



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

## **Report to the National Advisory Council on Alzheimer's Research, Care, and Services**

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Additional information can be found at the Summit website (<https://aspe.hhs.gov/national-research-summit-care-services-and-supports-persons-dementia-and-their-caregivers>) or the National Alzheimer's Project Act website (<https://aspe.hhs.gov/national-alzheimers-project-act>). The opinions and views expressed in this report are those of the authors. They do not necessarily reflect the views of HHS, the contractor or any other funding organization.

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# ABSTRACT

This report to the Advisory Council on Alzheimer's Research, Care and Services presents the results of the first National Research Summit on Care, Services, and Supports for Persons with Dementia and their Caregivers (the Summit), held on the National Institutes of Health (NIH) campus on October 16-17, 2017. The Summit complements the National Institute on Aging's (NIA) Alzheimer's Disease Research Summits and the National Institute for Neurological Disease and Stroke (NINDS) Alzheimer's Disease Related Dementias Summits, and follows the same general structure. These conferences are coordinated planning efforts that respond to the National Plan to Address Alzheimer's Disease, first released in 2012 and now updated annually. Following the example of the earlier NIA and NINDS Summits, this Summit was intended to set national research recommendations that reflect critical scientific priorities for research on care and services for persons with dementia and their families. The Steering Committee and organizers of this Summit solicited input from nationally and internationally recognized experts and researchers, and other public and private sector stakeholders, to develop prioritized recommendations. The recommendations included in this report will help guide investments by a number of public and private stakeholders in the field of care, services, and supports, and will provide the structure for future summits.

# INTRODUCTION

Persons living with dementia and their caregivers confront significant emotional, physical, and financial stress. As dementia progresses, often over many years, individuals with the condition experience physical, cognitive, and emotional changes that affect the quality of their daily life and ability to remain engaged with meaning and purpose. The lived experience of dementia, adaptive processes of individuals, and perceived and structural stigma are important aspects of the disease process. Caregivers provide the majority of care for people with dementia in the community. These individuals often do not identify themselves as such; they may be a spouse, child, parent, or friend helping a person whom they care about. However, the intensive support that is typically required for a person with dementia as the condition progresses can impact the caregiver's emotional and physical health, well-being, and ability to work. Caregivers often report symptoms of depression and anxiety, financial strain, and have poorer health outcomes than their peers who do not provide such care.

The National Alzheimer's Project Act (NAPA) creates an important opportunity to build upon and leverage HHS programs and other federal efforts to help change the trajectory of Alzheimer's disease and related dementias (AD/ADRD). The law calls for a National Plan to Address Alzheimer's Disease with input from a public-private Advisory Council on Alzheimer's Research, Care and Services. The Advisory Council is required to meet quarterly to discuss programs that affect people with AD/ADRD and their caregivers; make recommendations about ways to reduce the financial impact of AD/ADRD and to improve the health outcomes of people with these conditions; and provide feedback on the National Plan developed by the government.

The idea for the National Research Summit on Care, Services, and Supports for Persons with Dementia and their Caregivers grew out of similar summits held by NIH on clinical and biomedical research on AD/ADRD. Although previous summits included some talks on research related to care and services, members of the Advisory Council believed that the evidence in this area and further research needs warranted a dedicated summit to review and identify research

priorities. This is necessary in order to propel innovation and advancement in the area of clinical care and services, and to develop recommendations that can be used by federal agencies, non-federal organizations, and research institutes to improve their work. The specific goal of the Summit was to identify what we know and what we need to know in order to accelerate the development, evaluation, translation, implementation, and scaling up of comprehensive care, services, and supports for persons with dementia, families, and other caregivers. The Summit also focused on research needed to improve quality of care and outcomes across care settings, including quality of life and the experience of persons with dementia and their caregivers. Summit participants were asked to consider cross-cutting themes including: diversity, disparities, etiologies and disease stages, settings of care, training and workforce issues, technology, and the differential impact of dementia and caregiving on women.

## **ADVANCE PREPARATION FOR THE 2017 SUMMIT**

In order to implement a comprehensive approach to understanding research needs, preparation for the Summit involved creating an organizational structure to systematically obtain input from various stakeholders. It was very important to the Summit organizers and the Advisory Council that the greatest number of possible voices be involved in developing the agenda and guiding its work.

*Steering Committee:* The Advisory Council felt that a Steering Committee would be the most efficient way to guide the planning process, organize the many stakeholders wishing to participate, and insure that the Summit would be as comprehensive as possible. The Steering Committee was charged with developing the goals for the Summit, determining potential topics to be addressed, determining expected outcomes, reaching out to the varied stakeholders for input, and guiding and setting the final agenda. The Steering Committee was made up of two co-chairs and 17 members, representing a mix of federal agencies, non-federal members of the Advisory Council, outside experts, and advocacy organizations (see Appendix A).

*Stakeholder Groups:* In order to capture the breadth of stakeholders and viewpoints needed, and to allow them an opportunity to contribute towards the content of the Summit, the following six stakeholder groups were formed: Persons Living with Dementia; Family Caregivers; Service Providers; State Government Programs; Workforce; and Payers. Each group was tasked with providing input on session topics, identifying gaps in topic areas, identifying potential audiences for the Summit, and generating research recommendations (see Appendix B).

*Background Papers and Issue Briefs:* RTI International was tasked with writing six short background papers on important areas of focus in care and services for people living with dementia and their caregivers, which provided additional material for each of the six main Summit sessions. RTI also produced three issue briefs on topics related to caregiving research, care, and services that were not covered by the Summit agenda and could form the basis for future work (see Appendix C).

*Pre-summits:* A number of pre-planned and pre-funded scientific meetings conducted prior to the Summit, which focused on topics of relevance to the Summit, were considered pre-summit activities. These pre-summits were approved by the Steering Committee and provided foundational knowledge and specific recommendations presented at the Summit. Pre-summit activities leveraged and linked existing scientific activity relevant to the Summit, and produced

white papers, journal publications, and background materials. Final products of these efforts have been posted on the NAPA website (See Appendix D).

## ACKNOWLEDGEMENTS

Staff at NIA was essential to the planning and logistics of the Summit, with special acknowledgement of the efforts of Drs. Richard Hodes, Melinda Kelley, Elena Fazio, and Courtney Wallin. Brenda Veazey in the Office of the Assistant Secretary for Planning and Evaluation (ASPE) was essential to putting together the Summit website, and updating and disseminating all materials. The Office of Women's Health (OWH) provided a substantial donation to support discussion of issues affecting women specifically. The Centers for Medicare & Medicaid Services (CMS) provided the logo for the Summit. Additional sponsors included the Foundation for NIH, the Alzheimer's Association, Leaders Engaged on Alzheimer's Disease Coalition, UsAgainstAlzheimer's, Accelerate Cure/Treatments for Alzheimer's Disease, AARP, Association for Frontotemporal Degeneration, Avanir Pharmaceuticals, Biogen, Home Instead Senior Care, and WellMed Charitable Foundation. The Gerontological Society of America also contributed significant staff time and assisted with social media during the Summit.

## SUMMIT OVERVIEW

The first National Research Summit on Care, Services, and Supports for Persons with Dementia and their Caregivers occurred on October 16-17, 2018. The Summit was well-attended, with over 500 attendees on each day, while many more watched the live webcast online. Summit materials and videos can be found at the Summit website.<sup>1</sup> The six topic area sessions included a brief introduction by the session co-chairs, followed by a series of speakers sharing research and recommendations, and brief reports and commentaries, including comments by people living with dementia and caregivers. This was followed by moderated audience discussion to solicit public input. Further public comment was sought concurrently through Twitter and emails to the official NAPA email. The full agenda is available in Appendix E. The six main sessions are listed below:

- I. ***Research on Care Needs and Supportive Approaches for Persons with Dementia:*** This session explored research related to care and support for persons with dementia, including mitigating behavioral symptoms, understanding care in varied settings, and caring for those living alone with the condition.
- II. ***Research on Supportive Approaches for Family and Other Caregivers:*** This session focused primarily on how caring for a person with dementia affects the caregiver and what is known about effective ways to support caregivers, including examples of effective interventions, common elements of these interventions, and areas where more research is most needed.
- III. ***Involving Persons with Dementia and Caregivers as Members of the Research Team:*** This session examined important reasons for including persons with dementia

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<sup>1</sup> See <https://aspe.hhs.gov/national-research-summit-care-services-and-supports-persons-dementia-and-their-caregivers>.

and caregivers as members of the research team in studies of dementia care, services, and research, and challenges that researchers may face in doing so. These challenges included deciding which parts of the research process persons with dementia and caregivers would participate in, determining how to identify and recruit people with dementia and their caregivers to serve as co-researchers, and establishing how to effectively engage them as co-researchers.

- IV. ***Involving Persons with Dementia as Study Participants***: This session addressed key issues related to involving persons with dementia as participants in research on care and services, including evaluating their capacity to respond to particular research questions, recruiting participants, and understanding the processes of informed consent and assent/dissent to participate in research.
- V. ***Research on Models of Care for Persons Living with Dementia and Their Families Across the Disease Trajectory***: This session examined comprehensive models of dementia care, factors that may be important to successful implementation, evidence about the effectiveness of various models, and areas where further research is needed.
- VI. ***Thinking Outside the Box***: This session was intended to encourage the field to reconsider how it does research on dementia care, services, and supports, evaluate the strengths and limitations of the methods currently used in this research, and think of new ways to do research that would show clearer, faster results.

The Summit also included a number of plenary sessions, both to set the stage and context for the Summit, as well as to highlight the importance of the cross-cutting themes. The Plenary Sessions are listed below:

- I. ***Context for the Summit***: This session laid the groundwork from the perspective of the Advisory Council and provided background on status of biomedical research on AD/ADRD to date and its relationship to the Summit.
- II. ***Demographic Framework***: This session addressed the demographics of dementia and caregiving and the implications of diversity in dementia care and services.
- III. ***Nomenclature: Words Matter***: This session was intended to encourage the field to reconsider how it does research on dementia care, services, and supports, evaluate the strengths and limitations of the methods currently used in this research, and think of new ways to do research that would show clearer, faster results.

## RECOMMENDATIONS

Through the work of the Stakeholder groups, Pre-summit activities, six Summit Sessions, Cross-cutting Themes, Plenary Sessions, Public input, and the third day Writing Session, the 2017 Summit produced approximately 694 recommendations. These recommendations were then combined, consolidated, and organized into 12 major themes.

1. **Heterogeneity of Persons Living with Dementia and their Caregivers**
2. **Research Methods to Develop More Effective Dementia Care, Services and Supports**

3. **Caregiver Relationships, Roles, and Networks**
4. **Clinical Approaches and the Lived Experience of Dementia**
5. **Engaging Persons Living with Dementia and Caregivers in Research**
6. **Dementia-Related Terminology, Nomenclature, and Stigma: Words Matter**
7. **Comprehensive Models for Dementia Care, Services, and Supports**
8. **Strategies for Scaling and Disseminating Existing Evidence, Drawing Upon Implementation Science**
9. **Living Places, Physical and Social Environments, and Processes of Care for Persons with Dementia, Including Those who Live Alone**
10. **Financial Burden and Out-of-Pocket Costs to Persons Living with Dementia and their Caregivers**
11. **Ensuring an Adequate and Qualified Workforce to Support Persons with Dementia and their Caregivers**
12. **Technology to Support Persons with Dementia and their Caregivers**

Over 694 suggestions for research were categorized and synthesized into broad recommendations that are relevant to various agencies and organizations. The recommendations are not prescriptive, and they are not targeted to any particular agency or organization. The purpose of providing broad recommendations is to enable more stakeholders to use them in the context of their interests and the mission and interests of their organizations.

