

2017 Research Subcommittee Recommendations

Ron Petersen

Research Subcommittee Members

- **Richard Hodes**
- **Laura Gitlin**
- **Angela Taylor**
- **Harry Johns**
- **Billy Dunn**
- **Ron Petersen**

Recommendation 1

The 2017 National Plan should continue to provide a robust, comprehensive, and transformative scientific roadmap for achieving the goal of preventing, effectively treating and providing effective care and services for Alzheimer’s Disease and related dementias by 2025.

- Roadmap should include input from experts in the field through research summits on ADRD including a research summit on care and services
- Recommendations from summits and the research community should be re-evaluated each year and translated into milestones

Recommendation 1 Cont.

- Include specific research milestones to:
 - Reduce racial/ethnic/socioeconomic disparities in Alzheimer’s disease and related dementias
 - Re-evaluate research priorities among ADRD across all research areas (e.g., from identifying disease modifying treatments to identifying effective care and services)
 - Include and prioritize specific milestones for populations at high risk for ADRD (e.g., people with Down Syndrome, African Americans)
 - Increased attention should be paid to person- and family-centered outcomes with respect to research planning and the delivery of care and services

Recommendation 2

A top priority remains the urgent need to continue to increase annual federal research funding sufficient to meet the 2025 goal.

- At present, the US spends less than 0.5% of its annual care costs for ADRD on research, therefore investments in research should be increased to achieve the primary goal of the National Plan
- Initial estimates suggested that \$2 billion or more per year is needed, and more accurate estimates can be generated by the Professional Judgment Budget.
- The annual Professional Judgment Budget recommended by the Alzheimer’s Accountability Act and prepared by the NIH should reflect the science-driven funding needs for the budget year to enable investigators to reach the 2025 goal of the plan.
- This investment would be applied to ADRD research initiatives spanning basic, translational, clinical, care and services research.

Recommendation 3

The 2017 National Plan should develop research goals aimed at the establishment of recommendations to improve uptake, spread and delivery of evidence-based and evidence-informed care and services.

- Enhance methodologies to effectively engage persons with dementia and families in research on care decision making and planning
- Develop and implement quality care measures across all settings that include person-and family-centered outcomes
- Identify and evaluate (non-drug) care strategies that reduce disease burden and delay disease progression and evaluate their costs and downstream effectsStudy comprehensive dementia care from time of diagnosis to end of life and associated costs

Recommendation 3 Cont.

- Develop and evaluate effective care programs across diverse settings (e.g., home, nursing home, assisted living, community-based programs, primary care), disease etiologies and disease trajectories to address key clinical features including neuropsychiatric symptoms and functional decline.
- Develop and evaluate technologies to link families to care providers, share information more efficiently, deliver care interventions, monitor health and symptom status and promote home safety.
- Convene a conference of key stakeholders to identify a meaningful pathway or pipeline for developing and testing nonpharmacological treatments, and scaling up and implementing effective approaches.

Recommendation 4

Emphasis should be given to the standardization of terminology in dealing with cognitive and dementing disorders.

- A federally-led working group of thought leaders should be convened to identify existing barriers, opportunities and recommend strategies to develop consistent language for cognitive disorders among the scientists, care providers and the public.
- Engage all of the stakeholders around these issues to reduce the use of confusing or conflicting terminology and propose improved terminology for the benefit of persons with dementia, their family members and caregivers and the scientific and service communities

Recommendation 5

As recommended in the National Plan the US government should support global efforts to address issues of research, care and services.

- US public and private entities should acknowledge and scrutinize the work of the World Dementia Council and the World Health Organization
- Continued collaborations on international research efforts should be promoted

Recommendation 6

A major area of emphasis for the 2017 National Plan should include the enhancement of recruitment efforts for randomized controlled trials for ADRD

- A major challenge in the development of effective therapies for ADRD has been the inefficient recruitment of participants in clinical trials
- Emphasis should be placed on the enhancement of diversity and inclusiveness in these efforts
- The documentation of recruitment goals should be required in applications for randomized controlled trials and incentives should be in place for meeting those goals

April 27, 2018 -- Advisory Council Meeting #28

The meeting was held on Monday, April 17, 2017, in Washington, DC. The Advisory Council spent the majority of the April meeting considering recommendations made by each of the three subcommittees for updates to the 2017 National Plan. Afternoon presentations included a presentation on results from a research project on dementia care components, planning progress towards a 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#Apr2017>.

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

General Information

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

Handouts

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| LTSS Subcommittee 2017 Recommendations | [HTML Version] [PDF Version] |
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Presentation Slides

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| 2017 Research Subcommittee Recommendations | [HTML Version] [PDF Version] |
| Alzheimer's and Related Dementias Research | [HTML Version] [PDF Version] |
| Clinical Care Subcommittee Report | [HTML Version] [PDF Version] |
| Clinical Services Subcommittee Federal Update | [HTML Version] [PDF Version] |
| Examining Models of Dementia Care | [HTML Version] [PDF Version] |
| Long Term Services and Supports Subcommittee Recommendations | [HTML Version] [PDF Version] |

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| Long-Term Services and Supports Committee Update | [HTML Version] [PDF Version] |
| National Research Summit on Care, Services and Supports for Persons with Dementia and Their Caregivers Progress to Date | [HTML Version] [PDF Version] |

Videos

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| Welcome, LTSS, and Clinical Care Recommendations | [Video] |
| Research Recommendations, Council Discussion/Vote, Overview of Legislative Processes | [Video] |
| Public Comments and Examining Models of Dementia Care | [Video] |
| Care Summit Update and Federal Workgroup Updates | [Video] |

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