

# Stakeholder Engagement Panel Summary

**2023 National Research Summit on Care, Services, and Supports for Persons with  
Dementia and Their Care Partners/Caregivers**

**National Institute on Aging**

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This meeting summary was prepared by RLA, under contract to the National Institute on Aging (NIA). The opinions, thoughts, and themes expressed in this document reflect both individual and collective opinions of the Stakeholder Engagement Panel members and not necessarily those of NIA. Contributions to the panel recruitment and facilitation and to the meeting summary by the following individuals are gratefully acknowledged: Jessica Boten, Malaz A. Boustani, Dana Carluccio, Gary Epstein-Lubow, Heidi Gil, Chandra Keller, Amy Kiefer, Ian Kremer, Monica Moreno, Quincy Seamus, Sarah Sjöström, Nancy Tuvevesson, and Alicia Villegas.

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## Panel Overview

As part of the 2023 National Research Summit on Care, Services, and Supports for Persons Living with Dementia and Their Care Partners/Caregivers (“The Summit”), the National Institute on Aging convened a Stakeholder Engagement Panel to solicit feedback from a variety of formal dementia care and caregiving stakeholders, including direct care workers, health services providers, patient advocates, payer representatives, and researchers. The overarching purpose of the Stakeholder Engagement Panel was to further a key goal of The Summit: To identify remaining unmet research needs with input from the research community, persons living with dementia (PLWD) and their care partners, those who provide healthcare or services and supports to PLWD, and other stakeholders. (PLWD refers to persons living with cognitive symptoms including mild cognitive impairment or diagnosed dementia.)

Stakeholders participated in two 90-minute virtual feedback sessions focused on gathering their individual and collective views of unmet dementia caregiving needs; stakeholders were invited to summarize their overall experience and not to provide specific evidence to support their views, although a few citations are provided for reference. The topics discussed are organized into 12 themes where new or additional research might meaningfully impact the lives of PLWD and their care partners and caregivers.

## Feedback Summary

### **Detection and Diagnosis of Alzheimer’s Disease and Related Dementias**

Panelists noted that an estimated 50-80 percent of people with mild to moderate dementia remain undiagnosed. To diagnose people earlier in the disease process, more screening—through tests and questionnaires—is likely needed, particularly of people without clinical signs of dementia. Panelists felt that much progress has been made on tools and processes that enable screening outside of traditional clinical settings, such as within large pharmaceutical chains, but these tools should be brought more fully into communities to increase their use. Longer-term predictive analytics and artificial intelligence using medical records, such as the electronic health record (EHR)-based Framingham Heart Study Dementia Risk Score, may help improve dementia screening and move screening outside the clinic. Several studies on these approaches are under way. For example, voice analysis through cell phones could provide a particularly accessible screening method given the breadth of cell phone use, both within the United States and internationally.

With the recent approvals of potential disease-modifying therapies, the demand for screening and early detection may rise. These therapies may lead the U.S. Preventive Services Task Force (USPSTF) to update its current finding that the current evidence is insufficient to assess the balance of benefits and harms and potential unintended consequences of screening for cognitive impairment in older adults. Panelists suggested that updated recommendations could resemble those for fall risk, which recommend annual screening by primary care physicians. As screening becomes more widespread, efforts to ensure that detection and diagnoses are

Equitable, Timely, Accurate, Compassionate, and Actionable (E-TACA) will become increasingly important.

Screening and early detection may benefit individuals and families by prompting them to start medical, legal, financial, care, and spiritual decision-making. Social services may help families anticipate their care needs and costs during the subsequent stages of disease. Failure to plan for the later stages of care often results in families facing substantial financial challenges as the disease progresses. More generally, panelists felt that research is needed on the impact of screening and early detection on caregiver outcomes and costs to help inform future screening recommendations.

