



The Healthy Brain Initiative:

The Public Health Road Map for State and National Partnerships, 2013–2018

Interim Progress Report



**Centers for Disease
Control and Prevention**
National Center for Chronic
Disease Prevention and
Health Promotion



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Introduction

Formal recognition of Alzheimer's disease (AD) as a public health issue, and the genesis of the Centers for Disease Control and Prevention's (CDC) active involvement in this issue, dates back to 2005. Research over the previous decade had begun documenting the growing public health burden of AD and other dementias. AD is now the sixth leading cause of death for all ages; one out of every 3 older adults dies with dementia. Twice as many Americans fear the loss of mental capability more than they do diminished physical ability. In 2010, the total estimated cost of dementia was between \$159 and \$215 billion (Hurd, Martorell, Delavande, Mullen, & Langa, 2013).

Concern for stemming this public health crisis spurred a series of collaborative national efforts among numerous private, non-profit, and governmental agencies (see *Notable Milestones*). One of the most recent was an 18-month strategic planning effort led by CDC and the Alzheimer's Association to delineate more clearly the role of public health in addressing and promoting cognitive function. The resulting report—*The Healthy Brain Initiative: The Public Health Road Map for State and National Partnerships, 2013-2018*—is the second in a series of road maps for cognitive health. Two years have passed since this second Road Map (2013) was finalized, affording an ideal opportunity to take stock of what has been accomplished and what challenges remain. Towards that end, we offer this progress report to:

- Convey CDC's priorities for years 2013-2015 of the Healthy Brain Initiative to date
- Highlight accomplishments and ongoing activity in these priority areas for 2013-2015
- Share CDC's currently planned priorities for moving the Healthy Brain Initiative forward in 2016-2018
- Reflect on opportunities for future progress while ensuring that the Healthy Brain Initiative remains flexible and responsive to new and emerging issues.

Notable Milestones in *The Healthy Brain Initiative*

2005: Congress appropriated funds to create an AD segment within CDC's Healthy Aging Program, subsequently called The Healthy Brain Initiative.

2007: CDC partnered with the Alzheimer's Association to create the first in a series of road maps to integrate cognitive health and functioning into the routine practice of public health: [The National Public Health Road Map to Maintaining Cognitive Health](#).

2011: CDC published a progress report that captured collective accomplishments toward achieving the objectives in the Road Map (2007) and activities to be pursued over the next five years, contingent on funding and CDC priorities: [The CDC Healthy Brain Initiative: Progress 2006-2011](#).

2012: [The National Plan to Address Alzheimer's Disease](#) was issued by the Department of Health and Human Services (DHHS), as mandated by the National Alzheimer's Project Act (NAPA), documenting current federal activities and initial recommendations for priority actions to expand, eliminate, coordinate, or condense these activities across all federal agencies.

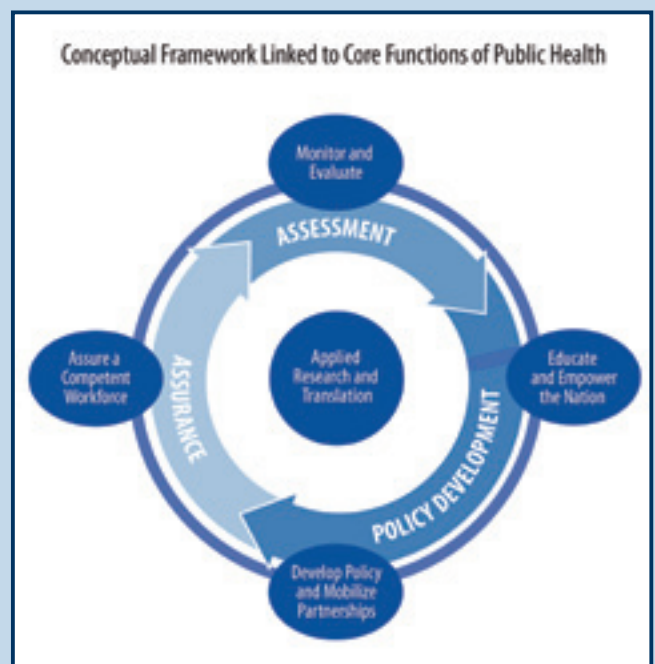
2013: CDC and the Alzheimer's Association partnered to produce the second road map, outlining specific priority actions for public health and for building on outcomes of the initial road map: [The Healthy Brain Initiative: The Public Health Road Map for State and National Partnerships, 2013-2018](#).





