RESEARCH SUMMIT ON
DEMENTIA CARE
Building Evidence for Services and Supports

FINAL REPORT TO THE NAPA ADVISORY COUNCIL

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Presentation to the Advisory Council on Alzheimer's Research, Care, and Services
April 27, 2018

Overview and Context for the Recommendations

- The recommendations in this report are distilled from nearly 700 research recommendations submitted by summit participants.
- The summit brought together a wide array of stakeholders to build understanding about the many different topics and issues they are working on and concerned about.
- The summit recommendations are relevant to this wide array of stakeholders (persons living with dementia, caregivers, researchers, research funders, foundations, service providers, advocacy groups, payers, professional and provider organizations, and others).
- The recommendations were made by attendant stakeholders and experts and are not intended to commit any organization or group to any particular action

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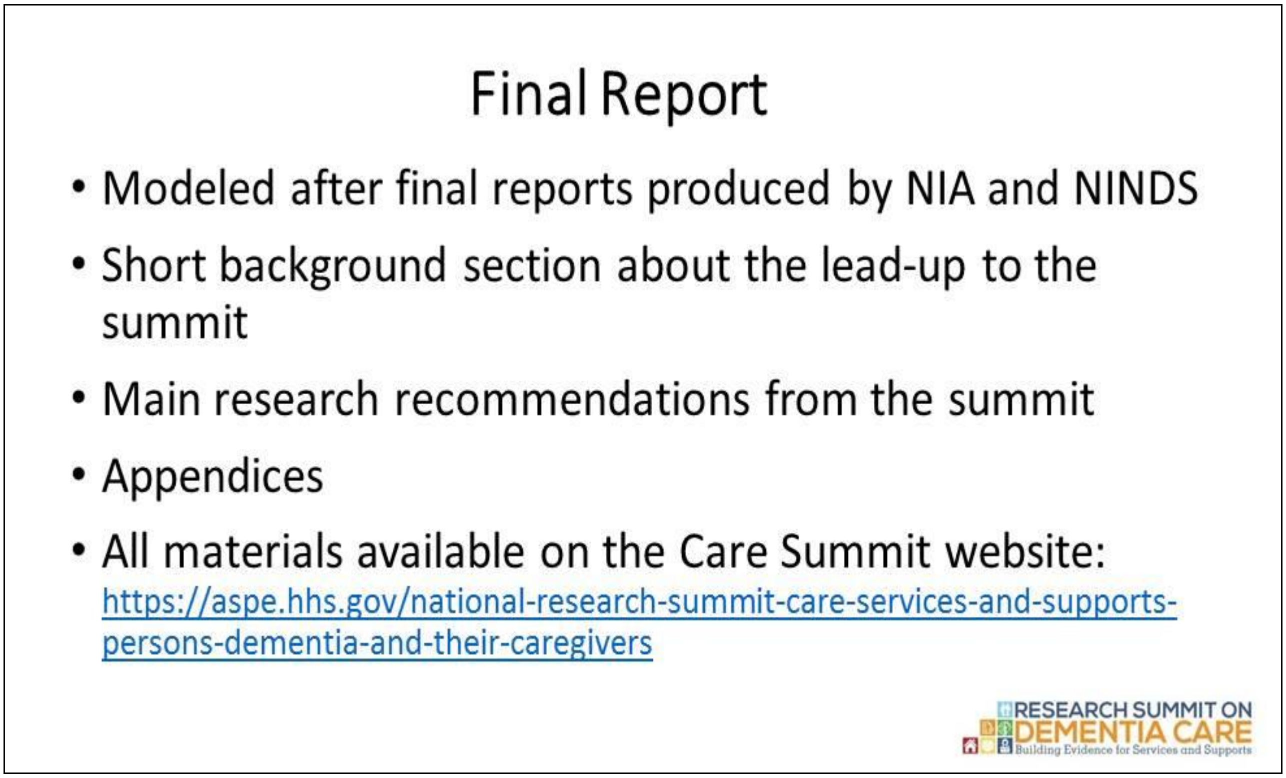

Final Report

- Modeled after final reports produced by NIA and NINDS
- Short background section about the lead-up to the summit
- Main research recommendations from the summit
- Appendices
- All materials available on the Care Summit website: https://aspe.hhs.gov/national-research-summit-care-services-and-supports-persons-dementia-and-their-caregivers

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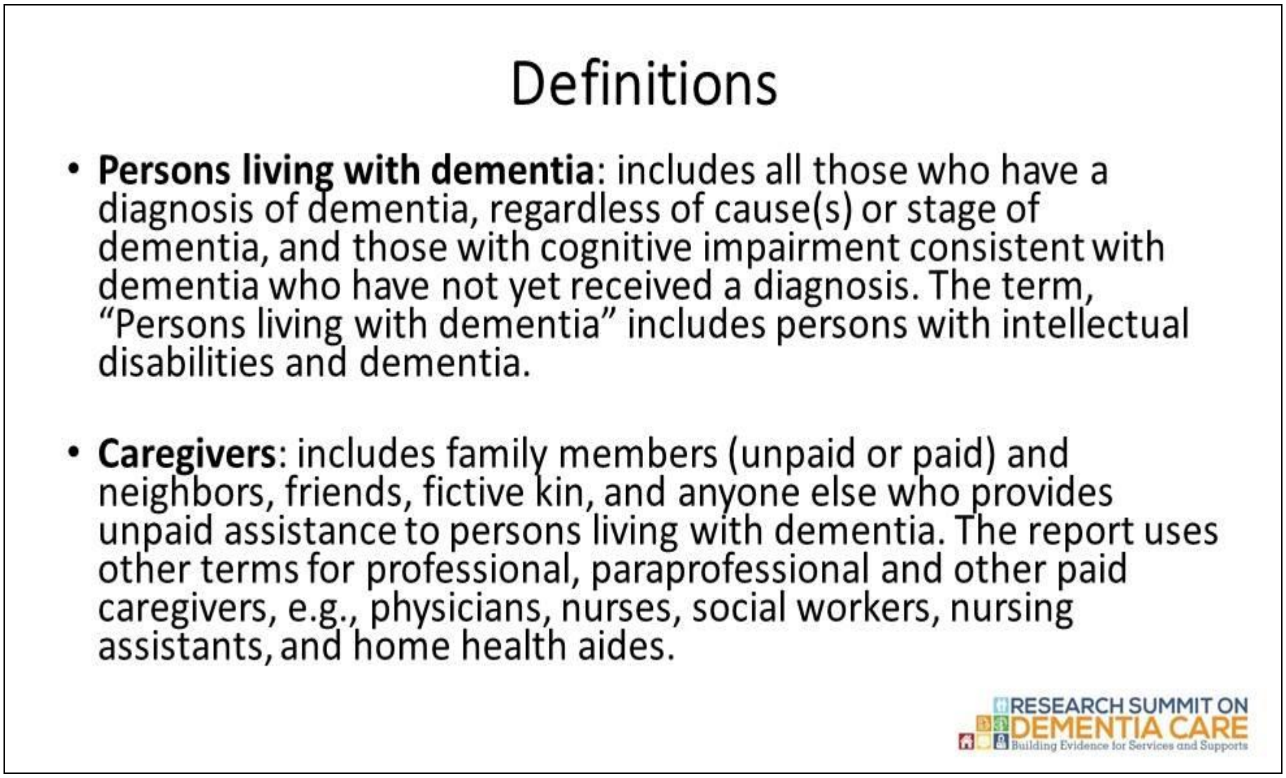

Definitions

- **Persons living with dementia**: includes all those who have a diagnosis of dementia, regardless of cause(s) or stage of dementia, and those with cognitive impairment consistent with dementia who have not yet received a diagnosis. The term, "Persons living with dementia" includes persons with intellectual disabilities and dementia.
- **Caregivers**: includes family members (unpaid or paid) and neighbors, friends, fictive kin, and anyone else who provides unpaid assistance to persons living with dementia. The report uses other terms for professional, paraprofessional and other paid caregivers, e.g., physicians, nurses, social workers, nursing assistants, and home health aides.

