Research Summit on Dementia Care

Building Evidence for Services and Supports
Process Report

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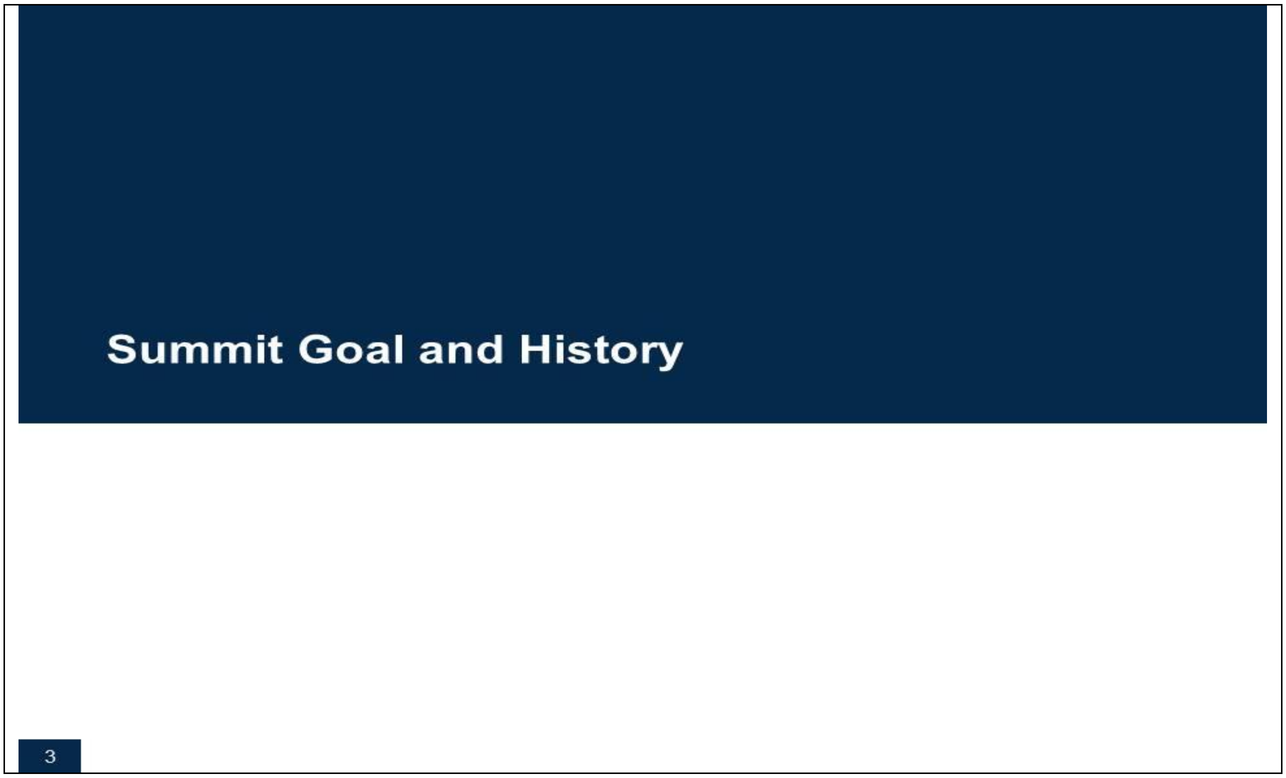
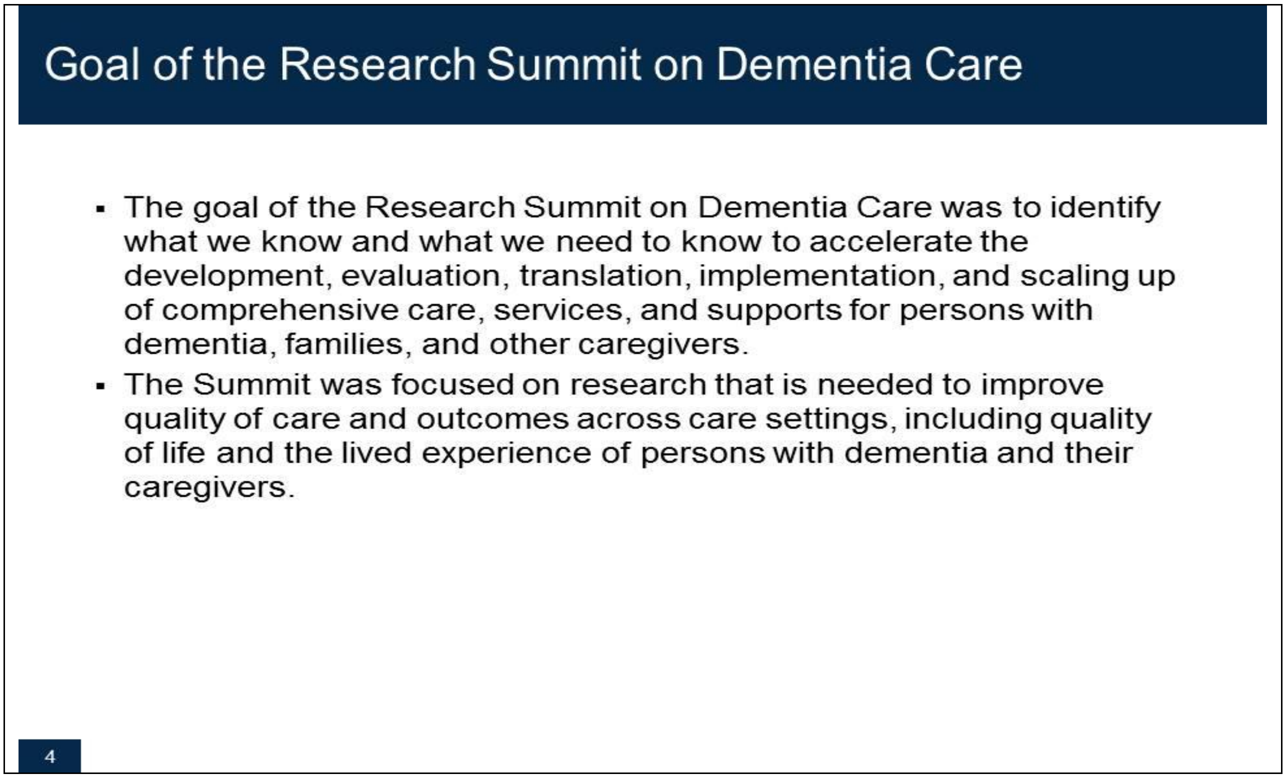
www.rti.org

Part I: Summit Background and Process



Summit Goal and History



Goal of the Research Summit on Dementia Care

- The goal of the Research Summit on Dementia Care was to identify what we know and what we need to know 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 was focused on research that is needed to improve quality of care and outcomes across care settings, including quality of life and the lived experience of persons with dementia and their caregivers.

Attaining Approval for Research Summit on Dementia Care

February 2015
NIA Alzheimer's Disease research meeting

→

March 2015
Katie Maslow of GSA introduces idea of a research summit on dementia care

→

April 2015
Ian Kremer of LEAD Coalition raises research summit on dementia care idea at NAPA meeting

↓

May 2015
LEAD Coalition makes proposal to HHS, NIH, and ACL for research summit on dementia care

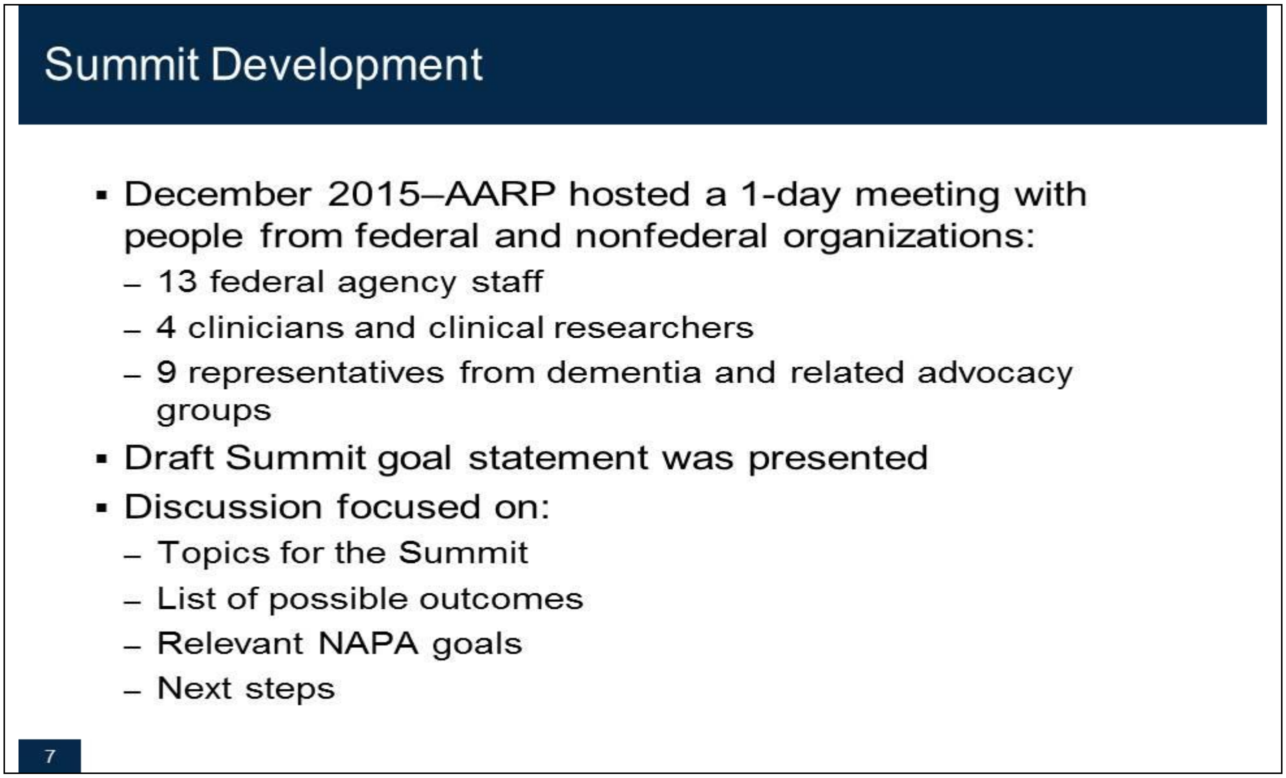
→

July 2015
ASPE agrees to consider the idea of a research summit on dementia care; LEAD Coalition pledges to begin summit planning

