

2026 Dementia Care and Caregiving Research Summit



2
0
2
6

Dementia Care & Caregiving Research Summit

HOSTED BY THE NATIONAL INSTITUTE ON AGING

Summit Virtual Meeting Series

March 17-19, 2026

Hosted by:
The National Institute on Aging,
National Institutes of Health

Table of Contents

About the Dementia Care and Caregiving Research Summit.....	2
Care Summit Goal	2
2026 Care Summit Session Titles and Descriptions	3
Session 1: Economic Impacts of Dementia: Focus on Dementia Care & Caregiving	3
Session 2: The Role of Community in Dementia Care Research.....	3
Session 3: Rigorous Dementia Care & Caregiving Intervention Development.....	3
Session 4: Advances in AD/DRD Data Infrastructure to Support Dementia Care & Caregiving Research	4
Session 5: Dementia Care Models and Care Coordination Strategies Across Systems and States	4
2026 Care Summit Steering Committee.....	5
Summit Co-Chairs.....	5
Steering Committee.....	5
National Institute on Aging Core Planning Team	5
Detailed Agenda	6
Day 1	6
Setting the Stage	6
Session 1: Economic Impacts of Dementia: Focus on Dementia Care and Caregiving .	6
Session 2: The Role of Community in Dementia Care Research	7
Day 2	9
Session 3: Rigorous Dementia Care & Caregiving Intervention Development	9
Session 4: Advances in AD/DRD Data Infrastructure to Support Dementia Care & Caregiving Research.....	10
Day 3	12
Early Career Investigator Event.....	12
1:00 – 3:00 p.m. ET: Session 5: Dementia Care Coordination Models and Strategies Across Systems and States	12
Post-Care Summit Public Listening Session	13

About the Dementia Care and Caregiving Research Summit

The Dementia Care and Caregiving Research Summit, the [Alzheimer's Research Summits](#), and the [Alzheimer's Disease-Related Dementia Summits](#) provide coordinated planning efforts that respond to the [National Plan to Address Alzheimer's Disease](#). Each Summit provides an opportunity for individuals to share perspectives about critical scientific gaps and opportunities that reflect critical scientific priorities for Alzheimer's disease and Alzheimer's disease related dementias (AD/ADRD) research. The Summits can inform updates to the [NIH AD+ADRD Research Implementation Milestones](#) that address the National Plan.

The first [National Research Summit on Care, Services, and Supports for Persons with Dementia and Their Caregivers](#) was held on the NIH campus on October 16-17, 2017, the [second care-focused Summit](#) was held virtually in the summer of 2020, and the [third care-focused Summit](#), now known as the Dementia Care and Caregiving Research Summit was held virtually on March 20-22, 2023.

Care Summit Goal

The 2026 Dementia Care and Caregiving Research Summit builds on progress of the previous Care Summits to review research progress, highlight innovative and promising research, and identify remaining unmet research needs with input from the research community, persons living with dementia (PLWD) and their care partners, those who provide healthcare or services and supports to persons living with dementia, and other interest holders. The Summit will be held virtually on March 17-19, 2026.

Visit the [2026 Care Summit website](#) for the most up-to-date information.

2026 Care Summit Session Titles and Descriptions

Session 1: Economic Impacts of Dementia: Focus on Dementia Care & Caregiving

Session Chair: Courtney Van Houtven

This session will highlight recent research progress on understanding the costs of dementia, lessons learned, the challenges people continue to face, and the research needed to address them. Topics include the intersection of health services research and care quality for persons living with dementia, as well as health services and economics research that provide the necessary data to inform payor coverage. This session will consider the costs of dementia to both patients and care partners, health systems, payors, and society. Often hidden, the session will consider the evidence on the economic consequences to family members of persons living with dementia, including those who provide unpaid care and support along the full spectrum of disease: at home and continuing in the nursing home setting, including what costs are likely missing in the data.