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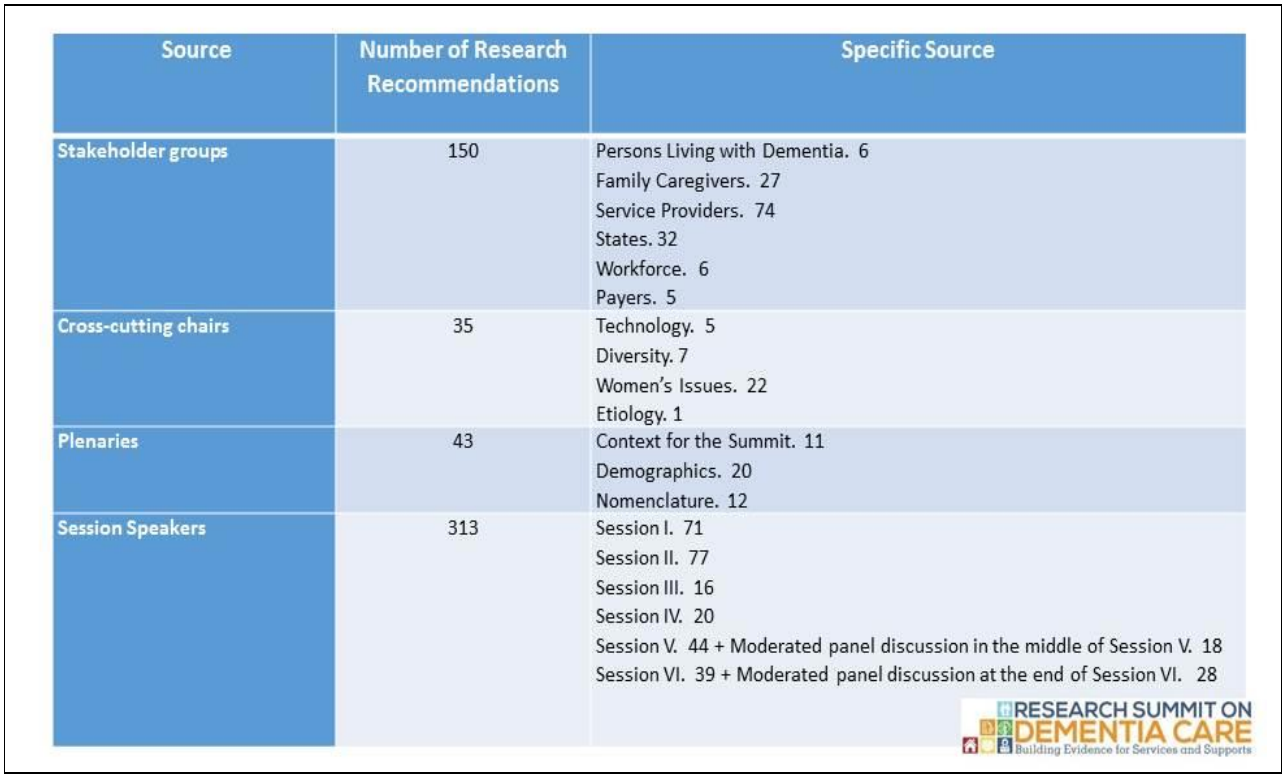

Source	Number of Research Recommendations	Specific Source
Stakeholder groups	150	Persons Living with Dementia. 6 Family Caregivers. 27 Service Providers. 74 States. 32 Workforce. 6 Payers. 5
Cross-cutting chairs	35	Technology. 5 Diversity. 7 Women's Issues. 22 Etiology. 1
Plenaries	43	Context for the Summit. 11 Demographics. 20 Nomenclature. 12
Session Speakers	313	Session I. 71 Session II. 77 Session III. 16 Session IV. 20 Session V. 44 + Moderated panel discussion in the middle of Session V. 18 Session VI. 39 + Moderated panel discussion at the end of Session VI. 28

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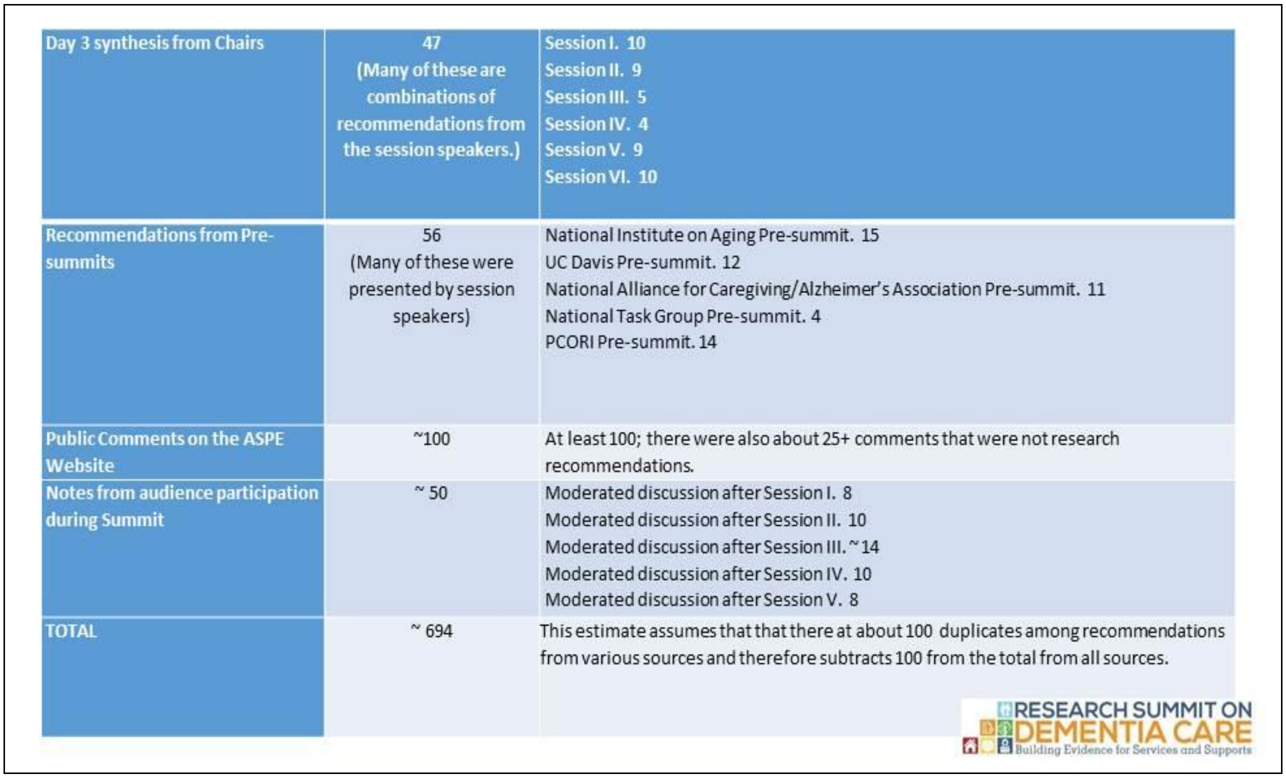

