Milestones for Goals 2 and 3 of the National Alzheimer's Plan

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Goal 1 Milestones

1. **Prevent and Effectively Treat Alzheimer's Disease by 2025**
2. Enhance Care Quality and

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National Plan to Address Alzheimer's Disease: 2015 Update

NIH

U.S. Department of Health and Human Services

Alzheimer's Disease Research Implementation Milestones 2013-2025

Time Required	Research Implementation Area	Alzheimer's Disease (AD) Research Implementation Milestones	Success Criteria
2016-2018	Population Studies	1.A. Create research programs aimed at extensive molecular endophenotyping of existing, at-risk cohorts from longitudinal studies that are genetically, epigenetically, or otherwise at risk (e.g., due to cerebrovascular, metabolic, or neuroinflammatory compromise), as well cohorts and/or individuals who resist disease despite high genetic risk (e.g., Down syndrome, ApoE 4 homozygous, FAD mutation carriers). [2015 AD Summit: 1A, 2A, 2B, and 3A] This is consistent with the longer-term goals of the Precision Medicine Initiative.	Initiate at least three programs which include dense molecular phenotyping (genomic, epigenomic, proteomic, metabolomics, microbiome) and incorporate the collection of nontraditional data modalities using wearable sensors and mobile health technologies as dimensions of health and disease. These programs should include big-data infrastructure resources to ensure that the data are made available as a public resource and support for collection, storage, and rapid distribution of biosamples including brain tissue.
2016-2018	Population Studies	1.B. Incorporate environmental context in human studies (e.g., epidemiological cohorts) and in clinical trials, such as biomarkers of environmental exposure and geocodes, to assess personal and shared environmental contribution to AD pathogenesis and response to therapy. [2015 AD Summit: 3B and 3D]	Provide supplemental funding to at least six clinical research studies to explore the impact of environmental exposure on AD pathogenesis and/or response to therapy.
2016-2018	Population Studies	1.C. Create new cohorts to accelerate the identification of genomic variants and other risk and protective factors contributing to the heterogeneity and multifactorial etiology of dementia. [2015 AD Summit: 1B and 3C] This is consistent with the longer-term goals of the Precision Medicine Initiative.	Establish at least three new cohorts for extensive endophenotyping with participants of African, Native American, Asian, and mixed ancestry, e.g., Latinos as well as younger cohorts (midlife and younger participants). The phenotyping should include cognitive, behavioral, imaging, exposome measurements, multidimensional "omics" data, and multiple types of physiologic measurements that can be used for systems biology and gene-environment interaction studies. These programs should include big-data infrastructure resources to ensure that the data are made available as a public resource and support for collection, storage, and rapid distribution of biosamples including brain tissue.

1 July 2015

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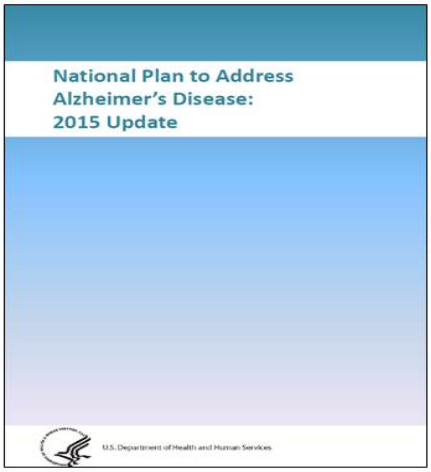
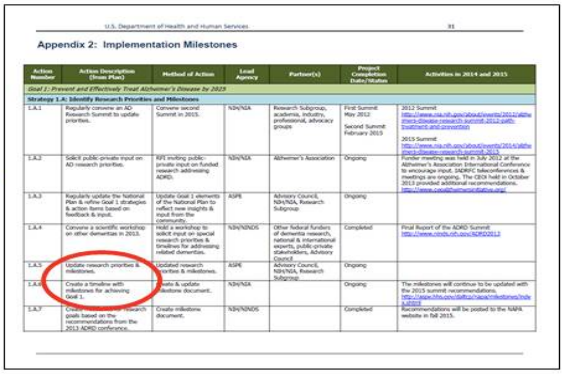
Goal 1 Milestones vs. Appendix 2





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Appendix 2: Implementation Milestones

