

MILKEN INSTITUTE ALLIANCE TO IMPROVE DEMENTIA CARE

GUIDING THE CARE JOURNEY:

Building Dementia Workforce and System Capacity through Care Navigation

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ABOUT THE ALLIANCE TO IMPROVE DEMENTIA CARE

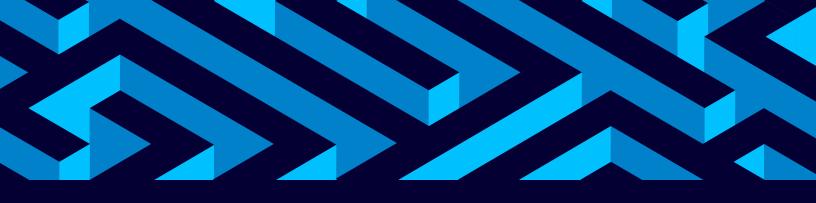
The Alliance to Improve Dementia Care brings together a multisector coalition of over 100 leaders to advance timely detection, access to treatment and coordinated care, and health equity for people at risk of, and living with, dementia and their caregivers. Through expert workgroups, convenings, and collaborative initiatives, the Alliance amplifies and promotes the adoption of proven solutions and promising innovations. While a consensus-building approach informs this report, it may not reflect the views of all Alliance members.

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EXECUTIVE SUMMARY

The US health-care system is facing significant challenges as it prepares to meet the growing demand for care among individuals living with Alzheimer's disease and related dementias (ADRD). According to the Milken Institute, the number of people living with ADRD in the US is expected to nearly double from 7.2 million to almost 13 million by 2040.¹ This increase will exacerbate current gaps in care and capacity constraints in the dementia-care workforce, including a shortage of trained primary care providers (PCPs), specialists, and direct- and skilled-care workers. Implementing care navigation can help overcome these barriers by providing vital linkages between health- and social care services and the "care dyad"—individuals living with dementia and their caregivers.

Care navigation is defined as "individualized assistance offered to patients, families, and caregivers to overcome health-care system barriers and facilitate timely access to quality health and psychosocial care through all phases of the dementia-care journey, which encompasses early detection and diagnosis, care planning and delivery, end-of-life wishes and care, and all the transition points and moments of crisis in between." Care navigators can play a crucial role in dementia care by coordinating medical and social services, increasing access to disease education and community-based services, and promoting person-centered dementia care by partnering with families and identifying care needs and

goals.² Across care settings, dementia-care navigators provide ongoing disease education, care guidance, counseling, behavioral symptom management, and referrals to community-based supports. This approach has proved effective across comprehensive dementia-care models, resulting in reduced emergency department visits, hospital readmissions, behavioral symptoms, caregiver depression, and unmet needs, with improved quality of life.³ However, despite its success, care navigation is still underutilized in dementia care due to a lack of workforce training and inadequate payment systems.⁴

Informed by more than 40 expert interviews, a roundtable discussion, and desktop research, this report provides a framework for health systems. community-based organizations (CBOs), and Medicare payers to implement care-navigation services. It puts forth recommendations to improve provider training for ADRD and expand the dementia-capable workforce; elevate the role of care navigators on interprofessional dementia-care teams to increase coordination and access to services, and support caregivers managing the complexities of the healthcare and long-term care systems; leverage innovative digital and artificial intelligence-powered tools to automate specific navigation tasks; and improve payment for care navigation in traditional Medicare and Medicare Advantage.

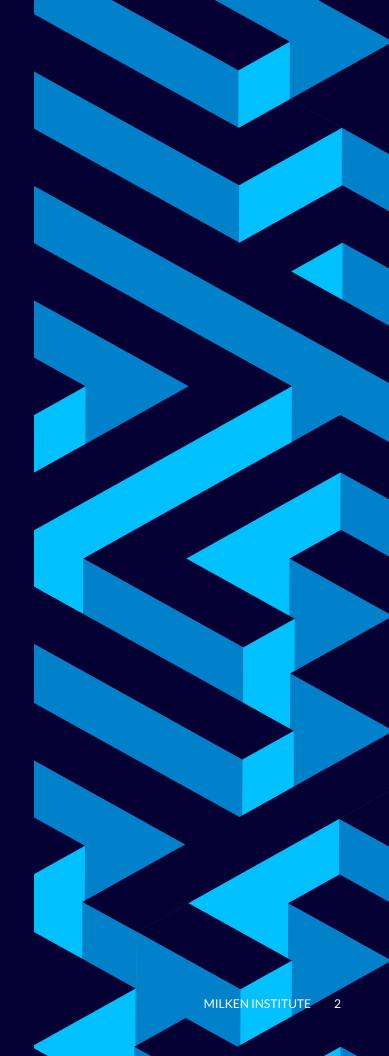
The report makes the following six recommendations centered around two overarching themes to improve dementia-care navigation:

Theme 1: Develop a Framework to Embed and Scale Care Navigation on Dementia-Care Teams

- Define and adapt the core services of dementiacare navigators across care settings, licensures, and levels of need
- 2. Identify and promote best practices to recruit, train, and retain dementia-care navigators
- 3. Leverage online and technology-based solutions to support dementia-care navigation tasks

Theme 2: Expand Payment Mechanisms in Medicare to Incentivize the Adoption of Care Navigators

- 4. Implement alternative payment models for comprehensive dementia care that deliver carenavigation services
- 5. Expand and clarify Centers for Medicare & Medicaid Services guidance on using traditional fee-for-service Medicare payment mechanisms for dementia-care navigation services
- Embed care-navigation services within Medicare Advantage plans



INTRODUCTION

There is an escalating shortage of health-care professionals qualified and specialized to work in dementia care (known as the "dementia-capable workforce") in the United States, which contributes to gaps in care experienced by individuals living with dementia and their families. Care navigation can help close these gaps by coordinating medical and social services, facilitating access to disease education and community-based services, and supporting personcentered dementia care.⁵ In existing comprehensive dementia-care models, care navigators have helped reduce the use of high-cost health-care services and improve the quality of life for individuals living with dementia and their caregivers. 6 They also play essential roles in other chronic conditions. Cancer care patient navigators have been effective in improving cancer screening rates among racially and ethnically diverse populations; facilitating access to health services; providing disease education; and reducing health-care costs associated with hospitalizations, emergency department (ED) visits, and intensive care unit admissions.7

Increased funding for care navigation can help augment this role for conditions such as cancer or dementia, but the integration of care navigators into health-care delivery models has been slow due to a lack of sustainable funding mechanisms. This report provides actionable recommendations to define the role of a care navigator, increase training, integrate supportive technology, and expand payment mechanisms to elevate care navigation in dementia care.

