

Alzheimer's Disease and Related Dementias Research Update

Advisory Council on Alzheimer's Research, Care, and Services Meeting

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 Director, NIA
 April 27, 2018



Appropriations

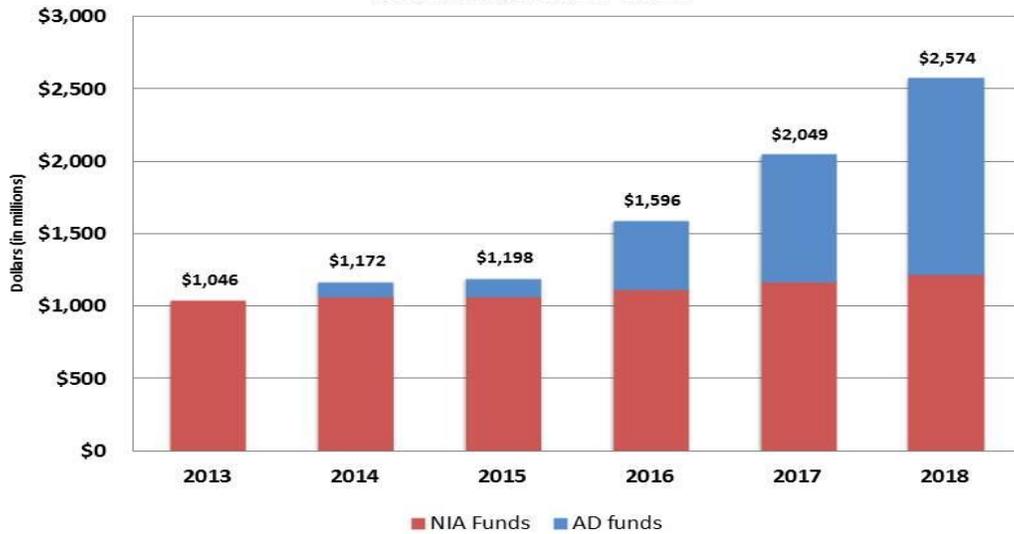


*one-year money

Years displayed are Fiscal Years

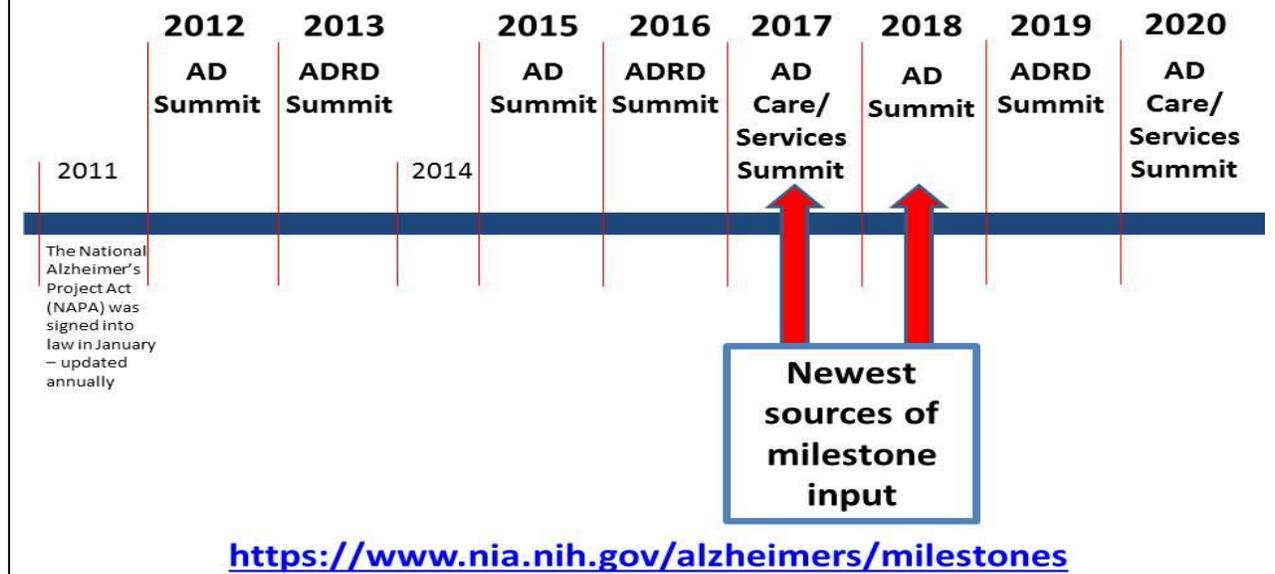
NIA Appropriations

Fiscal Years 2013-2018



AD/ADRD Research Implementation Milestones and Bypass Budget Process

NIH Research Implementation Milestones are *Based on Broad Input*



What Counts as AD/ADRD Research?