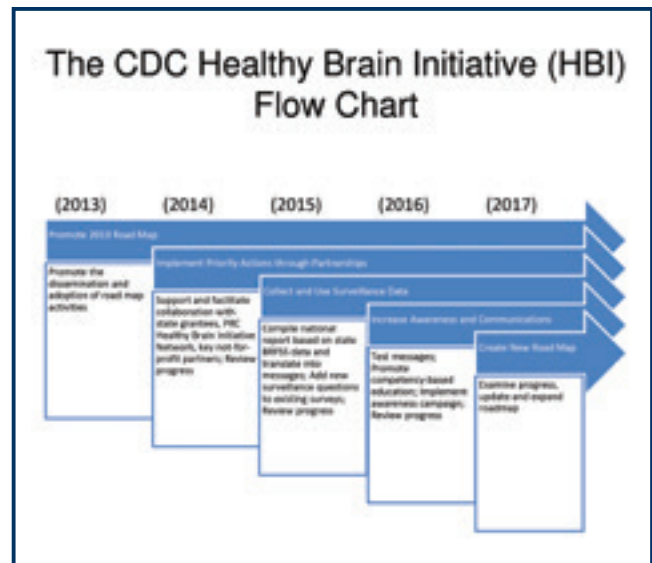
Background

The broad group of stakeholders involved in designing the second Road Map (2013) coalesced around actions in four traditional domains of public health: monitor and evaluate; educate and empower; develop policy and mobilize partnerships; and assure a competent workforce. These domains align with the three core functions of public health: assessment, policy development, and assurance. At the core is applied research and translation activities. Public health agencies and private, non-profit, and governmental partners at the national, state, and local levels were encouraged to collaborate on actions that best fit their missions, needs, interests, and capabilities.



CDC devoted the first year of implementing the Road Map (2013) to promoting its framework and gaining adoption of priority actions at national, state, and local levels. As an example, CDC sponsored a podcast, [Actions States and Communities Can Take to Address Cognitive Health](#), to highlight the important roles that states and communities can play in addressing cognitive health as part of overall health.

Subsequent work concentrated on two domains: *develop policy and mobilize partnerships*, with an emphasis on implementing priority actions through partnerships with national and state organizations, CDC’s Prevention Research Centers (PRCs) program, CDC’s Healthy Brain Research Network, and other key non-profit partners; and *monitor and evaluate*, focusing primarily on the collection and use of surveillance data. While CDC has done some work thus far on *assure a competent workforce* and *educate and empower*, these domains will be emphasized more directly in 2016 and 2017. In addition, work will begin to design a third Road Map for 2018 and beyond.



The graphic displays key areas of focus since the release of the Road Map.

The Road Map belongs to many agencies and reinforces the value of combining forces and aligning efforts with organizational missions and capacities. CDC recognizes the many organizations and individuals who have been instrumental in laying the policy framework for the Healthy Brain Initiative, and for pursuing its priority actions with energy and conviction. In tribute to the power of partnerships, this interim progress report highlights those areas in which CDC is the designated lead and shares examples of partnering agencies’ achievements. It conveys the multifaceted accomplishments that have been realized and the ongoing work that is underway, and sets the stage for future work.



Accomplishments

The Road Map (2013) outlines how state and local public health can promote cognitive functioning, address cognitive impairment for individuals living in the community, and help meet the needs of family members who serve as care partners in home settings. It is intended to be a dynamic document, able to incorporate new knowledge and lessons learned through research and practice. It stresses the fundamental importance of partnerships and collaborative action as key hallmarks of success.

This section highlights activities and their outcomes aimed at accomplishing the 2013-2018 Road Map priority actions for CDC in each of the four Healthy Brain Initiative (HBI) domains. The priority actions are labeled exactly as they are in the Road Map, with the supporting rationale for their importance to public health repeated to provide context. The accomplishments recognize the power of leveraging CDC resources by providing funding and technical assistance to support national and state agencies invested in the goals of the Healthy Brain Initiative. Since partnerships are essential to advancing the work of all domains, examples of products and outcomes resulting from CDC support of other key agencies are described throughout the document.

CDC ROAD MAP PRIORITY ACTIONS

Surveillance, defined as the “ongoing, systematic collection, analysis, and interpretation of health-related data,” is a fundamental tool of public health. Its methodologies have been applied for decades to numerous causes of disease, injury, disability, and death. Incorporating measures concerning cognition and caregiving into existing surveillance, particularly CDC’s state-based Behavioral Risk Factor Surveillance System (BRFSS), can help further understand the public health burden, inform public health policy and strategies, and monitor quality of life.

- **M-01** Implement the Behavioral Risk Factor Surveillance System’s cognitive impairment and caregiver modules.
- **M-02** Use surveillance data to enhance awareness and action in public health programming (e.g., link Behavioral Risk Factor Surveillance System questions on cognition to health-related quality of life or falls prevention).
- **M-04** Engage national organizations and agencies to develop standardized questions that can be used at the national, state, and local levels to track awareness and perceptions about cognitive health and impairment, including decline in cognitive functioning.

