

# Reducing the Impact of Dementia in America

## A NASEM Decadal Survey of the Behavioral and Social Sciences

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## Presentation Outline

? What is the Decadal Survey?

🔍 Decadal Survey **Research Priorities** and **Detailed Research Needs**

✓ Current NIA AD/ADRD Behavioral and Social Science Activities

📅 Informing Future Activities



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# What is the Decadal Survey?

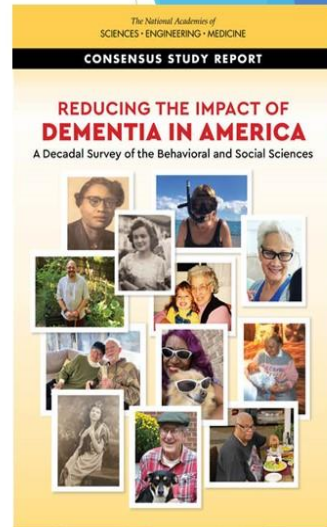
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## NASEM AD/ADRD Decadal Survey

[Reducing the Impact of Dementia in America: A Decadal Survey of the Behavioral and Social Sciences](#) released August 4, 2021

- NIA spearheaded support for this major effort and was joined by several co-funders, including NIH OBSSR, VA, ASPE, AARP, Alzheimer's Association, American Psychological Association, JPB Foundation, and John A. Hartford Foundation
- An ad hoc expert committee was charged with developing a 10-year AD/ADRD research agenda in behavioral and social sciences



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## Decadal Survey Activities and Process

Visit the [NASEM AD Decadal Website](#) for more information.



- ▶ **Who:**
  - ▶ Expert ad hoc committee
  - ▶ Advisory panel to the committee comprised of persons living with dementia (PLWD) and care partners
- ▶ **Process:** (1) Information gathering and (2) Committee deliberation and report development
- ▶ **Information gathering:**
  - ▶ Four public workshops
  - ▶ Six commissioned papers
  - ▶ Multiple opportunities for public comment
  - ▶ Advisory panel input

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## Advisory Panel to the Committee: Input Themes

- ▶ Theme 1: Difficulty in obtaining accurate and timely dementia diagnosis
- ▶ Theme 2: Problems in obtaining supports and services
- ▶ Theme 3: Communication challenges with doctors and other health care professionals
- ▶ Theme 4: Fear and loss

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## Why did NIA and partners invest in a Decadal Survey?

- ▶ BSR AD portfolio includes wide range of disciplines, inquiries, and research topics
- ▶ NASEM uses a method to identify lines of research with the greatest potential for impact over a 10-year period
- ▶ NIA was interested in input on wide ranging research areas and topics that cover the full range of its portfolio



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## Decadal Survey 10-Year Research Priorities and Detailed Research Needs

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## Chapter 2: Prevention and Protective Factors



- ▶ Understand modifiable factors that can prevent AD/ADRD or reduce or delay their symptoms
  - ▶ Causal effects of social factors
  - ▶ Effects of health-related behaviors and their management over lifecourse
  - ▶ **Modifiable drivers of racial/ethnic inequality in dementia incidence**
  - ▶ **Mechanisms through which SES factors influence brain health**
  - ▶ Modifiable risk factors that can be the basis for precise recommendations to individuals about decision making and for population level policies to promote brain health
  - ▶ Effective means of communicating the magnitude and degree of potential risk and protective factors to support informed decision making

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## Chapter 3: PLWD Outcomes and Lived Experience



- ▶ **Substantively improve experience of PLWD by supporting their dignity and well-being, including balancing safety and autonomy**
  - ▶ Improved screening and diagnosis, including guidance for clinicians that also addresses issues related to disclosure
  - ▶ **Guidance to support ethical and responsible decision making by and for PLWD**
  - ▶ **Outcome measures that reflect perspectives and values of PLWD, their care partners, and communities**
  - ▶ Improved design and evaluation of nonpharmacological interventions to slow or prevent cognitive and functional decline, reduce behavioral and psychological symptoms, improve comfort and well-being, and adequately and equitably serve diverse populations

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## Chapter 4: Family Care Partners

▶ **Substantively improve experience of family care partners/caregivers**



- ▶ Identify highest-priority needs for resources and support for family caregivers and how needs vary by subgroup
- ▶ Identify assets family caregivers bring to their work and needs for supplement skills and training
- ▶ **Innovations to address practical and logistical challenges of family caregiving, including use of technology**
- ▶ **Continued progress in data collection and research methods**

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## Chapter 5: Role of Community

▶ **Facilitate development of communities that support PLWD and care partners, allow for PLWD to live independently, maintain social connections, and mitigate negative effects of past and current SES and environmental stressors**



- ▶ **Characteristics of communities that influence risk of developing dementia and experience of living with disease**
- ▶ Documentation of opportunities and resources available in communities and evaluation of their impact, particular attention to disparities in resource access
- ▶ **Analysis of characteristics of dementia-friendly communities**
- ▶ Evaluation of innovative approaches to adapting housing, services, and supports to keep PLWD in community and out of institutional care

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## Chapter 6: Health Care, Long-term Care, End-of-Life Care



- ▶ **Substantially strengthen the quality and structure of health care and long-term care**
  - ▶ Documentation of diagnosis and care management for PLWD and care partners
  - ▶ **Clarification of disease trajectories to help health systems plan care**
  - ▶ Identification of effective methods for providing services throughout disease trajectory
  - ▶ Development and evaluation of standardized systems of coordinated care for PLWD with multiple chronic conditions
  - ▶ **Effective approaches for integrating and coordinating care services across health care systems and community-based organizations**