Session 2: The Role of Community in Dementia Care Research

Session Chair: Fayron Epps

This session will focus on academic and community partnerships to advance dementia care research. In this session, researchers, community organizations, and families will share their experiences: a) co-designing or participating in dementia-focused studies/trials, b) implementing and disseminating evidence-based caregiving programs in the community, c) using technology to increase the accessibility of dementia care, and d) navigating care systems. Guest speakers will share their perspectives on the current research needs to improve the lives of persons living with dementia and their care partners.

Session 3: Rigorous Dementia Care & Caregiving Intervention Development

Session Chair: Karina Davidson

This session will discuss the opportunities, challenges, lessons learned, and what is still needed for dementia care and caregiving intervention research, with the overarching goal to develop interventions that are maximally potent and efficacious, and maximally implementable in real-world settings. Topics will focus on scientific methods, including the mechanisms and governing principles of dementia care intervention research across the NIH Stage Model (focused on Stages 3-5); the types of interventions that are demonstrating

promise; and what is needed for successful adoption and implementation in health systems.

Session 4: Advances in AD/ADRD Data Infrastructure to Support Dementia Care & Caregiving Research

Session Chair: Jinkook Lee

This session will emphasize scientific advances that have been made leveraging existing data infrastructure in dementia care and caregiving research and identify current gaps and future opportunities for the data infrastructure. Topics to be discussed include highlighting how data users are leveraging current infrastructure and what data is needed to move forward in their research, discussing the opportunity to advance dementia care and caregiving research, and identifying potential approaches to further innovate in building and analyzing data in home and community-based settings.

Session 5: Dementia Care Models and Care Coordination Strategies Across Systems and States

Session Chair: Lee Jennings

This session will focus on dementia care coordination research and how it informs the policy to practice pipeline. Topics will address what evidence is still needed for policymakers and payors to invest in care coordination and dementia care models.

2026 Care Summit Steering Committee

Summit Co-Chairs

- **Julie Bynum, MD, MPH**, University of Michigan
- **Joseph Gaugler, PhD**, University of Minnesota

Steering Committee

- **Karina Davidson, PhD**, Northwell Health
- **Fayron Epps, PhD, RN**, UT Health San Antonio
- **Lee Jennings, MD, MSHS**, University of Oklahoma
- **Jinkook Lee, PhD**, University of Southern California
- **Courtney Van Houtven, PhD**, Duke University

National Institute on Aging Core Planning Team

- **Jessica Boten**
- **Elena Fazio**
- **Nicole Kidwiler**
- **Cathony Reid**

Detailed Agenda

Day 1

Tuesday, March 17, 2026

12:30 – 5:10 p.m. Eastern Time

Setting the Stage

- | | |
|-----------------------|--|
| 12:30pm | Welcome

<i>Speakers:</i> Julie Bynum, University of Michigan
Joe Gaugler, University of Minnesota |
| 12:40pm | NIA Opening Remarks

<i>Speakers:</i> Richard Hodes, National Institute on Aging |
| 12:55pm | Lived Experience Remarks

<i>Speakers:</i> Pat Krebs, Living with Alzheimer's disease
Dave Krebs, CPA, Care partner |
| 1:10pm | State of the Science: Dementia Care and Caregiving Research – NIA Updates

<i>Speaker:</i> Elena Fazio, National Institute on Aging |
| 1:40 – 1:50 pm | Break |

Session 1: Economic Impacts of Dementia: Focus on Dementia Care and Caregiving

Session Chair: Courtney Van Houtven , Duke University

- | | |
|---------------|---|
| 1:50pm | Introduction |
| 1:55pm | Fireside Chat: A Conversation on the costs of dementia to persons living with dementia, care partners, health systems, payors, and society

<i>Moderator:</i> Courtney Van Houtven

<i>Panelists:</i>
Norma Coe, University of Pennsylvania |

Paige Lin, Tufts University
Jon Skinner, Dartmouth College
Julie Zissimopoulos, University of Southern California

2:40pm

Lived Experience Interview Panel

Moderator: Sam Fazio, Alzheimer's Association

Panelists:

