

National Research Summit on

Care, Services, and Supports for Persons with Dementia and Their Caregivers

Summit Virtual Meeting Series – Summary Report

July 10, July 21, and August 13, 2020

National Institute on Aging, National Institutes of Health



National Institute
on Aging



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

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National Institutes of Health**

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Virtual Summit Series Summary Report

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Executive Summary

The [2020 National Research Summit on Care, Services, and Supports for Persons Living with Dementia \(PLWD\) and Their Caregivers](#) convened for three virtual sessions in July and August 2020 to identify gaps and opportunities in dementia-related research.¹ The Summit summarized the current state of dementia care and care partner research as well as progress made since the 2017 National Summit on Care, Services, and Supports for PLWD and Their Caregivers.

The goal of the Summit was to bring together individuals with a variety of backgrounds to identify evidence-based programs, strategies, approaches, and other research that can be used to improve the care, services, and supports of persons living with Alzheimer’s disease and Alzheimer’s disease-related dementias (AD/ADRD) and their care partners. The 2020 Summit Virtual Meeting Series and the Request for Information provided opportunities for individuals to share perspectives about critical scientific gaps and opportunities for research to help inform federal agencies, foundations, and private sector organizations. Individual members of the Summit Steering Committee, including academic researchers, PLWD, care partners, and other stakeholders, contributed to the development of research gaps and opportunities that were organized into [six broad themes and one integrated theme](#).² These research gaps and opportunities—which are enumerated in the scientific highlights of each session as well as in Appendix 1—are designed to highlight areas in which new or additional research can inform efforts that meaningfully impact the lives of PLWD and their care partners. These six themes were broadly organized in consideration of the impacts on PLWD and their care partners and the settings in which they receive care (Themes 1-3) and the methodological rigor and impact of AD/ADRD care and services research (Themes 4-6).

For each theme, two co-chairs—an academic researcher and a policy or practice expert in dementia care and services—guided presentations and discussion during the Summit. All questions submitted for discussion, even those that were not discussed at the Summit itself, were reviewed by the group as it revised gaps and opportunities to reflect Summit proceedings.

Across the themes, five cross-cutting topics were also emphasized: perspectives from PLWD and their care partners,³ health disparities, ethics, technology, and etiologies. These cross-

¹ Visit <https://www.nia.nih.gov/2020-dementia-care-summit#Materials> to access meeting materials from and YouTube recordings of each virtual session.

² The research gaps and opportunities do not represent consensus advice, and the Summit Steering Committee is not advisory to NIA. Discussion of such input should not be construed to mean these research ideas will lead to funding opportunities or other specific agency activity. The research gaps and opportunities suggested by members of the Steering Committee may be used at NIA’s discretion to inform new or revise current AD/ADRD Research Implementation Milestones, but NIA is under no obligation to do so.

³ **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. The term **caregiver** can refer to family members, neighbors, friends, fictive kin, or anyone else providing unpaid health and function-related assistance to persons living with dementia. For the purposes of this

cutting areas, which were discussed in relation to each theme, highlighted the need for person-centered study designs and outcomes as well as infrastructure-level modifications to the dementia care research landscape, with a particular focus on data collection and access.

The research gaps and opportunities address areas of scientific inquiry that hold promise for propelling advances in policy, practice, and care to improve the lives of persons who are affected by AD/ADRD and their care partners and encompass a broad swath of topics related to care and services. For some areas of scientific inquiry, important knowledge gaps persist despite substantial prior research. For example, there is strong evidence of profound disparities in dementia care among subpopulations most affected by AD/ADRD. But this evidence base is incomplete and new research is needed to explore effects on health and receipt of care in subpopulations that are less well understood, such as PLWD with specific types of dementia and among those who self-identify as members of sexual and gender minorities and those who live alone. Additional research is also needed to better understand heterogeneity, not only between subpopulations but within subpopulations, which might affect the scope and magnitude of AD/ADRD consequences and inform promising opportunities for intervention. In other areas, such as preclinical AD/ADRD, the science is only now emerging but is likely to grow in importance as diagnostic tests improve and persons are diagnosed in the absence of clinical symptoms.

Finally, it is important to note that the Summit activities were planned throughout 2019 and early 2020, preceding most of the COVID-19 outbreak, for what was originally conceived as an in-person March 2020 event. The pandemic and concurrent racial unrest have elevated awareness of the importance of identifying and eliminating structural barriers that create and propagate disparities in care, services, and supports. These events serve to accentuate the importance and timeliness of the research gaps and opportunities.

Theme One: Impact of Dementia

Theme co-chairs Dr. María P. Aranda and Ian Kremer moderated presentations and discussion related to heterogeneity and trends in the lived experience of dementia. Dr. Rachel Whitmer presented first on population trends in AD/ADRD and the importance of embracing a lifecourse approach to studying AD/ADRD to account for long-term drivers of disparities between groups. Dr. Ladson Hinton gave the second presentation on disparities that permeate the full course of dementia care. Dr. Julie Zissimopoulos delivered the final presentation on the economic impacts of dementia care. Panelists Cynthia Huling Hummel and Laura Trejo provided comments and then joined theme co-chairs and presenters for the Q&A discussion, which included disparities and the lived experience of PLWD in dementia care and research.

Theme Two: Long-Term Services and Supports (LTSS) in Home, Community, and Residential Care Settings for PLWD and their Caregivers

Theme co-chairs Dr. Robyn Stone and Dr. Sheryl Zimmerman moderated presentations and discussion on the organization, financing, and delivery of LTSS in home, community, and

report, the term care partner is used throughout for consistency, and its use means care partners and/or caregivers. See the glossary in Appendix 2 for more information.

residential settings. Dr. Kimberly Van Haitsma presented first on evidence-based person-centered practices for PLWD and their care partners. Dr. Joanne Spetz delivered the second presentation on the LTSS workforce. Dr. David Stevenson gave the final presentation on the financing and organization of LTSS. Panelists Dr. Alice Bonner and Laurie Scherrer commented and then joined theme co-chairs and presenters for the Q&A discussion, which primarily focused on workforce considerations and person-centered LTSS care models.

Theme Three: Services and Supports in Medical Care Settings for PLWD

Theme co-chairs Dr. Susan Beane and Dr. Christopher Callahan served as the moderators of this session, which focused on the organization, financing, and delivery of AD/ADRD medical care across the continuum of care. Dr. Joshua Chodosh presented an overview of care components in different models of dementia care, the integration of dementia care in primary care settings, and issues and challenges to address the care needs of people from underrepresented groups and in comparative effectiveness research. Dr. Cynthia Boyd's presentation focused on the complex care needs and challenges in developing evidence-based and patient-centered care strategies for PLWD and with multiple other chronic conditions. Dr. Norma Coe delivered the final presentation on the direct and indirect costs incurred by unpaid caregivers of PLWD and financing the care of PLWD. Panelists Dr. Shari Ling and Dr. George Hennawi provided commentary on these presentations and then joined theme co-chairs and presenters for the Q&A discussion, which focused on primary care model design and implementation and on benefit eligibility.

Integration of Themes Two and Three: The Present and Future of Integrated Long-Term and Medical Care

Integration theme co-chairs Dr. Christopher Callahan and Dr. Robyn Stone moderated presentations and discussion on topics at the intersection of themes 2 and 3. Kerry Branick delivered a presentation on the integration of LTSS, medical care, and financing. Dr. Bruce Leff delivered a second presentation on successful approaches to integrating LTSS and medical care. Theme co-chairs and presenters participated in the Q&A discussion, which centered on the interaction of care implementation strategies and payment models.

Theme Four: Participation of PLWD and their Caregivers in Research

After recorded welcoming remarks from theme co-chair Dr. Jason Karlawish, his co-chair Dr. Lori Frank moderated presentations and discussion, which focused on the engagement and involvement of PLWD and their care partners as partners in research. Dr. Lee Jennings's presentation addressed the importance of person-defined outcomes in dementia care research. Dr. Ronald Petersen's presentation considered the impact and implications of nomenclature for research participation from the perspective of clinicians and patients. Dr. Tabassum Majid's presentation covered the spectrum of patient engagement and strategies to engage PLWD and their care partners in research. Panelists Dr. Andrea Gilmore-Bykovskiy and Dr. Lonni Schicker provided commentary on the presentations and then joined the theme co-chair and speakers for the Q&A discussion, which highlighted challenges and opportunities for the engagement of PLWD and their care partners in research as well as dementia-specific considerations for data sources.

Theme Five: Intervention Research, Dissemination, and Implementation

Theme co-chairs Dr. Michael Monson and Dr. Malaz Boustani moderated presentations and discussion on methods to improve intervention research, dissemination, and implementation. Dr. Jürgen Unützer presented first on an evidence-based depression practice model that may serve as an exemplar for successful implementation and dissemination of dementia care programs. Dr. Luci Leykum gave the second presentation on current challenges in implementation science. Dr. Elizabeth A. McGlynn delivered the third presentation on how learning health systems might facilitate research, implementation, and improvement of dementia care models. Panelist Dr. Lisa Onken provided prepared remarks and then joined theme co-chairs and presenters for the Q&A discussion, which included keys to successful implementation of interventions and data needs.

Theme Six: Research Resources, Methods, and Data Infrastructure

Theme co-chairs Dr. Joanne Pike and Dr. Vincent Mor moderated presentations and discussion on methods, data, and processes needed to facilitate dementia care research. Dr. Julie P.W. Bynum presented first on the identification of PLWD for research. Dr. Thomas G. Trivison delivered the second presentation on opportunities for embedded pragmatic clinical trials for PLWD and their care partners. Dr. David Wendler gave the final presentation on ethical considerations surrounding consent in dementia care research. Panelists Joe Chung, Dr. Craig W. Thomas, and Dr. Maggi C. Miller provided comments and then joined theme co-chairs and presenters for the Q&A discussion, which highlighted consent and engagement from PLWD and care partners as well as questions about data sources and infrastructure.

Emerging Topics

Session co-chairs Dr. David Reuben and Dr. Jennifer Wolff moderated presentations and a discussion on emerging topics in dementia care research. Dr. Joan K. Monin presented first on the emotional functioning and experience of PLWD and care partners. Dr. Jared F. Benge presented on the concept of technological reserve and technology-based supports for PLWD. Dr. Christine Cassel gave the final presentation on the identification of preclinical-stage dementia. Panelists Venoreen Browne-Boatswain and Michael R. Bellville provided comments and then joined theme co-chairs and presenters for the Q&A and moderated discussion, which included discussion of the value of PLWD and care partner input on interventions and how cultural sensitivity can mediate the impact of dementia care strategies.

Summary Report

Background

The [2020 National Research Summit on Care, Services, and Supports for Persons Living with Dementia \(PLWD\) and Their 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. The Summit sought to expand upon what was learned in the 2017 National Research Summit on Care, Services, and Supports for Persons with Dementia and Their Caregivers and spark new, innovative ideas from multiple stakeholder groups, including those living with dementia, care partners, researchers, providers, and advocacy communities.

The 2020 Summit brought together individuals with a variety of backgrounds to identify evidence-based programs, strategies, approaches, and other research that can be used to improve the care, services, and supports of persons living with Alzheimer's disease and Alzheimer's disease-related dementias (AD/ADRD) and their care partners. The process provided opportunities for individuals to share perspectives about critical scientific gaps and opportunities for research to help inform federal agencies, foundations, and private sector organizations. Individual members of the Summit Steering Committee, including academic researchers, PLWD, care partners, and other stakeholders, contributed to the development of research gaps and opportunities that were organized into [six broad themes and one integrated theme](#). These research gaps and opportunities—which are enumerated in the scientific highlights of each theme as well as in Appendix 1—are designed to highlight areas in which new or additional research can inform efforts that meaningfully impact the lives of PLWD and care partners.

The NIA and the 2020 Summit Steering Committee members reviewed a broad range of background material to assist in its summit planning, including the [2017 National Research Summit on Care, Services, and Supports for Persons with Dementia and Their Caregivers](#), [2018 NIH Alzheimer's Research Summit](#), [2019 Alzheimer's Disease-Related Dementias Summit](#), [National Plan to Address Alzheimer's Disease](#), and the [AD/ADRD Research Implementation Milestones](#) to meet the goals of the National Plan to Address Alzheimer's Disease.

