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Roadmap for Investment in Dementia Care

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ABOUT US

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The [Milken Institute](#) is a nonprofit, nonpartisan think tank. For the past three decades, the Milken Institute has served as a catalyst for practical, scalable solutions to global challenges by connecting human, financial, and educational resources to those who need them. Guided by a conviction that the best ideas, under-resourced, cannot succeed, we conduct research and analysis and convene top experts, innovators, and influencers from different backgrounds and competing viewpoints. We leverage this expertise and insight to construct programs and policy initiatives.

These activities are designed to help people build meaningful lives in which they can experience health and well-being, pursue effective education and gainful employment, and access the resources required to create ever-expanding opportunities for themselves and their broader communities.

About the Alzheimer's Society

[Alzheimer's Society](#) is the UK's leading dementia charity. Founded in 1979, it addresses the issue of dementia holistically, campaigning for change, funding ground-breaking research, and supporting people affected by dementia today.

Acknowledgment

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INTRODUCTION

On average, people with Alzheimer’s disease and frontotemporal dementia live six to ten years after diagnosis. People with vascular dementia and Lewy body dementia live on average five to six years after diagnosis.¹ A great deal can and should be done to ensure that people with dementia and their caregivers live well post-diagnosis. Because of the complexity of dementia, people living with dementia need a combination of drug treatments, comprehensive care, and supportive services to help them live meaningful lives after diagnosis.

The Milken Institute Alliance to Improve Dementia Care recently released a [series of recommendations outlining the core elements of comprehensive dementia care](#). Comprehensive dementia care should provide medical, neuropsychological, and social services to individuals across their dementia-care journey. Care should be coordinated across health- and long-term care settings, provide choice and control for people living with dementia, and include caregivers as vital care team members.

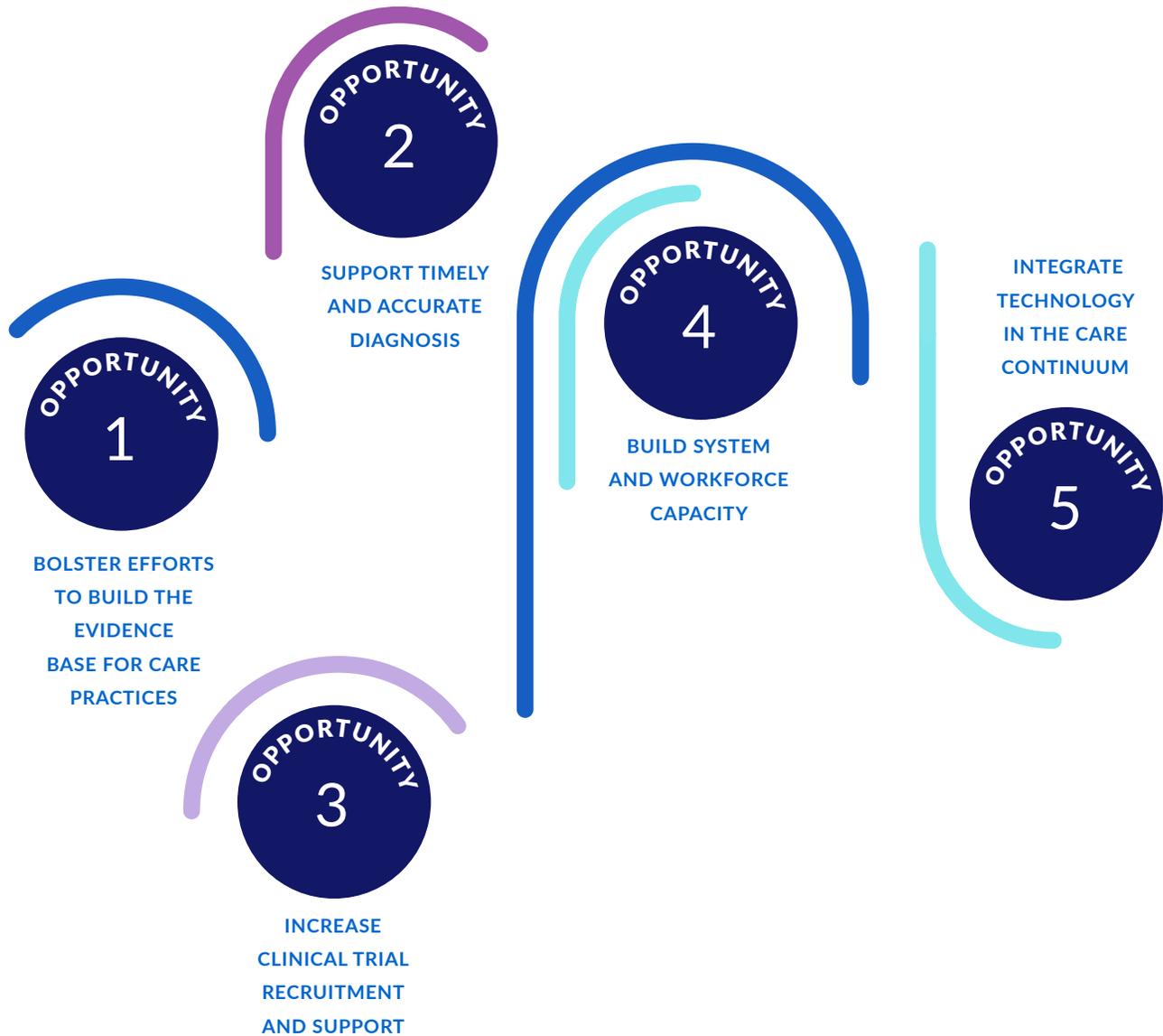
Unfortunately, in much of the world, people living with dementia and their caregivers do not receive high-quality, coordinated, comprehensive care. For example, in the US, dementia care is delivered by health-care providers and community-based social services organizations with limited coordination. Similarly, families in the UK straddle health services provided by the National Health Service (NHS) and the social support services managed by local authorities but paid for out-of-pocket. To address this fragmented approach to care (not limited to dementia), the UK government put forward a plan in fall 2021 to integrate, better fund, and reform health and social care. The goals are to “protect individuals and families against unpredictable and potentially catastrophic care costs” as well as offer choice, control, and independence to care users, provide quality care, and be fair and accessible to all.² The opportunities for collaboration and translation to realize this goal are vast.

Investments addressing Alzheimer’s disease and related dementias (ADRD) have primarily focused on developing disease-modifying therapies to prevent or slow disease progression and accelerate diagnostic tools’ development. Significantly less investment and attention have been given to the complex care journey that people living with dementia and their caregivers must navigate. Available practices and recommendations for dementia care and symptomatic treatment are limited and not standardized globally or locally.³ Public and private investment is necessary not only to develop disease-modifying therapies but also to improve care and quality of life for people living with ADRD. This journey encompasses early detection and diagnosis, care planning and delivery, end-of-life care, and all the transition points and moments of crisis in between.

