

2016 Research Subcommittee Recommendations

Ron Petersen

Research Subcommittee Members

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- **Laura Gitlin**
- **Angela Taylor**
- **Harry Johns**
- **Billy Dunn**
- **Jane Tilly**
- **Shari Ling**
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Recommendation 1

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 disorders by 2025

- Roadmap should include input from experts in the field through research summits on AD and AD-related dementias 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 Continued

- Include specific research milestones to:
 - Reduce racial/ethnic/socioeconomic disparities in Alzheimer’s disease and related dementias
 - Make significant improvements in research recruitment rates and outreach among diverse populations
 - Re-evaluate priorities among AD and related dementias across all research areas
 - Include and prioritize specific milestones for populations at high risk for AD
 - Increased attention on person-centered outcomes, specifically research planning and the delivery of care and services

Recommendation 2

Increase annual federal research funding sufficient to meet the 2025 goal

- Initial estimates of that level are \$2 billion/yr. but may be more; would be applied to AD research initiatives spanning basic, translational, clinical, care and services.
- Annual research funding target should be dynamically modified to approximate 1% of the cost of caring for persons with AD and related dementias.
- Annual professional judgment budget should reflect science-driven funding needs for budget year to enable investigators to reach 2025 goal of the plan.

Recommendation 3

Develop research goals aimed at the establishment of evidence-based recommendations to improve delivery of care and services

- Enhance methodologies to effectively engage persons with dementia and families in care decision making and planning
- Develop and implement quality care measures across all settings that include person-centered outcomes
- Identify and evaluate (non-drug) care strategies that reduce disease burden and delay disease progression and evaluate their costs and downstream effects

Recommendation 4

Standardization of terminology in dealing with cognitive and dementing disorders

- Convene an integrated conference to develop consistent language for cognitive disorders among the scientists, care providers and public
- Engage all stakeholders around these issues to reach a consensus for the benefit of persons with dementia, their family members and caregivers and the scientific and service communities

Recommendation 5

US Government should support global efforts to address issues of research, care and services as recommended in the National Plan

- US public and private entities should acknowledge and scrutinize the work of the World Dementia Council
- Promote continued collaborations on international research efforts