Day 3 synthesis from Chairs	**47** **(Many of these are combinations of recommendations from the session speakers.)**	**Session I. 10** **Session II. 9** **Session III. 5** **Session IV. 4** **Session V. 9** **Session VI. 10**
Recommendations from Pre-summits	56 (Many of these were presented by session speakers)	National Institute on Aging Pre-summit. 15 UC Davis Pre-summit. 12 National Alliance for Caregiving/Alzheimer's Association Pre-summit. 11 National Task Group Pre-summit. 4 PCORI Pre-summit. 14
Public Comments on the ASPE Website	~100	At least 100; there were also about 25+ comments that were not research recommendations.
Notes from audience participation during Summit	~ 50	Moderated discussion after Session I. 8 Moderated discussion after Session II. 10 Moderated discussion after Session III. ~14 Moderated discussion after Session IV. 10 Moderated discussion after Session V. 8
TOTAL	~ 694	This estimate assumes that that there at about 100 duplicates among recommendations from various sources and therefore subtracts 100 from the total from all sources.

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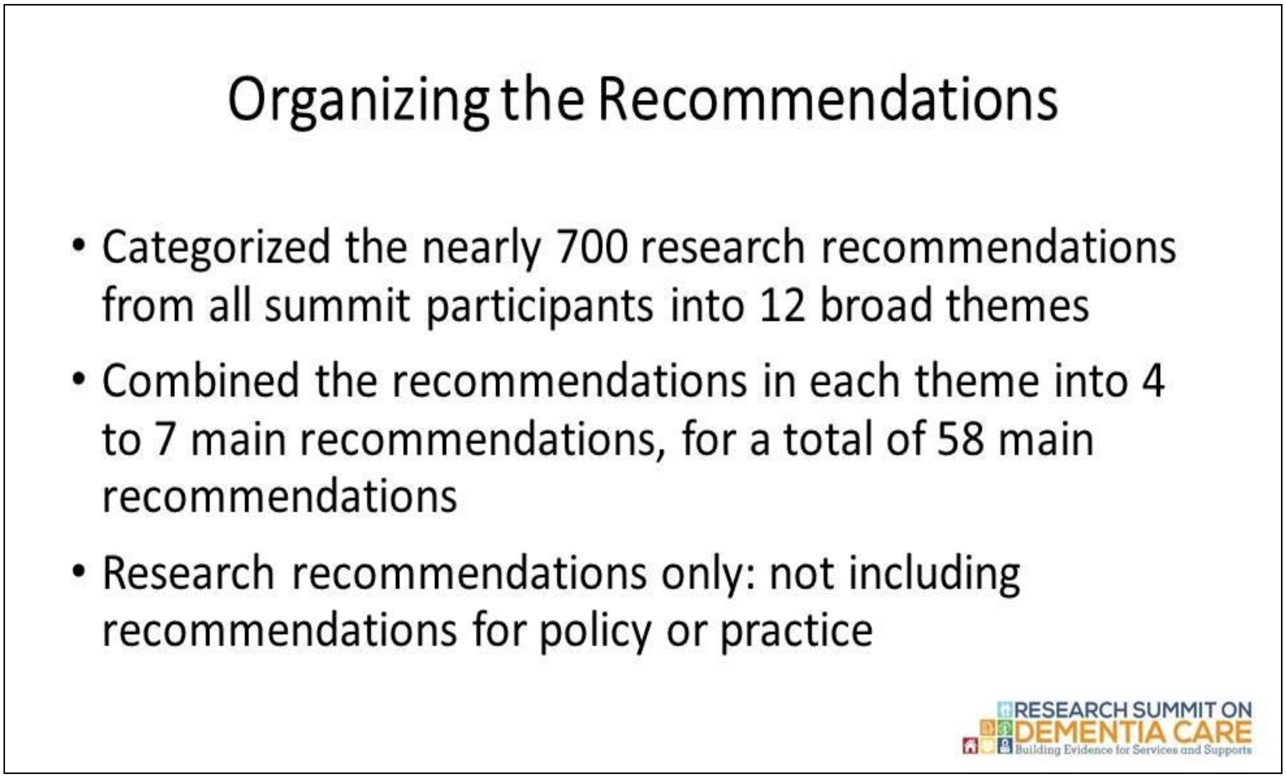

Organizing the Recommendations

- Categorized the nearly 700 research recommendations from all summit participants into 12 broad themes
- Combined the recommendations in each theme into 4 to 7 main recommendations, for a total of 58 main recommendations
- Research recommendations only: not including recommendations for policy or practice

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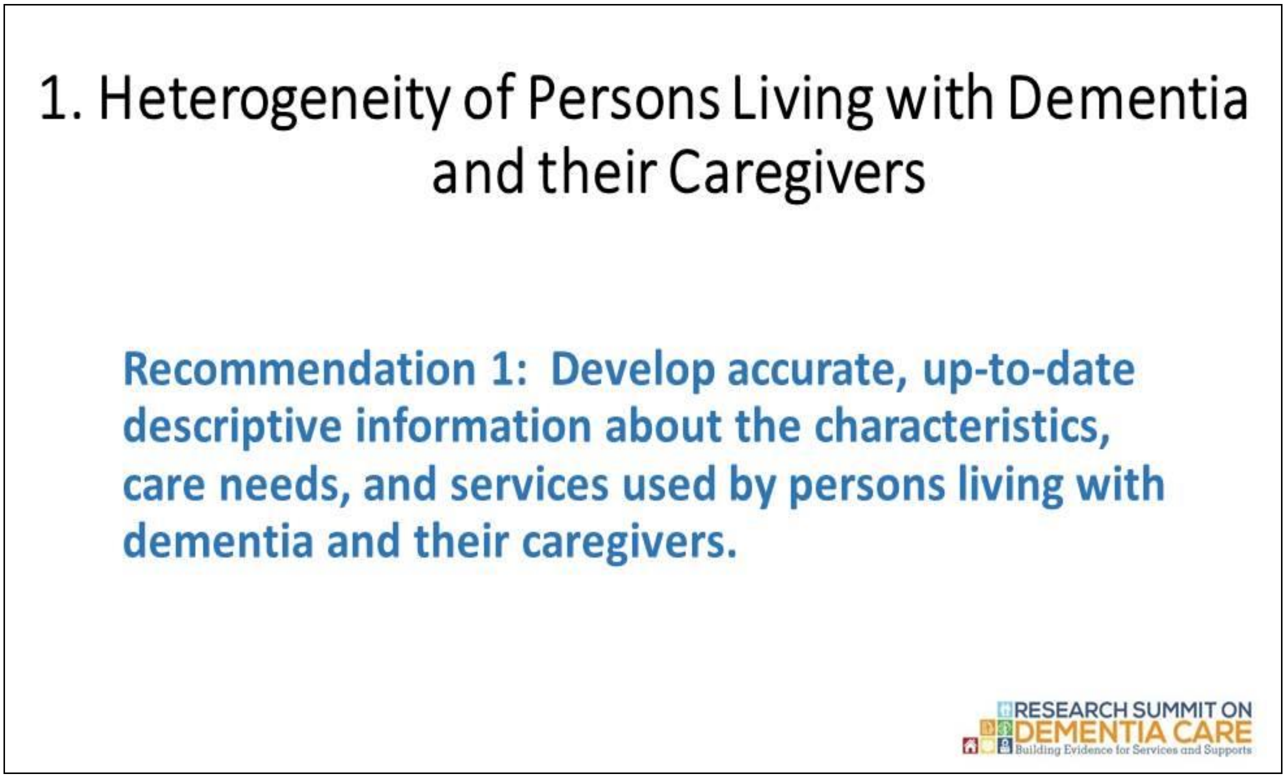

1. Heterogeneity of Persons Living with Dementia and their Caregivers

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.

