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

National Institute on Aging
National Institutes of Health
March 20-22, 2023
Virtual Meeting

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List of Acronyms

AD	Alzheimer’s disease
ADRD	Alzheimer’s disease and Alzheimer’s disease-related dementias
AHRQ	Agency for Healthcare Research and Quality
CNA	certified nursing assistant
EHR	electronic health record
ED	emergency department
HCBS	Home- and community-based services
HIT	health information technology
LEP	Lived Experience Panel
MA	Medicare Advantage
MCI	mild cognitive impairment
MOST	multiphase optimization strategy
TM	traditional Medicare
NASEM	National Academies of Sciences, Engineering, and Medicine
PLWD	persons living with dementia
QALY	quality-adjusted life year
RCT	randomized controlled trial
SDOH	social determinants of health
SEP	Stakeholder Engagement Panel

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Executive Summary

The 2023 National Research Summit on Care, Services, and Supports for Persons Living with Dementia (PLWD) and Their Care Partners/Caregivers ("the Summit") convened for three virtual sessions on March 20-22, 2023, to review scientific progress, highlight innovative and promising approaches, and identify unmet research needs.[1] The Summit was designed to build on progress since the first National Research Summit on Care, Services, and Supports for Persons with Dementia and Their Caregivers in October 2017 and the second care-focused Summit in summer 2020.

The Summit considered input from the research community, persons living with cognitive symptoms (including mild cognitive impairment or diagnosed dementia; PLWD), their care partners/caregivers, persons who provide health care or services and supports to PLWD, and other stakeholders. On behalf of NIA, Rose Li and Associates, Inc. convened a Lived Experience Panel consisting of 9 PLWD and current and former caregivers and a Stakeholder Engagement Panel consisting of 11 patient advocates, direct care workers, long-term services and supports workers, researchers, and health service providers (some of whom also have personal experience as care partners). These panels each met for two 90-minute virtual feedback sessions. By engaging individuals with multiple perspectives, the Summit helped to identify scientific gaps and opportunities for Alzheimer's disease and Alzheimer's disease related dementias (AD/ADRD) research that hold promise to meaningfully impact the lives of PLWD and their care partners.

With input from research presenters, panelists, PLWD and care partners, and other stakeholders, members of the Summit Steering Committee identified research gaps and opportunities in the eight areas of dementia care and caregiving research that correspond to the Summit scientific sessions. These gaps and opportunities can inform updates to the NIH AD+ADRD Research Implementation Milestones, which guide progress toward the National Plan to Address Alzheimer's Disease.

We know that words matter to individuals and communities. The terms included in this report reflect language used by presenters and discussants during the 2023 Summit. Nomenclature and terms used in research are evolving and will be considered in future Summit planning.

Session One: What Matters Framework and Living Well with AD/ADRD
Co-Chairs Drs. Antonia V. Bennett and Basil Eldadah

Session One focused on the outcomes that matter most to PLWD. Dr. Siobhan Reilly summarized research that identified 13 core outcomes. Next, Dr. Sheila L. Molony reviewed assessments of PLWD's well-being through measures of affect balance and at-homeness. In the third presentation, Dr. Lee A. Jennings described the use of goal attainment scaling in research and clinical settings as an individualized measure of core outcomes. Panelists Dr. Emmanuelle Belanger, Dr. Sam Fazio, and Dr. Jim Mangi provided brief remarks and then joined the session

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[1] Video recordings of the Summit proceedings are publicly available at https://www.nia.nih.gov/2023-dementia-care-summit#recordings.

co-chairs and presenters for the Q&A and discussion, which covered the need for brief, easy-to-administer, validated measures of core outcomes that can be used across disease stages.

Session Two: Impact of Detection and Diagnosis on Individuals and Care Partners
Co-Chairs Drs. Luis D. Medina and Luke Stoeckel

Session Two focused on the need for early and equitable detection and diagnosis. Dr. Raj C. Shah reviewed risk-based approaches and algorithms for identifying individuals with cognitive symptoms. Next, Dr. Ellen McCreedy described potential methods to identify undiagnosed individuals for enrollment in pragmatic trials. In the third presentation, Dr. Emmanuel Fulgence Drabo discussed racial and ethnic disparities in diagnosis and post-diagnosis care. Panelists Dr. Nathaniel Chin, Dr. Emily Largent, and Deborah Jobe discussed the importance of expanding screening and early diagnosis and of identifying caregivers in clinical records.

Session Three: Dementia Care Models and Coordination of Care
Co-Chairs Drs. Katherine Possin and Marcel Salive

Session Three focused on comprehensive dementia care models. First, Dr. Eric B. Larson described a National Academies report on meeting the challenges of caring for PLWD and supporting their care partners and caregivers informed by a systematic review of the evidence on existing dementia care interventions. Next, Dr. David B. Reuben summarized research on implementing and adapting comprehensive dementia care models to a wide range of settings and populations. In the third presentation, Dr. Ula Hwang highlighted the potential for partnering with emergency departments on early detection and care referrals. Panelists Dr. Shari M. Ling, Dr. Carolyn Clevenger, and Roberta Cruz discussed the need to assess the broad impacts of dementia care models on PLWD, their caregivers, and families.

Session Four: Disparities in Health Care Access, Utilization, and Quality
Co-Chairs Drs. Chanee Fabius and Emerald T. Nguyen

Session Four focused on racial, ethnic, and geographic disparities in health care access, utilization, and quality. Dr. Shekinah Fashaw-Walters discussed place-based disparities in dementia care. Next, Dr. Jie Chen highlighted the potential for health information technology to reduce health disparities and improve care quality while reducing costs. In the third presentation, Dr. Norma B. Coe described how the transition to Medicare Advantage and other insurance and policy changes are affecting dementia care. Panelists Dr. Emmanuel Fulgence Drabo, Dr. Maricruz Rivera-Hernandez, and Dr. Tina Sadarangani discussed the need to address geographic and other disparities and improve care integration across settings.

Session Five: Support for Care Partners and Caregivers
Co-Chairs Drs. Kenneth W. Hepburn and Liz Necka

Session Five focused on the need for research on policies and interventions to support caregivers. Dr. Karen A. Roberto described the characteristics and unique challenges of rural caregivers. Next, Dr. Joseph E. Gaugler discussed the importance of determining interventions' mechanisms of action for subsequent implementation and adaptation. In the third presentation, Dr. Courtney Van Houtven reviewed research opportunities for assessing the impact of policies intended to support caregivers. Panelists Rita Choula, Jason Resendez, and

Cassandra Thomas discussed the need for culturally sensitive research communications and protocols and for additional research on PLWD who may not have a primary caregiver.

Session Six: Dementia Care Workforce

Co-Chairs Drs. Joanne Spetz and Elena Fazio

Session Six focused on the need for additional data on the care workforce and interventions to support their recruitment and retention. First, Dr. Bianca K. Frogner described the care workforce, its size, roles, and characteristics. Dr. Jasmine L. Travers then discussed interventions and strategies to improve the wages and working conditions of certified nursing assistants. In the third presentation, Dr. Jennifer Reckrey highlighted the need for additional data on the home-based care workforce, care quality, and outcomes. Panelists Dr. David C. Grabowski and Melissa Myers-Bristol discussed the need for research on interventions and policies that aim to recruit and retain the direct care workforce.

Session Seven: Economic Impacts, Implications, and Approaches

Co-Chairs Drs. Pei-Jung Lin and Priscilla Novak

Session Seven focused on the economic impact of dementia on individuals, caregivers, families, and health care systems. Dr. Duke Han reviewed the potential impacts of aging and of dementia on financial decision making. Next, Dr. Mireille Jacobson described the financial incentives in and care impacts of Medicare Advantage versus traditional Medicare. In the third presentation, Dr. Peter J. Neumann discussed the cost-effectiveness of dementia interventions and treatments, including the new monoclonal antibodies that target amyloid. Panelists Dr. Darius Lakdawalla, Dr. Helen Lamont, and Dr. Rachel Werner discussed the need for better data infrastructure to determine the costs and benefits of dementia care interventions and policies.

Session Eight: Approaches to Participatory Research and Diverse Recruitment and Retention in Dementia Care Research

Co-Chairs Drs. Crystal M. Glover and Cerise Elliott

Session Eight focused on strategies for engaging with diverse PLWD and their caregivers throughout the research process. Dr. Jordan P. Lewis discussed developing culturally responsive interventions for Indigenous caregivers. Dr. Van Ta Park summarized research on culturally tailored, multilingual educational interventions for Vietnamese and Korean Americans. In the final presentation, Dr. Fayron Epps reviewed approaches to improve research participation among African Americans. Panelists Dr. Christine Nguyen, Robert Reid, and Martha Williams focused on the importance of building trust and developing culturally and linguistically appropriate study materials and protocols.

Plenary Talk: Challenges and Best Practices for Development and Evaluation of Interventions for PLWD and Their Care Partners

Plenary Speaker Dr. Linda M. Collins

The recent Agency for Healthcare Research and Quality (AHRQ) systematic review and the National Academies of Sciences, Engineering, and Medicine care interventions report find that most behavioral interventions for PLWD and/or their caregivers lack evidence regarding their mechanisms, which hinders their widespread adoption. Dr. Linda Collins described how alternative intervention trial methodologies consistent with the NIH Stage Model can help to build a coherent knowledge base and facilitate the implementation and adaptation of interventions with high public health impact.

