

# Update

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

Progress to Date  
Laura N. Gitlin and Katie Maslow

Presentation to Advisory Counsel of the National Alzheimer's Project Act  
February 3, 2017



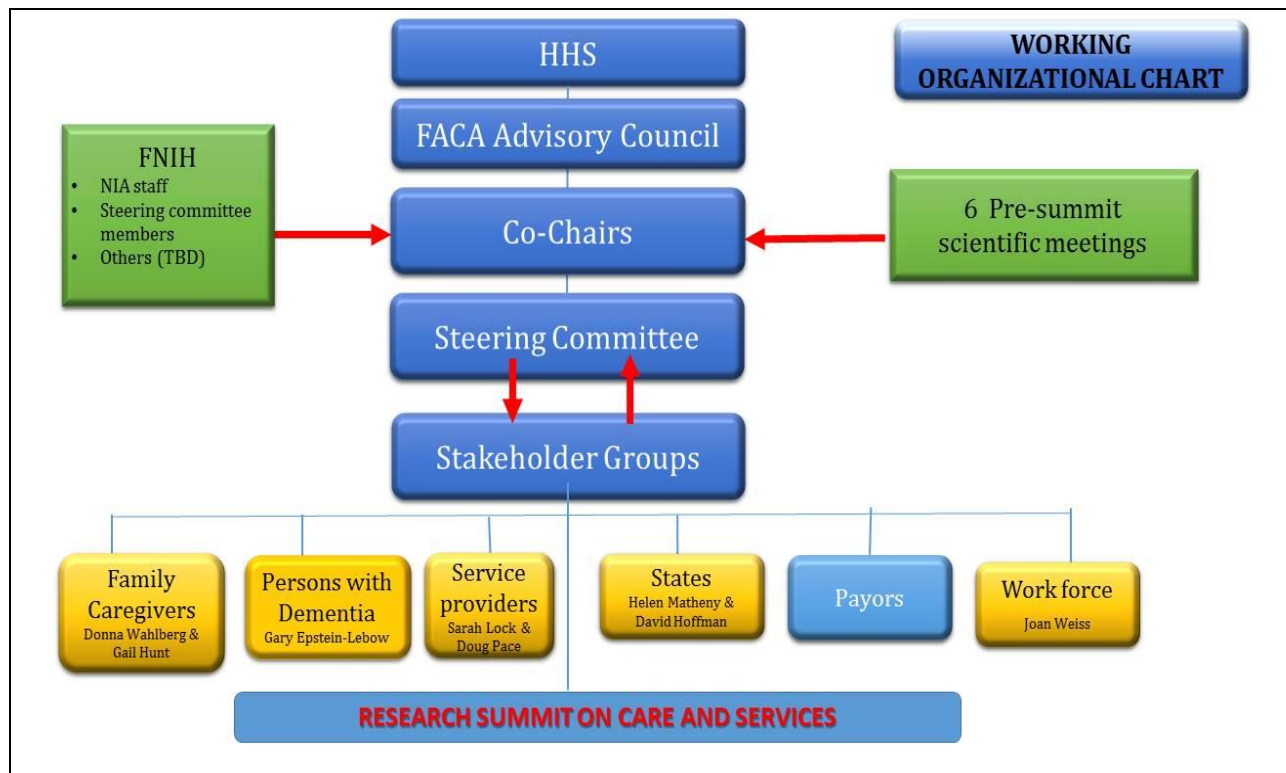
**SAFE THE DATE**

**OCTOBER 16-17, 2017**

**NATCHER BUILDING, NIH CAMPUS**

## Goal of the National Research Summit

- Identify what we know and what we need to know to accelerate development, evaluation, translation, implementation, and scaling up of comprehensive care, services, and supports for persons with dementia, families, and other caregivers
- Focus on research needed to improve quality of care and outcomes including quality of life and the lived experience of persons with dementia and their caregivers across care settings, etiologies, diverse families