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2. Research Methods to Develop More Effective Dementia Care, Services, and Supports

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.

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3. Caregiver Relationships, Roles, and Networks

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

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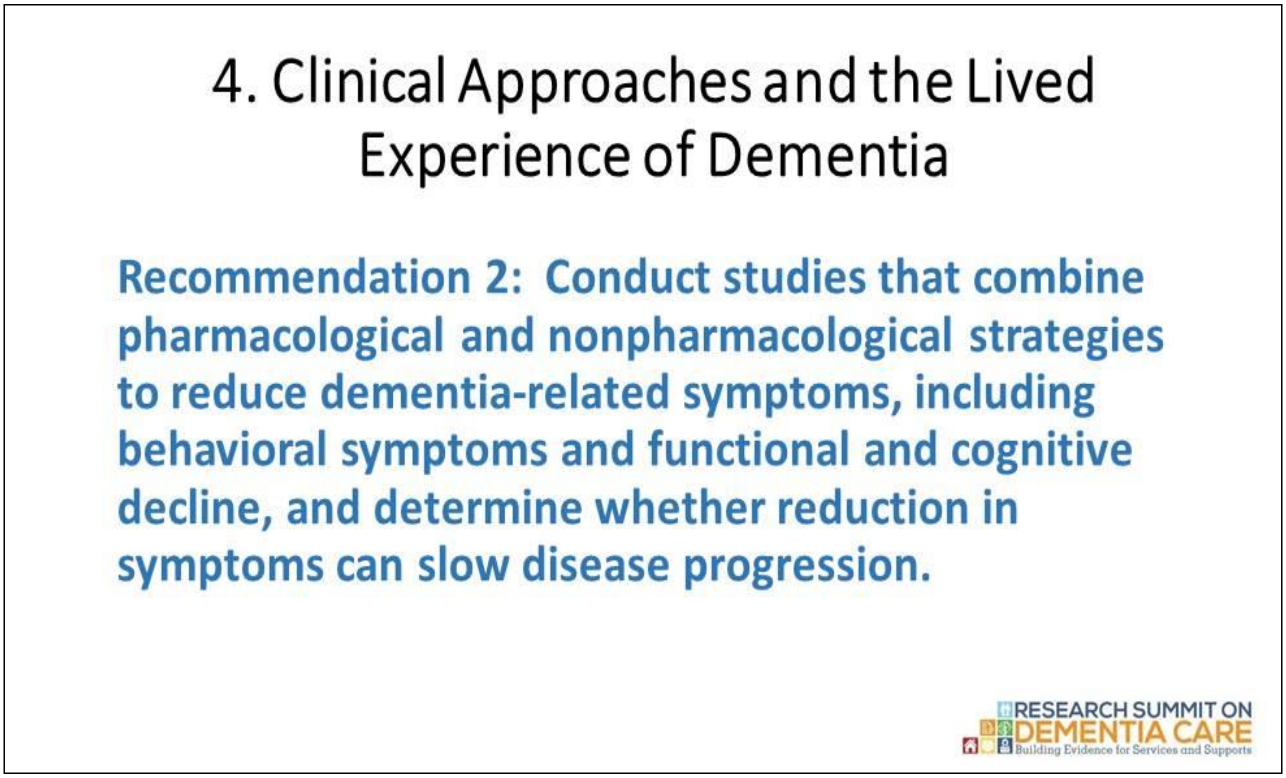

4. Clinical Approaches and the Lived Experience of Dementia

Recommendation 2: Conduct studies that combine pharmacological and nonpharmacological strategies to reduce dementia-related symptoms, including behavioral symptoms and functional and cognitive decline, and determine whether reduction in symptoms can slow disease progression.

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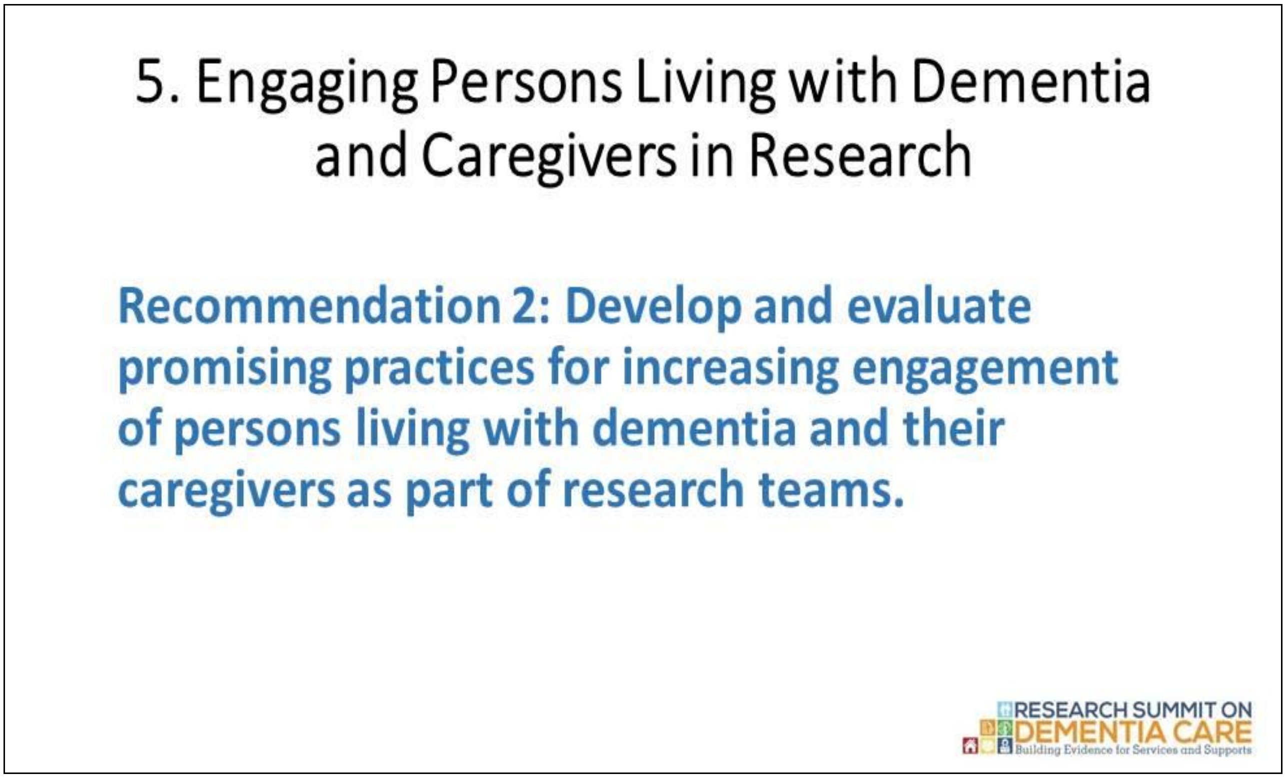

5. Engaging Persons Living with Dementia and Caregivers in Research

Recommendation 2: Develop and evaluate promising practices for increasing engagement of persons living with dementia and their caregivers as part of research teams.