*“It’s not about cure versus care—it’s about investing in cure and care simultaneously.”—
Sube Banerjee, Executive Dean & Professor of Dementia, Faculty of Health, University of Plymouth*

This roadmap assesses the needs and gaps in dementia care and research and identifies the most promising opportunities to address them. The Milken Institute interviewed more than 25 experts,

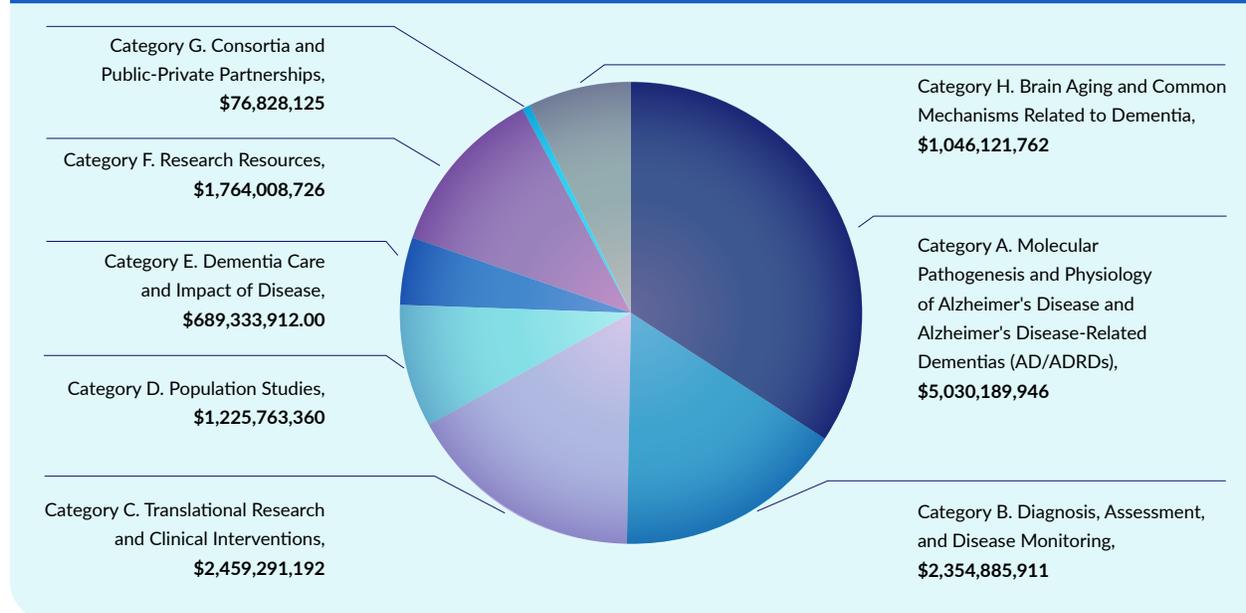
convened three cross-sector roundtable discussions, and conducted desktop research to develop these opportunities. Specifically, in these five opportunity areas, philanthropic investment and private capital can dramatically improve the quality of life for people living with dementia and their caregivers. While predominantly focused on opportunities in the UK and US, this roadmap can be applied to many countries with secure and sophisticated economies.



OPPORTUNITY 1: BOLSTER EFFORTS TO BUILD THE EVIDENCE BASE FOR CARE PRACTICES

Stakeholders agree on the paucity of translational research to advance care practices for people living with dementia. Moreover, the available evidence is often not presented in a way that stimulates policy action or investment.⁴ Clinicians and groups that review and recommend care best practices and guidelines also indicate a need for more robust evidence. Data compiled by the US National Institute on Aging show that more than 30,000 projects are recorded in the International Alzheimer's Disease Research Portfolio database.⁵ To illustrate the disparity in cure- versus care-related research investment in the US, of USD10.8 billion in funds awarded to these projects, less than 4 percent was devoted to dementia care and impact research (Figure 1, Category E). The largest share of funding supported research on disease pathogenesis and physiology (34 percent, Category A) and the development of therapeutics (12 percent, Category C).⁶

FIGURE 1: DEMENTIA CURE- AND CARE-RELATED RESEARCH INVESTMENT IN THE US (\$BILLIONS)



Source: Adapted from [International Alzheimer's Disease Research Portfolio Database, Project Search Results, "Proportion of Funding across Selected CADRO by Total," \(US Only\), accessed December 17, 2021.](#)

Care research will be critical to building an evidence base to support people to live well with dementia, from identifying metrics that capture the impact of care interventions to supporting studies on the ideal staffing mix for specific care models and settings to translating research into clinical practice. Across these objectives, investment in care-related research can increase the quality of life for people living with dementia and their caregivers by supporting efforts in the following three areas:

Foster Interdisciplinary Research

The treatment of dementia requires a multidisciplinary approach because of the heterogeneous nature of the condition and its symptoms. Interdisciplinary research integrates two or more disciplines to increase understanding of or solve a problem beyond the scope of a single research area.⁷ The [*Dementia Prevention, Intervention, and Care: 2020 Report of the Lancet Commission*](#) found evidence of 12 modifiable risk factors that account for around 40 percent of worldwide dementia: lack of education, hypertension, hearing impairment, smoking, obesity, depression, physical inactivity, diabetes, excessive alcohol consumption, traumatic brain injury, air pollution, and low social engagement. Many of these risk factors are associated with other age-related diseases and bolster the case for interdisciplinary research and action.

The Framingham Heart Study, a study identifying the common factors and characteristics contributing to cardiovascular disease, has helped researchers understand the risk factors for dementia.⁸ Individual voice recordings captured during this longitudinal study offer promising new ways to conduct dementia screening using voice analysis.⁹ Another example of interdisciplinary research success comes from the US National Institute on Aging. Researchers found that existing and emerging cancer drugs could be repurposed as therapies to be tested in clinical trials focused on people at genetic risk of AD.¹⁰ These findings could help scientists identify drugs to test as potential interventions more quickly and highlight the value of data-driven interdisciplinary research.

Interdisciplinary research can accelerate our understanding of age-related chronic conditions, but funding can be elusive because this work often falls outside the bounds of typical grant programs. In addition, only 10 percent of the total STEM undergraduate population participates in interdisciplinary studies—even less at the doctoral level.¹¹ Philanthropy can accelerate high-risk, high-reward interdisciplinary research. Continued efforts to connect researchers and clinicians in different fields of study can ultimately result in optimized, person-centered care for people living with dementia and their caregivers.¹²

Support Research on Care Interventions and Symptom Treatment

Funding to strengthen and translate into practice evidence-based care interventions and symptom treatment can significantly improve the quality and consistency of dementia care. The dementia drug research pipeline provides hope that clinicians will soon have a range of medications to customize treatments. However, a robust evidence base that enables clinicians to make recommendations specific to an individual is lacking. Research is needed to understand how timing, duration, and frequency of intervention can be tailored to address the heterogeneity of the symptoms of ADRD in individuals. Evidence to refine recommendations about when and to whom to prescribe therapeutics to treat agitation, delirium, sleep disturbances, and other symptoms will enable clinicians to make successful, personalized recommendations for individuals. Stakeholders agree that the future of quality dementia care will rely upon personalized precision medicine involving combination therapies that target the underlying biology of dementia and its symptoms.



“I expect that soon clinicians will have a range of medications and care interventions from which to customize treatments, and patients will benefit from a combination. New therapies will slow the progression and allow patients to better retain their cognitive function and quality of life.”—Howard Fillit, Co-Founder and Chief Science Officer, Alzheimer’s Drug Discovery Foundation

Thought leaders identified a gap in research between early detection of dementia and full symptomatic onset. A longitudinal disease progression cohort study that follows diverse participants across the entire care continuum could provide crucial evidence on disease progression and course heterogeneity so clinicians and caregivers can make informed treatment and care decisions. This type of study would require long-term funding and support to be successful.

