

National Alzheimer's Project Act (NAPA)

The information that follows was included as an Advisory Council meeting handout.

For more information about NAPA, visit the NAPA website at:

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

NAPA Driver Diagram - Draft - 2018 Recommendations

Aim	Primary Drivers	Secondary Drivers	Owner (Source)	Partner (Who will make this happen)	Recommendations	Timeframe	Actions	Progress	Opportunities/Next Steps
(Goals)	(Strategies)	(Subcommittee)					Federal Activities/ Action Steps	Non-Federal Activities	Measurement
Eliminate the burden of Alzheimer's Disease and Related Dementias	Prevent and Effectively Treat Alzheimer's Disease by 2025	Identify Research Priorities and Milestones	Research	All agencies involved in NAPA and relevant partners	1. The 2018 National Plan should continue to provide a robust, comprehensive, collaborative and transformative research road map for achieving the goal of preventing, effectively treating, and providing effective care and services for AD/ADRD by 2025.	Annually			
			Research	Academia, industry, NGO's, and the dementia community	1.a. A road map for accomplishing the primary goal of the Plan should include input from experts in the field through recurring research summits on AD/ADRD, and care and services.	Annually			
			Research	All agencies involved in NAPA	1.a.1. Cross-agency collaboration between federal agencies on the annual summits is essential to advance progress. Representatives of all federal agencies that fund dementia research should attend the summits and coordinate efforts	Annually			
			Research	NIH and all agencies involved in NAPA, PCORI, academia, industry, NGO's	7. Establish the engagement of research stakeholders as a standard practice in both setting national research priorities for AD/ADRD and throughout all stages of clinical research and care, services and support research.	Annually			
		Expand Research Aimed at Preventing and Treating	Research	Congress, NIH	2. A top priority remains the urgent need to continue to increase annual federal research funding sufficient to meet the 2025 goal.				
			Research	NIH	2.a. The annual professional judgment budget required 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.				
			Research	NIH	2.a.1. This investment would be applied to AD/ADRD research initiatives spanning basic, translational, clinical, care and services research.				
			Research	NGO's and Congress	2.b. Additional investments are needed by other federal agencies to implement milestones out of the Care and Services Summit. New legislation or modification to existing legislation may be required to identify funding needed by other federal agencies to reach the 2025 goals.				
			Research	All agencies involved in NAPA	2.c. All federal agencies should submit dementia research funding awards and amounts annually to the National Institutes of Health International Alzheimer's Disease Research Portfolio (IADRP).				
			Research	All agencies involved in NAPA, academia, biotech and information system industries, NGO's	6. Develop a strategy and infrastructure to increase ethical and open sharing of, access to, and utilization of research data. This strategy should accelerate the pace of scientific discovery in dementia science by addressing a comprehensive range of issues including data sharing practices and policies, data harmonization and interoperability, and the training of data scientists in AD/ADRD research.				
			Research	All agencies involved in NAPA, academia, biotech and information system industries, NGO's	6.a. Special emphasis is needed on data sharing of completed biomarker studies and drug and non-drug clinical trials, including industry-sponsored trials. Patient advocacy and regulatory changes may be required.)				
			Research	All agencies involved in NAPA, academia, industry, NGO's	6.c. The documentation of recruitment goals should be required in applications for randomized controlled trials and incentives should be in place for meeting those goals.				