### **Addressing Stigma Around Alzheimer’s Disease and Related Dementias**

Although tremendous progress has been made to raise awareness of Alzheimer’s disease and related dementias, panelists felt that stigma around dementia is a significant issue. Stigma prevents screening and early diagnosis in sometimes surprising ways. In 2021, an AARP survey found that health care providers perceive high levels of stigma around dementia; respondents estimated that nearly 70 percent of their patients would feel ashamed or embarrassed about a dementia diagnosis, when in fact only 20 percent of older adults reported that they would feel that way.<sup>1</sup> Providers may be reluctant to enter such diagnoses into patients’ medical records, in part to protect their patients from this perceived stigma and in part to protect them from potential limitations related to the diagnoses, such as the inability to drive.

Some people experiencing the early stages of dementia may be reluctant to seek a diagnosis. The lack of screening and early diagnosis has numerous implications for care and caregiving, affecting families’ ability to receive early care, services, and supports and to adequately plan for future financial, legal, spiritual, and health care needs.

Research to date has focused primarily on identifying stigma. Fewer studies have assessed interventions to reduce stigma and its potential impact on dementia care and caregiving, which might be modeled on past efforts to reduce stigma around issues of mental health. Panelists emphasized that research on stigma and its alleviation should consider potentially distinct cultural, racial, and ethnic perspectives of dementia.

Panelists shared how language they used to talk about dementia interacted with people’s different perspectives and experiences of stigma. For some people, the terms dementia and Alzheimer’s disease can be frightening and can cause people to disengage from education outreach efforts and from obtaining support. In some communities, individuals are more comfortable talking about “memory problems” than dementia, Alzheimer’s disease, or related diagnoses. Panelists suggested that use of less emotionally loaded terms may help improve education and research recruitment.

“Brain health” is another term used in multiple settings that may cause confusion. Brain health is sometimes used to describe dementia-prevention efforts through risk reduction and prevention, including those focused on the social determinants of health. Other times, brain health is used as a euphemism for existing neurocognitive impairment.

As with screening, the emergence of disease-modifying therapies for Alzheimer’s disease, particularly if covered by Medicare, may reduce the stigma around disease and improve consumer demand and provider willingness to engage in screening, detection, and diagnosis.

### **The Impact, Limitations, and Reach of Comprehensive and Collaborative Dementia Care Models**

The Centers for Medicare & Medicaid Services and the Center for Medicare & Medicaid Innovation are implementing and piloting a variety of alternative payment models for dementia care. Alternative payment models aim to incentivize providers to provide high-quality, cost-efficient care. Traditional fee-for-service reimbursements incentivize care volume, whereas alternative payment models aim to focus on the value of care.

The move toward alternative payments models may foster the development of comprehensive dementia care management programs. Panelists suggested that these programs can provide PLWD and their care partners with help navigating and coordinating care from multiple providers and can enhance access to home- and community-based care services and supports.

Panelists noted that, with the move toward alternative payment models, research has increasingly focused on comprehensive and collaborative care models. Comprehensive care refers to models that consist of several core care elements and provide medical, neuropsychological, and social services to individuals across the stages of their dementia care journey. Collaborative care refers to models in which two or more professionals work together to deliver dementia care as a coordinated team and generally occurs when the lead clinician is not the individual’s primary care provider. Evidence suggests that collaborative care models can reduce behavioral symptoms of dementia, caregiver burden, and the use of acute medical services. Comprehensive care can be delivered through collaborative or primary care models.

Collaborative and comprehensive care models are still being developed for people with non-Alzheimer’s forms of dementia or mixed dementias, and for people with mild cognitive impairment. Panelists emphasized that more research on these models is needed, particularly on their implementation and impact among people with intellectual and developmental disability or Down Syndrome, people living in rural areas, non-English speakers, and Hispanic individuals. Research is also needed to understand how well these models prevent acute hospitalizations and provide care to people without an informal care partner and people with commonly co-occurring disabilities, such as depression, hearing or vision loss, and mobility limitations. Beyond these traditional health care system outcomes, panelists felt that assessments should consider outcomes that are important to individuals and their families, such as convenience and ease of obtaining care from multiple providers. A one-size-fits-all approach to collaborative care may be inappropriate. In addition, the current collaborative care models often do not include home- and community-based care or more creative approaches to care, such as facilitating the sharing of care across families.