NIA and Summit planning committees sought input from individuals with diverse expertise and perspectives—including academic researchers, public policy experts, PLWD, their family members, and other care partners. Their efforts included:

- Seeking input during the Summit planning process through a published [Request for Information](#) in the NIH Guide.
- Convening a Summit Steering Committee, led by Dr. Jennifer Wolff (Johns Hopkins University) and Dr. David Reuben (University of California, Los Angeles), composed of academic researchers as well as other stakeholders, including a person living with dementia and a care partner.

- Seeking input from the National Alzheimer’s Project Act (NAPA) Advisory Council.
- Working with the HHS Office of the Assistant Secretary of Planning and Evaluation (ASPE) to convene and consider written input from five Stakeholder Groups including persons with dementia, informal care partners, service providers, workforce development, and payers (Stakeholder Group recommendations are available on [ASPE’s NAPA website](#)).
- Seeking input from federal partners.
- Providing opportunities before, during, and after each Virtual Session of the Summit for audience participation and engagement.
- Seeking input on the draft research gaps and opportunities through a second published [Request for Information](#) in the NIH Guide.

The Steering Committee members participated in numerous in-person and virtual meetings from July 2019 through July 2020 to consider stakeholder input and develop a set of draft research gaps and opportunities aligning with six broad themes of dementia care and caregiving research plus one integrated theme. The gaps and opportunities were designed to encompass targeted areas where new knowledge could lead to efforts that would meaningfully improve the lives of PLWD and their care partners. [Themes](#) included:

- Theme 1: Impact of Dementia
- Theme 2: Long-Term Services and Supports (LTSS) in Home, Community, and Residential Care Settings for Persons Living with Dementia and their Care Partners
- Theme 3: Services and Supports in Medical Care Settings for Persons Living with Dementia
- Integration of Themes 2 and 3: The Present and Future of Integrated Long-Term and Medical Care
- Theme 4: Participation of Persons Living with Dementia and their Caregivers in Research
- Theme 5: Intervention Research, Dissemination, and Implementation
- Theme 6: Research Resources, Methods, and Data Infrastructure

The Summit also included five cross-cutting themes—perspectives from PLWD and their care partners, health disparities, ethics, technology, and etiologies—and an emerging topics session.

Originally planned as a 2-day in-person meeting to take place on March 24-25, 2020, the Summit was transformed in response to COVID-19 into a series of three interactive virtual sessions that each included research presentations, introduction of draft research gaps and opportunities, panelist reactions and perspectives, opportunities for questions from the audience, and moderated discussion among speakers. The Summit virtual sessions were held via Zoom Webinar on July 10, July 21, and August 13, and a Twitter poster session was held on August 6, 2020 using #DementiaCareSummit.⁴ For the purposes of this report, scientific highlights and research gaps and opportunities are presented in order of theme even though

⁴ Visit <https://www.nia.nih.gov/2020-dementia-care-summit#Materials> to access meeting materials from and YouTube recordings of each virtual session.

logistical circumstances led NIA to present the themes somewhat out of order during the three virtual sessions.

Following the virtual Summit series, the Steering Committee members received a summary of RFI input and a draft report summarizing scientific highlights of the virtual Summit and began revising research gaps and opportunities. The committee members met virtually in September 2020 to review and further refine the revised research gaps and opportunities (Appendix 1) based on individual input from the committee members.

Setting the Stage

The first meeting of the Virtual Summit featured a series of short presentations to provide context for the overall Summit. NIA Director Dr. Richard Hodes reviewed NIA's long-standing commitment to Alzheimer's disease and Alzheimer's disease-related dementias (AD/ADRD) research. Steering Committee members Dr. Lonni Schicker and Ms. Katie Brandt provided remarks on the lived experience of PLWD and care partners. Mr. Arne Owens, Deputy Assistant Secretary for Disability, Aging, and Long-Term Care Policy at ASPE, delivered an overview of the NAPA, the National Plan, and the NAPA Advisory Council.

Dr. Laura Gitlin highlighted progress achieved since the 2017 National Research Summit on Care, Services, and Supports for Persons with Dementia and Their Caregivers, for which she served as co-chair. This historic care Summit articulated established knowledge about dementia care and services and identified knowledge needed to improve the lives of PLWD and their care partners. The Summit initiated a paradigm shift that underscored the importance of involving multiple stakeholders—including PLWD and their care partners—in the development of person-centered research questions and outcomes. This first Summit generated 464 research priorities that were broadly categorized into twelve broad themes: heterogeneity, lived experiences, care partner relationships, person/family-centered care models, engaging PLWD as research team members, financial burden and cost of care, living environments, nomenclature, workforce development, research methods, dissemination of evidence, and technology.

The [AD/ADRD Research Implementation Milestones](#) on NIA's public website provide information on implementation activities for each milestone, including progress made (e.g. funding opportunities, research programs and resources, and research highlights).

Theme One: Impact of Dementia

Co-Chairs: María P. Aranda, PhD, University of Southern California, and Ian Kremer, JD, Leaders Engaged on Alzheimer's Disease (LEAD)

This theme included issues related to heterogeneity and trends in the lived experience of dementia, including the clinical impact and trajectory for PLWD and their care partners across the range of etiologies; the economic impact of dementia for patients, care partners, payers, public programs, and society; and the effects of dementia, including the impact of health disparities on diverse populations – for example by sex and gender, socioeconomic status (SES),

geography, race and ethnicity, language, education, and living arrangements, including people living alone or without caregivers.

Population Trends of ADRD: Importance of Lifecourse and Diversity

Rachel Whitmer, PhD, University of California, Davis

Rates of AD/ADRD vary across racial and ethnic groups, with incidence highest among African Americans and lowest among Asian Americans.⁵ These disparities reflect social determinants of health that accumulate over the lifecourse in ways that differ across populations. As the U.S. population becomes increasingly diverse, AD/ADRD studies that reflect that diversity will not only improve study precision in the present, but also ensure that findings are relevant to the population of the future. Addressing disparities in prevalence and incidence of AD/ADRD requires not only recruiting and retaining diverse study participants, but also contextualizing research questions with cultural sensitivity, balancing depth and breadth, pooling studies to answer unique questions, harmonization, employing correct methods to navigate potential confounds (e.g., the healthy volunteer effect), and embracing a lifecourse approach to account for long-term drivers of disparities between groups.

Disparities in Health, Services, and Interventions for PLWD and Family Caregivers: Evidence and Future Directions

Ladson Hinton, MD, University of California, Davis

Emerging evidence from disparities research suggests that disparities permeate the course of dementia care among African American and Latinx PLWD—from diagnosis to differences in treatment interventions and end-of-life care—and include disproportionate impacts on family care partners. However, the drivers of disparities are unknown, and detection in many vulnerable populations has not been thoroughly assessed. Moreover, evidence gaps can widen as trials move from efficacy to pragmatic studies in healthcare systems where disparities exist. These gaps may be narrowed through broad inclusion of populations underrepresented in research (e.g., racial and ethnic minorities, gender and sexual minorities, people of low socioeconomic status) in pragmatic clinical trials that are sufficiently powered to detect and understand inequities between subgroups.

Economic Impact of Alzheimer's Disease and Related Dementias for Individuals, Care Partners, and Society

Julie Zissimopoulos, PhD, University of Southern California

Annual per-person medical and caregiving costs are four times higher for PLWD, with higher costs incurred by non-white PLWD.⁶ The total national cost of dementia care in the U.S. is anticipated to rise to \$1.6 trillion by 2050. There is a need to better understand the

⁵ Mayeda, ER et al. (2016) Inequalities in dementia incidence between six racial and ethnic groups over 14 years. *Alzheimers Dement* 12(3): 216-224.

⁶ Zissimopoulos, J et al. (2014) The value of delaying Alzheimer's Disease onset. *Forum Health Econ Policy* 18(1): 25-39.

heterogeneity of economic impact and the drivers of cost differences and their impacts on policies and programs. Researchers must have access to longitudinal data sets and use rigorous methods to create models that can compare relative costs and health impacts of dementia care interventions. These models utilize national data to identify factors associated with cognitive decline, dementia onset, and related costs, and can be used to project how different interventions may reduce dementia prevalence and cost for future generations.

Moderated Discussion Highlights

Panelists: Cynthia Huling Hummel, BS, MDi, DMin, and Laura Trejo, MSG, MPA, City of Los Angeles Department of Aging

Centering Disparities in Dementia Care Research

Racial and ethnic disparities in dementia care represent a central gap in dementia care research with many opportunities for evaluation and improvement. But studies must treat these disparities not just as one potential topic among many, but instead as an essential element of their design. For example, community representatives and underrepresented minority researchers can be embedded throughout the research process to provide cultural and linguistic expertise that may increase engagement with underrepresented communities, improve appropriateness and accuracy of population-based measures, and promote research programs' accountability. Recognition of disparities may reveal not only areas of increased burden, but also opportunities to evaluate the characteristics of communities that demonstrate resilience in some domains (e.g., lower psychological distress among African American care partners). Disparities emerge across not only populations but also among those who have different types of dementia, and diagnostic challenges create knowledge gaps that further increase these disparate experiences in dementia care and research.

Centering the Experiences of PLWD in Dementia Care

"Don't talk about us without us" is panelist Cynthia Huling Hummel's call to center the experiences of PLWD in dementia care and research. While some dementia care programs mandate the presence of a care partner, it is insufficient for researchers and clinicians to interact with care partners alone when providing care or researching effective interventions, and not offering options for those without care partners leaves many independent PLWD out. Such a focus implicitly denies the fact that many people live successfully with dementia for long periods of time, and this denial contributes to pervasive stigma that precedes diagnosis and often becomes a barrier to seeking diagnosis, treatment, and research opportunities. It is also important for researchers to account for the specificities of the lived experience of dementia when engaging PLWD and evaluating research priorities—for example, anticipating increased difficulty with noisy environments or feelings of loneliness.

Theme One Research Gaps and Opportunities

- 1.1 ***Conduct research to describe the nature, trajectory, and impacts of common and rare forms of AD/ADRD, or AD/ADRD with complex co-occurring conditions, on individuals, families, and society.*** Impacts should include particular attention to the needs, preferences, and strengths of individuals with and without care partners.

Complex co-occurring conditions refers to both medical conditions (e.g. diabetes, hypertension), as well as other conditions that affect daily function and interaction (e.g., sensory impairments, urinary incontinence).

- 1.2 **Conduct research to assess the extent to which differences in the nature, trajectory, and impact of AD/DRD are mediated by heterogeneity among individuals and families.** Heterogeneity includes disease etiology, age of onset, disease severity, presence of complex co-occurring conditions (see 1.1), familial relationship (e.g. spouse/partner, adult child, sibling, in-law), race and ethnicity, socioeconomic status, health disparities, gender identity, sexual orientation, and geography.
- 1.3 **Conduct research on the positive and negative effects of pre-clinical diagnoses on persons receiving this diagnosis and their care partners as well as on health systems, utilization, and costs of care.** Positive effects include opportunities to self-advocate, participate in research, and engage in quality of life decision-making and advance care planning. Negative effects include labeling and stigma, emotional stress, and legal and financial repercussions.
- 1.4 **Conduct research to examine the impact of explicit and implicit bias and stigma against PLWD and their care partners on their wellbeing.** Impact includes understanding the lived experience of membership in more than one stigmatized group, (i.e., the intersectionality of gender, race, socioeconomic status, rurality, and immigration status) that may heighten vulnerabilities and health disparities and decrease personal and family capabilities of PLWD with and without care partners.
- 1.5 **Conduct research to better describe how social determinants of health and attributes of the neighborhood and community in which individuals live as well as national-level cultural and political factors affect the well-being of both PLWD with and without care partners and on care partners.** Social determinants include education, social and economic resources, health disparities, housing and transportation, healthcare and aging services infrastructure, disability policy, and immigration policy.
- 1.6 **Conduct research to determine how risks to well-being differ among care partners based on caregiving circumstances, and how such differences are mediated by individual, family, and disease characteristics.** Dimensions of well-being include social isolation; marital breakdown; loneliness; financial, legal, and psychological vulnerabilities; injuries; and self-neglect. Caregiving circumstances include living arrangement, competing family and work responsibilities, availability and interpersonal dynamics of family and other helpers, social and economic resources, and health disparities.
- 1.7 **Conduct research to characterize and identify gaps in the care settings in which PLWD with and without care partners receive personal care services, medical, psychiatric, substance use, and recreational services, as well as issues related to aging in place.** Settings include community-based, residential care, nursing facilities, and senior housing, among other settings.
- 1.8 **Conduct research to describe how economic and financial burdens affect the lived experiences of persons with dementia with and without care partners and their care partners, including choices about diagnosis, treatment, supportive services use, and research participation.**

- 1.9 **Conduct research to describe the effects of AD/ABRD on financial status and financial outcomes.** Financial outcomes include spousal/family impoverishment, reduction or loss of employment opportunities, disruption of employee benefits (e.g., health insurance, accrual of social security benefits and/or private retirement), health disparities, uptake of long-term care insurance, and eligibility for long-term services and supports for PLWD with and without care partners and their families and other care partners.

