

2018 Current Fiscal Year Report: Advisory Council on Alzheimer's Research, Care, and Services

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1. Department or Agency

Department of Health and Human Services

2. Fiscal Year

2018

3. Committee or Subcommittee

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

3b. GSA Committee No.

76866

4. Is this New During Fiscal Year?

No

5. Current Charter

08/10/2017

6. Expected Renewal Date

08/10/2019

7. Expected Term Date

8a. Was Terminated During Fiscal Year?

No

8b. Specific Termination Authority

8c. Actual Term Date

9. Agency Recommendation for Next Fiscal Year

Continue

10a. Legislation Req to Terminate?

No

10b. Legislation Pending?

Not Applicable

11. Establishment Authority

Statutory (Congress Created)

12. Specific Establishment Authority

Public Law 111-375 (42 U.S.C. 11225), the National Alzheimer's Project Act

13.

Effective Date

01/04/2011

14.

Committee Type

Continuing

14c.

Presidential?

No

15. Description of Committee

Other Committee

16a. Total Number of Reports

2

16b. Report Date

09/14/2018

Report Title

2018 Non-Federal Member Recommendations

09/14/2018

2018 Update - National Plan to Address Alzheimer's Disease

Number of Committee Reports Listed: 2

17a. Open 4 17b. Closed 0 17c. Partially Closed 0 Other Activities 0 17d. Total 4

Meetings and Dates

Purpose

The meeting was held on Friday, October 27, 2017, in Washington, DC. The Advisory Council welcomed its new members and invited them to share their experiences and where they see the Council going over the length of their terms. The Advisory Council also spent some time discussing the process of developing recommendations and how those recommendations relate to the National Plan. The Council then spent much of the meeting discussing the National Research Summit on Care, Services, and Supports for Persons with Dementia and Their Caregivers, held on October 16-17.

Start

End

10/27/2017 - 10/27/2017

The meeting was held on Friday, January 26, 2018, in Washington, DC. The Research Subcommittee took charge of this meeting's theme, focusing on the process from targets to treatments. The Council heard speakers on the preclinical pipeline, the clinical trial pipeline, and the industry perspective. The meeting also included discussion of a driver diagram to guide the Council's future work, updates and a report from the October Care Summit, and federal workgroup updates. 01/26/2018 - 01/26/2018

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. 04/27/2018 - 04/27/2018

The meeting was held on Monday, July 30, 2018, in Washington, DC. The Advisory Council spent the majority of the July meeting considering recommendations made by each of the three subcommittees to present to the Secretary of HHS and Congress. Additional presentations in the afternoon included a presentation on a recent study by RAND on the health care infrastructure, the CDC/Alzheimer's Association's joint Healthy Brain Initiative Roadmap, federal workgroup updates, and updates on work by the non-federal members. 07/30/2018 - 07/30/2018

Number of Committee Meetings Listed: 4

	Current FY	Next FY
18a(1). Personnel Pmts to Non-Federal Members	\$9,600.00	\$9,600.00
18a(2). Personnel Pmts to Federal Members	\$0.00	\$0.00
18a(3). Personnel Pmts to Federal Staff	\$83,086.00	\$80,721.00
18a(4). Personnel Pmts to Non-Member Consultants	\$71,332.00	\$75,000.00
18b(1). Travel and Per Diem to Non-Federal Members	\$33,652.00	\$35,000.00
18b(2). Travel and Per Diem to Federal Members	\$0.00	\$0.00
18b(3). Travel and Per Diem to Federal Staff	\$0.00	\$0.00
18b(4). Travel and Per Diem to Non-member Consultants	\$0.00	\$0.00
18c. Other(rents,user charges, graphics, printing, mail, etc.)	\$0.00	\$0.00
18d. Total	\$197,670.00	\$200,321.00
19. Federal Staff Support Years (FTE)	0.85	0.80

20a. How does the Committee accomplish its purpose?

The Advisory Council on Alzheimer’s Research, Care, and Services meets quarterly to discuss programs that impact people with Alzheimer’s disease and related dementias and their caregivers. The Advisory Council shall make recommendations about ways to reduce the financial impact of Alzheimer’s disease and related dementias and to improve the health outcomes of people with these conditions. The Advisory Council shall provide feedback on a National Plan for Alzheimer’s disease. On an annual basis, the Advisory Council shall evaluate the implementation of the recommendations through an updated national plan.

20b. How does the Committee balance its membership?