Action Number	Action Description (from Plan)	Method of Action	Lead Agency	Partner(s)	Project Completion Date/Status	Activities in 2014 and 2015
Goal 1: Prevent and Effectively Treat Alzheimer's Disease by 2025						
Strategy 1.A: Identify Research Priorities and Milestones						
1.A.1	Regularly convene an AD Research Summit to update priorities.	Convene second Summit in 2013.	NIH/NIA	Research Subgroup, academia, industry, professional, advocacy groups	First Summit: May 2012 Second Summit: February 2013	2012 Summit http://www.nia.nih.gov/about/events/2012/alzheimers-disease-research-summit-2012-path-treatment-and-prevention 2015 Summit http://www.nia.nih.gov/about/events/2014/alzheimers-disease-research-summit-2015
1.A.2	Solicit public-private input on AD research priorities.	RFI inviting public-private input on funded research addressing ADRD.	NIH/NIA	Alzheimer's Association	Ongoing	Further meeting was held in July 2012 at the Alzheimer's Association International Conference to discuss the RFI responses. Discussions & meetings are ongoing. The CEO held in October 2013 provided additional recommendations. http://www.cdcalzheimersconference.org/
1.A.3	Regularly update the National Plan & refine Goal 1 strategies & action items based on feedback & input.	Update Goal 1 elements of the National Plan to reflect new insights & input from the community.	ASPE	Advisory Council, NIH/NIA, Research Subgroup	Ongoing	
1.A.4	Convene a scientific workshop on other dementias in 2013.	Convene workshop to solicit input on special research priorities & timelines for addressing related dementias.	NIH/NINDS	Other federal funders of dementia research, national & international experts, public-private stakeholders, Advisory Council	Completed	Final Report of the ADRD Summit http://www.ninds.nih.gov/ADRD2013
1.A.5	Update research priorities & milestones.	Updated research priorities & milestones.	ASPE	Advisory Council, NIH/NIA, Research Subgroup	Ongoing	
1.A.6	Create a timeline with milestones for achieving Goal 1.	Create & update milestone document.	NIH/NIA		Ongoing	The milestones will continue to be updated with the 2015 summit recommendations. http://aspe.hhs.gov/daltcp/napa/milestones/index.shtml
1.A.7	Create additional research goals based on the recommendations from the 2013 ADRD conference.	Create milestone document.	NIH/NINDS		Completed	Recommendations will be posted to the NAPA website in fall 2015.

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The Expert Workgroup

Soo Borson *University of Washington*	**Lisa Gwyther** *Duke University*
Malaz Boustani *Indiana University*	**Mary Jane Koren** *The Commonwealth Fund (retired)*
Kathleen Buckwalter *University of Iowa (emeritus)*	**Joanne Lynn** *Altarum Institute*
Lou Burgio *University of Alabama*	**Martha Roherty** *NASUAD*
Joshua Chodosh *New York University*	**Cheryl Phillips** *Leading Age*
Richard Fortinsky *University of Connecticut*	**Judah Ronch** *University of Maryland*
David Gifford *American Health Care Association*	**Claudia Stahl** *Society of Hospital Medicine*

BCG

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Why Create Milestones?

- The aim was NOT:
  - An official set of milestones to be voted on yea/nay by the Advisory Council
  - A benchmark by which to judge the activities under the National Plan
- The aim WAS:
  - Itemize and demonstrate – as the research milestones have done – the care and support milestones needed to achieve the Plan's 2025 goals
  - Stimulate and provoke thinking and ideas among the Advisory Council and the federal government
  - Prompt establishment of official milestones

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The Workgroup's Marching Orders

- Use the research milestones as a guide
- Work within the existing plan structure
- Establish milestones for each existing strategy
- Do not worry about process details
  - Regulation vs. statute
  - Existing funding capacity vs. additional funding
  - Federal vs. state
  - Whether realistic (at the start)

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The Workgroup's Marching Order to Itself

Incorporate and expand on existing federal efforts

- HRSA (Health Resources & Services Administration): Dementia primary care curriculum
- CDC: *Healthy People 2020* dementia objectives
- CMS (Centers for Medicare & Medicaid Services): Annual Wellness Visit detection of cognitive impairment
- ACL: ADSSP & alzheimers.gov