- The AD/ADRD payline applies to applications/awards that are coded as AD or Alzheimer's disease- related dementias (ADRD)
- The ADRD RCDC categories that report related dementias specifically named in the National Plan to Address Alzheimer's Disease are:
 - Lewy Body dementia (LBD)
 - Frontotemporal dementia (FTD)
 - Vascular Cognitive Impairment/Dementia (VCI/D)

Combined External and Internal Input – FY20 AD/ADRD Bypass Budget

Input at 2012-2018 meetings:

- Academic research community
- Industry
- Non-governmental organizations

Other Input:

- 2017 Request for Information

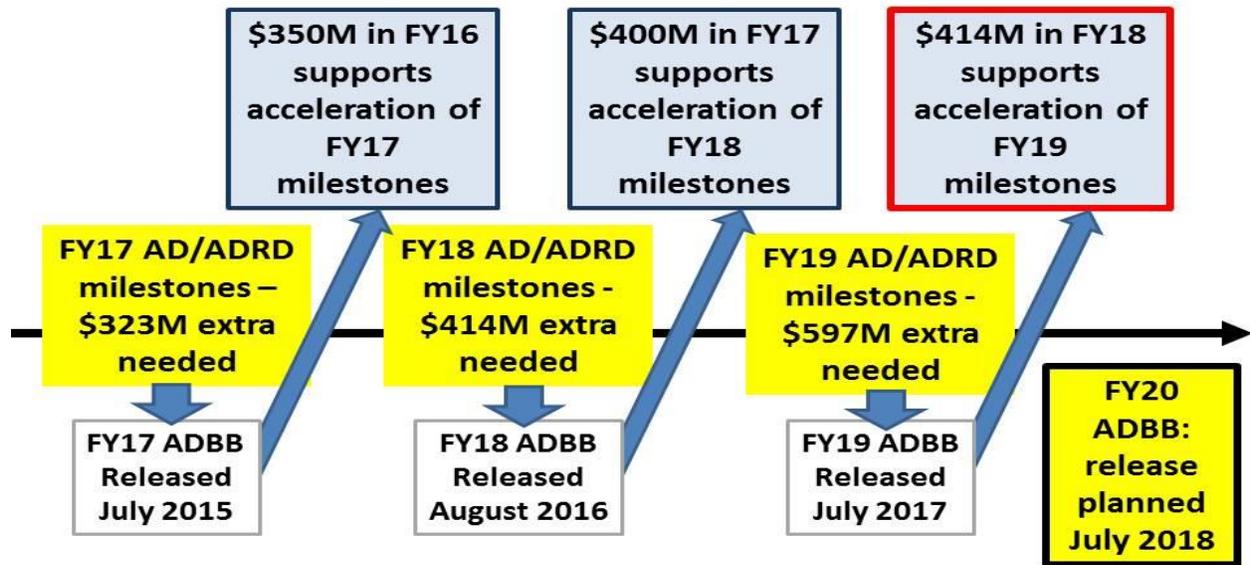
Development of comprehensive milestones
(NIH staff) – based on summit and
other input

Trans-NIH (including NINDS) staff discussion;
milestones edited to ensure comprehensive
inclusion of priorities for FY20