The Advisory Council shall consist of at least 10 Federal members including designees from the Centers for Disease Control and Prevention, Administration on Aging, Centers

for Medicare and Medicaid Services, Indian Health Service, Office of the Director of the National Institutes of Health, National Science Foundation, Department of Veterans Affairs, Food and Drug Administration, Agency for Healthcare Research and Quality, and the Surgeon General. The Advisory Council shall also consist of 12 non-federal members selected by the Secretary or designee who are Alzheimer's patient advocates, one of whom is living with dementia (2), Alzheimer's caregivers (2), health care providers (2), representatives of State health departments (2), researchers with Alzheimer's-related expertise in basic, translational, clinical, or drug development science (2), and voluntary health association representatives (2). The Secretary, or designee, shall appoint one of the members to serve as the Chair. In order to ensure reasonable continuity of membership, half of the initial members shall be invited to serve 2 year terms and half of the initial members shall be invited to serve 4 year terms. After the first two years, members shall be invited to serve for overlapping 4 year terms, except that any member appointed to fill a vacancy for an unexpired term shall be appointed for the remainder of such term. A member may serve after the expiration of the member's term until a successor has taken office. Non-federal members will serve as Special Government Employees.

20c. How frequent and relevant are the Committee Meetings?

The Advisory Council meets four times a year to discuss progress made on dementia research, care, and services. The Council also uses these quarterly meetings to discuss and create recommendations, which are sent to the Secretary of Health and Human Services and to Congress for possible action. The quarterly meetings allow the Council to have enough time to consider and evaluate progress and programs on dementia around the country. Meetings also have themes, where experts are invited to provide insight into less well-known issues around dementia, and to help the Council focus in on gaps in information and research.

20d. Why can't the advice or information this committee provides be obtained elsewhere?

The Committee is required by Public Law 111-375 (42 U.S.C. 11225), the National Alzheimer's Project Act.

20e. Why is it necessary to close and/or partially closed committee meetings?

Not applicable- all meetings are open.

21. Remarks

In FY2018, this Advisory Committee released the following recommendations:

<https://aspe.hhs.gov/pdf-document/public-member-advisory-council-alzheimers-research-care-a>

The Advisory Committee also provided input on the 2018 Update to the National Plan to Address Alzheimer's Disease:

<https://aspe.hhs.gov/pdf-report/national-plan-address-alzheimers-disease-2018-update>

Designated Federal Officer

Helen Lamont DFO

Committee Members	Start	End	Occupation	Member Designation
Brandt, Katherine	10/01/2017	09/30/2021	Caregiver Support Services Director, FrontoTemporal Dementia Unit, Mass General Hospital	Special Government Employee (SGE) Member
Cherry, Debra	10/01/2017	09/30/2021	Executive Vice President, Alzheimer's Greater Los Angeles	Special Government Employee (SGE) Member
Dionne-Vahalik, Michelle	01/08/2018	09/30/2021	Director, Quality Monitoring Program & Initiatives, Texas Health & Human Services Commission	Special Government Employee (SGE) Member
Dunn, Billy	07/21/2014	10/31/2025	FDA Representative	Regular Government Employee (RGE) Member
EGge, Robert	10/01/2017	09/30/2021	Chief Public Policy Officer, Alzheimer's Association	Special Government Employee (SGE) Member
Epstein-Lubow, Gary	10/01/2015	09/30/2019	Hebrew SeniorLife	Special Government Employee (SGE) Member
Finke, Bruce	09/27/2011	10/31/2025	IHS Representative	Regular Government Employee (RGE) Member
Gitlin, Laura	10/01/2015	09/30/2019	Drexel University College of Nursing and Health Professions	Special Government Employee (SGE) Member
Hodes, Richard	09/27/2011	10/31/2025	NIH Representative	Regular Government Employee (RGE) Member
Hummel, Cynthia	10/01/2017	09/30/2019	Retired	Special Government Employee (SGE) Member
Hyman, Bradley	10/01/2017	09/30/2021	Director, Massachusetts Alzheimer's Disease Research Center	Special Government Employee (SGE) Member
Kurtz, Becky	10/01/2017	09/30/2021	Manager, Aging and Health Resources Division, Atlanta Regional Commission	Special Government Employee (SGE) Member
Levey, Allan	10/01/2017	09/30/2021	Director, Emory University Alzheimer's Disease Research Center	Special Government Employee (SGE) Member
Ling, Shari	09/27/2011	10/31/2025	CMS Representative	Regular Government Employee (RGE) Member
Long, Erin	04/29/2016	10/31/2025	ACL Representative	Regular Government Employee (RGE) Member
McGuire, Lisa	10/26/2015	10/31/2025	CDC Representative	Regular Government Employee (RGE) Member
Pacifico, Anthony	12/02/2013	10/31/2025	Department of Defense Representative	Regular Government Employee (RGE) Member
Shaughnessey, Marianne	10/27/2017	10/31/2025	VA Representative	Regular Government Employee (RGE) Member
Spector, William	09/27/2011	10/31/2025	AHRQ Representative	Regular Government Employee (RGE) Member
Taylor, Angela	10/01/2015	09/30/2019	Director of Programs at the Lewy Body Dementia Association	Special Government Employee (SGE) Member
Tichawonna, Sowande	10/01/2015	09/30/2019	Independent filmmaker and actor	Special Government Employee (SGE) Member
Weiss, Joan	09/27/2011	10/31/2025	HRSA Representative	Regular Government Employee (RGE) Member

