

*The National Academies of*  
SCIENCES • ENGINEERING • MEDICINE

**CARE INTERVENTIONS FOR INDIVIDUALS WITH DEMENTIA AND  
THEIR CAREGIVERS: A WORKSHOP**

Wednesday, April 15, 2020  
**VIRTUAL MEETING VIA ZOOM**  
**All times below are Eastern Time (EDT)**

**Background:** Research on care interventions for individuals with Alzheimer's disease and related dementias, as well as on interventions aimed at their caregivers, has expanded tremendously in recent years. And, some care-related programs are starting to be disseminated and more broadly implemented. Despite important progress in this domain, however, there remain gaps in understanding. The National Institute on Aging has asked the National Academies of Sciences, Engineering, and Medicine to convene an expert committee to take stock of the current state of knowledge, and make recommendations to inform decision making about which care interventions for individuals with dementia and their caregivers are ready for dissemination and implementation on a broad scale.

The National Academies committee's work will be based on a systematic review commissioned by the Agency for Healthcare Research and Quality (AHRQ) and conducted by the Minnesota Evidence-based Practice Center (EPC). This systematic review will examine the evidence on care interventions relevant to Alzheimer's disease and related dementias (including Lewy body dementia, frontotemporal dementia, and vascular cognitive impairment/dementia), considering both potential effects on individuals with dementia and on their caregivers. To help inform the National Academies committee's recommendations, this public workshop will bring together key stakeholders to provide input to the committee on the draft AHRQ/EPC systematic review. The National Academies committee report is anticipated to be released in February 2021.

**Workshop Objectives:**

- Provide a briefing on the draft AHRQ/EPC systematic review on care interventions for individuals with dementia and their caregivers.
- Collect reactions to the draft AHRQ/EPC systematic review from a wide range of stakeholders.
- Explore the current state of evidence and discuss which care interventions for individuals with dementia and their caregivers may be considered ready for dissemination and implementation on a broad scale.
- Discuss emerging data on care interventions that did not meet the evidentiary standard of the systematic review and data expected from studies underway that were not published in time for inclusion in the systematic review, and identify gaps and areas for future research.

[www.nationalacademies.org/dementiacare](http://www.nationalacademies.org/dementiacare)

## SESSION 1: INTRODUCTION, STUDY CHARGE, AND DRAFT SYSTEMATIC REVIEW

### Session Objectives:

- Receive a briefing from the study sponsor on the committee's charge.
- Receive an overview of the draft AHRQ/EPC systematic review.
- Discuss care interventions and outcomes that are of most interest to people living with dementia and their caregivers.

10:00am	<b>Welcome and Overview of Workshop Objectives</b> <i>Eric Larson, Committee Chair; Kaiser Permanente Washington Health Research Institute</i>
10:10am	<b>Background and Overview of the Committee's Charge</b> <i>Richard Hodes, National Institute on Aging</i>
10:25am	<b>Overview of the Draft AHRQ/EPC Systematic Review</b> <i>Mary Butler, Minnesota Evidence-based Practice Center</i> <i>Joseph Gaugler, Minnesota Evidence-based Practice Center</i>
10:45am	Discussion with Committee Members
11:30am	<b>Perspectives from a caregiver: What care interventions and outcomes are most important?</b> <i>Janet Michel, family caregiver</i>
11:40am	Discussion with Committee Members
11:50am	Lunch

## SESSION 2: PERSPECTIVES ON "READINESS FOR DISSEMINATION AND IMPLEMENTATION"

### Session Objectives:

NIA has asked the National Academies committee to make recommendations regarding which care interventions for individuals with dementia and their caregivers are "ready for dissemination and implementation on a broad scale." To explore this concept in the specific context of the draft AHRQ/EPC systematic review, this session will engage stakeholders and decision makers from advocacy organizations, associations, foundations, care systems, and implementation science to:

- Discuss what "ready for dissemination and implementation on a broad scale" means. How should this be assessed? What kinds of evidence do different stakeholders and decision makers look for?
- Provide input on the AHRQ/EPC draft systematic review.

12:30pm	Session Objectives <i>Jason Karlawish, University of Pennsylvania, Committee member and session moderator</i>
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- 12:35pm      **Panel 1: Perspectives from Advocacy Organizations and Associations**  
*Moderated discussion with:*  
*Lynn Feinberg, AARP*  
*Kathleen Kelly, Family Caregiving Alliance*  
*Douglas Pace, Alzheimer's Association*
- 1:10pm      Discussion with Committee Members
- 1:30pm      **Panel II: Perspectives from Care Systems and Payers**  
*Moderated discussion with:*  
*Patrick Courneya, HealthPartners*  
*David Gifford, American Health Care Association*  
*Shari Ling, Centers for Medicare and Medicaid Services*  
*Lewis Sandy, UnitedHealth Group*
- 2:10pm      Discussion with Committee Members
- 2:30pm      **Panel III: Perspectives from Implementation Science**  
*Moderated discussion with:*  
*Laura Gitlin, Drexel University*  
*Melissa Simon, Northwestern University*
- 3:00pm      Discussion with Committee Members
- 3:20pm      Break

### SESSION 3: STATE OF THE EVIDENCE AND METHODOLOGICAL CONSIDERATIONS

#### Session Objectives:

- Continue to reflect on the draft AHRQ/EPC systematic review results, explore the current state of evidence, and discuss which care interventions for individuals with dementia and their caregivers may be ready for dissemination and implementation on a broad scale.
  - Particular focus will be given to racial, ethnic, cultural, language, and socioeconomic considerations, across all aspects of the systematic review results.
- Discuss emerging data on care interventions that did not meet the evidentiary standard of the systematic review and data expected from studies underway that were not published in time for inclusion in the systematic review, and identify gaps and areas for future research.

- 3:30pm      Session Objectives  
*XinQi Dong, Rutgers University, Committee member and session moderator*
- 3:35pm      Interventions for people with dementia  
*Linda Teri, University of Washington*

- 3:45pm Interventions for caregivers and care delivery interventions  
*Richard Schulz, University of Pittsburgh*
- 3:55pm Cultural modifications  
*J. Neil Henderson, University of Minnesota*
- 4:05pm Methodological considerations and treatment of non-RCT data  
*Jennifer Weuve, Boston University*
- 4:15pm Discussion among speakers and committee members
- 4:50pm Closing Remarks  
*Eric Larson, Committee chair*
- 5:00pm Public Session Adjourns