

# *Update on the 2020 National Research Summit on Care, Services, and Supports for Persons with Dementia and Their Caregivers*

Elena Fazio, National Institute on Aging  
Katie Maslow, Gerontological Society of America  
David Reuben, University of California, Los Angeles

October 21, 2019



## Save the Date



**Dementia Care, Caregiving, & Services Summit**  
**March 24-25, 2020**  
**Natcher Conference Center**  
**Bethesda, MD**

## Outline

- History of the Summits – *Elena Fazio*
- The 2017 Dementia Care & Services Summit – *Katie Maslow*
- Planning for the 2020 Summit – *David Reuben*

5

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

## *History of the Summits*

Elena Fazio, National Institute on Aging



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

## General Overview

- Multi-stakeholder, strategic planning meetings tied to NAPA
- Summit recommendations serve as the basis for research implementation

7

## Purpose of the Summits

- To develop research recommendations by:
  - presenting the state of the science and highlighting promising research findings
  - identifying research gaps
  - gathering input on future research priorities from the community
- NIH and other stakeholders act on research recommendations.
- NIH uses recommendations to inform the development of research implementation milestones.
  - <https://www.nia.nih.gov/research/milestones>

8

# Purpose of the Summits

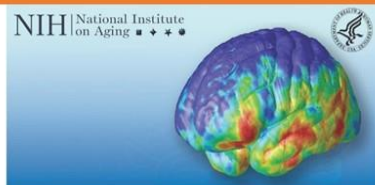
## NAPA Research Goals



9

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

# Alzheimer's Disease Research Summits

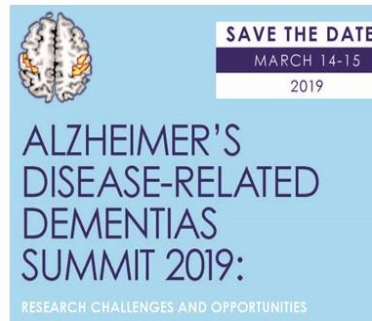
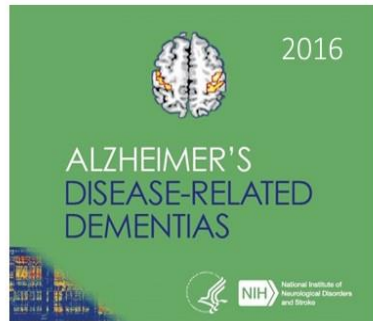


**Alzheimer's Disease Research  
Summit 2012:  
Path to Treatment and Prevention**  
May 14-15, 2012

Program Booklet



# ADRD Research Summits



## Summits and the Work of the National Plan



<https://www.nia.nih.gov/research/milestones>

## Milestone 13.B

Launch research programs to develop and validate assessments of the psychological, financial, and physical health impact of caregiving.

### Success Criteria

- Identification and validation of assessments suitable for use in a range of research contexts including observational and interventional studies and large population-based surveys.
- Identification and validation of at least one sensitive and robust measure for the detection of the earliest manifestations of caregiving burden and for monitoring its long-term consequences.
- Identify and validate at least one improved and cost-effective model of care that includes research on caregiver outcomes following the cessation of caregiving role.

Research Implementation Area	Timeline	Status
Research on Care and Caregiver Support	2017–2020	In Progress

## Now Triennial Rotation

- Alzheimer's Disease Summits – 2012, 2015, 2018, 2021
- Alzheimer's Disease Related Dementias Summits – 2013, 2016, 2019, 2022
- Dementia Care, Caregiving, & Services – 2017, 2020

15



## *The 2017 Dementia Care Summit*

Katie Maslow, Gerontological Society of America



## How the 2017 Summit Came to Be

- After the 2015 Alzheimer's Disease Research Summit, a few of us began talking about the possibility (read 'fantasy') of a similar summit on care and services for people with dementia and their families
- This idea was first presented in the 'Public Comments' section of the April 2015 NAPA Advisory Council meeting.
- LEAD (Leaders Engaged in Alzheimer's Disease) sent a letter asking for a care summit to the USDHHS Secretary; it was signed by 137 LEAD members and suggested that:
  - Such a summit would help in developing research priorities to address Goals 2, 3, and 4 of the National Plan, and
  - Organizing and sponsoring the summit should be done by a partnership of public and private organizations.

