

## Update

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

Progress to Date

Presentation to Advisory Counsel of the National Alzheimer's Project Act  
October 31, 2016

## Pending Final Approvals

**TENTATIVE DATE FOR SUMMIT  
OCTOBER 16-17, 2017**

**TENTATIVE LOCATION  
NATCHER BUILDING**

## Research Summit Goal and Potential Outcomes

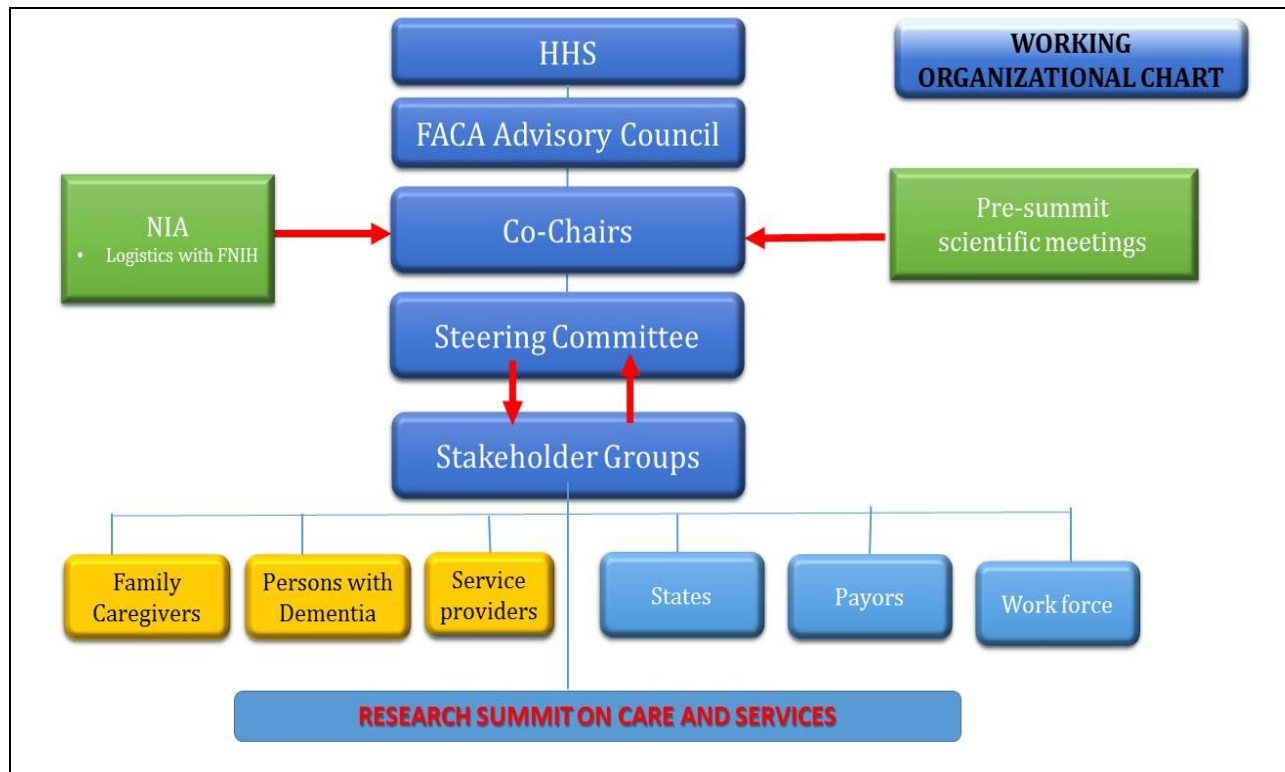
### Goal

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.

- **Cross-cutting themes: Diversity (SES, race, ethnicity, culture, language, literacy, geographic locations); Disparities; Etiologies, and Disease Stages; Care Settings (home, community, assisted living, nursing home, and medical/health care settings); training and workforce issues; technology**

### Potential Outcomes (work in progress)

- 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



## Steering Committee Members

- Person with dementia TBA
- Gary Epstein-Lubow, MD (Brown Univ.)
- Lori Frank, PhD (PCORI)
- Richard Hodes MD (NIA)
- 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, PhD (Mayo)  
Linda Elam, PhD, MPH (HHS)  
Rohini Khillan, MPH (HHS)

## Potential Roles of Stakeholder Groups

(will differ by group)

- Review, flesh out or indicate emphases of sessions
- Review list of speakers, panelists and/or identify candidates
- Help identify ways to disseminate Summit date
- Help identify ways to populate audience
- Help identify ways to implement/use outcomes
- Generate/review research recommendations
- Provide insights in terms of unmet needs and ways to address through research

## Pre-Summit Activities

- Scientific meetings conducted prior to Research Summit to:
  - Provide foundational knowledge
  - Offer specific recommendations to be presented and/or discussed at Summit
  - Provide working documents (white papers)
  - Leverage and link existing scientific activity relevant to Research Summit on Care and Services
- Criteria:
  - “Naturally occurring” and have own funding source
  - Focus on topic of high relevance to Research Summit
  - Will contribute a research report or publication to serve as background materials for the Research Summit
  - Potentially contribute to or inform a panel or nominate speakers for the Research Summit on topic covered
  - Generate recommendations, guidelines for future research addressing care and services

## Update on Pre-summit Activities

### 2 in progress:

- Funded by Brightfocus - Accelerating development, testing and dissemination of home-based dementia care interventions
  - Dr. Lyketsos chair
  - Presentation at AAIC
  - Manuscript under development
- Supported by American Academy of Nursing - State of the Science Systematic Review
  - Dr. Ann Kolonowski, chair
  - Presentation at Council of Nursing Science
    - Personal, Interpersonal, and Environmental Determinants Of Behavioral And Psychological Symptoms of Dementia
  - Manuscript under development

### Other Pre-summit activities being developed

## Other Pre-Summit Activity Ideas

- Epidemiology and demographics for persons with dementia and family and other caregivers
- Methodological challenges, e.g., engaging persons with dementia and families and creating a pipeline for interventions
- Next generation of interventions
- International research/activities concerning care and services
- Role of technology

## Summit Agenda

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

- Plenary – Demographics now and into the future
- **Session I:** Research on Care Needs and Supportive Approaches for Persons with Dementia
- **Session II:** Research on Supportive Approaches for Family and Other Caregivers
- **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
- **Session IV:** Research on Care Coordination and Care Management for Persons with Dementia and Family Caregivers
- **Session V:** Challenges in Involving Persons with Dementia as Study Participants in Research on Care and Services
- **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

## NEXT STEPS

- Katie and Laura continue to meet weekly and periodically with ASPE and RTI
- Steering committee will begin meeting monthly
- Steering committee currently providing recommendations for session chairs (confirmation of chairs sought by end of November)
- Session chairs and stakeholder groups will give input on speakers, panelists, and specific topics of sessions
- Process of generating recommendations currently being articulated
- Once Date/FNIH confirmed:
  - Organization of press release and dissemination
  - Fundraising
  - Development of graphic and tagline (CMS has volunteered to produce)
  - Working timeline
  - Working budget