Summit Cross-Cutting Themes

Three cross-cutting themes were emphasized across Summit sessions: (1) inclusive science and health equity, (2) the What Matters Framework, and (3) the rigor and reproducibility of dementia care research.

Inclusive Science and Health Equity

Summit presenters and panelists discussed the importance of pursuing patient-centered research and outcomes; engaging meaningfully with participant communities to build trust and to ensure respectful, culturally sensitive research communications and protocols; and incorporating the perspectives of PLWD, their care partners and caregivers, and other key stakeholders throughout the research process, from study design to dissemination of results. Presenters and panelists also discussed the growing diversity of the population living with dementia and their caregivers and emphasized that diverse and intersecting identities, backgrounds, cultures, family structures, and locations affect access to care, services and supports, and health outcomes. Research approaches and care interventions should aim to meet people where they are to address these diverse needs, perspectives, and challenges.

The What Matters Framework

Summit presenters and panelists described the disconnect between existing patient-reported outcome measures and the outcomes that PLWD report are their priorities. Presenters described existing person-specific measures and their potential adaptation for use across disease stages and settings, and the need for additional sensitive, valid measures of the outcomes that matter most to PLWD and their caregivers for both research and clinical purposes.

The Rigor and Reproducibility of Dementia Care Research

Across sessions, presenters and panelists described the need for implementation and adaptation of evidence-based interventions that benefit PLWD and their caregivers. To facilitate implementation, researchers should anticipate and consider feasibility when designing and testing interventions. Conducting intervention research in line with the NIH Stage Model and using trial methodologies that allow researchers to optimize key components of an intervention can help not only improve the dissemination of those interventions, but also help build a body of evidence regarding effective intervention components. Researchers should attempt to gather input from key stakeholders, consider implementation when designing interventions, to engineer interventions that meet specific cost, time, staffing, and other key requirements.

Summit Report

Summit History and Planning Process

The 2023 National Research Summit on Care, Services, and Supports for Persons Living with Dementia (PLWD) and Their Care Partners/Caregivers, hosted by the National Institute on Aging (NIA), was convened to identify gaps and opportunities to inform dementia-related research priorities of federal agencies, foundations, and private-sector organizations.

To assist in the Summit planning process, NIA and the 2023 Summit Steering Committee members reviewed the National Plan to Address Alzheimer's Disease, the relevant NIA AD/ADRD Research Implementation Milestones, and the 2020 Dementia Care and Caregiving Summit Gaps and Opportunities. They also sought input from individuals with diverse backgrounds and experiences, including academic researchers, public policy experts, direct care workers, health care and social service providers, PLWD, and their caregivers. These efforts included the following:

- Publishing a Request for Information to seek input from the public representing various interested communities, including PLWD and their care partners, researchers, health care providers, and advocacy organizations.
- Convening a Steering Committee of 20 academic researchers and NIA scientific program staff members with relevant expertise, led by Dr. Andrea Gilmore-Bykovskyi (University of Wisconsin-Madison) and Dr. Julie Zissimopoulos (University of Southern California).
- Convening a Lived Experience Panel composed of four PLWD and five care partners/caregivers of PLWD from across the country.
- Convening a Stakeholder Engagement Panel that solicited feedback from 11 dementia care and caregiving stakeholders, including direct care workers, health care and social service providers, and patient advocates.
- Providing opportunities for audience engagement during the Summit sessions through submission of questions and comments.
- Holding a 1-hour post-Summit Listening Session for audience members with the NIA Summit planning committee and Steering Committee co-chairs.

Session co-chairs worked with the research presenters and panelists to draft three research gaps and opportunities based on their session's research priorities. On March 29, 2023, the Steering Committee met to revise the draft gaps and opportunities based on input received during the Summit and the Summit Listening Session (see Appendix 1).

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Setting the Stage

To set the stage on each Summit day, Lived Experience Panel (LEP) and Stakeholder Engagement Panel (SEP) members gave brief remarks about their experiences. On Day 1, Dr.

Amy Kelley provided a brief welcome message, and Dr. Elena Fazio highlighted NIA-supported dementia care and caregiving initiatives and research.

NIA Dementia Care and Caregiving Research

Elena Fazio, PhD

NIA is committed to advancing rigorous dementia care intervention research that is consistent with the NIH Stage Model, supporting the development and use of data infrastructure, and examining the impact of social determinants of health (SDOH)—including features of the health care landscape—on dementia care outcomes and the wellbeing of PLWD and their care partners. Aligned with the NIH AD/ADRD Research Implementation Milestones, the NIA Division of Behavioral and Social Research manages a large portfolio of dementia care and caregiving research, including intervention studies and studies of caregiver wellbeing, societal and economic costs of care, and disparities in care access, use, and quality. As part of these efforts, NIA made a flagship investment in the IMPACT Collaboratory, whose mission is to build the nation's capacity to conduct pragmatic clinical trials within health care systems for PLWD and their care partners. NIA is also continuing investments in AD/ADRD-focused Roybal Translational Research Centers, which fund pilot studies in accordance with the NIH Stage Model and AD/ADRD-focused Demography and Economics Centers and data resources such as the National Health and Aging Trends Study (NHATS) and the National Study of Caregivers (NSOC).

Lived Experience Panel and Stakeholder Engagement Panel Highlights

Dave Arnold; Willetha Barnette; Leslie Burger, MD; Roberta Cruz; Gary Epstein-Lubow, MD; Heidi Gil; Reda Harrison; Ian Kremer, JD; Monica Moreno; and Petra Niles, MSG

Panel members living with dementia emphasized their desire to remain independent, socially engaged, and to live as well as possible despite their cognitive symptoms. Mr. Arnold described his sorrow at his diagnosis, and his commitment to maintaining his independence and remaining at home and living well for as long as he can. Ms. Harrison, who was diagnosed with mild cognitive impairment (MCI) at age 58, emphasized the need to combat the stigma associated with dementia. She has been open with family, friends, and church members regarding her diagnosis, and although she lost some friends who were uncomfortable being with her, she gained new friends who are also dealing with cognitive symptoms. She started to learn to play piano at 63. She gardens, is learning Spanish, and enjoys quilting and beadwork. She refuses to feel sorry for herself and does not want pity. She has become resilient.

Caregivers emphasized the need for additional supports, particularly those that reduce isolation, financial strain, and stress. Dr. Burger explained that he retired early to care for his wife, who passed away from Alzheimer's disease (AD) in 2021. They thrived during the disease's early stages, managing with technology and reminders, but as the disease progressed, he felt increasingly helpless, limited to providing comfort but unable to maintain her diet and hygiene or handle her paranoia. He emphasized that people need to know where to seek help and support, especially financial support. Ms. Barnette described the tremendous financial costs she bore caring for her mother for more than 20 years, which led her to deplete her retirement savings and to neglect her own health. She emphasized that dementia could affect anyone; “dementia is no respecter of age, ZIP code, or socioeconomic status.” Ms. Cruz emphasized the importance of care partners remaining socially engaged, having breaks from caregiving, and recognizing that what constitutes “good caregiving” varies from family to family.

Ms. Moreno described the LEP recruitment strategy and her and Dr. Epstein-Lubow's approach to facilitating the feedback sessions. Dr. Epstein-Lubow then summarized broad themes from the LEP, noting that members described the need for more accessible supports, particularly home-based and financial supports, and expressed concerns regarding disease progression, planning for the future, and family burden. They reported a range of screening and diagnosis experiences and a lack of adequate guidance, referrals, and post-diagnosis support. Several panel members described positive research experiences, although their ability to participate was constrained by travel requirements and costs.

Ms. Gil and Mr. Kremer reviewed additional cross-cutting themes from the LEP and SEP, which included the need for research on reducing stigma across the disease course; helping people navigate care systems and plan for later stages of disease; adapting collaborative care models to a wider range of populations and settings; addressing tensions between maintaining independence, engagement, and safety; and ensuring detection and diagnosis are equitable, timely, accurate, compassionate, and actionable. SEP panelists highlighted the need for care navigation programs that extend beyond the dominant medical care model and include well-being and healthy lifestyles such as stress management, sleep, nutrition, physical fitness, social connection, and finding meaning and purpose. With the increasing reliance on electronic health record (EHR) data, research must also determine sources and frequencies of errors and omissions in order to improve health outcomes (particularly in care transitions), reduce care partner burden, and improve accuracy of aggregated data that will be used for subsequent research. Person-centered research is paramount: PLWD and their caregivers must be involved in all phases of the research process and help set research priorities. Ms. Niles noted that researchers can gain valuable information by connecting with community service providers who are aware of the gaps and barriers to care within their communities, and who can provide feedback on culturally tailored research and appropriate nomenclature. The full LEP and SEP reports are available online.

Session 1: What Matters Framework and Living Well with AD/ADRD

Co-Chairs: Antonia V. Bennett, PhD, University of North Carolina, and Basil Eldadah, MD, PhD, NIA

This session considered outcomes that matter most to PLWD and their care partners. Presenters discussed the need for measurement tools that align with patient-centered goals measures that are designed/appropriate for the study population (reflective of their language, culture, priorities, and values) and responsive to change (able to capture the effect of an intervention).