Theme Two: Long-Term Services and Supports in Home, Community, and Residential Care Settings for Persons with Dementia and their Caregivers

Co-Chairs: Robyn Stone, DrPh, LeadingAge LTSS Center at University of Massachusetts, Boston, and Sheryl Zimmerman, PhD, The University of North Carolina at Chapel Hill

This theme included issues related to the organization, financing, and delivery of long-term services and supports (LTSS) in the home and community and in residential settings, such as assisted living and nursing homes. Issues related to the formal care and provider workforce, services provided by community-based organizations, payment and financing, industry, and care partners needs were addressed.

Evidence-based Person-centered Practices for Persons Living with Dementia and Their Care Partners: What do we know, where to next?

Kimberly Van Haitsma, PhD, FGSA, The Pennsylvania State University

Promising nonpharmacological interventions currently exist to treat cognitive decline, functional decline, and behavioral expressions for PLWD and to improve the well-being and capability of care partners and staff care providers. Yet more work is needed to address research rigor, pragmatic dissemination and implementation, social determinants of health, and the inclusion of positive outcomes. Questions remain about how to implement these interventions most effectively across varied environments and populations. Furthermore, many of these interventions focus on mitigating deficits rather than optimizing quality of life. Next steps include seeking PLWD and care partner perspectives, using holistic theoretical models and frameworks to guide research, and using measures to capture positive processes and impacts. Future research may adopt process-based pragmatic measures like preference congruence (i.e., how well care processes align with preferences of PLWD) to design and study care approaches that yield meaningful, holistic, and person-centered outcomes.

Understanding the Long-Term Services and Supports Workforce in a New Way

Joanne Spetz, PhD, University of California, San Francisco

Many aspects of the LTSS workforce, including highly variable formal training requirements and inconsistent state restrictions on the scope of direct care workers' services, may impact PLWD quality of life in ways that have not been thoroughly examined. To foster a robust LTSS workforce, interprofessional teams that integrate medical specialists and direct care workers

must be developed, which requires research on payment structures and implementation strategies as well as meaningful person-centered and culturally sensitive outcomes. As emerging LTSS technologies are increasingly adopted, care must be taken to evaluate how these technologies can complement the workforce in effective ways. Additionally, research is needed to inform promising culturally-sensitive efforts to advance person-centered care.

Organization and Financing of Long-Term Services and Supports for People Living with Dementia (PLWD)

David Stevenson, PhD, Vanderbilt University

The lack of universal coverage for LTSS leaves many PLWD to rely on unpaid care partners and to bear exorbitant out-of-pocket costs. It also disrupts continuity of care as coverage changes from one service to the next, resulting in higher costs and worse outcomes. While managed care plans can help to integrate the financing and delivery of care services, no evidence is available for the impact of these plans specifically on PLWD. Research on benefit structures that encompass affordability as well as quality measures (e.g., quality of care, accountability and incentives, payment adequacy) and assessment of the preferences of PLWD are necessary to meet current challenges in LTSS and end-of-life care.

Moderated Discussion Highlights

Panelists: Alice Bonner, PhD, RN, FAAN, Institute for Healthcare Improvement, and Laurie A. Scherrer

Workforce Considerations

Feedback from direct care workers themselves can help to identify the most effective strategies for improving training, evaluation, care team coordination, and career paths for LTSS. Addressing these challenges is particularly important in rural and under-resourced communities, where staff shortages are more common. More research is also needed on the impact of alternative payment models on LTSS quality and cost, although preliminary evidence suggests such models reduce institutionalizations for PLWD.

Person-Centered LTSS Care Models

The experiences of PLWD are central to quality of dementia care and, if not included, the diagnostic and care experience can be ineffective and even “inhumane,” as described by panelist Laurie Scherrer. By contrast, educating and supporting PLWD and their care partners to be proactive participants in the proposed care regimen is not just a form of care delivery, but ultimately contributes to PLWD wellbeing and can positively influence outcomes and quality of life. Early integration of PLWD in care research can also be a cost-effective way to design interventions that may be more likely to succeed without major post hoc revision.

Theme Two Research Gaps and Opportunities

- 2.1 ***Use theory-driven frameworks to develop and test interventions that address the complex challenges experienced by PLWD and their care partners over the full course of the disease.*** For example, approaches can be guided by theories related to socio-

ecological levels and social determinants of health and heterogeneity, including such issues as cultural diversity, and be used to reduce health disparities. The full course of the disease recognizes the evolving role of care partners over the disease course, including new care partners introduced later in the disease.

- 2.2 ***Assess how interventions' effects on clinical endpoints of PLWD (e.g., cognition, function, well-being) relate to other considerations, including intensity of caregiving demands, care partner health, movement into residential long-term care, and costs to individuals, families, and society.***
- 2.3 ***Develop and evaluate interventions that address the social and emotional needs, including isolation, of PLWD, their care partners, and direct care workers.***

Interventions could include mindfulness-based approaches, physical activity, cognitive behavioral therapy, music, positive affect training, and technology.
- 2.4 ***Develop and evaluate training for direct care workers to identify specific competencies and modalities that best contribute to improved health, quality of life, and financial and social outcomes for PLWD, their care partners, and the direct care workers themselves.*** Training includes technology to assist training and training in use of technology.
- 2.5 ***Analyze the impact of heterogeneity among PLWD and the direct care worker and clinician workforce (paid and unpaid) and develop and test approaches that promote cultural awareness and respect, cultural competence, and communication skills.***

Heterogeneity includes racial, ethnic, and cultural identity and other factors that may affect underrepresentation in research and/or health disparities.
- 2.6 ***Determine the relative effectiveness and efficiency of interprofessional workforce models in providing high-quality care to PLWD, and how to support workforce collaboration across home, community, and residential settings.***
- 2.7 ***Analyze the interactions between care partners, direct care workers, and clinicians, in relation to technologies designed for the care of PLWD; determine how technological change will affect future workforce needs, and design and evaluate effective education and training for care partners, direct care workers, and clinicians to use new technologies effectively.***
- 2.8 ***Conduct research to improve the supportive and care-related technologies available for and used by PLWD and their care partners, especially in populations with more limited social and economic resources.*** Examples of technological advances include smart phones, monitoring devices, remote technology, and smart assistive devices.
- 2.9 ***Using measures that evaluate quality across LTSS settings in which PLWD receive care, evaluate alternative payment models, quality oversight efforts, and public reporting initiatives.***
- 2.10 ***Conduct research to examine the adequacy of payments for care received by PLWD in value-based payment efforts in the Medicaid and Medicare programs and other alternative payment models, as well as the effects on out-of-pocket expenses and on care partners.*** Medicare and Medicaid programs include Medicaid managed care plans, Medicare Advantage, and Special Needs Plans. Alternative payment models include accountable care organizations and bundled payment initiatives.

- 2.11 ***Assess whether and how eligibility and payment policies for specific benefits pose barriers to receipt of supportive, palliative, and end-of-life care services, and evaluate ways in which these policies might be reformed to better meet the needs of PLWD and their care partners and reduce health disparities.*** Specific benefits include hospice, post-acute care, and psychological services.

Theme Three: Services and Supports in Medical Care Settings for Persons with Dementia

Co-Chairs: Susan Beane, MD, Healthfirst, Inc., and Christopher Callahan, MD, MCAP, Indiana University

This session addressed issues related to the organization, financing, and delivery of health care across the continuum of care for people at risk for and living with dementia, including the provision of care at home, care provided in urgent care facilities and emergency departments, hospital inpatient and post-acute care (both in skilled nursing facilities and home health care), and hospice care. Issues related to the professional health care and provider workforce, payment and financing, and industry were addressed.

Providing High-Quality Care in Medical Care Settings

Joshua Chodosh, MD, MSHS, FACP, New York University

Many care models offer comprehensive dyad-focused services (e.g., psychosocial support, medical interventions), with roots in communities or academic health systems and involvement of both trained non-professionals and professional providers (e.g., nurse, social worker). Some models focus on care transitions. Yet primary care is often left out of these otherwise comprehensive care models because few models are directly embedded in a medical care system and assessment of cognitive function is often overlooked in primary care appointments; early-stage impairments are therefore often missed. Many dementia care model research questions remain unanswered, including questions about what the most meaningful care interventions are, especially for those who are from underrepresented groups; the minimum effective dose of care (e.g., variations of care provider, intensity, frequency); and whether dementia care models may be improved through “triadic” care strategies that engage the patient, care partner, and primary care provider.

Care of PLWD with Multiple Chronic Conditions

Cynthia M. Boyd, MD, MPH, Johns Hopkins University

PLWD living in the community have an average of 3.2 other chronic medical conditions, which may play a role in quality of life, functional capacity, and reversible disability, and medical care for PLWD works best when this fact is recognized. Management of co-occurring conditions is costly and complicated, because dementia and co-occurring conditions exacerbate one another. However, cohesive treatment that tends to both dementia-related cognitive symptoms and the co-occurring condition can lead to mutual improvement. New knowledge is needed to facilitate a paradigm shift from disease-oriented treatment to a person-driven and

goal-directed research agenda. Promising research opportunities include designing and adapting strategies for management of chronic conditions for PLWD, addressing opportunities for under- and overtreatment, and designing person- and family-centered care strategies.

Financing the Care of PLWD

Norma B. Coe, PhD, University of Pennsylvania

Care for PLWD is often uninsured, particularly LTSS. Care provided by family and other unpaid caregivers accounts for nearly 50 percent of the total cost of dementia care and is considerably larger than direct costs to insurance programs.⁷ Comprehensive models of dementia care costs estimate that the true cost to caregivers is at least 20 percent higher than estimates that measure indirect caregiving only in lost wages, because a care partner's own health and long-term career plans are often negatively impacted.⁸ Gaps in research on financing dementia care include how financing influences PLWD and care partner/caregivers' care decisions and outcomes, how insurance programs can coordinate to improve outcomes and reduce cost, and whether widespread early detection would be cost-effective.

Moderated Discussion Highlights

Panelists: Shari Ling, MD, Centers for Medicare & Medicaid Services, and George Hennawi, MD, MedStar Good Samaritan Hospital

Primary Care Model Design and Implementation

A dementia care model embedded within a primary care setting offers an opportunity to provide comprehensive, person-centered treatment, tailored advance care planning, individualized management of multiple chronic conditions, and coordinated care transitions that help prevent unnecessary hospitalizations. Clearly defined parameters (e.g., who provides what service), participant roles (e.g., within dyads or families), and goals for this and other models of dementia care facilitate successful implementation and replication among dementia care studies.

Eligibility for Benefits

In circumstances in which resources are insufficient to cover dementia care, some individuals can become dually eligible for separate Medicare and Medicaid plans (not a specific combined dementia-care coverage plan). Opportunities to make Medicare benefits more easily navigable or for Medicare and Medicaid coverages to work harmoniously to provide quality care and save money (particularly before PLWD become dually eligible) have not been adequately assessed.

Theme Three Research Gaps and Opportunities

- 3.1 ***Evaluate and compare comprehensive models of care and develop new models for subgroups of PLWD that are not effectively served by existing models.*** Specifically compare “stand-alone” care models that support primary care of PLWD/dyads versus

⁷ Hurd, MD et al. (2013). Monetary costs of dementia in the United States. *N Engl J Med* 368: 1326-1334.

⁸ Coe, NB et al. (2018). A comprehensive measure of the costs of caring for a parent: differences according to functional status. *J Am Geriatr Soc* 66(10): 2003-2008.

those embedded in primary care programs and other mainstream models of care delivery.

