

Development of the FY19 NIH Bypass Budget for Alzheimer's Disease and Related Dementias

NAPA Advisory Council Meeting

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July 28, 2017

Growth of AD and ADRD Research Spending at NIH

Research/Disease Areas (Dollars in millions and rounded)	FY 2015 Actual	FY 2016 Actual	FY 2017 Estimate (Enacted)
Alzheimer's Disease	\$589	\$929	\$1,348
Alzheimer's Disease including Alzheimer's Disease Related Dementias (AD/ADRD)	\$631	\$986	\$1,414
Alzheimer's Disease Related Dementias (ADRD)	\$120	\$175	\$234
Frontotemporal Dementia (FTD)	\$36	\$65	\$68
Lewy Body Dementia	\$15	\$22	\$23
Vascular Cognitive Impairment/ Dementia	\$72	\$89	\$93

Bypass Budget Language

SEC. 230. Hereafter, for each fiscal year through fiscal year 2025, the Director of the National Institutes of Health shall **prepare and submit directly to the President for review and transmittal to Congress, after reasonable opportunity for comment, but without change, by the Secretary of Health and Human Services and the Advisory Council on Alzheimer's Research, Care, and Services, an annual budget estimate (including an estimate of the number and type of personnel needs for the Institutes) for the initiatives of the National Institutes of Health pursuant to the National Alzheimer's Plan**, as required under section 2(d)(2) of Public Law 111-375.

NIH Meetings Provided the Basis for Priorities, Milestones, and Budget Estimates

- 2012 Alzheimer's Disease Research Summit
- 2013 meeting on Alzheimer's Disease-Related Dementias: Research Challenges and Opportunities
- 2013 meeting on Advancing Treatment for Alzheimer's Disease in Individuals with Down Syndrome
- 2015 Alzheimer's Disease Research Summit
- 2016 meeting on Alzheimer's Disease-Related Dementias

Recommendations used to create milestones for developing the Alzheimer's Disease (and related dementias) Bypass Budget

Combined External and Internal Input – FY19 AD Bypass Budget

Input at 2012-2017 meetings:

- Academic research community
- Industry
- Non-governmental organizations

Other Input:

- 2017 Request for Information

Development of comprehensive milestones (NIH staff) – based on recommendations and milestones from meetings

Trans-NIH (including NINDS) staff discussion; milestones edited to ensure comprehensive inclusion of priorities for FY19

NIH staff “price” the milestones

Final budget estimate for FY19

Trans-NIH Input for FY19 ADBB

- Nine Institutes and Centers provided feedback that contributed to the development of this year’s professional judgment budget:

- | | |
|---------|---------|
| ▪ NIA | ▪ NIEHS |
| ▪ NINDS | ▪ NIDDK |
| ▪ NIMH | ▪ NIDCR |
| ▪ NINR | ▪ NHLBI |
| ▪ NICHD | |

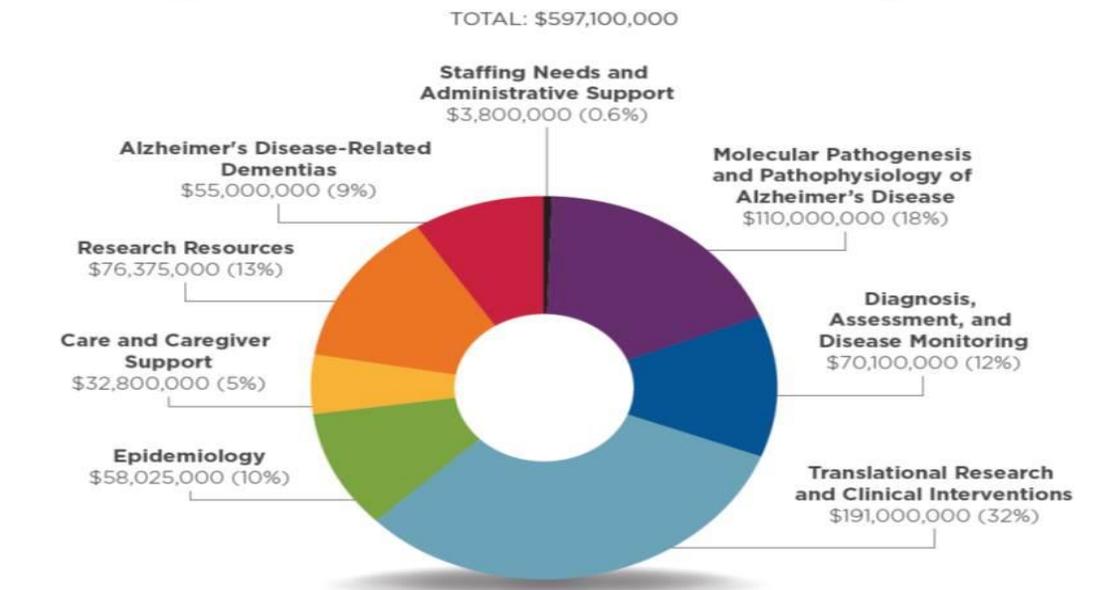
Using CADRO as a Framework

- The eight CADRO (Common Alzheimer’s Disease Research Ontology) categories provide the overarching framework for the FY19 AD Bypass Budget and narrative.
- CADRO provides the framework for IADRP (the International Alzheimer’s Disease Research Portfolio) and will allow tracking of implementation in the budget areas in future years.

