



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

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 person- and family-centered care and outcomes across care settings, including quality of life and the lived experience of persons with dementia and their caregivers.*

*The term 'caregivers' refers to family members, neighbors, friends, fictive kin, and formal, paid caregivers.

Crosscutting Themes: 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; and technology.

Note: Speaker topics listed in this agenda are for planning purposes only. Speakers will specify the exact title of their presentation in discussion with the summit co-chairs.

DAY ONE – October 16, 2017

7:00am – 8:00am: Registration

8:00am – 8:15am: Welcome and introductory remarks, including sponsor comments

8:15am – 8:30am: NAPA Research Milestones: Process and Progress
Ron Petersen, MD, PhD, Mayo Clinic

8:30am – 8:45am: Context for Dementia Care and Services Research
Maria Carrillo, PhD, Alzheimer's Association

8:45am – 9:45am: **Plenary Lectures (Population Level).** These three lectures will provide foundational information about prevalence and characteristics of persons with dementia, family caregivers and caregiving situations, emphasizing diversity and heterogeneity. This information will create the demographic framework for summit sessions.

- Demographics of dementia and dementia caregiving
Ken Langa, MD, PhD, University of Michigan
- Differential effects of race, ethnicity and culture
Jennifer Manly, PhD, Columbia University
- Implications of diversity and heterogeneity among persons with dementia, caregivers, and caregiving situations for research to support person- and family-centered care, services, and supports
Maria Aranda, PhD., MSW, MPA, LCSW, University of Southern California

9:45am – 12:00pm Session I: Research on Care Needs and Supportive Approaches for Persons with Dementia

Co-Chairs:

Richard Fortinsky, PhD, University of Connecticut

Ann Kolanowski, PhD, RN, FAAN, Pennsylvania State University

9:45am - 10:50am SPEAKERS

Notes: Each speaker will summarize available evidence about his/her topic and then identify knowledge gaps and research recommendations. The order of presentations has not been set.

- Preventing and mitigating behavioral and psychological symptoms of dementia; This presentation will include research recommendations from the Council for the Advancement of Nursing Science pre-summit
Helen Kales, MD, PPA, University of Michigan
- Maintaining and supporting function in persons with dementia
Barbara Resnick, PhD, RN, CRNP, FAAN, FAANP, University of Maryland
- Preventing and slowing cognitive decline; supporting cognitive resilience in persons with dementia
Invited speaker: TBD
- Using technologies to support independence and monitor for safety in persons with dementia
Jeffrey Kaye, MD, Oregon Health & Science University
- Home as the nexus of care: findings and recommendations from the Bright Focus Foundation pre-summit
Constantine Lyketsos, PhD, Johns Hopkins University

10:50am-11:30am: BRIEF REPORTS AND COMMENTARIES

- Living well with dementia; what does it mean?
Person with dementia: TBD
- Emerging research targets: relationship of activity to circadian rhythms and sleep
Nancy Hodgson, PhD, RN, FAAN, University of Pennsylvania
- Physical and social environments for care and services: research recommendations for the design of care settings
Maggie Calkins, PhD, The Mayer-Rothschild Foundation
- Intellectual disabilities and dementia: findings and research recommendations from the National Task Group on Intellectual Disabilities and Dementia Practices pre-summit
Tamar Heller, PhD, University of Illinois, Chicago
- Persons with dementia who live alone: research recommendations on care and service needs and delivery
Elizabeth Gould, MSW, LCSW, National Alzheimer's and Dementia Resource Center, RTI

11:30am - 12:00pm MODERATED AUDIENCE DISCUSSION

12:00pm – 1:00pm: Lunch

1:00pm – 3:00pm Session II: Research on Supportive Approaches for Family and Other Caregivers

Co-Chairs:

Linda Teri, PhD, University of Washington

Lisa Fredman, PhD, Boston University

1:00pm – 2:00pm SPEAKERS

Notes: Each speaker will summarize available evidence about his/her topic and then identify knowledge gaps and research recommendations. The order of presentations has not been set.

