



## Main Summit Recommendations

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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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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.<sup>1</sup> 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>

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<sup>1</sup> This paper is taken from the final Summit report -- *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* -- available at <https://aspe.hhs.gov/basic-report/national-research-summit-care-services-and-supports-persons-dementia-and-their-caregivers-final-summit-report>.

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

# 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 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	

<b>THEME 1 TABLE (continued)</b>	
<b>Person Living with dementia</b>	<b>Caregivers</b>
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
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

## 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.

## 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.

## 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.



## 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.

## 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

# 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.

## 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)
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

<b>THEME 12 TABLE (continued)</b>
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