BACKGROUND: THE DEMENTIA-CARE WORKFORCE

The US health-care system will face significant challenges in the coming years as it prepares to care for a growing population living with Alzheimer's disease and related dementias (ADRD). According to

the Milken Institute, the total number of people living with ADRD in the US is expected to nearly double from 7.2 million to almost 13 million by 2040.8 But there are capacity constraints in the current dementia-care workforce, including a shortage of trained primary care providers (PCPs), specialists, and direct- and skilled-care workers.

Projected increases in these roles over the next 10 years are unlikely to match demand. For example, the Association of American Medical Colleges predicts a shortage of 21,100 to 55,200 PCPs nationwide by 2032. Further, the number of practicing geriatricians would have to quadruple from roughly 7,000 to 30,000 by 2030 to meet the care needs of individuals over age 65 projected to have ADRD. These shortages will disproportionately affect older populations, particularly in rural areas, who may have limited access to care.

Fortunately, substantial job growth over the next 10 years is projected in occupations that can help overcome these shortages and play integral roles in dementia care. The Bureau of Labor Statistics projects a nearly 52 percent increase in the number of nurse practitioners (NPs), a 32 percent increase in physician associates (PAs), and a nearly 18 percent increase in social workers by 2031. Leveraging the projected growth of these roles to deliver care-navigation services on interprofessional dementia-care teams can help build workforce capacity to care effectively for the growing proportion of older adults with ADRD.

To address these opportunities, the Milken Institute Alliance to Improve Dementia Care (Alliance) interviewed more than 40 key opinion leaders and convened a virtual roundtable in 2022 to understand the challenges facing individuals with dementia and their caregivers following a dementia diagnosis. This effort builds on the recommendations put forth in the Alliance's 2021 reports on <u>Building Workforce Capacity to Improve Detection and Diagnosis of Dementia</u> and <u>Scaling Comprehensive Dementia-Care Models</u> to advance workforce strategies that support a population-health

approach to delivering comprehensive dementia care. 13 Longstanding workforce challenges identified by the Alliance include provider shortages, fragmented care, and insufficient payment policies.

A new and significant theme identified by our interviews and desktop research focused on one role in the dementia-care workforce: the care navigator. This role has demonstrated success across dementiacare models in helping reduce ED visits, hospital readmissions, behavioral symptoms, caregiver depression, and unmet needs, while improving selfreported quality of life. However, care navigation is currently underutilized in dementia care.14

The expert interviews, roundtable discussion, and desktop research inform the following recommendations. Two overarching themes the Alliance identified for dementia-care navigation are (1) to develop a framework to embed and scale care navigation on dementia-care teams and (2) to expand payment mechanisms in Medicare to incentivize the adoption of care navigators.

Theme 1: Develop a Framework to Embed and Scale Care Navigation on **Dementia-Care Teams**

Dementia care is complex, costly, and unique relative to other chronic conditions because of the profound and progressive impact that ADRDs have on a person's cognition, behavior, and functional capacity. 15 These effects focalize the role of the person's proxy—often a family caregiver—in navigating the health-care and community-based social services necessary to maintain the individual's quality of life. Successful care navigation in dementia care must not only maximize the individual's independence and state of health but also minimize the strain his or her caregiver faces. 16

In 2020, the Alzheimer's Association convened a panel of experts to define dementia-care navigation, its key principles, and appropriate process and outcome indicators to measure quality. This working group emphasized the need for tailored medical care and supportive social services across all stages of dementia to deliver patient- and family-centered, culturally sensitive, and evidence-based care-navigation services.¹⁷ The Alliance incorporated learnings from this expert panel into the report's definition of care navigation (see box) and proposed considerations in delivering these services across levels and settings of care.

DEFINING DEMENTIA-CARE NAVIGATION

Current dementia-care models use various names to categorize their respective carenavigation services across levels and settings of care. Examples include "dementia-care specialist," "care consultant," or "care team navigator." The use of more than one term to describe dementia-care navigation can cause confusion. As such, **Table 1** captures frequent responsibilities by licensure and population served.

For the purposes of this report, the Alliance proposes the following definition of dementiacare navigation to encompass the breadth of services delivered by this role: "Individualized assistance offered to patients, families, and caregivers to overcome health-care system barriers and facilitate timely access to quality health and psychosocial care through all phases of the dementia-care journey, which encompasses early detection and diagnosis, care planning and delivery, end-of-life wishes and care, and all the transition points and moments of crisis in between." (Adapted from the Oncology Nursing Society, National Association of Social Workers, and Alzheimer's Association)

RECOMMENDATION 1: DEFINE AND ADAPT THE CORE SERVICES OF DEMENTIA-CARE NAVIGATORS ACROSS CARE SETTINGS, LICENSURES, AND LEVELS OF NEED.

The Alliance recommends that services used to coordinate and provide care navigation for chronic conditions such as cancer and diabetes be similarly applied in dementia care while tailoring to ADRD-specific care needs, such as supporting daily functional tasks, ensuring a safe living environment, managing behavioral and psychological symptoms, and providing emotional support. Care navigators may be licensed (e.g., NPs, PAs, or social workers) or paraprofessionals with a particular certification or required training. Effective care navigators

partner with families to identify care needs and goals and help them overcome health-care system-related access barriers.²⁰

Across settings of care, effective dementia-care navigators provide a mix of ongoing disease education, health-care system guidance, counseling, behavioral symptom management, and referrals to community-based supports for individuals with dementia and their caregivers. The reliance on clinically licensed roles to help manage medications, comorbid conditions, and behavioral symptoms varies by individual and may increase as dementia progresses. **Table 1** shows how dementia-care navigators help manage dementia across settings of care-navigation delivery and professional licensures.