FY19 Professional Judgment Budget

Area of Research	Amount <small>(dollars in thousands)</small>
A. Molecular Pathogenesis and Physiology of Alzheimer's Disease	\$110,000
B. Diagnosis, Assessment and Disease Monitoring	\$70,100
C. Translational Research and Clinical Interventions	\$191,000
D. Epidemiology	\$58,025
E. Care and Caregiver Support	\$32,800
F. Research Resources	\$76,375
H. Alzheimer's Disease-Related Dementias	\$55,000
Staff Needs, Support, and Misc.	\$3,800
Total Additional Resources Needed	\$597,100

Distribution of *Additional* Budget Funding Request Across Research Areas, FY19



FY19 Professional Judgment Budget Baseline

Baseline Estimate, President's Budget, Fiscal Year 2018

(dollars in thousands)

Alzheimer's Disease including Alzheimer's Disease Related Dementias (AD+ADRD)

\$837,000

FY19 Professional Judgment Budget Considerations

Resources needed for new AD/ADRD research

(dollars in thousands)

\$597,100

Difference between FY18 President's Budget Request and the FY17 Omnibus Appropriation

(dollars in thousands)

\$577,000

TOTAL ADDITIONAL RESOURCES NEEDED

(dollars in thousands)

\$1,174,100

TOTAL RESOURCES NEEDED

(dollars in thousands)

\$2,011,100

Implementation Tracking

- **IADRP: <http://iadrp.nia.nih.gov/>**
 - *Will continue to offer detailed tracking of initiatives and awards with respect to our research milestones, under the CADRO categories*
- **Web-based tool for tracking funding initiatives and activities:**
<https://www.nia.nih.gov/alzheimers/milestones>
 - *Developed by the NIH and other AD funding organizations*
 - *Aimed at addressing the research milestones associated with NAPA*

Other Federal Updates



ALZHEIMER'S DISEASE-RELATED DEMENTIAS

ADRD Non-Governmental Organizations (NGO) Roundtable Meeting

June 16, 2017

Hosted by NINDS and NIA

- To share updates about research activities, funding-related information, and progress on the ADRD Research Milestones
- To discuss opportunities for NIH and NGOs to work together toward preventing or effectively treating AD/ADRD by 2025

Participants: NINDS and NIA Leadership and staff, and 9 NGOs, including

Alzheimer's Association
American Heart Association & American Stroke Association
Association for Frontotemporal Degeneration
The Bluefield Project to Cure Frontotemporal Dementia
BrightFocus Foundation
CurePSP
Lewy Body Dementia Association
The Michael J. Fox Foundation for Parkinson's Research
Rainwater Charitable Foundation

2017 VHA-NIA Collaboration/Partnership Alzheimer's Disease and Related Disorders

Goals:

- Foster new networks between VA- and NIA- investigators.
- Leverage each Institution's state-of-the-art instrumentation, data information, clinical resources, and Centers of Excellence to synergistically move the field forward.

Timelines (in process):

- Request for Information (RFI)- NOT-AG-16-083 (9-received)
 - Potential AD and ADRD research topics to address.*
 - Barriers & challenges that could prevent coordination and collaboration.*
 - How to leverage resources*
- Meeting between VA point of contact (Dr. Block) and NIA (Drs. Opanashuk and Liggins) points of contact (2-29-17).
- Development of Work Groups (April 15, 2017) - ~10 people/group
 - Basic Disease Mechanisms Work Group*
 - Genetic and Population Studies Work Group*
 - Diagnoses and Disease monitoring Work Group*
 - Translation and Clinical Research Work Group*
 - Care and Caregiving Research Work Group*

July 28, 2017 -- Advisory Council Meeting #25

The meeting was held on Friday, July 28, 2017, in Washington, DC. The Advisory Council spent the morning discussing information gaps across the three areas of research, clinical care, and long-term services and supports. There was also a presentation on the recently released National Academy of Sciences, Engineering, and Medicine (NASEM) report on preventing cognitive decline. Additional presentations included a presentation on planning and progress towards the October Care and Services Summit and federal workgroup updates. Material available from this meeting is listed below and is also available at <https://aspe.hhs.gov/advisory-council-alzheimers-research-care-and-services-meetings#Jul2017>.

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]

Presentation Slides

2017 National Plan Update and Non-Federal Recommendations	[HTML Version] [PDF Version]
Clinical Services Subcommittee Federal Update	[HTML Version] [PDF Version]
CommunityRx for Community-Residing People with Dementia and Their Caregivers	[HTML Version] [PDF Version]
Dementia Caregiving in the U.S.	[HTML Version] [PDF Version]
Development of the FY 19 NIH Bypass Budget for Alzheimer's Disease and Related Dementias	[HTML Version] [PDF Version]
Implications of a Biologically Based Definition of Alzheimer's Disease	[HTML Version] [PDF Version]
Increasing Opportunities for Choice and Control for Persons with Dementia	[HTML Version] [PDF Version]
Interventions to Prevent or Slow Cognitive Decline, MCI and Dementia in Individuals without Dementia	[HTML Version] [PDF Version]
Living Alone With Dementia	[HTML Version] [PDF Version]

Long-Term Services and Supports Committee Update	[HTML Version] [PDF Version]
Managing Chronic Conditions in People Living with Dementia	[HTML Version] [PDF Version]
Preventing Cognitive Decline and Dementia	[HTML Version] [PDF Version]
Research Summit on Dementia Care	[HTML Version] [PDF Version]
The Many Challenges of Alzheimer's Disease	[HTML Version] [PDF Version]

Videos

Welcome thru Clinical Care	[Video]
LTSS Research	[Video]
Public Comments thru Federal Workgroup Updates	[Video]
Recommendations thru Adjourn	[Video]

Last Updated: 06/27/2018