DAY ONE: OCTOBER 16, 2017

7:00 a.m.–8:00 a.m. REGISTRATION

8:00 a.m.–8:30 a.m. WELCOME AND INTRODUCTORY REMARKS
Summit Co-Chairs: Laura N. Gitlin, PhD, Johns Hopkins University
Katie Maslow, MSW, The Gerontological Society of America

Sponsor Remarks
Advancing Research Toward Care and Support Solutions
Harry Johns, Alzheimer’s Association

The Imperative of Diverse Voices and Collaborative Decision Making
Ian Kremer, JD, LEAD Coalition (Leaders Engaged on Alzheimer’s Disease)

Setting Care Goals for 2025
George Vradenburg, UsAgainstAlzheimer’s

8:30 a.m.–9:00 a.m. PLENARY LECTURES: Context for the Summit

View from the Advisory Council on Alzheimer’s Research, Care, and Services
Ronald C. Petersen, MD, PhD, Mayo Clinic College of Medicine

Biomedical and Care Research in Dementia: Interdependent and Complementary
Maria C. Carrillo, PhD, Alzheimer’s Association

9:00 a.m.–10:00 a.m. PLENARY LECTURES: Demographic Framework

Demographics of Dementia and Dementia Caregiving: Key Changes in the Decades Ahead
Ken Langa, MD, PhD, University of Michigan

Deconstructing Race, Ethnicity, and Culture for ADRD Research
Jennifer Manly, PhD, Columbia University

Implications of Diversity in Dementia Care, Services, and Supports
Maria Aranda, PhD, MSW, MPA, LCSW, University of Southern California

10:00 a.m.–10:15 a.m. BREAK
SESSION I: Research on Care Needs and Supportive Approaches for Persons with Dementia

Co-Chairs: Richard H. Fortinsky, PhD, University of Connecticut School of Medicine
Ann Kolanowski, PhD, RN, FGSA, FAAN, Colleges of Nursing and Medicine, Pennsylvania State University

Speakers

Causality Matters: Preventing and Mitigating Behavioral and Psychological Symptoms of Dementia
Helen Kales, MD, PPA, University of Michigan

Maintaining and Supporting Function in Persons with Dementia
Barbara Resnick, PhD, RN, CRNP, FAAN, FAANP, School of Nursing, University of Maryland

Slowing Cognitive Decline and Supporting Resilience in Patients with Dementia
Davangere P. Devanand, MD, Columbia University Medical Center

Home Is Where the Future Is: BrightFocus Foundation Consensus Panel on Dementia Care
Constantine Lyketsos, MD, MHS, DFAPA, FAPM, FACNP, Johns Hopkins Medicine

Dementia Care in Residential Long-Term Care
Sheryl Zimmerman, PhD, University of North Carolina at Chapel Hill

Technologies for Assessment and Interventions to Improve and Accelerate Dementia Care Research
Jeffrey Kaye, MD, Oregon Health & Science University

Brief Reports and Commentaries

Living Well with Dementia
Melanie (Lonni) Schicker, EdD, MHSA, RN, Persons Living with Dementia Stakeholder Group

Researching Rhythms of Daily Life: The Role of Sleep and Daily Activity in Entraining Circadian Patterns
Nancy A. Hodgson, PhD, RN, FAAN, University of Pennsylvania School of Nursing

Physical and Social Environments for Care and Services: Research Recommendations for the Design of Care Settings
Margaret Calkins, PhD, EDAC, Mayer-Rothschild Foundation

Living Alone with Dementia: Identification, Unmet Needs, and Safety Concerns
Elizabeth Gould, MSW, National Alzheimer's and Dementia Resource Center, RTI International

Caregiving and Intellectual and Developmental Disabilities and Dementia: Report of the Pre-Summit Workgroup on Caregiving and Intellectual and Developmental Disabilities
Tamar Heller, PhD, University of Illinois at Chicago

Moderated Audience Discussion

12:30 p.m.–1:30 p.m. LUNCH
SESSION II: Research on Supportive Approaches for Family and Other Caregivers

Co-Chairs: Linda Teri, PhD, University of Washington
Lisa Fredman, PhD, Boston University School of Public Health