NIH staff
“price” the
milestones

**Final budget
estimate for
FY20**

Timing of ADBB Releases and AD/ADRD Appropriations

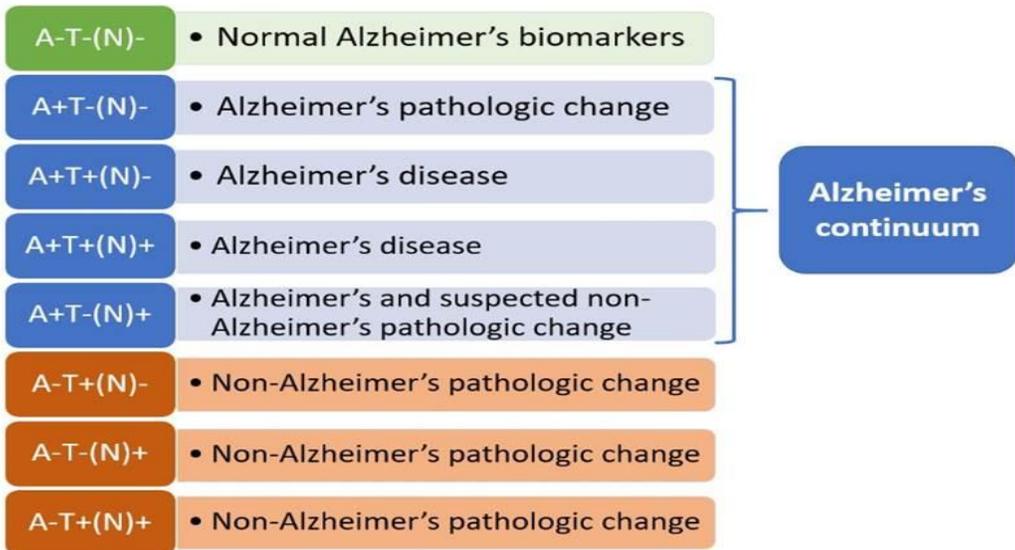


Complex Considerations for Future Bypass Budgets

- Past/current appropriations, including funds that have allowed us to address milestones “in advance”
- Progress on milestones – what have we accomplished? what new milestones are emerging?
- Incorporating new care/services research milestones along with other milestones that are focused on drug development, etc.
- Large project needs – emerging clinical trials, etc.
- Emerging investments by other groups – what gaps are best filled by the NIA/NIH?
- Successes in recruiting new and established researchers to AD/ADRD research and capacity of the field

NIA-Alzheimer’s Association Research Framework

NIA-AA Research Framework

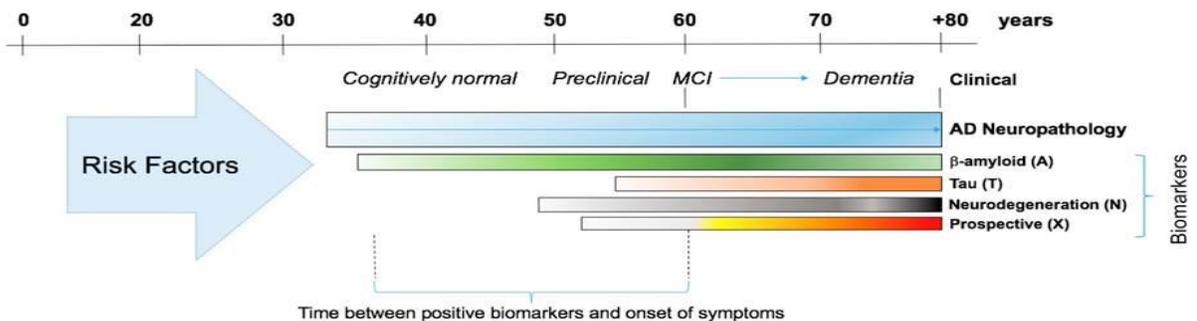


**A = Amyloid; T = Tau;
N = Neurodegeneration**

Adapted from Jack et al.,
Alzheimer's & Dementia
(2018) 14(4): 535-562.

NIA-AA Research Framework

The framework will hopefully aid researchers in identifying individuals at risk for disease sufficiently early to test new prevention strategies as they emerge



Silverberg et al., *Alzheimer's & Dementia* (2018) 14(4):576-578.

Summit Updates



National Research Summit on Care, Services and Supports for Persons with Dementia and Their Caregivers

NIH Campus, Natcher Building #45 | 45 Center Drive | Bethesda, Maryland

October 16-17, 2017

Registration opening soon



Convened by the National Institute on Aging at the NIH with support from the Foundation for the National Institutes of Health.