		Research	NIH and all agencies involved in NAPA, PCORI, academia, industry, NGO's	7.a. Develop evidence-base for optimal methods, assessment and impact of engaging persons with cognitive impairment or dementia and their care partners, leveraging international expertise as needed.					
		Research	Congress, NIH	7.b. Establish funding methods to support participant/caregiver engagement in all AD/ADRD clinical research, including leveraging ongoing guidance to the field on methods of research engagement from PCORI through its reauthorization.					
		Research	NIH and all agencies involved in NAPA, PCORI, academia, industry, NGO's	7.c. Through participant/caregiver engagement, identify meaningful person-centered and caregiver-centered outcomes and validated measures for AD/ADRD by disease etiology.					
		Research	NIH and all agencies involved in NAPA, PCORI, academia, industry, NGO's	8.d. Establish method for researchers and other stakeholders to identify how research engagement is integrated into study planning, conduct and reporting, as well as dissemination and implementation.					
	Accelerate Efforts to Identify Early and Pre-symptomatic Stages	Research	All agencies involved in NAPA	5. A major area of emphasis by all federal agencies involved in the National Plan should be the enhancement of recruitment efforts for research involving those with, or at risk of developing, AD/ADRA.					
		Research	All federal and non-federal agencies involved in NAPA, academia, service providers, community partners	5.a. Emphasis should be place by federal and non-government agencies, academia, service providers and community partners on the enhancement of diversity and inclusiveness in these efforts.					
		Research	NIH	5.b. NIH should advance innovative recruitment efforts to increase recruitment and retention in randomized controlled clinical trials (see recommendation on clinical care).					
		Research	All federal and non-federal agencies involved in NAPA	5.c. All federal and non-federal agencies funding AD/ADRD research should require documentation of recruitment goals in applications for clinical research; incentives should also be in place for meeting those goals.					
	Coordinate research with International, Public, and Private Entities	Research	All agencies involved in NAPA	3. Emphasis should be given to the standardization of terminology across the spectrum of cognition in neurocognitive disorders by all agencies involved in the National Plan, to reduce ambiguity over confusing or overlapping terms, reduce stigma associated with AD/ADRD, and improve public awareness of AD/ADRD and access to relevant resources and services.					
		Research	All agencies involved in NAPA, academia, industry, NGO's, and the dementia community	3.a. Convene a working group of thought leaders to develop an inclusive process that will define the challenges of today's dementia-related nomenclature and propose strategies to develop improved, standardized terminology for use across different audiences without sacrificing scientific accuracy.					
		Research	All agencies involved in NAPA	3.b. Updated terminology should improve public awareness of cognitive impairment and diseases causing dementia, be culturally sensitive, be free of stigma and negative stereotypes, provide clarity between disease etologies and clinical syndroms, address both staging of disease progression and stages of functional abilities from preclinical stage through advanced dementia, and improve identification of caregivers and also address the training needs of the workforce providing AD/ADRD care and services.					
		Research	All agencies involved in NAPA	3.c. The issue of dementia nomenclature should be considered in the planning of any annual summits.					

		Research	HHS, NIH, CDC	4. As recommended in the National Plan the United States government (HHS, NIH, CDC) should support global efforts to address issues of research, care and services, and workforce development in order to facilitate international collaboration and minimize silos of knowledge.					
		Research	U.S. public and private entities, international organizations	4.a. United States public and private entities should collaborate in the work of international organizations focused on reducing the burden of AD/ADRD.					
		Research	All agencies involved in NAPA, U.S. public and private entities, international organizations	4.b. Continued collaborations on international research efforts should be promoted.					
	Facilitate Translation of Findings into Medical Practice and Public Health Programs	Clinical		1a. Federal agencies and others should review the research findings presented at the Care Summit and enact evidence-based care delivery models which have demonstrated efficacy and effectiveness at improving care for AD/ADRD, including advancing a public health approach to promote the health and well-being of persons living with AD/ADRD and their caregivers. (available here: https://aspe.hhs.gov/national-research-summit-care-services-and-supports-persons-dementia-and-their-caregivers-final-report#FinalRpt).					
		Clinical	Congress	1b. Additional investments are needed for federal agencies in addition to NIH to implement milestones out of the Care and Services Summit. New legislation or modification to existing legislation may be required to identify funding needed by other federal agencies to reach the 2025 goals.					
		Clinical	NIH, CMS	1c. Federal agencies should issue requests for applications to address research recommendations.					
		Clinical	Non-governmental funders	1d. Non-governmental organizations should allocate funding and issue requests for applications to address research recommendations.					
		Clinical	ASPE	1d. ASPE should integrate the 12 themes from the Care Summit into the goals and strategies of the National Plan					
	Enhance Care Quality and Efficacy	Clinical	ASPR, DOJ	3a1. Federal agencies and others should prepare specific new training modules and implement them nationally to advance workforce readiness regarding: Disaster Preparedness – to train health care workers, first-responders and individuals to better protect the health and safety of persons living with AD/ADRD and their family members and caregivers who experience a disaster.					
		Clinical	CMS, HRSA	3a2. Federal agencies and others should prepare specific new training modules and implement them nationally to advance workforce readiness regarding: Acute Care – to train individuals, first-responders and health care workers caring for persons living with AD/ADRD in urgent care, emergency room and hospital settings to better address needs of persons living with AD/ADRD.					
Clinical		SAMHSA	3a3. Federal agencies and others should prepare specific new training modules and implement them nationally to advance workforce readiness regarding: Behavioral Health – to train health care workers, first-responders and individuals to 1) better address needs of persons living with AD/ADRD who experience mental health concerns such as substance abuse, depression or suicidal thoughts; and, 2) identify, distinguish, and appropriately manage symptoms of AD/ADRD when they occur concurrently with signs and symptoms of other conditions such as pain, reduced communication abilities, and reduced mobility.						