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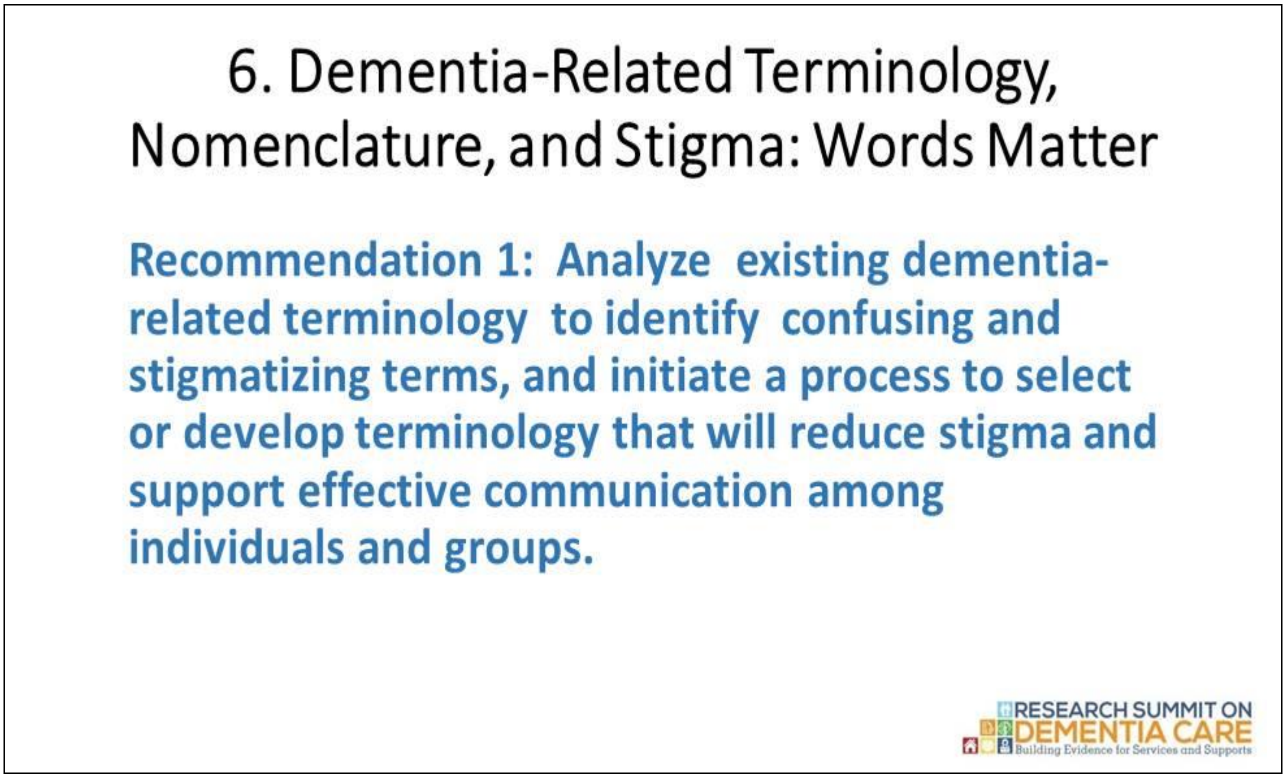

6. Dementia-Related Terminology, Nomenclature, and Stigma: Words Matter

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.

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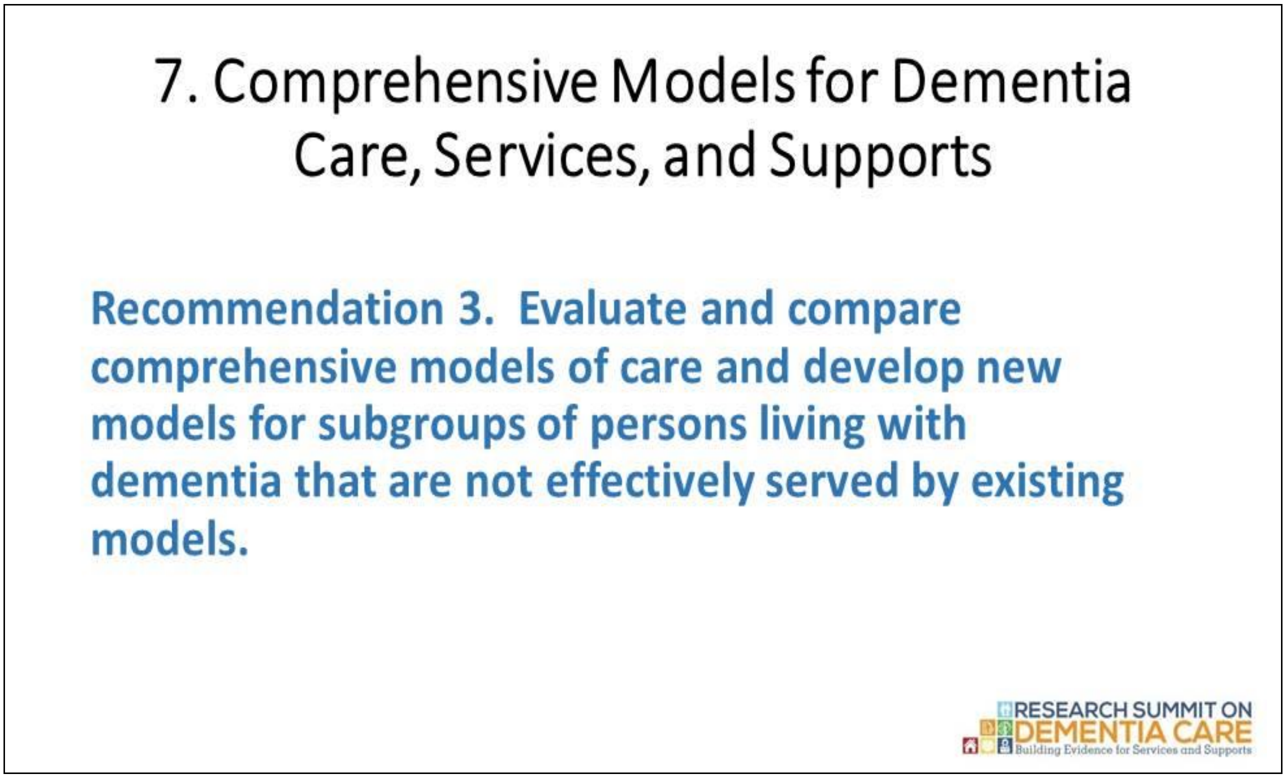

7. Comprehensive Models for Dementia Care, Services, and Supports

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.