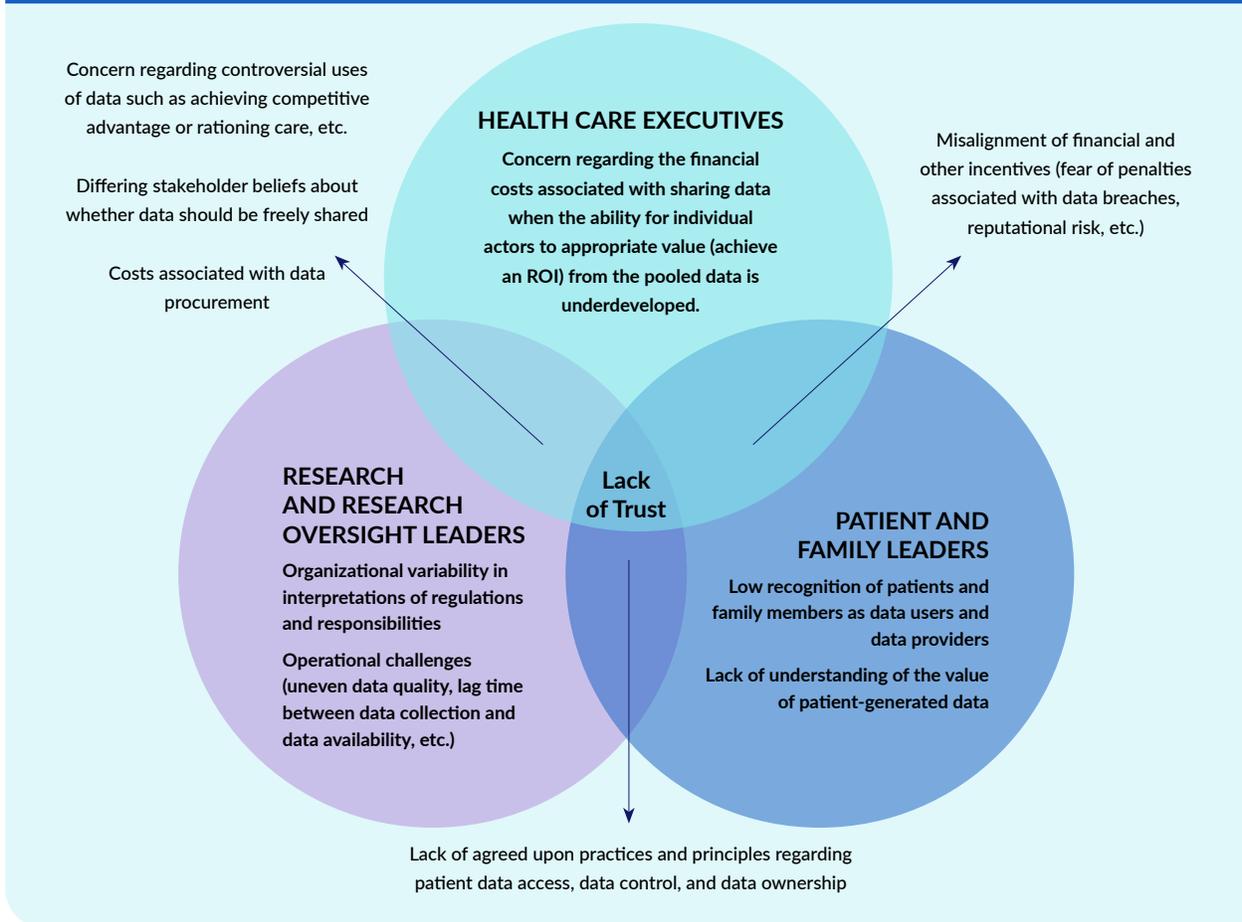
Clinicians and researchers can also collaborate to collect data and refine treatment recommendations via a learning health system. Individuals and their families gain a collaborative role in current and future treatment decisions through participation in such a system. As a benefit, clinicians and people living with dementia could have more options to improve outcomes in the near real-time.

Facilitate Data Sharing and Harmonization

Data cannot be treated as a scarce resource; data sharing allows for more robust analytics and better tools for problem-solving. Relevant data are derived from biological samples, cognitive assessments, brain imaging, and general health data collected at doctor’s visits. De-identified and aggregated datasets can facilitate decision-making, innovation, and discovery. Experts agree that harmonized data from past and current studies could be helpful to researchers who are applying machine learning and other research methods in their work. The COVID-19 pandemic demonstrated that society benefits when standardized data are shared. However, challenges span the research field, including different data collection methodologies, restricted access to and availability of health records, and consumer worries about their privacy (see Figure 2 for additional challenges¹³). Experts agree that an extensive, harmonized dataset is vital to better predict the progression of AD and comorbidities for each disease phenotype. Philanthropy can help overcome the challenges listed above by investing in a centralized dataset such as the one spearheaded by the [Davos Alzheimer’s Collaborative](#). In this example, a consortium of organizations rallied around a shared framework. Commitment to stewarding data linkage, sharing, and use could enhance collaboration and accelerate progress.



FIGURE 2: CULTURAL, ETHICAL, REGULATORY, AND FINANCIAL BARRIERS TO DATA SHARING, LINKAGE, AND USE



Source: Adapted from *Health Data Sharing to Support Better Outcomes*, National Academy of Medicine (2021, Figure ES-1), <https://nam.edu/health-data-sharing-special-publication>

While policy change at the national and international level will drive movement in this area, philanthropic and private capital funding can also facilitate data-sharing innovation by seeking solutions outside the dementia research field. For example, the private sector uses blockchain to enable data transfer and security. Experts agree that health data could support overall health and health-care improvements. Investment is needed to engage stakeholders routinely and systematically across the health- and long-term care systems. As a result of increased investment to support care improvements, individuals can have greater ownership over their data and increased choice in their care plans. Further, health professionals can better identify the most appropriate patients for specific treatments, moving the precision medicine field forward.

OPPORTUNITY 2: SUPPORT TIMELY AND ACCURATE DIAGNOSIS

Early and accurate diagnosis of ADRD can provide individuals and their families with the time needed to create a care plan that enables them to live their lives to the fullest. In addition, Aduhelm, the first drug approved by the US Food and Drug Administration to treat Alzheimer's disease, is intended for patients in the early stages of the disease, as are several other drugs in the pipeline. Thus, it is critical to detect and diagnose AD earlier in the disease process. Detection and diagnostic tools currently in development could allow for more timely and equitable diagnosis for all. These tools under development include digital cognitive screening tools and the use of noninvasive biomarkers such as analyzing blood, retinal scans, or voice patterns.

Advance Low-Cost and High-Access Digital Cognitive Screening Tools

Researchers and clinicians have identified the need for more accurate cognitive screening tools to improve the current generation of pencil-and-paper assessments used in doctor's offices and memory clinics. One of the most widely used tests, MMSE (Mini-Mental State Examination), is limited in its ability to distinguish between mild cognitive impairment (MCI) and healthy cognition. The General Practitioner Assessment of Cognition (GPCOG) performs similarly to the MMSE.¹⁴ It is also unclear among the dozens of available tests whether any are sensitive enough to detect early-stage ADRD.¹⁵ Moreover, the accuracy of paper-based assessments is influenced by demographic factors such as age, gender, and education level. Finally, the "learning effect" can introduce bias when patients are familiar with the test and anticipate and prepare responses in advance.