### **Support for Care Transitions**

Panelists emphasized that care transitions—both for short-term illness (e.g., hospital to home transitions) and for long-term care—present challenges for care providers and for families of PLWD. Limited information about the home environment (e.g., care and functioning at home) is captured in medical records. Despite efforts to connect medical records across the care continuum, information about personal preferences and baseline functioning is often lost. This loss of knowledge about baseline function can limit providers' ability to prevent or identify delirium, which is prevalent among PLWD but poorly identified and treated. More research is likely needed to understand how delirium contributes to and interacts with ADRD disease progression and how its prevention, early identification, and treatment may benefit PLWD.

Although efforts to extend care at home are valuable, many PLWD require hospitalization for acute medical events and transfer to long-term care as their disease progresses. Panelists noted that more work is needed to create a dementia-friendly and home-like environment that reflects personal preferences for PLWD in the hospital and long-term care settings.

Panelists shared that families, care partners, and caregivers are often underprepared for disease progression and the need to seek additional care, even though many PLWD pass away in hospitals or long-term care settings. Lack of preparation, in combination with denial and grief, can delay finding additional support and care. The stigma associated with residential living and long-term care facilities can also lead families to postpone transitions to higher levels of care, sometimes posing risks to the health and wellbeing of both the PLWD and informal care partners. As a result, care transitions such as movement into long-term care are often forced by acute events without the benefit of adequate preparations (e.g., time to select an appropriate care facility, financial planning, and legal arrangements such as power of attorney).

Some families prefer to provide care in the home throughout the disease, provided they have the necessary formal and informal supports. Inappropriately delayed transitions to long-term care, however, can create conflict between family members caring for PLWD—and between caregivers and care teams—and contribute to caregiver exhaustion and burnout. Widespread stigma regarding long-term care can also prevent advanced financial and logistical planning for this transition. Moreover, even within long-term care settings, stigma can affect families' willingness to allow their loved ones to transfer to memory care units and to initiate hospice and palliative care. A lack of awareness and stigma may exacerbate existing disparities in access to hospice and palliative care.

PLWD and their care partners and caregivers may benefit from proactive conversations about care transitions and the events that may necessitate a higher level of care. Addressing disease progression is emotionally challenging for everyone involved. However, panelists emphasized that the failure to plan often worsens caregiver burnout, exhaustion, and health—along with potentially worsening legal and financial challenges.

### **Dependence on Electronic Health Records**

The dependence on EHRs increases the potential for reliance on mis-entered or erroneous data (i.e., not only medical history, but also topics such as whether to resuscitate and who holds power of attorney (POA)). Panelists suggested that more research is needed to quantify and remediate such errors, especially in the context of increased data sharing across health systems. Errors in EHRs may include information overload or underload, erroneous information, conflicting information, and information scatter. Errors involving PLWD, who may not be able to detect or report errors, may be especially difficult to detect and address.

### **Incorporation of Care Partners and Caregivers into Health Care**

Panelists emphasized that health systems should incorporate care partners and caregivers into appointments. Flagging PLWD for health care staff in clinical settings (e.g., in a medical file) may help staff prepare appropriate accommodations. In the panelists' experience, all clinical staff need training in how to assist PLWD and their care partners and caregivers. In general, evidence-based training is needed across the care spectrum to ensure that PLWD and their family members receive consistent, accurate, and up-to-date information.

Panelists also expressed the need for home care delivery to emphasize transferring knowledge into the PLWD's circle of support, including caregivers and family members, so that they can manage issues that arise when formal care workers are not present.

### **Understanding and Scaling Home-Based Care and Support Programs**

Panelists noted that the home is the most common health care setting and the least understood. They felt that more research is needed on what informal and formal care PLWD receive at home, how to assess its quality, how to assess safety, and whether training for caregivers and formal care workers is improving outcomes—particularly those outcomes that matter most to PLWD and their caregivers—and enhancing the safety of PLWD and their caregivers.