- 3.2 ***Determine the core competencies, domains, and quality metrics needed to ensure that medical care for PLWD is consistent with evidence-based clinical standards.***
- 3.3 ***Develop and test the efficiency and effectiveness of strategies to provide PLWD with diagnostic and longitudinal comprehensive care, including co-existing conditions, in various settings.*** These settings include typical clinical settings such as ambulatory care network settings and small practice settings, settings serving PLWD who have limited resources, including rural and safety net settings (such as Federally-Qualified Health Centers), and residential care.
- 3.4 ***Assess the impact of promoting care planning, assessment, evaluation of preferences, and advanced care coordination across the range of disease stages, from preclinical to severe dementia, on the efficiency, effectiveness, and experience of care of PLWD and their care partners.*** Advanced care coordination includes advance care planning, end-of-life, palliative care, and hospice.
- 3.5 ***Determine the qualitative and quantitative impact of improvements in detection, diagnosis, treatment, and care management of PLWD across all treatment settings, on individuals, families, and society.***
- 3.6 ***Study the effect of access to health insurance on the receipt of person-centered care and the location of care for PLWD.***
- 3.7 ***Determine how payment affects access and quality of care received by PLWD in a variety of community and residential settings.***
- 3.8 ***Develop and test the ethical implications and cost-effectiveness of inclusion of the caregiver in the care team of the PLWD.***

Integration, Themes Two and Three: The Present and Future of Integrated Long-Term and Medical Care

Co-Chairs: Christopher Callahan, MD, MCAP, Indiana University, and Robyn Stone, DrPh, LeadingAge LTSS Center at University of Massachusetts, Boston

This session addressed the integration of Themes 2 and 3, including innovations in organization, financing, and delivery to support integration of medical care and LTSS across the range of settings in which PLWD and their care partners live and receive care.

Building the Case for Integrating LTSS, Medical Care, and Financing

Kerry Branick, Centers for Medicare & Medicaid Services

Approximately 12 million individuals are dually eligible for Medicare and Medicaid benefits, but these programs were not designed to work together, and most dually eligible individuals are not enrolled in an integrated program to make them more cohesive. The Centers for Medicare & Medicaid Services (CMS) Financial Alignment Initiative demonstration projects aim to address the financial misalignment between the two programs and test one combined Medicare and

Medicaid product (e.g., one enrollment process, identification card, and benefit package) for dually eligible individuals. These demonstration projects offer an opportunity to study coordinated LTSS and medical care that may offer more cost-effective, tailored benefits; aligned financial incentives; comprehensive risk assessment; and oversight for quality assurance.

Signals on Successful Approaches to Integrating LTSS and Medical Care

Bruce Leff, MD, Johns Hopkins University

Successful care delivery relies on the careful alignment of a targeted recipient population, the care model itself, and the desired outcome. For LTSS, this alignment entails matching specific LTSS and medical services to individual PLWD based on their needs, desired outcomes, and unique environment. It is also important to assess how services used in combination influence each other, in terms of efficacy, practicality, and affordability; evidence from a recent integrated service effort shows that less desirable outcomes (e.g., long-term institutionalization) can be reduced when primary care is integrated with LTSS.⁹

Moderated Discussion Highlights

Models of Implementation Financing and Outcomes

Multiple care implementation strategies will likely be needed to account for the variable Medicaid and coverage programs nationwide. More research on the interaction of care implementation and payment models is needed to effectively compare the impact of various alignment structures on health outcomes and disparities, as well as how different coverage programs can harmonize to save money.

Integration Research Gaps and Opportunities

- Int.1 ***In the context of integrated long-term services and supports (LTSS) and medical care for PLWD, determine what services are appropriate for integration versus coordination, in what manner, for whom, toward what ends, and with what payer arrangements.*** Integrated care may include co-location or care provided within a single delivery system or source of funding of services or supports, whereas coordination refers to deliberate organization of services through exchange of information by care providers responsible for varied aspects of care. Research should examine the broad spectrum of PLWD, from diagnosis and early intervention through mid-stage to end-of-life.
- Int.2 ***Develop, evaluate, and optimize approaches to quality measurement in the context of value-based care initiatives, so as to encourage and support optimal integrated and coordinated care delivery models and approaches for PLWD.*** Approaches include health information technology.
- Int.3 ***Develop and evaluate evidence-based strategies for the optimal integration and coordination of AD/ADRD care services across healthcare delivery and community-***

⁹ Valluru, G et al. (2019). Integrated home and community based services improves community survival among Independence at Home Medicare beneficiaries without increasing Medicaid costs. *J Am Geriatr Soc*: 67(7): 1495-1501.

based organizations, including examining whether models of integrated LTSS and medical care are best designed as carve out (separate) models or as add-in models that are coordinated within the broader system. Evidence-based strategies include tools and assessments, models of care, and technologies that focus on the range of rural and urban settings. Integrated care includes both Medicaid supported and other populations and financing models, such as Medicare Advantage and Alternative Payment Models.

- Int.4 **Conduct research to develop, implement, and evaluate public health emergency preparedness and disaster responsiveness systems that meet the social, emotional, and medical needs of PLWD and their care partners.** Needs include ensuring personal emergency response equipment and immediate emergency response; safe evacuation and transportation; basic food, lodging, medical, and support services; and long-term management and monitoring. In addition, ensuring that medical facilities, including emergency departments, hospitals, and nursing homes are capable of providing comprehensive care for PLWD that accounts for their range of needs. Such research should address potential disparities of PLWD with limited social and economic resources.
- Int.5 **Conduct research to develop and evaluate tools, strategies, and models that more effectively train, support, and involve care partners in the care of PLWD.** Such research should consider efforts to better prepare the workforce to address the needs of care partners of persons affected by various types of dementia etiologies and from subgroups at heightened risk for health disparities (e.g., by educational attainment, health literacy, or with less access to care).
- Int.6 **Conduct research to develop and study mechanisms to support the involvement of care partners when they play essential roles implementing the care plan of the PLWD.** Such research may encompass a wide range of compensation to care partners as well as the organizations that pay for the care of PLWD, such as traditional Medicare, Medicare Advantage, Medicaid, and other private payers.

Theme Four: Participation of Persons with Dementia and their Caregivers in Research

Co-Chairs: Lori Frank, PhD, RAND Corporation, and Jason Karlawish, MD, University of Pennsylvania

This theme addressed participation in research, including the consideration of PLWD and their care partners as research participants and as engaged research partners. Topics included the importance of patient activation and care partner engagement in research study design and health outcomes; the significance of nomenclature in participant recruitment and retention strategies and how research is conducted; and optimizing the collection of information derived from a variety of sources, including PLWD and care partner reports, technology-based assessments, and meta-data.

Reporters, Data Sources, and Outcomes in Dementia Research

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

Person-defined dementia care outcomes may be preferable to disease-based outcomes because they can account for multiple co-occurring conditions and capture overall quality of life. Several opportunities already exist to operationalize these personalized outcomes in research. Individual goals can be measured in standardized units by adhering to SMART attributes (Specific, Measurable, Attainable, Relevant, and Time-bound), and goal attainment can be quantified according to whether the PLWD or care partner met, exceeded, or failed to meet expected goals. Validated patient-reported outcome measures (PROMs) may be refined to address the impact of worsening cognition or changes in relationships with care partners who provide proxy reports. Despite the challenges of using PROMs in assessments of PLWD, there are also many opportunities for future research, for example, to further develop methods and measures. Wearable devices or digital applications may be leveraged to create triangulated measures of person-defined outcomes.

Nomenclature

Ronald C. Petersen, MD, PhD, Mayo Clinic

Researchers have long recognized the impact of nomenclature on all aspects of dementia care, from research to the clinic. Over recent decades, terminology to describe AD/ADRD has evolved to distinguish between pathophysiology (i.e., biological causes or correlates of dementia) and syndrome (i.e., clinical symptoms). While a precise pathophysiological definition of AD/ADRD facilitates diagnosis and research, it may be difficult to translate to PLWD, care partners, and other stakeholders outside of the medical field. Nomenclature has implications for research stakeholders: researchers must be able to use precise terms, clinicians must be able to translate scientific terms to patients and vice versa, and public stakeholders' concerns with language must be addressed to address stigma and willingness to participate in research.

Putting the “Me” in Dementia Research

Tabassum Majid, PhD, MAgS, University of Maryland, Baltimore County

Engagement between researchers, patients, and other stakeholders in the conduct of research is expanding in many therapeutic areas. Few studies engage PLWD as research partners, however. While partnering with individuals with progressive cognitive impairment presents unique challenges, PLWD can provide insight into the lived experience of dementia to the benefit of study design and selection of outcomes to measure. Engaged PLWD research partners can also help to disseminate research findings.

Moderated Discussion Highlights

Panelists: Andrea Gilmore-Bykovskyj, PhD, RN, University of Wisconsin-Madison, and Lonni Schicker, EdD, RN

Challenges and Opportunities for PLWD Engagement with Research

Dementia research often focuses on deficit-oriented measurements while overlooking measures of positive ability and strengths; including person-centered outcomes can optimize ability rather than merely stave off decline. In addition to careful selection of measures, thoughtful use of clear terminology is critical to effective engagement with PLWD. For example, intentional use of concrete language can help PLWD understand and engage with research more meaningfully. Nomenclature can also be chosen to reduce potential sources of stigma within and beyond the research setting (e.g., using the term “study partner” rather than “caregiver” to describe people who accompany research participants with mild cognitive impairment).

Dementia-Specific Considerations for Data Sources

Empirical data are needed to inform evidence-based efforts to increase inclusivity in dementia care research. Definitions and evaluations of assent for PLWD must also be improved to ensure that PLWD and their self-reported outcome measures are not excluded from dementia research. To appropriately include self-report data, more research is needed on the impact of fluctuating cognitive ability and insight on these reports. Additionally, the environments in which data are collected must be carefully chosen to ensure that the full scope of heterogeneity among PLWD (e.g., race/ethnicity, SES, social norms, access to care, range of experience with cognitive changes) is accurately captured. Heterogeneity can also be assessed more thoroughly if researchers place an emphasis on person-centered care approaches.

Theme Four Research Gaps and Opportunities

- 4.1 ***Test research strategies, practices, or methods to increase recruitment of heterogeneous samples in AD/ADRD research and improve representation of underserved and under-included groups to understand and reduce health disparities.*** These methods should increase understanding of the lived experience of groups that have heightened risk, more limited access to care, and greater disease burden, and are from stigmatized or otherwise culturally disadvantaged groups (see 1.3).
- 4.2 ***Develop and implement broader conceptualizations and measures of outcomes that are informed by the perspectives of PLWD and their care partners.*** Such measures should be person- and family-centered in orientation, holistic in focus, positive in nature, and able to be used pragmatically across medical and long-term services and supports settings, and should incorporate an equity lens.
- 4.3 ***Develop and test methods to address fluctuating and/or declining cognition, including loss of insight, to enhance appropriate use of self-report by PLWD.*** Attention should be devoted to understanding the implications of new methods of data collection and reporting in the context of various types of dementia.
- 4.4 ***Develop and test methods to integrate multiple sources of information to optimize outcomes measurement; address multiple reporter concordance, discordance, and***

weighting strategies. Multiple sources of information may include clinical data, information reported from PLWD, information reported by a knowledgeable informant (e.g., caregiver/care partner), and technology-derived data.

4.5 **Develop and test personalized outcomes as endpoints in intervention trials.**

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

4.6 **Develop and test methods to capture well-being and health-related quality of life across all stages of disease and symptomatology.**

Well-being and health-related quality of life includes that of PLWD and paid and unpaid care partners.

4.7 **Conduct research to determine how language about aging and cognitive disorders affects the conduct of dementia studies.**

4.8 **Undertake research to understand how nomenclature influences recruitment into research and identify best practices for disclosure of research results.**

This includes consideration of the impact of nomenclature and language on diverse groups, including those at heightened risk of dementia and those from stigmatized or otherwise culturally disadvantaged groups.

4.9 **Determine how nomenclature for AD/ABRD and caregiving contributes to stigma and develop and test strategies that can mitigate stigma about dementia and dementia caregiving.**

Stigma may be on a personal or societal level.

4.10 **Identify methods to improve the validity, value, and efficiency of studies given increased sharing of information among participants and potential participants.**

Such efforts should address impact on the methodological rigor of studies for which activated patient communities might share information that breaks the study blind, influences recruitment in a non-systematic way, or otherwise challenges traditional study design and conduct.