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## Chapter 6 (cont.): Care Payment Models



- ▶ **Substantially strengthen the arrangements through which most dementia care is funded - traditional Medicare, Medicare Advantage, alternative payment models, and Medicaid**
  - ▶ **Comparison of effects of different financing structures on quality of care and clinical outcomes**
  - ▶ Examination of ways to modify incentives in reimbursement models to optimize care and reduce unnecessary hospitalizations
  - ▶ Development and testing of approaches to integrated financing of medical and social services

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## Chapter 7: Economic Costs



- ▶ **Improve understanding of the economic impact of dementia and identify high value, cost-effective interventions**
  - ▶ **Improved understanding of drivers of dementia-related costs**
  - ▶ Estimate of value to PLWD, families, and society of innovations in prevention, diagnostics, and treatment, including pharmacologic treatments
  - ▶ Assessment and quantification of total economic impact of dementia for PLWD and families including current and future national costs

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## Chapter 8: Data Collection and Research Methodology



- ▶ **Address key methodological objectives to support needed research**
  - ▶ Expansion of data infrastructure and improved data collection
  - ▶ **Improved measurement of exposures and outcomes**
  - ▶ Adoption of more rigorous study designs, particularly in realm of implementation science, so research findings can be successfully integrated into clinical and community practices
  - ▶ **Development of systematic approaches for integrating evidence from disparate studies**
  - ▶ Improved inclusion and representation of diverse individuals among research participants and researchers

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# Current NIA Behavioral and Social Research Activities

## Example Areas of Alignment

Decadal Survey Research Need	Current NIA Activity
Improved screening and diagnosis	<a href="#">SCREENing for Cognitive impairment: Decision-making approved concept</a> and NIA/BSR-sponsored <a href="#">NASEM workshop on preclinical diagnostics</a>
Complex social exposures or behaviors that are relevant to dementia risk	<a href="#">RFA-AG-22-025</a> Data Enhancements and Analyses to Clarify the Relationship between Education and Cognitive Function (including AD/ADRD)
Leverage existing data sources	Future pilot award opportunities via newly funded <a href="#">Artificial Intelligence and Technology Collaboratories for Aging Research</a>



## Example Areas of Alignment

Decadal Survey Research Need	Current NIA Activity
Platforms to facilitate fielding pragmatic trials embedded in health care systems	<a href="#">PAR-21-308</a> Pragmatic Trials for Dementia Care and Caregiver Support
Methods for estimating the impacts of new treatments	<a href="#">Health equity and the cost of novel treatments for AD/ABDR</a> approved concept
Improved study designs to facilitate adaptation of nonpharmacological interventions	<a href="#">PAR-21-307</a> Dementia Care and Caregiver Support Intervention Research



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## Alignment with New Care-focused Research Implementation Milestones

Decadal Detailed Research Need	New AD/ABDR Care Milestone Area
Approaches for integrating and coordinating care	Research focused on integration care with particular attention paid to transitions
Financing structure effects on quality of care and clinical outcomes	Research to address the impact of policy and payment models and insurance

Visit [NIA's website](#) to see forthcoming new care-related milestones.



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## Alignment with New Care-focused Research Implementation Milestones

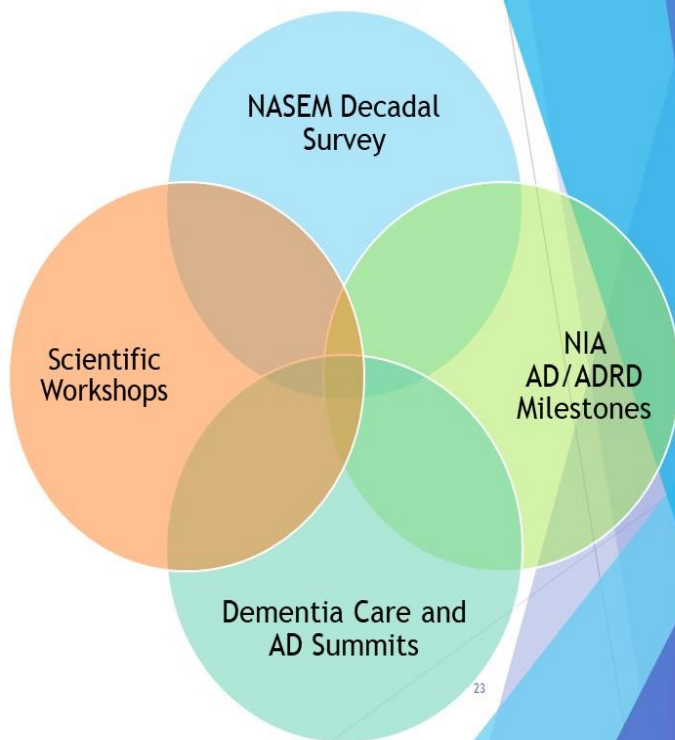
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Decadal Detailed Research Need	New AD/ADRD Care Milestone Area
Expansion of data infrastructure and improved data collection	Further develop AD/ADRD data and clinical infrastructure and harmonization processes
Guidance to support ethical and responsible decision making by and for PLWD	Research focused on the ethical implications of inclusion of the care partner in the care team



## Informing Future Activities

## Convergence Among Multiple Sources of Input on BSR AD/ADRD Research Priorities



## Visit our Website!

- ▶ NIA/BSR recently updated its ADRD webpages describing the behavioral and social science research portfolio areas
- ▶ Visit for more information at <https://www.nia.nih.gov/research/dbsr/ad-adrdrd>
- ▶ More questions? Email me at [elena.fazio@nih.gov](mailto:elena.fazio@nih.gov)







# Q&A