

Update National Research Summit on Care and Services

Progress to Date

Presentation to National Advisory Counsel

August 1, 2016

Research Summit Goal and Potential Outcomes

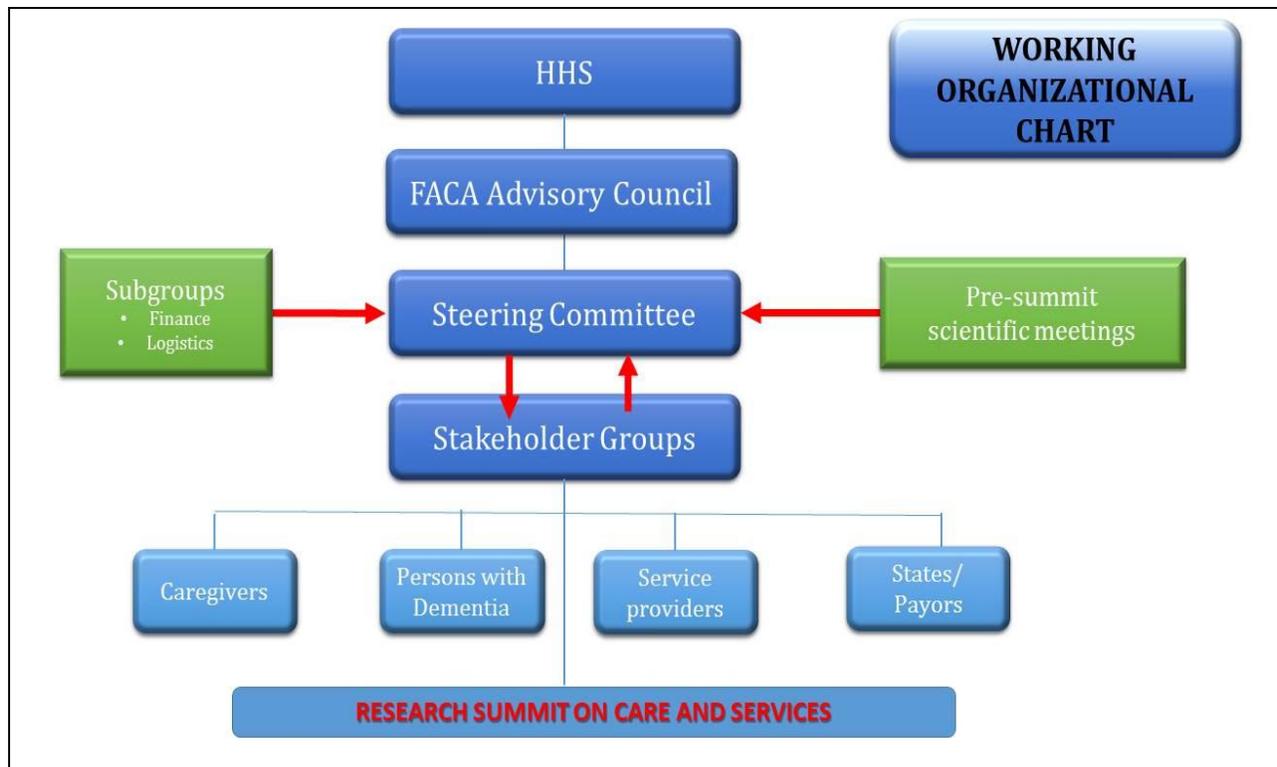
Goal:

To accelerate the development, evaluation, translation, implementation and scaling up of strategies to improve quality of care and outcomes across settings, including quality of life and the lived experience of persons with dementia, family members, and caregivers.

- **Attention to: Diversity (SES, race/ethnicity, locations, literacy), Disparities; Etiologies, and Disease Stages**

Potential Outcomes (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)

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

AAIC Featured Research Symposium – July 25, 2016 Accelerating development, testing and dissemination of home-based dementia care interventions

Chairs: Constantine G. Lyketsos, MD, MHS, Johns Hopkins Medicine; Diane Bovenkamp, Brightfocus Foundation

Dr. Gitlin - Status of the field: clinical trials evaluating home based dementia care

Dr. Samus - Clinical trial example: “Maximizing Independence at Home” for people with dementia: design, outcomes, and future directions

Dr. Kales – Clinical trial example: “WeCare Advisor” a clinical trial of a caregiver focused, iPad administered algorithm to manage behavioral symptoms

Dr. Callahan - Dissemination science: Addressing challenges to the widespread use of evidence-based, home dementia care

Final Report will include recommendations for the Summit concerning home-based dementia care interventions and ways to assure acceleration of proven approaches

Other Pre-Summit Activity Ideas

- Epidemiology and demographics for persons with dementia and family and other caregivers
- Methodological challenges including pipeline for interventions
- Next generation of interventions
- International research/activities concerning care and services
- Role of technology

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SUMMARY OF STRUCTURE, POSSIBLE SESSIONS

- 2 days, 8 am to 4 pm, 6 main sessions
- **Possible Main Sessions**
 - Family caregiving (e.g., what we know and what we need to know to provide effective care and services)
 - Persons with dementia (e.g., what we know and what we need to know to provide effective care and services)
 - Implementation and scaling up (e.g., needed research on translation and scaling of effective care and services)
 - Research methodology (e.g., measurement issues and approaches for involving persons with dementia and family caregivers in research; measurement of quality of life, outcomes; pragmatic trial and other adaptive designs for rapid research)
 - Technology to provide/support care and services (e.g., use of technologies for service delivery, monitoring)
 - Setting-specific care delivery issues (e.g., home and community services, including care coordination; residential care, including assisted living and nursing home)

Progress To Date

- Katie and Laura meet weekly and periodically with ASPE
- Steering committee meets every 6 weeks
- HHS contract to assist with pre-summit activities, summit planning and a post-summit summary
- Broad Time line:
 - Pre-summit activities are being planned for the time between now and the summit
 - Stakeholder groups of persons with dementia and caregivers are currently being organized
 - Ways to obtain input from other Stakeholder groups (service providers, payors, and states) are being considered
 - Summit planned for Fall 2017