What Matters to People Living with Dementia Living at Home? Developing Outcomes and the Evidence Base When Evaluating interventions

Siobhan Reilly, PhD, University of Bradford

To determine what matters most to PLWD, Dr. Reilly and her research team conducted a two-phase mixed methods study that identified 13 core outcomes: positive social relationships; ability to communicate; feeling safe and secure at home; feeling valued and respected by others; being able to have a laugh with other people; being able to engage in activities you enjoy; keeping interested in things you like; being aware of your surroundings; finding your way around a familiar place; being as clean and as comfortable as you would like; not falling; being able to see, hear, and understand; and feeling able to maintain your identity. A review of 76 existing outcome measures revealed a disconnect between those measures and the core outcomes. Researchers must work with PLWD to develop and test new measures that assess outcomes that matter.

Observable Expressions of Positive and Negative Emotion: Affect-Balance

Sheila L. Molony, PhD, RN, Quinnipiac University

Models of well-being and life satisfaction among PLWD emphasize positive emotions. Affect balance is the ratio of observable positive to negative emotions and is associated with greater wellbeing. Researchers should determine correlates of affect balance for PLWD in community settings and whether targeted interventions improve affect balance. Future studies may use technologies to capture facial, postural, or behavioral expression of emotion; employ ecological momentary assessment and within-individual time series analyses; and conduct longitudinal mixed-methods studies that combine self-report, caregiver, and observational measures. To address language challenges, measures can be modified with yes/no options or pictures.

Personalized Health Outcome Measurement in Dementia Care and Services Research

Lee Jennings, MD, MSHS, University of Oklahoma Health Sciences Center

One measure of person-centered outcomes is goal attainment scaling. For this measure, the goal and outcome are individualized but measurement is standardized. Compared to patient reported outcome measures (PROMs), goal attainment scaling is sensitive to small changes and allows goal revision over time but requires more intensive training to administer. Three ongoing pragmatic trials of dementia care are using goal attainment scaling as a primary or secondary outcome. Next steps include training toolkits that translate these measures into clinical practice, with attention to the complexities of triadic communication among providers, PLWD, and care partners.

Moderated Discussion Highlights

Panelists: Emmanuelle Belanger, PhD, Brown University, Sam Fazio, PhD, Alzheimer's Association®, and Jim Mangi, PhD, Lived Experience Panel Member

Tailoring Measures of "What Matters Most" to Disease Stage and Other Factors

Core outcome measures need to be brief, easy to administer, and applicable across disease subtypes, stages, and trajectories. Progress in this area is evidenced by measures available in the Minimum Data Set, the IMPACT Collaboratory, and the Long-Term Care Data Cooperative, and the LINC-AD effort to develop an online repository of person-centered measures. However, more national data and mixed methods research are needed to ensure that the voices of PLWD and their care partners are reflected in outcome measures.

Researchers face great challenges obtaining valid proxy-rated measures from caregivers once self-report becomes infeasible for PLWD. Affect balance may be a useful indicator of wellbeing throughout the disease course. To use goal attainment scaling at later disease stages, caregivers may need to help identify goals; therefore, research on goal concordance between caregivers and PLWD is needed.

Respect Is a Core Outcome for PLWD

A core outcome highlighted by Dr. Reilly's research and Mangi's remarks is being treated with respect. Mangi's wife, who is living with advanced dementia, wants to be recognized as a person—not as a patient, victim, gemstone, or a "used-to-be."

Session 2: Impact of Detection and Diagnosis on Individuals and Care Partners

Co-Chairs: Luis D. Medina, PhD, University of Houston, and Luke Stoeckel, PhD, NIA

This session addressed approaches to early and equitable detection of dementia as an entry point into dementia care and considered the social, economic, and institutional barriers to and facilitators of detection and diagnosis within care settings, including in primary care and in the Medicare annual wellness visit; the high prevalence of underdiagnosis; and benefits and disparities in early diagnosis and resulting disparities in care, services received, and survival.

Risk Prediction of Alzheimer's Disease and Related Dementias in Primary Care Settings

Raj C. Shah, MD, Rush University

Screening all individuals aged 65 and older for AD/ADRD yearly is costly and potentially ineffective, but risk-based screening is a promising alternative. Currently, only a few valid late-life risk assessments tools are in the public domain and suitable for clinical use, and none have adequate sensitivity and specificity. Researchers have also used different approaches to validating tools, which limits their comparability. As new risk assessment tools are developed, researchers should consider incorporating biofluid biomarkers into these assessments. Researchers should also conduct clinical trials to ensure that risk assessment algorithms are fair, equitable, and appropriate for diverse patient populations.

Challenges to Equitable Identification of People Living with Dementia for Pragmatic Clinical Trials

Ellen McCreedy, PhD, Brown University

Pragmatic real-world trials aim to enroll people who represent the population of PLWD. However, formal diagnoses or claims data in EHR fail to identify many PLWD, particularly individuals of minoritized populations and those living in geographically underserved areas. Researchers have developed EHR-based algorithms to identify likely PLWD, but these algorithms are often developed in academic medical centers and may not apply to community-based or underserved populations. Key next steps include further validation of algorithms in usual care populations, expanding the use of unstructured data in clinical records, democratizing the use of algorithms and access to rapid validation tools, monitoring ethical issues arising from algorithmic identification, and improving identification of PLWD who lack access to care.

Disparities in Diagnosis and Post-diagnosis Care

Emmanuel Fulgence Drabo, PhD, Johns Hopkins University

Benefits of early dementia diagnosis include early and optimal disease management, access to support and services, enrollment in clinical trials, and facilitating planning for later care. However, there are large racial disparities in diagnosis: Black and Hispanic individuals are more likely than White individuals to have missed or delayed diagnoses, less likely to receive treatments or specialty care, and more likely to receive emergency department (ED) and inpatient care, resulting in higher health care costs. Additional research is needed on the root causes of these disparities. Future efforts should promote equitable brain health, increase diversity in study populations, and build a more robust and diverse workforce for the diverse older adult population.

Moderated Discussion Highlights

Panelists: Nathaniel Chin, MD, University of Wisconsin, Deborah Jobe, Lived Experience Panel Member, and Emily Largent, JD, PhD, RN, University of Pennsylvania

The Role of Community Support and Care Partners in Post-Diagnosis Care

Following diagnosis, Ms. Jobe was referred by her provider to cognitive, speech, physical, and occupational therapy, and counseling, and to the Alzheimer's Association®, which connected her with support groups and local elder care resources. She knows her experience is atypical and hopes more people will receive timely diagnoses, appropriate referrals, and follow-up care. Intervention research concerning early diagnosis must consider the impact on care partners as well as on PLWD. Research is needed on the effects of early diagnosis on care partners, given preliminary evidence that it does not dispel the stigma associated with dementia. Care partners participate in myriad decisions beyond advanced care planning—a decision-making process that merits study. To facilitate research and improve care, care partners should be identified in clinical records. Additional work is also needed on how to support older adults who do not have care partners or family caregivers, or who have distributed care networks with care provided by multiple persons.

Expanding Equitable Screening and Diagnosis

In 2020, the U.S. Preventive Services Task Force found insufficient evidence for recommending cognitive screening in asymptomatic older adults. A lack of routine screening amplifies the potential for bias and stigma to contribute to missed and delayed diagnoses, particularly among people of color. Screening tools could help address diagnostic challenges, provided they are validated in diverse populations and implemented in a standardized way. Community health workers, first responders, and emergency medical technicians, and Meals on Wheels volunteers could also screen for MCI and dementia symptoms and provide health care referrals and education to counter stigma.

Plenary Talk: Challenges and Best Practices for Development and Evaluation of Interventions for PLWD and Their Care Partners

Linda Collins, PhD, New York University

Three objectives of dementia care and caregiving intervention development are to build a coherent knowledge base about what interventions work for whom under what conditions and why; use the knowledge base to develop and disseminate interventions that have high public health impact; and to be able to make improvements to the interventions over time. These objectives are not easily reached with the classical approach to intervention development, in which researchers pilot test individual components of an intervention and then test them in an evaluation randomized controlled trial (ERCT) as a single package. Many multi-component interventions developed this way are impractical—too expensive, complex, or burdensome. Researchers cannot streamline interventions without potentially rendering them ineffective, and even if an intervention works, it is not clear why it worked. Researchers instead should develop interventions that balance effectiveness with affordability and practicality. Multiphase optimization strategy (MOST) is an alternative framework for intervention development that can achieve the desired objectives. With MOST, researchers first identify a set of candidate intervention components, then optimize their intervention based on results obtained with optimization RCTs (e.g., factorial experiment, fractional factorial experiment, SMART, micro-randomized trial, system identification). Once they determine the optimal intervention, they test its effectiveness with an ERCT. This approach enables researchers to engineer interventions that meet specific objectives, such as adhering to a specific per person cost. Resources and training are available for those who want more information about MOST (i.e., Collins, 2018 and https://cadio.org/).

Moderated Discussion Highlights

Moderator: Lisa Onken, PhD, NIA; Panelists: Kathi Heffner, PhD, University of Rochester, Brent Mausbach, PhD, University of California, San Diego, and Christina S. McCrae, PhD, University of Florida

Implementation Science Approaches for Multi-Component Interventions

A common objection to optimization trials is that the intervention components are believed to be synergistic and work only in combination. However, whether individual components deliver benefits in isolation or in lower order combinations can be tested with a factorial design. Understanding of interventions' mechanisms of benefit and the needs of stakeholders who will fund and implement the intervention is critical for widespread implementation and adaptation. Moreover, even if only the highest order interaction showed significant benefits, MOST could be used to develop additional needs-driven, or "wrap around," interventions that improve engagement or adherence to an existing intervention. It could also be used to reduce costs or time required for participation, and to facilitate adaptation to new settings and populations.