Several computerized or digital cognitive assessment tools are available today. These tools hold the promise of being more sensitive to subtle cognitive impairment. They can also capture a participant's response speed and are consistent in test administration and automated scoring. Having patients self-administer a digital cognitive assessment tool at home or in a waiting room could address the issue of physicians' limited time with patients during a visit. However, although strides have been made to validate and implement computerized cognitive assessments, adoption in clinical settings has been slow. Additional research is needed to assist clinicians with selecting the right digital cognitive assessment tools for their particular setting and population, to validate further smartphone-based assessment tools,¹⁶ and to determine the most effective way to integrate the tools into clinical workflows.

Accelerate the Deployment of Noninvasive Biomarkers into Diagnostic Protocols

Receiving an accurate diagnosis of dementia can be difficult. The process generally involves an evaluation of other potential causes for cognitive impairment, referral to a specialist, and, in some cases, further evaluation using biomarker testing such as magnetic resonance imaging (MRI) or computerized tomography (CT) scan. Other biomarker tests such as a positron emission tomography (PET) scan or cerebrospinal fluid (CSF) extraction are expensive, difficult to access for some

people, and invasive in the case of CSF. All of these factors combine to create barriers to an accurate diagnosis. As noted, research and development to improve diagnostic capabilities through noninvasive biomarkers such as analyzing blood and saliva, retinal scans, or voice patterns are under way. The first blood-based beta-amyloid test, PrecivityAD™ from C2N Diagnostics, became available in 49 states in the US in 2021¹⁷ and received a CE (Conformité Européenne) mark as a diagnostic medical device in the European Union—indicating it has met safety, health, and environmental protection standards for the region.¹⁸ Experts agreed that portable MRI machines such as Swoop® by [Hyperfine](#) offer increased and lower-cost access to brain imaging for diagnostic purposes.

The brain is complex, and the lived experience with dementia and its diagnosis across the globe are varied. It is unlikely that one tool will be able to meet all needs. Researchers and subject matter experts have indicated that a suite of diagnostic tools should be available to achieve the highest impact. Investors and researchers have highlighted the importance of improving noninvasive biomarkers and embracing an iterative design process. Once implemented, new tools should be refined and advanced through further investment.

“The good news is that the best tech talent is moving into health care, and there’s a lot of capital flowing into this space. But we need to see more investable opportunities and success stories specifically in brain health.”—Joe Stringer, Partner, Octopus Ventures

Philanthropic support and investment can aid the scaling and integration of new digital cognitive screening and diagnostic tools. Standardized screening protocols will also create the infrastructure needed to identify individuals living with or at risk for AD as more disease-modifying therapies become available. In addition, accurate, less invasive, and accessible diagnostics can be implemented into clinical trials protocols and eventually clinical practice.

OPPORTUNITY 3: INCREASE CLINICAL TRIAL RECRUITMENT AND SUPPORT

Clinical trials to test the efficacy of therapeutics and care interventions are vital for building evidence for treatment and care guidance. Trials must have adequate support and participation to ensure that new therapies and interventions benefit a broad range of patients. Historically, attaining sufficient clinical trial participation for dementia-care research has been challenging for several reasons. Barriers include diagnosis later than MCI or early-stage AD, insufficient participation from underrepresented communities, the requirement for a study partner who can accompany patients to study visits, and the use of invasive procedures such as lumbar punctures.¹⁹ Thought leaders identified a need for a strengthened relationship between the clinical and research communities to improve clinical trial participation and retention. This is achievable in the critical ways described below.

Invest in Clinical Trials That Increase Access and Reach a Diverse Global Cohort

Randomized controlled trials are crucial for evaluating the impact of an intervention and building the evidence base for its use. Clinical trials remain the primary avenue through which therapeutics receive market approval. Yet, a disconnect remains between the need for data from a globally diverse population and clinical trial design and recruitment methods. Currently, 90 percent of genetic analysis has been conducted on Western European legacy White populations, while 90 percent of the world's population is not of this demographic.²⁰ This underrepresentation is particularly problematic because Black and Latino older adults are disproportionately at risk for ADRD.

“Decentralizing clinical trials away from bricks and mortar can increase access, mitigate the strain on caregivers, and reach a more racially and ethnically diverse population.”—David Dolby, CEO, Dolby Family Ventures

Currently, some people who want to take part in clinical trials cannot do so because they live far away from trial centers or have existing comorbidities. For people living with dementia, participation also requires a significant time commitment from their caregivers. Populations that lack access to research centers or other means of participating in clinical trials may have smartphones that can enable virtual access and trial participation. The need to continue clinical trials during the pandemic resulted in researchers re-imagining their study designs to accommodate remote data collection and review. A shift to virtual trials could encourage more low-income, rural, and underrepresented populations to enroll in dementia trials, increasing equity and efficiency along the way.²¹ In November, the US Food and Drug Administration updated its standards to accommodate patients participating in clinical trials from home.

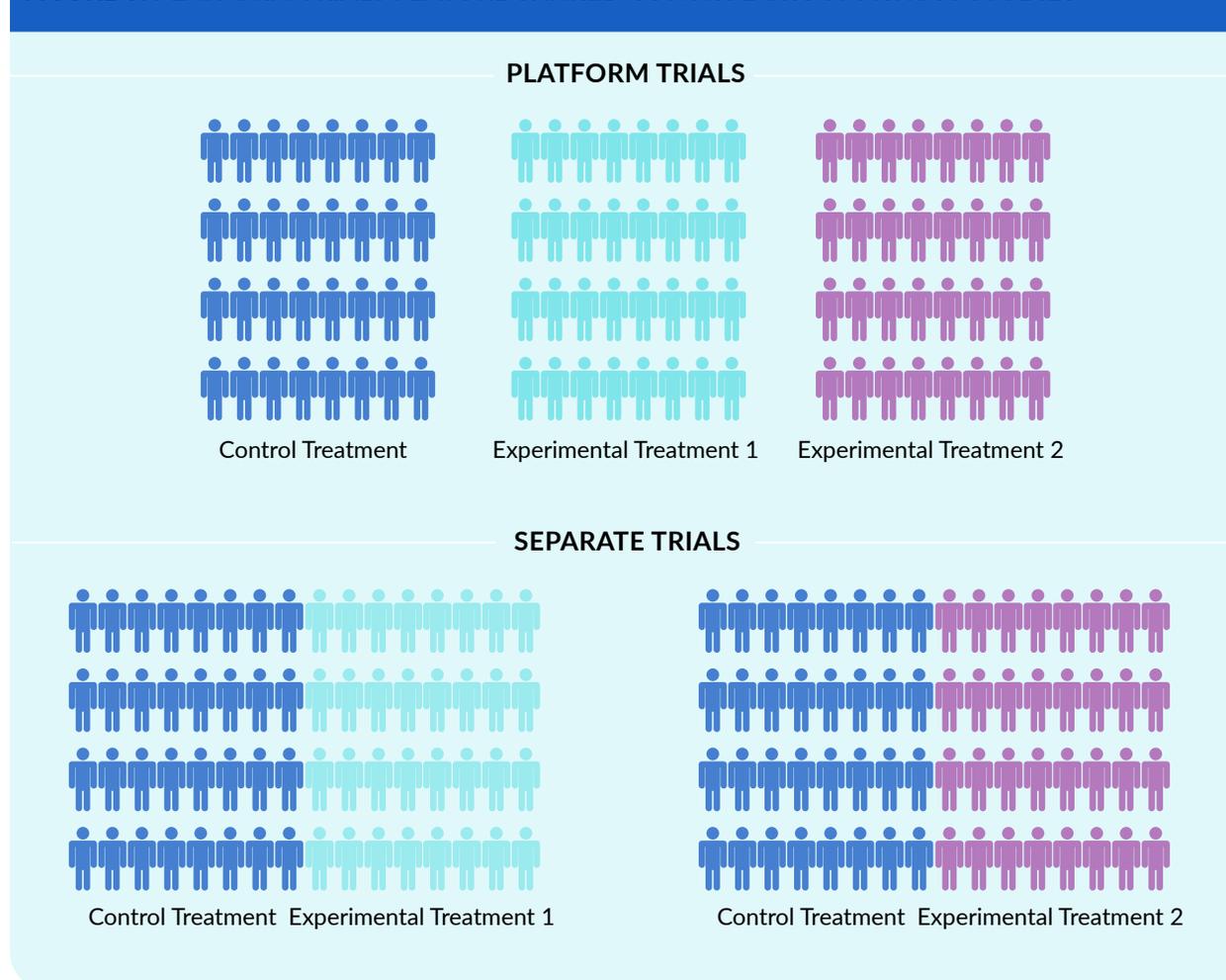
“The private sector uses social engagement technologies and targeted algorithms to reach new customers. These methods have the potential to expand recruitment for clinical trials. Another opportunity: smartphones have, at minimum, 27 sensors available that could be incredibly transformative in designing dementia research.”
—Rhoda Au, Professor, Anatomy & Neurobiology, Boston University School of Medicine