→

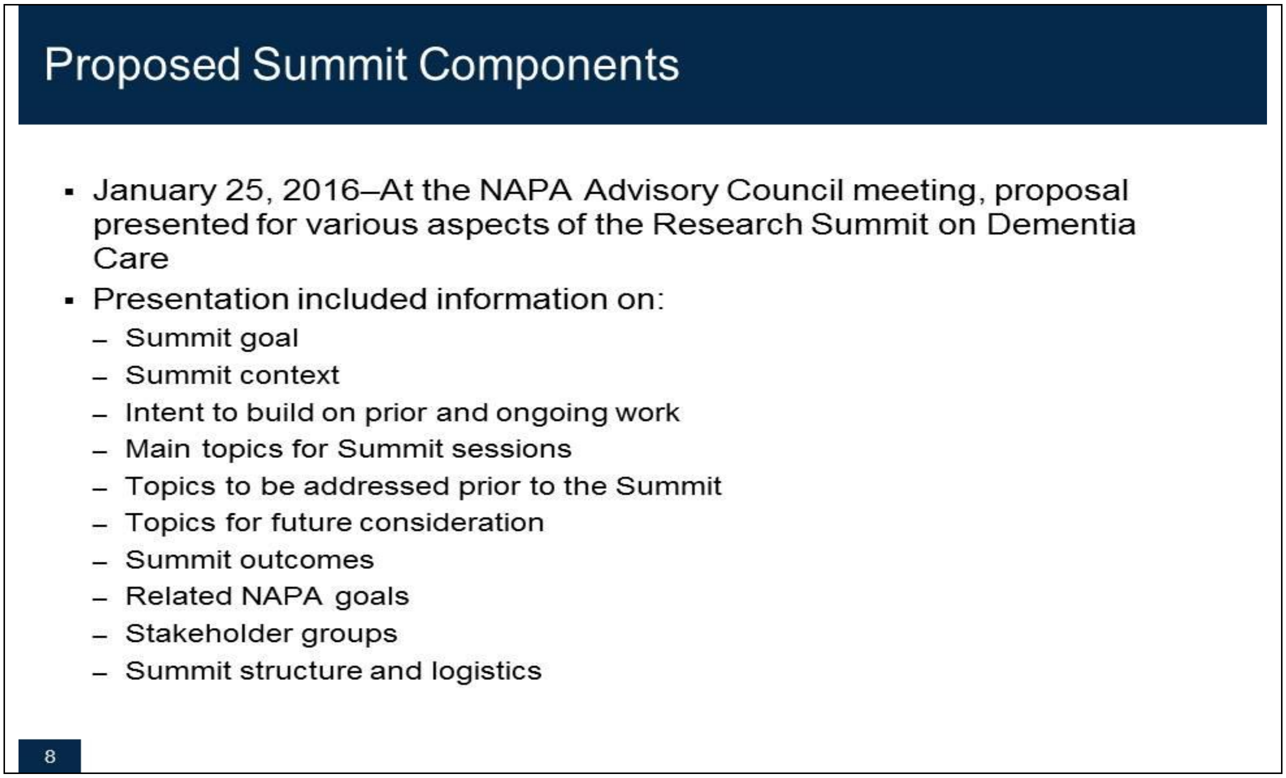
October 2015
NAPA Advisory Council gives official approval for the summit, and planning with public and private partners for the Research Summit on Dementia Care begins

Development of Summit Structure



Summit Development

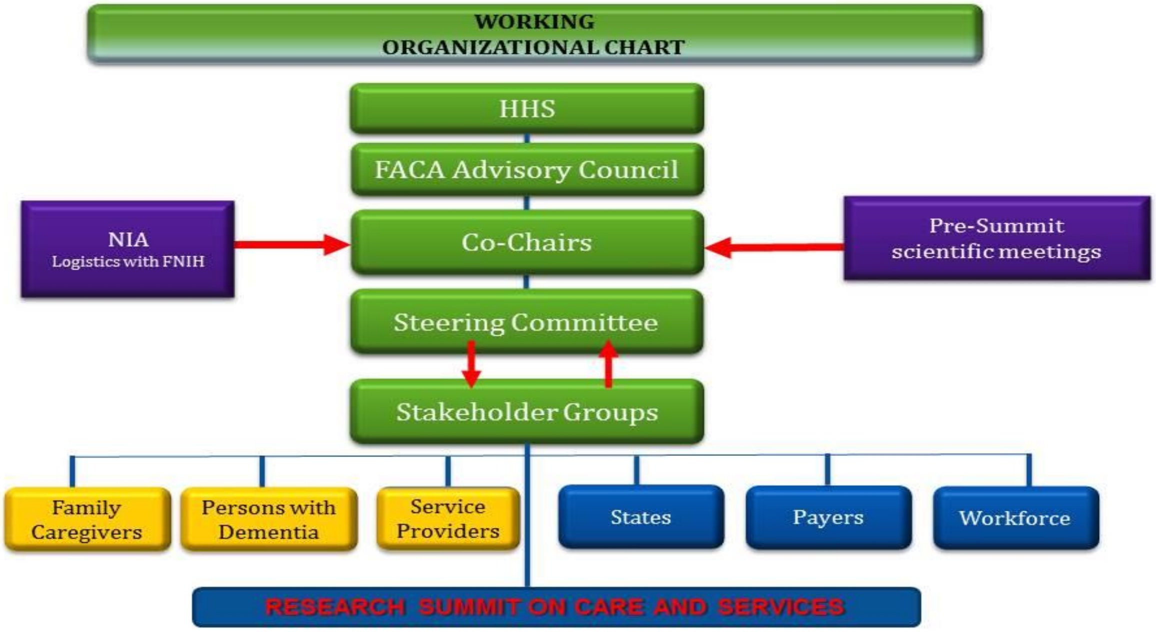
- December 2015–AARP hosted a 1-day meeting with people from federal and nonfederal organizations:
  - 13 federal agency staff
  - 4 clinicians and clinical researchers
  - 9 representatives from dementia and related advocacy groups
- Draft Summit goal statement was presented
- Discussion focused on:
  - Topics for the Summit
  - List of possible outcomes
  - Relevant NAPA goals
  - Next steps



Proposed Summit Components

- January 25, 2016–At the NAPA Advisory Council meeting, proposal presented for various aspects of the Research Summit on Dementia Care
- Presentation included information on:
  - Summit goal
  - Summit context
  - Intent to build on prior and ongoing work
  - Main topics for Summit sessions
  - Topics to be addressed prior to the Summit
  - Topics for future consideration
  - Summit outcomes
  - Related NAPA goals
  - Stakeholder groups
  - Summit structure and logistics

Mechanisms to Obtain Input and Buy-In



WORKING
ORGANIZATIONAL CHART

HHS

FACA Advisory Council

NIA
Logistics with FNIH

Co-Chairs

Pre-Summit
scientific meetings

Steering Committee

Stakeholder Groups

Family Caregivers

Persons with Dementia

Service Providers

States

Payers

Workforce

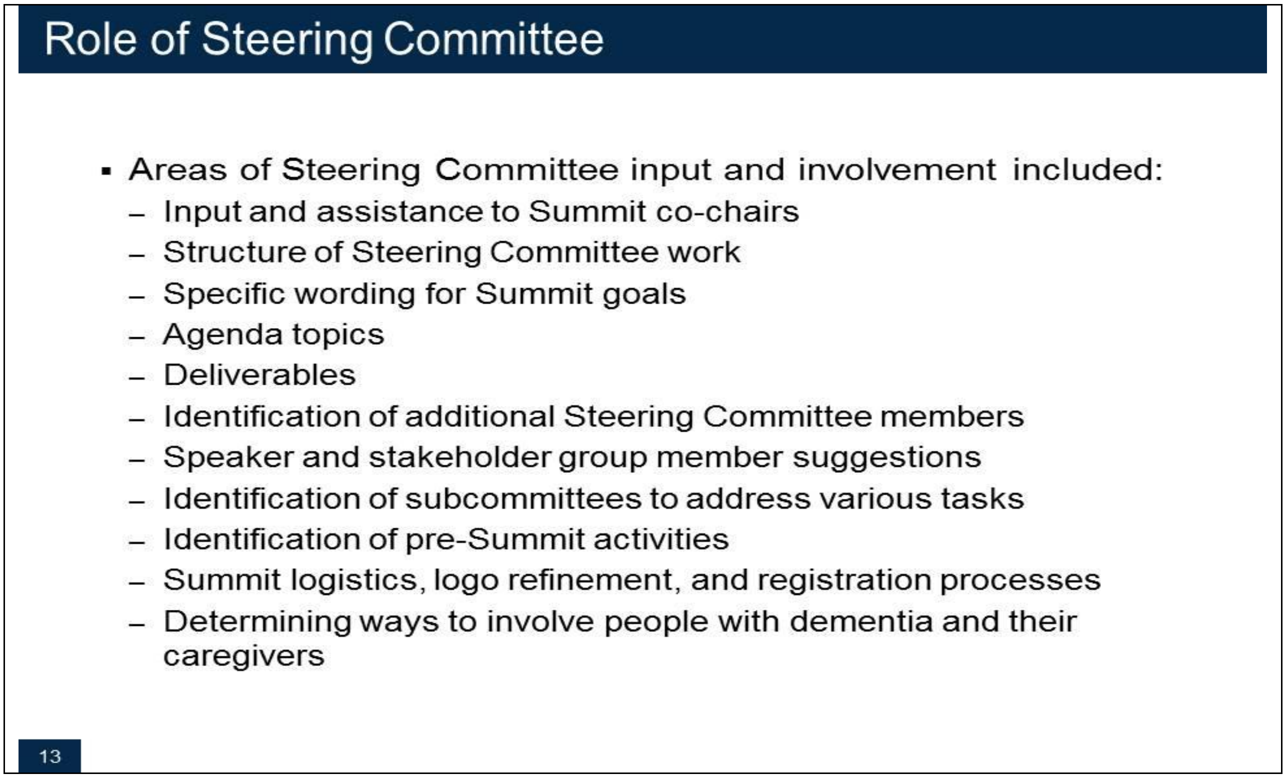
RESEARCH SUMMIT ON CARE AND SERVICES

From NAPA Council Summit Update Presentation, October 31, 2016

Steering Committee

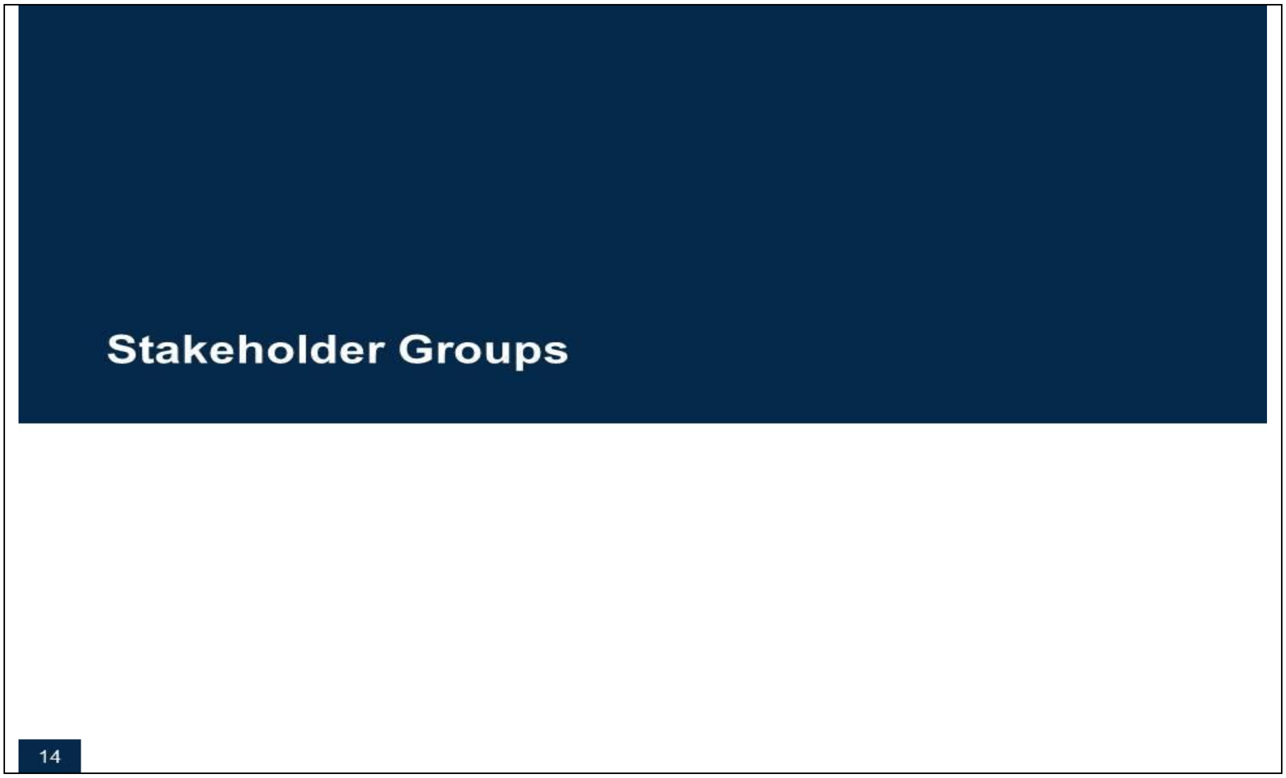
Steering Committee Background

- March 2016
  - NAPA Advisory Council agreed to lead the Summit effort
  - Laura Gitlin and Katie Maslow were appointed co-chairs for the Summit
  - Appointees to Steering Committee begin
- April 2016–Summit Steering Committee meetings begin
- October 2016–RTI logistical support begins