Session 3: Dementia Care Models and Coordination of Care

Co-Chairs: Katherine L. Possin, PhD, UCSF, and Marcel Salive, MD, MPH, NIA

Dementia care models and coordination of care are complex and involve a multilevel framework that includes individual and family, community, policy, and societal levels. Care is provided and received in a variety of health and community-based settings with varying levels and types of resources at differing stages of disease, including end-of-life. This session explored community- and health system-based dementia care models as well as the inherent challenges in developing and disseminating evidence-based models of integrated care in real-world settings to meet the diverse needs of PLWD.

The NASEM Report: Rationale, Illustrative Findings and Expectations of a Way Forward

Eric B. Larson, MD, MPH, University of Washington

An Agency for Healthcare Research and Quality systematic review and subsequent consensus report found that most care interventions lacked sufficient evidence of benefit. Absence of evidence (or sufficient evidence) does not mean absence of benefit. Generating high strength evidence for dementia care interventions is challenging due to the complexity of dementia care interventions, the diversity of populations affected, and the importance of contextual effects. Two intervention types were supported by low-strength evidence: collaborative care models and discrete adaptations of REACH II, a multicomponent intervention for care partners and caregivers. Various collaborative care interventions share multiple components, such as coordination of services, development of care plans, case tracking, and provider collaboration. Next steps include implementing and evaluating these intervention types in a variety of real-world settings and with diverse groups.

The Vanguard of Comprehensive Dementia Care: Much Done, Much More to Do

David B. Reuben, MD, University of California, Los Angeles

Comprehensive dementia care models have several core components: continuous monitoring and assessment, ongoing care plans, psychosocial interventions for PLWD and caregivers, self-management, medication management, treatment of related conditions, and coordination of care. To date, six models have been implemented, several of which are more intensive and may be more appropriate for PLWD with greater care needs. Payment models for Medicare beneficiaries should cover comprehensive dementia care and address both beneficiary and caregiver needs; be widely available, including in rural and underserved communities; and be capitated based on symptom severity and available resources. Research is needed on model effectiveness and dissemination, addressing needs of diverse populations in various regions and settings, and payment models.

Dementia in the Acute Setting: Expanding and Improving Care

Ula Hwang, MD, MPH, Yale University

The ED is a common site of care for older adults and PLWD, and ED visits spike in the months prior to a dementia diagnosis. The ED could be a key partner in recognizing dementia early and providing appropriate referrals, which would also help to reduce strain on the health care system. However, the ED does not routinely screen patients for cognitive impairment. To improve ED care for PLWD, the Geriatric Emergency care Applied Research (GEAR) initiative aims to advance science in four key areas: care transitions, communication and shared decision making, detection, and ED practices.

Moderated Discussion Highlights

Panelists: Carolyn Clevenger, DNP, RN, Emory University, Roberta Cruz, Lived Experience Panel Member, and Shari Ling, MD, Centers for Medicare & Medicaid Services

Impacts of Delayed Diagnosis

The primary care provider for Ms. Cruz's mother initially dismissed her mother's cognitive symptoms as merely the result of aging. This dismissal posed logistical challenges to her care, as Ms. Cruz needed her mother diagnosed before moving her across state lines. However, Ms. Cruz emphasized the value and knowledge she gained from building relationships with several local providers who cared for her mother.

Assessing Care Models' Effects on What Matters Most

The effort to move from a volume-based health care system to a value-based one presents the opportunity to focus on what matters most to PLWD and their caregivers. Researchers should assess care holistically, by evaluating its impact on clinical outcomes and wellbeing and quality of life. Dr. Clevenger directs an integrated memory care center that provides comprehensive dementia care following diagnosis including full-scope primary care, cognitive assessment and staging, treatment of minor acute illnesses, along with cognitive engagement, family counseling and psychotherapy, caregiver support groups, and advanced care planning. She shared that its care model is financially sustainable and may reduce hospitalizations.

Session 4: Disparities in Health Care Access, Utilization, and Quality

Co-Chairs: Chanee Fabius, PhD, and Emerald T. Nguyen, PhD

This session considered the policies; health care structures and practices; and neighborhood, social, and economic factors that impact health equity in care access, use, care transitions and quality of care.

It's About the Who and the Where: The Role of Person and Place in Access and Quality of Care

Shekinah Fashaw-Walters, PhD, University of Minnesota

Although Black and Hispanic Americans are 1.5 to 2 times more likely to have dementia than White Americans, they are less likely to receive a dementia diagnosis, and more likely to be diagnosed at later disease stages. Disparities also affect dementia care. Compared to White Americans, Black Americans living with dementia have higher rates of hospitalization and feeding tube insertion at the end of life, and these rates correlate with area-based social deprivation. Addressing SDOH can reduce such place-based disparities. Additional work is needed to understand how place influences care and interacts with policies at the local, state, and federal levels.

Evidence of Health Information Technology and Reduced Health Disparities in Dementia Care

Jie Chen, PhD, University of Maryland

The use of health information technologies (HIT) by PLWD and caregivers has risen dramatically since 2019. However, older individuals—particularly those from minoritized populations, those with cognitive challenges, and those living in rural areas—may lack access to HIT or have difficulty using HIT. Evidence suggests that HIT can reduce costs, readmissions, and preventable hospitalizations while mitigating racial and ethnic disparities and urban and rural disparities in health care quality and cost. It is critical to conduct further research to understand how to leverage HIT to enhance patient engagement, care coordination, and cross-sector collaboration for PLWD and caregivers. Research is also needed to understand the impact of policies promoting the expansion of HIT and data interoperability on health disparities and inequities.

Health Care and Insurance Policies Affecting Care Use and Quality

Norma B. Coe, PhD, University of Pennsylvania

More than half the older population has transitioned from traditional fee-for-service Medicare to Medicare Advantage (MA); the transition rate is greatest among Black and Hispanic enrollees. However, Black Americans tend to enroll in lower quality MA plans, and Black and Hispanic Americans with MA are more likely to be admitted to segregated nursing homes with fewer resources and lower quality of care. Disparities also affect use of home- and community-based services (HCBS). HCBS increases paid care utilization, decreases institutionalizations, and benefits caregivers, but is associated with more hospitalizations and lower levels of social engagement. HCBS use varies widely across states and populations, and research is needed to understand what drives these differences.

Moderated Discussion Highlights

Panelists: Emmanuel Fulgence Drabo, PhD, Johns Hopkins University, Maricruz Rivera-Hernandez, PhD, Brown University, and Tina Sadarangani, PhD, RN, New York University

Addressing Geographic and Racial and Ethnic Disparities

Researchers must study how well comprehensive care models work among diverse populations and settings. These studies can provide data that health care organizations need to show a programs' financial viability. Medicare has done much work to address disparities in dementia care, but more efforts are needed to address geographic disparities, in part through increased use of telehealth. HIT could address disparities by bringing care to PLWD, but because of disparities in access to broadband, HIT could also exacerbate existing disparities.

Care Integration and Data Sharing Across Care Settings

To deliver higher standards of dementia care, care must be integrated across neighborhoods, the home, hospitals, and community-based care centers. For example, one-third to one-half of people enrolled in adult day care services are living with dementia. These centers are frequently under resourced and lack technology to facilitate collaborative care, increasing fragmentation and costly outcomes. Yet, they are an invaluable source of clinical information and support better health. Research should focus on gathering data to elucidate disparities in understudied settings—like adult day care—as well as how payers and providers to can incentivize data exchange and interoperability.

Policy Impacts
Older adults often find it difficult to understand how different care plans such as MA affect care quality and to determine which plan has the most appropriate benefits. Additional research is needed on why Black and Hispanic MA enrollees have worse outcomes than White enrollees.

Session 5: Support for Care Partners and Caregivers

Co-Chairs: Kenneth W. Hepburn, PhD, Emory University, and Liz Necka, PhD, NIA

Each year, more than 11 million Americans provide more than 16 billion hours of unpaid care for PLWD, valued at $271 billion. The few existing evidence-based programs for caregivers are not widely disseminated or culturally tailored. This session explored caregiving needs, supports, and sources of strength and resilience, which can vary by culture, caregiving networks, stage of disease, and living situation (e.g., kinlessness, PLWD living alone).

Informal Dementia Care: Context Matters
Karen A. Roberto, PhD, Virginia Tech

Relative to their non-rural counterparts, rural caregivers report less choice in caregiving responsibilities, simultaneously caring for multiple people, more weekly hours of care, greater difficulty finding affordable services, and fewer conversations with care providers about their own needs. Rural extended family caregivers are more likely to report exhaustion, lack of personal time, physical health problems, and not attending support and educational programs. Lack of access to care and services, income, education, and resistance to using community services may contribute to low use of services and supports in rural areas. To tailor interventions and service models to rural communities, research is needed on variation across places and families.