Brent Beasley, Retired physician, living with younger-onset Alzheimer's disease
Cindy Beasley, Care partner
Andrea Lucas, Living with Mild Cognitive Impairment due to younger-onset Alzheimer's disease
Leyda Paz, Caregiver

3:10pm

Present Research Gaps & Opportunities and Moderated Question and Answer (Q&A) with Audience

3:40 – 3:50 pm

Break

Session 2: The Role of Community in Dementia Care Research

Session Chair: Fayron Epps, UT Health San Antonio

3:50pm

Introduction

3:55pm

**Adapting Caregiver Interventions for Responsiveness:
Centering Community Knowledge & Values**

Speakers:

Lexie Jackson, Laulima Grant Writing and Evaluation LLC
Puni Kekauoha, Senior Vice President of Kula no nā Po'e Hawai'i

People Power: Advancing the Translational Potential of Dementia Research

Speakers:

Sara Masoud, University of Texas
Howaida Werfelli, Community Partner

From Evidence to Infrastructure: Leveraging Adult Day Services Partnerships to Support People Living with Dementia and Their Families

Speakers:

Lauren Parker, Johns Hopkins University

Bill Zagorski, CEO of American Senior Care Centers, Inc.

Community at the Core: Dementia Care Research with Purpose and Partnership

Speakers:

Gina Green-Harris, University of Wisconsin

Sam Holland, Community citizen scientist and caregiver

4:35pm

Present Research Gaps & Opportunities and Moderated Q&A with Audience

5:05pm

Closing Remarks for Day 1

Speakers: Julie Bynum and Joe Gaugler

Day 2

Wednesday, March 18, 2026

1:00-5:10pm Eastern Time

1:00pm

Welcome

Speakers: Julie Bynum and Joe Gaugler

1:05pm

Lived Experience Remarks

Speaker: Kevin Rhodes, Living with Frontotemporal Degeneration and volunteer with Association for Frontotemporal Degeneration

Session 3: Rigorous Dementia Care & Caregiving Intervention Development

Session Chair: Karina Davidson , Northwell Health

1:20pm

Introduction

1:30pm

Panel Presentations and Dialogue

Framing the Future: The NIH Stage Model and Advancing Dementia Care Interventions

Speaker: Melissa Riddle, National Institute on Aging

From the Front Lines: Leveraging Formal Caregiver Lived Experience for Intervention Development

Speaker: Kaitlin Tangredi, Northwell Health

From Trial to Translation: Building Implementation Ready Dementia Interventions through Rigorous Efficacy Testing

Speaker: Nancy A. Hodgson, University of Pennsylvania

Bridging Efficacy to Everyday: Considerations in Scaling and Testing interventions for Patients Living with Dementia and their Caregivers in Routine Settings

Speaker: Julie Lauffenburger, Harvard University

Making a Policy Impact

Speaker: Jason Doctor, University of Southern California

Moderated Panel Discussion

Moderator: Melissa Riddle

Panelists: Kaitlin Tangredi, Nancy A. Hodgson, Julie Lauffenburger, Jason Doctor

2:15pm **Present Research Gaps & Opportunities and Moderated Q&A with Audience**

2:45 – 2:55 pm **Break**

Session 4: Advances in AD/ABRD Data Infrastructure to Support Dementia Care & Caregiving Research

Session Chair: Jinkook Lee, University of Southern California

2:55pm **Introduction**

3:00pm ***Hot Off the Press Presentations***

Insight on AD/ABRD from the National Health and Aging Trends Study (NHATS) and National Study of Caregiving (NSOC)