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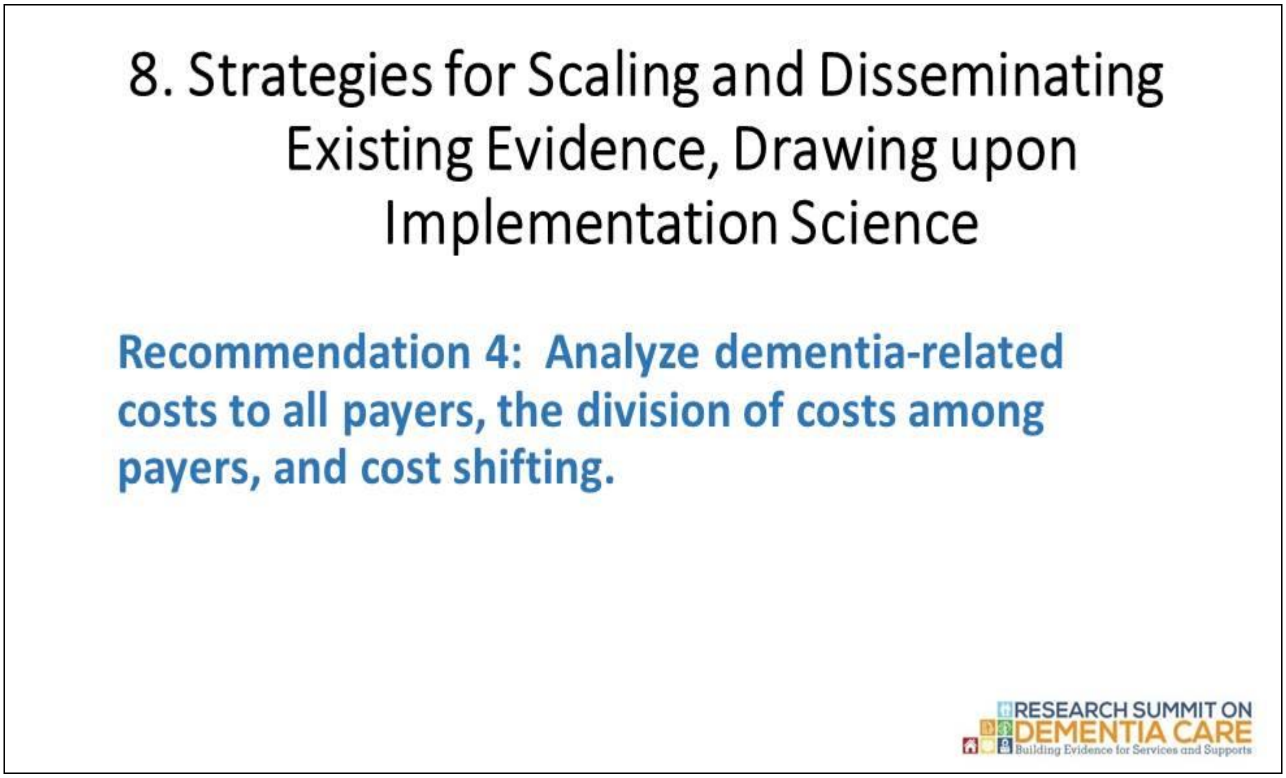

8. Strategies for Scaling and Disseminating Existing Evidence, Drawing upon Implementation Science

Recommendation 4: Analyze dementia-related costs to all payers, the division of costs among payers, and cost shifting.

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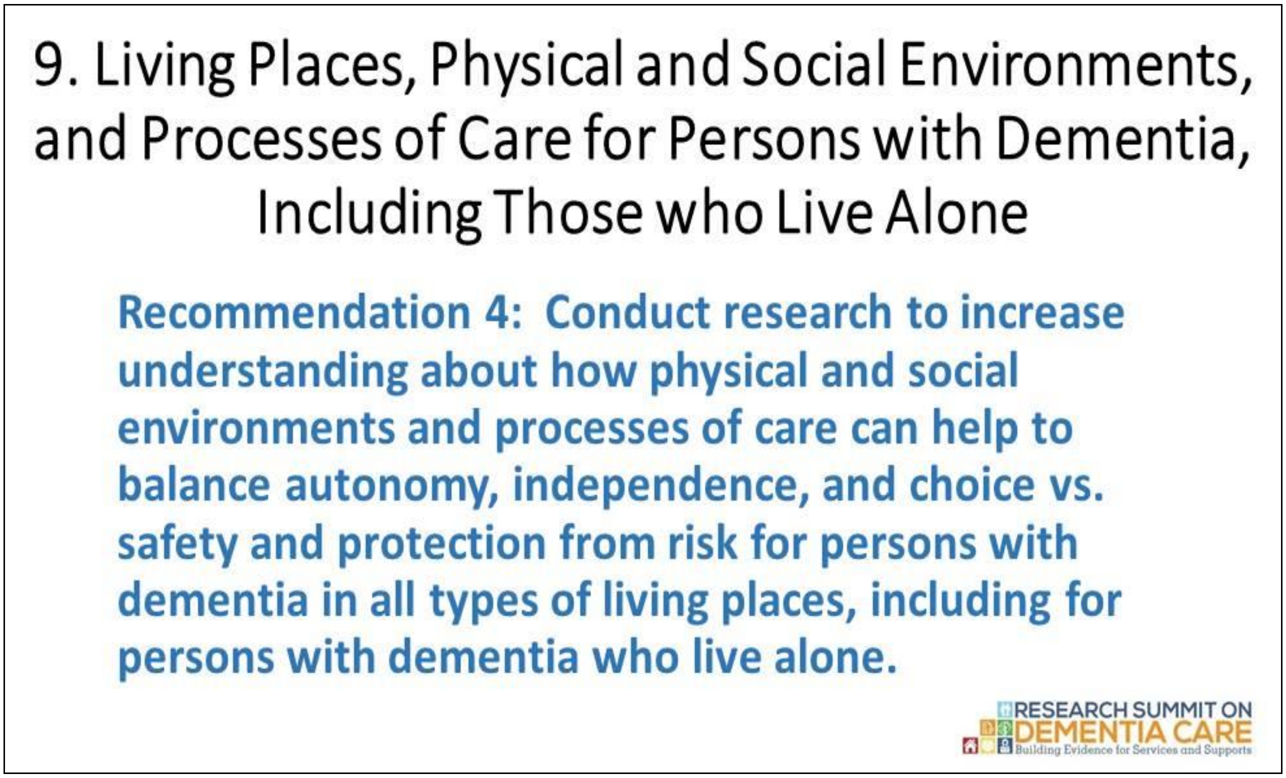

9. Living Places, Physical and Social Environments, and Processes of Care for Persons with Dementia, Including Those who Live Alone

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.