► Implementing Behavioral Risk Factor Surveillance System Modules

Working with numerous partners including the states, CDC revised the Behavioral Risk Factor Surveillance System (BRFSS) Cognitive Decline and Caregiver Optional Modules for use in 2015 and 2016.

Annually, each state decides which optional modules they will add to their survey for a given year. In 2015, 35 states added the Cognitive Decline module and 24 states added the Caregiver Module. Support to states to include these modules was made possible through CDC funding to the Alzheimer’s Association.

CDC also developed supplemental resources to support these BRFSS Optional Modules, including [Frequently Asked Questions](#) and a [BRFSS statistical brief providing guidance for analyzing 2012 data from the Cognitive Decline Module](#).

(See [HBI Domain: Develop Policy and Mobilize Partnerships](#) in this report for further discussion of the CDC-Alzheimer’s Association partnership.)

State-level data derived from the modules have been used to inform state plan development and implementation and to create awareness and education about cognitive decline and caregiving through webinars, proclamations, and media events. Additionally, the Alzheimer’s Association educated its staff about using surveillance data to communicate to broad audiences about these issues, and to shape planning and programmatic priorities.

Sampling of States' Use of BRFSS Data

To increase public and professional awareness

- **Georgia** incorporated cognitive decline and caregiver data into a dementia education webinar for physicians co-sponsored by the Georgia Department of Public Health and the Alzheimer's Association, Georgia Chapter.
- **Indiana** featured caregiver data in the state's BRFSS [newsletter](#) disseminated to the public health community, state primary care association, and other public health and healthcare partners.
- **West Virginia** highlighted cognitive decline and caregiver data in [media outreach](#) to increase public awareness.

To educate policymakers and decision makers

- **Kentucky** used cognitive decline data to draw attention to the barriers surrounding both self-care and caregiver assisted care, helping to address the state's co-morbidity rates as a focal point for state leaders.
- **Louisiana** used cognitive decline data to engage decision makers and insurers in discussions about Alzheimer's disease and related dementias.

To shape strategic planning process

- **Georgia** used cognitive decline and caregiver data to inform Georgia's state Alzheimer's disease planning process. The [Georgia Alzheimer's and Other Dementias State Plan](#) was released in July 2014.
- **Hawaii** used cognitive data in the development of the [Hawaii 2025: State Plan on Alzheimer's Disease & Related Dementias](#).
- **Indiana** presented cognitive data to the state's Alzheimer's Disease Plan task force and disseminated a fact sheet with BRFSS data to a wide group of decision makers.
- **Mississippi** cognitive decline and caregiver data helped inform the state Alzheimer's disease planning process in developing [Mississippi's Strategic Plan for Alzheimer's Disease and Related Dementias](#).
- **Oregon** used cognitive decline and caregiver data in the decision-making process for including dementia as a topic for Oregon's Healthy Aging Summit, a part of the state's Healthy Aging Initiative.
- **Wisconsin** used cognitive decline and caregiver data to inform decisions about developing an Alzheimer's State Plan and to increase awareness among decision makers at the state's Dementia System Redesign Plan Summit in 2013. BRFSS data were subsequently included in the [Wisconsin Dementia Care System Redesign: A Plan for a Dementia-Capable Wisconsin](#).



To inform program and policy design

- **Missouri** used cognitive decline and caregiver data to help build the Seniors Count campaign, designed to increase services at the local level for seniors. The state also incorporated BRFSS data into presentations aimed at advancing early detection and increasing awareness among local public health agencies; webinars for state employees and public health staff; and other educational programs.
- **West Virginia** utilized cognitive decline and caregiver data to develop strategies for rural initiatives that enhance support for people living alone and experiencing increased confusion or memory loss, and facilitated efforts by the Partnership for Elder Living to develop an ongoing task force that assesses and plans for housing issues related to the state's aging population.