Additional work is also likely needed to incorporate home events into the medical record—for example, through clinical observation, video monitoring, and caregiver reports. Primary care physicians can learn from direct care workers and family caregivers about the day-to-day care in the home, and funding can help bring health care professionals into the home environment to make these observations.

Tensions arise between honoring individuals' desire to remain at home and independent and maintaining safety for PLWD and their caregivers. Many caregivers face complex tradeoffs between promoting quality of life and ensuring safety. Their decisions are often constrained by financial resources, forcing them into decisions simply because other affordable options are not available.

Panelists noted that the COVID-19 pandemic has raised awareness about the potential benefits of delivering acute care in the home environment, as opposed to transferring PLWD to hospitals, which can have unintended adverse consequences and cause disorientation or delirium for the person living with dementia, mild cognitive impairment, or other cognitive

symptoms. New technologies and alternative payment models may help improve acute care delivery in the home.

### **Addressing Caregiver Burnout**

Panelists felt that care partners and caregivers require additional support and training to avoid burnout. The problem of burnout has become increasingly acute during the COVID-19 pandemic and with the move toward keeping PLWD at home. Low-income individuals often lack access to home-based supports, caregiver reliefs such as adult day care, and social and activity groups.

Caregivers may become physically and psychologically exhausted as their loved one's disease progresses, which negatively affects their own health and ability to provide care. Caregivers may pass away while their loved ones survive. In some communities, the need for caregiver supports is stigmatized. Caregivers may fail to ask for help or be unaware of the supports that exist or may have limited ability to access the resources available.

Financial constraints can increase stress for caregivers. Unpaid caregivers are often forced to leave the people they are caring for unattended and in unsafe conditions in order to work. Panelists emphasized that caregivers need additional training and supports, both financial and care related, such as access to adult day care. As the disease progresses, caregivers may experience significant denial and grief.

### **Improved Care Partner and Caregiver Training**

Panelists discussed how caregiver training related to healthy lifestyles, sleep, nutrition, and hearing may be inadequate because these topics exist outside the dominant biomedical model. Panelists noted that approximately 1 in 5 PLWD live alone, and their family members may not fully appreciate the safety and health implications of this situation. Technology can enable PLWD and their non-local family members to check in with one another, but individuals may require training to use the technology available.

Training may help caregivers to understand the medical, emotional, and psychological experiences of their loved ones with dementia. A lack of understanding can lead to therapeutic conflict with care providers and among family members.

Beyond training, care partners and caregivers must be able to implement the advice they receive, in the context of their lived experiences, communities, and other systems they inhabit. Advice to eat nutritiously, for example, might be impractical for low-income individuals living in a “food desert”—an area with few grocery stores and fresh food options.

Panelists felt that current efforts to help people navigate the health care system are insufficient. Care navigators can support families in emotional and logistical preparation for disease-related life changes and disease progression, but policy and workforce issues limit access to this type of support. Robust research and evaluation on the potential benefits of care navigators could help make the case for policy change.

When designing and assessing such education and support, researchers could move beyond population averages to provide personalized, tailored, and adaptive messages. An overreliance on averages when crafting messaging and educational outreach programs can inadvertently exacerbate health disparities and contribute to structural racism, classism, ageism, ableism, and other forms of discrimination.

### **Incontinence, Behavioral Issues, and Neuropsychiatric Symptoms**

Panelists noted that wandering, incontinence, behavioral issues, and neuropsychiatric symptoms often lead families to transition their loved ones into long-term care. More research is needed on interventions to help caregivers prevent wandering, manage incontinence, and understand and resolve behavioral issues (many of which are driven by unmet needs) in the home setting.

Conversely, when behavioral issues and neuropsychiatric symptoms are unaddressed or inappropriately addressed, they can lead to the removal of PLWD from long-term care settings, but little research has explored the consequences of this action on PLWD and their caregivers. Relatedly, panelists felt that the research supporting FDA’s “black box” warning on psychotropics in PLWD is dated and that this warning may need to be revisited, especially as new psychotropic therapies become commercially available. Several psychotropic therapies in development have been tested in people with Alzheimer’s disease and related dementias. Panelists added that additional research is also needed on holistic, non-pharmacological approaches to managing behavioral and psychological symptoms of dementia.