Table 1: Dementia-Care Navigation Roles and Services across Settings of Care

	Telephonic or Online Setting	Home- or Community-Based Setting	Clinical Setting		
Relevant Dementia-Care Models	University of California, San Francisco Care Ecosystem ²¹ Benjamin Rose Institute Care Consultation ²²	Wisconsin Department of Health Services Dementia-Care Specialist program ²³ Maximizing Independence (MIND) At Home ²⁴	Emory Integrated Memory Care Clinic ²⁵ University of California, Los Angeles Alzheimer's and Dementia Care program ²⁶ Eskenazi Health Aging Brain Care program ²⁷		
Frequent Name(s)	Care team navigator Care consultant	 Dementia-care specialist Coordinator Community health worker or promotora²⁸ 	 Patient care coordinator Dementia-care specialist Dementia-care assistant Care coordinator assistant Journey coordinator²⁹ 		
Varying Qualifications	Paraprofessional: Minimum high school or bachelor's degree; care navigation training Licensed professional: Minimum bachelor's degree in social work, nursing, or other health-related fields	Paraprofessional: Minimum high school or bachelor's degree; care navigation training Licensed professional: Minimum bachelor's degree in social work, nursing, or other health-related fields	Paraprofessional: Minimum high school or bachelor's degree; care navigation training Licensed professional: Minimum bachelor's degree in social work, nursing, or other health-related fields Professional degree such as licensed clinical social worker (LCSW), nurse practitioner, or physician associate and care navigation training		
Responsibilities and Services Provided	Screening questions regarding behavior, function, and care needs Scheduling assistance Care triage Disease education Coordination among interprofessional dementia-care team members Guidance on public benefits (e.g., Medicaid eligibility) and community-based services (e.g., adult day services, home-delivered meals, elder law attorneys, etc.) Care team point of contact for individuals with dementia and their caregivers Patient-caregiver dyad support and education Behavioral interventions	Dementia-friendly community training Memory screening Disease education Informational counseling Guidance on and referrals to public benefits (e.g., Medicaid eligibility), community-based services (e.g., adult day services, home-delivered meals, elder law attorneys, etc.), and research opportunities Recommendations for remote care devices (i.e., to monitor wandering or falls) Facilitating transportation Patient-caregiver dyad support and education Ongoing assistance with care planning	Scheduling assistance 24/7 telephonic support Initial and ongoing assessments Disease education Medication management Care for comorbid conditions Behavioral interventions Advanced care planning Crisis resolution Facilitating transitions of care Patient-caregiver dyad support and education Referrals to community-based services (e.g., adult day services, home-delivered meals, elder law attorneys, etc.) Facilitating transportation Ongoing assistance with care planning		

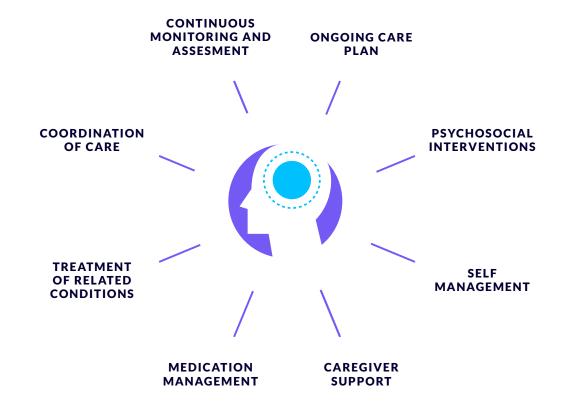
Source: Milken Institute (2023)

"The personal characteristics and aptitudes of the individuals that come to the Dementia-Care Specialist (DCS) program are enormously varied. Backgrounds include nursing, social work, direct care, and gerontology. Many people have been clinical educators, community educators, teachers, therapists, and even business professionals. What unites them all is a desire and a passion for helping families experiencing dementia."

Kristen Felten, Dementia Care Specialist,
 Office on Aging, Wisconsin Department of
 Health Services

The Alliance recommends that dementia-care teams tailor these core roles and responsibilities to reflect staff with varying licensures or levels of training and individuals with varying levels of need in delivering comprehensive dementia care. The diverse care-navigation services included in **Table 1** support the eight core elements of comprehensive dementia care that improve outcomes and lower costs, previously identified by the Alliance in its 2021 report on Scaling Comprehensive Dementia-Care Models. Figure 1 displays these elements, which include establishing an ongoing care plan, coordinating care, and providing continuous monitoring and assessment and caregiver support. The qualifications and expertise of care navigators can help care teams facilitate components of comprehensive dementia care for individuals with ADRD and their caregivers in clinical, communitybased, and online care settings.

Figure 1: Eight Core Elements of Comprehensive Dementia Care



Source: Milken Institute (2021), adapted from Haggerty et al. (2020)



There are significant shortages of qualified and trained dementia-care navigators, particularly in low- and middle-income communities and rural areas. The Alliance recommends the following strategies to help increase the number of dementia-care navigators across health systems, community-based organizations (CBOs), and public health agencies:

Strategy 1: Focus recruitment efforts on the growing numbers of nurse practitioners, physician associates, and social workers. In light of the predicted job growth over the next 10 years, the Alliance recommends that recruitment efforts for care navigators focus on elevating the roles of NPs, PAs, and social workers on interprofessional dementia-care teams. In particular, PAs—known as physician associates or assistants—are licensed clinicians who can practice in any specialty or setting and perform a wide variety of healthcare duties, such as taking medical histories, conducting physical examinations, and creating treatment plans.

According to Lisa M. Gables, CEO of the American Association of Physician Associates (AAPA), "PAs play an essential role in the battle against Alzheimer's disease. Across all specialties, and especially in primary care, PAs are often the first to see and treat patients displaying symptoms associated with ADRD. It is incumbent that primary care providers are adequately trained to recognize warning signs of this heartbreaking disease to ensure early intervention and treatment." AAPA, Cleveland Clinic, and the PA Foundation, with grant support from the Davos Alzheimer's Collaborative, are developing a cognitiveassessment toolkit, which will offer a standard protocol and training resources for PCPs on the early detection of Alzheimer's disease.

As with PAs, the number of NPs is large and growing. There are roughly 300,000 NPs compared to fewer than 7,000 geriatricians and 1,600 geriatric psychiatrists.³⁰ According to David Reuben, MD, director, Multicampus Program in Geriatric Medicine and Gerontology and chief, Division of Geriatrics at the University of California, Los Angeles (UCLA), and Terry Fulmer, PhD, president of The John A. Hartford Foundation, NPs are an ideal profession from which to focus recruitment efforts.31

NPs follow a holistic and team-based approach to managing care. Their prescription-writing and clinical assessment authority can also expand access to essential dementia-care services for individuals in advanced stages. As the importance of dementia-care navigation becomes more widely recognized, recruitment and training of NPs and PAs for these roles can help coordinate the activities of interprofessional teams and strengthen the connection between families and health-care professionals.

