The Third National Dementia Strategy acknowledges that while the returns on the investment are innumerable for patients and their families, the potential return for the government and society can and will be measured. It is suspected that these returns will include delays in admission to residential and formal care services, decreased admission to hospitals, and decreased deployment of emergency services.¹⁴⁶

Scotland serves as a strong example of improving the lives of dementia patients using national strategies, but they are not finished yet. In 2016, they released a "2020 Vision" outlining their goals for a more integrated health and social care system, high-quality, patient-centered treatment, and the ability for everyone to live healthier lives in a home setting.¹⁴⁷



Brain Health Partnership: United States

The Brain Health Partnership is a multi-sectoral publicprivate collaboration, with the aim of producing an actionable Transition Plan for moving from the United States' current ecosystem to a brain health ecosystem via a three-year, scalable plan to equip providers and prepare consumers across the country to timely and effectively recognize and address cognitive impairment. The goal is to make a check-up from the neck up as routine as a check-up from the neck down. The initiative recognizes that making brain health an integral part of routine primary physician practice will require a multitude of systems-level changes, orchestrated simultaneously, to shift the entire landscape of how consumers, physicians and payers/insurers view and deal with brain health.

The initiative has identified nine defining "elements" that collectively comprise a Brain Health Partnership. Each of the defined elements must be addressed in order to prepare and optimize the Brain Health Partnership in the United States to grapple with the rising demands of dementia and Alzheimer's disease. The nine elements of a Brain Health Partnership are defined as: cultural attitude shifts, consumer engagement, and behavior change; optimal care paths; integrated optimal care path in electronic medical records (EMR); care coordination and referral relationships; health care systems change;

health plans and insurers; policies, regulations, and reimbursement; health care provider preparation; and medical education. The Brain Health Partnership convenes Task Forces of multi-sectoral relevant experts within each of the Ecosystem's elemental areas and tasks members with designing a three-year implementation plan.

Within the first phase of the initiative, partners are focused on three prioritized activities: first, developing a consensus-based, recommended optimal care path and training health care providers, aligning payment models and effective consumer engagement strategies; second, preparing health care and payer systems to support the optimal care path; and, third, identifying and seeking high priority policy, regulatory, and financing changes that will advance and incentivize a Brain Health Partnership.

Early pilot programs to educate health care providers and embed dementia detection and care protocols into electronic medical records (EMR) have proven successful. HealthPartners, a network of hospitals, clinics, and an insurance provider, has implemented an optimal brain health care path. The network embedded brain health care pathways into its EMR and provided in-depth trainings with its health care providers to ensure that the care pathways are utilized appropriately and effectively.

This approach may provide a framework for a country, a region within a country or a health system to develop and execute a transition to improved brain health.



Recommendations

he following set of recommendations represent a roadmap to inform the global policy conversations and actions on dementia management, with an eye to utilizing early detection and treatment activities to capitalize on the complementary advances in our understanding of brain health and the development of treatments for early stage dementia:

Improve public awareness of dementia: Healthy aging campaigns can both educate patients and caregivers on the signs of cognitive impairment and of dementia, and on techniques for preserving memory and cognition. The launch of such public awareness campaigns will accelerate efforts to increase detection and diagnosis by activating people to engage with the topic of brain health. This can also help decrease the stigma associated with the disease. Any awareness campaign must be coupled with a defined process for people to seek clinical and community help if they suspect they may be suffering from cognitive impairment or dementia symptoms. The Lancet's Neurology Commission has publicly stated that public awareness of dementia needs to be improved through outreach activities such as public lectures and open-house sessions in clinical care settings, and information provided through mass news media, social media, and patient organizations.¹⁴⁸

It will also be important to identify opportunities for scaling awareness campaigns across diverse geographic contexts. An illustrative 2016 study in Puerto Rico points to the potential efficacy of pairing public education sessions with social media campaigns to increase awareness of dementia and disseminate health information—the program incorporated informal educational sessions on dementia at coffee shops and a Facebook social media campaign.¹⁴⁹

Further include goals and activities related to Alzheimer's disease and dementia within national plans: The World Health Organization has adopted a Global Action Plan on Dementia, and the plan includes actions and targets to hold Member States, international, regional, and national partners accountable for advancements in dementia awareness, risk reduction, diagnosis, care and treatment, and support for caregivers.¹⁵⁰ In order to remain actionable, national plans ought to call for new treatment guidelines and the launch of specific dementia-related policy initiatives.