The Sooner the Better: Implementation Considerations When Initiating Intervention Development
Joseph E. Gaugler, PhD, University of Minnesota

To develop interventions for caregivers that can be implemented broadly, researchers must engage caregivers and other stakeholders at the earliest stages of intervention design to solicit and incorporate their feedback. Researchers should use implementation science approaches (e.g., hybrid effectiveness studies and MOST) to understand why and how an intervention works (its mechanisms of benefit) and to collect information about whether it is likely to be widely adopted (e.g., its feasibility, acceptability, and perceived utility). Interventions can only be adapted to a wide range of contexts when their mechanisms of benefit are understood.

Expanding Policy Supports to Promote Caregiver Resilience and Well-Being

Courtney Van Houtven, PhD, Duke University

Caregivers—especially female and Black caregivers—have worse economic wellbeing than non-caregivers. To address caregivers' poor economic outcomes, researchers need to explore policies that are systems-level, evidence-based, and targeted for maximum impact; relying on individuals to seek out services is not an equitable approach. Providers and public health workers should screen patients for caregiver status to match them with financial programs, services, and supports and to monitor them for poor health outcomes. Little research has been done on effective caregiver-focused policies, with a few notable exceptions, including state-level tax credits and paid leave for caregivers and the National Veterans Affairs Comprehensive Caregiver Policy.

Moderated Discussion Highlights

Panelists: Rita Choula, AARP Public Policy Institute, Jason Resendez, National Alliance for Caregiving, and Cassandra Thomas, Care Assistant

Influence of Cultural Sensitivity on Caregivers' Wellbeing and Research Participation

Interventions and policies must be culturally sensitive and rooted in caregivers' lived experiences. Ms. Thomas shared that a lack of cultural sensitivity led her to feel shame and anxiety when communicating her grandmother's care needs to health providers. Cultural sensitivity is especially important in research on family caregiving because definitions of family vary across cultures, geographies, races, ethnicities, and gender and sexual identities. Many family caregivers, particularly in rural areas, do not see themselves as caregivers but as "doing what they are supposed to do." Recruiting research participants based on tasks they perform rather than a self-identified label of "caregiver" can help identify people who do not view themselves as caregivers. However, caregivers who describe themselves as such may receive more respect and compassion from health care providers.

PLWD Who Lack Primary Caregivers

An increasing number of PLWD lack primary caregivers, and this particularly vulnerable subgroup is understudied. Some of these individuals may have secondary caregivers, including nonrelatives, or a network of caregivers who provide intermittent care.

Session 6: Dementia Care Workforce

Co-Chairs: Joanne Spetz, PhD, University of California, San Francisco, and Elena Fazio, PhD, NIA

This session explored research innovations and challenges pertaining to the paid dementia care workforce across a range of settings, including clinical care, nursing homes, assisted living, and HCBS settings. Presenters discussed the 2022 NASEM consensus study report The National Imperative to Improve Nursing Home Quality and implications for future research.

Setting the Stage: What We Know (and Don't Know) About the Dementia Care Workforce

Bianca K. Frogner, PhD, University of Washington

The United States lacks national data on characteristics and roles of care workers who provide care for PLWD. State data are also often lacking because many care workers serve in positions that do not require licensure. Even when licensure data are available, states lack information regarding the specific jobs held. Home health aides and care workers who work in long-term care settings (e.g., residential care facilities and nursing homes) tend to be majority non-White, have low educational attainment (80% lack bachelor's degrees), and have high turnover rates.

Challenges for the Nursing Home Direct Care Workforce and the Way Forward

Jasmine L. Travers, PhD, RN, New York University

Approximately 600,000 certified nursing assistants (CNAs) work in nursing homes, where half of residents are PLWD. These CNAs receive low pay, limited benefits, and limited training. To improve CNA recruitment and retention, a 2022 NASEM report recommended wage passthroughs (funds provided by Medicaid for the express purpose of increasing compensation), quality incentive programs, minimum staffing and staffing standards, appropriation of funds to staffing, and adjusting of pay to living wage and competitive wage indicators. Beyond raising compensation, the report called for additional education and training, empowering workers through teamwork and shared decision making, and providing respect, recognition, and career advancement opportunities. Research is needed on worker demographics, pay equity, staff satisfaction, and the effectiveness of various recruitment and retention strategies.

The Direct Care Workforce in Home-Based Dementia Care: Opportunities to Improve Care

Jennifer Reckrey, MD, Mount Sinai

Approximately one in four community dwelling PLWD receive paid direct care. Care workers provide functional support, help identify new medical issues, assist with chronic disease management, support caregiver mental health and well-being, and may play dual and potentially conflicting roles as "part of the family" and as "the eyes and ears" of the health care team. However, little data exist on the workers providing this care, the types of care provided, its quality and relationship to health outcomes, and how care workers collaborate with family caregivers and health care teams. Research is needed on this workforce, their training, pay, and characteristics, and on home care quality, its impacts on caregivers and PLWD, and how to better incorporate direct care workers in health care teams.

Moderated Discussion Highlights

Panelists: David C. Grabowski, PhD, Harvard University, and Melissa Myers-Bristol, MPA, Clayton County Senior Services Department, Georgia

Assessing the Impacts of Organizational Efforts to Improve Recruitment and Retention

Many organizations are piloting efforts to improve recruitment and retention of the direct care workforce, but their impacts are not being assessed. Nursing homes need to partner with researchers and other stakeholders who can disseminate information and scale successful programs and strategies.

Studying State-Level Variation in Policies Supporting the Direct Care Workforce
States have employed multiple approaches to using Medicaid funds for long-term care and HCBS. This state-level variation in Medicaid coverage affects direct care workforce training, benefits, and wages, leading some workers to move to other states to obtain better jobs. It also creates an opportunity to study how different policies affect the direct care workforce and PLWD and their caregivers.

Need for Additional Data on Racial and Ethnic Disparities Among the Direct Care Workforce
Some evidence suggests that people of color working in nursing homes disproportionately work night shifts and understaffed shifts. However, the lack of demographic data on the direct care workforce precludes the ability to understand racial and ethnic disparities and their drivers.

Session 7: Economic Impacts, Implications, and Approaches

Co-Chairs: Pei-Jung Lin, PhD, Tufts Medical Center, and Priscilla Novak, PhD, NIA

This session described the economic impact of dementia on families and the health care system and opportunities to alleviate economic burden. Presentations considered financial incentives in the health care system to improve dementia care coordination and patient outcomes and to reduce costs. They addressed novel approaches to measuring the value of innovations in dementia care and treatment, and the impact of dementia on health care and economic decision making.

Financial Decision Making, Cognitive Decline, and Alzheimer's Disease

Duke Han, PhD, University of Southern California

As some people age, their decision-making ability declines, increasing their susceptibility to poor financial and health decisions and exploitation; this decline is especially a problem for PLWD. Neuropathological brain changes in AD often precede cognitive symptoms and can affect decision making as well as memory. Changes in decision making may be an early sign of AD. Early financial planning may help ensure individuals' wishes are respected. Racial disparities in financial and health decision making exist; a recent study found these disparities are fully mediated by differences in health and financial literacy, which could be addressed through early financial planning.

Health Care Utilization Before and After a Dementia Diagnosis in Medicare Advantage (MA) and Traditional Medicare

Mireille Jacobson, PhD, University of Southern California

MA plans receive a risk-adjusted per patient payment and have stronger incentives than traditional Medicare (TM) to coordinate care and to code diagnoses, but also to potentially skimp on care (quality metrics offset this risk). Compared to TM beneficiaries, MA beneficiaries are more likely to receive yearly cognitive screening during annual wellness visits. Falls, ED visits, and potentially avoidable hospitalizations spike more sharply among TM than MA beneficiaries in the months leading to a dementia diagnosis. Research is needed to determine whether lower MA costs result from care coordination, care shifting, or health system differences, and to assess the impact of MA versus TM on stress, disease management, caregiver well-being, and care access and satisfaction.

Costs and Cost-Effectiveness in Dementia Care

Peter J. Neumann, ScD, Tufts Medical Center

The Institute for Clinical and Economic Review assessed the cost-effectiveness of new monoclonal antibodies that reduce amyloid burden in the brain, finding that their current costs range from $200,000-275,000 per life year and quality-adjusted life year (QALY) gained. However, these estimates will fluctuate with changes in drug pricing. According to some studies, interventions such as support for unpaid caregivers or the use of cerebrospinal fluid biomarkers for diagnosis cost between $11,000-13,000 per QALY. To determine whether the new treatments are cost effective, additional research is needed on the economic burden of dementia on families and society, particularly of non-medical costs; risk preferences of patients and their caregivers; and the effects of different interventions and treatments on caregivers and extended families.

Moderated Discussion Highlights

Darius Lakdawalla, PhD, University of Southern California, Helen Lamont, PhD, Office of the Assistant Secretary for Planning and Evaluation, Rachel Werner, MD, PhD, University of Pennsylvania

Research Needed to Inform Dementia Care Policies

Policymakers need additional information on the cost to recruit and retain staff to deliver interventions and to make EHR, IT, and other workflow-related changes, as well as on how intervention impacts vary by race, ethnicity, neighborhood, eligibility for Medicaid and Medicare, health system, and other characteristics. Researchers should share any selection issues in their studies so that policymakers understand which findings generalize across populations.