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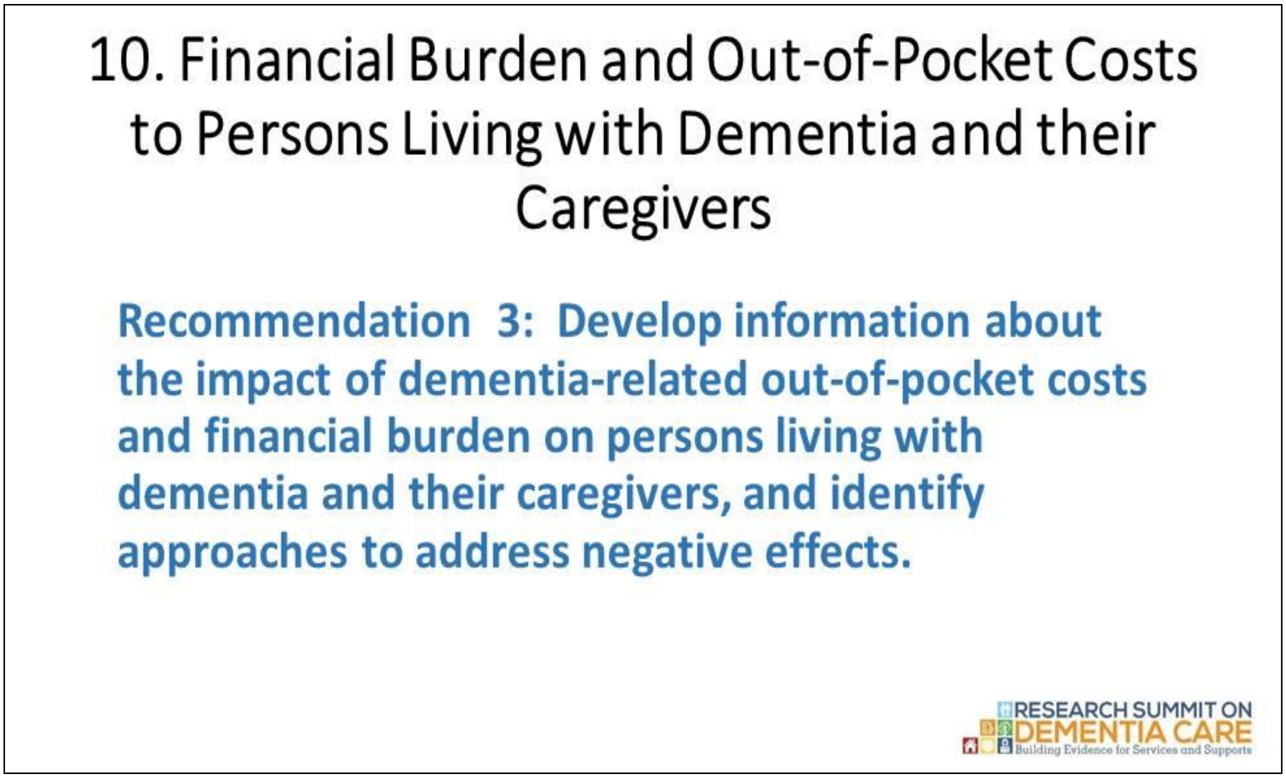

10. Financial Burden and Out-of-Pocket Costs to Persons Living with Dementia and their Caregivers

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.

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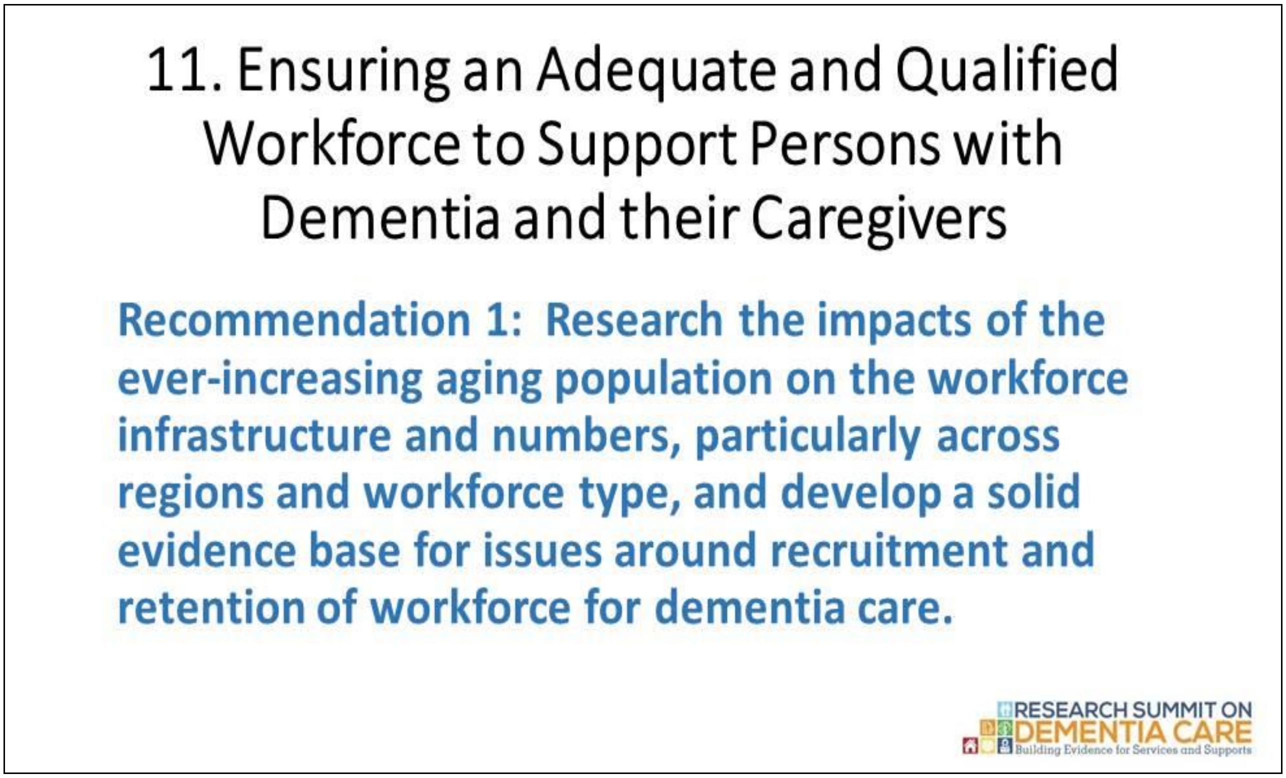

11. Ensuring an Adequate and Qualified Workforce to Support Persons with Dementia and their Caregivers

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.

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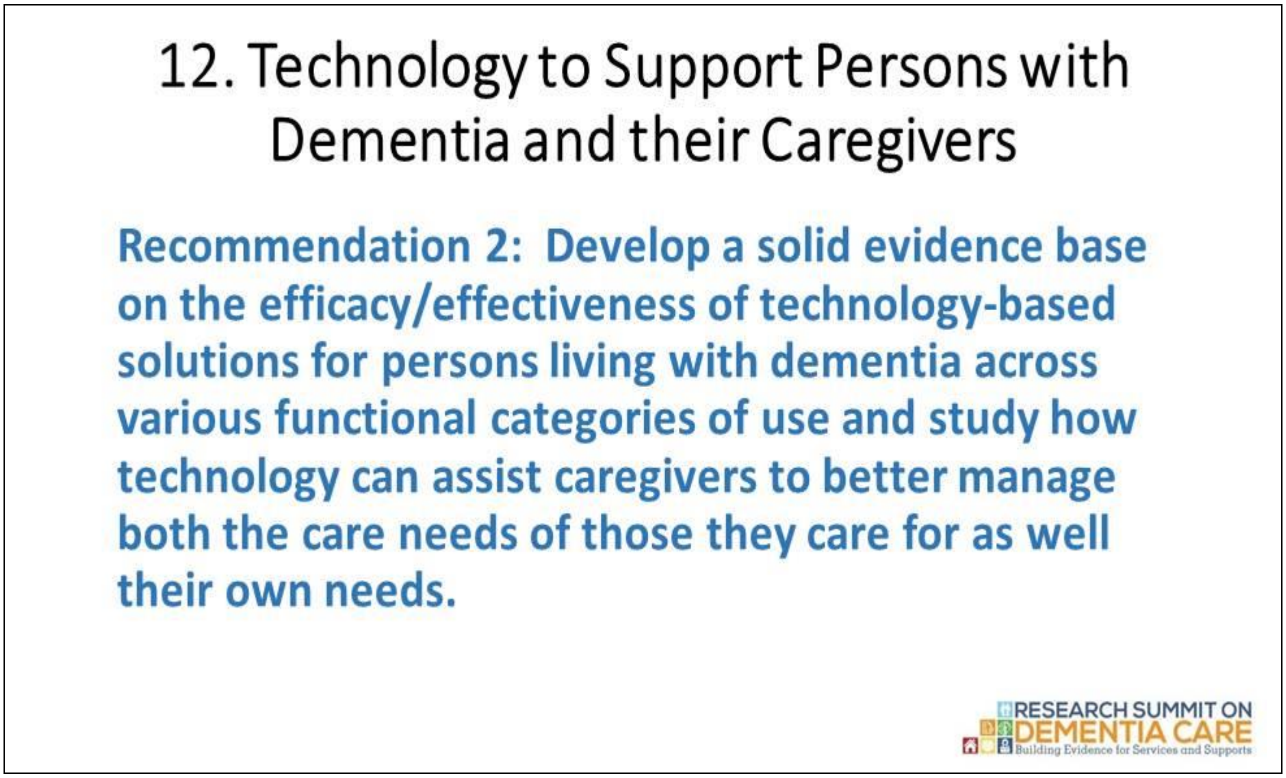

12. Technology to Support Persons with Dementia and their Caregivers

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.