17

## A Year of Questions

- Would there be enough content/discussion to justify a 1-day or even 2-day summit?
- Would the summit be only an advocacy opportunity for organizations and individuals to ask for more care, services, and supports?
- Who would authorize and sponsor such a summit?
- Who would pay for it?
- Where could it be held?
- Who would come?

18



## Identifying Possible Research Topics and Reporting Back to the Council

- In late 2015, AARP convened a 1-day meeting of about 50 federal agency staff members, researchers, care and service providers, and advocates to identify important research topics.
- A surprisingly large number of research topics were identified.
- In Jan. 2016, supporters of the summit were invited to present plans for a possible summit to the NAPA Advisory Council.
- At the April 2016 Advisory Council meeting, the council chair appointed 2 summit co-chairs and a steering committee, consisting of federal and state agencies, Advisory Council members, advocacy organizations, PCORI, and 2 slots for persons with dementia.
- And we began to build the summit.

19

## General Goals of the 2017 Summit

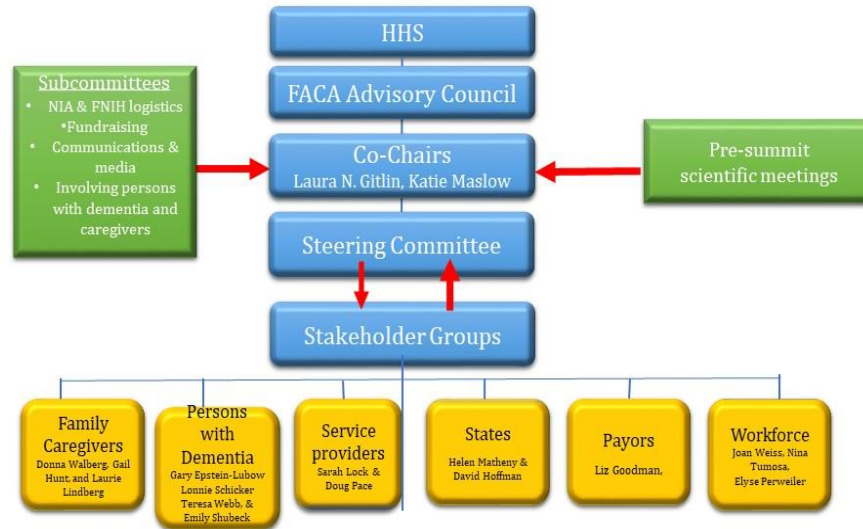
- The goal of this research summit is to identify what we know and what we need to know in order to accelerate the development, evaluation, translation, implementation, and scaling up of comprehensive care, services, and supports for persons with dementia, families, and other caregivers. The summit is 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.

### Anticipated Outcomes

- Recommendations for research priorities to inform federal agencies, foundations, and other private sector organizations
- Identification of evidence-based programs, strategies, and approaches that can be used now to improve care and services
- Research milestones to track and guide acceleration and advancement of evidence-informed care and services

20

# 2017 Organizational Structure



## Pre-Summits and Stakeholder Groups

**8 Pre-Summits:** Intended to leverage existing research activities to bring ideas and recommendations to the summit

Examples:

- Alzheimer’s Association work on outcome measures for dementia care research
- NIA work on research innovations for the next generation of dementia care interventions
- PCORI work on involving patients and families in research on care

### **6 Stakeholder Groups**

- Persons living with dementia
- Family caregivers
- Service providers
- States
- Workforce
- Payers