## **DEFINITIONS**

Throughout the report, the term “persons living with dementia,” is meant to include all those who are currently living with a diagnosis of dementia, regardless of its cause(s) or stage, and those with cognitive impairment consistent with dementia, who have not yet received a diagnosis, including those with intellectual disabilities. The term “caregivers” refers to family members, neighbors, friends, fictive kin, and anyone else providing unpaid services and supports to persons living with dementia. A clear distinction has been made when referring to any other type of caregiving, such as paid supports provided by members of the health or long-term service systems.

## **POST-SUMMIT FOLLOW-UP**

There are a number of lessons and steps to be addressed prior to the next National Research Summit on Care, Services, and Supports for Persons with Dementia and their Caregivers scheduled to occur in March 2020.

### **Lessons Learned**

The most important lesson learned from this Summit was the value of the input provided by having diverse stakeholder voices involved in generating research recommendations. Although the process of involving stakeholders can be time-consuming and complex, invaluable input from a wide range of individuals and groups critically added to the scope and breadth of the recommendations provided to advance care and services research. Inclusion of stakeholder groups represented an innovation of this Summit and serves as a model for other summits and activities designed to identify priorities for research on care, services, and supports for individuals living with dementia and their family members.

However, given the large number of stakeholders involved, the process of producing recommendations needed better management. As stated previously, the Summit produced over 694 recommendations from a vast number of sources. These needed to be distilled, categorized, clarified and made useful to the widest number of stakeholders possible. Future summits in this area will need to develop a more efficient process involving prioritization and temporalization of recommendations. This will aid in the development of milestones and the tracking of progress made over time.

### **Unaddressed Topics**

Given the limited time available in the Summit, decisions were made early in the Summit planning process to exclude several important topics. One of these topics was research on detection and diagnosis of dementia, and should be one of the sessions for the next Summit in 2020. Another was general medical care, including hospital care, and its relation to care and services. The connection between the health care system and the long-term care system did appear in some of the recommendations produced by the Summit.

Many of the research recommendations presented in this report would support the development of care, services, and supports that would be available primarily to people who have received a diagnosis of dementia, and to those who have a regular source of care and access to the health care and long-term care systems. Many other people who have dementia but have not received a diagnosis of the condition would be less likely to access the care, services and supports. Those who are unable to access services, and are therefore unable to receive appropriate care for their condition, should be an important area of focus at the next summit.

### **Post-summit Activities**

Following the Summit, there were a few planned activities and some suggested ones that are necessary to follow-up on recommendations. On December 1, 2017, researchers from the Brown University School of Public Health and the Hebrew SeniorLife Institute for Aging Research convened a workshop at the NIA to review the state of the science for pragmatic clinical trials of non-pharmacological interventions for persons with dementia and their caregivers. The goals of the workshop were to: (1) review the state of the evidence regarding the effect of interventions to improve care and outcomes for persons with dementia; (2) establish criteria for determining which interventions are ready for launch as pragmatic trials; and (3) consider the infrastructure necessary to conduct, translate, and disseminate such a program of research.

Based on the recommendations received from participants in the Summit, additional conferences or workshops are critical to pursue in the following areas:

- Care and services for early stage dementia.
- Care and services for late stage dementia and end-of-life.
- Defining technology and better understanding the different uses of technology for care of persons with dementia.
- Providing services to those who lack access to the health care and/or long-term care systems.

### **Next Steps**

Milestones must be developed for specific research recommendations that may be adopted by various agencies, organizations, and the Advisory Council. These recommendations can and



should be used to build a research framework, and set of milestones that will assist in tracking progress made on the recommendations over time. Any research projects that come from these recommendations will be presented at the 2020 summit, and every 3 years thereafter.

We present here broad categories and concise recommendations. All recommendations and details thereof are available on the website.

# **Main Recommendations from the 2017 National Research Summit on Care, Services, and Supports for Persons with Dementia and their Caregivers**

The main research recommendations from the 2017 National Research Summit on Care, Services, and Supports for Persons with Dementia and their Caregivers are listed below, organized by theme. The 58 main research recommendations from the Summit were distilled from almost 700 recommendations submitted by Summit participants by combining similar recommendations and eliminating some detail. The steering committee and organizers of this Summit solicited input from nationally and internationally recognized experts and researchers, as well as from public and private stakeholders, to develop recommendations to guide research on care and services for persons living with dementia and their caregivers. The recommendations included in this report will help guide investments by a number of public and private stakeholders, including funders, foundations, professional organizations, researchers, advocacy groups, and individuals on care and services research, and will provide the structure for future Summits. Complete research recommendations from all Summit participants are available on the Summit website, and can also be seen in Summit PowerPoints and Summit Stakeholder Group reports.<sup>2</sup>

## **Theme 1: Heterogeneity of Persons Living with Dementia and their Caregivers**

The heterogeneity of persons living with dementia and their caregivers was an important theme throughout the Summit and is relevant to every aspect of research on dementia care, services, and supports. Heterogeneity was defined broadly to include all kinds of differences among persons living with dementia and their caregivers. In addition to important differences in race and ethnicity, Summit participants identified many other characteristics that differ among these individuals and are likely to affect their experience of dementia, their needs for care and support, and the acceptability and effectiveness for them of particular programs and services (see Theme 1 table). Such differences include, for example, differences in the cause(s) of the person's dementia and its symptoms and severity, and differences among caregivers in their gender, relationship to the person living with dementia, experiences of caregiving, and caregiving-related stress.

This section presents the main Summit recommendations for research to increase awareness and understanding about the heterogeneity of persons living with dementia and their caregivers. The recommendations are intended to provide accurate, up-to-date information to support the evaluation of existing programs and services and the development of new programs and services that better accommodate heterogeneity and reduce disparities.

The Summit used the term, *heterogeneity*, rather than the term, *diversity*, because *diversity* is often assumed to imply differences in race and ethnicity, instead of the many kinds of

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<sup>2</sup> See <https://aspe.hhs.gov/national-research-summit-care-services-and-supports-persons-dementia-and-their-caregivers>.

differences identified by Summit participants. The term, *disparities*, is used for differences that are believed to be unfair.

## **Recommendations**

*Recommendation 1: Develop accurate, up-to-date descriptive information about the characteristics, care needs, and services used by persons living with dementia and their caregivers.* Determine the number and proportion of such individuals by differences in the cause(s), age of onset, symptoms, stage, and severity of the person's dementia and other characteristics that can impact their needs for assistance and the acceptability and effectiveness of programs and services intended to benefit them (see Theme 1 table). Identify differences in the types and amounts of medical, residential, and in-home care and services they receive. Analyze changes in successive studies and implications for future needs for and use of care and services.

*Recommendation 2: Conduct research to increase knowledge about differences in dementia trajectories.* Embed questions about dementia trajectories in existing and new longitudinal studies. Oversample by the cause(s) of the person's dementia to obtain enough research subjects to support cross-group analyses of differences in trajectories by cause of dementia. Identify the associations between various dementia trajectories and individuals' care needs, access to care, and use of care and services.

*Recommendation 3: Analyze available descriptive information to increase understanding about disparities among persons living with dementia and their caregivers.* Identify disparities in the incidence of dementia and disproportionate effects of dementia on women, particular racial and ethnic groups, and persons with dementia and caregivers who are poor. Advance theoretical models and conceptual frameworks to identify underlying mechanisms that may increase risk for disparities among persons living with dementia and their caregivers.

*Recommendation 4: Disseminate information to all relevant stakeholders about differences and disparities among persons living with dementia and caregivers.* Include researchers, research funders, care and service providers, and payers and regulators. Identify important implications for particular groups, e.g., implications for researchers and research funders about needed changes in research topics and methods to accommodate heterogeneity, and implications for care and service providers, payers, and regulators about the heterogeneity of their clients and beneficiary populations.

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The table lists the large number of characteristics that differ among persons living with dementia and their caregivers and were identified by Summit participants as likely to affect individuals' experience of dementia, their needs for care and support, and the acceptability and effectiveness for them of particular programs and services. Any of these characteristics could be used as variables in research on dementia care, services, and supports. The characteristics could be categorized in various ways, but Summit participants generally did not identify them in categories.

<b>THEME 1 TABLE: Characteristics that Differ Among Persons Living with Dementia and their Caregivers and are Important for Research on Care, Services, and Supports, as Identified by Summit Participants</b>	
<b>Person Living with Dementia</b>	<b>Caregivers</b>
Age	Age
Gender	Gender
Marital status	Marital status
Relationship to the primary caregiver(s) (spouse, parent, in-law, other relative, friend, neighbor, customer/client, other)	Primary caregiver(s) relationship to the person living with dementia (spouse, adult child, in-law, sibling, niece/nephew, other relative, friend neighbor, paid caregiver/aide, other)
Relationship to other caregivers (sibling, other relative, friend, neighbor, customer/client, other)	Other caregiver(s) relationship to the person living with dementia (spouse, adult child, in-law, other relative, friend, neighbor, paid caregiver/aide, other)
Race / Ethnicity	Race / Ethnicity
Country of origin	Country of origin
Culture	Culture
Education	Education
Primary language	Primary language
Literacy / Health literacy	Literacy / Health literacy
Health and medical conditions	Health and medical conditions
Sexual orientation	Sexual orientation
Financial status	Financial status
Insurance status (health, long-term care, other)	Insurance status (health, long-term care, other)
Employment	Employment in addition to caregiving
Cause(s) of dementia	
Stage and severity of dementia	
Age at onset	
Intellectual disability status	Intellectual disability status
Cognitive abilities: strengths and deficits	Cognitive abilities: strengths and deficits
Decision-making capacity	Decision-making capacity
Functional abilities: strengths and deficits	Functional abilities: strengths and deficits
Depression	Depression
Stress	Stress
Behavioral symptoms	
Communication abilities: strengths and deficits	Communication abilities: strengths and deficits
Vision and hearing	Vision and hearing
Living place (single-family home, assisted living, nursing home, congregate or shared living place)	
Living situation (alone, with others)	Living with the person with dementia or not
Distance to primary caregiver	Distance to person living with dementia
Caregiving situation (no caregiver, informal caregiver(s), paid in-home caregiver(s), other)	
Geographic location (urban, rural, frontier)	Geographic location
Children and grandchildren by age and proximity	Children and grandchildren of the person living with dementia, the caregiver, or both, by age and proximity
Duration of caregiving received	Duration of caregiving provided

THEME 1 TABLE (continued)	
Person Living with Dementia	Caregivers
Amount and types of care received	Amount and types of care provided
Religion / Spirituality	Religion / Spirituality
Caregiving responsibilities	Other caregiving responsibilities
Goals and preferences for care	Caregiver goals and preferences for the person's care and their goals and preferences for their own care
Resilience	Resilience

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## Theme 2: Research Methods to Develop More Effective Dementia Care, Services, and Supports

An important goal of the Summit was to identify research methods that will result in evidence-based programs and services that can be implemented sooner and more effectively in real-world settings where persons living with dementia and their caregivers can access and benefit from them. This section presents Summit recommendations to achieve these objectives. The recommendations focus on how to design and conduct the research, rather than recommending which dementia-related problems and issues should be studied.

### Recommendations

*Recommendation 1: Use innovative research designs to increase the generalizability of research findings and speed up dissemination of effective dementia programs and services to real-world settings.* Include pragmatic trials; rigorous, quasi-experimental designs; hybrid designs; mixed methods; rapid-cycle quality improvement methods; and standardized process measurement. Incorporate approaches from community-based participatory research and practice-based research models (e.g., to address challenges to usual methodological standards, such as random assignment, in studies conducted in nursing homes and other congregate living places). Create a research collaborative to build infrastructure, including investigator capacity and research partnerships, to support pragmatic trials and other research designs and research methods.