Experts also discussed the opportunity to tap an existing network for clinical trial recruitment: the global [Dementia Friends](#) network. The [Alzheimer's Society](#) initiated this international network of volunteers to raise awareness of dementia and change people's perceptions. Participants in dementia research could be recruited from this network.

Identify and Prioritize Innovative Clinical Trials

Platform trials with master protocols (shown in Figure 3) were used in COVID-19 trials and have been successfully used in oncology research. This trial design is becoming recognized as a more efficient mechanism for performing clinical trials because they allow for a streamlined standard of care for participants. Bringing together researchers from multiple disciplines, as previously mentioned, can result in the design of and recruitment of multi-arm multi-stage (MAMS) trials.²² MAMS trials enable the assessment of multiple treatments against a single control group. Therefore, more treatments can be evaluated, and more trial participants can be in treatment arms or groups and receive the potential benefits of cutting-edge therapeutics and care models. A philanthropic effort to identify and prioritize trials, ensuring that they are well-powered and yield actionable results, will be crucial to building evidence for care recommendations.

FIGURE 3: PLATFORM TRIALS FEATURE SHARED CONTROL GROUP ACROSS STUDIES



Source: Adapted from James M.S. Wason, Lynne Stetcher, and Adrian P. Mandler, "Correcting for Multiple-Testing in Multi-Arm Trials: Is It Necessary and Is It Done?" *Trials* 15, no. 1 (September 17, 2014): 364, <https://doi.org/10.1186/1745-6215-15-364>

OPPORTUNITY 4: BUILD SYSTEM AND WORKFORCE CAPACITY

Living well with dementia includes living safely in the place one calls home, maintaining a positive outlook, managing to cope with memory loss, and being active and staying healthy. Caregivers and multiple health- and social-care professionals provide support throughout the dementia-care journey, but the shortage of dementia-care workers is growing. Across the Organisation for Economic Co-operation and Development (OECD) countries, the number of care workers must increase by 60 percent by 2040 to maintain the current ratio of care workers to older people. That equates to a needed supply of 13.5 million new workers.²³ There are also shortages of dementia specialists—geriatricians, neurologists, neuropsychologists—across OECD countries. However, the number of specialists ranges substantially by country.²⁴ According to the Alzheimer’s Association, half of the primary care physicians (PCPs) in the US admit that the medical profession is unprepared to meet the growing demand for dementia care.²⁵ The social care sector in the UK is struggling with workforce shortages as well, with more than 40,000 social care staff leaving in the last six months of 2021.²⁶

Identify Points Where Health- and Social-Care Professionals Can Receive Training in Dementia Care

Some care providers may not fully understand how dementia can complicate clinical care and undermine a person’s ability to manage other health conditions. Moreover, dementia is a critical factor in the higher use of emergency services and referrals to nursing homes and care homes. To serve people living with dementia and their caregivers, the health- and social care workforce must be robust and well-trained in caring for people living with dementia. This workforce must be equipped to tailor their services to individual needs and incorporate technologies and other supportive approaches, as appropriate. Given the time and resource constraints on PCPs, increasing the dementia training of all health professionals and paraprofessionals will help meet the growing demand for care. Allowing health professionals and paraprofessionals to practice at the top of their licenses can expand workforce capacity. Individuals with fewer needs will receive appropriate, less intensive care, while PCPs and dementia specialists can focus on people with more complex needs.

Investment can support knowledge sharing by developing reciprocal partnerships among academia, primary care delivery sites, advocacy and research organizations, and community-based organizations. Philanthropy can also make a difference by supporting direct education and training on dementia to ensure that the care workforce understands how cognitive and behavioral impairments impact health outcomes. In addition, family caregivers should be considered members of the care team and receive training and support to provide essential long-term services and supports. Raising awareness of training and support programs for paid and unpaid caregivers can help all communities. These opportunities may help to improve care, reduce the gap between research and practice, and create a national shared language and understanding around the different stages of dementia.

Invest in the Care Workforce

Currently, people living with dementia and their families must navigate a patchwork of care options. This situation is due primarily to underfunded social or long-term care systems, a growing older adult population, and a severe shortage of care workers. The caregiving profession is underpaid, physically demanding, undertrained, and typically offers inflexible schedules with no career ladder.²⁷ The Global Coalition on Aging (GCOA) released a report on [Building the Caregiving Workforce Our Aging World Needs](#) with Home Instead that wrestles with these realities and provides calls to action. Roundtable participants echoed GCOA's clarion call about the need to expand and professionalize the caregiving workforce, transforming mindsets about caregiving so it is appreciated for its value to society. A stronger living wage increases the well-being of care workers while signaling that their work is valuable. It can also help with recruitment, retention, and productivity. Studies show that improving compensation is "the single most important thing" to address the worker shortage for the caregiving profession.²⁸ Training all care workers in age-related conditions such as dementia, fragility, and osteoporosis will also significantly impact the quality of care and workforce retention. As care workers employ their experience and knowledge to deliver higher levels of complex care, they should be recognized and rewarded with career advancement opportunities, mentorship, hands-on learning, and compensation.²⁹