- Lessons learned from research on how to support family caregivers effectively (including importance of caregiver assessment for tailoring interventions)
Linda Nichols, PhD, University of Tennessee
- Evolving knowledge about the health effects of dementia caregiving
Lisa Fredman, PhD, Boston University
- Dyadic interventions
Carol Whitlatch, PhD, Benjamin Rose Institute
- Using technology to assess and support family caregivers
Sara Czaja, PhD, University of Miami
- Caregivers and care providers. This presentation will focus on findings and research recommendations from the NIA pre-summit on care interventions,
Vincent Mor, PhD, Brown University

2:00pm – 2:30 pm: BRIEF REPORTS AND COMMENTARIES

- Personal perspectives on family caregiving
Member of the Summit Family Caregiving Stakeholder Group, TBD
- Diversity and disparities in family caregiving. This presentation will focus on findings and research recommendations from the U.C. Davis pre-summit
Oanh Le Meyer, PhD, University of California, Davis
- LGBT perspectives
Karen I. Fredriksen-Goldsen, PhD, University of Washington
- Findings and research recommendations from the National Alliance for Caregiving pre-summit
Gail Hunt, National Alliance for Caregiving
- Women's health perspectives on family caregiving
Mary Worstell, MPH, U.S. Office of Women's Health

2:30pm – 3:00pm: MODERATED AUDIENCE DISCUSSION

3:00pm - 3:15pm: Break

3:15pm – 4:45pm Session III: Involving Persons with Dementia and Caregivers as Members of the Research Team

Co-chairs:

Mark Snowden, MD, MPH, University of Washington

Lee Jennings, MD, MSHS, University of Oklahoma

3:15pm – 4:00pm: SPEAKERS

Notes: Each speaker will summarize available evidence about his/her topic and then identify knowledge gaps and research recommendations. The order of presentations has not been set.

- Current goals and practices in involving patients and families in general and persons with dementia and their caregivers specifically as members of the research team. The presentation will include findings from the PCORI pre-summit on this topic.
Lori Frank, PhD, Patient-Centered Outcomes Research Institute (PCORI)
- Challenges and solutions for involving persons with dementia and dementia family caregivers as members of the research team
Jason Karlawish, MD, University of Pennsylvania
- European perspectives and experience in involving persons with dementia and dementia family caregivers as members of the research team
James Pickett, PhD, Alzheimer's Society (UK)

4:00pm - 4:15pm: BRIEF REPORTS AND COMMENTARIES

- Persons with dementia: perspectives on participating as a member of the research team
Person with dementia, TBD
- Family caregivers: perspectives on participating as a member of the research team
Family caregiver, TBD

4:15pm – 4:45pm: MODERATED AUDIENCE DISCUSSION

DAY TWO – October 17, 2017

7:00am – 7:55 am: Registration

7:55am - 8:00am: Introduction to Day: Summit Co-Chairs

8:00am – 8:30am Plenary: Nomenclature: Words Matter

Co-Chairs:

Angela Taylor, Lewy Body Dementia Association

Ron Petersen, MD, PhD, Mayo Clinic

This plenary will address the confusing array of terms used for persons with dementia and family caregivers, stigma associated with various terms, and the impact of terms and stigma on access to and use of information and services for persons with dementia and caregivers.

Session structure and speakers TBD

8:30am – 9:45am Session IV: Involving Persons with Dementia as Study Participants

Co-Chairs:

Darby Morhardt, PhD, Northwestern University

David Bass, PhD, Benjamin Rose Institute

8:30am – 9:05am: SPEAKERS

Notes: Each speaker will summarize available evidence about his/her topic and then identify knowledge gaps and research recommendations. The order of presentations has not been set.

- Heterogeneity of dementia and impact on self-report
Sandy Weintraub PhD, Northwestern University
- Involving persons with dementia as study participants: findings and recommendations from the PCORI pre-summit
Darby Morhardt, PhD, Northwestern University, and **Lisa Gwyther, MSW**, Duke University
- Quantitative and qualitative information obtained from research interviews with persons with dementia and study accommodations to support involvement for as long as possible
Kathie Judge, PhD, Cleveland State University

9:05am – 9:15am: BRIEF REPORTS AND COMMENTARIES

- Perspectives on involvement as a study participant
Person with dementia, TBD
- Perspectives on the person with dementia's involvement as a study participant and their own involvement as a study partner
Study partner/family caregiver, TBD

9:15am – 9:45am: MODERATED AUDIENCE DISCUSSION

9:45am-12:30pm Session V: Research on Care Coordination and Care Management across the Continuum of Disease Stages and Settings

Co-Chairs:

David Reuben, MD, University of California, Los Angeles

Vincent Mor, PhD, Brown University

9:45am – 11:00am: Models of Care Coordination

Notes: Each speaker will summarize available evidence about his/her topic and then identify knowledge gaps and research recommendations. The order of presentations has not been set.