## Steering Committee Members

- Person with dementia (TBN)
- Gary Epstein-Lubow, MD (Brown Univ.)
- Lori Frank, PhD (PCORI)
- Richard Hodes MD (NIA; John Haaga, Melinda Kelley, Elena Fazio)
- Ian N. Kremer JD (LEAD)
- Shari M. Ling, MD (CMS)
- Sarah Lenz Lock JD (AARP)
- Helen Matheny, MS (West Virginia Univ)
- Lisa McGuire, PhD (CDC)
- Jennifer Mead, MPH (Oregon Dept. of HS)
- Linda O. Nichols, PhD. (VA Medical Center)
- Douglas D. Pace, NHA (Alzheimer's Assoc)
- Jane Tilly, DrPH (ACL)
- Lois A. Tully, PhD. (NINR)
- Joan Weiss, PhD, RN (HRSA)

### Co-chairs

Laura N. Gitlin, Ph.D.  
Katie Maslow, MSW

### Executive Committee

Ron Petersen MD, Ph.D.  
(Mayo)  
Rohini Khillan, MPH (HHS)

## 6 Pre-Summit Activities

- Evidence for home-based dementia care – systematic literature review and think tank (Drs. Lyketsos, Samus & team, Johns Hopkins University)
- Determinants of behavioral symptoms – systematic literature review (Dr. Kolanswki and team, Penn State University)
- Diversity and Alzheimer's Disease Caregiving Conference Race/ethnicity and caregiving (Dr. Meyer, University of California, Davis)
- Caregivers of Persons with Intellectual and Developmental Disabilities (IDD) and Dementia (Dr. Janicki, National Task Group on Intellectual Disabilities and Dementia Practices)
- 2015 Survey data on Family Caregivers of Persons with Dementia (National Alliance on Caregiving, Alzheimer's Association)
- Methodological considerations in research on care and services (Dr. Frank, PCORI)

## Snapshot of Summit Sessions and Co-chairs

- 2 days, 8 am to 4 pm, 6 main sessions

- **Opening session Plenary –setting the stage**

- Maria Carillo, Ph.D.
- Ken Langa, MD, Ph.D.
- Jennifer Manly, Ph.D.
- Maria Aranda, Ph.D.

- **Session I:** Research on Care Needs and Supportive Approaches for Persons with Dementia (Co-chairs: Richard Fortinsky, Ph.D., Ann Kolanowski, Ph.D.)
- **Session II:** Research on Supportive Approaches for Family and Other Caregivers (Co-chairs: Linda Teri, Ph.D, Lisa Fredman, Ph.D.)
- **Session III:** Involving Persons with Dementia and Family and Other Caregivers as Active Members of the Research Team to Identify Research Topics and Meaningful Outcomes (Co-Chairs: Mark Snowden, MD, M.P.H, Lee Jennings, MD, M.S.H.S.)

## Snapshot of Summit Agenda and Co-chairs

- **Session IV:** Research on Care Coordination and Care Management for Persons with Dementia and Family Caregivers (Co-chairs: David Reuben, MD., Vincent Mor, Ph.D.)
- **Session V:** Challenges in Involving Persons with Dementia as Study Participants in Research on Care and Services (Co-chairs: Darby Morhardt, Ph.D., David Bass, Ph.D.)
- **Session VI:** Research on Translation, Dissemination, Implementation, and Scaling Up of Effective Care, Services, and Supportive Approaches for Persons with Dementia and Family and Other Caregivers (Co-chairs: Chris Callahan, MD., Alan Stevens, Ph.D.)
- **Cross-cutting chairs:** Technology – Dr. Czaja; Race/ethnicity/culture – Dr. Hinton; Etiologies/disease stage – Angela Taylor

## Co-Chair Responsibilities

- Identify content to be covered in particular session and structure
  - E.g., number of speakers, panelists, moderated audience participation
- Identify speakers for session (15 minute focused talks)
- Identify panelists (who might provide 5 minute reactions or insights into a focused topic)
- Hold one to 3 calls prior to Summit with speakers/panelists to begin to develop research recommendations
- At dinner Oct. 16, meet with speakers to finalize recommendations from this session
- After summit – review final set of recommendations and provide comments/direction/feedback.