### **Recruitment, Retention, and Representativeness of the Care Workforce**

Panelists noted the widespread shortages of care workers throughout the health care continuum. Geriatrics, for example, has seen a marked decline in new specialist providers. Care navigators might help alleviate some of the demands on physicians and nurse practitioners.

Improvements are needed throughout the pipeline to promote direct care work for PLWD. Efforts to improve training and wages as well as to create career ladders may help address direct care worker shortages, and improving staffing ratios may improve patient outcomes and reduce direct care worker burn-out; however, the impact of such efforts is not well understood and may have unintended consequences. For example, imposing education requirements can raise barriers to career entry and exacerbate staffing shortages. Mandating staffing levels could counterproductively contribute to facility closures. Panelists noted that several facilities closed during the COVID-19 pandemic, and staffing requirements could exacerbate the existing shortage. Regulations on care provision in long-term care facilities can limit their ability to provide care and needed services effectively and lead to closures.

A more research-based approach to worker requirements is a critical component of workforce development. Several panelists expressed that direct care workers need more and better training. Although some training requirements are in place, the training is generally inadequate to the job requirements and especially to the challenge of handling heavy patient caseloads, particularly when there are significant behavioral issues, which are common among residents in

long-term care settings. Regulations currently focus on avoiding negative outcomes, but more work is needed to create systems and environments that foster (“nudge”) positive behaviors and outcomes. One area of improvement might be greater facilitation of intergenerational interactions among long-term care residents, to more closely resemble elder care in the past.

### **Participatory Research**

Logistical barriers impede research participation, particularly among socially marginalized groups. Such barriers include the need to travel and associated costs, the cost of alternative care, and the need for time off from work.

To help address these barriers and to improve research participant diversity, researchers should better communicate to potential research participants the time required, the information that will be requested, and travel requirements. They may need to provide travel support and facilitate alternative care arrangements.

Interventions should be appropriately tailored to individuals’ circumstances, lived experiences, and cultural needs. Research on slowing the progression of dementia or protecting the health of caregivers, for example, could consider and reflect how larger realities (e.g., food insecurity, built environment, housing insecurity) influence community members’ ability to take advantage of lifestyle changes to improve their overall health.

Further, researchers should clearly communicate how research participation could benefit the participants and their communities. To improve participation among historically excluded groups—including African American, Native American, and Hispanic/Latino populations—who have high rates of distrust of the research process, researchers must build trust and partner with communities. Introductions by trusted sources may facilitate the building of trust and partnerships. This process requires time. Grant proposals therefore should explicitly allot time and resources to the process of building trust. Beyond individual researchers, institutions should ensure that the research conducted within their institutions is inclusive.

## **About the Stakeholder Engagement Panel**

The Stakeholder Engagement Panel sought input from direct care workers, health service and long-term services and supports (LTSS) providers, patient advocates, payer representatives, and researchers. Under contract to NIA, RLA recruited 11 stakeholders based on prominence in their area of expertise and knowledge of and/or experience providing dementia care and caregiving for a variety of patient populations in a variety of geographical regions. The Stakeholder Engagement Panel consisted of three advocacy group representatives, a health system provider representative, two direct care worker representatives (one from a nursing home perspective and one from a home health perspective), a LTSS service provider representative, and two researchers (with experience consulting on, developing, and testing health care insurance coverage plans) for dementia care and alternative payment models.

Stakeholders participated in two 90-minute virtual feedback sessions to discuss ways to improve the care, services, and supports of persons living with Alzheimer's disease and Alzheimer's disease-related dementias (AD/ADRD) and their care partners and caregivers. Heidi Gil, LiveWell's chief strategy officer and an executive committee member of the Stakeholder Engagement Team for the IMPACT Collaboratory, facilitated both feedback sessions.

## Panel Members

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