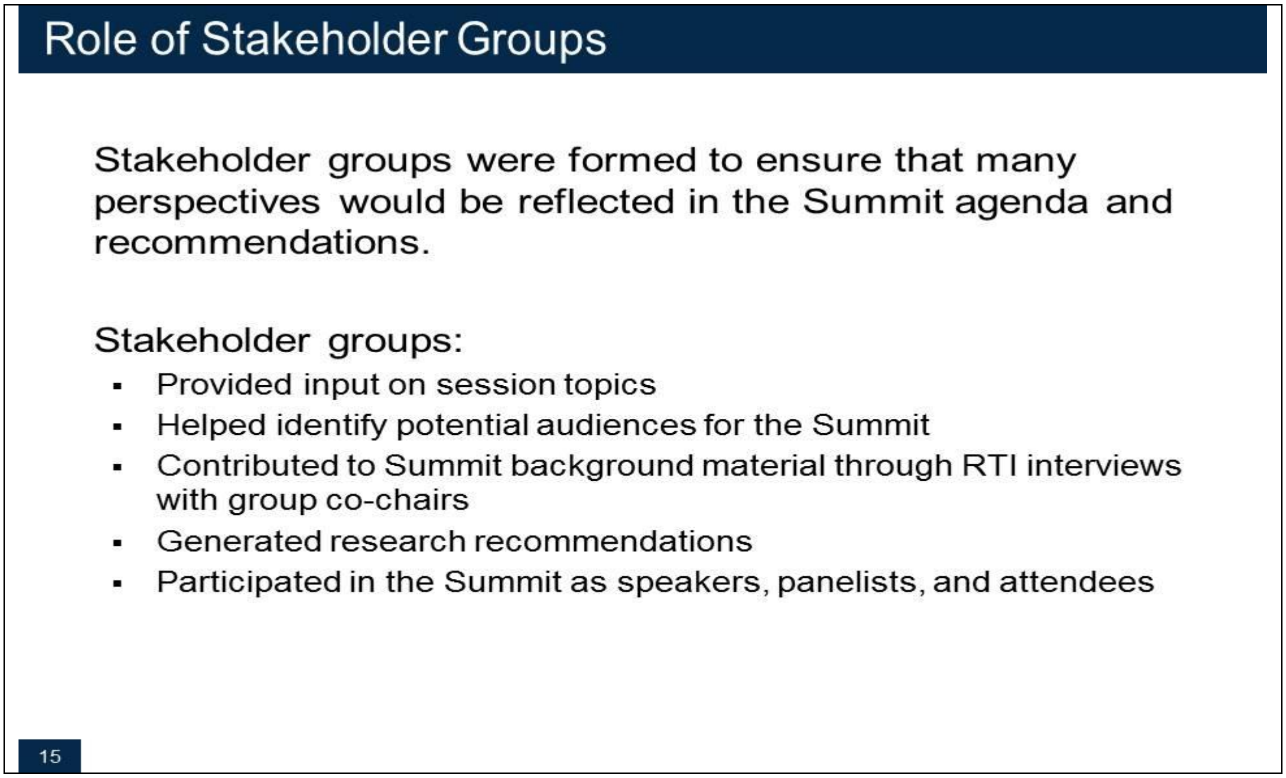


Role of Steering Committee

- Areas of Steering Committee input and involvement included:
  - Input and assistance to Summit co-chairs
  - Structure of Steering Committee work
  - Specific wording for Summit goals
  - Agenda topics
  - Deliverables
  - Identification of additional Steering Committee members
  - Speaker and stakeholder group member suggestions
  - Identification of subcommittees to address various tasks
  - Identification of pre-Summit activities
  - Summit logistics, logo refinement, and registration processes
  - Determining ways to involve people with dementia and their caregivers



Stakeholder Groups



Role of Stakeholder Groups

Stakeholder groups were formed to ensure that many perspectives would be reflected in the Summit agenda and recommendations.

Stakeholder groups:

- Provided input on session topics
- Helped identify potential audiences for the Summit
- Contributed to Summit background material through RTI interviews with group co-chairs
- Generated research recommendations
- Participated in the Summit as speakers, panelists, and attendees

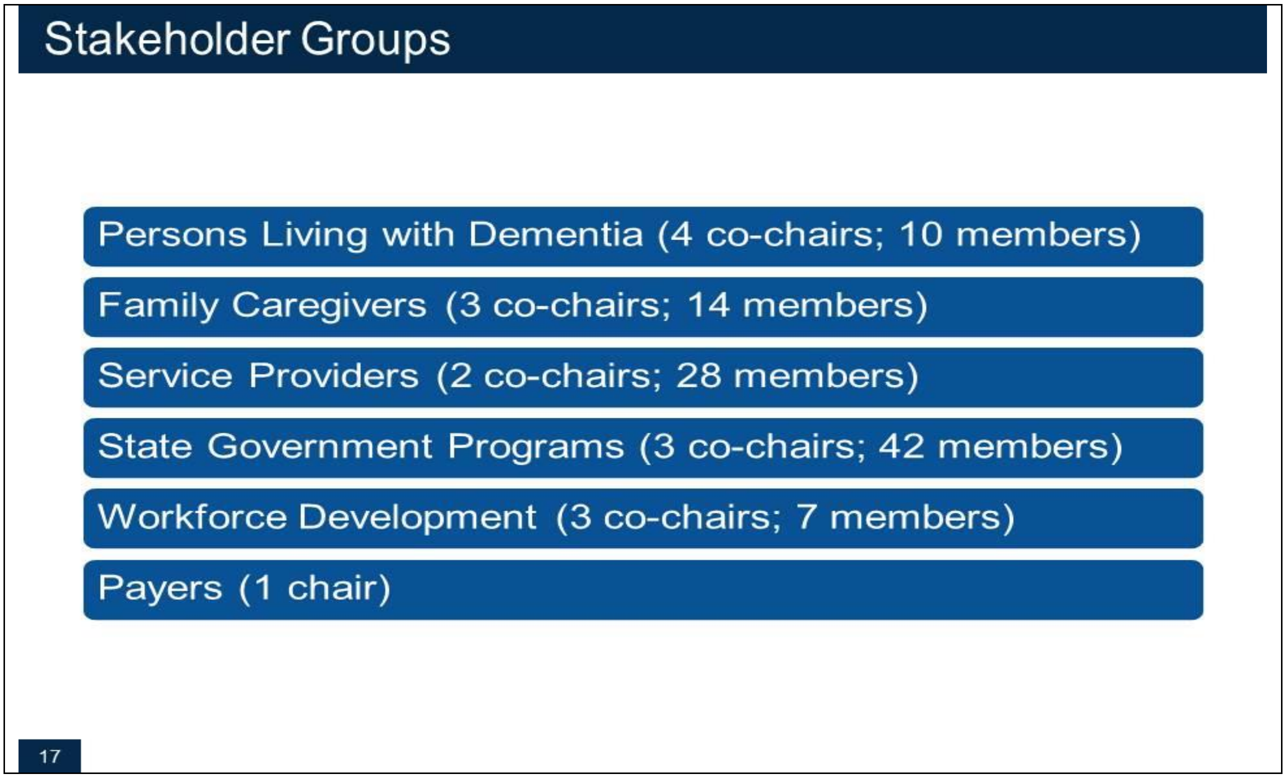
Stakeholder Group Recruitment

Stakeholder group co-chairs

- Most groups had at least one co-chair who was a Steering Committee member
- Each co-chair recruited one or more additional co-chairs
- Family Caregiver and Payer stakeholder group co-chairs were identified by the Summit co-chairs and Steering Committee

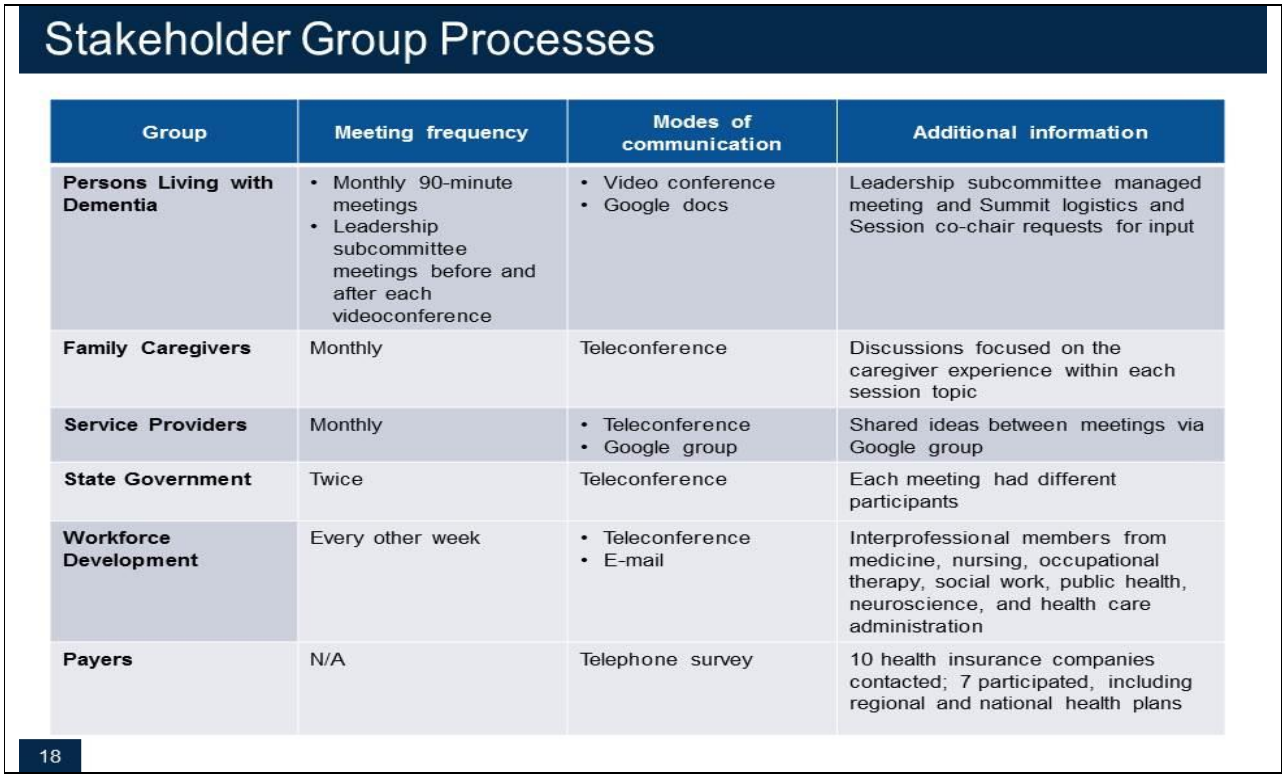
Stakeholder group members

- Recruited by group co-chairs, with assistance from Steering Committee, during January and February 2017
- Racial, ethnic, cultural, and geographic diversity was a goal for Persons Living with Dementia and Family Caregiver groups