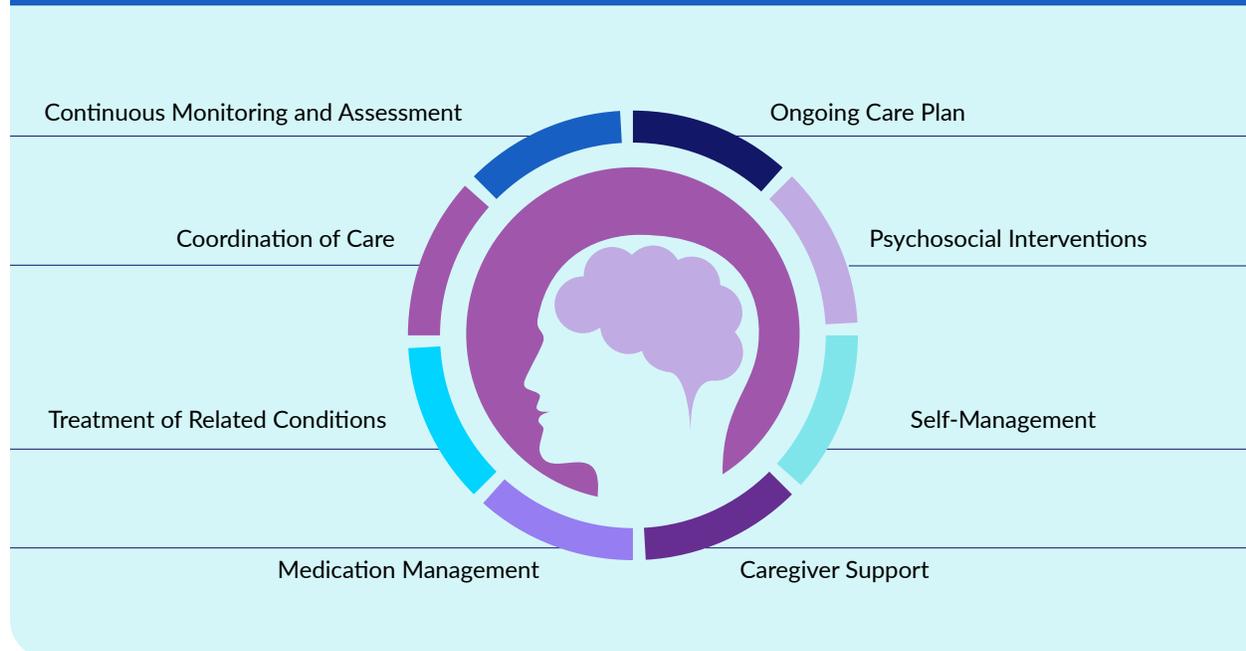
However, as wages increase, so will the cost of care, especially for individual families. Given the workforce shortages and growing number of older adults across the globe, the public, private, and philanthropic sectors must work together to invest in the care workforce to ensure retention and growth. Multisector collaborations can help match older adults with professionals who care for them in their homes while training and integrating family members as part of the care team. Home Instead, a global home care agency, was acquired by Honor Technology in a deal that the CEOs say will help recruit and retain valuable talent.³⁰ The technology that Honor brings to the partnership allows Home Instead to better match care workers to recipients, understand care worker motivations, and provide an electronic client profile and personalized training to a care worker before entering a new client's home. Collaboration and investment are needed to ensure that people living with dementia and their families and friends can rely on a robust and well-trained care workforce.

"The introduction of technology in the care space may serve to recruit new people to the field, like how Uber's technology platform drew new people to the transportation industry with the promise of flexibility and lower barriers to entry."—Chad Brough, Vice President Healthcare Transformation, Home Instead

Develop Dementia-Care Standards and Invest in Scalable Initiatives to Reduce Moments of Crisis

In the US, comprehensive dementia care models have yielded evidence of improved outcomes for people living with dementia and their caregivers and of reduced health-care utilization.³¹ The models differ in staff structure, the scope of services provided, level of intensity, and cost but share eight core elements (see Figure 4). Coordination of care across hospitals, nursing homes, ambulatory care, and community-based settings is vital to reduce the risk of medical errors, hospital admissions, and inefficiency.³²

FIGURE 4: EIGHT CORE ELEMENTS OF COMPREHENSIVE DEMENTIA CARE



Note: See Appendix for definitions and descriptions of each core element.

Source: Adapted from Joshua M. Wiener et al., "Examining Models of Dementia Care: Final Report," accessed August 21, 2021, <https://aspe.hhs.gov/reports/examining-models-dementia-care-final-report-0>

Sadly, in 2017, hospital admissions in England for people with dementia had increased by 35 percent (or 100,000) since 2012, with many people remaining in the hospital for many months because of a lack of social care support in the community, as an analysis by the Alzheimer's Society showed.³³ Roundtable experts agreed that dementia care standards and scalable initiatives, such as the US [Geriatric Emergency Department Accreditation Program](#), are needed to reduce strain and prevent crises such as hospital admissions.³⁴

Geriatric Emergency Departments (EDs) embrace a variety of best practices, including the following:

- Ensuring geriatric-focused education and interdisciplinary staffing;
- Providing comprehensive, geriatric, emergency care-specific assessments to older adults who present in the ED (treatment is initiated based on the needs revealed during the assessment);
- Following standardized approaches to care that address common geriatric issues;
- Ensuring optimal transitions of care from the ED to other settings (inpatient, home, community-based care, rehabilitation, long-term care); and
- Promoting geriatric-focused quality improvement and enhancements of the physical environment and supplies.

Philanthropic and private investment is vital to address fundamental questions and implement best practices in all UK Accident and Emergency (A&E) departments and US EDs. The fundamental questions are: (1) When is the A&E/ED the appropriate place for people with dementia, and how do we help ensure that the experience is as safe and effective as possible? and (2) When is the A&E/ED not the appropriate setting, and how do we reduce A&E/ED use for people with dementia?³⁵

“Everyone deserves to be able to live a life with meaning, purpose, and connection. Where people need support to do this—as many people with dementia do as the condition progresses—care should be there.”—Fiona Carragher, Director of Research and Influencing, Alzheimer’s Society

OPPORTUNITY 5: INTEGRATE TECHNOLOGY IN THE CARE CONTINUUM

Experts observed that current science- and engineering-led initiatives tend to focus problem-solving skills on the prevention and cure side of ADRD. During our roundtable series, experts agreed that investment should also be directed to integrate technology into the dementia-care continuum. **Passive technology applications** can help prevent crises by utilizing in-home sensors, data collection, and predictive analytics to track daily activity patterns and create alerts in the event of a noticeable change or departure from routine. Because these technologies can monitor various vital signs such as pulse, respiration, heart rate, temperature, and even hydration status, they can assist people living with dementia with living independently at home. Moreover, the data collected can inform artificial intelligence's understanding of how activities of daily living (ADLs) change during the different stages of dementia.

The use of technology to monitor people with dementia remotely can reduce or potentially eliminate the use of emergency services and expensive hospital visits. At the same time, placement in nursing homes can be delayed. For example, urinary tract infections are among the most commonly diagnosed infections in older adults and can be particularly problematic for people with dementia.³⁶ Changes in body temperature may signify an infection; early intervention through testing and treatment in the home could prevent a severe infection from developing and causing an ED visit. However, experts noted gaps in the evidence base, differing data standards, and a relatively small number of people living with dementia and their caregivers involved in pilot studies that test care technologies that support living at home.

Assistive technologies describe “products or systems that support or assist individuals with disabilities, restricted mobility, or other impairments in performing functions that might otherwise be difficult or impossible.”³⁷ Mobility assistive technologies include stairlifts, stand lifts, and sling lifts, making transfers from a wheelchair or bed easier to accomplish safely and comfortably. Robotic vacuums can help maintain a clean home. GPS trackers in shoes can help prevent wandering. Technologies such as Google Home or Amazon Echo use voice-activation to play music or audiobooks, set reminders, and provide information such as the date, time, weather, and news. If connected to smart home devices, these devices can control room temperature and lighting. However, many promising technologies designed to support and prolong home-based care have not been clinically validated and therefore are not widely utilized. Moreover, studies indicate a research gap between the use of technology to support aging at home and its long-term effectiveness.³⁸

Therapeutic technologies are another category of applications to support people living with dementia and their caregivers. Reminiscence therapy involves interventions that prompt memories. Therapeutic technologies such as chatbots facilitate social interactions, while robotic pets have been shown to reduce stress, anxiety, and the use of psychoactive and pain medications for people living with dementia.³⁹ Like the above studies of passive and assistive technologies for people living with dementia, current studies of therapeutic technologies are limited by small sample sizes and are not refined by stage of dementia.