Speaker: Jennifer Wolff, Johns Hopkins University

Understanding the Daily Lives of Caregivers: The UAS-CLEAR Study

Speaker: Kira Birditt, University of Michigan

Linking Survey and Medicare Data: A Leap Forward in Dementia Research

Speaker: Kenneth Covinsky, University of California, San Francisco

3:30pm	<i>Presentations highlighting data infrastructure and methods using real world data</i> Opportunities for longitudinal interventions, risks, and outcomes analyses with Real World Data (RWD) <i>Speaker:</i> Christopher Chute, Johns Hopkins University LTC Data Cooperative: Clinical EHR data from Skilled Nursing Facilities and Assisted Living Communities <i>Speaker:</i> Stephanie Kissam, Americal Health Care Associations
3:50pm	<i>Presentations Highlighting Data Infrastructure on Policies and Programs</i> Gateway to Global Aging Data: LTC policy and understanding the care journey <i>Speaker:</i> Dave Knapp, University of Southern California Using State Data Infrastructure to Improve Dementia Care – Initial Lessons from State Alzheimer’s Research Support Center (StARS) <i>Speaker:</i> Eric Jutkowitz , Brown University
4:10pm	<i>Challenges Presentation</i> Strategically Aligning Research Initiatives to Catalyze Real-World Change <i>Speaker:</i> Amy Kind, University of Wisconsin
4:20pm	Present Research Gaps & Opportunities and Moderated Discussion with Presenters
4:45pm	Moderated Q&A with Audience
5:05pm	Closing Remarks for Day 2 <i>Speakers:</i> Julie Bynum and Joe Gaugler

Day 3

Thursday, March 19, 2026

11:00am- 4:15pm Eastern Time

Early Career Investigator Event

- | | |
|----------------|---|
| 11:00am | Introduction |
| | <i>Speaker:</i> Laura Major, National Institute on Aging |
| 11:05am | Training and Research Opportunities for Early to Midcareer Investigators |
| | <i>Speaker:</i> Laura Major |
| 11:35am | Moderated Q&A with the Audience |
| 11:50am | Dementia Care & Caregiving Research Overview and Data Resources |
| | <i>Speaker:</i> Melissa Riddle, National Institute on Aging |
| 12:20pm | Moderated Q&A with the Audience |
| 12:30pm | Closing Remarks |
| | <i>Speaker:</i> Laura Major |

1:00 – 3:00 p.m. ET: Session 5: Dementia Care Coordination Models and Strategies Across Systems and States

Session Chair: Lee Jennings, University of Oklahoma

- | | |
|---------------|--|
| 1:00pm | Welcome and Lived Experience Remarks |
| | <i>Speakers:</i> Julie Bynum and Joe Gaugler,
Senior Managing Director at Cushman & Wakefield,
Tenny Tsai, caregiver |
| 1:05pm | Introduction |
| | <i>Speaker:</i> Lee Jennings |
| 1:10pm | Scientific Presentations |

Ideal Care Map: Overview of the Complexity of the Dementia Care Ecosystem

Speaker: Wen Dombrowski, Catalaize

Progress in Early Detection of Dementia in Older Adults Across Care Settings

Speaker: Anna Chodos, University of California San Francisco

Home-based Clinical and Long-term Care for People Living with Dementia: Opportunities to Improve Coordination

Speaker: Jennifer Reckrey, New York University

Updates on the GUIDE Model in Clinics and Communities

Speaker: Hillary Lum, University of Colorado

Dementia Care Navigation Implementation: Barriers, Facilitators, and Evidence Gaps

Speaker: Kristin Lees Haggerty, EDC

2:00pm Presentation of Gaps & Opportunities

Speaker: Lee Jennings

2:05pm Policy and Practice Perspectives Panel

Panelists: Shari Ling, Centers for Medicare and Medicaid Services (CMS)

Wendy Fox-Grage, National Academy for State Health Policy

Erin Long, Administration for Community Living (ACL)

2:35pm Moderated Question & Answer (Q&A) with Audience

2:50pm Closing Remarks for Day 3

Speakers: Julie Bynum and Joe Gaugler

Post-Care Summit Public Listening Session

3:15pm Introduction

Speakers: Elena Fazio, Julie Bynum, and Joe Gaugler

3:20pm

Public Remarks

4:13pm

Closing Remarks

Speakers: Elena Fazio, Julie Bynum, and Joe Gaugler