► Using Surveillance Data to Enhance Awareness and Action

A critical aspect of public health surveillance is the analysis and use of data to increase awareness and inform public health action. Using surveillance data from the 2011 BRFSS Cognitive Decline Module Module, CDC released four publications:

- The initial article, published in the MMWR, shared the first available data for 21 states about [self-reported increased confusion or memory loss and associated functional difficulties among adults aged ≥60 years](#). Among other findings, the article highlighted the need for greater communication between individuals concerned about increased confusion or memory loss and their healthcare providers. A diagnosis for dementia, including Alzheimer's disease, is often missed or delayed. Talking with a healthcare provider about cognitive changes is important to begin determining why an individual may be experiencing increased confusion or memory loss.
- A second article, [Demographic and health status differences among people aged 45 or older with and without functional difficulties related to increased confusion or memory loss](#), expanded what we know about the general public's perceptions about increased confusion or memory loss and its relationship to other physical and mental health issues.
- Two additional articles examined increased confusion and memory loss (ICML) in households, highlighting the magnitude of the problem of cognitive decline and painting a clearer picture of the characteristics and needs of those experiencing cognitive decline. In [Increased confusion and memory loss in households](#), CDC authors reported



that individuals or others within their household may notice changes in memory or confusion over time and estimated that 4 million households studied have a member with ICML, potentially affecting more than 10 million people in these 13 states.

- [Proxy reports about household members with increased confusion or memory loss](#) describe primary respondents' reports about another person in their household experiencing ICML. The results showed that about 3% (n = 3,075 households) of primary respondents reported living with a household member with ICML; 75% of these household members with ICML needed some type of assistance, and nearly 60% had discussed ICML with a healthcare professional.

Two state-specific briefs shared data reported by 21 states from the BRFSS Cognitive Decline Module and implications for public health programs and policies: [self-reported increased confusion or memory loss and co-occurring conditions among adults aged 60 or older \(2011 BRFSS data\)](#) and [self-reported increased confusion or memory loss \(ICML\) and discussions with healthcare providers among adults aged 45 years or older \(2012 BRFSS data\)](#).

In addition to publications, CDC created two podcasts based on BRFSS data. [Memory Maintenance](#) discusses the difficulties associated with self-reported confusion or memory loss among adults aged 60 or older (2011 BRFSS data); and in [Increased Confusion or Memory Loss](#), CDC introduces 2012 survey data from 21 states showing that about 1 in 8 people aged 60 or older report some amount of confusion or memory loss.

► Tracking Awareness and Perceptions about Cognitive Health and Impairment

To help inform national and international education efforts about cognitive health and impairment, investigators from CDC's Healthy Aging Research Network conducted a review of studies published since the first Road Map in 2007, examining the public's perceptions about risk and protective factors related to cognitive health and impairment. (Friedman et al, 2015)

Being able to identify what measures are being used to assess public perceptions and attitudes towards cognitive health, cognitive impairment, and caregiving will help prevent duplication and aid in comparisons across future studies. As a result, CDC funded a project with the New York University PRC to identify and develop a compendium of identified questions or measures. Project investigators are now creating an electronic database of all relevant measures identified with copies of the measures (copyright/usage agreements, permitting), psychometrics, and hyperlinks to relevant articles for widespread dissemination through the PRC and Healthy Brain Research Network.

CDC ROAD MAP PRIORITY ACTIONS

At the same time that surveillance is conducted and suitable measures of cognitive health for public health surveillance are developed or refined, the effects of cognitive impairment on economic and social systems need to be monitored. Assessments can help clarify the cost burden to states and communities as well as the important health inequities affecting the lives of people with cognitive impairment and their care partners.

Research has focused on the needs of individuals with cognitive impairment and their care partners as well as on the effectiveness of various interventions on their health and quality of life. This information continues to be a critical resource for developing the evidence base for intervention. Updated systematic reviews that analyze available research and practice information and disseminate conclusions are invaluable for public health use in designing effective programs and policies.

- **M-05** Assess information about the economic impact of dementia, including Alzheimer's disease, on states and communities and disseminate the findings.
- **M-07** Conduct a review of the literature on co-occurring chronic conditions and dementia, including Alzheimer's disease, to understand the effect of dementia on various outcomes such as depression, disease management, morbidity, and mortality.
- **M-09** Conduct a national-level literature review to identify public health interventions that are effective in decreasing preventable hospitalizations among persons with dementia, including Alzheimer's disease, and disseminate findings.
- **M-10** Conduct a national-level review of caregiver programs and policies consistent with The Guide to Community Preventive Services methodologies.

► Forecasting Economic Cost of Dementia

To better understand the economic costs associated with Alzheimer's disease and dementia, CDC funded the University of Washington PRC to examine different economic models for estimating community and inpatient care, as well as the societal costs associated with losses of productivity and quality of life by persons living with Alzheimer's disease and their caregivers. Researchers are conducting a review of the literature and will analyze data from a large nonprofit healthcare system to help states and localities better calculate and forecast dementia care costs.