*Recommendation 2: Adopt or develop research methods to study complex, multicomponent programs and services intended to accommodate the many factors that affect care and service needs of persons living with dementia and their caregivers.* Such factors include the heterogeneity of persons living with dementia and their caregivers and differences in who will deliver the programs and services (e.g., agency staff or caregivers) and the intended target (e.g., the person, caregiver, dyad, agency staff, or environment). Develop analytical approaches to identify the core components of effective programs and services, determine what works for whom, and understand mediators, moderators, and mechanisms of action. Build heterogeneous research teams, and use more representative samples, appropriate control and comparison groups, and oversampling to support meaningful analyses across subgroups.

*Recommendation 3: Increase the collection of self-reported data from persons living with dementia and develop standards for determining which individuals can self-report about which outcomes, at which stages of dementia.* Tailor data collection protocols to capitalize on remaining cognitive strengths and reflect capacity differences across various types of dementia.

Identify the kinds of information persons living with dementia are most likely to be able to report (e.g., their subjective experiences of dementia and responses to programs and services intended to benefit them). Develop alternate methods to collect self-report data from persons who can no longer respond verbally. Collect data from caregivers about their experiences of caregiving and their observations of the person's status. Use caregivers as proxy respondents only when the person living with dementia cannot self-report. Develop guidance for Institutional Review Boards and ethics committees to facilitate the collection of self-report data.

*Recommendation 4: Involve end-users in the identification of dementia research priorities and relevant research outcomes.* Include end-users, such as health care, residential care, and community-based organizations and service providers that could decide to offer the programs and services; policy makers and payers that could decide to fund the programs and services; professional and paraprofessional care and service providers, including home health aides and nursing assistants, who will deliver the programs and services, and persons living with dementia and caregivers who will receive them. Create portals for all stakeholders, including end-users and the public, to submit their research priorities and suggested research outcomes.

*Recommendation 5: Develop research measures that are important for studying dementia care, services and supports.* Include person-centered and family-centered measures that are responsive to variable and complex structures and changes over time, especially in nursing homes and other congregate living facilities. Test the measures in heterogeneous samples and adapt as needed. Include measures of the lived experience of dementia for persons with the condition and their caregivers. Research funders should support consistent use of the identified measures to facilitate comparison of findings across studies.

*Recommendation 6: Develop standards for the evidence needed to determine which programs and services are ready for widespread implementation and dissemination.* In developing the standards, consider the various needs for and uses of such standards among researchers, research funders, and public and private sector organizations that provide and fund programs and services for persons living with dementia and their caregivers. Establish criteria for making decisions about readiness for implementation and dissemination, and adopt or adapt a staging model that identifies necessary steps from pilot testing through dissemination.

*Recommendation 7: Require research reporting that supports accurate replication of effective dementia programs and services in community and other care settings.* Research reports should include clear and sufficiently detailed information about recruitment procedures; the characteristics of sample members; staff credentials, experience, training and supervision; program and service delivery methods; retention strategies; methods for collecting self-report and proxy-report data; procedures for supporting and monitoring fidelity; costs and cost-effectiveness; unexpected challenges, and how the challenges were addressed.

## Theme 3: Caregiver Relationships, Roles, and Networks

Caregiver relationships, roles, and networks were an important theme throughout the Summit and are relevant to almost every aspect of research on dementia care, services, and supports. The recommendations presented in this section cover the breadth of all the Summit sessions. Some of the recommendations overlap with those in the sections on Comprehensive Models of Care, Financial Burden, Technology, and Workforce. They range from better understanding about what a caregiver is and how caregivers from various backgrounds and cultures define themselves, to understanding networks of caregiving, issues around employment and the financial burden of caregiving. The importance of understanding how the nature of caregiving changes as the person's dementia progresses and the benefits and burden of those changes was often repeated in recommendations. Another much-repeated issue was the need for more research into supportive services for caregivers themselves, such as the importance of support groups and the effectiveness of respite care.

### Recommendations

*Recommendation 1: Identify types of dementia caregivers, their needs, and how they self-identify, study the caregiving course to understand roles, needs, preferences, and both positive and negative consequences.* Greater understanding is needed to identify preferred terms for different groups. Research should take into account multiple domains and contextual situations due to the complexity of care provision. Adopt more inclusive definitions of care partners in research and determine the numbers of individuals in various caregiver groups and their service needs. Identify what aspects of dementia and caregiving are considered stigmatizing, and how stigma affects perceptions of roles and responsibilities. Identify changing needs, care challenges, and financial outlays for caregivers from different racial/ethnic/linguistic groups, geographic locations, and socioeconomic levels over time and across disease stages.

*Recommendation 2: Understand care decision-making in caregivers and across dementia trajectories, including how decisions are made about care, use of care plans, living arrangements, and seeking support and social services.* Better understand who becomes a caregiver and why, and examine how the decision to become a caregiver differs across various groups and regions. Examine the role of multiple caregivers, how caregiving responsibilities are shared and divided among caregivers, and the impact of size of caregiver networks on caregiver outcomes. Develop new measures that capture dyadic relationships and caregiver networks. Understand how caregiving will be handled in the future as the number of available caregivers declines. Special focus should be given to how current HIPAA law impacts decision-making and caregiver involvement in care decisions.

*Recommendation 3: Identify the impact of dementia stage and severity on caregiver well-being, care challenges and supportive needs, and how heterogeneity of caregiver experience may affect receipt of and participation in programs.* Understand the impact of different dementia-related symptoms on caregiver health and well-being, care responsibilities, and quality of daily life. Examine changes in roles and responsibilities over time by cause(s) and stages of dementia, and identify which caregivers are most at risk for poor health and at which point along the care trajectory. Adapt existing proven caregiver programs for delivery to different cultural groups, and identify ways to expand or add to proven programs to address the needs of various caregiving populations. Determine how employment affects caregiving responsibilities, whether type of caregiving affects employment status, and how caregivers weigh the pros and cons of reducing work hours or leaving work entirely to provide care vs. the short and long-term financial effects of lost income and retirement benefits.

*Recommendation 4: Conduct a review of the established research on caregiver programs across dementia stages to determine what additional research or evidence would be needed to incorporate these evidence-based programs as a covered benefit.* Determine approaches for enabling agencies/services to identify and integrate proven caregiver programs, identify strategies for effectively involving various caregivers and other stakeholders in disseminating proven caregiver interventions for caregivers at all stages of dementia. Researchers should consider how caregiver programs measure resilience, readiness to change, costs, and cost-effectiveness. Develop dyadic interventions, targeting both the caregiver and the care recipient for each stage of dementia and particularly those stages that have not previously been addressed (e.g., early and end-of-life). Focus efforts on interventions that help caregivers prepare for future needs, and that address financial burdens of caregiving.

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## **Theme 4: Clinical Approaches and the Lived Experience of Dementia**

The recommendations presented in this section cover the breadth of all the Summit sessions. Some of the recommendations in this section overlap with those in Comprehensive Models, Financial Burden, Technology, and Caregiver Relationships. Overall, the recommendations for this theme take into account the solid, existing research base for effective clinically-based psychosocial and behavioral programs targeted to persons living with dementia. The recommendations, however, also acknowledge that new interventions should expand and adapt these programs to meet the needs of underserved persons living with dementia who are not adequately represented in existing studies. Given the heterogeneity of persons living with dementia, caregivers, caregiving situations, and changes in the care needs of persons living with dementia over time, it is unlikely that any single evidence-based program will be effective for all persons living with dementia and caregivers. However, little research has been conducted to identify what works for which persons living with dementia and caregivers under what circumstances and in what settings. It is also clear that more must be done to include the voices of persons living with dementia in determining what they need throughout the stages of the condition.

### **Recommendations**

*Recommendation 1: Identify determinants of behavioral and psychological symptoms, ascertain how persons living with dementia experience these symptoms, and determine long-term effects of evidence-based programs.* Examine psychosocial, environmental, and genetic determinants of and risks for the full range of behavioral and psychological symptoms for persons living with dementia. Conduct quantitative and qualitative studies to ascertain how persons living with dementia and their caregivers experience and cope with different behavioral symptoms across the trajectory of the condition, and if current assessment tools are culturally appropriate for screening for behavioral symptoms in different care settings and for different groups.

*Recommendation 2: Conduct studies that combine pharmacological and non-pharmacological strategies to reduce dementia-related symptoms, including behavioral symptoms and functional and cognitive decline, and determine whether reduction in symptoms can slow disease progression.* Increase understanding of functional and cognitive decline in dementia and develop and evaluate approaches to support and maintain cognitive and functional abilities and



reduce behavioral symptoms. Conduct larger and longer trials of proven approaches to determine whether they can slow disease progression. Identify interventions targeted at persons with intellectual disabilities and dementia and approaches to support their particular cognitive and functional needs.

*Recommendation 3: Obtain consensus as to definitions of different cognitive strategies and understand impacts of cognitive training.* Derive consensus as to the differences between and definitions of different cognitive approaches (e.g., cognitive training, stimulation, rehabilitation). Identify better research measures, and derive consensus to enable cross-study comparisons to examine outcomes of cognitive approaches. Understand the best time in the course of cognitive impairment and dementia to intervene with cognitive approaches and the frequency and intensity needed to achieve desired effects. Examine whether training in specific cognitive domains (e.g., executive function) leads to functional improvement.

*Recommendation 4: Understand what outcomes are important to persons living with dementia and develop programs and services to derive consensus as to what constitutes person-centered care, and improve measures of quality of care and quality of life.* Conduct research to understand the lived experience of persons with dementia, and identify areas amenable to intervention across all stages of the condition. Identify effective approaches to help persons living with dementia participate in their health care decisions, including person-centered advance planning and end-of-life decisions. Identify strategies to support persons living with dementia to participate in meaningful ways their communities, and conduct studies to support the goal of living well with dementia across the trajectory of the condition.

*Recommendation 5: Understand adaptive and coping mechanisms used by persons living alone with dementia.* Determine effective strategies for expanding the support systems of persons with dementia who live alone, including the very large proportion of older women with dementia that lives alone. Study ways to facilitate ongoing connections between persons with dementia who live alone and family, friends, and community. Study approaches to maintain a connection to community-based and social services that evolves as dementia progresses in persons with the condition who live alone. Identify the special needs of persons with dementia who live alone for protection from financial exploitation. Determine whether an assessment can help to identify risk, ability to live alone safely, and strategies for supporting maximum possible functioning.

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## **Theme 5: Engaging Persons Living with Dementia and Caregivers as Members of the Research Team**

The Patient-Centered Outcomes Research Institute (PCORI), established in the United States in 2010, has worked to promote inclusion of meaningful input and partnership with patients, caregivers, and other stakeholders affected by the disease or condition being studied. Engagement has increased in research on many diseases and conditions, but background reviews conducted for the Summit found very few examples of meaningful engagement of persons living with dementia or their caregivers in research on dementia care, services, and supports conducted in the United States. Other countries, including the United Kingdom and Canada, are ahead of the United States in this facet of dementia-related research. This section presents the main Summit recommendations for increasing engagement of persons living with

dementia and their caregivers in all stages of research on dementia care, services, and supports.

## **Recommendations**

*Recommendation 1: Engage persons living with dementia and their caregivers as part of research teams that are studying dementia care, services and supports.* Include them as partners in all stages of the research process (e.g., identification of research priorities, design of programs and services to be studied, selection of study questions and outcomes to be measured, and assistance with study implementation, data collection, data analysis and interpretation, and dissemination of study findings).

*Recommendation 2: Develop and evaluate promising practices for increasing engagement of persons living with dementia and their caregivers as part of research teams.* Examine engagement models developed for other research topics, and study lessons learned from United States and international engagement procedures in dementia research to identify methodologically robust practices. Test recommended approaches to support engagement (e.g., financial reimbursement, use of technology, such as Skype and Zoom, to facilitate communication, and training about research and the roles of persons living with dementia and caregivers in the research team). Disseminate best practice guidelines to researchers, research funders, and organizations that represent and advocate for persons living with dementia and their caregivers.