# 2017 Summit Agenda

- **Plenary Topics:**
  - Demographic profiles, diversity, and implications for care and services
  - Interdependence of biomedical and care and services research
  - Nomenclature – words matter
- **Six Session Topics:**
  - Research on Care Needs and Supportive Approaches for Persons with Dementia
  - Research on Supportive Approaches for Family and Other Caregivers
  - Involving Persons with Dementia and Caregivers as Members of the Research Team
  - Involving Persons with Dementia as Study Participants
  - Research on Models of Care for Persons Living with Dementia and Their Families across the Disease Trajectory
  - Thinking Outside the Box

23



# Limits on What Could Be Covered

- Even with very short presentation times, we were unable to fit all the topics we wanted to include into the Summit.
- We created cross-cutting themes that addressed some of those topics:
  - Diversity (gender, race, ethnicity, culture, language, literacy, sexual orientation, socio-economic status, geographic location, and living situation [alone or with a caregiver])
  - Disparities
  - Etiologies and Disease Stages
  - Care Settings (home, community, assisted living, nursing home, and medical/health care settings)
  - Employment, training, and workforce issues
  - Technology
- Ultimately, there were major topics we could not fit in: most importantly, 1) detection and diagnosis and 2) ongoing medical care.

24



## Enthusiastic Responses

- For all but one speaking slot at the summit, the first person we invited said yes!
- All 500 seats in the Natcher Auditorium were spoken for, and about 1,000 people watched the summit on their computer.

We received more than 700 research recommendations, including from

- Pre-summits
- Stakeholder groups
- The public, in online submissions up to the end of the summit
- Plenary speakers, session chairs, session speakers, and panelists
- Cross-cutting Chairs
- Audience members in summit discussion sessions

25

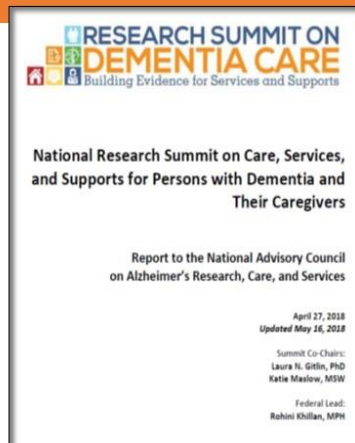
## 12 Themes & 58 Recommendations

**We combined the 700 research recommendations into 12 broad themes:**

- Heterogeneity of Persons Living with Dementia and their Caregivers
- Research Methods to Develop More Effective Dementia Care, Services and Supports
- Caregiver Relationships, Roles, and Networks
- Clinical Approaches and the Lived Experience of Dementia
- Engaging Persons Living with Dementia and Caregivers in Research
- Dementia-Related Terminology, Nomenclature, and Stigma: Words Matter
- Comprehensive Models for Dementia Care, Services, and Supports
- Strategies for Scaling and Disseminating Existing Evidence
- Living Places, Physical and Social Environments, and Processes of Care for Persons with Dementia, Including Those who Live Alone
- Financial Burden and Out-of-Pocket Costs to Persons Living with Dementia and their Caregivers
- Ensuring an Adequate and Qualified Workforce to Support Persons with Dementia and their Caregivers
- Technology to Support Persons with Dementia and their Caregivers

26

# Final Report



All summit materials are available on the ASPE Care Summit website:  
<https://aspe.hhs.gov/national-research-summit-care-services-and-supports-persons-dementia-and-their-caregivers>

27



## Observations from the 2017 Summit

- There are plenty of important topics to be addressed in a research summit on care, services, and supports for persons with dementia and their families.
- The stakeholder groups were a very important element:
  - Having persons with dementia and family caregivers speak at the summit allowed for expanded perspectives
  - The people with dementia and family caregivers who spoke felt included and heard. Maybe stigma was reduced at least a little.
- A lot of progress has been made since the 2017 Summit:
  - New funding announcements were produced.
  - New projects began, and speakers and attendees with similar interests who didn't know each other before the summit met, and some began new, joint research endeavors.
- We never could have imagined when we started that the summit would become part of the triennial rotation. **So exciting - On to the 2020 Summit.**

28



## *Planning for the 2020 Summit*

David Reuben, University of California, Los Angeles



## General Overview & Goals

- The goal of the Summit is to highlight progress that has been made since, and as a result of, the 2017 Summit.
- The primary anticipated outcome of the 2020 summit is to elicit recommendations for research priorities to inform federal agencies, foundations, and private sector organizations.