"Care navigation saves money. We avoided ED visits, specialist visits, and even surgery. We feel well-supported, cared for, and part of the team at the Integrated Memory Care Clinic (IMCC). The model works for families who are unpaid care partners ... So what can a care navigator do to alleviate the stressors [of caregiving]? A qualified dementia specialist will know your local resources for funds, classes, placement, support groups, and certified elder law attorneys. They'll be able to coordinate your comorbidities, your prescriptions, your tests, and so forth."

-Sharon Hall, Family Care Partner, Young Onset Dementia Advocate and Co-Founder, Innovative Care Partners with Real Experience (iCARE), on her experience with care-navigation services from Emory University's IMCC for her husband, who lives with frontotemporal dementia

Strategy 2: Adopt a training curriculum for care navigators who deliver comprehensive dementia care. A curriculum for care navigators in clinical, community-based, and online models of dementia care can help identify learning outcomes, standards, and core competencies that navigators should demonstrate. These may include knowledge of and referrals to CBOs, symptom recognition, effective handoffs and triage, and engaging in compassionate conversations. Effective training curricula increase the clinician's dementia care knowledge and skills and provide specific training on dementia-care model implementation.

The John A. Hartford Foundation and the Gerontological Advanced Practice Nurses Association (GAPNA) provided support to the UCLA <u>Alzheimer's and Dementia Care</u> (ADC) program to develop a curriculum for the <u>Dementia-Care Specialist</u> (DCS) role.³² This 22-module online curriculum provides a knowledge base for advanced practice nurses and PAs looking to advance their expertise in caring for dementia patients. The ADC program also provides an online curriculum for Dementia-Care Assistants (DCAs), which is available to interested sites <u>upon request</u>. Within this program, DCAs can be nonlicensed or licensed staff trained to assist DCSs by reaching out to lesseracuity individuals with dementia and their caregivers, offering resources, and providing administrative assistance.

The University of California, San Francisco (UCSF) Memory and Aging Center's <u>Care Ecosystem</u> model, which offers telephone- and web-based support for people living with dementia and their caregivers, offers a <u>Care Ecosystem</u> <u>Toolkit</u> to provide organizations with training and implementation guidance for

their care team navigators (CTNs).³³ The Benjamin Rose Institute on Aging (BRI) Care Consultation program also provides extensive online training to its care "consultants" delivering navigation services.³⁴

Strategy 3: Disseminate toolkits that integrate online resources with personalized mentorship. Dementia-care training that adopts a multifaceted approach, including e-learning, mentor-led online support, and in-person mentoring support group meetings, can help improve dementia-care knowledge, attitudes, and competence.³⁵ Training may include online resources and support materials, and pairing dementia-care navigators with experienced mentors who can provide guidance and support as they develop their expertise. Examples of online training for clinical staff and paraprofessionals include UCLA's GAPNA DCS Training and UCSF's Care Ecosystem Training Toolkit.³⁶

Other existing training resources geared toward caregivers or home health aides can also help inform the work of dementia-care navigators by providing disease education and foundational knowledge of the needs of individuals with dementia and their caregivers. These include the <u>UCLA ADC Caregiver Training videos</u>, <u>CareAcademy's Home Health Aide Training videos</u>, and <u>Alzheimer's Los Angeles videos</u>.³⁷

In addition to providing online training, Leslie Evertson, a DCS NP for the UCLA ADC model, mentors new DCSs in the program. After new DCS NPs complete their online training, Evertson and other established DCSs conduct virtual and in-person practice with them and audit their notes after they begin meeting with patients (see Case Study on pages 11–12). During the roundtable, Evertson noted that this approach "allows for more holistic preparation and helps adjust the [ADC] model to the NP's unique needs." The ADC model demonstrates that integrating online learning with personalized mentorship can help train dementia-care navigators to face the complex challenges associated with dementia care and prepare them to provide compassionate and effective care.

Strategy 4: Leverage existing certifications to include paraprofessional dementia-care navigators. Certification programs can formally acknowledge a person's skill set, which can significantly benefit career development and retention. This effort can include establishing formal certification programs that recognize the skills and knowledge of dementia-care navigators and augment their professional credibility and position on care teams. The Certified Dementia Practitioner (CDP) program, offered by the National Council of Certified Dementia Practitioners (NCCDP), provides all health-care professionals, frontline staff, and clergy who work in health-care settings with the opportunity to become certified as CDPs.³⁸ Per the NCCDP, "a CDP certification reflects a deep personal commitment on the part of the frontline staff, health-care professional, and the organization's sense of accountability by abiding by the NCCDP ethics statement, inspiring confidence and dedication in

an individual's professional knowledge through quality of life and quality of care provided by the CDP to the dementia patient."39

Likewise, <u>HealthCare Interactive</u> provides its CARES Dementia Certification after completing various training programs. These training programs are tailored to organizations that are required to meet state dementia training requirements, professionals seeking to advance their careers, and families looking to reduce stress. 40 <u>CareAcademy's specialized certifications</u> include competency-based training programs that build functional skills in specific areas of dementia care and provide disease education about ADRD.⁴¹ Overall, increasing opportunities for paraprofessionals to augment career skills with professional certifications can help boost the credibility and prestige of care navigators. The Alliance recommends that certification programs be vetted by dementia experts and professional organizations, and include people living with dementia and their caregivers in identifying and developing curricula to ensure that their care needs and preferences are reflected in training materials.

SPOTLIGHT: ALZHEIMER'S JOURNEY COORDINATOR CERTIFICATE **PROGRAM**

Launched in 2017 in collaboration between Otsuka America Pharmaceutical, Inc. and Rowan University/Rutgers-Camden Board of Governors, the <u>Alzheimer's Journey</u> <u>Coordinator Certificate Program™</u> trains and implements care navigators ("journey coordinators") within hospitals and health systems. 42 Camden County College implements this certification program to empower community members with backgrounds in health care and social work to become coordinators and serve their larger community. The program targets an escalating need for Alzheimer's disease care in Camden and southern New Jersey, particularly among low-income and racially and ethnically diverse populations facing disparities and health-care barriers.⁴³

Operating both within and outside clinical walls, the journey coordinators are trained to serve as liaisons between individuals with Alzheimer's disease, their families, and the clinical care team throughout the care continuum. They help manage home safety needs, schedule medical appointments and coordinate care, facilitate transportation, manage paperwork, make referrals to community-based resources, and provide disease education and legal and financial guidance. Modeled on successful cancer patient navigator programs and learnings from a collaborative white paper released by the Global Council on Alzheimer's Disease, the Alzheimer's Journey Coordinator Certificate Program and its journey coordinators apply an "ecosystem approach" to supplement the work of care teams by addressing the challenges individuals with dementia face outside the clinical setting.⁴⁴