<https://aspe.hhs.gov/national-research-summit-care-services-and-supports-persons-dementia-and-their-caregivers>

Save the Date

AD/ADRD Care/Services Summit (II)
March 24-25, 2020
Natcher Conference Center
Bethesda, MD



NEW Planned Evidence Review: *Care Interventions for Individuals with Dementia and Their Caregivers*

- Hundreds of studies have looked at the efficacy and effectiveness of care/caregiving interventions, but *what is the quality of evidence supporting readiness for dissemination of any of these?*
- NIA is funding a two-part study similar to that used for the recent dementia prevention literature review

NEW Planned Evidence Review:
*Care Interventions for Individuals
with Dementia and Their Caregivers*

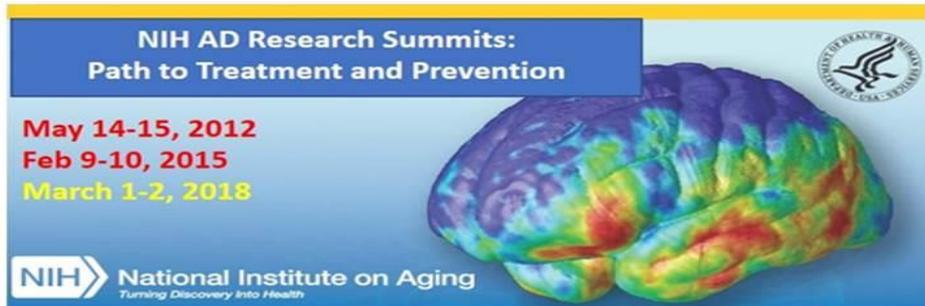
Initial steps:

- **National Academies of Sciences, Engineering, and Medicine:** *Expert panel input on questions and study design*
www.nationalacademies.org/dementiacare
- **Agency for Healthcare Research & Quality:** *Evidence review*

NEW Planned Evidence Review:
*Care Interventions for Individuals
with Dementia and Their Caregivers*

Draft study questions, and other planned study parameters will be posted for public comment

The URL will be shared widely once available



Goal: The 2018 Summit was built on the foundation laid by the NIH AD Research Summits held in 2012 and 2015. It featured progress towards achieving the AD research implementation milestones and continue development of an integrated multidisciplinary research agenda necessary to *enable precision medicine for AD*.

<https://www.nia.nih.gov/research/nih-ad-summit-2018-program-agenda>

AD Research Summit Program

The Summit Program was organized around 7 sessions and featured 86 speaker

- 1) Novel Mechanistic Insights into the Complex Biology and Heterogeneity of AD
- 2) Enabling Precision Medicine for AD
- 3) Translational Tools and Infrastructure to Enable Predictive Drug Development
- 4) Emerging Therapeutics
- 5) Understanding the Impact of the Environment to Advance Disease Prevention
- 6) Advances in Disease Monitoring, Assessment and Care
- 7) Building an Open Science Research Ecosystem to Accelerate AD Therapy Development

Central programmatic themes of the 2018 Summit:

- ❖ Understanding disease heterogeneity
- ❖ Enhancing research rigor, reproducibility and translatability
- ❖ Enabling rapid translational learning through open science systems and incentives.