Policymakers also need better data to understand how Medicare, Medicaid, and community organizations and family payments interact throughout the disease course. Such data would help determine whether Medicare payments early in the disease course forestall nursing home placement and reduce overall costs and reveal how payments impact caregivers. For example, Medicare's shift to bundled payments and use of accountable care organizations—meant to increase the value of care—has led to a decline in Medicare-funded post-hospital nursing home stays and home health care, which may inadvertently increase caregiver burden. Medicare determines the value of diagnostic and prognostic information based on how such information affects treatment decisions—a perspective that overlooks its potential value for families' financial and care planning and its effects on treatment decisions for co-morbidities.

Session 8: Approaches to Participatory Research and Diverse Recruitment and Retention in Dementia Care Research

Co-Chairs: Crystal M. Glover, PhD, Rush University, and Cerise Elliott, PhD, NIA

This session explored approaches to the integration of demographically diverse caregivers of PLWD throughout the research process, including community-based approaches to outreach, engagement, recruitment, and sustainability that begin prior to research question development.

Unique Identity Challenges for the Recruitment of American Indian/Alaska Native caregivers into Dementia Care Research

Jordan P. Lewis, PhD, University of Minnesota

Although they do not always identify as caregivers, Indigenous caregivers have a strong cultural commitment to caregiving and possess a wealth of knowledge and experience that can be leveraged to develop culturally responsive training and education. Developing caregiver advisory committees of local caregivers and tribal health and other providers can help researchers connect with the community and individuals who do not identify as caregivers, learn their values, and ensure that study protocols are culturally responsive and respectful. Researchers should provide respite, transportation, and food to reduce barriers to research participation.

Insights to Engaging and Recruiting Vietnamese Americans in Dementia Caregiving Research

Van Ta Park, PhD, University of California, San Francisco

To pilot a culturally tailored, evidence-based psychoeducational program for Vietnamese American caregivers, Dr. Park conducted qualitative interviews with health care professionals and others serving Vietnamese Americans and used culturally and linguistically tailored outreach and study materials as well as bilingual study materials, staff, and facilitators. Participants in control and intervention arms expressed gratitude for being included in research. Dr. Park has also developed culturally tailored, multilingual materials for Korean American caregivers and a registry for Asian American caregivers. Her work demonstrates the value of multilingual, culturally sensitive interventions for under included groups.

Community Relationships Are Critical for the Recruitment of African American Families in Dementia Care Research

Fayron Epps, PhD, RN, Emory University

African American caregivers may distrust the research process and have concerns about the confidentiality of their information. Researchers should be open, present, responsive, and address all caregiver questions. They should form community-based partnerships with organizations and leaders who are key within African American communities (e.g., Black fraternities and sororities, barbershops, faith communities) and ensure that recruitment events and other study activities occur when community members are available. Researchers should be flexible about study protocols by providing backup options for participation as many African American caregivers have competing priorities (e.g., jobs, multiple care obligations).

Moderated Discussion Highlights

Panelists: Martha Williams, MS, MFT, Christine Nguyen, MD, and Deacon Robert Reid

Building Trust and Understanding Community Needs and History

Panelists described participating in research to help their loved ones and communities, gain caregiving knowledge, advance recognition of caregivers, and reduce stigma associated with dementia. They emphasized the importance of researchers building trust, avoiding labels and jargon, reducing language barriers, and understanding different communities' histories. Dr. Christine Nguyen's parents, for example, lost the ability to speak English as they developed dementia and exhibited PTSD from the Vietnam War, being refugees, and later social isolation, all which may have contributed to their diagnoses.

Conclusion

Following the 2023 Summit, the Steering Committee met to revise the draft gaps and opportunities based upon the Summit discussions, presentations, and Listening Session, and to identify research gaps and opportunities that reflected the Summit's cross-cutting themes of inclusive science and health equity, as well as additional cross-cutting themes that emerged during the Summit.

The research gaps and opportunities do not represent consensus advice. The 2023 Summit research gaps and opportunities represent a synthesis of the individual contributions of the PLWD, care partners, researchers, and other stakeholders involved in the Summit process regarding the most critical areas of dementia care research. The lessons learned at the 2023 Summit and encapsulated by these gaps and opportunities offer the dementia care and caregiving research community a chance to build on the progress made since the 2020 Summit, support the continued development of person-centered dementia care and caregiving research, and contribute to meaningful outcomes for PLWD and their care partners and caregivers.

Appendix 1: 2023 Summit Research Gaps and Opportunities

Session 1: What Matters Framework and Living Well With AD/ADRD

G&O 1.1: Create core outcome measure sets that effectively evaluate outcomes of central importance to diverse persons living with dementia and their care partners that are standardized methods and harmonizable across studies.

- Ensure suitability for clinical trials and allow for progression and type of dementia. Research should identify the extent to which core outcome measure sets need to vary by dementia type, stage of life (e.g., working age vs. retired), or other major characteristics.
- Facilitate collaborative research among investigators worldwide involved in person-centered measurement and evaluation.

G&O 1.2: Develop and refine approaches to measuring meaningful outcomes for persons living with dementia and their care partners.

- Consider such important aspects as well-being, affect, positive/negative emotions experienced or exhibited by persons living with dementia, meaningfulness, a sense of purposefulness, and safety.
- Understand the potential differences in values, priorities, and measurement considerations for meaningful outcomes between individuals' living with dementia and their care partner(s).
- Incorporate strategies for validating self-reported and/or observer-reported instruments, for defining thresholds for meaningful and clinically significant improvement and maintenance of outcomes in the context of disease progression.

G&O 1.3: Develop and refine approaches for individual goal setting and assessment of goal attainment that are suitable for use in dementia care and caregiving research, including pragmatic trials. This includes developing instruments/toolkits and processes for clinical implementation.

Session 2: Impact of Detection and Diagnosis on Individuals and Care Partners

G&O 2.1: Conduct NIH Stage I and II Model for Behavioral Intervention Development research in diverse populations, geographic settings, and environments of care to understand desirability, feasibility, and accessibility of early detection tools for dementia risk and the impacts on health decisions.

G&O 2.2: Curate representative, real-world primary care and population-based data resources to accelerate research on the development and approval of fair and equitable detection and risk stratification tools for dementia and to elucidate the mechanisms driving disparities in diagnosis, diagnosis timing, and post-diagnosis care; and improve equity in care.

G&O 2.3: Conduct research to determine data sufficiency and algorithmic fairness considerations across dementia screening and detection tools that engage routine health-related data to promote equitable validation, use, and adoption of these tools in real world settings.

Session 3: Dementia Care Models and Coordination of Care

G&O 3.1: Develop and evaluate care management models that integrate medical and psychosocial approaches, starting at the point of acute and post-acute treatment settings such as in emergency department, urgent care, inpatient, and post-acute settings, and extending across the care continuum.

- Conduct research to address and evaluate the models' impacts on avoidable emergency department visits and revisits, hospitalizations, and care transitions.

G&O 3.2: Expand, adapt, and evaluate care management models that merge medical and psychosocial approaches to care for different patient populations across varied locales and health systems such as underrepresented minority groups, rural and urban locales, large health systems and small practices, different disease types, and patients with minimal caregiver support.

G&O 3.3: Enhance the effectiveness and implementation of care management models by evaluating key components using innovative research designs. Interventions should be optimized for outcomes important to people living with dementia and caregivers, and by parameters of interest to health systems and payers, including but not limited to program cost, dosage, setting, and staffing models.

Session 4: Disparities in Health Care Access, Utilization, and Quality

G&O 4.1: Identify and implement strategies to expand data availability and linkages between data sources at local, state, and federal levels—as well as across health care settings in and out of traditional health systems.

- Develop methods to improve data interoperability and integration or health information exchange across different health care settings, including care settings outside health systems, such as adult day centers or federally qualified health centers, as well as informal care settings.
- Ensure that data enhancement strategies facilitate the investigation of social determinants of health and increase representation of vulnerable and underrepresented populations to enable examination of disparities in dementia care access and quality.

G&O 4.2: Examine how health information technology affects care access, quality, and costs for people living with dementia and caregivers for populations disproportionately affected and underrepresented in research.

- Identify and describe the factors driving disparities in health information technology accessibility, availability, and utilization—including the importance of user-friendly design of patient portals to engage patients and caregivers and telemedicine to monitor post-discharge care coordination—as they relate to disease and disability prevention, treatment, and care management.
- Examine variabilities in health information technology access and develop strategies to address disparities in accessibility and use across different settings, including traditional community, residential care, and nursing home sites.

G&O 4.3: Research how health care policies and payment models differentially affect access and quality of care received by people living with dementia in community and residential settings to guide interventions.

- Analyze how the use of medical care, long-term services and supports, as well as care quality, are impacted by Medicare, Medicaid, and other health insurance models such as private long-term-care coverage. Also examine the effects on provider performance and the pathways to accessing care.

Session 5: Support for Care Partners and Caregivers

G&O 5.1: Develop and evaluate new methods while gauging and refining existing techniques that enable health systems to improve equitable identification of caregivers for provision of supports and services as well as enhance care-focused interventions.

G&O 5.2: Conduct culturally informed research on caregivers’ physical, emotional, and financial well-being and the provision of caregiving supports and services.

G&O 5.3: Build robust evidence about how systems-level policies and practices at the local, state, and national levels impact caregivers’ resilience, health, overall well-being (including financial security), and inequities in access to supports and services.

