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

RESEARCH SUMMIT ON DEMENTIA CARE
Building Evidence for Services and Supports

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)

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**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

• 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.

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Handouts

| Panelist Bios                  | [HTML Version] | [PDF Version] |

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Last Updated: 06/29/2018