	Identify High-Quality Dementia Care Guidelines and Measures Across Care Settings	Clinical		4a. A federally-organized work group of thought leaders should be established to review practice guidelines for AD/ADRD. This work group should: (1) Involve comprehensive stakeholder input including from people living with cognitive symptoms, care partners and other stakeholders; (2) Consider public health approaches, data for action, and training opportunities for health professionals; (3) Consider federal guidance regarding person-centered care such as the guidance issued by the ACL on implementation of Section 2402(a) of the Affordable Care Act (https://www.acl.gov/news-and-events/acl-blog/person-centered-planning-and-self-direction-hhs-issues-new-guidance)					
		Clinical		4b. The work group should consider factors such as the following: (1) Elements of care and services that are based on level of function; (2) Health disparities and cultural competencies to advance best practices; (3) Data elements included in a person-centered care plan for AD/ADRD and best practices for care plan use; (4) Use of electronic health records to enhance person-centered planning; (5) The development and evaluation of technologies to link persons living with AD/ADRD and family members to care providers, share information more efficiently, deliver care interventions, monitor health and symptom status, and promote safety; (6) Risks related to quality of life that are either perceived or actual in response to disclosure of a diagnosis of a cognitive disorder; including, for example, loss of employment or insurance in response to knowledge of a diagnosis; (7) The ability of person-centered planning to function continuously over time and to transcend setting; specifically, best practices for use of a person-centered plan that can function well when a person with AD/ADRD lives alone, does or does not have an identified family member or caregiver, and/or transitions to a hospital or residential care setting; (8) Definitions of “dementia capability” in a health system or community, including adaptability of the processes based on a person’s level of function and the setting in which the person lives; (9) Alignment of services with the principles of “age friendly” health systems (https://www.johnhartford.org/grants-strategy/current-strategies/age-friendly-hospitals/) and community activities (http://www.who.int/ageing/age-friendly-world/en/); (10) <i>Pros and cons, barriers and supports, bioethics of various advances</i>					
		Clinical		4c. The work group should make recommendations to the Advisory Council regarding the goals of the National Plan related to best practices for comprehensive care.					
	Explore the Effectiveness of New Models of Care	Clinical	CMS, VA, states, and healthcare payers	5a. Increase the use of value-based care* for persons living with AD/ADRD to pay for health care services in a manner that directly links health services payments to performance on cost, quality, and resource use metrics; this alignment will better support comprehensive person-centered care leading to improved health and quality of life for persons living with AD/ADRD. Using the definitions of value outlined by CMS and others.					
		Clinical		5b. Initiatives to assess value should rely on a framework such as the CMS Meaningful Measures initiative; and then apply such a framework specifically for persons living with known AD/ADRD or cognitive impairment and their family members and caregivers. This could be combined with other reporting of metrics of health care use and performance such as Cognitive Impairment and Assessment Care Planning Codes, Quality Payment Program measures relevant to AD/ADRD, Use of the Annual Wellness Visit.					
		Clinical		5c. Congress and/or federal agencies should authorize and/or designate funding to conduct large-scale evaluation of comprehensive models which include a per-beneficiary-per-month (PBPM) payment to provide care and services to eligible persons living with AD/ADRD as described in Recommendation 11 of the 2017 National Plan.					
		Clinical		5d. States and other payers (Medicare, Medicaid) should increase attention to cost-effective home and community-based services (HCBS), which support person-centered care for persons living with AD/ADRD and their caregivers.					
	Ensure Safe and Effective Transitions between Care								