*Recommendation 3: Evaluate the impact of research engagement of persons living with dementia and their caregivers on the validity, value, and credibility of the research findings.* Examine questions about representativeness in engaged research models (e.g., questions about whether including one or two persons living with dementia and one or two caregivers on the research team can adequately represent all such individuals), especially given the heterogeneity of persons living with dementia and their caregivers. Study approaches developed by PCORI and others to address these questions, and develop guidance for researchers, research funders, and persons living with dementia and caregivers who may participate in dementia-related research.

*Recommendation 4: Encourage the use of engaged research models in studies of dementia care, services, and supports.* Use incentives, such as requiring or recommending that application forms for research funding include a section on engagement practices; requiring inclusion of engagement practices in reports to funders and publications about research results; and creating career incentives for effective engagement practices (e.g., awards, recognition, funding). Develop guidance for Institutional Review Boards and ethics committees about engaging persons living with dementia and caregivers as part of research teams.



## Theme 6: Dementia-Related Terminology, Nomenclature, and Stigma: Words Matter

A confusing array of terms is used to refer to four dementia-related topics: (1) cognitive impairment and dementia; (2) the diseases and conditions that cause dementia; (3) family members and others who provide care for persons living with dementia; and (4) formal care, services, and supports that are intended to benefit such persons. Awareness, understanding, and acceptability of particular terms differ among persons living with dementia, caregivers, clinicians, service providers, biomedical and health service researchers, payers and regulators of government and private sector programs and services, and the general public. These differences interfere with shared understanding and effective communication among individuals in all the groups. Numerous Summit participants emphasized that some terms used to refer to cognitive impairment and dementia and the diseases and conditions that cause dementia invoke stereotypes and stigma that have strong negative effects on self-perceptions and quality of life for persons living with dementia and caregivers. These stereotypes and stigma can reduce their willingness to participate in research, acknowledge the person's cognitive impairment, obtain a diagnostic evaluation, and access care and services that could benefit them.

This section presents the main research recommendations from the Summit about dementia-related terminology, nomenclature, and associated stigma. It includes recommendations for research needed to reduce confusing and negative dementia-related terminology and associated stigma and enable clear and effective communication among affected individuals and groups.

### Recommendations

*Recommendation 1: Analyze existing dementia-related terminology to identify confusing and stigmatizing terms, and initiate a process to select or develop terminology that will reduce stigma and support effective communication among individuals and groups.* Establish a working group under the auspices of the Advisory Council to oversee the analysis of existing terminology and the selection or development of terminology that can be understood by affected individuals and groups and is, to the greatest extent possible, positive and free of negative stereotypes and stigma. Include in the process persons living with dementia; caregivers; representatives of government agencies, advocacy organizations, and clinical, scientific, industry, and regulatory groups; and communications and public health experts.

*Recommendation 2: Examine current awareness of and perspectives on frequently used dementia-related terms.* Include terms for: (1) cognitive impairment and dementia; (2) diseases and conditions that cause of dementia; (3) caregivers; and (4) care and services intended to benefit persons living with dementia and their caregivers. Study differences in awareness of and perspectives on particular terms among individuals and groups. Examine the impact of existing dementia-related terminology and associated stigma on self-perceptions, depression, anxiety, social isolation, and quality of life for persons living with dementia and on public understanding about dementia and public acceptance and support for persons living with dementia and their caregivers.

*Recommendation 3: Study planned changes in the definition of Alzheimer's disease (often referred to as "nomenclature" in this context) and evaluate the need for information about the changes for affected individuals and the public.* The new definition of Alzheimer's disease includes early manifestations in biological markers long before symptoms of cognitive impairment emerge. Although the planned changes are mainly known to biomedical researchers

at present, the new definition will be reported in public media and eventually affect awareness and understanding about the disease among care and service providers, persons living with dementia, caregivers, and the public.

*Recommendation 4: Disseminate new and revised dementia-related terminology, monitor uptake, and evaluate impacts on communication among individuals and groups, negative stereotypes, and stigma.* Design information and education materials and public health strategies to build awareness of the new and revised terminology. Measure uptake of the terminology, and evaluate impacts on communication and terminology-related barriers to research participation, recognition of cognitive impairment, willingness to obtain a diagnostic evaluation, and use of care, services, and supports. Identify groups for whom the new and revised terms are confusing or unacceptable, and revise as needed.

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## **Theme 7: Comprehensive Models of Care for Persons Living with Dementia**

Comprehensive models of care for persons living with dementia are intended to reduce difficulties, frustration, and negative health-related and emotional outcomes experienced by such persons and their caregivers as they try to understand and access care, services, and supports that can help them. This section presents the main Summit recommendations for research to evaluate and compare the effectiveness of comprehensive models of care, including dementia-specific and general models. The section also includes recommendations for evaluation of Dementia Friendly Community models and dissemination of findings about all types of models to potential users, providers, and payers.

### **Recommendations**

*Recommendation 1: Identify the core components of comprehensive models of care for persons living with dementia.* Include dementia-specific models, that is, models specifically intended for persons with dementia, and general models that are not dementia-specific but include such persons among their clients and enrollees (e.g., U.S. Department of Veterans Affairs (VA) Home-Based Primary Care and Medicare/Medicaid dual eligible models). Building on draft components identified by Summit speakers (see Theme 7 table), develop consensus about the core components, and identify other important features that differ among models (e.g., where the model is based (medical or community setting, home, or multiple settings), staff composition, and partnerships).

*Recommendation 2: Identify core outcomes for measuring the effectiveness of comprehensive models of care for persons living with dementia and their caregivers.* Include outcomes that are important to these individuals and to organizations that provide and pay for medical, residential, and home and community-based care for them, such as CMS, VA, health care systems, and community-based organizations. Include quality of life and cost and cost-effectiveness outcomes to support value-based decision-making by end-users, including providers, payers, persons living with dementia and their caregivers.

Recommendation 3: Evaluate and compare comprehensive models of care and develop new models for subgroups of persons living with dementia that are not effectively served by existing models. Compare models that include the core components but vary in other features. Identify groups that are not effectively served by existing models (e.g., persons with early stage dementia, persons with dementia who live alone, persons with advanced dementia, residents with dementia in assisted living and other congregate living places, persons with dementia who do not have a caregiver, and persons with intellectual disabilities and dementia). Incorporate evidence-based programs (e.g., evidence-based transitional care programs), and/or develop and evaluate new comprehensive models to address their needs.

Recommendation 4: Identify and evaluate features of comprehensive models of care for persons living with dementia that may affect their real-world feasibility and acceptability in particular communities and geographic locations. Evaluate the feasibility of model requirements for staff competencies and staff travel to meet with clients. Evaluate the acceptability of methods used to communicate with persons living with dementia and caregivers, (e.g., in-person communication with an individual or group at home or in a medical or community setting and communication by telephone, email, telehealth and other online meeting options).

Recommendation 5: Examine Dementia Friendly Community models and evaluate their impact on persons living with dementia, caregivers, and communities. Identify or develop and test evaluation methods, measures, and relevant outcomes for studying Dementia Friendly Communities. Compare processes by which these communities share and adapt strategies and best practices. Evaluate outcomes, such as increased awareness and acceptance of persons living with dementia, increased support for independent living, reduced stigma, reduced nursing home placement, increased research participation, and improved quality of life. Document costs and sustainability.

Recommendation 6: Disseminate findings from research on comprehensive models of care and Dementia Friendly Community models to potential users, including persons living with dementia and their caregivers, medical, residential, and community-based providers, health care systems, and payers. Provide information in language and formats that are understandable and useful to particular groups and will help them select the model(s) that will be relevant, feasible, and acceptable in their communities and geographic locations.

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Summit participants identified many possible components and features of comprehensive models of care for persons living with dementia. This table lists six components consistently identified by speakers in the Summit session, Research on Models of Care for Persons Living with Dementia and Their Caregivers across the Disease Trajectory. The table may be a useful starting point for Theme 7, Recommendation 1.

<b>THEME 7 TABLE: Draft Core Components of Comprehensive Models of Care for Persons Living with Dementia</b>	
1.	Inclusion of both the person living with dementia and the caregiver.
2.	Ongoing, long-term assistance that spans the trajectory of dementia from early to late stage and end-of-life, addresses the changing needs and preferences of the person living with dementia and caregivers over time, and follows the person with dementia as he/she transitions from one living place to another.
3.	Inclusion of both medical care and long-term services and supports.
4.	Assessment and ongoing, systematic reassessment to identify changing medical and non-medical problems and concerns, care needs, goals, and preferences of the person living with dementia and his/her caregivers.
5.	Care planning to establish and update action steps to address unmet needs and concerns of the person living with dementia and caregivers.
6.	Connection of the person living with dementia and his/her caregivers to information, care, services and supports to meet needs, address concerns, and improve outcomes.

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## **Theme 8: Strategies for Scaling and Disseminating Existing Evidence, Drawing upon Implementation Science**

Some existing evidence-based programs and services are currently available to persons living with dementia and their caregivers in various communities across the country. Summit participants pointed out, however, that despite demonstrated positive outcomes, most of the programs and services have not been adopted by health care or social service organizations outside of research or grant-funded projects. Moreover, even when the programs and services have been adopted by one or more health care or community-based organizations, sustaining the programs and services has been difficult. This section presents the main Summit recommendations for scaling, disseminating, and sustaining evidence-based programs and services for persons living with dementia and their caregivers.

### **Recommendations**

*Recommendation 1: To make evidence-based programs and services for persons living with dementia and their caregivers more widely available in communities across the country, researchers and program developers should begin planning for dissemination and sustainability early in the process of program development.* They should draw on conceptual frameworks and strategies from the growing disciplines of implementation and translation science to identify and address the many factors that determine whether evidence-based programs and services for persons living with dementia and their caregivers are disseminated and sustained.

*Recommendation 2: Conduct research to increase understanding about organizational readiness and capacity to implement and sustain evidence-based programs and services for persons living with dementia.* Examine organizational barriers to implementation of such programs and services (e.g., competing organizational priorities, workforce issues, and financial disincentives, and identify strategies to overcome the barriers). Examine characteristics of existing evidence-based programs and services that make them more or less feasible for particular organizations, and develop measures to assess an organization’s readiness and capacity to implement and sustain particular programs and services.

Recommendation 3: Study approaches to optimize working relationships between health care and community-based organizations that are critical to providing the coordinated medical care and social services needed by persons living with dementia and their caregivers. Identify communication, contractual and financial alignment strategies that can support collaboration among organizations, and examine solutions to problems, such as incompatibility of patient/client record systems between organizations that are providing care and services for the same individual.

Recommendation 4: Examine dementia-related costs to all payers, the division of costs among payers, and cost shifting. Identify discrepancies between organizations that pay for dementia care and services and organizations that benefit from positive effects of the care and services (e.g., cost savings from reduced use of more expensive types of care). Evaluate cost shifting between health care and community-based organizations and caregivers that provide unpaid care and pay out-of-pocket for dementia care and services.

Recommendation 5: Identify payment models and financial incentives to support dissemination and sustainability of evidence-based programs and services for persons living with dementia. Using simulation and economic modeling, determine the cost-benefit and cost-effectiveness of particular evidence-based programs and services for a range of outcomes of importance to different stakeholders, including persons living with dementia, caregivers, providers, and payers. Evaluate the likely impact of financial incentives associated with reporting on quality measures (e.g., financial penalties for failure to report having provided specified care and services and/or financial bonuses for reporting that the care and services were provided).

Recommendation 6: Develop and evaluate approaches to increase willingness to use, provide, and/or pay for evidence-based programs and services among persons living with dementia, caregivers, and provider organizations. Identify strategies to increase awareness among all stakeholders about the positive outcomes of evidence-based dementia programs and services. Study how and why persons living with dementia and their caregivers decide to use and sometimes pay out-of-pocket for particular programs or services. Evaluate the likely impact of approaches, such as readily available training and certification for individual providers and assistance for provider organizations for integrating evidence-based programs and services into their ongoing programs and services.