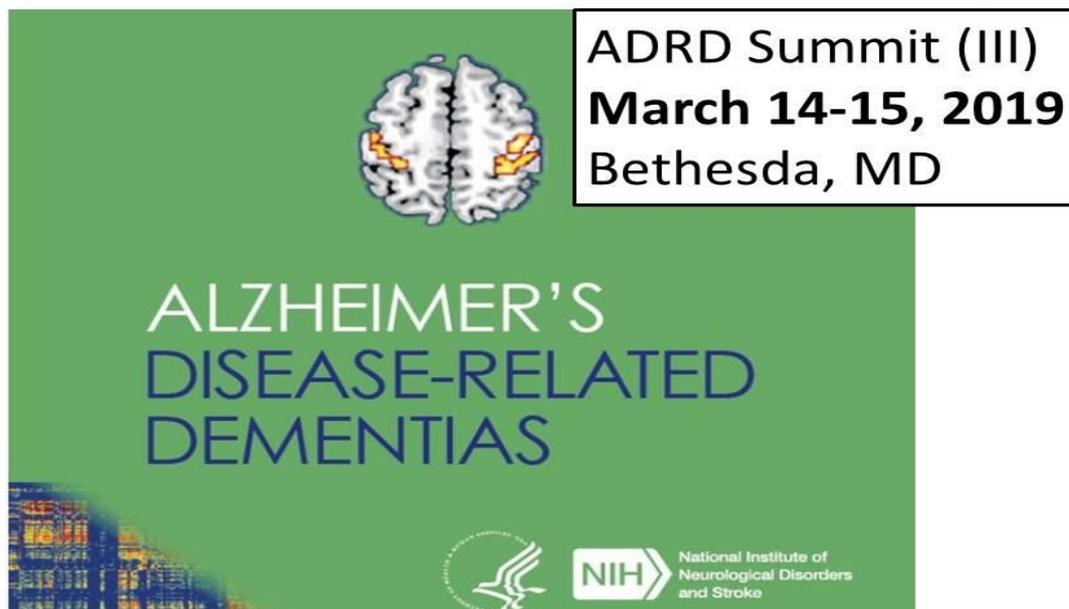
AD Research Summit Program

- Day 1 hosted over 400 in-person attendees and ~2300 online viewers
 - Videocast from day 1 is available:
<https://videocast.nih.gov/summary.asp?Live=26922&bhcp=1>
- The Day 2 Program was cancelled due to inclement weather. Day 2 Program rescheduled for May 24 as a live video-cast event.
 - Registration for Day 2:
<https://www.eventbrite.com/e/2018-nih-alzheimers-disease-research-summit-rescheduled-day-2-program-tickets-44164510239>

DAY 2 of the Program will feature:

- Emerging Therapeutics – part II
- Understanding the Impact of the Environment to Advance Disease Prevention
- Advances in Disease Monitoring, Assessment and Care
- Building an Open Science Research Ecosystem to Accelerate AD Therapy Development

Additional Save the Date



ADRD Summit (III)
March 14-15, 2019
Bethesda, MD

ALZHEIMER'S
DISEASE-RELATED
DEMENTIAS

 National Institute of
Neurological Disorders
and Stroke

Co-hosted by the NIA

April 27, 2018 -- Advisory Council Meeting #28

The meeting was held on Friday, April 27, 2018, in Washington, DC. During the meeting, the Clinical Care Subcommittee took charge of the theme, focusing on advancing consensus on dementia care elements to guide new outcomes measurement. The Council heard speakers in two sessions, one focused on developing consensus about dementia care elements, and the second on models that are informing outcomes measurement. The meeting also included updates on work from the previous meetings, a presentation on the final report from the October 2017 Care Summit, and federal workgroup updates. Material available from this meeting is listed below and at <https://aspe.hhs.gov/advisory-council-alzheimers-research-care-and-services-meetings#Apr2018>.

Comments and questions, or alerts to broken links, should be sent to napa@hhs.gov.

General Information

Agenda	[HTML Version] [PDF Version]
Meeting Announcement	[HTML Version] [PDF Version]
Meeting Summary	[HTML Version] [PDF Version]
Public Comments	[HTML Version]

Handouts

Main Summit Recommendations	[HTML Version] [PDF Version]
National Research Summit on Care, Services, and Supports for Persons with Dementia and Their Caregivers: Report to the National Advisory Council on Alzheimer's Research, Care, and Services	[HTML Version] [PDF Version]

Presentation Slides

Age-Friendly Health Systems	[HTML Version] [PDF Version]
Alzheimer's Disease and Related Dementias Research Update	[HTML Version] [PDF Version]
Care Planning and Health Information Technology: How to Aid Dementia Quality Care	[HTML Version] [PDF Version]

Clinical Care Subcommittee Agenda: Advancing Consensus on Dementia Care Elements to Guide New Outcomes Measurement	[HTML Version] [PDF Version]
Clinical Subcommittee Update	[HTML Version] [PDF Version]
Defining Quality Dementia Care	[HTML Version] [PDF Version]
Final Report to the NAPA Advisory Council	[HTML Version] [PDF Version]
Long-Term Services and Supports Committee Update	[HTML Version] [PDF Version]
Quality Care from the Perspectives of People Living with Dementia	[HTML Version] [PDF Version]
Research Summit on Dementia Care: Building Evidence for Services and Supports Process Report	[HTML Version] [PDF Version]
Testing the Promise of Primary Care: Comprehensive Primary Care Plus (CPC+)	[HTML Version] [PDF Version]
Updates and Follow-Up from January Meeting	[HTML Version] [PDF Version]

Videos

Introductions and Updates	[Video]
Clinical Care Agenda Session 1	[Video]
Public Comments	[Video]
Clinical Care Agenda Session 2	[Video]
Care Summit Final Report	[Video]
MEETING WRAP-UP: Final Report to the NAPA Advisory Council	[Video]

Last Updated: 06/09/2018