## Input from Various Sources Leads to Diverse Perspectives

- Publishing a Request for Information in the NIH Guide.
- Convening a Summit Steering Committee
- Working with the HHS Office of the Assistant Secretary of Planning and Evaluation (ASPE) to gather and consider input from several Stakeholder Groups
- Seeking input from federal partners.
- Seeking input from the NAPA Advisory Council.
- Providing opportunities during the Summit for audience participation and engagement, to ensure that the voices of persons living with dementia and family caregivers are heard and that interaction is maximized

31

## Request for Information (RFI)

Invitation for Input on the 2020 National Research Summit on Care, Services, & Supports for Persons with Dementia and their Caregivers

Notice Number: NOT-AG-19-016

### Key Dates

**Release Date:** April 15, 2019  
**Response Date:** June 28, 2019

### Related Announcements

None

### Issued by

National Institute on Aging (NIA)

### Purpose

The purpose of this Request for Information (RFI) is to invite comments and suggestions for the second National Research Summit on Care, Services, & Supports for Persons with Dementia and their Caregivers, set to occur on March 24 & 25, 2020. The National Institute on Aging (NIA), in conjunction with the Department of Health and Human Services as part of the National Alzheimer's Project Act (NAPA), seeks input on topics of consideration from its stakeholders, including persons living with dementia, caregivers, members of the scientific community, academic institutions, the private sector, health professionals, professional societies, advocacy groups, patient communities, as well as other interested members of the public. All input will be considered in the development of the agenda for this Summit.

### Background

The first National Research Summit on Care, Services, and Supports for Persons with Dementia and their Caregivers was held on the National Institutes of Health (NIH) campus on October 16-17, 2017. This summit followed the example of previous Alzheimer's Disease and Alzheimer's Disease Related Dementias Summits (organized by the NIA and the National Institute of Neurological Disorders and Stroke (NINDS), respectively). These conferences are all a part of the coordinated planning efforts that respond to the National Plan to Address Alzheimer's Disease, first released in 2012 and now updated annually. The intent of each of these summits is to produce research recommendations that reflect critical scientific priorities for research on Alzheimer's disease and related dementias.

The 2017 Dementia Care & Services Summit Report summarizes the structure of the 2017 Summit and the research recommendations generated from these activities. The 2020 Dementia Care & Services Summit aims to expand upon what was learned in the previous summit and spark new innovative ideas in the fields of care, services, and supports.

### Information Requested

We are requesting input through this RFI from all stakeholders in the previous summit and individuals/organizations that may be newly interested in this topic; this input will contribute to the development of an agenda and organization of the 2020 Summit.

32

## Current List of Steering Committee Members

- Jennifer Wolff, Johns Hopkins University, Steering Committee Co-chair
- David Reuben, UCLA, Steering Committee Co-chair
- María Aranda, University of Southern California
- Susan Beane, Healthfirst
- Malaz Boustani, Indiana University School of Medicine
- Katie Brandt, Massachusetts General Hospital
- Chris Callahan, Indiana University School of Medicine
- Elena Fazio, National Institute on Aging
- Lori Frank, RAND
- Jason Karlawish, University of Pennsylvania
- Ian Kremer, LEAD Coalition
- Helen Lamont, Office of the Assistant Secretary for Planning and Evaluation, HHS
- Katie Maslow, Gerontological Society of America
- Michael Monson, Centene Corporation
- Vincent Mor, Brown University
- Joanne Pike, Alzheimer's Association
- Melanie Schicker, Minnesota State University (Retired)
- Robyn Stone, LeadingAge
- Sheryl Zimmerman, University of North Carolina



## Stakeholder Groups

- Persons Living with Dementia
- Family Caregivers of Persons Living with Dementia
- Service Providers, including in-home and community-based services, nursing home, rehabilitation, assisted living and hospice care, public health services, and health care professional groups
- Workforce Development
- Payers



## Six Themes

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

35

## Theme 1: Impact of Dementia

This theme includes issues related to heterogeneity and trends in:

- the **lived experience of dementia**
- the **economic impact of dementia**
- the **effects of dementia**, including the impact of health disparities **on diverse populations**

36

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

This theme includes issues related to:

- the organization, financing, and delivery of **long-term services and supports** (LTSS) in the **home and community and in residential settings**, such as assisted living and nursing homes.