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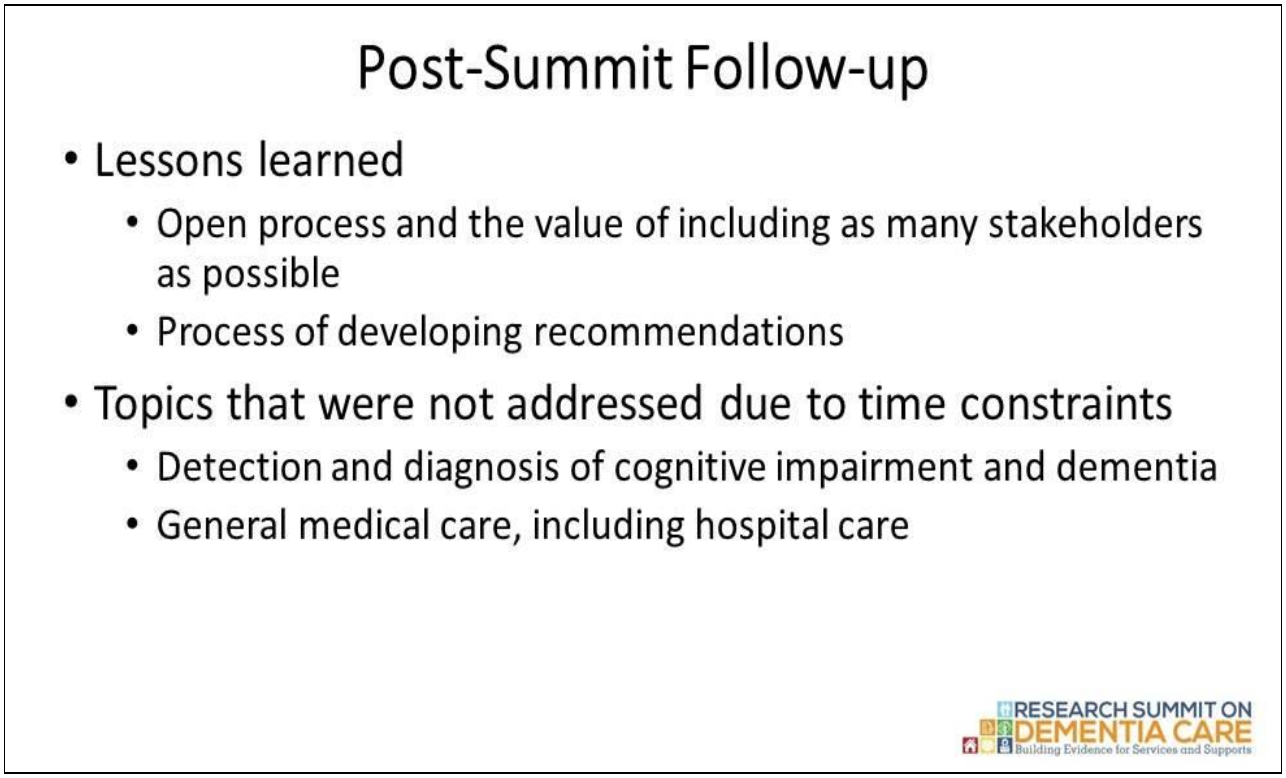

Post-Summit Follow-up

- Lessons learned
  - Open process and the value of including as many stakeholders as possible
  - Process of developing recommendations
- Topics that were not addressed due to time constraints
  - Detection and diagnosis of cognitive impairment and dementia
  - General medical care, including hospital care

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Follow-Up continued

- Post-summit activities
  - Pragmatic clinical trials – completed Dec 2017
  - Early stage dementia
  - Late stage dementia and end-of-life
  - Defining technology and its uses
  - Reaching those without access
  - Living places
- Next steps before 2020
  - Dissemination of the recommendations
  - Developing milestones

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Dissemination Plan

- Release of the Final Report on April 27
  - Available on the ASPE website
- Video presentation about the report
- Encouragement for summit participants and others to write journal and other articles, blog, and speak about recommendations that are most relevant to their interests and the mission and focus of their organizations.
- Role of NAPA Council
- Other (?)

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April 27, 2018 -- Advisory Council Meeting #28

The meeting was held on Friday, April 27, 2018, in Washington, DC. During the meeting, the Clinical Care Subcommittee took charge of the theme, focusing on advancing consensus on dementia care elements to guide new outcomes measurement. The Council heard speakers in two sessions, one focused on developing consensus about dementia care elements, and the second on models that are informing outcomes measurement. The meeting also included updates on work from the previous meetings, a presentation on the final report from the October 2017 Care Summit, and federal workgroup updates. Material available from this meeting is listed below and at https://aspe.hhs.gov/advisory-council-alzheimers-research-care-and-services-meetings#Apr2018.

Comments and questions, or alerts to broken links, should be sent to napa@hhs.gov.

General Information

Agenda	[HTML Version] [PDF Version]
Meeting Announcement	[HTML Version] [PDF Version]
Meeting Summary	[HTML Version] [PDF Version]
Public Comments	[HTML Version]

Handouts

Main Summit Recommendations	[HTML Version] [PDF Version]
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	[HTML Version] [PDF Version]

Presentation Slides

Age-Friendly Health Systems	[HTML Version] [PDF Version]
Alzheimer's Disease and Related Dementias Research Update	[HTML Version] [PDF Version]
Care Planning and Health Information Technology: How to Aid Dementia Quality Care	[HTML Version] [PDF Version]

Clinical Care Subcommittee Agenda: Advancing Consensus on Dementia Care Elements to Guide New Outcomes Measurement	[HTML Version] [PDF Version]
Clinical Subcommittee Update	[HTML Version] [PDF Version]
Defining Quality Dementia Care	[HTML Version] [PDF Version]
Final Report to the NAPA Advisory Council	[HTML Version] [PDF Version]
Long-Term Services and Supports Committee Update	[HTML Version] [PDF Version]
Quality Care from the Perspectives of People Living with Dementia	[HTML Version] [PDF Version]
Research Summit on Dementia Care: Building Evidence for Services and Supports Process Report	[HTML Version] [PDF Version]
Testing the Promise of Primary Care: Comprehensive Primary Care Plus (CPC+)	[HTML Version] [PDF Version]
Updates and Follow-Up from January Meeting	[HTML Version] [PDF Version]

Videos

Introductions and Updates	[Video]
Clinical Care Agenda Session 1	[Video]
Public Comments	[Video]
Clinical Care Agenda Session 2	[Video]
Care Summit Final Report	[Video]
MEETING WRAP-UP: Final Report to the NAPA Advisory Council	[Video]

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