Number of Committee Members Listed: 22

Narrative Description

The Advisory Council on Alzheimer's Research, Care, and Services consists of 22 members who will meet quarterly to discuss the efficacy of government programs targeting the needs of individuals and caregivers coping with the consequences of Alzheimer's disease and related dementias. On an annual basis, the Advisory Council makes recommendations to the Secretary of HHS and to Congress. To the extent possible, these recommendations are incorporated into the annually-updated National Plan to Address Alzheimer's Disease.

What are the most significant program outcomes associated with this committee?

Checked if Applies

- | | |
|---|-------------------------------------|
| Improvements to health or safety | <input checked="" type="checkbox"/> |
| Trust in government | <input type="checkbox"/> |
| Major policy changes | <input checked="" type="checkbox"/> |
| Advance in scientific research | <input checked="" type="checkbox"/> |
| Effective grant making | <input type="checkbox"/> |
| Improved service delivery | <input checked="" type="checkbox"/> |
| Increased customer satisfaction | <input checked="" type="checkbox"/> |
| Implementation of laws or regulatory requirements | <input checked="" type="checkbox"/> |
| Other | <input type="checkbox"/> |

Outcome Comments

Not Applicable

What are the cost savings associated with this committee?

Checked if Applies

- | | |
|----------------------------|-------------------------------------|
| None | <input type="checkbox"/> |
| Unable to Determine | <input checked="" type="checkbox"/> |
| Under \$100,000 | <input type="checkbox"/> |
| \$100,000 - \$500,000 | <input type="checkbox"/> |
| \$500,001 - \$1,000,000 | <input type="checkbox"/> |
| \$1,000,001 - \$5,000,000 | <input type="checkbox"/> |
| \$5,000,001 - \$10,000,000 | <input type="checkbox"/> |
| Over \$10,000,000 | <input type="checkbox"/> |
| Cost Savings Other | <input type="checkbox"/> |

Cost Savings Comments

NA

What is the approximate Number of recommendations produced by this committee for the life of the committee?

156

Number of Recommendations Comments

The recommendations include recommendations made to the Secretary of HHS, Congress, states and healthcare providers. In FY2018, 15 of the 15 recommendations were made specifically to HHS.

What is the approximate Percentage of these recommendations that have been or will be Fully implemented by the agency?

43%

% of Recommendations Fully Implemented Comments

67/156

What is the approximate Percentage of these recommendations that have been or will be Partially implemented by the agency?

72%

% of Recommendations Partially Implemented Comments

112/156

Does the agency provide the committee with feedback regarding actions taken to implement recommendations or advice offered?

Yes No Not Applicable

Agency Feedback Comments

Federal agencies provide feedback and formal responses at the Council meetings as part of their updates. Recommended items are often implemented in the National Plan.

What other actions has the agency taken as a result of the committee's advice or recommendation?

Checked if Applies

- Reorganized Priorities
- Reallocated resources
- Issued new regulation
- Proposed legislation

Approved grants or other payments



Other



Action Comments

Not Applicable

Is the Committee engaged in the review of applications for grants?

No

Grant Review Comments

Not Applicable

How is access provided to the information for the Committee's documentation?

Checked if Applies

Contact DFO



Online Agency Web Site



Online Committee Web Site



Online GSA FACA Web Site



Publications



Other



Access Comments

<http://aspe.hhs.gov/national-alzheimers-project-act>