► Understanding Dementia and Co-occurring Chronic Conditions

Multiple chronic conditions pose a significant and increasing burden on the health of Americans (Department of Health and Human Services, 2010). In response to [Multiple Chronic Conditions: A Strategic Framework](#), CDC funded a series of projects examining dementia and co-occurring chronic conditions. The first project, conducted by the University of Washington PRC, examined the effects of dementia, multiple chronic diseases, and geriatric syndromes on health outcomes such as daily functioning, quality of life, and survival. Phase 1 included a comprehensive review, guided by a panel of experts, of the published literature on multiple chronic conditions. This review described current issues in

managing dementia and chronic diseases, and identified gaps where research is needed. In Phases 2 and 3, researchers identified data sources and conducted a secondary data analysis on cardiovascular health.

The investigators found a number of high-quality data sets to support collaborative studies of the effects of dementia or other significant cognitive impairment on chronic conditions. (Bell et al, 2014)

One of the major areas of needed research was in depression. As a consequence, the investigators examined whether depression prevalence, incidence, and severity are higher in individuals with dementia than those with mild cognitive impairment or normal cognition. (Snowden et al, 2014)

Several other analyses are ongoing. One secondary data analysis examines the influence of dementia on health service utilization and costs associated with patients with diabetes or hypertension. A second examines the influence of cognitive impairment on falls in women with a history of falls.

Expanding on this work, CDC funded Case Western Reserve University to study clusters of chronic conditions (i.e., co-occurring chronic conditions, functional limitations, and geriatric syndromes) across individuals with no, mild, and moderate/severe cognitive impairment. This project will also include a review of literature examining use of cognitive assessment tools in ambulatory healthcare settings to help promote chronic disease support and management.

► Reducing Preventable Hospitalizations Among Persons with Dementia

To help inform the current state of evidence-based strategies related to the Healthy People “Dementias, including Alzheimer’s disease” objective, “to reduce the proportion of preventable hospitalizations in persons with diagnosed Alzheimer’s disease and other dementias,” CDC funded a review of interventions related to dementia and reducing preventable hospitalizations. Researchers from the University of Washington, Johns Hopkins University, CDC, and the Directors of Health Promotion and Education conducted a systematic literature review and found 10 studies that met inclusion criteria. Most included hospitalizations as a secondary outcome and only 1 intervention, involving multidisciplinary assessment and management, was found to have an effect on hospitalizations. (Phelan, Debman, Anderson, & Owen, 2014)

► Reviewing Caregiver Programs and Policies

[The Community Guide to Preventive Services](#) provides information for public health practitioners about which interventions are effective for specific populations and, in some cases can help estimate the cost effectiveness of the program and potential for return on investment. CDC, in partnership with the Association of State and Territorial Health Officials (ASTHO), is supporting a Community Guide for Preventive Services systematic review on caregiver strategies. Investigators at the University of California at Berkeley and the University of Washington are leading the review.

CDC ROAD MAP PRIORITY ACTIONS

The Healthy Brain Initiative is committed to integrating cognitive health into the broad spectrum of public health work and focuses on quality of life for those with cognitive decline. To the extent possible, cognitive health needs to be considered in the context of strategic planning efforts for multiple chronic conditions and other issues related to aging and caregiving. In addition, dedicated state plans for Alzheimer's disease and other dementias can be considered as part of that larger picture.

- **P-01** Collaborate in the development, implementation, and maintenance of state Alzheimer's disease plans.
- **P-02** Integrate cognitive health and impairment into state and local government plans (e.g., aging, coordinated chronic disease, preparedness, falls, and transportation plans).
- **P-03** Promote incorporation of cognitive health and impairment into state and local public health burden reports.

► Using Public Health Approaches to Plan and Implement Programs – A Cooperative Agreement with the Alzheimer's Association (2010-2015)

CDC has funded the Alzheimer's Association through a cooperative agreement to plan and implement public health strategies related to Alzheimer's disease, cognitive impairment, and cognitive health. The partnership has resulted in increased utilization of public health strategies and tools by the Alzheimer's Association and their chapters, in part due to technical assistance provided by CDC. [The Public Health Alzheimer's Resource Center](#), on the Alzheimer's Association website, reflects the extensive scope of the partnership and its activities.

One of the major accomplishments of the national partnership is the development of state-level partnerships for Alzheimer's Association chapters and public health agencies to implement action items from the Road Map and to collect and disseminate data from the BRFSS Cognitive Decline and Caregiving modules. As an example, in 2013, five chapters were chosen by the Alzheimer's Association to pilot Road Map implementation in the states of Georgia, Maine, Minnesota, Oregon, and Wisconsin. The chapters met monthly in a community of practice and shared lessons learned. Additionally, the Alzheimer's Association selected six priority Road Map action items for all of their chapters nationwide to focus implementation efforts in 2014-2015. The Alzheimer's Association created a toolkit to provide chapters with background information and strategies for moving forward, and extensive training was conducted for chapter staff at their annual meeting.