- Examine the impacts on caregivers across sectors including but not limited to public health, health systems, and commercial and corporate entities — especially in terms of the differential effects of policies based on caregivers’ race, socio-economic status, place, and health literacy.
- Conduct research that comprehensively and equitably identifies and includes caregivers in studies aimed at evaluating and/or enhancing their capabilities (including individual capacity and that enabled by policy) within intersecting socio-cultural, organizational,

and policy-enabled contexts so their efforts are understood and supported and the care they provide is improved.

Session 6: Dementia Care Workforce

G&O 6.1: Develop data systems that support tracking of workforce education, training, diversity, experience, skills, staffing levels, service to diverse communities, and satisfaction. In addition, identify data linkages to support research on the relationship between the workforce and person-centered outcomes for people living with dementia and their care partners.

- Incorporate workforce information into datasets related to the care of people living with dementia, even when the dataset is not primarily focused on the workforce.
- Include information about the direct care workforce in all dataset development to support research that reflects the roles of and contributions of the dementia workforce.

G&O 6.2: Identify and evaluate interventions and strategies to advance and equitably support all members of the dementia workforce — in every professional level and care setting — to support the replication and dissemination of the most successful approaches.

- Include interventions that consider unpaid caregivers and those working outside of regulated agencies in caregiving positions.

G&O 6.3: Develop measures and research methods to understand the interactions within caregiving teams that include direct care workers and care partners.

- Analyze how the relationships within caregiving teams impact quality of care and outcomes of people living with dementia.
- Conduct research on best approaches for advancing equitable person-centered care and on best approaches for supporting high-quality dementia workforce jobs.

Session 7: Economic Impacts, Implications, and Approaches

G&O 7.1: Examine the relationships among dementia, health insurance, and health care decision making across the disease continuum.

- Analyze how dementia influences health care plan choices between traditional Medicare and Medicare Advantage, as well as across Medicare Advantage plans.
- Assess how different insurance models influence access to care, dementia diagnosis, disease management, and end-of-life care.

G&O 7.2: Examine the relationship between dementia and financial decision making among persons living with dementia and their families across the lifespan.

- Develop, test, and refine technologies to better predict the course of the disease and improve financial and medical decision making.

- Analyze how social determinants of health impact how patients and families pay for care across disease stages, how their retirement savings plans change due to dementia, and the health and financial implications for caregivers in the post-caregiving phase.

G&O 7.3: Expand research to characterize the value of diagnostic and prognostic information.

- Analyze how persons living with dementia and their families make decisions about new treatments, including but not limited to how much they are willing to pay, what side effects and risks they are willing to tolerate, and how they make financial tradeoffs with other care and support services.
- Assess the value of diagnostic innovations and economic implications of blood-based biomarkers.

Session 8: Approaches to Participatory Research and Diverse Recruitment and Retention

G&O 8.1: Conduct research that advances our understanding of culturally, linguistically, and demographically diverse conceptualizations and operationalizations of caregiving and caregiver-related identities.

- Analyze the impact of culturally acceptable and culturally responsive nomenclature on research question development, study design, and sampling, as well as on caregiver engagement, recruitment, and retention.

G&O 8.2: Examine the influence of study design and methodological approaches on engagement, recruitment, and retention in ADRD care and caregiving research.

- Determine strategies to facilitate equitable study sampling and representative recruitment and retention of understudied caregiving populations, including but not limited to, diverse racial and ethnic groups, male-identified caregivers, those who identify as LGBTQIA+, and those in rural and dense micropolitan areas.
- Assess the use of diverse methodologies such as qualitative, mixed methods, and design thinking approaches in the toolkit of rigorous and acceptable study designs for advancing equitable care and caregiving research.

G&O 8.3: Conduct research to understand factors such as culturally relevant and individually driven beliefs, values, and practices that shape diverse lived experiences across the care continuum.

- Assess care continuum that includes end of life and the post-caregiving period after the person living with dementia has passed away.
- Analyze the impact of the post-caregiving period on caregiver health and quality of life, including physical health, mental health, and socioeconomic factors.

Appendix 2: Glossary

Alzheimer's disease and Alzheimer's disease-related dementias (AD/ADRD) refers to the most common forms of dementia. While AD is the most common dementia diagnosis, ADRDs share many cognitive and pathological features and can be difficult to distinguish from AD. In fact, more often than not, patients with an AD diagnosis present with different mixtures of brain pathologies, complicating both the diagnosis and the treatment. ADRDs include frontotemporal degeneration, Lewy body dementia, vascular contributions to cognitive impairment and dementia, and mixed etiology dementias.[2]

Persons living with dementia (including AD/ADRD) (PLWD) refers to persons living with cognitive symptoms, including mild cognitive impairment or diagnosed dementia.

Care coordination is the deliberate organization of patient care activities between two or more participants (including the patient) involved in a patient's care to facilitate the appropriate delivery of health care services. Organizing care involves the marshalling of personnel and other resources needed to carry out all required patient care activities and is often managed by the exchange of information among participants responsible for different aspects of care. Care coordination for PLWD can range from establishing a dementia care diagnosis, through person-centered management of dementia and other conditions, to end-of-life and palliative care, and to hospice.

Care partner refers to a person with whom the PLWD has a reciprocal relationship who is involved in co-managing the demands of AD/ADRD through such activities as providing emotional support and participating in decision making. Most often, care partners are family members. Care partners may or may not be involved in the provision of hands-on assistance with daily activities as a caregiver. The term **caregiver** can refer to family members, neighbors, friends, fictive kin, or anyone else providing unpaid health and function-related assistance to PLWD. For the purposes of this report, the term care partner is used throughout for consistency, and its use means care partners and/or caregivers.

Clinicians refers to state-licensed physicians, psychologists, nurses, advance practice providers, pharmacists, physical therapists, occupational therapists, social workers, and other skilled health care workers who are credentialed to care for individual patients.

Direct care workers are paid caregivers who provide hands-on care and personal assistance to PLWD who are living with disabilities, including certified nursing assistants and nursing assistants who generally work in nursing homes, home health aides who assist people in their homes or in community settings (including people who may be receiving skilled home health care), medication aides, and personal care assistants and aides who work in private or group homes.

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[2] See https://www.ninds.nih.gov/current-research/focus-disorders/alzheimers-related-dementias and https://www.nia.nih.gov/health/alzheimers/related-dementias for more information.

Disparities are preventable significant differences in the burden of disease, injury, violence, or opportunities to achieve optimal health that are experienced by socially disadvantaged populations across dimensions such as race or ethnicity, gender, education, income, disability, geographic location (e.g., rural or urban), or sexual orientation. Health disparities are directly related to the historical and current unequal distribution of social, political, economic, and environmental resources, including access, use, and quality of care.

Personalized outcomes refers to measures that reflect individual preferences and/or goals that can be used to tailor and individualize services and supports.

Pre-clinical diagnosis refers to individuals who have measurable brain changes that indicate the earliest signs of AD (biomarkers), but who have not yet developed symptoms such as memory loss.

Research gaps and opportunities refers to scientific areas that merit research attention, for which additional scientific investigation holds promise for propelling advances in policy, practice, and care that would improve the lives of persons who are affected by ADRD and their care partners.

Social determinants of health (SDOH) are the conditions in which people are born, grow, live, work, and age shaped by the distribution of money, power, and resources at the global, national, and local levels.

Appendix 3: Summit Agenda

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

Day 1: March 20, 2023
11:00 a.m. to 4:00 p.m. Eastern Time

11:00 a.m. Welcome and Meeting Charge
Speakers: Andrea Gilmore-Bykovskyi and Julie Zissimopoulos

11:15 a.m. Lived Experience Panel and Stakeholder Panel Highlights
Speakers: Leslie Burger, Gary Epstein-Lubow, Reda Harrison, and Monica Moreno

11:30 a.m. NIA Welcome
Speaker: Amy Kelley

11:35 a.m. NIA Dementia Care and Caregiving Research
Speaker: Elena Fazio

12:00 p.m. Session 1 | What Matters Framework and Living Well with AD/ADRD
Session Co-chairs: Antonia V. Bennett and Basil Eldadah

What Matters to People Living with Dementia Living at Home? Developing Outcomes and the Evidence Base When Evaluating Interventions
Speaker: Siobhan Reilly

Observable Expressions of Positive and Negative Emotion: Affect-Balance
Speaker: Sheila L. Molony

Personalized Health Outcome Measurement in Dementia Care and Services Research
Speaker: Lee A. Jennings

Session 1 Research Gaps and Opportunities
Speaker: Antonia V. Bennett

Panelist Remarks
Speakers: Emmanuelle Belanger, Sam Fazio, and Jim Mangi

Moderated Discussion and Q&A

1:45 p.m. Session 2 | Impact of Detection and Diagnosis on Individuals and Care Partners
Session Co-Chairs: Luis D. Medina and Luke Stoeckel

Risk Prediction of Alzheimer’s Disease and Related Dementias in Primary Care Settings
Speaker: Raj C. Shah

Challenges to Equitable Identification of People Living with Dementia for Pragmatic Clinical Trials
Speaker: Ellen McCreedy

Disparities and Challenges in Dementia Care after Diagnosis
Speaker: Emmanuel Fulgence Drabo