	Transitions between Care Settings and Systems								
	Advance Coordinated and Integrated Health and Long-Term Services and Supports	LTSS	CMS (with States)	2a. Issue Informational Bulletin(s) or other policy guidance on AD/ADRD and dementia care to states, insurers, and medical and LTSS providers; and develop follow-up strategies to encourage adoption of recommendations in the Bulletin(s)					
		LTSS	CMS and ONC	2b. Develop standards, policies and programs that leverage health IT to: (i) Designate the caregiver in the care recipient's medical record, (ii) Designate caregiver status in caregiver's own medical record; and (iii) Encourage providers to connect people living with AD/ADRD and caregivers to disease education and LTSS.					
		LTSS	AHRQ and CMS	2c. Use existing measurement strategies and consider developing new measures to obtain feedback on (i) the seamlessness of integration between clinical care and HCBS; and (ii) the experience of caregivers to people living with AD/ADRD who are served by the healthcare system. Then, establish baselines and monitor change overtime in satisfaction with caregiver engagement and with the referral process to HCBS LTSS.					
		LTSS	HHS	2d. Address HIPAA issues through federal AD/ADRD education outlets to assure that HIPAA does not create a barrier to the provision of care by caregivers					
	Improve Care for Populations Disproportionately Affected by Alzheimer's Disease and for Populations Facing Care Challenges	LTSS	Congress	1a. Increase funding for the ACL Alzheimer's Program Initiative (ADPI) from \$23.5M to \$50M by 2025 to increase the number of individuals benefitting from tailored education and supports.					
		LTSS	Congress, ACL	1b. Increase funding for the Older Americans Act National Family Caregiver Support Program (NFCSP) from \$180M to \$360M by 2025.					
		LTSS		1c. Funding should be sufficient to evaluate the reach and benefits of these two programs.					
		LTSS	ACL & NADRC	1d. Coordinate validation of the Dementia Capability Assessment Tool to make available a valid and reliable tool for federal, state, and local HCBS providers, including those delivering the NFCSP.					
		Research	All federal and non-federal agencies involved in NAPA, academia, service providers, community partners	5. A major area of emphasis by all federal agencies involved in the National Plan should be the enhancement of recruitment efforts for research involving those with, or at risk of developing, AD/ADRA.					
Expand Supports for People with Alzheimer's Disease and Related Dementias and their Families	Ensure Receipt of Culturally Sensitive Education, Training, and Support Materials	LTSS	HHS Office of Minority Health	1f. Prioritize both AD/ADRD and dementia support programs that demonstrate cultural competency and language accessibility, to better address appropriate education and outreach to diverse communities that are disproportionately impacted by AD/ADRD.					
		LTSS	The VA and operating divisions within HHS such as CMS, ACL, CDC and HRSA	1g. Tailor programs to address the HCBS needs of a heterogeneous population living with AD/ADRD, their families and caregivers.					
	Enable Family Caregivers to Continue to Provide Care while Maintaining Their Own Health and Well-Being								
	Assist Families in Planning for Future Care Needs								
	Maintain the Dignity, Safety and Rights of Persons with AD/ADRD								
	Assess and Address the Housing Needs								
	Educate the Public								

Enhance Public Awareness and Engagement	Work with State, Tribal, and Local Governments to								
	Coordinate United States Efforts with Those of the Global Community								
Track Progress and Drive Improvement	Enhance the Federal Government's Ability to Track Progress	Research	Agencies involved in NAPA	1.b. Recommendations from these summits and the research community should be re-evaluated each year and translated into milestones by federal agencies involved in NAPA and relevant partners					
	Monitor Progress on the National Plan	Research	Agencies involved in NAPA	1.c. Federal agencies should monitor progress of research milestones as described in the summit recommendations.					