Recommendation 7: Identify methods that individual communities can use to begin planning for the array of care, services, and supports required to meet the needs of that community's residents living with dementia and their caregivers. Examine options for providing multiple evidence-based programs and services through a single public or private sector organization or providing complementary programs and services through several organizations.

## **Theme 9: Living Places, Physical and Social Environments, and Processes of Care for Persons with Dementia, Including Those Who Live Alone**

It is often assumed that persons with dementia live either in a private, single-family residence with caregiver(s) or in an assisted living facility or nursing home. Most programs and services for persons with dementia and their caregivers have been designed for and evaluated in samples of persons with dementia who live in these three types of places. Summit participants noted, however, that some, and perhaps many persons with dementia live in other types of places, such as senior and retirement housing and group homes, referred to here as *other congregate and shared living places* (see Theme 9 table). Little is known about similarities and differences among the various types of places where persons with dementia live, including similarities and differences in physical environments (e.g., home-like design and access to the outdoors), social environments (e.g., social and recreational activities and support for continuing engagement with relatives, friends, and community) and processes of care (e.g., usual staffing, consistency of staff assignment, and the kinds of care, services, and supports provided).

This section presents the main Summit recommendations for research to increase knowledge about the types of places where persons with dementia live and the number, characteristics, and needs of persons with dementia who live in each type of place, including persons with dementia who live alone. A growing body of evidence shows that physical and social environments and processes of care can either support or be a barrier to cognitive, physical, and emotional functioning in persons with dementia. This section includes Summit recommendations for research to design, develop, and evaluate physical and social environments and processes of care that support the highest possible levels of functioning and improve quality of life and the lived experience of dementia for persons with the condition and their caregivers. This theme differs from the comprehensive models of care theme in two ways: first, most models are not limited to persons with dementia who live in a specific type of place or setting; second, living places can have physical and social environments and processes of care that are not addressed in models and can either augment or detract from the feasibility and effectiveness of the model of care.

### **Recommendations**

*Recommendation 1: Develop up-to-date, descriptive information about the types of places where persons with dementia live, the number, proportion, and characteristics of persons with dementia who live in each type of place, and their needs for and use of care, services and supports.* Provide specific information about persons with dementia who live alone, including those who live alone in private, single-family homes and those who live in congregate and shared residential settings but should be considered to live alone for purposes of understanding their needs for care, services and supports.

*Recommendation 2: Conduct studies to increase understanding about transitions of persons with dementia from one type of living place to another or one level of care to another in multi-level facilities.* Analyze the reasons for transitions, and develop approaches for weighing the pros and cons of adapting physical and social environments and processes of care in a person's current living place vs. facilitating a transition to another type of living place. Develop and evaluate protocols to coordinate and facilitate desired and needed transitions from one living place to another.



Recommendation 3: Develop and evaluate approaches to improve physical and social environments and processes of dementia care that will be useful across various types of living places, rather than focusing only on one particular type of living place. Use positive outcomes, such as quality of life, social engagement, and maintenance of meaningful connections with family and community. Examine what constitutes a “home-like” environment for persons with dementia, and develop “home-like” environments for all types of living places. Study the pros and cons of integrated vs. dementia-specific living places, especially as they affect mutual acceptance and perceived stigma among residents and their caregivers.

Recommendation 4: Conduct research to increase understanding about how physical and social environments and processes of care can help to balance autonomy, independence, and choice vs. safety and protection from risk for persons with dementia in all types of living places, including for persons with dementia who live alone. Develop and evaluate physical and social environments and processes of care to protect persons with dementia from physical injury, abuse, neglect, and financial exploitation, while maintaining support for autonomy, independence, and choice.

Recommendation 5: Disseminate up-to-date descriptive information about the places where persons with dementia live to relevant groups. Adapt the content and formats of the information to address each group’s interests, and identify relevant implications for particular groups (e.g., implications for architects, developers and managers of various types of living places and implications for government and private sector organizations that provide and/or fund programs and services for persons with dementia and their caregivers and need to understand the characteristics of the places where their clients and beneficiaries live in order to plan for and deliver appropriate care, services, and supports).

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This table shows various terms used by Summit participants for places where persons with dementia live. With the exception of the first three types of places (private, single-family home or residence; assisted living facility or residence; and nursing home or skilled nursing facility), the remaining types of places are referred to in the Summit report with the general term, *other congregate and shared living places*, which means places other than assisted living and nursing homes, where multiple, usually unrelated, individuals live in separate units or rooms in the same place. Nursing homes have Federal Government requirements for Medicare and Medicaid purposes, and all states license nursing homes. Assisted living facilities and residences and other congregate and shared living places are generally licensed by states, if at all.

The terms used for particular types of living places vary greatly in communities and geographic locations across the country, in part because of differences in licensing terms. Moreover, different terms are often used for types of living places that are similar in their physical and social environments and processes of care, and conversely, the same terms are often used for living places that differ greatly in their physical and social environments and processes of care. This confusing use of terms adds to the difficulty of understanding similarities and differences among living places for persons with dementia.

<b>THEME 9 TABLE: Types of Places Where Persons with Dementia Live</b>
Private, single-family home or residence
Assisted living residence or facility
Nursing home, skilled nursing facility, with or without a separate unit for persons with dementia
<b>Other congregate and shared living places</b>
Adult care home
Adult foster care home
Board and care home
Boarding home
Co-housing places (these are places that allow persons with dementia and caregiver(s) to continue living together)
Community living center (VA nursing home)
Congregate residence or facility
Continuing care retirement community
Group home
Independent living residence or facility
Long-term care residence or facility
Medical foster home (VA residence)
Memory care residence (free standing)
Personal care home
Residential care facility or home, residential living facility
Rest home
Retirement care home, retirement housing
Retirement living facility or complex
Senior housing, senior living facility or complex
State veterans home
Supportive housing
Shared housing, shared residential housing

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## **Theme 10: Financial Burden and Out-of-Pocket Costs to Persons Living with Dementia and their Caregivers**

Summit participants emphasized the need for research on approaches to reduce financial burden and out-of-pocket costs to persons living with dementia and caregivers. The Summit stakeholder groups of persons living with dementia and their caregivers identified reduced financial burden as one of their highest priority research outcomes, and other Summit participants agreed. Some research-based information about financial burden and out-of-pocket costs to persons living with dementia and their caregivers is available now, and numerous anecdotal reports describe individuals' experiences of these problems. Comprehensive, population-based information is needed, however, to support the development and implementation of effective approaches to address the problems. This section presents Summit recommendations for research to increase knowledge about dementia-related out-of-pocket costs and financial burden and their effects on persons living with dementia and caregivers, and recommendations to develop and evaluate approaches to reduce negative effects.

**NOTE:** Financial burden and out-of-pocket costs to persons living with dementia and their caregivers occur within the broader context of dementia-related costs to all payers. Summit

recommendations for research on this broader topic, which includes the division of costs among all payers and cost-shifting, are presented in the report section on Strategies for Scaling and Disseminating Existing Evidence.

## **Recommendations**

*Recommendation 1: Develop comprehensive, descriptive information about dementia-related out-of-pocket costs to persons living with dementia and their caregivers.* Use data from representative, population-based samples to develop and periodically update information about out-of-pocket costs for diagnosis, medical treatment, medications, and paid care. Examine out-of-pocket costs for those who receive Social Security Disability Insurance but are in the 24-month wait period for Medicare. Study differences in out-of-pocket costs according to the cause(s), age of onset, symptoms, stage, and severity of the person's dementia.

*Recommendation 2: Analyze the relationship of dementia-related out-of-pocket costs to objective and perceived financial burden and examine other factors that may affect that relationship.* Include factors, such as income and financial resources of the person living with dementia and caregiver, their other financial obligations, and residence in geographic locations where government and private sector funding for care and services is or is not available.

*Recommendation 3: Develop information about the impact of dementia-related out-of-pocket costs and financial burden on persons living with dementia and their caregivers, and identify approaches to address negative effects.* Examine effects on quality of life; access to and use of care and services; participation in clinical trials; engagement in advance care planning; decisions about obtaining a diagnosis and using medical treatments and medications; and risk of depleted resources and poverty. Identify, for example, approaches researchers and research funders can use to reduce negative effects on clinical trial participation and approaches health care plans and providers can use to reduce negative effects on decisions of persons living with dementia and their caregivers about engagement in advance care planning.

*Recommendation 4: Develop and evaluate information and educational materials to improve financial decisions and reduce dementia-related out-of-pocket costs and financial burden.* Identify and describe financial options in language and formats persons living with dementia and caregivers can understand and use, and determine whether such information facilitates financial decisions and reduces out-of-pocket costs and financial burden. Develop and evaluate educational materials to increase what financial advisors and elder law and other attorneys know about dementia-related out-of-pocket costs and financial burden and determine whether such information improves the guidance they provide to persons living with dementia and caregivers.

## Theme 11: Ensuring an Adequate and Qualified Workforce to Support Persons with Dementia and their Caregivers

The theme of Workforce was among those that emerged through discussion at the Summit as participants felt that it was essential to address gaps and increase understanding of workforce issues in order to be effective in other areas. The Workforce Development Stakeholder group also presented a number of recommendations that provide a framework for other participants to build upon and connect to other themes of the Summit, especially Strategies for Scaling, Comprehensive Models for Care, and Clinical Approaches. Overarching areas of focus in this theme included considering workforce in all stages of development, evaluation, implementation and scaling up of care, services, and supports for persons with dementia and their caregivers. Recommendations emphasized the need to look at a wide range of care settings and provider types, and account for the various kinds of help persons with dementia need throughout the course of the condition. Another important focus area concerned the need for a stronger workforce infrastructure, particularly around training and building competency standards.

### Recommendations

*Recommendation 1: Research the impacts of the ever-increasing aging population on the workforce infrastructure and numbers, particularly across regions and workforce type, and develop a solid evidence base for issues around recruitment and retention of workforce for dementia care.* Researchers should examine the impact of an aging population, more numbers of persons with dementia, and diminution of numbers of care workers and caregivers -- on the current workforce. Special focus should be applied to understanding workforce diversity (type of work, settings, racial/ethnic make-up, geographic location, and composition). Identify recruitment and retention strategies for expanding the caregiver workforce, including issues such as wages, geographic limitations, and shifting demographics. These strategies should include, but are not limited to, cultural, gender, educational, and socioeconomic issues, as well as addressing health literacy disparities.

*Recommendation 2: Examine and include the interdisciplinary team in all phases of research development and implementation, and account for the real-world nature of services to persons living with dementia and their caregivers, such that varied professional and non-professional groups are targeted.* Research should focus on using leverage points for diffusion of efficacious and effective interventions for persons with dementia and their caregivers, understanding that no one single component, or single type of worker, within the care system is exclusively responsible for providing care.

*Recommendation 3: Define "effective training" for the workforce, including determining what training will increase knowledge and skills for dementia care.* Researchers, academics, educators, and various governmental agencies should work together to catalog and standardize available training and develop measures of competence, and further study innovation in training methods. These groups should collaborate to develop core competencies, domains, and milestones to ensure that care is appropriate. Some areas for competency development include health inequities, cultural competence, health literacy, addressing caregiver stress, and training persons living with dementia and their caregivers in how to access and navigate health care and supportive services.

Recommendation 4: Determine how existing workforce models can be refined to improve efficiency and cost-effectiveness of dementia care, study impediments to implementation in the existing care system, and develop a better understanding of how these models may affect current infrastructure challenges. Research is needed on translating existing care models, services, and technologies to improve the lives of persons with dementia and their caregivers into real-world settings. It is important to study the impediments to implementing such interventions, which include training the workforce, caregivers (both formal and informal), and insuring that the interventions can be integrated into standard operating procedures of the existing care system be it the home, residential care setting, or a senior center.