Priority Road Map Action Items for Alzheimer's Association State Chapters in 2014-2015

Monitor and Evaluate

- Implement the Behavioral Risk Factor Surveillance System's cognitive impairment and caregiver modules. (M-01)
- Use surveillance data to enhance awareness and action in public health programming. (M-02)

Educate and Empower

- Encourage public health entities to provide links on their Web sites to local, state, and national dementia resources, including those specific to Alzheimer's disease and caregiving, such as www.alzheimers.gov. (E-03)
- Promote advance care planning and advance financial planning to care partners, families, and individuals with dementia in the early stages before function declines. (E-07)
- Promote appropriate partnerships and strategies to educate and increase local participation in clinical trials and studies on cognitive health and impairment. (E-08)

Assure a Competent Workforce

- Develop introductory, basic materials for public health professionals on cognitive health and impairment to help them understand their role. (W-02)

Due in large part to activities funded through the cooperative agreement, the BRFSS Cognitive Decline and Caregiving Optional Modules have been included in 50 state and territorial BRFSS surveys between the years 2011-2015. Using data analyzed by CDC, the Alzheimer's Association [published state-specific fact sheets](#) for use in disseminating the 2011 and 2012 data. Alzheimer's Association's Chapters continue to educate state and local public health stakeholders and local media about the findings of the BRFSS data and implications for their states. (See HBI Domain: Monitor and Evaluate in this report for a sampling of how states have used the data.)

The Alzheimer's Association also sponsored a series of webinars to highlight data and other road map action items.

- The Alzheimer's Association partnered with the Administration for Community Living (ACL) to present a webinar: *Brain Health as You Age*. The webinar featured the community education resource by the same name and discussed how public health could use it to educate older adults and others in a community.
- The National Council on Aging (NCOA) and the Alzheimer's Association conducted a webinar: *Chronic Disease Self-Management Programs: Relevance for Persons with Dementia*. The webinar recording and slides may be accessed from the [NCOA website](#).
- The Association for State and Territorial Health Organizations (ASTHO) held [Using Data for Action to Promote the Health of Older Adults](#), discussing the connection between chronic disease and cognitive health and providing strategies for using data to shape public health programs and policies that promote older adults' health.

- The Alzheimer's Association hosted a webinar entitled *Public Health Implications of the IOM Report on Cognitive Aging*, to discuss the Institute of Medicine report, [Cognitive Aging: Progress in Understanding and Opportunities for Action](#), and highlighting actions for the public health community.
- [The White House Conference on Aging](#) hosted a webinar about Alzheimer's disease that focused on cognitive health, federal efforts to promote healthy aging, and tools that public health practitioners can use to effectively address Alzheimer's disease.

► Partnering with Association for State and Territorial Health Organizations (ASTHO) to Integrate Cognitive Health into State Plans

In 2014, CDC formally partnered with ASTHO to promote policies and programs related to cognitive health and impairment. From February through June 2014, ASTHO sponsored a series of [Healthy Aging Webinars](#) on topics related to the Road Map:

- Healthy Brain Initiative Road Map and Role of State Leaders
- Cognition and Injury Prevention
- Cognition and Physical Activity
- Program and Policy Considerations for Supporting Caregivers
- Preparedness Planning for Older Adults with Cognitive Impairment

In addition, ASTHO developed and disseminated a series of public health and aging Issue Briefs and Case Studies to highlight relevant topics and successful state efforts that promote healthy aging.

- [Issue Brief: How State Health Agencies Can Support Healthy Aging](#)
- [Issue Brief: Program and Policy Considerations for Supporting Caregivers](#)
- [Issue Brief: Support and Services at Home - A Care Management Model Utilizing Community Health Workers](#)
- [California: The Dementia Care Network Model: Enhancing Caregiving for Persons with Alzheimer's and Other Dementias in Culturally Diverse Groups](#)
- [Georgia: Empowering Caregivers and Care Receivers with Benjamin Rose Institute Care Consultation](#)
- [Maine: Improving Dementia Care through the Savvy Caregiver Program](#)
- [Michigan: Encouraging Physical Activity Among Older Adults with EnhanceFitness](#)

Sampling of Outcomes from ASTHO Participation in the Healthy Aging/Public Health Learning Community

The **Georgia** Department of Public Health developed an Alzheimer's and Related Dementias Registry web portal.

The **New Mexico** Department of Health partnered with the National Indian Council On Aging, Area Health Education Center, Aging and Long-Term Services Department, Indian Area Agency on Aging, and the Alzheimer's Association, New Mexico Chapter, to increase available trainings on Savvy Caregiver for Indian Country.