Strategy 5: Explore expanding the role of existing cancer and diabetes care navigators by training them to deliver dementia-specific navigation services. Care navigators are actively engaged in coordinating care for other high-prevalence chronic conditions, including diabetes and cancer.⁴⁵ Expanding the role of these existing care navigators and leveraging their expertise across health systems and CBOs that provide dementia care could help address the challenges of building a robust dementia-care workforce. This strategy could involve training existing cancer and diabetes care navigators to deliver the dementia-specific navigation services highlighted in **Table 1.** However, there are challenges to providing collaborative care management for individuals with multiple chronic diseases (e.g., heart failure and comorbid depression).⁴⁶

Care management for dementia also differs from other chronic conditions and requires specialized symptom management and caregiver support. Although expanding training for existing diabetes- or cancer-care navigators may help build the capacity of dementiacare teams, further research should help determine whether care navigators serving multiple chronic conditions perform as well as care navigators exclusively serving one condition, such as dementia.47

CASE STUDY: TRAINING IN THE ALZHEIMER'S AND DEMENTIA CARE MODEL

The UCLA ADC program is a health systembased dementia care co-management model. Most individuals in the program have moderate to severe dementia. The DCS advanced practice provider (i.e., NP, PA, or clinical nurse specialist) collaborates with the PCP of the person living with dementia and experts in other medical specialties, such as neurology and psychiatry. The DCS engages with the individual and his or her family either in person or via video to discuss current behaviors, mood, functional ability, safety, medications, legal considerations, and advance care planning. Recommendations are provided in a comprehensive care plan, which is updated at least annually.

In addition to DCSs, the ADC program utilizes non-licensed, trained DCAs who make quarterly outreach calls, educate family members on non-pharmacologic behavioral interventions,

and connect families to community resources. If an individual with dementia is hospitalized, the DCS often serves as an intermediary between the inpatient treatment team and the family of the person living with dementia. The ADC model also partners with CBOs to build a support system of resources in participants' neighborhoods. The program aims to provide comprehensive dementia care that reduces caregiver strain, educates and supports families, and reduces health-care utilization.

Advanced practice providers (APPs), such as NPs and PAs, are highly skilled clinicians. However, like their physician colleagues, most receive little education on ADRD during training. To train APPs for the DCS role, the ADC partnered with GAPNA to create a dementia care-focused set of 22 online modules and a live eight-hour skills training. A new DCS spends time with

DCS mentors and participates in weekly case conferences to discuss complex cases and understand the different types of dementia how they present and progress, and how they affect those around the individual. DCSs report job satisfaction from meaningful work and take pride in becoming experts in the field.⁴⁸

At the end of one year in the DCS-led program, patients showed fewer problem behaviors (e.g., agitation, irritability, apathy, and nighttime

behaviors) and depressive symptoms. Moreover, caregivers reported greater confidence in handling dementia-related problems, as well as reduced distress, strain, and depressive symptoms.⁴⁹

Source: Leslie Evertson, Dementia Care Specialist Nurse Practitioner, UCLA Alzheimer's and Dementia Care Program

RECOMMENDATION 3: LEVERAGE ONLINE AND TECHNOLOGY-BASED SOLUTIONS TO SUPPORT DEMENTIA-CARE NAVIGATION TASKS.

The escalating shortage of a dementia-capable workforce highlights the need to leverage online and technology-based solutions to support dementia-care navigators. Technology-based solutions can help care navigators manage daily tasks, communicate with health-care providers, and share patient information with an interprofessional care team. The Alliance recommends better support for dementia-care navigators through access to online and technology-based solutions targeting the following objectives (Note that the solutions cited below illustrate examples of technology applications but do not represent an endorsement by the Alliance):

1. Facilitate communication and home-based care: Tools such as video conferencing and messaging apps can help navigators communicate with individuals living with dementia and their families. These tools can support and guide individuals who may have difficulty leaving home or accessing traditional in-person care. Telehealth innovations created by National Institute on Agingsupported researchers are creating promising solutions for dementia care and caregiving. 50 Video conference services such as **Zoom** have demonstrated success in helping older adults stave off the effects of dementia.⁵¹

Rippl Care is an example of a mental health company focused on caring for seniors with dementia and other neurocognitive conditions. Its new care model provides 24/7 access to clinicians on the phone, online, or in patients' homes.⁵² Remo Health is another example of a technology company that helps facilitate communication. It uses telehealth to simplify care for individuals living with dementia and their families and bring services traditionally provided

- in office settings into the home.⁵³ A care navigator could use virtual platforms to connect better with an individual with dementia and his or her caregiver in discussing care needs or providing advice and support.
- 2. Track and manage care: Technology-based solutions can help care navigators coordinate and manage care tasks, including care planning, appointments, medication management, and other daily activities. <u>Synapticure</u> is an example of an online tool that provides personalized online care by allowing individuals to contact their care team, access critical resources, receive answers to treatment questions, and develop a personalized care plan specifically for people diagnosed with amyotrophic lateral sclerosis (ALS)—which has overlapping symptoms and pathologies with frontotemporal dementia (FTD)—and their caregivers.⁵⁴ CareBrains is another example of a technology company that helps families determine a person's ability to perform day-to-day tasks and manage optimal care options, including referrals to care providers, assistance applying for public benefits, and identification of financial options.⁵⁵ And Evva Health is a caregiving ecosystem that helps caregivers collect and maintain information about medical conditions, medications, functional status, and available care resources.⁵⁶ Such care management tools could help care navigators create and track care plans for individuals with dementia, document progress, and identify additional support needs.
- 3. **Provide virtual support:** Online support groups and telehealth services can provide access to emotional and instrumental support without visiting a healthcare facility. UsAgainstAlzheimer's <u>BrainGuide</u> provides guided telephone and online tools to receive Alzheimer's disease resources tailored to individual needs.⁵⁷ The <u>Alzheimer's Association's virtual support groups</u>, led by groups of caregivers and individuals living with dementia, provide a platform to ask questions, seek advice, and receive support.⁵⁸ Care navigators could use online portals or apps like these to access information about local support groups and resources, or to connect with other professionals—such as social workers or health-care providers—to coordinate care.

The fragmentation of resources listed above can make it difficult for care navigators to access helpful resources. Additionally, physicians and other health-care professionals may lack time to keep track of all available toolkits and information. To address this, the Alliance recommends professional associations or advocacy organizations collate existing online resources into a single toolkit supporting the core services that dementia-care navigators provide. This would help overcome such challenges by creating a central access location for resources. It would also make it easier for individuals with dementia and their caregivers to find vetted sources of information, as the toolkit could be curated by experts in the field and regularly updated with the latest tools.