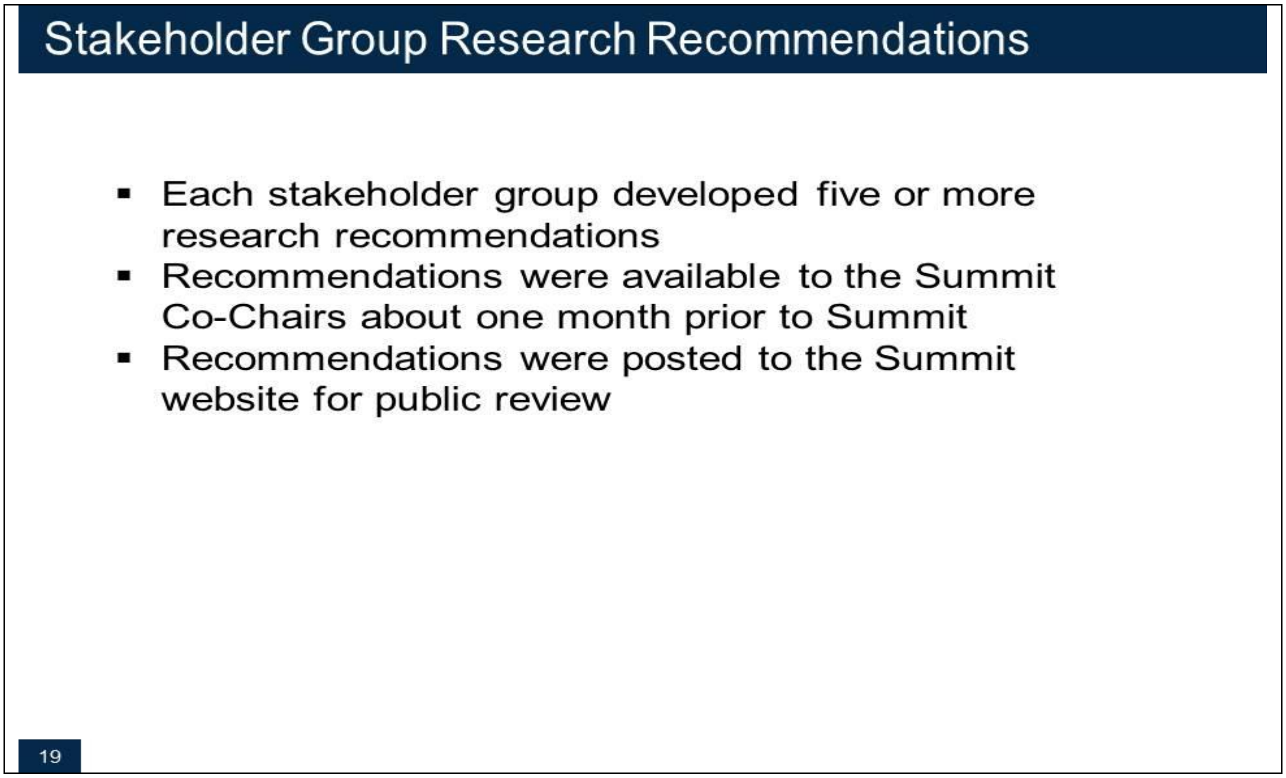
Stakeholder Groups

- Persons Living with Dementia (4 co-chairs; 10 members)
- Family Caregivers (3 co-chairs; 14 members)
- Service Providers (2 co-chairs; 28 members)
- State Government Programs (3 co-chairs; 42 members)
- Workforce Development (3 co-chairs; 7 members)
- Payers (1 chair)



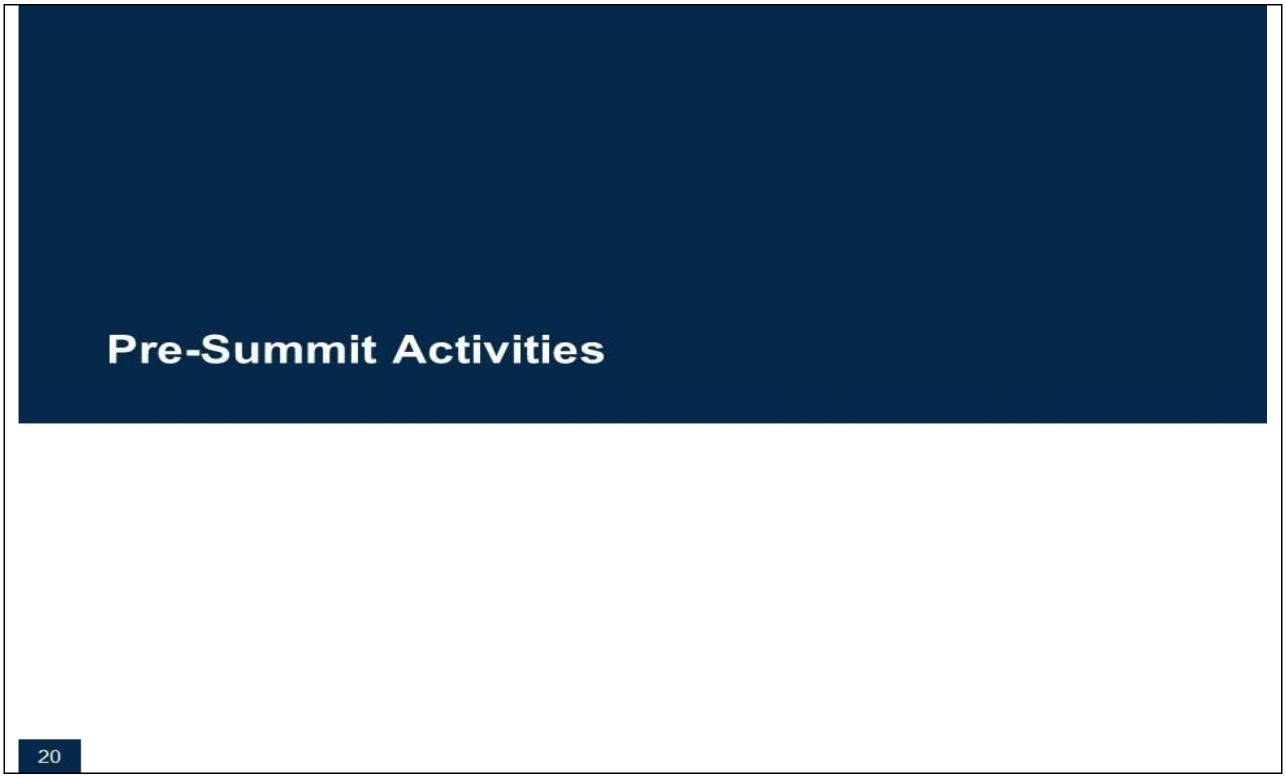
Stakeholder Group Processes

Group	Meeting frequency	Modes of communication	Additional information
Persons Living with Dementia	• Monthly 90-minute meetings • Leadership subcommittee meetings before and after each videoconference	• Video conference • Google docs	Leadership subcommittee managed meeting and Summit logistics and Session co-chair requests for input
Family Caregivers	Monthly	Teleconference	Discussions focused on the caregiver experience within each session topic
Service Providers	Monthly	• Teleconference • Google group	Shared ideas between meetings via Google group
State Government	Twice	Teleconference	Each meeting had different participants
Workforce Development	Every other week	• Teleconference • E-mail	Interprofessional members from medicine, nursing, occupational therapy, social work, public health, neuroscience, and health care administration
Payers	N/A	Telephone survey	10 health insurance companies contacted; 7 participated, including regional and national health plans

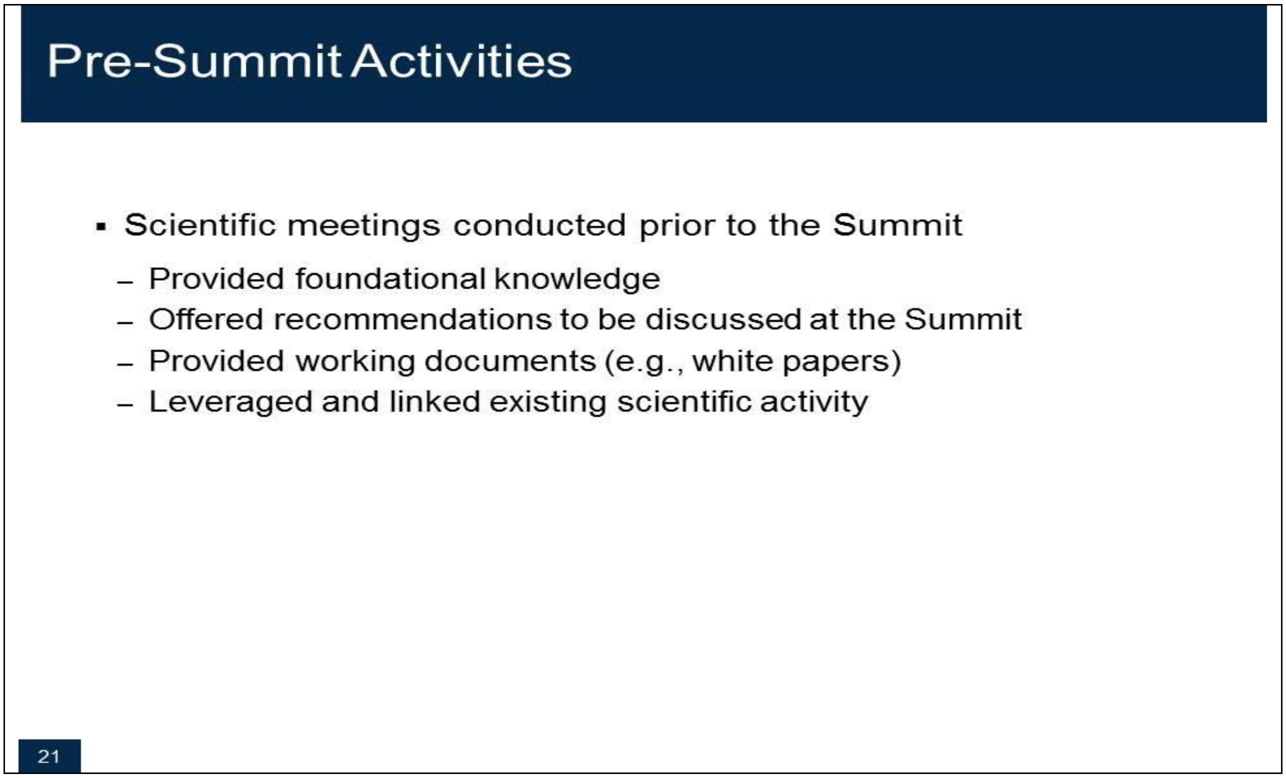


Stakeholder Group Research Recommendations

- Each stakeholder group developed five or more research recommendations
- Recommendations were available to the Summit Co-Chairs about one month prior to Summit
- Recommendations were posted to the Summit website for public review