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## **Theme 12: Technology to Support Persons with Dementia and their Caregivers**

Many Summit participants recommended use of technology to address a wide array of functions, activities, and problems related to care, services, and supports for persons living with dementia and their caregivers. Given the broadness of the topic, and the lack of a clear characterization of technology, some recommendations were very general, and some were more specific, including the suggestion of specific products. Generally, the Summit participants felt that technology and technology-based interventions could address health and wellness, social connectivity, independent living, and/or caregiver supports in different settings. Such interventions could be targeted to the caregiver, the person living with dementia, or both, and could include the use of mobile devices, online platforms, telehealth, wearables, and home sensors. Despite the large number of suggestions and the enthusiasm of Summit participants, this theme remains largely unexplored and there was a great deal of variation in ideas about what technology is and what it should do.

### **Recommendations**

Recommendation 1: Develop and evaluate technologies specifically with and for persons living with dementia and their caregivers at various stages of the person's dementia and across various settings and expand the currently available array of technologies, incorporating novel approaches to increase reach. Determine what combination of technologies can achieve meaningful benefits for one or more well-defined subgroups of persons living with dementia, and use advances in technology to personalize needed care for such persons in an efficient and cost-effective manner. Research should extend beyond the examination of the delivery of technology-based (or technology-assisted) intervention programs.

Recommendation 2: Develop a solid evidence base on the efficacy/effectiveness of technology-based solutions for persons living with dementia across various functional categories of use, and study how technology can assist caregivers to better manage both the care needs of those they care for as well their own needs. Develop a research consensus among researchers to determine how “effectiveness” is measured, including the impacts of heterogeneity on technology feasibility and acceptability, and understand how design and implementation of technology is driven by the needs, preferences and abilities of inclusive user groups in various contexts. Evaluate how technology-based approaches may make interventions more efficient and more accessible for caregivers, and identify and evaluate technologies that can simplify care planning for the caregiver, the person living with dementia, and the healthcare provider. Include various caregiver populations in research and throughout the development process.

Recommendation 3: Conduct research on what types of technology applications are optimal to support various functions for various user groups, determine the impact of the use of technology on providing high quality care to persons living with dementia and their caregivers, and understand how to best integrate these applications within existing models of care. Study the impact of new technologies on health and wellness outcomes and include data on challenges, measurement and data gaps, and negative outcomes. Build an evidence base of what technology applications (existing and emerging) work, for whom and in what context. Test whether technology-based interventions improve the efficiency and effectiveness of programs to improve care for persons with dementia, such as in facilitating earlier diagnoses, care coordination, accessing assessments, tracking and collecting data, and encouraging a more user-friendly experience.

Recommendation 4: Determine whether heterogeneous populations of persons living with dementia and their caregivers are able to access and utilize technology applications, and determine what technology is unavailable and why. Determine what challenges are more common in particular populations (e.g., lack of meaningful access to the Internet due to contextual, socioeconomic constraints) and how they can be addressed. Conduct research on how to provide isolated populations with access to technological applications and better understand what barriers exist to access. Conduct further research on implementation costs of various technological applications, both to the health system and to individuals and caregivers.

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The table below lists the wide array of uses of technology identified by Summit participants, many of which may not be easily categorized. Each of the uses of technology listed in the table below will require exploration on its own and then further exploration of how it relates to the needs of caregivers and persons living with dementia.

<b>THEME 12 TABLE: Uses of Technology Identified in Summit Recommendations</b>
Electronic medical records
Telehealth options
Cognition assistance, and providing in-the-moment information
Wayfinding both outside and inside buildings
Averting or delaying sensory loss
Collecting and tracking data
Enabling individuals living with dementia to continue to live at home longer
Outreach to persons living with dementia and their caregivers
Evaluating behavior and function for persons without proxy historians
Evaluating function and sleep
Facilitating access to needed care and services especially for those whose access is limited or compromised due to geographic, logistic or functional constraints
Facilitating access to treatment for individuals with dementia and their care partners
Activities to engage persons living with dementia
Bringing research into the home
Care coordination
Facilitating earlier and more precise diagnosis (e.g., monitoring and sensing technologies)
New forms of assessment
Participation in research studies
Facilitating the development of the most effective interventions
Training of the workforce or community care providers (e.g., online/webinar training for intervention protocols or certifications for care providers)

<b>THEME 12 TABLE (continued)</b>
Monitoring, assisting or maintaining daily functioning
Helping those in isolation
Imaging behaviors: recording behavior up to 30 min before behavior to help caregivers evaluate triggers
Efficiency and cost-effectiveness of models and supporting scalability
Access to assessment and interventions
Locating lost persons living with dementia
Making integrated care available in many homes
Measuring stress and other outcomes (e.g., with wearables)
In-home sensor technology to monitor in-home activity
Monitoring for safety (e.g., driving)
Providing a flexible format for presenting information to persons living with dementia, their caregivers, and other members of the health and services systems
Cognitive support
Robotic applications
Support for independent living through assistive devices and technologies
Therapy
Reducing bed confinement and facilitating activities of daily living in the home
Remediating problems with social isolation and fostering engagement
Simplifying care planning for the caregiver, person with dementia, and health care provider
Tracking biometric markers and symptoms, including personal wearables, microchips, etc. for psychosocial and behavioral issues

# APPENDICES



# APPENDIX A: STEERING COMMITTEE MEMBERS<sup>3</sup>

## CO-CHAIRS

- Laura N. Gitlin, PhD (Drexel University/Johns Hopkins University)
- Katie Maslow, MSW (Gerontological Society of America)

## EXECUTIVE COMMITTEE

- Ron Petersen, MD, PhD (Mayo Clinic)
- Ruth Katz, MA (U.S. Department of Health and Human Services)
- Rohini Khillan, MPH (U.S. Department of Health and Human Services)

## COMMITTEE MEMBERS

- Gary Epstein-Lubow, MD (Brown University)
- Lori Frank, PhD (Patient-Centered Outcomes Research Institute)
- Richard Hodes, MD (National Institute on Aging)
- Ian N. Kremer, JD (Leaders Engaged on Alzheimer's Disease)
- Shari M. Ling, MD (Centers for Medicare & Medicaid Services)
- Sarah Lenz Lock, JD (AARP)
- Helen Matheny, MS (West Virginia University)
- Lisa McGuire, PhD (Centers for Disease Control and Prevention)
- Jennifer Mead, MPH (Oregon Department of Health Services)
- Linda O. Nichols, PhD (U.S. Department of Veterans Affairs)
- Douglas D. Pace, NHA (Alzheimer's Association)
- Lonni Schicker, EdD, MHSA, RN (Persons with Dementia Stakeholder Group)
- Jane Tilly, DrPH (Administration for Community Living)
- Lois A. Tully, PhD (National Institute of Nursing Research)
- Teresa Webb, RN (Persons with Dementia Stakeholder Group)
- Joan Weiss, PhD, RN (Health Resources and Services Administration)

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<sup>3</sup> See <https://aspe.hhs.gov/national-research-summit-care-services-and-supports-persons-dementia-and-their-caregivers-steering-committee>.

# APPENDIX B: STAKEHOLDER GROUPS AND REPORTS<sup>4</sup>

## FAMILY CAREGIVERS

### MEMBERS

#### *Co-chairs:*

- Gail Hunt (National Alliance for Caregiving)
- Laurie Lindberg (Gerontological Society of America)
- Donna Walberg (Alzheimer's Disease Initiative)

#### *Members:*

- Venoreen Browne-Boatswain
- Bridget Fultz
- Ellen J. Goudeau
- Sharon Hall
- Ronald R.J. Hendler
- Mary C. Hogan
- Dorothy Horne
- Kamala Jones
- Janna Kaplan
- Felita Ramirez
- Delma Salazar
- Sowande Tichawonna
- Geraldine Woolfolk
- Anita Yuskas

### REPORTS

- **Family Caregivers Stakeholder Group Interviews** <https://aspe.hhs.gov/pdf-report/family-caregivers-stakeholder-group-interviews>
- **Family Caregiver Stakeholder Workgroup Research Recommendations** <https://aspe.hhs.gov/pdf-report/family-caregiver-stakeholder-workgroup-research-recommendations>
- **Top Six Research Outcomes: Family Caregiver Stakeholder Workgroup** <https://aspe.hhs.gov/pdf-report/top-six-research-outcomes-family-caregiver-stakeholder-workgroup>

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## PERSONS LIVING WITH DEMENTIA

### MEMBERS

#### *Co-chairs:*

- Gary Epstein-Lubow (Brown University)
- Lonni Schicker
- Emily Shubeck (Alzheimer's Association)
- Teresa Webb

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<sup>4</sup> See <https://aspe.hhs.gov/national-research-summit-care-services-and-supports-persons-dementia-and-their-caregivers-stakeholder-groups>.

**Members:**

- Pat Etienne
- Bill Holmstrom
- Cynthia Huling Hummel
- Edward K. Kaplan
- Brian LeBlanc
- Myriam Marquez
- Brenda Nicholson
- Greg O'Brien
- Louise Phillips
- Brian Van Buren

**REPORTS**

- **Persons Living with Dementia Stakeholder Group Interviews**  
<https://aspe.hhs.gov/pdf-report/persons-living-dementia-stakeholder-group-interviews>
- **Research Recommendations: Top 6 Outcomes that Matter** <https://aspe.hhs.gov/pdf-report/research-recommendations-top-6-outcomes-matter>

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**STATE GOVERNMENT PROGRAMS**

**MEMBERS**

**Co-chairs:**

- David Hoffman (New York State Department of Health)
- Helen M. Matheny (West Virginia University Health Sciences Center)
- Jennifer Mead (Oregon Department of Human Services)

**Members:**

- Tomas Aguilar
- Kirsten Aird
- Danni Atkins
- Basia Belza
- Heather Borski
- Devin Bowers
- Debra Cherry
- Paula Clayton
- Mehul Dalal
- Leisa Easom
- Molly French
- Judith Gabriele
- W.T. Geary Jr.
- Thea Griffin
- Whitney C. Hammond
- Julie Hohn
- Melita Jordan
- Gabriel Kaplan
- Lisa McGuire
- Carol McPhillips-Tangum
- Lynn M. Meinor
- Sharon Moffatt
- Gwen Moni
- Lisa Morley
- B. Michael Nayeri
- Caroline Newkirk
- Jean O'Connor
- Caroline Peck
- Kristi Pier
- Kristen Rego
- Sharon Rhyne
- John W. Robitscher
- Kathy Rocco
- Linda Scarpetta
- Peggy Spaulding
- Sally Steiner
- Lesly Steinman
- Robyn Taylor
- Pamela Van Zyl York
- Kaylene Way
- Rhonda Williams
- Namvar Zohoori

## REPORTS

- **State Programs Stakeholder Group Interviews** <https://aspe.hhs.gov/pdf-report/state-programs-stakeholder-group-interviews>
- **Final Recommendations on Outcomes that Matter** <https://aspe.hhs.gov/pdf-report/final-recommendations-outcomes-matter>

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## SERVICE PROVIDERS

### MEMBERS

#### **Co-chairs:**

- Sarah Lock (AARP)
- Douglas Pace (Alzheimer's Association)

#### **Members:**

- Lisa Baron
- Ellen Blackwell
- Alice Bonner
- Malaz Boustani
- Goldie Byrd
- Kelly Carney
- Molly Carpenter
- Jennifer Carson
- Deke Cateau
- Jill Cigililana
- Patrick Doyle
- Vanessa Emm
- Jonathan Evans
- Maribeth Gallagher
- Molly Rees Gavin
- Matthew P. Janicki
- Juliet Holt Klinger
- Neda McGuire
- Amy McLean
- Sheila Molony
- Lori Nisson
- Henry Pacheco
- Cathy Piersol
- Lindsay Schwartz
- Kelly Smith Papa
- Nora Super
- Teresa Theophano
- Liz Weaver