4.11 **Identify methods to understand, increase, and evaluate stakeholder engagement in dementia studies across the full range of potential stakeholders, research processes, and residential and care delivery settings.**

Such efforts should address engaging stakeholders from underserved and under-included groups, particularly those from stigmatized or otherwise culturally disadvantaged groups. Stakeholder engagement can include participation in research question generation and prioritization, review of funding applications, participation in the conduct of research (e.g., recruitment and retention, review of study materials), and dissemination of study results.

Theme Five: Intervention Research, Dissemination, and Implementation

Co-Chairs: Michael Monson, MPP, Social Health Bridge, and Malaz Boustani, MD, MPH, Indiana University

This theme addressed methods to improve intervention research relating to dementia care and caregiving that targets individuals, dyads, or organizations and approaches to improve the implementation and dissemination of evidence-based interventions, including strategies to motivate systems change to promote adoption and sustainability. More specifically,

presentations and discussion focused on methods to design, implement, and disseminate scalable dementia care interventions, including tools, processes, and strategies to create demand for adoption and sustainability.

Developing and Disseminating an Evidence-based Practice Model

Jürgen Unützer, MD, MPH, MA, University of Washington

The Improving Mood-Promoting Access to Collaborative Treatment (IMPACT) collaborative care management program for late-life depression model may serve as an example from another scientific domain that could inform successful implementation and dissemination of effective dementia care programs. The IMPACT model was designed to expand depression treatment by including a mental health care manager and psychiatric consultant on primary care teams. The IMPACT model standardizes evaluation and treatment protocols at participating practices, defines relevant outcome measures, and maintains a population registry. Primary care teams are supported with training to implement new protocols and are supplemented by psychiatric and mental health consultants to provide specialist expertise on an individual patient basis. Evidence supports the ability of the IMPACT model to increase treatment effectiveness while simultaneously cutting health care costs, as well as its capacity to provide strong support to practicing clinicians. The Advancing Integrated Mental Health Solutions (AIMS) center was developed to disseminate this evidence-based care model and has trained more than 5,000 clinicians and more than 3,000 consulting psychiatrists in the implementation of this intervention.

Current Challenges in Implementation Science, and Implications for Improving the Care of Persons Living with Dementia

Luci K. Leykum, MD, MBDA, MSc, FACP, SFHM, The University of Texas at Austin

Hybrid study designs reduce the time between gathering and implementing therapeutic evidence and putting it into practice. Researchers can enhance implementation science further by increasing early participation of PLWD, care partners, and clinicians in ways that more closely align care provider and recipient goals. Participatory approaches to research *begin* with the experiences of PLWD (rather than with pre-defined research outcomes) and define unmet needs, gaps, problems, and potential solutions based on those experiences. Implementation science must also distill the essential components of an intervention to maintain effectiveness and identify how the intervention is impacted by varied environmental and individual contexts.

Learning Health Systems

Elizabeth A. McGlynn, PhD, Kaiser Permanente School of Medicine

A learning health system is a system in which “science, informatics, incentives, and culture are aligned for continuous improvement and innovation.” As new data emerge, these systems reveal research opportunities, the results of which are implemented as updated best practices at points of interaction with care recipients. These best practices are monitored, ultimately generating more data to perpetuate the cycle of research, implementation, and improvement.

Learning health systems often leverage patient registries and can generate various types of data (e.g., randomized controlled trials, pragmatic clinical trials); these systems therefore provide an opportunity to systematically examine the best methods for augmenting currently existing dementia care data (e.g., through standardization or identification of desirable but lacking data).

Panelist Remarks

Panelist: Lisa Onken, PhD, National Institute on Aging

Dr. Onken noted several common threads among the theme five research presentations. Replicating interventions with fidelity and reliability can be problematic because interventions are often complex and difficult to learn. Delivering interventions with fidelity is difficult when training is necessary, but training procedures are not available for use in the community and are not tested to ensure that interventions can be delivered correctly and that fidelity can be sustained. Ways to address some of these issues include determining the principles and essential ingredients of an intervention so that fidelity to principles can be measured, planning intervention development studies with implementation in mind at the outset, and developing and testing scalable training procedures.

Moderated Discussion Highlights

Keys to Successful Implementation

Identifying and understanding the essential elements of an intervention's success and the principles governing the efficacy of an intervention are crucial for achieving sustainability, replication, fidelity of implementation, and reliability of an intervention in varied contexts. For interventions that require training, it is important that training procedures are scalable for use by the people delivering the intervention in the community, and that these training procedures have been tested to ensure the intervention can be delivered correctly.

Data Infrastructure for Learning Health Systems

Learning health systems leverage data that are not traditionally collected in electronic health records (EHRs), such as priorities and preferences; these data often arise at the point of care, which requires infrastructure investments to accurately capture the information. Smaller health systems with limited resources need comprehensive data infrastructure solutions that are easy to implement and allow for the participation of care recipients and providers who may reside in distant locations. These smaller health systems could mitigate the costs of data infrastructure investments through collaborative efforts.

Theme Five Research Gaps and Opportunities

- 5.1 ***Identify strategies to shorten the timeline of translating innovative AD/ADRD care services for widespread use.*** Research should assess contextual and structural features of the environment and organizations that catalyze interaction, collaboration, and coordination of interdisciplinary teams and organizations.
- 5.2 ***Identify strategies that create market demand for the rapid implementation and diffusion of evidence-based AD/ADRD care models within various payment models.***

Market demand encompasses both individuals and families as well as public and private payers.

- 5.3 **Conduct innovative research using designs that increase the generalizability of research findings and promote the translation of effective dementia programs and services to real-world settings.** Diverse methodologies should be encouraged, including pragmatic trials, adaptive trials, quasi-experimental designs, hybrid designs, mixed methods, rapid-cycle iterative design, and agile process measurement. Person-centered outcomes research models with stakeholder engagement and practice-based research models should be considered to facilitate this translation.
- 5.4 **Develop and evaluate approaches to incorporate AD/ADRD-focused intervention strategies into the current and future workflow of busy primary care settings.** Such strategies may refer to tools such as screening and assessment instruments or care processes such as counseling or advance care planning.
- 5.5 **Conduct research to understand the effects of strategies to financially compensate community-based organizations that have essential roles in the care of PLWD.**
- 5.6 **Conduct research to evaluate how principles of design, implementation, and diffusion that integrate science and engineering can promote dissemination of care innovations for PLWD.** Such research should draw on the science of improvement and process evaluation techniques such as agile methodology and Plan-Do-Study-Act cycles.
- 5.7 **Develop and evaluate tools, processes, and strategies to reduce health disparities in AD/ADRD care by disseminating evidence-based models.** Such research should address disparities by geography (e.g., urban vs. rural), providers (e.g., federally qualified health centers and those disproportionately serving stigmatized and lower socio-economic status groups), and underserved populations.
- 5.8 **Develop scalable, sustainable, and actionable AD/ADRD interventions that payers and providers can use “off the shelf” in practice.** Such efforts should provide evidence on quality, safety, and financial return on investment, and guidelines on how to implement the intervention, including key contextual factors.

Theme Six: Research Resources, Methods, and Data Infrastructure

Co-Chairs: Joanne Pike, DrPH, Alzheimer’s Association, and Vincent Mor, PhD, Brown University

This theme focused on methods, data, and processes to facilitate cross-cutting, high-impact research, such as approaches to intervention research (including pragmatic trials) and observational studies to enable monitoring of progress toward achieving research implementation milestones. Issues included survey infrastructure, ethical frameworks, costs, and access to data from EHRs.

Identification of People Living with Dementia for Population and Health Care Research

Julie P. W. Bynum, MD, MPH, University of Michigan

Strategies for identifying PLWD to participate in studies depend on “fitness for use” (i.e., the alignment of the strategy with a study’s unique purposes and needs). In dementia care

research, this alignment includes assessing level of disease identification and the tradeoffs required to achieve diagnostic specificity (e.g., cost, ethical implications, recruitment barriers). As diagnostic criteria become more nuanced, evaluations of fitness for use may become more refined and thus represent an opportunity to improve dementia care research. However, when PLWD participants are identified, consistency in diagnostic nomenclature is critical for accurate interpretation and harmonization of data. In addition, studies may need to look beyond healthcare data (e.g., EHRs) to identify PLWD who do not engage with clinical settings.

Opportunities for Embedded, Pragmatic Clinical Trials Among People Living with Dementia and Their Caregivers

Thomas G. Trivison, PhD, Harvard Medical School

Embedded pragmatic trials are inclusive and PLWD-centered by design, because of their positioning directly within healthcare systems and their focus on care delivery methods and outcomes that are practical and meaningful to PLWD and care partners. However, these trials present challenges inherent in the complexity of a real-world environment, which often requires sacrificing the control of a conventional trial design as well as achieving high levels of participation to generate meaningful results. Opportunities to mitigate these challenges include leveraging contemporary study designs that facilitate group comparisons (e.g., stepped wedge), investing in data infrastructure, and emphasizing interdisciplinary engagement among researchers and clinical practitioners to promote successful implementation.

Consent for Research Involving Dementia: Some Ethical Considerations

David Wendler, PhD, NIH Clinical Center

Improvements are needed in the process of formally assessing decision-making capacity of individuals considered “at-risk” of declining cognition and PLWD. The “at-risk” designation, which conflates cognitive capacity with capacity to provide informed consent, may stigmatize designated people, and may not capture the range of individuals whose informed consent needs protection. Instead, a task-specific assessment of an individual’s ability to consent, commensurate with a study’s risk profile, should be conducted for all potential participants. Care should also be taken to assess the influence of external factors (e.g., comfort in the test setting) on ability to consent. Early identification of a surrogate who will make decisions with the PLWD based on the PLWD’s own values mitigates the need to explicitly define a point of decisional incapacity, which can be traumatizing for PLWD. There is also a growing movement that promotes supported decision making, which would allow all individuals—without surrogates and independent of their level of cognitive capacity—to make decisions for themselves by providing necessary assistance.

Moderated Discussion Highlights

Panelists: Joe Chung, MS, Kinto Care, Craig W. Thomas, PhD, MS, Centers for Disease Control and Prevention, and Maggi C. Miller, PhD, University of South Carolina

Consent and Engagement from PLWD and Care Partners

Researchers have many opportunities to refine definitions of consent from PLWD as dementia progresses, as well as the role of proxy consent from a care partner over the course of treatment. It is also critical to design studies that can engage with PLWD throughout the course of dementia including in the absence of a care partner, rather than requiring a care partner in the inclusion criteria for studies.

Data Sources and Infrastructure

Statewide Alzheimer's disease registries (e.g., South Carolina's Alzheimer's Disease Registry) can link data from individual PLWD across multiple independent data sources—including mental health services, education, law enforcement, and social services—to paint a more comprehensive picture of dementia care outcomes. Opportunities to expand on this data model include replication in other states or integration with similar systems in other states to create larger data sets. Use of claims data and EHRs across health systems, however, requires careful comparison of currently heterogeneous administrative coding practices.

Theme Six Research Gaps and Opportunities

- 6.1 ***Develop a public-private consortium to support a national data repository and technical assistance infrastructure that promotes interventions to improve the lives of PLWD and their care partners.*** The repository would include secure data from existing research, access techniques, research and analytic models, and implementation and dissemination strategies. It would be curated and updated with technical assistance available to researchers, health systems, and policymakers to optimize utilization of the repository, informed by an engaged research model.
- 6.2 ***Undertake research to test the value of machine learning and artificial intelligence approaches to identify PLWD and their care partners that may be used to efficiently measure their needs for services, and outcomes of care.*** Diverse sources for this work may include electronic health records (EHR), health insurance claims, as well as financial credit and driving records. Attention should be devoted to understanding the ethical and other related implications of such approaches across various types of dementia etiologies and subgroups of PLWD who are at risk for disparities in access to AD/ADRD care.
- 6.3 ***Conduct research on methods to engage payer and provider organizations in applied research on dementia-related care, services, and supports.***
- 6.4 ***Develop measures and approaches to monitor the adoption, dissemination, and effectiveness of dementia capable communities on outcomes that matter to PLWD, their care partners, payers, and society.***
- 6.5 ***Evaluate new and modified measures for identifying and characterizing PLWD who may benefit from dementia care interventions being tested in population-based and***

healthcare system-based studies and for monitoring progress toward identified milestones at the national, state, and community-levels.