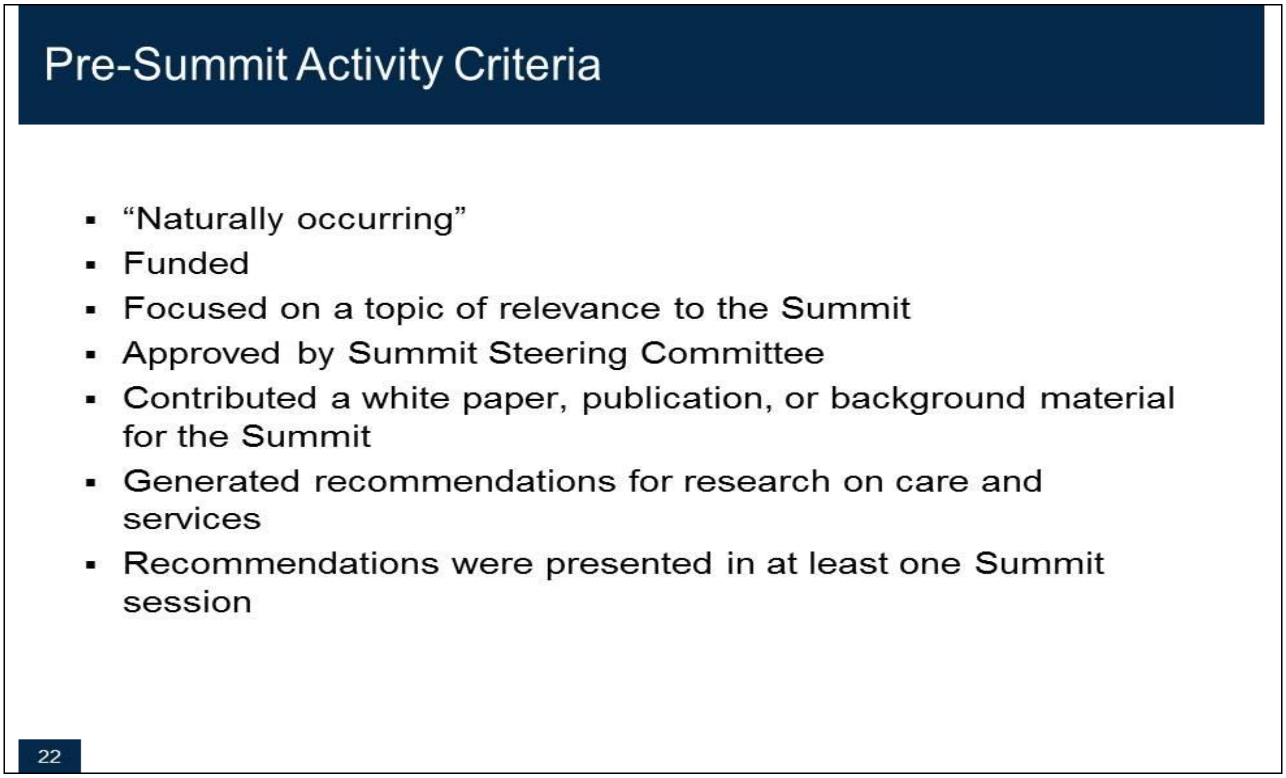


Pre-Summit Activities



Pre-Summit Activities

- Scientific meetings conducted prior to the Summit
  - Provided foundational knowledge
  - Offered recommendations to be discussed at the Summit
  - Provided working documents (e.g., white papers)
  - Leveraged and linked existing scientific activity



Pre-Summit Activity Criteria

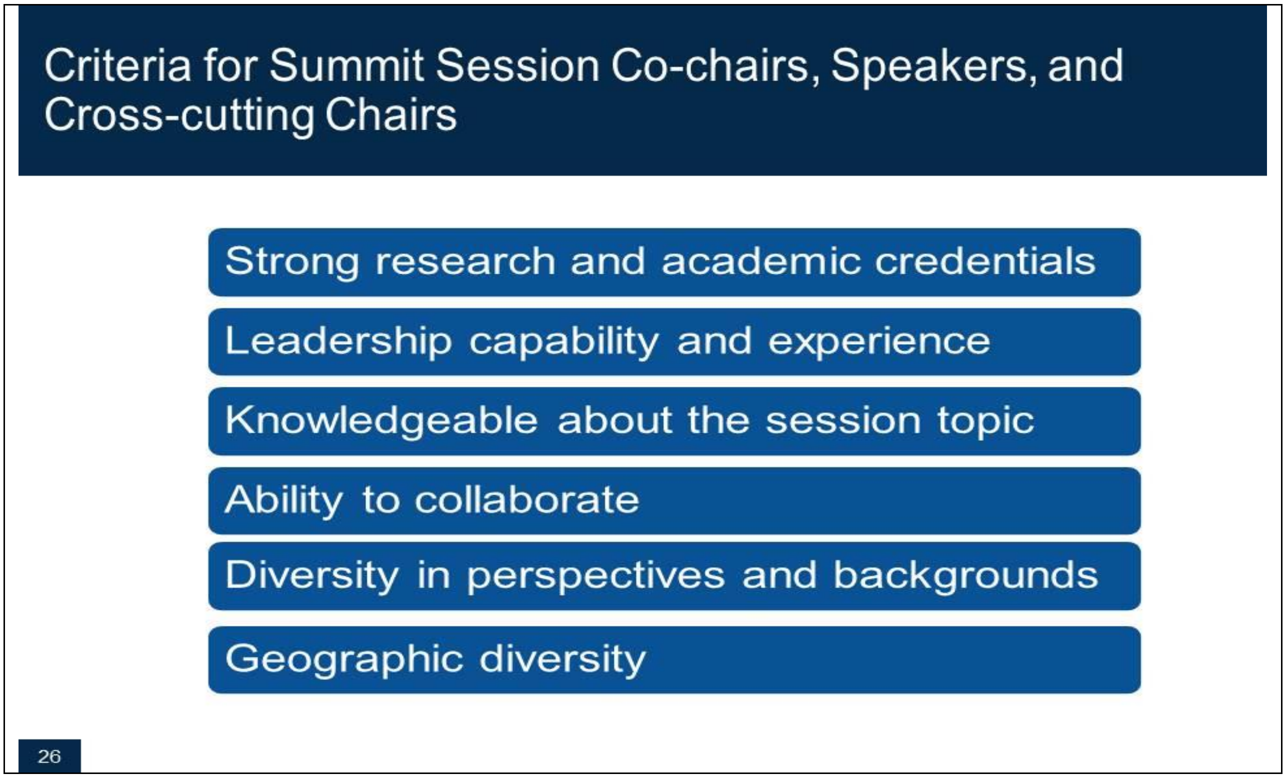
- “Naturally occurring”
- Funded
- Focused on a topic of relevance to the Summit
- Approved by Summit Steering Committee
- Contributed a white paper, publication, or background material for the Summit
- Generated recommendations for research on care and services
- Recommendations were presented in at least one Summit session

Development of Summit Agenda

Summit Topics

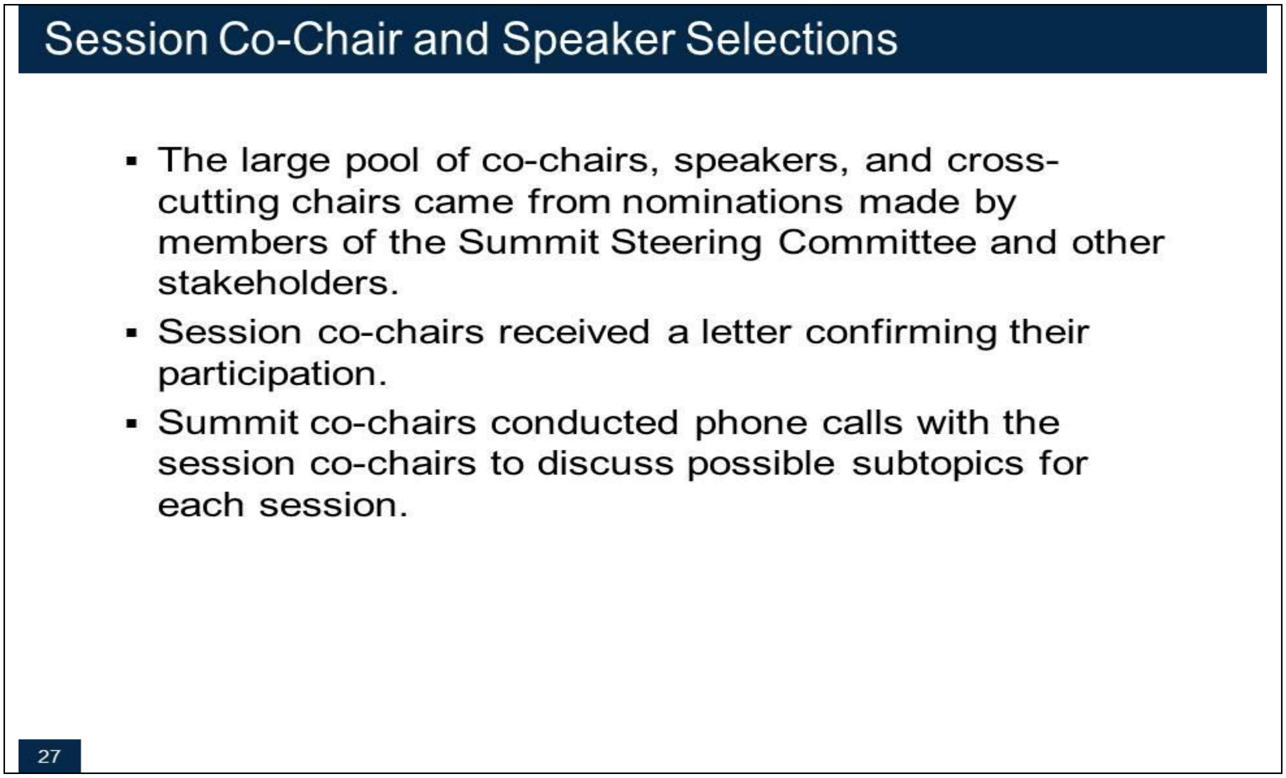
- After the December 2015 meeting at AARP, Summit topics continued to develop through Summit co-chair and Steering Committee discussions.
- Session, plenary, and cross-cutting topics for the Summit agenda were decided between April 2016 and April 2017.
- The Summit agenda was largely decided by the end of May 2017 after it was reviewed by the Steering Committee, cross-cutting chairs, and session co-chairs.
- The Steering Committee provided comments and feedback on all agenda topics, and Summit co-chairs made final agenda decisions.
- Cross-cutting chairs helped identify Summit speakers on technology, diversity, women's issues, and etiology of dementia.

Summit Session Co-Chairs and Speakers



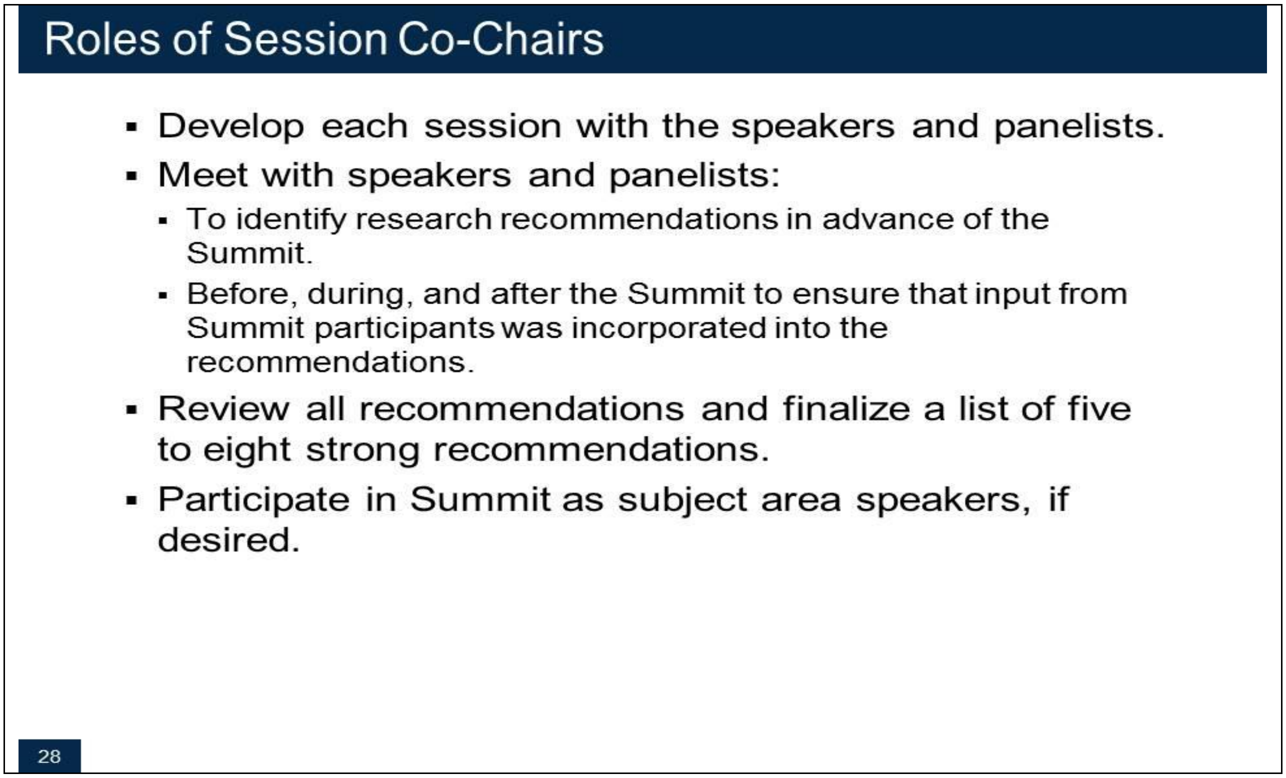
Criteria for Summit Session Co-chairs, Speakers, and Cross-cutting Chairs

- Strong research and academic credentials
- Leadership capability and experience
- Knowledgeable about the session topic
- Ability to collaborate
- Diversity in perspectives and backgrounds
- Geographic diversity



Session Co-Chair and Speaker Selections

- The large pool of co-chairs, speakers, and cross-cutting chairs came from nominations made by members of the Summit Steering Committee and other stakeholders.
- Session co-chairs received a letter confirming their participation.
- Summit co-chairs conducted phone calls with the session co-chairs to discuss possible subtopics for each session.