Like the above studies of passive and assistive technologies for people living with dementia, current studies of therapeutic technologies are limited by small sample sizes and are not refined by stage of dementia.

Philanthropy and private capital can accelerate the promising work to keep people living with dementia at home for as long as possible and provide them with greater choice and control over their care. Investment is needed to conduct developmental research on technology solutions that are responsive to the needs of different stakeholders in dementia care across settings and that build on existing technologies. More homes and residents are needed in studies that integrate care technologies, increase the volume of data collected, and enable clinical validation of care improvement metrics by stage of dementia.

Philanthropy can also facilitate neutral convenings and alliances to design integrated technology services that center on what matters most for people living with dementia and their caregivers. Philanthropy can support advocacy for standard care packages that include social services and proven technology products and services. It can also fund integrated care technology specialists in community-based organizations to help advise the local workforce on care technologies.

In the UK, the [Technology Enabled Care \(TEC\) Services Association](#) built a coalition with the Association of Directors of Adult Social Services to create a [vision and recommendations](#) to integrate technology into social care. The coalition's four main recommendations are as follows:

1. People, their families, and carers must be given more access and influence over the design of their care and support, integrated with technology as a default.
2. Digital infrastructure, skills, and approaches in social care must improve so individuals and the care workforce can maximize opportunities.
3. People must own and control their health and social care data and enable access by the right people at the right time.
4. More collaboration is needed in care and support across all levels, so services and policies are joined up and contribute to the broader well-being of people, their families, and carers.⁴⁰

CONCLUSION

Across the globe, individuals living with dementia and their caregivers face many challenges as they manage the progressive nature of their condition and navigate the health- and social care landscape. Strategic investment of philanthropic and private capital can help overcome the gaps and barriers identified by stakeholders and subject matter experts in the field. Our research indicates that these gaps and barriers can be addressed by focusing resources on the opportunities outlined in this document. Increasing translational care research and supporting efforts to enable a timely and accurate diagnosis will enable people living with dementia to plan for their care. Supporting clinical trial recruitment, including efforts to decentralize and diversify participation, will ensure that research in the field continues to thrive and evolve, producing additional opportunities for disease-modifying therapeutic and care-related interventions. Even as disease-modifying therapeutics become available, delivering comprehensive dementia care will remain a critical need. A suite of solutions will be necessary to offer personalized care for this heterogeneous condition. Building workforce capacity, integrating technology, and sharing data in the care system will ensure that people living with dementia and their caregivers receive every opportunity to live full, productive lives.

APPENDIX

Definition of Comprehensive Dementia-Care Elements

Source: Haggerty et al., “Recommendations to Improve Payment Policies for Comprehensive Dementia Care,” *Journal of the American Geriatrics Society*, Vol. 68 (11), (November 2020): 2478-2485, <https://doi.org/10.1111/jgs.16807>.

Caregiver support—Identify one or more caregivers to include in evaluation, decision-making, and care planning; provide culturally sensitive support and assistance designed to help the caregiver(s)

Continuous monitoring and assessment—Continuously monitor and assess cognitive, functional, behavioral, and psychological needs and safety and the level of caregiver stress

Coordination of care—Coordinate transitional and other health-care services across hospitals, nursing homes, ambulatory care, and community-based settings

Medication management—Use evidence-based medication management, including de-prescribing medications with adverse cognitive effects; includes efforts to increase medication adherence and education about opportunities for participation in research

Ongoing care plan—Develop and implement a care plan that is regularly evaluated and modified as needed, including advance care planning, wishes about the place of residence, and attention to end-of-life care

Psychosocial interventions—Implement interventions to prevent or reduce the burden of cognitive, functional, behavioral, and psychological challenges and caregiver stress, including care practices from innovative technology solutions

Self-management—Provide self-management tools to enhance the skills of the person living with dementia and the caregiver in managing ADRD, navigating the health-care system, and engaging in activities related to person-centered goals

Treatment of related conditions—Take steps to prevent and treat conditions related to ADRD, such as depression, falls, and delirium

ENDNOTES

- ¹ "The Later Stage of Dementia," Alzheimer's Society, accessed November 16, 2021, <https://www.alzheimers.org.uk/about-dementia/symptoms-and-diagnosis/how-dementia-progresses/later-stages-dementia>.
- ² "Build Back Better: Our Plan for Health and Social Care," GOV.UK, accessed December 9, 2021, <https://www.gov.uk/government/publications/build-back-better-our-plan-for-health-and-social-care/build-back-better-our-plan-for-health-and-social-care>.
- ³ 2021 *Alzheimer's Disease Facts and Figures* (The Alzheimer's Association, January 2021), <https://www.alz.org/media/Documents/alzheimers-facts-and-figures.pdf>.
- ⁴ Martin et al., "A Scoping Review of Gaps and Priorities in Dementia Care in Europe" (Sage Journals, November 29, 2019), <https://doi.org/10.1177/1471301218816250>.
- ⁵ "About," International Alzheimer's and Related Dementias Research Portfolio, Accessed January 4, 2022, <https://iadrp.nia.nih.gov/about>
- ⁶ Gloria Wong and Marin Knapp, "Should We Move Dementia Research Funding from a Cure to Its Care?" *Expert Review of Neurotherapeutics*, Vol. 20 (4), (March 2020): 303-305 <https://www.tandfonline.com/doi/pdf/10.1080/14737175.2020.1735364>.
- ⁷ *Facilitating Interdisciplinary Research* (National Academy of Sciences, National Academy of Engineering, and Institute of Medicine, 2005), <https://doi.org/10.17226/11153>.
- ⁸ "Framingham Heart Study," accessed November 16, 2021, <https://framinghamheartstudy.org/>; Chêne et al., "Gender and Incidence of Dementia in the Framingham Heart Study from Mid-Adult Life," *Alzheimer's & Dementia*, Vol. 11 (3), (March 2015), <https://alz-journals.onlinelibrary.wiley.com/doi/10.1016/j.jalz.2013.10.005>.
- ⁹ Xue et al., "Detection of Dementia on Voice Recordings Using Deep Learning: A Framingham Heart Study," *Alzheimer's Research & Therapy*, 13, 146 (2021), <https://doi.org/10.1186/s13195-021-00888-3>.
- ¹⁰ "Repurposed Cancer Treatments Could Be Potential Alzheimer's Drugs," National Institutes of Health, November 10, 2021, <https://www.nih.gov/news-events/news-releases/repurposed-cancer-treatments-could-be-potential-alzheimers-drugs>.
- ¹¹ Altimus et al., *The Value of Building an Interdisciplinary Scientific Workforce—A Call to Philanthropy* (Milken Institute, 2021), <https://milkeninstitute.org/report/value-building-interdisciplinary-scientific-workforce-call-philanthropy>.
- ¹² Rodriguez (Then) et al., "Interdisciplinary and Transdisciplinary Perspectives: On the Road to a Holistic Approach to Dementia Prevention and Care," *Journal of Alzheimer's Disease Reports*, Vol 4 (1), (January 2020): 39–48, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7081086/>.

