



**National Academies of  
Sciences - Engineering - Medicine**

# **Care Interventions for Individuals with Dementia and Their Caregivers**

## **NIH Charge and Perspectives**

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# Background

**October 2017:**



- Yielded 58 recommendations for care/caregiving
- NIA is already following up on research-related recommendations

# Background, cont'd

- Research on care/caregiving in the Alzheimer's and related dementias field is expanding.
- Some programs to improve care and caregiving have already been disseminated.
- ***A rigorous, independent review of which care/caregiving-related interventions are effective and ready for widespread dissemination was needed.***

# Background, cont'd

## Overall goals of this project:

- Take stock of the current state of knowledge
- Inform decision making about which care interventions for individuals with dementia and their caregivers are ready for dissemination and implementation on a broad scale.

# A Collaborative Effort

**AHRQ-EPC: Systematic Evidence Review**



**National Academies Committee:  
Development of Recommendations**



**NIA: Next steps**

# Why engage two independent organizations?

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- AHRQ offers a highly-refined systematic evidence review process that has been trusted by governmental organizations for its comprehensiveness and independence

# Why engage two independent organizations?

- NASEM offers an external, independent committee that can consider:
  - The EPC's findings on our current state of knowledge;
  - The EPC's findings in a larger context (of ongoing research, etc.); and
  - Whether dissemination & implementation is justifiable.
  - How the existing evidence and other information considered in the review may inform specific research priorities.

# Why engage two independent organizations?

- NASEM has well-established conflict of interest guidelines that will enable experts in the field to participate on the committee, without compromising its objectivity.



# Other Federal Input

Input on needed expertise for NASEM committee, committee nominations, and the Evidence-Based Practice Center's preliminary topic refinement plan was gathered from:

NIA

ACL

CDC

VA

DOD

ASPE

AHRQ

# Ongoing NIA Supported Activities

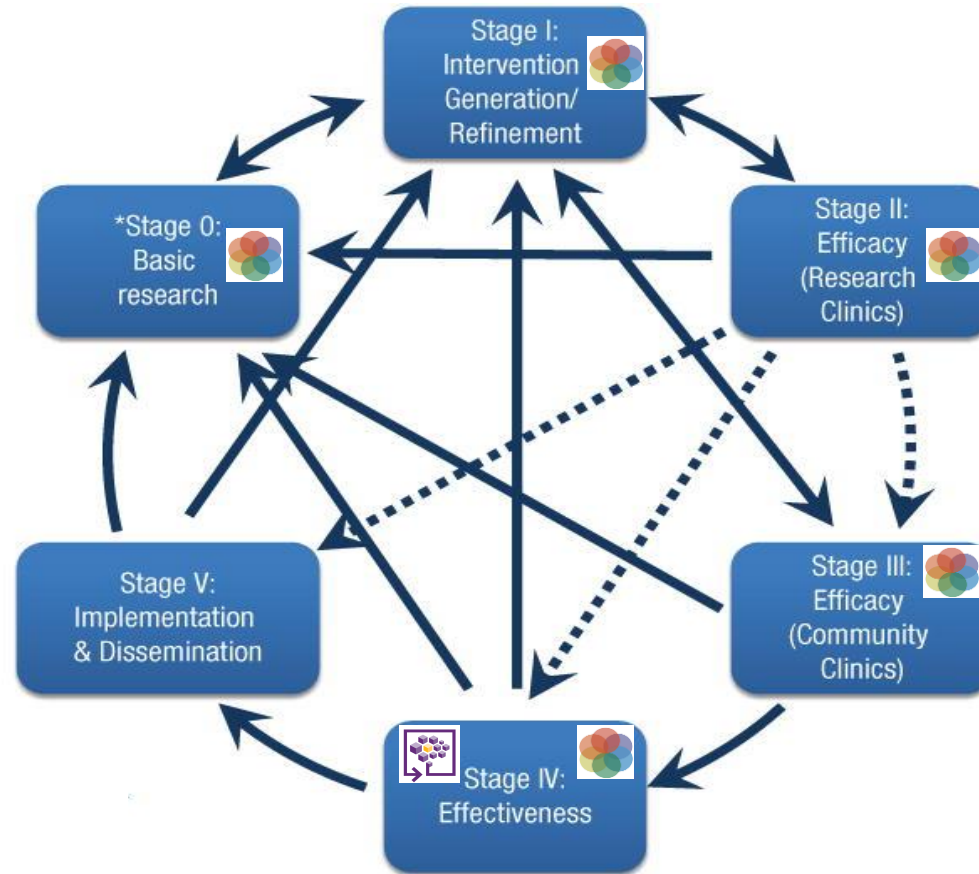
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# NIA Actions: NIA Dementia Care Clinical Trial Infrastructure

**ROYBAL**  
Center For  
Translational  
Research



Promotes development of **Stage 0 Through IV Clinical Trials** to improve the health, well-being and capacity of persons with AD/ADRD and/or design systems that provide care



Promotes development and implementation of **Stage IV Pragmatic Clinical Trials** to improve care and health outcomes for persons living with dementia and their caregivers

# NIA Actions: Example Initiatives Relevant to NASEM Deliberations

## Dementia Care and Caregiver Support Interventions (R01)

RFA-AG-18-030 (Stage I - III)

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- Adapt/modify/refine intervention to increase potency and scalability
- Insure adequate statistical power
- Test the mechanism of action
- Ensure intervention fidelity in the community
- Develop training interventions for care providers
- Produce preliminary data for Stage IV pragmatic trials

## Pragmatic Trials for Dementia Care in Long-term Services and Support (LTSS) Settings (R61/R33)

RFA-AG-17-065 and PAR-18-585 (Stage I/IV)

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### **R61 Phase**

- Operationalize intervention
- Identify mechanism of action
- Determine feasibility
- Validate training interventions for care providers
- Partner with healthcare providers to pilot
- Develop inexpensive delivery methods

### **R33 Phase**

- Run well powered effectiveness trial

# Reflections on the Committee's Next Steps

- Use the EPC findings as a guide to determine the balance for the NASEM recommendations (*“what to tell the public” and “research gaps” identified*)
- Prioritize implementable guidance to the NIA re: actions needed in future award solicitations, peer review changes, etc.