- 6.6 **Promote research that integrates different techniques to identify cognitive impairment and disease staging for inclusion in research studies.** Such research should draw on imaging, biomarkers, cognitive testing, and functional assessment and assess the effectiveness for persons with various types of dementia etiologies. Disease includes common and specific rare forms of AD/ADRD.
- 6.7 **Develop infrastructure for public health efforts and population-based studies of PLWD and care partners to monitor progress toward meeting national, state, and community milestones, including key subpopulations of interest.** Needed infrastructure includes measures, surveys, and reporting systems and should prioritize capacity to report progress toward reducing health disparities.
- 6.8 **Develop and test new approaches to engaging persons with cognitive impairments in research who may not have the capacity to provide consent using traditional standards.** Conduct research on the use of assent and dissent, with special consideration for understanding capacity, beneficence, and access to research both for individuals with dementia and their care partners.
- 6.9 **Conduct research to guide Institutional Review Boards and ethics committees on how to facilitate the appropriate collection of self-report data from PLWD and their care partners.**
- 6.10 **Develop secure and ethical approaches to data collection through home monitoring.**

Emerging Topics

Emotional Functioning in Persons with Dementia and Their Care Partners

Joan K. Monin, PhD, Yale University

Models of stress in dementia caregiving often focus on how stressors affect the psychological and physical health of the care partner. However, the *emotional* experience of PLWD and care partners is overlooked, due in part to the lack of scientific consensus on the definition of emotion and related challenges in measuring it. Much of the existing literature on emotions in dementia care centers on negative emotions (e.g., suffering, guilt) and their role in exacerbating dementia; examination of the protective impact of positive emotion is a more recent research endeavor. As emotion research in dementia care progresses, individual differences (e.g., dementia type, gender identity, race, and ethnicity) must be considered, as they can influence the experience of emotion as well.

Technological Reserve in Persons with Dementia

Jared F. Benge, PhD, ABPP-CN, Baylor Scott & White Health

Technological reserve is the process of leveraging technology to build an environment that buffers the impact of cognitive change on real world functioning in PLWD. Technologies that assist with functions that would otherwise be undermined by cognitive decline (e.g., GPS for navigation, smartphone apps for reminders, augmentative communication devices) could be

considered a form of “cognitive prosthetic.” Implementation of these technologies can increase the independence of PLWD safely and facilitate social connection. Technological reserve can also expand community-based dementia care models by monitoring treatment adherence, facilitating communication between PLWD and care partners, and increasing access to specialists for PLWD in underserved or remote areas. Despite the promise of technological reserve, high-quality research trials that address the pragmatic challenges and risks of these technologies are lacking and needed to support development and implementation.

Identification at Preclinical Stages of Dementia

Christine K. Cassel, MD, University of California, San Francisco

Early diagnosis of pre-clinical dementia is now possible; however, research on the *value* of pre-clinical diagnosis for treatment decisions and outcomes is lacking. Likewise, more work must be done to understand the factors that impact individuals’ interest in pre-clinical diagnosis for themselves or family members, including the contributions of stigma to delayed diagnosis-seeking or the influence of inadequate treatment options on the motivation to pursue a pre-clinical diagnosis. Additionally, the possibility of preclinical diagnosis raises many bioethical questions regarding advance care planning, disclosure of information, and access to diagnosis, which must be subjects of research themselves.

Moderated Discussion Highlights

Panelists: Venoreen Browne-Boatswain and Michael R. Belleville

Interaction of PLWD and Emerging Interventions

PLWD offer valuable voices in the assessment of dementia care options, both in terms of prioritizing preferred interventions and assessing the practicality of proposed interventions. As new care interventions and technologies emerge, relative risks must be communicated to PLWD even when those risks are only beginning to become clear to researchers themselves. Furthermore, as new or less expensive diagnostic tools become available (e.g., genetic testing, biomarkers, neuroimaging), care providers must be trained in how to communicate uncertainty, as these tests currently assess probabilistic risk.

Relation of Population Disparities and Emerging Interventions

Cultural sensitivity can mediate and modulate the impact of dementia care strategies and thus their effectiveness across populations; for example, the beneficial effects of music for PLWD may be achieved only if the music is culturally relevant to the individual. Underrepresented groups should therefore be involved in the research process as early as possible to establish trust with the medical and research communities, define interventions precisely, and maximize the likelihood of successful outcomes. Opportunities also exist to evaluate how variability of emotional processing and resilience across groups—as well as measurements of emotions themselves, and particularly positive emotions—impact clinical outcomes.

Conclusion

Following the 2020 Summit virtual sessions, the Steering Committee met to revise, refine, and add to the list of draft research gaps and opportunities based upon the presentations, Q&A, and moderated discussions described in this summary, as well as the feedback received in the Request for Information (RFI) ([NOT-AG-20-035](#)). The final set of research gaps and opportunities (Appendix 1) will be presented to NIA's National Advisory Council on Aging and the NAPA Advisory Council in early 2021.

The research gaps and opportunities do not represent consensus advice. The 2020 Summit research gaps and opportunities synthesize 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 2020 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 2017 Summit, support the continued development of person-centered dementia care and research, and contribute to meaningful outcomes for PLWD and their care partners.

Appendix 1: 2020 Summit Research Gaps and Opportunities

Theme One: Impact of Dementia

This theme includes issues related to heterogeneity and trends in the lived experience of dementia, including the clinical impact and trajectory for persons living with dementia (PLWD) and their care partners across the range of etiologies; the economic impact of dementia for patients, care partners, payers, public programs, and society; and the effects of dementia, including the impact of health disparities on diverse populations – for example, by sex and gender, socioeconomic status, geography, race and ethnicity, language, education, living arrangements, including people living alone or without caregivers.

- 1.1. ***Conduct research to describe the nature, trajectory, and impacts of common and rare forms of AD/ADRD, or AD/ADRD with complex co-occurring conditions, on individuals, families, and society.*** Impacts should include particular attention to the needs, preferences, and strengths of individuals with and without care partners. Complex co-occurring conditions refers to both medical conditions (e.g. diabetes, hypertension), as well as other conditions that affect daily function and interaction (e.g., sensory impairments, urinary incontinence).
- 1.2. ***Conduct research to assess the extent to which differences in the nature, trajectory, and impact of AD/ADRD are mediated by heterogeneity among individuals and families.*** Heterogeneity includes disease etiology, age of onset, disease severity, presence of complex co-occurring conditions (see 1.1), familial relationship (e.g. spouse/partner, adult child, sibling, in-law), race and ethnicity, socioeconomic status, health disparities, gender identity, sexual orientation, and geography.
- 1.3. ***Conduct research on the positive and negative effects of pre-clinical diagnoses on persons receiving this diagnosis and their care partners as well as on health systems, utilization, and costs of care.*** Positive effects include opportunities to self-advocate, participate in research, and engage in quality of life decision-making and advance care planning. Negative effects include labeling and stigma, emotional stress, and legal and financial repercussions.
- 1.4. ***Conduct research to examine the impact of explicit and implicit bias and stigma against PLWD and their care partners on their wellbeing.*** Impact includes understanding the lived experience of membership in more than one stigmatized group, (i.e., the intersectionality of gender, race, socioeconomic status, rurality, and immigration status) that may heighten vulnerabilities and health disparities and decrease personal and family capabilities of PLWD with and without care partners.
- 1.5. ***Conduct research to better describe how social determinants of health and attributes of the neighborhood and community in which individuals live as well as national-level cultural and political factors affect the well-being of both PLWD with and without care partners and on care partners.*** Social determinants include education, social and economic resources, health disparities, housing and transportation, healthcare and aging services infrastructure, disability policy, immigration policy.

- 1.6. **Conduct research to determine how risks to well-being differ among care partners based on caregiving circumstances, and how such differences are mediated by individual, family, and disease characteristics.** Dimensions of well-being include social isolation, marital breakdown, loneliness, financial, legal, psychological vulnerabilities, injuries, and self-neglect. Caregiving circumstances include living arrangement, competing family and work responsibilities, availability and interpersonal dynamics of family and other helpers, social and economic resources, and health disparities.
- 1.7. **Conduct research to characterize and identify gaps in the care settings in which PLWD with and without care partners receive personal care services, medical, psychiatric, substance use, and recreational services as well as issues related to aging in place.** Settings include community-based, residential care, nursing facilities, senior housing, among other settings.
- 1.8. **Conduct research to describe how economic and financial burdens affect the lived experiences of persons with dementia with and without care partners and their care partners, including choices about diagnosis, treatment, supportive services use, and research participation.**
- 1.9. **Conduct research to describe the effects of AD/ADRD on financial status and financial outcomes.** Financial outcomes include spousal/family impoverishment, reduction or loss of employment opportunities, disruption of employee benefits (e.g., health insurance, accrual of social security benefits and/or private retirement), health disparities, uptake of long-term care insurance, and eligibility for long-term services and supports for PLWD with and without care partners and their families and other care partners.

Theme Two: Long-Term Services and Supports in Home, Community, and Residential Care Settings for Persons Living with Dementia and their Caregivers

This theme includes issues related to the organization, financing, and delivery of long-term services and supports (LTSS) in the home and community and in residential settings, such as assisted living and nursing homes. Issues related to LTSS workforce, services provided by community-based organizations, payment and financing, industry, and care partner needs are addressed.

- 2.1 **Use theory-driven frameworks to develop and test interventions that address the complex challenges experienced by PLWD and their care partners over the full course of the disease.** For example, approaches can be guided by theories related to socio-ecological levels and social determinants of health and heterogeneity, including such issues as cultural diversity, and be used to reduce health disparities. The full course of the disease recognizes the evolving role of care partners over the disease course, including new care partners introduced later in the disease.
- 2.2 **Assess how interventions' effects on clinical endpoints of PLWD (e.g., cognition, function, well-being) relate to other considerations, including intensity of caregiving**

- demands, care partner health, movement into residential long-term care, and costs to individuals, families, and society.*
- 2.3 ***Develop and evaluate interventions that address the social and emotional needs, including isolation, of PLWD, their care partners, and direct care workers.***
Interventions could include mindfulness-based approaches, physical activity, cognitive behavioral therapy, music, positive affect training, and technology.
- 2.4 ***Develop and evaluate training for direct care workers to identify specific competencies and modalities that best contribute to improved health, quality of life, and financial and social outcomes for PLWD, their care partners, and the direct care workers themselves.*** Training includes technology to assist training and training in use of technology.
- 2.5 ***Analyze the impact of heterogeneity among PLWD and the direct care worker and clinician workforce (paid and unpaid) and develop and test approaches that promote cultural awareness and respect, cultural competence, and communication skills.***
Heterogeneity includes racial, ethnic, and cultural identity and other factors that may affect underrepresentation in research and/or health disparities.
- 2.6 ***Determine the relative effectiveness and efficiency of interprofessional workforce models in providing high-quality care to PLWD, and how to support workforce collaboration across home, community, and residential settings.***
- 2.7 ***Analyze the interactions between care partners, direct care workers, and clinicians, in relation to technologies designed for the care of PLWD; determine how technological change will affect future workforce needs, and design and evaluate effective education and training for care partners, direct care workers, and clinicians to use new technologies effectively.***
- 2.8 ***Conduct research to improve the supportive and care-related technologies available for and used by PLWD and their care partners, especially in populations with more limited social and economic resources.*** Examples of technological advances include smart phones, monitoring devices, remote technology, and smart assistive devices.
- 2.9 ***Using measures that evaluate quality across LTSS settings in which PLWD receive care, evaluate alternative payment models, quality oversight efforts, and public reporting initiatives.***
- 2.10 ***Conduct research to examine the adequacy of payments for care received by PLWD in value-based payment efforts in the Medicaid and Medicare programs and other alternative payment models, as well as the effects on out-of-pocket expenses and on care partners.*** Medicare and Medicaid programs include Medicaid managed care plans, Medicare Advantage, and Special Needs Plans. Alternative payment models include accountable care organizations and bundled payment initiatives.
- 2.11 ***Assess whether and how eligibility and payment policies for specific benefits pose barriers to receipt of supportive, palliative, and end-of-life care services, and evaluate ways in which these policies might be reformed to better meet the needs of PLWD and***

their care partners and reduce health disparities. Specific benefits include hospice, post-acute care, and psychological services.

Theme Three: Services and Supports in Medical Care Settings for Persons Living with Dementia

This theme includes issues related to the organization, financing, and delivery of medical care across the continuum of health care settings that serve individuals at risk for and living with dementia, including office and home, urgent care, emergency department, hospital inpatient, post-acute care (including skilled nursing facility and home health care), and hospice. Issues related to the care and provider workforce, payment and financing, and industry are addressed.