- ¹³ Whicher et al., *Health Data Sharing to Support Better Outcomes* (National Academy of Medicine, 2021), https://nam.edu/wp-content/uploads/2021/07/Health-Data-Sharing-to-Support-Better-Outcomes_508.pdf.
- ¹⁴ Brodaty et al., "Screening for Dementia in Primary Care: A Comparison of the GPCOG and the MMSE" <https://pubmed.ncbi.nlm.nih.gov/27811463/>.
- ¹⁵ De Roeck et al., "Brief Cognitive Screening Instruments for Early Detection of Alzheimer's Disease: A Systematic Review," *Alzheimer's Research & Therapy*, Vol. 11 (21), (2019), <https://doi.org/10.1186/s13195-019-0474-3>.
- ¹⁶ Adam M. Staffaroni et al., "Digital Cognitive Assessments for Dementia." *Practical Neurology*, November/December 2020, <https://practicalneurology.com/articles/2020-nov-dec/digital-cognitive-assessments-for-dementia>.
- ¹⁷ "Plasma A β Test Wins Approval—Are p-Tau Tests Far Behind?" ALZFORUM, accessed November 16, 2021, <https://www.alzforum.org/news/research-news/plasma-av-test-wins-approval-are-p-tau-tests-far-behind>.
- ¹⁸ Esther Landhuis, "Detecting Alzheimer's Gets Easier with a Simple Blood Test," *Scientific American*, February 4, 2021, <https://www.scientificamerican.com/article/detecting-alzheimers-gets-easier-with-a-simple-blood-test/>.
- ¹⁹ Watson et al., "Obstacles and Opportunities In Alzheimer's Clinical Trial Recruitment," *Health Affairs*, Vol. 33 (4), (April 2014), <https://doi.org/10.1377/hlthaff.2013.1314>.
- ²⁰ "Global Cohort Development," Davos Alzheimer's Collaborative, accessed November 16, 2021, <https://www.davosalzheimerscollaborative.org/global-cohort-development>.
- ²¹ Emily Anthes, "Clinical Trials Are Moving Out of the Lab and Into People's Homes," *The New York Times*, February 18, 2021, <https://www.nytimes.com/2021/02/18/health/clinical-trials-pandemic.html>.
- ²² Gerard Millen and Christina Yap, "Adaptive Trial Designs: What Are Multiarm, Multistage Trials?" *Archives of Disease in Childhood-Education and Practice Ed*, Vol. 105, (2020): 376–378. <https://ep.bmj.com/content/105/6/376>.
- ²³ "Who Cares? Attracting and Retaining Care Workers for the Elderly," OECD iLibrary, accessed November 16, 2021, <https://www.oecd-ilibrary.org/sites/92c0ef68-en/index.html?itemId=/content/publication/92c0ef68-en>.
- ²⁴ OECD Health Policy Studies, "Care Needed: Improving the Lives of People with Dementia" (OECD, 2018), <http://dx.doi.org/10.1787/9789264085107-en>.
- ²⁵ "Primary Care Physicians on the Front Lines of Diagnosing and Providing Alzheimer's and Dementia Care: Half Say Medical Profession Not Prepared to Meet Expected Increase in Demands," Alzheimer's Association, March 11, 2021, <https://www.alz.org/news/2020/primary-care-physicians-on-the-front-lines-of-diag>.

- ²⁶ Jemma Crew and Josh Luckhurst, "At Least 42,000 Social Care Staff Have Left Sector Since April, Figures Show," *Wales Online*, December, 1, 2021, <https://www.walesonline.co.uk/news/uk-news/42000-social-care-workers-left-22326167>.
- ²⁷ *Building the Caregiving Workforce Our Aging World Needs* (Global Coalition on Aging and Home Instead, 2021), https://globalcoalitiononaging.com/wp-content/uploads/2021/06/GCOA_HI_Building-the-Caregiving-Workforce-Our-Aging-World-Needs_REPORT-FINAL_July-2021.pdf.
- ²⁸ Rebecca Lazeration, "Gaps in the Dementia Care Workforce," National Academies of Science, Engineering, and Medicine's Committee on Population convening, October 14, 2019, <https://www.nia.nih.gov/research/dbsr/gaps-dementia-care-workforce-research-update-and-data-needs>.
- ²⁹ *Growing a Strong Direct Care Workforce: A Recruitment and Retention Guide for Employers* (PHI, May 13, 2018), <https://phinational.org/resource/growing-strong-direct-care-workforce-recruitment-retention-guide-employers/>.
- ³⁰ Diane Eastabrook, "Honor Technology and Home Instead Deal Will Provide Scale, Recruitment Edge, CEOs Say," *McKnight Senior Living*, August 11, 2021, <https://www.mcknightsseniorliving.com/home/news/home-care-daily-news/honor-technology-and-home-instead-deal-will-provide-scale-recruitment-edge-ceos-say/>.
- ³¹ Christopher Callahan and Kathleen Unore, "How Do We Make Comprehensive Dementia Care a Benefit?" *Journal of the American Geriatrics Society*, Vol. 16(11), (November 2020), <https://agsjournals.onlinelibrary.wiley.com/doi/10.1111/jgs.16805>.
- ³² Eric Coleman, "Falling through the Cracks: Challenges and Opportunities for Improving Transitional Care for Persons with Continuous Complex Care Needs," *Journal of the American Geriatrics Society*, Vol. 51 (4), (April 2003), <https://pubmed.ncbi.nlm.nih.gov/12657078/>.
- ³³ "Alzheimer's Society Analysis of NHS England's Hospital Episode Statistics Dataset 2012/13 to 2017/18," Alzheimer's Society, January 22, 2020, <https://www.alzheimers.org.uk/sites/default/files/2020-01/Hospital%20Admissions%202012-18%20for%20people%20with%20dementia%20Alzheimer%27s%20Society%202020.pdf>.
- ³⁴ Cat Urbain, "Geriatric Emergency Departments Associated with Lower Medicare Expenditures," Yale School of Medicine, March 2, 2021, <https://medicine.yale.edu/news-article/geriatric-emergency-departments-associated-with-lower-medicare-expenditures/>.
- ³⁵ Jennie Chin Hansen and Joanne Handy, "Transforming Emergency Care for Persons with Dementia," The Ray and Dagmar Dolby Fund (September 2018): 2.
- ³⁶ Therese Rowe and Manisha Juthani-Mehta, "Urinary Tract Infection in Older Adults," *Aging Health*, Vol. 9(5), (October 2013) <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3878051>.

- ³⁷ “Guidance: Assistive Technology: Definition and Safe Use,” GOV.UK, October 28, 2021, <https://www.gov.uk/government/publications/assistive-technology-definition-and-safe-use/assistive-technology-definition-and-safe-use#:~:text=1.,Introduction,otherwise%20be%20difficult%20or%20impossible.>
- ³⁸ Ollevier et al., “How Can Technology Support Ageing in Place in Healthy Older Adults? A Systematic Review,” *Public Health Reviews* 41, 26 (2020), <https://doi.org/10.1186/s40985-020-00143-4>.
- ³⁹ Petersen et al., “The Utilization of Robotic Pets in Dementia Care,” *Journal of Alzheimer’s Disease*, Vol. 55 (2), (2017): 569–574, <https://pubmed.ncbi.nlm.nih.gov/27716673/>.
- ⁴⁰ *Exploring How Technology Can Be Truly Integrated into Adult Social Care* (Directors of Adult Social Services, TEC Services Association, March 2021), https://www.tsa-voice.org.uk/downloads/pdfs/adass_tsa_commission_report_integrating_technology_into_social_care_final_pages.pdf.

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