The **Oregon** Department of Health included healthy aging related goals as part of the Oregon Public Health Division's 2015–2019 strategic plan in an effort to improve quality of life and increase years of healthy life for all Oregonians.

► Creating the Healthy Brain Research Network

In 2014, CDC established the Healthy Brain Research Network (HBRN) to strengthen linkages between PRCs and the public health and aging service professionals in states and communities. Its specific mission is to: better understand attitudes and perceived changes in cognitive functioning over time through public health surveillance; build a strong evidence base for communication (e.g., messaging) and programmatic interventions to improve or maintain cognitive function; and help translate the evidence base into effective public health programs and practices in states and communities. The PRCs participating in the Network include: University of Washington Health Promotion Research Center (Coordinating Center); Oregon Health and Science University Center for Healthy Communities; University of Arizona PRC; University of Illinois at Chicago; University of Pennsylvania PRC; and University of South Carolina PRC.

One of the Network's foundational activities is to develop a public health research agenda consistent with Road Map (2013) actions and aligned with select recommendations of the Institute of Medicine (IOM) Report on [“Cognitive Aging: Progress in Understanding and Opportunities for Action.”](#) The network also carries out several fundamental roles for the Healthy Brain Initiative. First, each network will work with designated fellows and diverse student populations to educate them about cognitive health and impairment. Additionally, the network structure will help disseminate information, create and promote innovative approaches, and translate evidence and findings into public health practice. Finally, the PRCs will provide technical assistance on select areas regarding state Alzheimer's disease plans and help ensure that states incorporate cognitive health and impairment into public health initiatives.

► Supporting Opportunity Grants to State Chronic Disease Programs (2013-2015)

With CDC funding, the National Association of Chronic Disease Directors (NACDD) awarded [one-year opportunity grants in 2014](#) to five states: Arizona, Hawaii, Illinois, Minnesota, and Wisconsin, and to Puerto Rico. The grants were designed to support state and territorial public health departments and their partners in implementing one or more priority action items from the Road Map (2013).

Building upon success from the first round of grants, NACDD used CDC funding to provide opportunity grants in 2015 to Puerto Rico and the following six states: Arizona, California, Hawaii, Illinois, Mississippi, and Oregon. [These grants](#) broadened the grantees' partnerships to include projects with the PRCs. They will focus on initiating, expanding, and/or continuing activities addressing one or more priority action items from the Road Map and sustaining these efforts beyond the funding period.

Sampling of Accomplishments from NACDD Grants

Two states, **Hawaii** and **Illinois**, already had state plans in place when applying for their NACDD opportunity grants. The Hawaii Executive Office on Aging, part of the Hawaii Department of Public Health, used its grant to partner with the University of Hawaii and create an evaluation matrix and logic model. These efforts helped inform the Hawaii State Plan 2015 update and provided crucial groundwork for Hawaii's future efficiency and success in plan implementation.

Similarly, the **Illinois** Department of Public Health had published its Illinois Alzheimer's Disease State Plan in January 2014. Partners were eager to prioritize recommendations and identify next steps, which led to the Illinois Department of Health and Illinois Public Health Institute designing a highly interactive consensus-based facilitation process. The approach included multiple interventions for providing information, soliciting feedback, discussing options, and ultimately reaching consensus on a manageable set of priorities to advance action and implement recommendations.

The **Puerto Rico** Department of Health was fortunate to have an Alzheimer's disease center and a registry created by law. Until 2015, however, there was no state plan to help guide the efforts of many committed and interested partners. Thanks to the NACDD grant, Puerto Rico was able to develop its first Alzheimer's disease plan and use it to guide partners' efforts to attend to the needs of people with Alzheimer's disease and diminish the burden of this disease.

CDC ROAD MAP PRIORITY ACTIONS

Efforts at the national level to integrate cognitive health into ongoing planning and policy initiatives offer opportunities to engage additional national and state partners. Adopted national health objectives can be leveraged by states, and synergies can be gained by examining potential policies in a concerted fashion.

- P-04 Integrate Healthy People 2020 objectives on “Older Adults” and “Dementias, including Alzheimer’s disease” topic areas into state-based plans.
- P-05 Engage national and state organizations and agencies to examine policies that may differentially impact persons with dementia, including Alzheimer’s disease.

► Integrating Dementia into Healthy People 2020

CDC co-chairs the Healthy People 2020 (HP 2020) topic area and related objectives on “Dementias, Including Alzheimer’s disease” (DIA) and has worked with several investigators to obtain and analyze data for these objectives. CDC’s Healthy Aging Program, in collaboration with CDC’s National Center for Health Statistics (NCHS) and National Institute on Aging/National Institutes of Health (NIA/NIH), presented current data to the HP 2020 Federal Interagency Work Group meeting. As a result, the objectives were moved from “developmental” to “baseline” and data were shared on the [Healthy People website](#). CDC also led the effort to create [two national snapshots](#) for NCHS for the DIA objectives that are posted on HP 2020 website.

