

NATIONAL RESEARCH SUMMIT ON CARE, SERVICES, AND SUPPORTS FOR PERSONS WITH DEMENTIA AND THEIR CAREGIVERS

National Institutes of Health
Bethesda, MD
October 16–17, 2017

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**

10:15 a.m.–12:30 p.m. 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

1:30 p.m.–3:30 p.m.

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

3:30 p.m.–5:00 p.m.

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

8:30 a.m.–9:45 a.m.

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

9:45 a.m.–12:30 p.m.

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

Service Provider and Payer Reactor Panel

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

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