Further, as governments work to develop national plans and strategies for dementia, it will be important to ensure that no one is "left behind." To that end, we must encourage this type of national planning in resource-limited settings. As of now, no dementia plans or strategies have been established by countries in sub-Saharan Africa.¹⁵¹ Additionally, the issue of dementia often falls within the remit of Ministries of Health and Social Affairs.¹⁵² In order to boost national investments in Alzheimer's disease and dementia and make the systematic changes necessary to implement brain healthy systems, we must develop an investment case that will be compelling to Ministries of Finance. The investment case ought to showcase the overall economic burden of dementia, as opposed to relying on economic arguments that solely focus on medical and caregiver expenses.

Educate primary care providers on appropriate dementia detection and follow-up actions: The perception amongst primary care providers that little or nothing can be done for patients with dementia is a documented impediment to early diagnosis.¹⁵³ Thus, increasing rates of early detection will rely upon improving providers' general understanding and awareness of the treatment strategies to preserve brain health, the prevalence of dementia, and the benefits of diagnosis. Clinicians also must be equipped to utilize diagnostics that can indicate heightened dementia risk, such as blood tests to identify ApoE proteins and imaging tests to detect amyloid proteins. Once this baseline knowledge has been established, primary care providers must be trained on adequately identifying the early signs and symptoms of cognitive impairment and, specifically, dementia.

Pilot programs to provide primary care providers with the skills needed to detect these conditions have already demonstrated results. A pilot program in Missouri, in the United States, targeted rural primary care providers with a three-day intensive training program to boost their dementia knowledge and diagnostic abilities.¹⁵⁴



The initiative involved a three-day "mini-residency" of didactic, observational, and skill-based teaching techniques and its results were promising—post-tests showed improvements in knowledge and confidence to diagnose and treat cognitive impairment, including dementia, and an increase in the providers' utilization of dementia screening tools.¹⁵⁵ The initiative has the potential for replication in rural settings in low- and middle-income countries.

Early detection and diagnosis are meaningless absent links to non-pharmacological treatment strategies and to longer term care plan development and follow-up care for disease management. Thus, health systems will need to couple primary care provider education programs with efforts to solidify treatment and referral protocols and ensure access to specialty care when needed. Combining a targeted physician practice-based educational intervention with community service engagement has been shown to improve dementia care competency in clinicians and promote linkages between clinical and community dementia care providers.¹⁵⁶

Boost the public's perception of the importance of caregivers and enhance mechanisms for caregiver support: Family caregivers are an especially critical piece of the dementia care landscape in resource-limited settings. For example, in sub-Saharan Africa, between twothirds and three-quarters of the total costs of dementia can be attributed to informal caregiving activities.¹⁵⁷ To support family caregivers, the 10/66 Dementia Research Group has designed a pilot package of support interventions for family caregivers in China, Peru, the Dominican Republic, Venezuela, Mexico, Russia, Chile, Argentina, and India.¹⁵⁸ Caregiver support mechanisms included: information on dementia, guidance on behavior management, a psychiatric assessment, and psychotropic medication when necessary.¹⁵⁹ Pilot results in India demonstrated a reduction in caregiver distress and an increase in caregiver health, suggesting that home-based interventions for caregivers in low-income settings are feasible for boosting support for family caregivers.¹⁶⁰