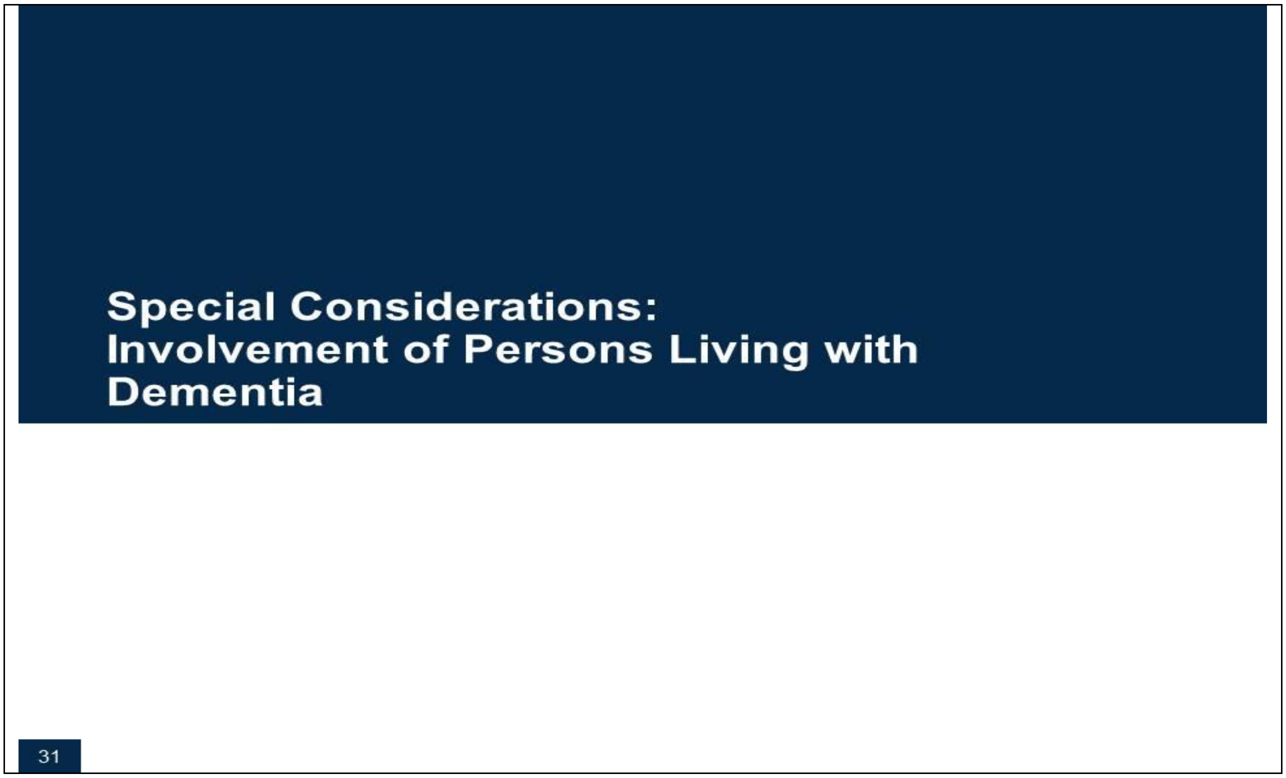
Roles of Session Co-Chairs

- Develop each session with the speakers and panelists.
- Meet with speakers and panelists:
  - To identify research recommendations in advance of the Summit.
  - Before, during, and after the Summit to ensure that input from Summit participants was incorporated into the recommendations.
- Review all recommendations and finalize a list of five to eight strong recommendations.
- Participate in Summit as subject area speakers, if desired.

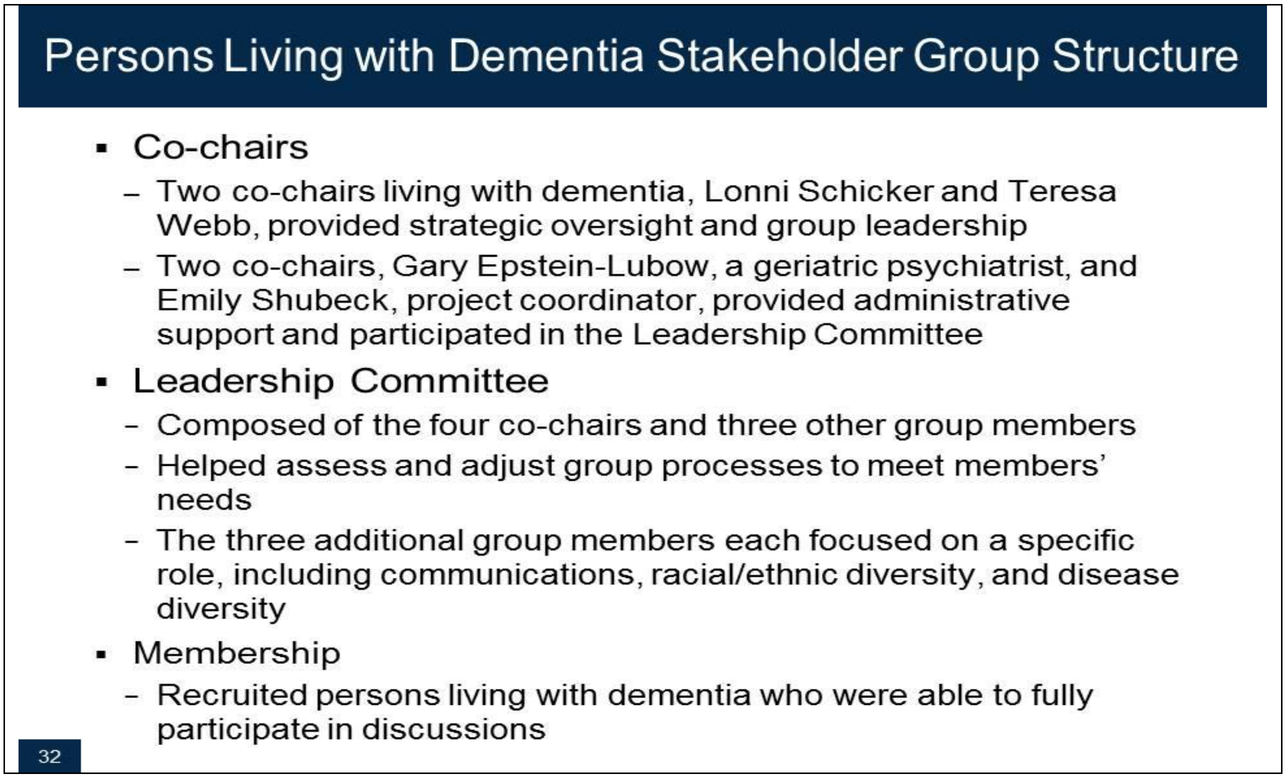
Role of Cross-Cutting Chairs

- The cross-cutting chairs helped identify possible Summit speakers on technology, diversity, women's issues, and etiology of dementia.
- The technology, diversity, and women's issues cross-cutting chairs also submitted research recommendations.
- The cross-cutting chair for etiology submitted comments on nomenclature in her session and on the ASPE website.

Part II: Special Considerations



Special Considerations: Involvement of Persons Living with Dementia



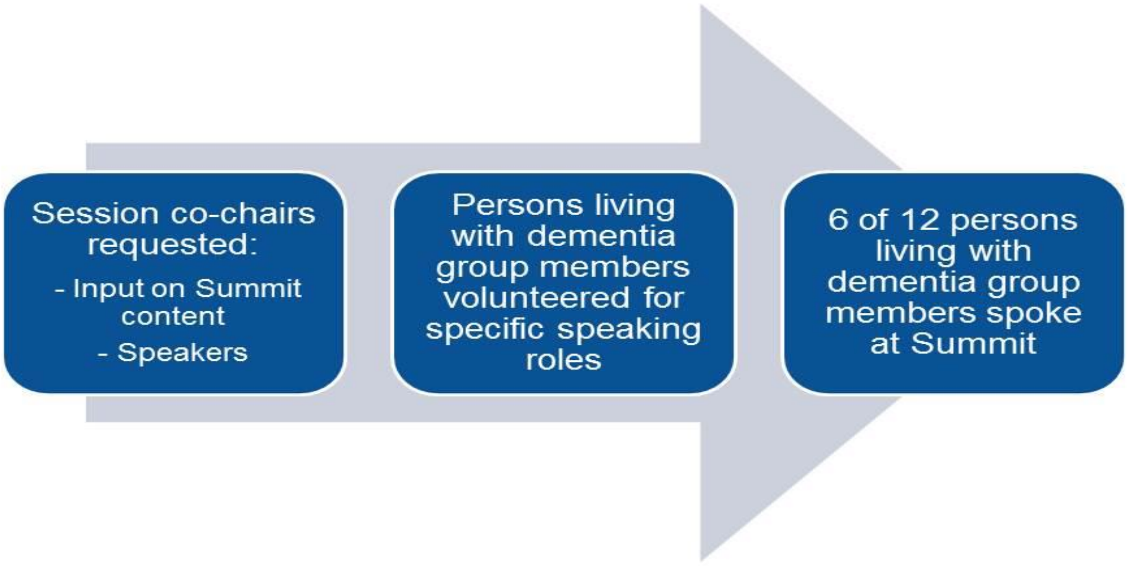
Persons Living with Dementia Stakeholder Group Structure

- Co-chairs
  - Two co-chairs living with dementia, Lonni Schicker and Teresa Webb, provided strategic oversight and group leadership
  - Two co-chairs, Gary Epstein-Lubow, a geriatric psychiatrist, and Emily Shubeck, project coordinator, provided administrative support and participated in the Leadership Committee
- Leadership Committee
  - Composed of the four co-chairs and three other group members
  - Helped assess and adjust group processes to meet members' needs
  - The three additional group members each focused on a specific role, including communications, racial/ethnic diversity, and disease diversity
- Membership
  - Recruited persons living with dementia who were able to fully participate in discussions

Persons Living with Dementia Meeting Process

- Monthly 90-minute video conference meetings using Zoom software
- Leadership Committee met before and after each group conference
- Each meeting was focused on one topic
- A Summit Session co-chair joined each call to share information and gather feedback to inform the Summit
- Emily Shubeck drafted meeting minutes and distributed to the co-chairs, then the group