- 3.1 ***Evaluate and compare comprehensive models of care and develop new models for subgroups of PLWD that are not effectively served by existing models.*** Specifically compare “stand-alone” care models that support primary care of PLWD/dyads versus those embedded in primary care programs and other mainstream models of care delivery.
- 3.2 ***Determine the core competencies, domains, and quality metrics needed to ensure that medical care for PLWD is consistent with evidence-based clinical standards.***
- 3.3 ***Develop and test the efficiency and effectiveness of strategies to provide PLWD with diagnostic and longitudinal comprehensive care, including co-existing conditions, in various settings.*** These settings include typical clinical settings such as ambulatory care network settings and small practice settings, settings serving PLWD who have limited resources, including rural and safety net settings (such as Federally-Qualified Health Centers), and residential care.
- 3.4 ***Assess the impact of promoting care planning, assessment, evaluation of preferences, and advanced care coordination across the range of disease stages, from preclinical to severe dementia, on the efficiency, effectiveness, and experience of care of PLWD and their care partners.*** Advanced care coordination includes advance care planning, end-of-life, palliative care, and hospice.
- 3.5 ***Determine the qualitative and quantitative impact of improvements in detection, diagnosis, treatment, and care management of PLWD across all treatment settings, on individuals, families, and society.***
- 3.6 ***Study the effect of access to health insurance on the receipt of person-centered care and the location of care for PLWD.***
- 3.7 ***Determine how payment affects access and quality of care received by PLWD in a variety of community and residential settings.***
- 3.8 ***Develop and test the ethical implications and cost-effectiveness of inclusion of the caregiver in the care team of the PLWD.***

Integration, Themes Two and Three: The Present and Future of Integrated Long-Term and Medical Care

These gaps and opportunities address the integration of Themes 2 and 3, including innovations in the organization, financing, and delivery to support integration of medical care and long-term services and supports (LTSS) across the range of settings in which PLWD and their care partners live and receive care.

- Int.1 ***In the context of integrated long-term services and supports (LTSS) and medical care for PLWD, determine what services are appropriate for integration versus coordination, in what manner, for whom, toward what ends, and with what payer arrangements.*** Integrated care may include co-location or care provided within a single delivery system or source of funding of services or supports, whereas coordination refers to deliberate organization of services through exchange of information by care providers responsible for varied aspects of care. Research should examine the broad spectrum of PLWD, from diagnosis and early intervention through mid-stage to end-of-life.
- Int.2 ***Develop, evaluate, and optimize approaches to quality measurement in the context of value-based care initiatives, so as to encourage and support optimal integrated and coordinated care delivery models and approaches for PLWD.*** Approaches include health information technology.
- Int.3 ***Develop and evaluate evidence-based strategies for the optimal integration and coordination of AD/ADRD care services across healthcare delivery and community-based organizations, including examining whether models of integrated LTSS and medical care are best designed as carve out (separate) models or as add-in models that are coordinated within the broader system.*** Evidence-based strategies include tools and assessments, models of care, and technologies that focus on the range of rural and urban settings. Integrated care includes both Medicaid supported and other populations and financing models, such as Medicare Advantage and Alternative Payment Models.
- Int.4 ***Conduct research to develop, implement, and evaluate public health emergency preparedness and disaster responsiveness systems that meet the social, emotional, and medical needs of PLWD and their care partners.*** Needs include ensuring personal emergency response equipment and immediate emergency response; safe evacuation and transportation; basic food, lodging, medical, and support services; and long-term management and monitoring. In addition, ensuring that medical facilities, including emergency departments, hospitals, and nursing homes are capable of providing comprehensive care for PLWD that accounts for their range of needs. Such research should address potential disparities of PLWD with limited social and economic resources.
- Int.5 ***Conduct research to develop and evaluate tools, strategies, and models that more effectively train, support, and involve care partners in the care of PLWD.*** Such research

should consider efforts to better prepare the workforce to address the needs of care partners of persons affected by various types of dementia etiologies and from subgroups at heightened risk for health disparities (e.g., by educational attainment, health literacy, or with less access to care).

Int.6 ***Conduct research to develop and study mechanisms to support the involvement of care partners when they play essential roles implementing the care plan of the PLWD.*** Such research may encompass a wide range of compensation to care partners as well as the organizations that pay for the care of PLWD, such as traditional Medicare, Medicare Advantage, Medicaid, and other private payers.

Theme Four: Participation of Persons with Dementia and their Caregivers in Research

This theme addresses participation in research and considers PLWD and their family caregivers as research participants and as engaged research partners. Topics include the impact of activated patient communities on study design and outcomes, nomenclature, and strategies for recruitment and retention; optimizing collection of information from a range of sources including PLWD and other informants, technology-based sources, and meta-data; considerations for returning genetic and biomarker information and other study data to participants; and talking about research and research results with PLWD and their care partners.

- 4.1 ***Test research strategies, practices, or methods to increase recruitment of heterogeneous samples in AD/ABRD research and improve representation of underserved and under-included groups to understand and reduce health disparities.*** These methods should increase understanding of the lived experience of groups that have heightened risk, more limited access to care, and greater disease burden, and are from stigmatized or otherwise culturally disadvantaged groups (see 1.3).
- 4.2 ***Develop and implement broader conceptualizations and measures of outcomes that are informed by the perspectives of PLWD and their care partners.*** Such measures should be person- and family-centered in orientation, holistic in focus, positive in nature, and able to be used pragmatically across medical and long-term services and supports settings, and should incorporate an equity lens.
- 4.3 ***Develop and test methods to address fluctuating and/or declining cognition, including loss of insight, to enhance appropriate use of self-report by PLWD.*** Attention should be devoted to understanding the implications of new methods of data collection and reporting in the context of various types of dementia.
- 4.4 ***Develop and test methods to integrate multiple sources of information to optimize outcomes measurement; address multiple reporter concordance, discordance, and weighting strategies.*** Multiple sources of information may include clinical data, information reported from PLWD, information reported by a knowledgeable informant (e.g., caregiver/care partner), and technology-derived data.

- 4.5 ***Develop and test personalized outcomes as endpoints in intervention trials.***
Personalized outcomes refer to measures that reflect individual preferences and/or goals that can be used to tailor and individualize services and supports.
- 4.6 ***Develop and test methods to capture well-being and health-related quality of life across all stages of disease and symptomatology.*** Well-being and health-related quality of life includes that of PLWD and paid and unpaid care partners.
- 4.7 ***Conduct research to determine how language about aging and cognitive disorders affects the conduct of dementia studies.***
- 4.8 ***Undertake research to understand how nomenclature influences recruitment into research and identify best practices for disclosure of research results.*** This includes consideration of the impact of nomenclature and language on diverse groups, including those at heightened risk of dementia and those from stigmatized or otherwise culturally disadvantaged groups.
- 4.9 ***Determine how nomenclature for AD/ADRD and caregiving contributes to stigma and develop and test strategies that can mitigate stigma about dementia and dementia caregiving.*** Stigma may be on a personal or societal level.
- 4.10 ***Identify methods to improve the validity, value, and efficiency of studies given increased sharing of information among participants and potential participants.*** Such efforts should address impact on the methodological rigor of studies for which activated patient communities might share information that breaks the study blind, influences recruitment in a non-systematic way, or otherwise challenges traditional study design and conduct.
- 4.11 ***Identify methods to understand, increase, and evaluate stakeholder engagement in dementia studies across the full range of potential stakeholders, research processes, and residential and care delivery settings.*** Such efforts should address engaging stakeholders from underserved and under-included groups, particularly those from stigmatized or otherwise culturally disadvantaged groups. Stakeholder engagement can include participation in research question generation and prioritization, review of funding applications, participation in the conduct of research (e.g., recruitment and retention, review of study materials), and dissemination of study results.

Theme Five: Intervention Research, Dissemination, and Implementation

This theme addresses methods to improve the methodological rigor of implementation science in AD/ADRD interventional research and facilitate the spread of evidence-based interventions relating to dementia care and caregiving that targets individuals, dyads, or organizations, including strategies to motivate systems change to promote adoption and sustainability.

- 5.1 ***Identify strategies to shorten the timeline of translating innovative AD/ADRD care services for widespread use.*** Research should assess contextual and structural features of the environment and organizations that catalyze interaction, collaboration, and coordination of interdisciplinary teams and organizations.

- 5.2 **Identify strategies that create market demand for the rapid implementation and diffusion of evidence-based AD/ADRD care models within various payment models.** Market demand encompasses both individuals and families as well as public and private payers.
- 5.3 **Conduct innovative research using designs that increase the generalizability of research findings and promote the translation of effective dementia programs and services to real-world settings.** Diverse methodologies should be encouraged, including pragmatic trials, adaptive trials, quasi-experimental designs, hybrid designs, mixed methods, rapid-cycle iterative design, and agile process measurement. Person-centered outcomes research models with stakeholder engagement and practice-based research models should be considered to facilitate this translation.
- 5.4 **Develop and evaluate approaches to incorporate AD/ADRD-focused intervention strategies into the current and future workflow of busy primary care settings.** Such strategies may refer to tools such as screening and assessment instruments or care processes such as counseling or advance care planning.
- 5.5 **Conduct research to understand the effects of strategies to financially compensate community-based organizations that have essential roles in the care of PLWD.**
- 5.6 **Conduct research to evaluate how principles of design, implementation, and diffusion that integrate science and engineering can promote dissemination of care innovations for PLWD.** Such research should draw on the science of improvement and process evaluation techniques such as agile methodology and Plan-Do-Study-Act cycles.
- 5.7 **Develop and evaluate tools, processes, and strategies to reduce health disparities in AD/ADRD care by disseminating evidence-based models.** Such research should address disparities by geography (e.g., urban vs. rural), providers (e.g., federally qualified health centers and those disproportionately serving stigmatized and lower socio-economic status groups), and underserved populations.
- 5.8 **Develop scalable, sustainable, and actionable AD/ADRD interventions that payers and providers can use “off the shelf” in practice.** Such efforts should provide evidence on quality, safety, and financial return on investment, and guidelines on how to implement the intervention, including key contextual factors.

Theme Six: Research Resources, Methods, and Data Infrastructure

This theme includes a focus on methods, data, and processes to facilitate cross-cutting, high-impact research including approaches to intervention research (including pragmatic trials) and observational studies to enable monitoring of progress toward achieving research implementation milestones. Issues include survey infrastructure, ethical frameworks, costs, access to data from electronic health records.

- 6.1 **Develop a public-private consortium to support a national data repository and technical assistance infrastructure that promotes interventions to improve the lives of PLWD and their care partners.** The repository would include secure data from existing

- research, access techniques, research and analytic models, and implementation and dissemination strategies. It would be curated and updated with technical assistance available to researchers, health systems, and policymakers to optimize utilization of the repository, informed by an engaged research model.
- 6.2 ***Undertake research to test the value of machine learning and artificial intelligence approaches to identify PLWD and their care partners that may be used to efficiently measure their needs for services, and outcomes of care.*** Diverse sources for this work may include electronic health records (EHR), health insurance claims, as well as financial credit and driving records. Attention should be devoted to understanding the ethical and other related implications of such approaches across various types of dementia etiologies and subgroups of PLWD who are at risk for disparities in access to AD/ADRD care.
 - 6.3 ***Conduct research on methods to engage payer and provider organizations in applied research on dementia-related care, services, and supports.***
 - 6.4 ***Develop measures and approaches to monitor the adoption, dissemination, and effectiveness of dementia capable communities on outcomes that matter to PLWD, their care partners, payers, and society.***
 - 6.5 ***Evaluate new and modified measures for identifying and characterizing PLWD who may benefit from dementia care interventions being tested in population-based and healthcare system-based studies and for monitoring progress toward identified milestones at the national, state, and community-levels.***
 - 6.6 ***Promote research that integrates different techniques to identify cognitive impairment and disease staging for inclusion in research studies.*** Such research should draw on imaging, biomarkers, cognitive testing, and functional assessment and assess the effectiveness for persons with various types of dementia etiologies. Disease includes common and specific rare forms of AD/ADRD.
 - 6.7 ***Develop infrastructure for public health efforts and population-based studies of PLWD and care partners to monitor progress toward meeting national, state, and community milestones, including key subpopulations of interest.*** Needed infrastructure includes measures, surveys, and reporting systems and should prioritize capacity to report progress toward reducing health disparities.
 - 6.8 ***Develop and test new approaches to engaging persons with cognitive impairments in research who may not have the capacity to provide consent using traditional standards.*** Conduct research on the use of assent and dissent, with special consideration for understanding capacity, beneficence, and access to research both for individuals with dementia and their care partners.
 - 6.9 ***Conduct research to guide Institutional Review Boards and ethics committees on how to facilitate the appropriate collection of self-report data from PLWD and their care partners.***
 - 6.10 ***Develop secure and ethical approaches to data collection through home monitoring.***

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 with and can be difficult to distinguish from AD. In fact, more often than not, patients with a diagnosis of Alzheimer’s disease 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. 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.