## NEXT STEPS

- Katie and Laura continue to meet weekly and periodically with ASPE and RTI and NIA
- Steering committee is meeting monthly
- Stakeholder groups will be finalized and have at least one meeting in February
- Katie and Laura meeting with co-chairs of each main session to identify topics/speakers/processes
- Process of generating recommendations currently being developed
- With FNIH:
  - Organization of press release and dissemination
  - Fundraising
  - Working timeline
  - Working budget

## February 3, 2017 -- Advisory Council Meeting #23

The meeting was held on Friday, February 3, 2017, in Washington, DC. The theme of this Advisory Council meeting was clinical trials for Alzheimer's disease and related dementias and recruitment challenges. Additional afternoon presentations included updates on progress towards a Care and Services Summit, federal workgroup updates, and preparation for the Advisory Council's 2017 Recommendations, due in April 2017. Material available from this meeting is listed below and is also available at <https://aspe.hhs.gov/advisory-council-alzheimers-research-care-and-services-meetings#Feb2017>.

Comments and questions, or alerts to broken links, should be sent to [napa@hhs.gov](mailto:napa@hhs.gov).

---

### General Information

<b>Agenda</b>	<a href="#">[HTML Version]</a> <a href="#">[PDF Version]</a>
<b>Meeting Announcement</b>	<a href="#">[HTML Version]</a> <a href="#">[PDF Version]</a>
<b>Meeting Summary</b>	<a href="#">[HTML Version]</a> <a href="#">[PDF Version]</a>
<b>Public Comments</b>	<a href="#">[HTML Version]</a>

### Handouts

<b>Panelist Bios</b>	<a href="#">[HTML Version]</a> <a href="#">[PDF Version]</a>
----------------------	--

### Presentation Slides

<b>2017 Recommendations</b>	<a href="#">[HTML Version]</a> <a href="#">[PDF Version]</a>
<b>Alzheimer's Association TrialMatch</b>	<a href="#">[HTML Version]</a> <a href="#">[PDF Version]</a>
<b>Clinical Services Subcommittee Federal Update</b>	<a href="#">[HTML Version]</a> <a href="#">[PDF Version]</a>
<b>Clinical Studies Recruitment Strategy</b>	<a href="#">[HTML Version]</a> <a href="#">[PDF Version]</a>
<b>Development and Use of Registries to Accelerate Enrollment into Alzheimer's Trials</b>	<a href="#">[HTML Version]</a> <a href="#">[PDF Version]</a>
<b>Long-Term Services and Supports Committee Update</b>	<a href="#">[HTML Version]</a> <a href="#">[PDF Version]</a>
<b>National Recruitment Strategy</b>	<a href="#">[HTML Version]</a> <a href="#">[PDF Version]</a>

<b>NINDS Update</b>	<a href="#">[HTML Version]</a> <a href="#">[PDF Version]</a>
<b>Randomized Controlled Trials for Alzheimer's Disease</b>	<a href="#">[HTML Version]</a> <a href="#">[PDF Version]</a>
<b>Strategies to Facilitate Recruitment and Screening for Alzheimer's Clinical Trials</b>	<a href="#">[HTML Version]</a> <a href="#">[PDF Version]</a>
<b>Transforming AD Therapy Development</b>	<a href="#">[HTML Version]</a> <a href="#">[PDF Version]</a>
<b>Update National Research Summit on Care, Services and Supports for Persons with Dementia and Their Caregivers</b>	<a href="#">[HTML Version]</a> <a href="#">[PDF Version]</a>

## **Videos**

<b>Welcome thru Perspectives</b>	<a href="#">[Video]</a>
<b>Rachel, Jessica, George Presentations</b>	<a href="#">[Video]</a>
<b>Keith Presentation and Panel Discussion</b>	<a href="#">[Video]</a>
<b>Public Comments</b>	<a href="#">[Video]</a>
<b>Care Summit and Milestones</b>	<a href="#">[Video]</a>
<b>Federal Workgroups and Adjourn</b>	<a href="#">[Video]</a>

---

Last Updated: 06/29/2018