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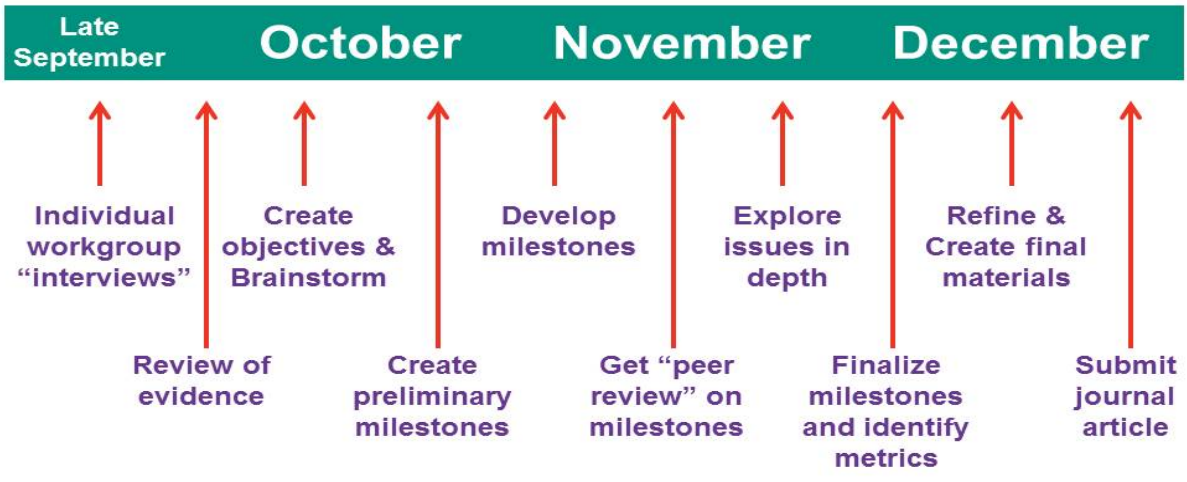
The Project's Timeline



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Where Should We Be in 2025?

Objective:

All persons living with Alzheimer's disease and related dementias, regardless of location, race, ethnicity, sexual orientation or socioeconomic class, should receive high-quality person/family-centered care by well-trained practitioners and workers from detection and diagnosis through end-of-life, across all health care and long-term services and supports settings and systems.

1. Prevent and Effectively Treat Alzheimer's Disease by 2025
2. **Enhance Care Quality and Efficiency**
3. Expand Supports for People with Alzheimer's Disease and Their Families
4. Enhance Public Awareness and Engagement
5. Improve Data to Track Progress

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Where Should We Be in 2025?

Objective:

People with Alzheimer's disease and related dementias, their families and their caregivers should have access to effective interventions and supports that expand their caregiving skillsets, enhance the meaningfulness and quality of their lives, and reduce the burden of Alzheimer's disease and related dementias.

1. Prevent and Effectively Treat Alzheimer's Disease by 2025
2. Enhance Care Quality and Efficiency
3. **Expand Supports for People with Alzheimer's Disease and Their Families**
4. Enhance Public Awareness and Engagement
5. Improve Data to Track Progress

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Building Milestones, Timelines, Success Criteria

Goal 2. Enhance Care Quality and Efficiency

Strategy 2A: Build a workforce with the skills to provide high-quality care

Milestone Sections

Build and retain a diverse dementia-capable workforce with the skills and capacity to provide high-quality care.

Milestones

- Identify and set targets for dementia-capable workforce needs at the state and county level.
- Increase dementia-capable workforce through financial incentives and competitive income.
- Increase dementia-specific technical education for direct care roles.
- Expand efforts to retain direct care workforce by building career pathways with supervisory and administrative support.
- Increase diverse dementia-capable workforce through financial incentives.

Ensure health care providers across settings are skilled and credentialed in dementia-specific care.

Ensure all direct care workers have proper training to effectively care for persons with ADRD and support their key family and friend caregivers in home, community, and institutional settings.

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Building Milestones, Timelines, Success Criteria

Goal 2. Enhance Care Quality and Efficiency

Strategy 2A: Build a workforce with the skills to provide high-quality care

Milestone Sections

Build and retain a diverse dementia-capable workforce with the skills and capacity to provide high-quality care.

Milestones

- Identify and set targets for dementia-capable workforce needs at the state and county level.

Milestone	Implementation detail	Success criteria
Identify and set targets for dementia-capable workforce needs at the state and county level*	Collect data on current dementia-capable workforce capacity and training needs at a state and county level, project growth in workforce demand, and estimate future shortages. Dementia-capable workforce should include primary care physicians, geriatricians, hospitalists, neurologists, psychiatrists, psychologists, nurses, social workers, health care administrators, and related disciplines, including physician assistants, nurse practitioners, and direct care workers. Collect information on current and projected levels of dementia-capable workforce diversity by location, race, ethnicity, and sexual orientation and set targets to increase representation of each underrepresented group over time. *Timeline: Short-term*	Data on number of state 2025 targets for dementia-capable workforce needs by setting and provider type, published by 2017
Increase dementia-capable workforce through financial incentives and competitive income	Create financial incentives (through tuition assistance, loan forgiveness, housing subsidies, and stipends) and ensure competitive income to increase the number of health care providers, including professionals and direct care workers, who pursue education and training to become dementia-capable, particularly those who make a commitment to work in underserved communities. *Timeline: Long-term*	Achieve dementia-capable workforce targets across settings and providers in 80% of states and counties by 2025
Increase dementia-specific technical education for direct care roles	Provide funding for dementia-specific direct care education for workforce positions that do not require a 4-year college degree for: 1) students pursuing education for direct care roles and 2) community / technical colleges, high school allied health career / technical programs, and on-line courses to provide the necessary education. *Timeline: Long-term*	Dementia-capable direct care workforce targets met in 80% of states and counties by 2025
Expand efforts to retain direct care workforce by building career pathways with supervisory and administrative support	Consult with national and state groups already devoted to developing direct care workforce career pathways and form a coalition of public-private partnerships to develop and implement career pathways that provide career ladders for direct care workers, offer employers a professional pipeline to aid in job recruitment and retention, and have supervisory and administrative commitment, especially in for profit facilities. Link workforce incentives (financial and not) to tenure in career pathway. *Timeline: Long-term*	Formal direct care career pathway established by 2020; dementia-capable direct care workforce targets met in 80% of states and counties by 2025