## REPORTS

- **Service Providers Stakeholder Group Interviews** <https://aspe.hhs.gov/pdf-report/service-providers-stakeholder-group-interviews>
- **Service Provider Stakeholder Workgroup Recommendations** <https://aspe.hhs.gov/pdf-report/provider-stakeholder-workgroup-recommendations>
- **Service Provider Stakeholder Workgroup Recommendations II** <https://aspe.hhs.gov/pdf-report/provider-stakeholder-workgroup-recommendations-ii>

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# WORKFORCE DEVELOPMENT

## MEMBERS

### *Co-chairs:*

- Elyse Perweiler (Rowan University School of Osteopathic Medicine)
- Nina Tumosa (Health Resources and Services Administration)
- Joan Weiss (Health Resources and Services Administration)

### *Members:*

- Daniel A. Bailey
- Mary Ann Forceia
- Toni P. Miles
- Elyse Perweiler
- Susan Tebb
- Scott A. Trudeau
- Mary E. Worstell

## REPORTS

- ***Workforce Development Stakeholder Group Interviews*** <https://aspe.hhs.gov/pdf-report/workforce-development-stakeholder-group-interviews>
- ***Workforce Gaps in Dementia Education and Training*** <https://aspe.hhs.gov/pdf-report/workforce-gaps-dementia-education-and-training>

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# PAYERS

## MEMBERS

### *Chair:*

- Elizabeth Goodman (Massachusetts Executive Office of Elder Affairs and MassHealth)

## REPORTS

- ***Feedback from Health Insurance Companies Regarding Evidence-Based Research for Dementia Care*** <https://aspe.hhs.gov/pdf-report/feedback-health-insurance-companies-regarding-evidence-based-research-dementia-care>

# APPENDIX C: RTI BACKGROUND PAPERS AND ISSUES BRIEFS<sup>5</sup>

## BACKGROUND PAPERS

***Research on Care Needs and Supportive Approaches for Persons with Dementia***

<https://aspe.hhs.gov/pdf-report/research-care-needs-and-supportive-approaches-persons-dementia>

***Research on Supportive Approaches for Family and Other Caregivers***

<https://aspe.hhs.gov/pdf-report/research-supportive-approaches-family-and-other-caregivers>

***Including People with Dementia and Their Caregivers as Co-Researchers in Studies of Dementia Care and Services***

<https://aspe.hhs.gov/pdf-report/including-people-dementia-and-their-caregivers-co-researchers-studies-dementia-care-and-services>

***Challenges in Involving People with Dementia as Study Participants in Research on Care and Services***

<https://aspe.hhs.gov/pdf-report/challenges-involving-people-dementia-study-participants-research-care-and-services>

***Research on Care Coordination for People with Dementia and Family Caregivers***

<https://aspe.hhs.gov/pdf-report/research-care-coordination-people-dementia-and-family-caregivers>

***Translation, Dissemination, Implementation, and Scaling Up of Effective Care, Services, and Supportive Approaches for Persons with Dementia and Their Caregivers***

<https://aspe.hhs.gov/pdf-report/translation-dissemination-implementation-and-scaling-effective-care-services-and-supportive-approaches-persons-dementia-and-their-caregivers>

## ISSUE BRIEFS

***The Use of Assistive Technology to Reduce Caregiver Burden***

<https://aspe.hhs.gov/pdf-report/use-assistive-technology-reduce-caregiver-burden>

***Caregiving for People with Non-Alzheimer's Dementias***

<https://aspe.hhs.gov/pdf-report/caregiving-people-non-alzheimers-dementias-issue-brief>

***Living Arrangements of People with Alzheimer's Disease and Related Dementias: Implications for Services and Supports***

<https://aspe.hhs.gov/pdf-report/living-arrangements-people-alzheimers-disease-and-related-dementias-implications-services-and-supports>

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<sup>5</sup> All available Summit material is available at <https://aspe.hhs.gov/national-research-summit-care-services-and-supports-persons-dementia-and-their-caregivers-available-material#SessionBackground>.

## APPENDIX D: PRE-SUMMIT TITLES AND REPORTS<sup>6</sup>

### PSYCHOSOCIAL OUTCOME MEASURES IN DEMENTIA CARE

Alzheimer's Association

#### CO-CHAIRS

- Sam Fazio, PhD (Alzheimer's Association)
- Beth Kallmyer, MSW (Alzheimer's Association)

#### PRESENTATION

- ***New Directions in Measurement for Psychosocial Research on Dementia Care and Services: Report from Two Pre-Summit Meetings*** (No formal paper was done for this Pre-Summit activity.) <https://aspe.hhs.gov/pdf-document/research-summit-dementia-care-new-directions-psychosocial-research>

### ACCELERATING DEVELOPMENT, TESTING AND DISSEMINATION OF HOME-BASED DEMENTIA CARE INTERVENTIONS

BrightFocus Foundation

#### CO-CHAIRS

- Constantine Lyketsos, MD, MHS, DFAPA, FAPM, FACNP (Johns Hopkins School of Medicine)
- Quincy Miles Samus, PhD, MS (Johns Hopkins School of Medicine)

#### PRE-SUMMIT PAPER

- ***Home is Where the Future Is: The BrightFocus Foundation Concensus Panel on Dementia Care*** [https://www.alzheimersanddementia.com/article/s1552-5260\(17\)33807-4/pdf](https://www.alzheimersanddementia.com/article/s1552-5260(17)33807-4/pdf)

### SYSTEMATIC REVIEW OF DETERMINANTS OF BEHAVIORAL SYMPTOMS

Council for the Advancement of Nursing Science, American Academy of Nursing

#### CHAIR

- Ann Kolanowski, PhD, RN, FGSA, FAAN (Pennsylvania State University)

#### PRE-SUMMIT PAPER

- ***Determinants of Behavioral and Psychological Symptoms of Dementia: A Scoping Review of the Evidence*** [https://www.nursingoutlook.org/article/S0029-6554\(17\)30097-0/fulltext](https://www.nursingoutlook.org/article/S0029-6554(17)30097-0/fulltext)

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<sup>6</sup> See <https://aspe.hhs.gov/national-research-summit-care-services-and-supports-persons-dementia-and-their-caregivers-pre-summit-activities>.

## **DEMENTIA CAREGIVING IN THE UNITED STATES: A SECONDARY DATA ANALYSIS OF THE CAREGIVING IN THE U.S. 2015 REPORT**

National Alliance on Caregiving and Alzheimer's Association

### **CO-CHAIRS**

- Gail Gibson Hunt (National Alliance for Caregiving)
- Grace Whiting, JD (National Alliance for Caregiving)

### **PRE-SUMMIT PAPER**

- *Dementia Caregiving in the U.S.: Research Recommendations*  
<https://aspe.hhs.gov/pdf-report/dementia-caregiving-us-research-recommendations>

## **INNOVATING THE NEXT GENERATION OF DEMENTIA AND ALZHEIMER'S DISEASE CARE INTERVENTIONS: ADDRESSING THE NEEDS OF PERSONS LIVING WITH DEMENTIA, CAREGIVERS, AND CARE PROVIDERS**

National Institute on Aging

### **CO-CHAIRS**

- John Haaga, PhD (National Institute on Aging)
- Elena Fazio, PhD (National Institute on Aging)
- Lisa Onken, PhD (National Institute on Aging)

### **PRE-SUMMIT PAPER**

- *Innovating the Next Generation of Dementia and Alzheimer's Disease Care Interventions: Addressing the Needs of Persons Living with Dementia, Caregivers, and Care Providers*  
<https://aspe.hhs.gov/pdf-report/innovating-next-generation-dementia-and-alzheimers-disease-care-interventions-addressing-needs-persons-living-dementia-caregivers-and-care-providers>

## **CAREGIVING AND INTELLECTUAL/DEVELOPMENTAL DISABILITIES: CAREGIVERS OF PERSONS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES AND DEMENTIA**

National Task Group on Intellectual Disabilities and Dementia Practices, Rehabilitation Research and Training Center in Developmental Disabilities and Health, University of Illinois at Chicago, and the Alzheimer's Association

### **CO-CHAIRS**

- Matthew Janicki, PhD (University of Illinois at Chicago)
- Tamar Heller, PhD (University of Illinois at Chicago)

### **PRE-SUMMIT PAPER**

- *Caregiving and Intellectual and Developmental Disabilities and Dementia: Report of the Pre-Summit Workgroup on Caregiving and Intellectual and Developmental Disabilities*  
<https://aspe.hhs.gov/pdf-report/caregiving-and-intellectual-and-developmental-disabilities-and-dementia-report-pre-summit-workgroup-caregiving-and-intellectual-and-developmental-disabilities>



## **METHODOLOGICAL CONSIDERATIONS IN RESEARCH ON DEMENTIA CARE AND SERVICES**

Patient-Centered Outcomes Research Institute

### **CHAIR**

- Lori Frank, PhD (Patient-Centered Outcomes Research Institute)

### **PRE-SUMMIT PAPER**

- ***Dementia Methods Pre-Summit Summary and Recommendations***  
<https://aspe.hhs.gov/pdf-report/dementia-methods-pre-summit-summary-and-recommendations>

## **DIVERSITY AND ALZHEIMER'S DISEASE CAREGIVING**

University of California, Davis

### **CO-CHAIRS**

- Ladson Hinton, MD (University of California, Davis)
- Dr. Charles DeCarli
- Oanh Meyer, PhD, MAS (University of California, Davis)

### **PRE-SUMMIT PAPER**

- ***Dementia Family Caregiving: Recommendations from the University of California Davis Conference, Alzheimer's Disease Diversity and Disparities in Family Caregiving: Progress and Future Challenges*** <https://aspe.hhs.gov/pdf-report/dementia-family-caregiving>

# APPENDIX E: AGENDA AND SESSION MATERIAL<sup>7</sup>

## DAY ONE - OCTOBER 16, 2017

### WELCOME AND INTRODUCTORY REMARKS

#### SUMMIT CO-CHAIRS

- Laura N. Gitlin, PhD, Johns Hopkins University
- Katie Maslow, MSW, Gerontological Society of America

#### SPONSOR REMARKS

- ***Advancing Research Toward Care and Support Solutions***
  - Harry Johns (Alzheimer's Association)
- ***The Imperative of Diverse Voices and Collaborative Decision Making***
  - Ian Kremer, JD (Leaders Engaged on Alzheimer's Disease)
- ***Setting Care Goals for 2025***
  - George Vradenburg (UsAgainstAlzheimer's)

### PLENARY LECTURES: CONTEXT FOR THE SUMMIT

- ***View from the Advisory Council on Alzheimer's Research, Care, and Services***
  - Ronald C. Petersen, MD, PhD (Mayo Clinic College of Medicine)
- ***Biomedical and Care Research in Dementia: Interdependent and Complementary***
  - Maria C. Carrillo, PhD (Alzheimer's Association)

### PLENARY LECTURES: DEMOGRAPHIC FRAMEWORK

- ***Demographics of Dementia and Dementia Caregiving: Key Changes in the Decades Ahead***
  - Ken Langa, MD, PhD (University of Michigan)
- ***Deconstructing Race, Ethnicity, and Culture for ADRD Research***
  - Jennifer Manly, PhD (Columbia University)
- ***Implications of Diversity in Dementia Care, Services, and Supports***
  - Maria Aranda, PhD, MSW, MPA, LCSW (University of Southern California)

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<sup>7</sup> See <https://aspe.hhs.gov/national-research-summit-care-services-and-supports-persons-dementia-and-their-caregivers-agenda-and-session-material> links to speaker biographies and presentation slides.