Persons Living with Dementia Group Members' Summit Participation

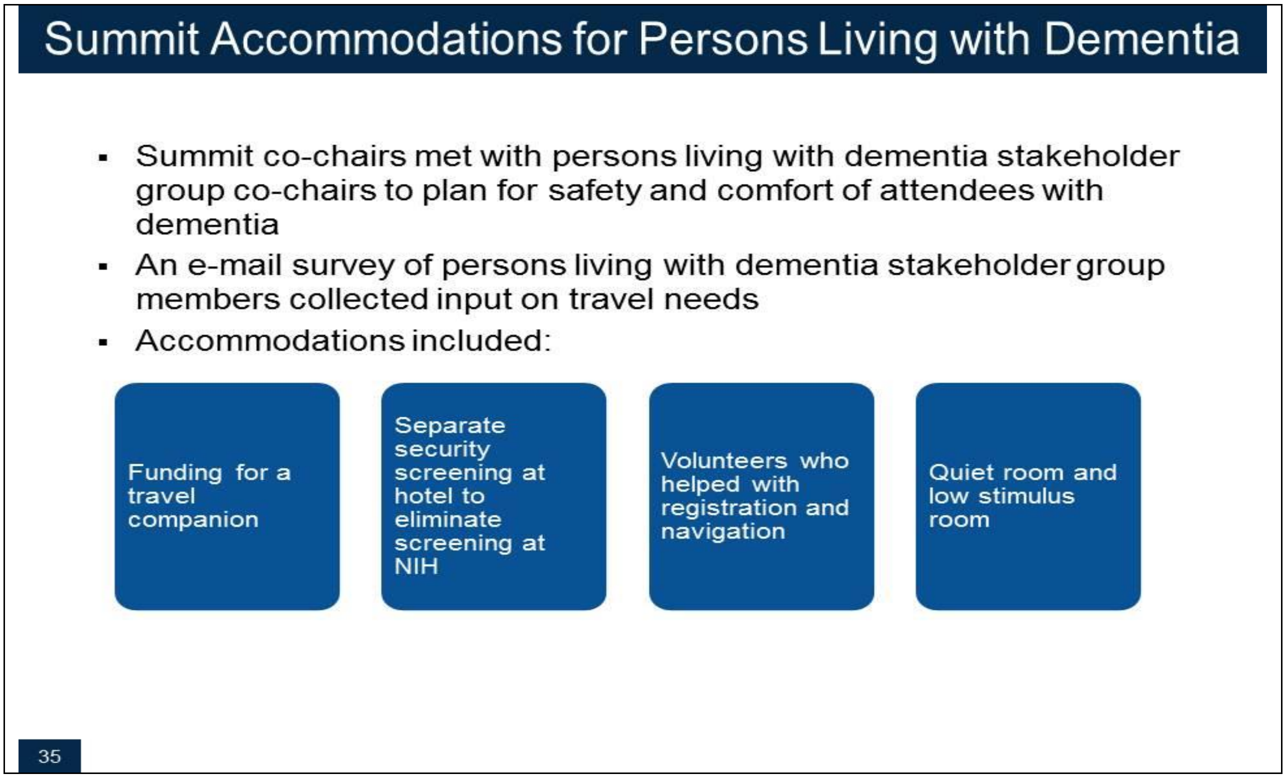


Session co-chairs requested:

- Input on Summit content
- Speakers

Persons living with dementia group members volunteered for specific speaking roles

6 of 12 persons living with dementia group members spoke at Summit



Summit Accommodations for Persons Living with Dementia

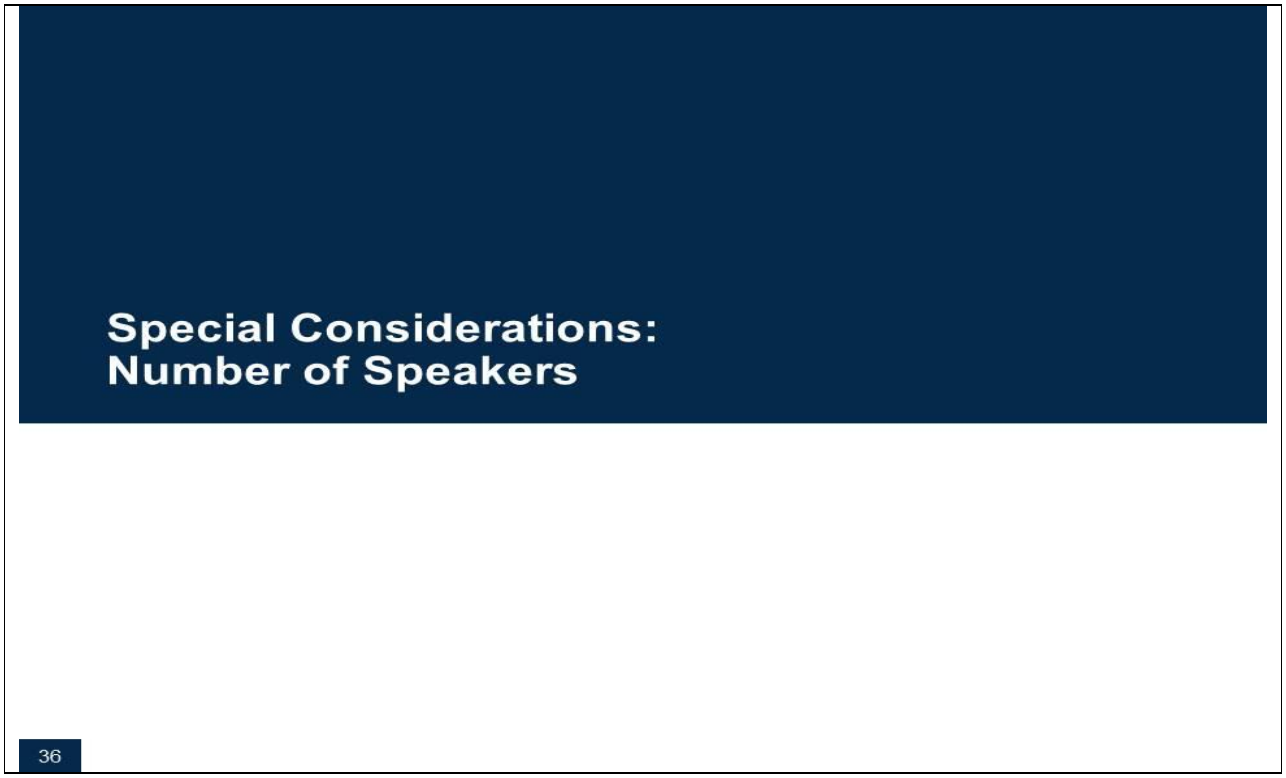
- Summit co-chairs met with persons living with dementia stakeholder group co-chairs to plan for safety and comfort of attendees with dementia
- An e-mail survey of persons living with dementia stakeholder group members collected input on travel needs
- Accommodations included:

Funding for a travel companion

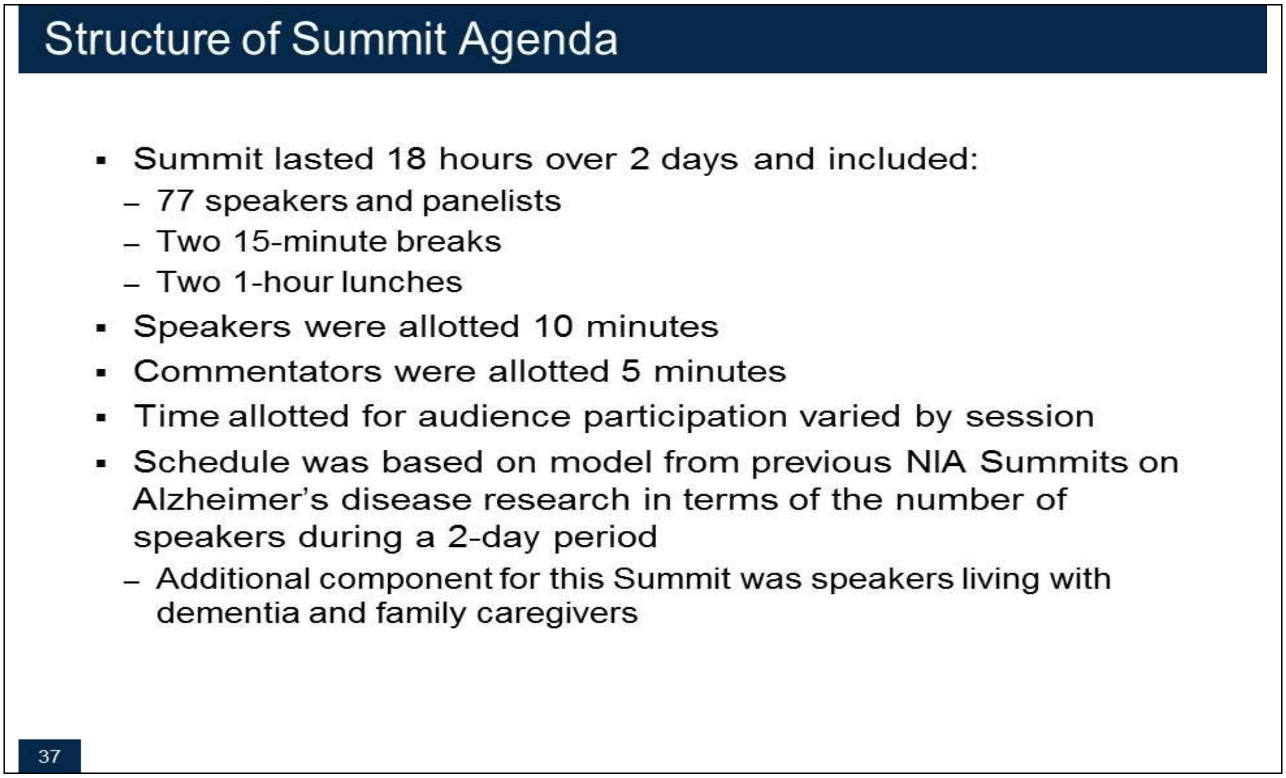
Separate security screening at hotel to eliminate screening at NIH

Volunteers who helped with registration and navigation

Quiet room and low stimulus room



Special Considerations:
Number of Speakers



Structure of Summit Agenda

- Summit lasted 18 hours over 2 days and included:
  - 77 speakers and panelists
  - Two 15-minute breaks
  - Two 1-hour lunches
- Speakers were allotted 10 minutes
- Commentators were allotted 5 minutes
- Time allotted for audience participation varied by session
- Schedule was based on model from previous NIA Summits on Alzheimer's disease research in terms of the number of speakers during a 2-day period
  - Additional component for this Summit was speakers living with dementia and family caregivers

Advantages of Many Speakers Over Two Days

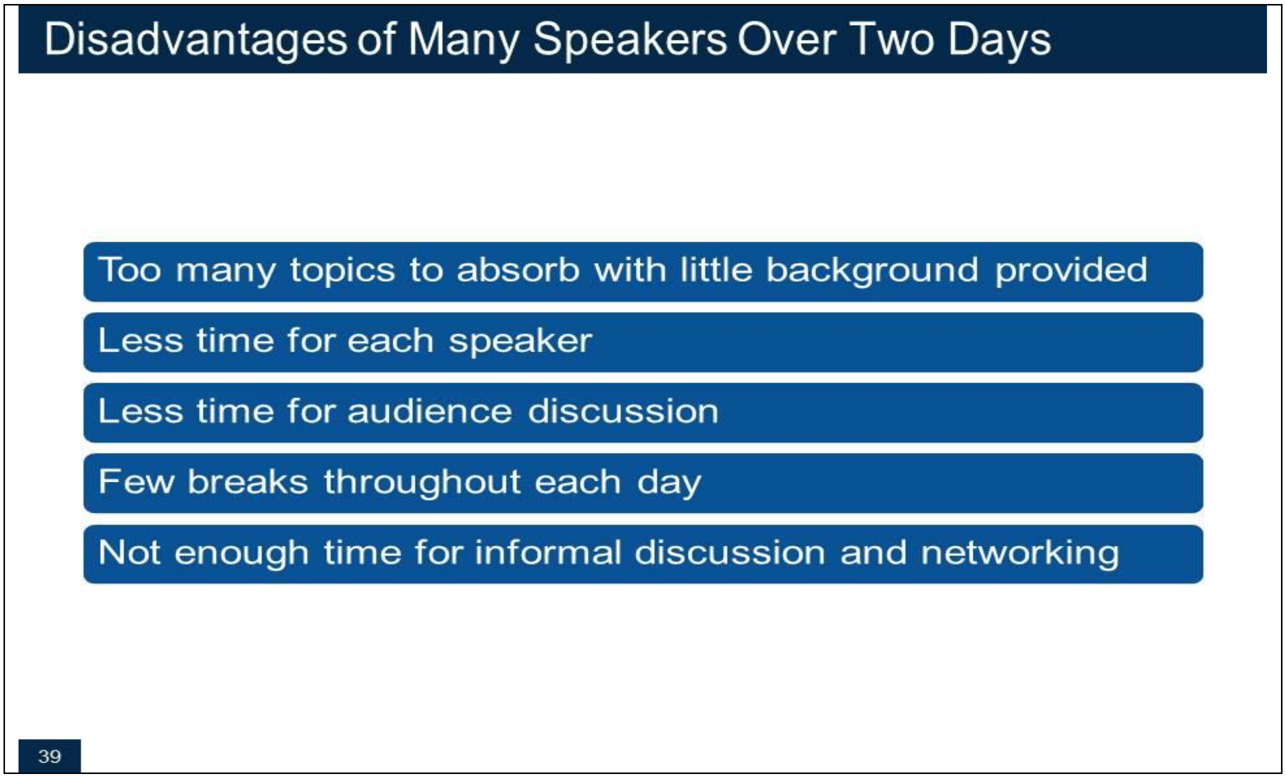
Wide range of topics and perspectives was presented