Speakers

Supporting Family Caregivers Effectively: Lessons Learned from Research
Linda Nichols, PhD, Memphis Veterans Affairs Medical Center

Evolving Knowledge About the Health Effects of Caregiving to Persons with Dementia and Other Conditions
Lisa Fredman, PhD, Boston University School of Public Health

Dyadic Intervention: From Early Stage to End of Life
Carol J. Whitlatch, PhD, Benjamin Rose Institute on Aging

The Use of Technology in the Support of Family Caregivers
Sara Czaja, PhD, University of Miami

Innovating the Next Generation of Dementia and Alzheimer’s Disease Care Interventions: Addressing the Needs of Persons Living with Dementia, Caregivers, and Care Providers
Vincent Mor, PhD, Brown University

Brief Reports and Commentaries

Personal Perspectives on Family Caregiving
Sowande Tichawonna, Family Caregiver Stakeholder Group

Dementia Family Caregiving: Recommendations from a Conference to Advance Interventions in Diverse Populations
Oanh Meyer, PhD, MAS, University of California, Davis, School of Medicine

Equity: A Powerful Force in the Future of Sexual and Gender Minority Dementia Caregiving
Karen Fredriksen Goldsen, PhD, University of Washington

Dementia Caregiving in the U.S. Research Recommendations
Gail Gibson Hunt, National Alliance for Caregiving

Family Caregiving’s Impact on Women
Mary E. Worstell, MPH, U.S. Department of Health and Human Services, Office of the Assistant Secretary for Health

Moderated Audience Discussion
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

**Speakers**
- **Principles and Practices for Engagement in Research**
  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, Penn Memory Center
- **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)

**Brief Reports and Commentaries**
- **Person with Dementia Perspective on Participating as a Member of the Research Team**
  Teresa Webb, RN, Persons Living with Dementia Stakeholder Group
- **The Who, What, Why, When, and Where of Care Partners in Research**
  Sharon Hall, Family Caregiver Stakeholder Group

**Moderated Audience Discussion**

**DAY TWO: OCTOBER 17, 2017**

**7:00 a.m.–7:55 a.m.**
REGISTRATION

**7:55 a.m.–8:00 a.m.**
INTRODUCTION TO DAY

**Summit Co-Chairs:** Laura N. Gitlin, PhD, Johns Hopkins University
                     Katie Maslow, MSW, The Gerontological Society of America

**8:00 a.m.–8:30 a.m.**
PLENARY SESSION: Nomenclature: Words Matter

- **The Terminology Issues**
  Ronald C. Petersen, MD, PhD, Mayo Clinic College of Medicine
- **Effect of Stigma on Access to Care and Services**
  Angela Taylor, Lewy Body Dementia Association
- **Perspectives of a Family Affected by Dementia**
  Edward K. Kaplan, PhD, Professor Emeritus, Brandeis University; Persons Living with Dementia Stakeholder Group
  Janna Kaplan, MSc, Brandeis University; Family Caregiver Stakeholder Group
SESSION IV: Involving Persons with Dementia as Study Participants

Co-Chairs: Darby Morhardt, PhD, LCSW, Northwestern University
David M. Bass, PhD, Benjamin Rose Institute on Aging

Speakers
Clinical Heterogeneity of Dementia and Impact on Research Participation
Sandra Weintraub, PhD, Northwestern University

Work with Us! We Want to Help: Perspectives of a Person with Dementia on Involvement as a Study Participant
Cynthia Huling Hummel, PhD, BS, MDiv, DMin, Persons Living with Dementia Stakeholder Group

Role of Research in Examining and Understanding the Illness Experience of Individuals with Dementia
Katherine S. Judge, PhD, Cleveland State University

Measuring Disease Impact on People Living with Dementia: PCORI Pre-Summit Summary
Darby Morhardt, PhD, LCSW, Northwestern University, and Lisa Gwyther, MSW, LCSW, Duke University

Moderated Audience Discussion

SESSION V: Research on Models of Care for Persons Living with Dementia and Their Families Across the Disease Trajectory

Co-Chairs: Vincent Mor, PhD, Brown University
David B. Reuben, MD, University of California, Los Angeles