# SESSION I: RESEARCH ON CARE NEEDS AND SUPPORTIVE APPROACHES FOR PERSONS WITH DEMENTIA

## SESSION CO-CHAIRS

- Richard H. Fortinsky, PhD (University of Connecticut School of Medicine)
- Ann Kolanowski, PhD, RN, FGSA, FAAN (Pennsylvania State University)

## SPEAKERS

- ***Causality Matters: Preventing and Mitigating Behavioral and Psychological Symptoms of Dementia***
  - Helen Kales, MD, PPA (University of Michigan)
- ***Maintaining and Supporting Function in Persons with Dementia***
  - Barbara Resnick, PhD, RN, CRNP, FAAN, FAANP (University of Maryland)
- ***Slowing Cognitive Decline and Supporting Resilience in Patients with Dementia***
  - Davangere P. Devanand, MD (Columbia University Medical Center)
- ***Home Is Where the Future Is: BrightFocus Foundation Consensus Panel on Dementia Care***
  - Constantine Lyketsos, MD, MHS, DFAPA, FAPM, FACNP (Johns Hopkins Medicine)
- ***Dementia Care in Residential Long-Term Care***
  - Sheryl Zimmerman, PhD (University of North Carolina at Chapel Hill)
- ***Technologies for Assessment and Interventions to Improve and Accelerate Dementia Care Research***
  - Jeffrey Kaye, MD (Oregon Health & Science University)

## BRIEF REPORTS AND COMMENTARIES

- ***Living Well with Dementia***
  - Melanie (Lonni) Schicker, EdD, MHSA, RN
- ***Researching Rhythms of Daily Life: The Role of Sleep and Daily Activity in Entraining Circadian Patterns***
  - Nancy A. Hodgson, PhD, RN, FAAN (University of Pennsylvania)
- ***Physical and Social Environments for Care and Services: Research Recommendations for the Design of Care Settings***
  - Margaret Calkins, PhD, EDAC (Mayer-Rothschild Foundation)
- ***Living Alone with Dementia: Identification, Unmet Needs, and Safety Concerns***
  - Elizabeth Gould, MSW (RTI International)
- ***Caregiving and Intellectual and Developmental Disabilities and Dementia: Report of the Pre-Summit Workgroup on Caregiving and Intellectual and Developmental Disabilities***
  - Tamar Heller, PhD (University of Illinois at Chicago)

# SESSION II: RESEARCH ON SUPPORTIVE APPROACHES FOR FAMILY AND OTHER CAREGIVERS

## SESSION CO-CHAIRS

- Linda Teri, PhD (University of Washington)
- Lisa Fredman, PhD (Boston University School of Public Health)

## **SPEAKERS**

- ***Supporting Family Caregivers Effectively: Lessons Learned from Research***
  - Linda Nichols, PhD (Memphis Veterans Affairs Medical Center)
- ***Evolving Knowledge About the Health Effects of Caregiving to Persons with Dementia and Other Conditions***
  - Lisa Fredman, PhD (Boston University School of Public Health)
- ***Dyadic Intervention: From Early Stage to End of Life***
  - Carol J. Whitlatch, PhD (Benjamin Rose Institute on Aging)
- ***The Use of Technology in the Support of Family Caregivers***
  - Sara Czaja, PhD (University of Miami)
- ***Innovating the Next Generation of Dementia and Alzheimer's Disease Care Interventions: Addressing the Needs of Persons Living with Dementia, Caregivers, and Care Providers***
  - Vincent Mor, PhD (Brown University)

## **BRIEF REPORTS AND COMMENTARIES**

- ***Personal Perspectives on Family Caregiving***
  - Sowande Tichawonna
- ***Dementia Family Caregiving: Recommendations from a Conference to Advance Interventions in Diverse Populations***
  - Oanh Meyer, PhD, MAS (University of California, Davis)
- ***Equity: A Powerful Force in the Future of Sexual and Gender Minority Dementia Caregiving***
  - Karen Fredriksen Goldsen, PhD (University of Washington)
- ***Dementia Caregiving in the U.S. Research Recommendations***
  - Gail Gibson Hunt (National Alliance for Caregiving)
- ***Family Caregiving's Impact on Women***
  - Mary E. Worstell, MPH (U.S. Department of Health and Human Services)

## **SESSION III: INVOLVING PERSONS WITH DEMENTIA AND CAREGIVERS AS MEMBERS OF THE RESEARCH TEAM**

### **SESSION CO-CHAIRS**

- Mark Snowden, MD, MPH (University of Washington)
- Lee Jennings, MD, MSHS (University of Oklahoma)

### **SPEAKERS**

- ***Principles and Practices for Engagement in Research***
  - Lori Frank, PhD (Patient-Centered Outcomes Research Institute)
- ***Challenges and Solutions for Involving Persons with Dementia and Dementia Family Caregivers as Members of the Research Team***
  - Jason Karlawish, MD (University of Pennsylvania)
- ***European Perspectives and Experience in Involving Persons with Dementia and Dementia Family Caregivers as Members of the Research Team***
  - James Pickett, PhD (Alzheimer's Society)

## BRIEF REPORTS AND COMMENTARIES

- ***Person with Dementia Perspective on Participating as a Member of the Research Team***
  - Teresa Webb, RN
- ***The Who, What, Why, When, and Where of Care Partners in Research***
  - Sharon Hall

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## DAY TWO - OCTOBER 17, 2017

### PLENARY SESSION: NOMENCLATURE: WORDS MATTER

#### SPEAKERS

- ***The Terminology Issues***
  - Ronald C. Petersen, MD, PhD (Mayo Clinic College of Medicine)
- ***Effect of Stigma on Access to Care and Services***
  - Angela Taylor (Lewy Body Dementia Association)
- ***Perspectives of a Family Affected by Dementia***
  - Edward K. Kaplan, PhD (Brandeis University)
  - Janna Kaplan, MSc (Brandeis University)

### SESSION IV: INVOLVING PERSONS WITH DEMENTIA AS STUDY PARTICIPANTS

#### SESSION CO-CHAIRS

- Darby Morhardt, PhD, LCSW (Northwestern University)
- David M. Bass, PhD (Benjamin Rose Institute on Aging)

#### SPEAKERS

- ***Clinical Heterogeneity of Dementia and Impact on Research Participation***
  - Sandra Weintraub, PhD (Northwestern University)
- ***Work with Us! We Want to Help: Perspectives of a Person with Dementia on Involvement as a Study Participant***
  - Cynthia Huling Hummel, BS, MDiv, DMin
- ***Role of Research in Examining and Understanding the Illness Experience of Individuals with Dementia***
  - Katherine S. Judge, PhD (Cleveland State University)
- ***Measuring Disease Impact on People Living with Dementia: PCORI Pre-Summit Summary***
  - Darby Morhardt, PhD, LCSW (Northwestern University)
  - Lisa Gwyther, MSW, LCSW (Duke University)

# SESSION V: RESEARCH ON MODELS OF CARE FOR PERSONS LIVING WITH DEMENTIA AND THEIR FAMILIES ACROSS THE DISEASE TRAJECTORY

## SESSION CO-CHAIRS

- Vincent Mor, PhD (Brown University)
- David B. Reuben, MD (University of California, Los Angeles)

## DEMENTIA-SPECIFIC MODELS OF CARE

- ***Components of a Comprehensive Care Model for Dementia***
  - David M. Bass, PhD (Benjamin Rose Institute on Aging)
- ***Health System-Based Models of Dementia Care: Characteristics, Challenges, and Opportunities***
  - Zaldy S. Tan, MD, MPH (University of California, Los Angeles)
- ***Community-Based Models of Dementia Care: Characteristics, Challenges, and Opportunities***
  - Quincy Miles Samus, PhD, MS (Johns Hopkins School of Medicine)

## GENERAL MODELS OF CARE THAT INCLUDE PERSONS WITH DEMENTIA

- ***Successful VA Innovations in Geriatric Care***
  - Thomas E. Edes, MD, MS (U.S. Department of Veterans Affairs)
- ***Dementia Care Management within the Federal Financial Alignment Demonstration***
  - Debra L. Cherry, PhD (Alzheimer's Greater Los Angeles)
- ***Consumer-Directed Care Models***
  - Julie Robison, PhD (University of Connecticut)
- ***Service Provider and Payer Reactor Panel***
  - Shari M. Ling, MD (Centers for Medicare & Medicaid Services)
  - Steve Waring, DVM, PhD (Essentia Institute of Rural Health)
  - Nora Super, MPA (National Association of Area Agencies on Aging)

## FACILITATORS OF MODELS OF CARE FOR PERSONS LIVING WITH DEMENTIA AND THEIR FAMILIES

- ***Workforce Size, Composition, Retention, and Competence***
  - Gregg Warshaw, MD (University of North Carolina at Chapel Hill)
- ***Quality Measures***
  - Gary Epstein-Lubow, MD (Brown University/Hebrew SeniorLife)
  - Louise Phillips, MD
  - off-site contribution from Brenda Nicholson, MD
- ***Scaling Up: Research to Promote Diffusion of Successful Model***
  - David B. Reuben, MD (University of California, Los Angeles)

## SESSION VI: THINKING OUTSIDE THE BOX

### SESSION CO-CHAIRS

- Christopher Callahan, MD ( Indiana University School of Medicine)
- Alan B. Stevens, PhD (Baylor Scott & White Health)

### PLENARY LECTURES: THINKING OUTSIDE THE BOX

- ***Moving Forward Faster to Provide Care Together***
  - Christopher Callahan, MD (Indiana University School of Medicine)
- ***Retail and the Consumer Lens: An Outside Perspective***
  - Raha Alavi (Nielsen Retail Services)
- ***Translation and Implementation of Effective Care, Services, and Supports Keeping Research Relevant: Moving from RCT to Practice***
  - Linda Teri, PhD (University of Washington)
- ***Adapting Effective Interventions to Accommodate Concerns About Delivery Time, Cost, and Available Staff***
  - Mary Mittelman, DrPH (New York University)
- ***Evidence-Based Programs: Mapping Out the Future***
  - Leisa R. Easom, PhD, RN (Rosalynn Carter Institute for Caregiving)
- ***Integrating Evidence-Based Dementia Care Programs into Existing Service and Reimbursement Systems***
  - Richard H. Fortinsky, PhD (University of Connecticut School of Medicine)

### INNOVATIVE RESEARCH METHODS AND OUTCOMES

- ***Research Methods for Dementia Care and Services***
  - Brian Mittman, PhD (Kaiser Permanente; U.S. Department of Veteran Affairs)
- ***Stakeholder Perspectives on Research Outcomes that Matter***
  - Sarah Lenz Lock, JD (AARP)
- ***New Directions in Measurement for Psychosocial Research on Dementia Care and Services: Report from Two Pre-Summit Meetings***
  - Sam Fazio, PhD (Alzheimer's Association)
- ***Understanding What Matters Most to Inform Care and Services Research***
  - Debra Lappin, JD (Faegre Baker Daniels Consulting)

### NEW DIRECTIONS FROM DIFFERENT VANTAGE POINTS

#### ***Moderator***

- Laura N. Gitlin, PhD (Johns Hopkins University)

#### ***Discussants***

- Mark Snowden, MD, MPH (University of Washington)
- Alan B. Stevens, PhD (Baylor Scott & White Health)
- Joseph E. Gaugler, PhD (University of Minnesota)
- Alice Bonner, PhD, RN, FAAN (Massachusetts Executive Office of Elder Affairs)
- Amy M. Kilbourne, PhD, MPH (Veterans Health Administration)
- Lisa Onken, PhD (National Institute on Aging)

## **WRAP UP**

### **SUMMIT CO-CHAIRS**

- Laura N. Gitlin, PhD (Johns Hopkins University)
- Katie Maslow, MSW (Gerontological Society of America)

### **SPEAKERS**

- Greg O'Brien
- Venoreen Browne-Boatswain, MEd