In addition to existing online- and technology-based solutions, emerging applications built on artificial intelligence (AI) and machine learning (ML) can automate repetitive and time-consuming navigation tasks and identify gaps in care. These technologies are

not meant to replace the importance of compassionate and high-touch dementia care. Rather, these emerging technologies demonstrate assistive tools to reduce administrative tasks, increase access to real-time information, and help members of dementia-care teams operate more efficiently. The technologies highlighted below offer examples of companies in this field, illustrating opportunities to address these challenges; the Alliance does not endorse them. An AI-powered application can:

- Automatically schedule appointments with health-care providers and other service providers based on the needs and preferences of individuals with dementia and their caregivers. This automation could free up time for care navigators to focus on more complex tasks and provide more personalized support. One company that offers a platform for care navigation is <u>CarePredict</u>, which uses AI and ML to automate care coordination tasks and provide realtime support to individuals with dementia and their caregivers.⁵⁹
- Analyze data from electronic health records (EHRs) and other sources to help care navigators identify health trends and patterns that indicate the healthcare service needs of an individual with dementia. An ML-powered application could analyze an individual's medication regimen to identify potential interactions, adverse effects, or patterns in health-care utilization that warrant additional support. MedyMatch uses ML algorithms to analyze medical images and EHRs to identify potential issues and provide care recommendations.⁶⁰
- Provide dementia-care navigators with personalized recommendations for care and support, connect individuals with dementia and their caregivers to relevant resources and services, and provide real-time support and guidance through virtual platforms and telehealth tools. One company that offers a virtual platform for connecting caregivers with supportive resources is <u>CareLinx</u>, which uses AI to match caregivers with services they might need.⁶¹

Theme 2: Expand Payment Mechanisms in Medicare to Incentivize the Adoption of Care Navigators

Payment remains a barrier to scaling care navigation in traditional or fee-forservice (FFS) Medicare. Often, initial implementation and short-term funding for dementia-care navigation programs are supported by philanthropic grants or Older Americans Act funding.⁶² Roundtable participants and key informant leaders agreed that reliance on this funding is not sustainable for the long-term delivery of care navigation to larger populations as the prevalence of dementia continues to rise. Thus, the Alliance recommends pursuing alternative payment models (APMs) and leveraging existing, underutilized payment mechanisms in FFS Medicare to build health-care system capacity for dementia-care navigation. There is greater flexibility for payment in Medicare Advantage, but dementia-care navigation has yet to scale.

RECOMMENDATION 4: IMPLEMENT ALTERNATIVE PAYMENT MODELS FOR COMPREHENSIVE DEMENTIA CARE THAT **DELIVER CARE-NAVIGATION SERVICES.**

The bipartisan Comprehensive Care for Alzheimer's Act (S.1125 and HR.2517) calls on the Center for Medicare & Medicaid Innovation (CMMI) to test an APM for comprehensive dementia care in FFS Medicare to move toward valuebased payment.⁶³ The bill's proposed Dementia Care Management Model, to be delivered as a stand-alone model or via an existing comprehensive care model, such as Primary Care First, would pay interdisciplinary health-care teams⁶⁴ to provide wraparound dementia-care management services, including ongoing health, financial, and environmental monitoring; self-management tools; medication management; psychosocial interventions; care coordination; and support for family caregivers. 65 Within this legislation, both "self-management" tools" and "care coordination" encompass various care-navigation services as defined in this report. Self-management tools are defined as "tools to enhance the skills of the unpaid caregiver [...] to manage the Alzheimer's disease or related dementia of the eligible individual and to navigate the health-care system," including disease management training, problem-solving strategies, and care navigation support. 66 Care coordination is defined as "necessary assistance or referrals to social and community-based organizations, collaboration with primary care providers and the interdisciplinary team of the eligible individual, and support for care transitions and continuity of care."67

To clarify the care-navigation services that individuals with dementia and their caregivers would receive through the proposed APM, the Alliance recommends that this legislation expand the definitions of self-management tools and care coordination to include all the services identified in **Table 1**. This expansion would more effectively cover the role of a dementia-care navigator across varying licensures, care settings, and levels of need. The Alliance continues to advocate for this and similar legislation and initiatives that support the widespread implementation of comprehensive dementia care.

RECOMMENDATION 5: EXPAND AND CLARIFY CMS GUIDANCE ON USING TRADITIONAL FEE-FOR-SERVICE MEDICARE PAYMENT MECHANISMS FOR DEMENTIA-CARE NAVIGATION SERVICES.

While legislation to test an APM is underway, there are existing levers within FFS Medicare that clinical practices can draw on to deliver components of comprehensive dementia care, including navigation services. Chronic Care Management (CCM) and Principal Care Management (PCM) Current Procedural Terminology (CPT) billing codes reimburse PCPs and specialists who establish, manage, and revise a Medicare beneficiary's care plan and coordinate care activities (see Table 2).⁶⁸ While CCM services focus on two or more chronic conditions, PCM services, developed in 2020 to furnish CCM services, focus on

a single high-risk condition.⁶⁹ The CPT codes to deliver CCM and PCM services are promising levers for interprofessional care teams to provide components of comprehensive dementia care, but associated challenges currently restrict the opportunity for widespread utilization.

"Good intentions by clinicians and systems are stymied by payment restrictions and the outright lack of payment for care coordination that may improve health and reduce costs."