Speakers
Dementia-Specific Models of Care
Components of a Comprehensive Care Model for Dementia
David M. Bass, PhD, Benjamin Rose Institute on Aging

Health System-Based Models of Dementia Care: Characteristics, Challenges, and Opportunities
Zaldy S. Tan, MD, MPH, University of California, Los Angeles

Community-Based Models of Dementia Care: Characteristics, Challenges, and Opportunities
Quincy Miles Samus, PhD, MS, Johns Hopkins School of Medicine

General Models of Care that Include Persons with Dementia
Successful VA Innovations in Geriatric Care
Thomas E. Edes, MD, MS, U.S. Department of Veterans Affairs

Dementia Care Management within the Federal Financial Alignment Demonstration
Debra L. Cherry, PhD, Alzheimer’s Greater Los Angeles

Consumer-Directed Care Models
Julie Robison, PhD, University of Connecticut
Facilitators of Models of Care for Persons Living with Dementia and Their Families

Workforce Size, Composition, Retention, and Competence
Gregg Warshaw, MD, University of North Carolina at Chapel Hill

Quality Measures
Gary Epstein-Lubow, MD, Brown University/Hebrew SeniorLife
Louise Phillips, MD, Persons Living with Dementia Stakeholder Group, with off-site contribution from Brenda Nicholson, MD, Persons Living with Dementia Stakeholder Group

Scaling Up: Research to Promote Diffusion of Successful Models
David B. Reuben, MD, University of California, Los Angeles

Moderated Audience Discussion

12:30 p.m.–1:30 p.m.  LUNCH
1:30 p.m.–4:45 p.m.  SESSION VI: Thinking Outside the Box

Co-Chairs: Christopher Callahan, MD, Indiana University School of Medicine
Alan B. Stevens, PhD, Baylor Scott & White Health

PLENARY LECTURES: Thinking Outside the Box

Moving Forward Faster to Provide Care Together
Christopher Callahan, MD, Indiana University School of Medicine

Retail and the Consumer Lens: An Outside Perspective
Raha Alavi, Nielsen Retail Services

Translation and Implementation of Effective Care, Services, and Supports
Keeping Research Relevant: Moving from RCT to Practice
Linda Teri, PhD, University of Washington

Balancing Treatment Fidelity with Feasibility and Acceptance by End Users
Mary Mittelman, DPH, New York University

Evidence-Based Programs: Mapping Out the Future
Leisa R. Easom, PhD, RN, Rosalynn Carter Institute for Caregiving

Integrating Evidence-Based Dementia Care Programs into Existing Service and Reimbursement Systems
Richard H. Fortinsky, PhD, University of Connecticut School of Medicine
Innovative Research Methods and Outcomes
Research Methods for Dementia Care and Services
Brian Mittman, PhD, Kaiser Permanente; U.S. Department of Veterans Affairs

Stakeholder Perspectives on Research Outcomes that Matter
Sarah Lenz Lock, JD, AARP

New Directions in Measurement for Psychosocial Research on Dementia Care and Services: Report from Two Pre-Summit Meetings
Sam Fazio, PhD, Alzheimer’s Association

Understanding What Matters Most to Inform Care and Services Research
Debra Lappin, JD, Faegre Baker Daniels Consulting

New Directions from Different Vantage Points
Moderator
Laura N. Gitlin, PhD, Johns Hopkins University

Discussants
Mark Snowden, MD, MPH, University of Washington
Alan B. Stevens, PhD, Baylor Scott & White Health
Joseph E. Gaugler, PhD, University of Minnesota
Alice Bonner, PhD, RN, FAAN, Massachusetts Executive Office of Elder Affairs
Amy M. Kilbourne, PhD, MPH, Veterans Health Administration
Lisa Onken, PhD, National Institute on Aging

Moderated Audience Discussion

4:45 p.m.–5:00 p.m.

WRAP UP

Speakers
Laura N. Gitlin, PhD, and Katie Maslow, MSW, Summit Co-Chairs
Greg O’Brien, Persons Living with Dementia Stakeholder Group
Venoreen Browne-Boatswain, MEd, Family Caregiver Stakeholder Group