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Final Milestones Product

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Some Examples

- By 2018, 80% of 65+ believe ADRD is not normal sign of aging.
- By 2018, 80% of 65+ are comfortable discussing memory problems with provider.

Strategy 2B: Ensure timely and accurate ~~diagnosis.~~ appropriate

- Develop consensus on ADRD prevalence measurements and report diagnosis levels.
  - Develop consensus on ADRD prevalence measurement.
  - Gather and report ADRD diagnostic data.
- Raise public awareness of ADRD and encourage detection of cognitive impairment.
  - Support awareness campaigns to increase understanding and encourage cognitive assessments.
  - Activate faith- and community-based organizations to increase awareness and understanding.
- Raise physician awareness, and equip physicians to detect, diagnosis, and disclose.
  - Support education campaigns on timely detection, including on the Annual Wellness Visit.
  - Encourage providers to have conversations/assessments in annual routine visits for those at risk.
  - Modify reimbursement to ensure adequate time to assess impairment.
  - Identify successful practices with AWV and evaluate approaches to increase participattion.
  - Issue CMS subregulatory guidance on assessment tools to be used in AWV.
  - Evaluate/develop guidelines for populations more likely to require specialists to diagnose.
  - Equip and require physicians to disclose status in cases of clinically consequential impairment.
  - Incorporate cognitive changes, diagnostic information, and caregivers into electronic health record.
  - Record all cognitive changes, diagnostic information, and caregivers in all patient medical records.

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Some Examples

- By 2018, 70% of physicians are knowledgeable on importance of detection, diagnosis, and disclosure.
- By 2022, 90%.

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Some Examples

- By 2020, 38% of those diagnosed, or their caregivers, are aware of the diagnosis (consistent with *Healthy People 2020*).
- By 2025, 80%.

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Some Examples

Strategy 2E. Explore the effectiveness of new models of care for people with AD.

- Identify state of science and develop a research road map regarding best practices.

SHORT-TERM

- Build coalition of cross-disciplinary experts to convene at a research summit on ADRD care and support.
- Release public report on ADRD care and support evidence-based interventions.
- Convene group annually to review most current ADRD care and support research.
- Ensure geriatric research on general medical conditions incorporates persons with ADRD.
- Provide ADRD Care and Support interventions research funding, informed by Annual Summit.

MEDIUM-TERM

- Identify and evaluate quality outcomes and cost effectiveness of interventions.
- Provide funding for community-based pragmatic and adaptive research methods in interventions.
- Provide funding to stimulate and support innovative learning for new models of care for persons with ADRD.
- Provide funding for ADRD care and support translation studies.
- Provide funding for comparative effectiveness studies to identify most effective supportive interventions.

LONG-TERM

- Provide funding to roll out interventions proven effective, and adaptive throughout community settings.

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Some Examples

Strategy 3D. Maintain the dignity, safety and rights of people with AD.

***[REVISED]* Strategy 3D. Maintain the dignity and rights of people with AD.**

- Ensure legal, financial, and social services are equipped to serve and protect persons with ADRD. *[8 milestones]*
- Reduce inappropriate use of antipsychotic and other psychotropic drugs for persons with ADRD in home, community, and institutional based settings. *[3 milestones]*
- Provide funding for community development and scale up of evidence-based meaningful activities for persons with ADRD. *[1 milestone]*

***[NEW]* Strategy 3F. Support communities that are inclusive and safe for persons with ADRD.**

- Ensure persons with ADRD are safe and cared for in emergency situations. *[5 milestones]*
- Ensure local community members who come in contact with persons with ADRD receive basic dementia training. *[2 milestones]*
- Ensure safe transportation options for persons with ADRD. *[2 milestones]*

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QUESTIONS
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