Attendees heard directly from many experts whose research informed the Summit

Helped generate many research recommendations

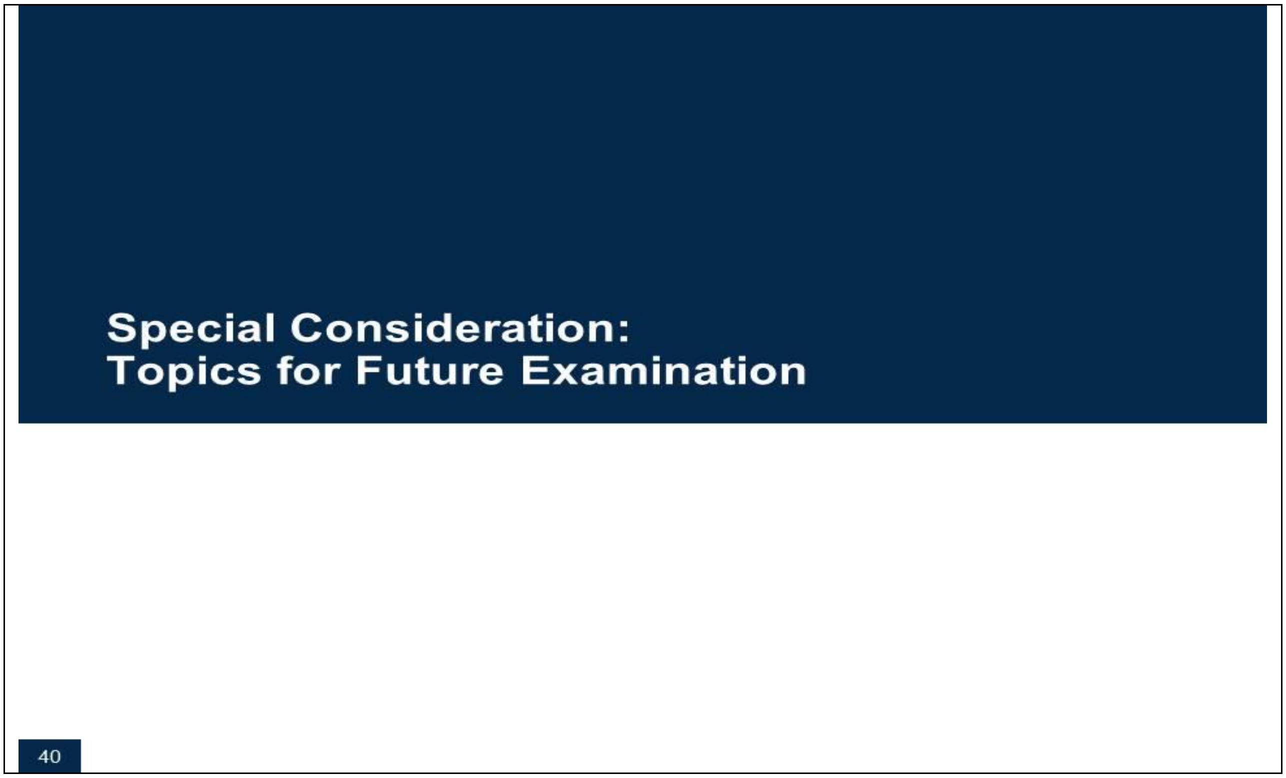
Pace of the Summit was lively

Limiting the Summit to 2 days made attendance feasible

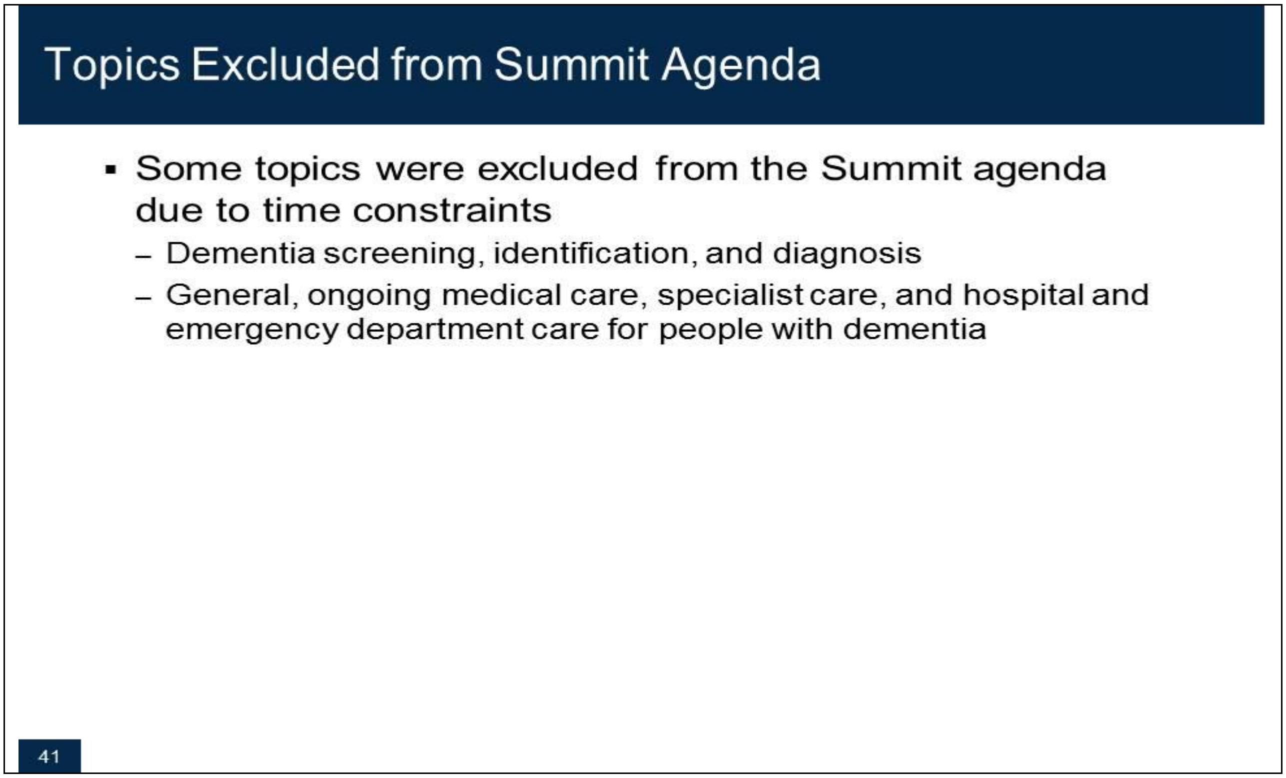


Disadvantages of Many Speakers Over Two Days

- Too many topics to absorb with little background provided
- Less time for each speaker
- Less time for audience discussion
- Few breaks throughout each day
- Not enough time for informal discussion and networking

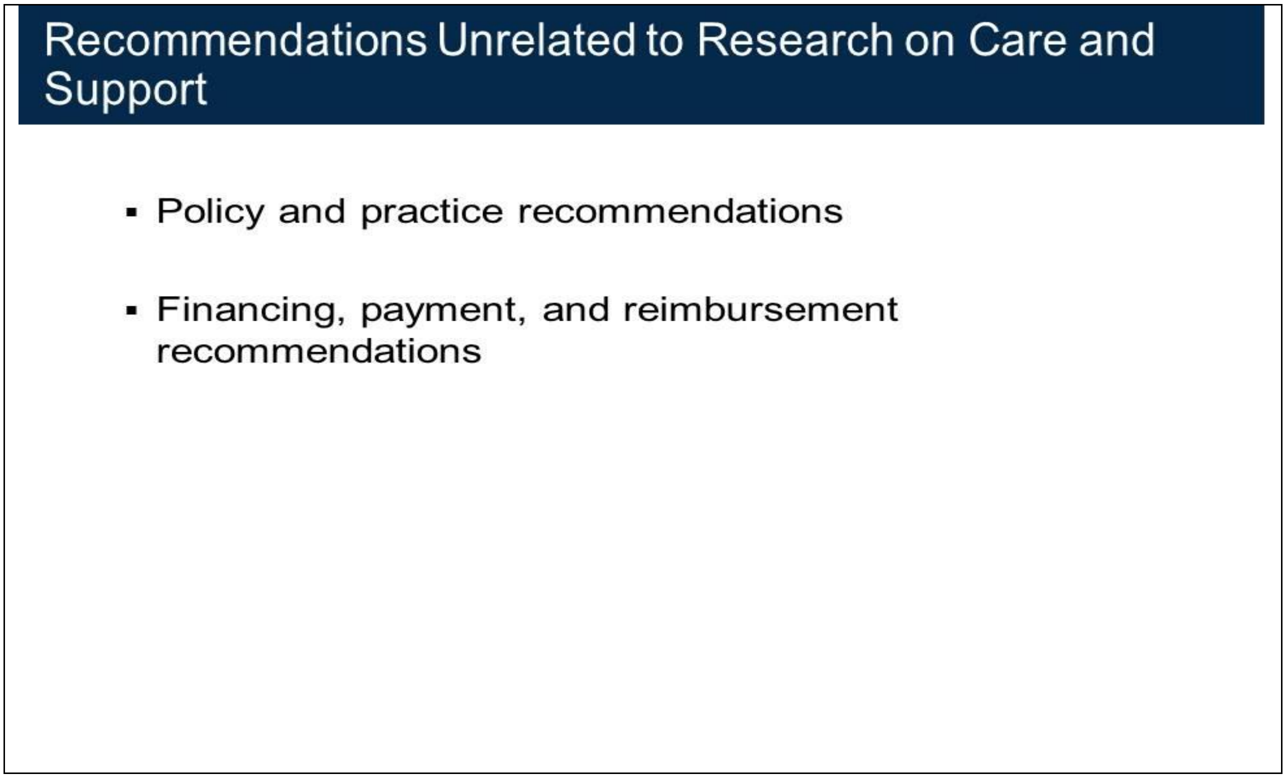


Special Consideration:
Topics for Future Examination



Topics Excluded from Summit Agenda

- Some topics were excluded from the Summit agenda due to time constraints
  - Dementia screening, identification, and diagnosis
  - General, ongoing medical care, specialist care, and hospital and emergency department care for people with dementia



Recommendations Unrelated to Research on Care and Support

- Policy and practice recommendations
- Financing, payment, and reimbursement recommendations

More Information

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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]

Last Updated: 06/09/2018