Persons living with dementia (including AD/ADRD) (PLWD) refers to all those who are currently living with a diagnosis of AD/ADRD and those with cognitive impairment consistent with dementia who have not yet received a diagnosis, including those with intellectual disabilities.

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.¹⁰ 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, palliative care, and 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, these are family relationships. 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 persons living with dementia. 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 refers to paid caregivers who provide hands-on long-term care and personal assistance to persons who are living with disabilities, including nursing assistants and nursing aides who generally work in nursing homes, home health aides who assist people in

¹⁰ Source: <https://www.ahrq.gov/ncepcr/care/coordination/atlas/chapter2.html>

their homes or in community settings (including people who may be receiving skilled home health care), and personal care aides who work in private or group homes.

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.

Heterogeneity refers to variability in the trajectory, experience, and consequences of AD/ADRD based on disease type, age of onset, disease severity, presence of complex co-occurring conditions, familial relationship (e.g., spouse/partner, adult child, sibling, in-law), race and ethnicity, socioeconomic status, health disparities, gender identity, sexual orientation, and geography.

Long-term services and supports (LTSS) encompass the broad range of paid and unpaid medical and personal care assistance that people may need to accommodate a short- or long-term disability. LTSS may be provided in nursing and other residential care facilities, in senior housing, or in the broad range of community settings, including individuals' homes.

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 Alzheimer's disease (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 global, national, and local levels.

Appendix 3: Summit Agendas

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

Summit Series Virtual Meeting 1

Friday, July 10, 2020

1:30 to 4:30 p.m. Eastern Time

1:30 Welcome and Summit Series Purpose

Speakers: Jennifer Wolff and David Reuben

1:40 Setting the Stage – Perspectives

Speakers: Richard Hodes, Lonni Schicker, Katie Brandt, and Arne Owens

2:00 Progress Since 2017 Summit

Speaker: Laura Gitlin

Impact of Dementia (Theme 1)

2:10 Introduction: María Aranda and Ian Kremer

2:15 Research Presentation 1: Population trends of Alzheimer's disease and related dementias

Speaker: Rachel Whitmer

2:25 Research Presentation 2: Disparities in health, services, and interventions for PWD and family caregivers: Evidence and future directions

Speaker: Ladson Hinton

2:35 Research Presentation 3: Economic impact of Alzheimer's disease and value of delaying onset for individuals, caregivers, and society

Speaker: Julie Zissimopoulos

2:45 Theme Co-Chairs Present Gaps and Opportunities

2:50 Panelist Perspectives on Gaps and Opportunities

- Laura Trejo
- Cynthia Huling Hummel

3:00 Moderated Q&A and Discussion

3:15 BREAK

Participation of Persons with Dementia and their Caregivers in Research (Theme 4)

3:25 Introduction: Lori Frank and Jason Karlawish

3:30 Research Presentation 1: Reporters, data sources, and outcomes
Speaker: Lee Jennings

3:40 Research Presentation 2: Nomenclature: Challenges, issues, and a plan
Speaker: Ron Petersen

3:50 Research Presentation 3: PLWD and caregiver research engagement
Speaker: Tabassum Majid

3:55 Theme Co-Chairs Present Gaps and Opportunities

4:00 Panelist Perspectives on Gaps and Opportunities

- Andrea Gilmore-Bykovskyi
- Lonni Schicker

4:10 Moderated Q&A and Discussion

4:25 Closing Remarks
Speakers: Jennifer Wolff and David Reuben

4:30 Adjourn

Summit Series Virtual Meeting 2**Tuesday, July 21, 2020****1 to 4:30 p.m. Eastern Time**

1:00 Welcome and Opening Remarks
Speakers: Jennifer Wolff and David Reuben

Services and Supports in Medical Care Settings for Persons Living with Dementia (Theme 3)

1:05 Introduction: Susan Beane and Chris Callahan

1:10 Research Presentation 1: Providing high-quality care in medical care settings
Speaker: Josh Chodosh

1:20 Research Presentation 2: Care of persons living with dementia and with multiple chronic conditions
Speaker: Cynthia Boyd

1:30 Research Presentation 3: Financing the care of persons living with dementia
Speaker: Norma Coe

1:40 Theme Co-Chairs Present Gaps and Opportunities

1:45 Panelist Perspectives on Gaps and Opportunities

- Shari Ling
- George Hennawi

2:00 Moderated Q&A and Discussion

2:15 BREAK

Long-Term Services and Supports in Home, Community, and Residential Care Settings for Persons Living with Dementia and their Caregivers (Theme 2)

2:25 Introduction: Sheryl Zimmerman and Robyn Stone

2:30 Research Presentation 1: Evidence-based person-centered practices for PLWD and their caregivers: What do we know, where to next?

Speaker: Kimberly Van Haitsma

2:40 Research Presentation 2: Understanding the long-term care workforce in a new way

Speaker: Joanne Spetz

2:50 Research Presentation 3: Organization and financing of long-term supports and services for persons living with dementia

Speaker: David Stevenson

3:00 Theme Co-Chairs Present Gaps and Opportunities:

3:05 Panelist Perspectives on Gaps and Opportunities

- Alice Bonner
- Laurie Scherrer

3:15 Moderated Q&A and Discussion

3:30 BREAK

Integration: The Present and Future of Integrated Long-Term and Medical Care

3:40 Introduction: Robyn Stone and Chris Callahan

3:45 Research Presentation 1: Building the Case for Integrating LTSS and Medical Care and their Financing for Persons Living with Dementia and their Families

Speaker: Kerry Branick

3:55 Research Presentation 2: Signals on Successful Approaches to Integrating LTSS and Medical Care for Persons Living with Dementia

Speaker: Bruce Leff

4:05 Theme Co-Chairs Present Gaps and Opportunities

4:10 Moderated Q&A and Discussion

4:25 Closing Remarks

Speakers: Jennifer Wolff and David Reuben

4:30 Adjourn

Summit Series Virtual Meeting 3

Thursday, August 13, 2020

1:30 to 4:45 p.m. Eastern Time

1:30 Welcome and Opening Remarks

Speakers: Jennifer Wolff and David Reuben

Emerging Topics

1:35 Presentation 1: Emotional functioning in persons living with dementia and their care partners

Speaker: Joan Monin

1:45 Presentation 2: Technological reserve in persons with dementia: The promises and pitfalls of smart systems for health, well-being, and independence

Speaker: Jared Bengte

1:55 Presentation 3: Implications of identification at preclinical stages of dementia

Speaker: Christine Cassel

2:05 Panelist Perspectives on Gaps and Opportunities

- Venoreen Browne-Boatswain
- Michael R. Belleville

2:15 Moderated Q&A and Discussion

2:30 BREAK

Intervention Research, Implementation, and Dissemination (Theme 5)

2:45 Introduction: Malaz Boustani and Michael Monson

2:50 Research Presentation 1: Developing and disseminating evidence-based care models
Speaker: Jürgen Unützer

3:00 Research Presentation 2: Current challenges in implementation science, and implications for improving the care of persons living with dementia
Speaker: Luci Leykum

3:10 Research Presentation 3: Learning health systems
Speaker: Elizabeth McGlynn

3:20 Theme Co-Chairs Present Gaps and Opportunities

3:25 Discussant: Lisa Onken

3:30 Moderated Q&A and Discussion

BREAK

Research Resources, Methods, and Data Infrastructure (Theme 6)

3:40 Introduction: Vincent Mor and Joanne Pike

3:45 Research Presentation 1: Identification of people living with dementia for population and health care research
Speaker: Julie Bynum

3:50 Research Presentation 2: System level research: Pragmatic clinical trials in dementia
Speaker: Thomas Trivison

4:00 Research Presentation 3: Consent for research involving persons with dementia: Ethical considerations
Speaker: David Wendler

4:10 Theme Co-Chairs Present Gaps and Opportunities

4:15 Panelist Perspectives on Gaps and Opportunities

- Joe Chung
- Maggi Miller
- Craig Thomas

4:25 Moderated Q&A and Discussion

4:40 Closing Remarks

Speakers: David Reuben and Jennifer Wolff

4:45 Adjourn

Appendix 4: List of Speakers

Summit Steering Committee

Co-Chairs

- Jennifer Wolff, Johns Hopkins University
- David Reuben, University of California, Los Angeles

Committee Members

- María Aranda, University of Southern California
- Susan Beane, Healthfirst
- Malaz Boustani, Indiana University School of Medicine
- Katie Brandt, Massachusetts General Hospital, NAPA Advisory Council Co-Chair, and Care Partner
- Chris Callahan, Indiana University School of Medicine
- Elena Fazio, National Institute on Aging
- Lori Frank, RAND Corporation
- Jason Karlawish, University of Pennsylvania
- Ian Kremer, LEAD Coalition
- Helen Lamont, Office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services, NAPA Advisory Council Federal Project Officer
- Katie Maslow, Gerontological Society of America
- Michael Monson, Centene Corporation
- Vincent Mor, Brown University
- Joanne Pike, Alzheimer's Association
- Lonni Schicker, Minnesota State University (Retired), Person Living with Dementia
- Robyn Stone, LeadingAge
- Sheryl Zimmerman, University of North Carolina

Research Presenters, Panelists, and Other Speakers

- Michael R. Belleville, Person Living with Dementia
- Jared F. Benge, Baylor Scott & White Health
- Alice Bonner, Brown University
- Cynthia Boyd, Johns Hopkins University
- Kerry Branick, Centers for Medicare & Medicaid Services
- Venoreen Browne-Boatswain, Care Partner
- Julie P.W. Bynum, University of Michigan
- Christine K. Cassel, University of California, San Francisco
- Joshua Chodosh, New York University

- Joe Chung, Kinto Care
- Norma Coe, University of Pennsylvania
- Andrea Gilmore-Bykovskyi, University of Wisconsin-Madison
- Laura Gitlin, Drexel University
- George Hennawi, MedStar Good Samaritan Hospital
- Ladson Hinton, University of California, Davis
- Richard Hodes, National Institute on Aging
- Cynthia Huling Hummel, Person Living with Dementia
- Lee Jennings, University of Oklahoma Health Sciences Center
- Bruce Leff, Johns Hopkins University
- Luci Leykum, The University of Texas at Austin
- Shari Ling, Centers for Medicare & Medicaid Services
- Tabassum Majid, University of Maryland, Baltimore County
- Elizabeth A. McGlynn, Kaiser Permanente School of Medicine
- Maggi C. Miller, University of South Carolina
- Joan K. Monin, Yale University
- Lisa Onken, National Institute on Aging
- Arne Owens, Office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services
- Ronald C. Petersen, Mayo Clinic
- Laurie Scherrer, Person Living with Dementia
- Joanne Spetz, University of California, San Francisco
- David Stevenson, Vanderbilt University
- Craig W. Thomas, Centers for Disease Control and Prevention
- Thomas G. Trivison, Harvard Medical School
- Laura Trejo, City of Los Angeles Department of Aging
- Jürgen Unützer, University of Washington
- Kimberly Van Haitsma, The Pennsylvania State University
- David Wendler, National Institutes of Health Clinical Center
- Rachel Whitmer, University of California, Davis
- Julie Zissimopoulos, University of Southern California



National Institute
on Aging



**RESEARCH SUMMIT ON
DEMENTIA CARE**
Building Evidence for Services and Supports

The logo for the Research Summit on Dementia Care features a vertical column of six small icons: a person, a brain, a gear, a house, a person with a speech bubble, and a person with a speech bubble. The text "RESEARCH SUMMIT ON" is in white, "DEMENTIA CARE" is in large orange letters, and "Building Evidence for Services and Supports" is in white below it.