Session 2 Research Gaps and Opportunities
Speaker: Luis D. Medina

Panelist Remarks
Speakers: Nate Chin, Deborah Jobe, and Emily Largent

Moderated Discussion and Q&A

2:50 p.m. Plenary Talk | Challenges and Best Practices for Development and Evaluation of Interventions for Persons Living with Dementia and Their Care Partners
Speaker: Linda M. Collins

Moderated Discussion and Q&A
Moderator: Lisa Onken
Speakers: Kathi Heffner, Brent Mausbach, and Christina S. McCrae

3:50 p.m. Day 1 Closing Remarks
Speakers: Andrea Gilmore-Bykovskyi and Julie Zissimopoulos

Day 2: March 21, 2023
11:00 a.m. - 3:30 p.m. Eastern Time

11:00 a.m. Welcome
Speakers: Andrea Gilmore-Bykovskyi and Julie Zissimopoulos

11:05 a.m. Lived Experience Panel and Stakeholder Panel Highlights
Speakers: Roberta Cruz, Heidi Gil, and Ian Kremer

11:20 a.m. Session 3 | Dementia Care Models and Coordination of Care
Session Co-chairs: Katherine Possin and Marcel Salive

The NASEM Report: Rationale, Illustrative Findings and Expectations of a Way Forward
Speaker: Eric B. Larson

The Vanguard of Comprehensive Dementia Care: Much Done, Much More to Do
Speaker: David B. Reuben

Dementia in the Acute Setting: Expanding and Improving Care
Speaker: Ula Hwang

Session 3 Research Gaps and Opportunities
Speaker: Katherine Possin

Panelist Remarks
Speakers: Carolyn Clevenger, Roberta Cruz, and Shari M. Ling

Moderated Discussion and Q&A

1:00 p.m. Session 4 | Disparities in Health Care Access, Utilization, and Quality
Session Co-Chairs: Chanee Fabius and Emerald T. Nguyen

It's About the Who and Where: The Role of Person and Place in Access and Quality of Care
Speaker: Shekinah Fashaw-Walters

Evidence of Health Information Technology and Reduced Health Disparities in Dementia Care
Speaker: Jie Chen

Health Care and Insurance Policies Affecting Care Use and Quality
Speaker: Norma B. Coe

Session 4 Research Gaps and Opportunities
Speaker: Chanee Fabius

Panelist Remarks
Speakers: Emmanuel Fulgence Drabo, Maricruz Rivera-Hernandez, and Tina Sadarangani

Moderated Discussion and Q&A

2:15 p.m. Session 5 | Support for Care Partners and Caregivers
Session Co-Chairs: Kenneth W. Hepburn and Liz Necka

Informal Dementia Care: Context Matters
Speaker: Karen A. Roberto

The Sooner the Better: Implementation Considerations When Initiating Intervention Development
Speaker: Joseph E. Gaugler

Expanding Policy Supports to Promote Caregiver Resilience and Well-Being
Speaker: Courtney Van Houtven

Session 5 Research Gaps and Opportunities
Speaker: Kenneth W. Hepburn

Panelist Remarks
Speakers: Rita Choula, Jason Resendez, and Cassandra Thomas

Moderated Discussion and Q&A

3:20 p.m. Day 2 Closing Remarks
Speakers: Andrea Gilmore-Bykovskyi and Julie Zissimopoulos

Day 3: March 22, 2023
11:00 a.m - 3:45 p.m. Eastern Time

11:00 a.m. Welcome
Speakers: Andrea Gilmore-Bykovskyi and Julie Zissimopoulos

11:05 a.m. Lived Experience Panel and Stakeholder Panel Highlights
Speakers: Dave Arnold, Willetha Barnette, and Petra Niles

11:20 a.m. Session 6 | Dementia Care Workforce
Session Co-chairs: Joanne Spetz and Elena Fazio

Setting the Stage: What We Know and Don't Know About the Dementia Care Workforce
Speaker: Bianca K. Frogner

Challenges for the Nursing Home Direct Care Workforce and the Way Forward
Speaker: Jasmine L. Travers

The Direct Care Workforce in Home-Based Dementia Care: Opportunities to Improve Care
Speaker: Jennifer M. Reckrey

Session 6 Research Gaps and Opportunities
Speaker: Joanne Spetz

Panelist Remarks
Speakers: David C. Grabowski and Melissa Myers-Bristol Moderated Discussion and Q&A

1:00 p.m. Session 7 | Economic Impacts, Implications, and Approaches
Session Co-Chairs: Pei-Jung Lin and Priscilla Novak

Financial Decision Making, Cognitive Decline, and Alzheimer's Disease
Speaker: Duke Han

Health Care Utilization Before and After a Dementia Diagnosis in Medicare Advantage and Traditional Medicare
Speaker: Mireille Jacobson

Costs and Cost-Effectiveness in Dementia Care
Speaker: Peter J. Neumann

Session 7 Research Gaps and Opportunities
Speaker: Pei-Jung Lin

Panelist Remarks
Speakers: Darius Lakdawalla, Helen Lamont, and Rachel Werner

Moderated Discussion and Q&A

2:20 p.m. Session 8 | Approaches to Participatory Research and Diverse Recruitment and Retention in Dementia Care Research
Session Co-Chairs: Crystal M. Glover and Cerise Elliott

Unique Identity Challenges for the Recruitment of AI/AN Caregivers into Dementia Care Research
Speaker: Jordan P. Lewis

Insights to Engaging and Recruiting Vietnamese Americans in Dementia Caregiving Research
Speaker: Van Ta Park

Community Relationships are Critical for the Recruitment of African American Families in Dementia Care Research
Speaker: Fayron Epps

Session 8 Research Gaps and Opportunities
Speaker: Crystal M. Glover

Panelist Remarks
Speakers: Christine Nguyen, Robert Reid, and Martha Williams

Moderated Discussion and Q&A

3:25 p.m. Summit Closing Remarks
Speakers: Andrea Gilmore-Bykovskyi and Julie Zissimopoulos

Appendix 4: References from Summit Presentations

Setting the Stage

Amy Kelley, PhD, NIA

NIA-funded active Alzheimer's and related dementias clinical trials and studies. (n.d.). National Institute on Aging. https://www.nia.nih.gov/research/ongoing-AD-trials

NIA Dementia Care and Caregiving Research

Elena Fazio, PhD, NIA

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Session 1: What Matters Framework and Living Well With AD/ADRD

What Matters to People Living with Dementia Living at Home? Developing Outcomes and the Evidence Base When Evaluating interventions

Siobhan Reilly, PhD, University of Bradford

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Observable Expressions of Positive and Negative Emotion: Affect-Balance
Sheila L. Molony, PhD, RN, Quinnipiac University

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Personalized Health Outcome Measurement in Dementia Care and Services Research

Lee Jennings, MD, MSHS, University of Oklahoma Health Sciences Center

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Session 2: Impact of Detection and Diagnosis on Individuals and Care Partners

Risk Prediction of Alzheimer's Disease and Related Dementias in Primary Care Settings

Raj C. Shah, MD, Rush University

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Disparities in Diagnosis and Post-diagnosis Care

Emmanuel Fulgence Drabo, PhD, Johns Hopkins University

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Plenary Talk: Challenges and Best Practices for Development and Evaluation of Interventions for PLWD and Their Care Partners

Linda Collins, PhD, New York University

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Session 3: Dementia Care Models and Coordination of Care

Co-Chairs: Katherine L. Possin, PhD, UCSF, and Marcel Salive, MD, MPH, NIA

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The NASEM Report: Rationale, Illustrative Findings and Expectations of a Way Forward

Eric B. Larson, MD, MPH, University of Washington

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The Vanguard of Comprehensive Dementia Care: Much Done, Much More to Do

David B. Reuben, MD, University of California, Los Angeles

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Dementia in the Acute Setting: Expanding and Improving Care

Ula Hwang, MD, MPH, Yale University

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It's About the Who and the Where: The Role of Person and Place in Access and Quality of Care

Shekinah Fashaw-Walters, PhD, University of Minnesota

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Evidence of Health Information Technology and Reduced Health Disparities in Dementia Care

Jie Chen, PhD, University of Maryland

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Health Care and Insurance Policies Affecting Care Use and Quality

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Session 5: Support for Care Partners and Caregivers

Co-Chairs: Kenneth W. Hepburn, PhD, Emory University, and Liz Necka, PhD, NIA

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Informal Dementia Care: Context Matters

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The Sooner the Better: Implementation Considerations When Initiating Intervention Development

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Session 6: Dementia Care Workforce

Setting the Stage: What We Know (and Don't Know) About the Dementia Care Workforce

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Challenges for the Nursing Home Direct Care Workforce and the Way Forward

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The Direct Care Workforce in Home-Based Dementia Care: Opportunities to Improve Care

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Session 7: Economic Impacts, Implications, and Approaches

Financial Decision Making, Cognitive Decline, and Alzheimer's Disease

Duke Han, PhD, University of Southern California

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Health Care Utilization Before and After a Dementia Diagnosis in Medicare Advantage (MA) and Traditional Medicare

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Session 8: Approaches to Participatory Research and Diverse Recruitment and Retention in Dementia Care Research

Unique Identity Challenges for the Recruitment of American Indian/Alaska Native caregivers into Dementia Care Research

Jordan P. Lewis, PhD, University of Minnesota

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Insights to Engaging and Recruiting Vietnamese Americans in Dementia Caregiving Research

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Community Relationships Are Critical for the Recruitment of African American Families in Dementia Care Research

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