Dementia–Specific Models of Care Coordination

- Overview of the evidence and challenges for care coordination models
David Bass, PhD, Benjamin Rose Institute
- Health system-based care coordination models
Zaldy Tan, MD, University of California, Los Angeles
- Community-based care coordination models
Quincy Samus, PhD, Johns Hopkins University

General Models of Care Coordination that Serve Persons with Dementia

- Geriatric care models
Tom Edes, MD, Veterans Health Administration
- Residential care models, including assisted living
Sheryl Zimmerman, PhD, University of North Carolina, Chapel Hill
- Medicare/Medicaid dual eligible demonstration models
Debra Cherry, PhD, Alzheimer’s Greater Los Angeles
- Consumer-directed care models
Julie Robison, PhD, University of Connecticut

11:00am - 11:30am Service Provider and Payer Reactor Panel: Moderator TBD Invited panelists:

- **Shari Ling, MD**, Centers for Medicare and Medicaid Services
- **Steve C. Waring, DVM, PhD**, Essentia Institute of Rural Health
- **Nora Super**, National Association of Area Agencies on Aging

11:30am – 12:00pm Facilitators of Dementia Care Coordination

- Workforce competence, education, training
Gregg Warshaw, MD, University of North Carolina Health Care
- Quality Measures
Gary Epstein-Lubow, MD, Brown University and **person with dementia, TBD**
- Costs, payment, cost-effectiveness, and implications for scaling up
David Reuben, MD, University of California, Los Angeles

12:00pm – 12:30pm: MODERATED AUDIENCE DISCUSSION

12:30pm – 1:30pm Lunch

1:30pm – 5:00pm Session VI: Thinking Outside the Box

Co-Chairs:

- Chris Callahan, MD**, Indiana University School of Medicine
- Alan Stevens, PhD**, Baylor Scott & White Health

1:30pm - 1:55pm: Thinking Outside the Box

- **Chris Callahan, MD**, Indiana University School of Medicine
- **Raha Alavi**, Senior Vice President, Retail Services, Nielsen **1:55pm – 4:15pm: SPEAKERS**

Notes: Each speaker will summarize available evidence about his/her topic and then identify knowledge gaps and research recommendations. The order of presentations has not been set.

A. Thinking Outside the Box: Translation and Implementation of Effective Care, Services, and Supports

- Making research relevant: moving from RCT to practice
Linda Teri, PhD, University of Washington
- Adapting effective interventions to accommodate concerns about delivery time, cost, and available staff
Mary Mittelman, DrPh, New York University
- Learning from translation of multiple evidence-based dementia interventions
Leisa Easom, PhD, RN, Rosalynn Carter Institute for Family Caregiving
- Integrating evidence-based programs in existing aging services
Richard Fortinsky, PhD, University of Connecticut.
- Building a staged array of dementia care programs to meet the heterogeneous needs of community populations of persons with dementia and family caregivers
Liz Weaver, MS, LSW, Southern Maine Area Agency on Aging

B. Thinking Outside of the Box: Innovative Research Methods and Outcomes

- Research methods for dementia care and services: findings and recommendations from the PCORI pre-summit
Brian Mittman, PhD, Kaiser Permanente Department of Research and Evaluation
- Stakeholder perspectives on outcomes that matter
Sarah Lenz Lock, JD, AARP
- Outcomes to measure in dementia care and services research: findings and recommendations from the Alzheimer's Association pre-summit
Sam Fazio, PhD, Alzheimer's Association
- AD PACE Initiative to gather family caregiver and person with dementia desired outcomes for research:
Debra Lappin, JD, Faegre Baker Daniels Consulting

C. New Directions from Different Vantage Points

Moderator: Laura Gitlin, PhD, Johns Hopkins University

Proposed Discussants:

- **Alan Stevens, PhD**, Baylor Scott & White Health

- **Mark Snowden, PhD**, University of Washington
- **Joseph Gaugler, PhD**, University of Minnesota
- **Alice Bonner, PhD, RN**, Massachusetts Department of Health and Human Services
- **Amy Kilbourne, PhD, MPH**, Acting Director of Health Services Research and Development, Veterans Health Administration

4:15pm - 4:45pm: MODERATED AUDIENCE DISCUSSION

4:45pm - 5:00pm: Next Steps

Speakers:

- **Ron Petersen, MD, PhD**, Mayo Clinic
- **Laura Gitlin and Katie Maslow**, Summit Co-Chairs
- **Person with dementia, TBD**
- **Sponsor comments**