-Robyn Golden, Associate Vice President, Social Work and Community Health, and Chair, Department of Social Work, Rush **University Medical Center**

Table 2: Chronic Care Management and Principal Care Management Services

	Chronic Care Management	Principal Care Management
Care Setting	Typically, primary care	Typically, specialty care
Eligible Billing Providers	 Doctor of Medicine (MD) or Doctor of Osteopathic Medicine (DO), Certified Nurse Midwives (CNMs), Clinical Nurse Specialists (CNSs), Nurse Practitioners (NPs), Physician Associates (PAs), or Clinical staff with appropriate scope of practice under the general supervision of the billing provider (listed above) 	 MD or DO, CNMs, CNSs, NPs, PAs, or Clinical staff with appropriate scope of practice under the general supervision of the billing provider (listed above)
Services Included	20-minute minimum billing requirement for services including: • Structured recording of patient health information • Keeping comprehensive electronic care plans • Managing care transitions and other care management services • Coordinating and sharing patient health information within and outside the practice	30-minute minimum billing requirement for services including: Full scope of CCM services, but limited to a specific, complex chronic condition
Patient Eligibility	Two or more chronic conditions (e.g., Alzheimer's disease, cancer, cardiovascular disease) expected to last at least 12 months or until death Requires patient's written or verbal consent to ensure awareness of cost- sharing responsibilities	 Single chronic condition, expected to last between three months and one year or until death, that is associated with a recent hospitalization or puts the patient at significant risk of decline or death Requires patient's written or verbal consent to ensure awareness of cost- sharing responsibilities
Limitations in Care- Navigation Delivery	 May require patient co-insurance Need access to billing-eligible clinical staff Does not cover initiating visit for patient and family consultative time 	 May require patient co-insurance Need access to billing-eligible clinical staff Does not cover initiating visit for patient and family consultative time

Source: Adapted from CMS Medicare Learning Network Booklet, "Chronic Care Management Services" (2022)

There is a lack of clarity regarding the consistent application of CPT codes for care navigation. For example, CMS defines PCM service practitioners as "clinical staff under the direction of a physician or other qualified health-care professional."70 Given their scope of practice, roles such as licensed clinical social workers are generally recognized as being able to serve as clinical staff under the general supervision of the billing practitioner for CCM and PCM services. However, this recognition is often up to the billing institution's compliance department and may require consultation with the state regulatory and licensing board and/or the Medicare administrative contractor.

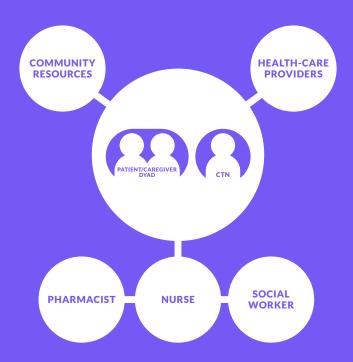
Another challenge associated with these codes is that they require 24/7 access to the eligible billing provider on the clinical team, which can prove difficult as a physician or NP, for example, may not always be reachable. Medicare also requires 20 percent cost-sharing with the use of these codes, an expense that falls on families who lack a supplemental plan or dual Medicaid coverage and may struggle to afford care.71

Together, these challenges create reluctance among health systems to bill using CPT codes for CCM and PCM services and a larger barrier to scalability. Broadening guidelines on who can bill using these codes, and for what services, will increase the use of the codes and improve workforce capacity to deliver care navigation.

The Alliance recommends that CMS clarify guidance on the roles considered "clinical staff" to include licensed clinical social workers. Beyond this step, the Alliance endorses the Bipartisan Policy Center's recommendation that Congress expand provider billing eligibility to include licensed clinical social workers. 72 Additionally, the Alliance recommends that non-clinical staff who deliver care-navigation services and report to clinical staff, such as a CTN or non-clinical social worker, be able to bill under the general supervision of the billing provider. Medicare should also reimburse for consultative time to discuss care-navigation needs with individuals with dementia and their families under these codes. These changes would enable and incentivize the uptake of CCM and PCM services among dementiacare teams and build system-level capacity to deliver care-navigation services.

The following case study demonstrates the current barriers associated with CCM and PCM codes identified by the UCSF Care Ecosystem model:

CASE STUDY: PAYMENT IN THE CARE ECOSYSTEM DEMENTIA-**CARE MODEL**



dementia care that employs a CTN as the main point of contact on an interdisciplinary team. This paraprofessional role receives care navigation training for telephonic delivery of screening questions, care triage, disease education, coordination on the dementiaspecialist team, and ongoing patient-caregiver dyad guidance and support. In a randomized 12-month trial, the model demonstrated improved patient quality of life and caregiver well-being, and reduced emergency room visits and potentially inappropriate medication use.⁷³

The Care Ecosystem model has expanded to more than 20 health systems with grant and philanthropic funding by demonstrating clinical value and utilizing CCM and PCM billing codes for FFS Medicare-covered patients. As noted previously, one challenge associated with using these codes by the CTN is that they require 24/7 access to the billing-eligible provider on the clinical team. Medicare plans may also require 20 percent patient coinsurance for individuals without dual Medicaid coverage or a supplemental plan, and no clear guidance is available for clinical practices to implement these codes effectively and maximize revenues. These challenges make interprofessional care teams implementing the Care Ecosystem model hesitant to bill using these codes.

RECOMMENDATION 6: EMBED CARE-NAVIGATION SERVICES WITHIN MEDICARE ADVANTAGE PLANS.

Medicare Advantage seeks to improve the health outcomes of its members at lower costs. This mission aligns with care navigation's goal of delivering services that reduce acute care episodes resulting in high-cost ED visits or hospital readmissions. Relative to FFS Medicare, Medicare Advantage plans offer more flexibility to provide and pay for navigation services via special supplemental benefits and special needs plans (SNPs). Since Medicare Advantage was launched in 1985, CMS has required plans to invest savings accrued from efficient care delivery into additional benefits that "supplement" Medicare or reduce member costs.⁷⁴

The Bipartisan Budget Act of 2018 allowed Medicare Advantage plans to start offering special supplemental benefits for the chronically ill (SSBCI) that are not primarily health-related, resulting in additional benefits for members, including food delivery, nonmedical transportation, pest control, companion care, and rent subsidies. CMS later expanded the definition of "primarily health-related" supplemental benefits, allowing nonmedical services that help prevent or address cognitive and functional decline, such as caregiver respite and in-home supports.⁷⁵

Continued annual growth in Medicare Advantage plans offering special supplemental benefits indicates that more older adults are receiving additional nonmedical care services. Still, care navigation is not typically its own stand-alone benefit. Instead, care-navigation services may be embedded in other benefits such as in-home support services, caregiver respite, and education. To increase coverage for care-navigation services in dementia care, the Alliance recommends that Medicare Advantage plans expand care-navigation services—as defined in this report—within SSBCI to ensure that older adults with dementia can receive care-navigation services. To this end, CMS should clarify that care navigation can be a stand-alone supplemental benefit to encourage the uptake of such services among Medicare Advantage plans.

SNPs implement interprofessional teams that tailor benefits, provider choices, and drug formularies to meet members' specific needs and include care coordination services to some degree. 76 All SNPs must implement a Model of Care (MOC) that provides the framework under which a plan will meet the specialized needs of its enrollees, thus encouraging high-quality care management and care coordination.⁷⁷ In 2022, 42 percent of SNPs offered SSBCI,78 indicating a significant opportunity for SNPs to deliver the nonmedical community-based services that individuals with dementia and their caregivers need.