In developed countries, there is now greater recognition among policymakers, researchers, and health and social services professionals that family caregiving is a critical piece of the health card landscape.¹⁶¹ It is important that we spread this message to the general public, and scale caregiver advocacy efforts across low- and middle-income country contexts. Some countries are already moving towards increasing caregiver skill-based immigration. Japan's Prime Minister Shinzo Abe recently instructed his cabinet to start making arrangements to accept 10,000 nursing caregivers from Vietnam by the Summer of 2020 to counter a national industry shortage.¹⁶² Silicon Valley is engaged in advocacy efforts advancing immigration reform, because increased immigration will improve their access to skilled labor.¹⁶³ There could be advocacy parallels to be made with the availability of caregiver labor for caring for people living with dementia. Improving the public's perceptions of the importance of caregivers in managing dementia would bolster immigration reform efforts aimed at increasing the supply of caregivers.

Increase investments in the development of introduction of innovative prevention, diagnosis, and treatment modalities: There is a significant need for further investments in research and development in the dementia field, with an opportunity for philanthropists, governments, private sector actors, and other public institutions to come together in a coordinated funding push.¹⁶⁴ In 2016, The Lancet's Neurology Commission urged European and international organizations to take the lead in investing in the development of new approaches to prevent or cure dementia.¹⁶⁵ The Commission cautioned against diverting funding away from research and drug discovery programs as the cost of care for dementia increases, and noted that a substantial increase in longterm funding for multidisciplinary research programs is essential to reducing the societal costs of dementia.¹⁶⁶

In particular, the development of low-cost, non-invasive biomarkers must be accelerated. Today, biomarkers within the brain can only be identified through the use of sophisticated diagnostic imaging technologies. The discovery of simple biomarkers, such as those found in blood, is necessary to scale early detection efforts across low- and middle-income country settings.¹⁶⁷ And, in all health care settings, regardless of income level, the development of simple, non-invasive laboratory tests will become even more important as health systems look to shift responsibility impairment diagnoses to primary care providers.

Options ought to be explored for de-risking the drug discovery investment case for developers. In this regard, it is a positive development that philanthropist Bill Gates recently invested \$50 million in the Dementia Discovery



Fund—a private fund working to diversify the clinical pipeline and identify new targets for treatment.¹⁶⁸ An examination of dementia through the lens of the Science, Technology, and Innovation Roadmaps for advancing the Sustainable Development Goals could also augment the resources available for research efforts.

Emphasize the collection and analysis of comprehensive data on Alzheimer's disease, dementia, and its common comorbidities: The Dementia Innovation Readiness Index reports that data on dementia remains limited, despite the disease's increasing importance in public health surveillance.¹⁶⁹ Alongside public health surveillance data collection, we should compile dementia research in common formats, to enhance our mutual understanding of how the disease progresses, its genetic and demographic risk factors, and its impact on other conditions and diseases.¹⁷⁰ Enhanced data collections efforts will be especially useful in understanding the links between dementia and the targets for non-communicable disease reduction embedded in the Sustainable Development Goals.

Readying our health systems and communities to manage a growing population of people living with dementia will require enhanced national commitments, awareness and educational interventions aimed at both health care providers and the general public and coordinated global investments in research and data collection. Prevention and early detection activities must be a central component of the global response in order to capitalize on scientific advancements within brain health and drug development. While the dementia challenge is great, new prevention strategies, diagnostic tools, and treatments are finally on the horizon, and the time for policy action on dementia is now.



About The Global CEO Initiative on Alzheimer's Disease

The Global CEO Initiative on Alzheimer's Disease (CEOi), founded in 2013, is an organization of private-sector leaders who have joined together to provide business leadership in the fight against Alzheimer's. CEOi believes that, during this era of aging populations, it will take visionary, coordinated, goal-oriented leadership of public and private leaders working together to solve our greatest challenges. It is convened by UsAgainstAlzheimer's, a US-based patient-led non-governmental organization.

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