37

## Theme 3: Services and Supports in Medical Care Settings for Persons with Dementia

This theme includes issues related to:

- the organization, financing, and delivery of **medical care in a range of settings**, including skilled home health care, home-based medical care, hospice, ambulatory care centers, emergency departments, hospitals, and post-acute care.

38

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

This sub-theme addresses:

- an integration of topics that fall within Themes 2 and 3, including innovations in the organization, financing, and delivery to support **integration of medical care and LTSS across the range of settings** in which persons with AD/ABRD and their caregivers live and receive care.

39

## Theme 4: Participation of Persons with Dementia and their Caregivers in Research

This theme includes issues related to:

- **the roles** of persons living with dementia and their family caregivers as both research **participants** and as engaged research **partners**
- the **impact of patient communities on study design and outcomes, nomenclature, and strategies for recruitment and retention**
- optimizing collection of information from a range of sources
- considerations for returning genetic and biomarker information and other study data
- talking about research and research results

40

## Theme 5: Intervention Research, Dissemination, and Implementation

This theme includes:

- methods to **improve research on interventions**, including interventions targeting individuals, dyads, or organizations,
- research on approaches to **increase the implementation and dissemination** of evidence-based interventions with sufficient fidelity in real-world settings to improve quality of care and quality of life for persons with dementia and their caregivers.
- Strategies to **motivate systems change to adopt and implement** evidence-based interventions.

41

## Theme 6: Research Resources, Methods, and Data Infrastructure

This theme includes a focus on:

- **methods, data, and processes** to facilitate cross-cutting, high-impact research including approaches to:
  - intervention research (including pragmatic trials) and
  - observational studies
- **data infrastructure** and data sources
- outcome measures, **ethical frameworks**, and consent/IRB issues.

42

## Cross-Cutting Themes

1. Perspectives from persons with dementia and their caregivers
2. Health disparities
3. Ethics
4. Technology
5. Etiologies

43

## Process for Producing Research Recommendations

- Research recommendations will be organized by theme
- Stakeholder groups will share recommendations from their perspective with the Steering Committee during the planning process, for consideration by the Steering Committee
- Preliminary recommendations will be presented at the Summit, by theme/session

44

## Current Status of Agenda

1. Plenary Talks, including stakeholders and related activities
2. Six sessions based on Themes
  - A. Three research presentations
  - B. Presentation of preliminary recommendations
  - C. Comments from panelists, stakeholders, and audience
3. Emerging Topics
4. Poster Presentations
5. Future Directions

45

## Call for Poster Presentations

Summit organizers are accepting applications for two types of poster presentations at the 2020 Summit:

1. **Scientific posters** describing a completed or ongoing study relevant to one or more of the Summit themes
2. **Informational posters** that display and describe a service, program, or data resource provided by an organization, federal partner, advocacy group, or service provider.

*We encourage scientific poster abstract submissions from graduate students, postdoctoral individuals, and early-stage investigators, especially those from underrepresented populations in the biomedical workforce, on a topic that identifies a significant research gap and is relevant to one of the Summit themes.*

**DEADLINE TO SUBMIT ABSTRACT: NOVEMBER 15<sup>TH</sup>**

46

# **Registration Will Open Tomorrow!**

<https://www.nia.nih.gov/2020-dementia-care-summit>

In-person attendance at the Summit is free.  
The event will also be live streamed via NIH Videocast.

47



**Questions?**