Three types of SNPs within Medicare Advantage serve populations based on disease status, coverage type, and personal characteristics. Chronic condition SNPs (C-SNPs) are limited to individuals with a specific condition diagnosis.⁷⁹ Dementia qualifies as one type of C-SNP, but a barrier to entry is the need for a concrete diagnosis to qualify for this type of coverage, which can be difficult for families to obtain. Some Medicare Advantage C-SNPs also focus on higher prevalence and more easily diagnosed conditions, such as diabetes, rather than dementia. Because of this, developing

strategies to address the under-diagnosis of dementia is essential to ensure that health plans have a critical mass of individuals in need of dementia-care navigation services via C-SNPs (read <u>Building Workforce Capacity to Improve Detection and Diagnosis</u> of Dementia). Dual-eligible SNPs (D-SNPs) are limited to lower-income beneficiaries covered by both Medicare and Medicaid.80

SPOTLIGHT: CALIFORNIA MEDICARE MEDI-CAL PLANS DEMENTIA-CARE SPECIALISTS

Launching in 2023, the California Medicare Medi-Cal Plans (MMPs) Dementia Care Model, a type of D-SNP, will be required by the state to have dementia-care specialists (navigators) embedded in interdisciplinary care teams serving individuals with documented dementia-care needs, regardless of formal diagnostic status.81 Dementiacare specialists must be trained to understand and manage ADRD symptoms, disease progression, and caregiver stress and be able to provide community-based resources for enrolled individuals with dementia and their caregivers. Care navigation delivered by these specialists is triggered by documented dementia-related symptoms or behaviors, such as wandering, poor self-care, issues with medication adherence, and/or inability to manage activities of daily living or instrumental activities of daily living.

D-SNPs are instructed to leverage available trainings from dementia-capable CBOs for dementia-care specialists. Care team members must be included in developing the member's individualized care plan to the extent possible and consistent with the member's preferences. The goal of the MMPs is to deliver care coordination and wraparound services that provide comprehensive care for individuals living with dementia and their caregivers.82

Institutional SNPs (I-SNPs) restrict enrollment to individuals with a long-term care level of need based on their state's nursing facility level of care assessment. Enrollment is generally limited to congregate settings such as assisted living or nursing facilities.⁸³ Given the rising number of individuals with dementia and older adults enrolled in Medicare Advantage as well as the opportunity for SNPs to deliver nonmedical supplemental benefits,84 the Alliance recommends that plans increase access to carenavigation services via SNPs to benefit older adults with ADRD and their caregivers

in need of coordinated, comprehensive care. To accomplish this, SNP MOCs should expand their "care coordination" component—designed to provide for enrollees' health-care needs, service preferences, and information sharing among clinical staff and facilities—to tailor care-navigation services identified in **Table 1** to their members. ⁸⁵ **Table 3** summarizes opportunities and considerations across Medicare Advantage offerings:

Table 3: Opportunities for Care Navigation in Medicare Advantage

	Special Needs Plans	Supplemental Benefits	Clinical Models and Quality- Improving Activities	Provider Capitation
What It Is	Medicare Advantage (MA) plan targeted to a subset of Medicare beneficiaries, with a formal Model of Care, interdisciplinary care team, and individualized care plan: • C-SNP • D-SNP • I/Institutional Equivalent (IE)-SNP	Filed MA benefits that exceed traditional Medicare Part A and B services and can include nonmedical supports (e.g., inhome support services)	Care team, digital application, or similar solutions targeted to a subset of MA enrollees but typically not a filed benefit	Physician group or provider contracts with MA plans under full risk, allowing for flexibility in the provider's care model approach (e.g., to offer care navigation)
Considerations	Most C-SNPs target high- prevalence conditions; diagnosis required to enroll D-SNP enrollment limited to dual-eligibles and subject to state parameters I/IE-SNP typically targeted toward congregate settings	 Dollars are limited, spread across many benefits (e.g., dental, vision) and change year over year Benefits need to be understandable and sellable to potential enrollees 	 Difficult to market More flexible than supplemental benefits Often limited based on predictive modeling or costs; may be limited to specific diagnoses 	 Full risk includes all services, not limited to care navigation Upside-only incentives could allow for navigation services, but dollars are limited

Source: Allison Rizer, Principal and Business Lead, ATI Advisory (2022)



CONCLUSION

The capacity constraints of the dementia-capable workforce in the US will only grow more significant as the proportion of older adults continues to rise. The current gaps in care experienced by individuals living with dementia and their families demonstrate the need to improve provider training on ADRD and expand the dementia-capable workforce through roles including care navigation. Elevating the role of care navigators on interprofessional dementia-care teams can help facilitate coordination and access to needed services, support caregivers managing the complex web of the health-care and long-term care systems, and improve the quality of life for individuals with ADRD. Leveraging innovative digital and Al-powered tools to perform navigation tasks in this effort could also complement and accelerate progress as the number of dementiatrained providers continues to lag behind demand. Further, ensuring payment for care navigation in FFS Medicare and Medicare Advantage through existing service delivery opportunities will build health-care system capacity to provide widespread, sustainable care for individuals living with dementia.

This report's recommendations are intended to provide a framework for health systems, CBOs, and Medicare payers to implement care-navigation services for the people they serve. The Alliance urges stakeholders to advance the opportunity care navigation presents to improve the quality of life for people living with dementia and those who care for them.

APPENDIX A: BUILDING WORKFORCE CAPACITY POST-DIAGNOSIS WORKING GROUP

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- Debra Cherry, PhD, Executive Vice President, Alzheimer's Los Angeles
- Michael Ellenbogen, International Dementia Advocate and Connector
- Phyllis Barkman Ferrell, Global Head, External Engagement, Alzheimer's Disease and Neurodegeneration, Lilly BioMedicines, Eli Lilly and Company
- Lisa Gables, CEO, American Academy of PAs
- Sharon Hall, Family Care Partner, Young Onset Dementia Advocate; Co-Founder, Innovative Care Partners with Real Experience (iCARE)
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- Erin Long, Team Lead, Alzheimer's Disease Programs Initiative, Administration for Community Living
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- Joan Weiss, PhD, Deputy Director, Division of Medicine and Dentistry, Health Resources and Services Administration



APPENDIX B: IMPROVING CARE NAVIGATION IN DEMENTIA CARE ROUNDTABLE PARTICIPANTS

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