In addition, CDC joined NIA/NIH, the Administration for Community Living, and the Centers for Medicare and Medicaid Services in the [HP 2020 Progress Review on “Older Adults, and Dementias, Including Alzheimer’s Disease.”](#)

► Developing Dementia-friendly Communities

The Healthy Brain Initiative supports the creation of [dementia-friendly communities](#) as an effective strategy for enhancing quality of life for individuals with cognitive decline. In these communities, residents, agencies, businesses, and service providers are learning about dementia through education and awareness efforts, and are assisting people with the condition and their caregivers as they go about their daily lives. CDC funding through NACDD allowed the State of Wisconsin to incorporate lessons learned from local dementia-friendly community projects into a [tool kit](#) of promising practices. Collaborators in Wisconsin’s Healthy Brain Initiative Project included the Department of Health Services, the Alzheimer’s Association, Southeastern Wisconsin Chapter, and AARP Wisconsin.

CDC ROAD MAP PRIORITY ACTIONS

Public health plays an important role in informing the nation about the causes of disease, injury, and disability; ways to prevent and treat them; and strategies to preserve overall quality of life. This role is critical for both physical and cognitive health issues. It is important to raise public awareness and improve access to available information and resources.

Helping the public take recommended actions to promote cognitive health requires clear and consistent messages about what is known—and what is yet to be discovered. Robust and reliable coordination of messages will minimize confusion and ensure that public, private, and non-profit organizations serve their respective constituencies effectively and reliably.

- E-01 Identify and promote culturally appropriate strategies designed to increase public awareness about dementia, including Alzheimer's disease, to reduce conflicting messages, decrease stigma, and promote early diagnosis.
- E-02 Create awareness by contributing public health information and data about cognitive health and impairment to national reports and partners.
- E-03 Encourage public health entities to provide links on their Web sites to local, state, and national dementia resources, including those specific to Alzheimer's disease and caregiving, such as www.alzheimers.gov.
- E-04 Coordinate national and state efforts to disseminate evidence-based messages about risk reduction for preserving cognitive health.

► Creating Culturally Appropriate Education

CDC provides technical assistance and consultation to federal agencies dedicated to healthy aging. As one example, a CDC representative serves on the Administration for Community Living's (ACL) Technical Expert Board (TEB). The TEB provides expertise on ACL's public education campaign to help older adults and their care partners among diverse racial and populations better understand aging and cognitive health.

Sampling of State Educational Activities

Education about dementia among gay, lesbian, bisexual, and transgender (GLBT) community members has been possible through a partnership between the Alzheimer's Association, Maine Chapter, and Services & Advocacy for GLBT Elders Maine (SAGE ME). The two organizations developed and provided training to health, aging, and community service professionals and community members. Additionally, the **Maine** Chapter now includes information for GLBT community members in their chapter training programs.

Soon after the **Minnesota** Department of Health released the *Advancing Health Equity in Minnesota: Report to the Legislature*, the Alzheimer's Association, Minnesota-North Dakota Chapter, provided educational outreach about the differential impact of Alzheimer's disease on Hispanic and African American communities in the State. These efforts helped inform decisions to create and fund a new program in the Minnesota Department of Health focused on outreach to African Americans, African-born residents, and Asian, Hispanic, and Native American populations. The program is expected to begin in late 2015 with education and outreach about dementia targeted to these populations by the Minnesota Department of Health and the Alzheimer's Association.

The Alzheimer's Association, **Oregon** Chapter, catalyzed a partnership with the Oregon Department of Human Services, Public Health Division, and Aging and Disability Resource Connection to develop an educational resource for Spanish-language communities about the basics of Alzheimer's and other dementias and the importance of early diagnosis and care planning. To assure the resource would be linguistically and culturally appropriate, the partners consulted with community health workers who are affiliated with a hospital system and serve Hispanic and Latino communities. Information was packaged in both English and Spanish as fotonovelas to convey content in words and pictures.



Fotonovelas created through a partnership in Oregon



► Contributing Public Health Information to National Reports and Partners

CDC published numerous articles to share surveillance data from the BRFSS Cognitive Decline and Caregiver Optional Modules. (See HBI Domain: Monitor and Evaluate in this report for descriptions and links.) In addition, CDC provided technical assistance and reviewed a series of [Brain Health Resources](#) developed by the Administration for Community Living (ACL) for aging services professionals. The materials were released jointly by ACL, NIH, and CDC and have four components: 1) a PowerPoint presentation designed to inform older adults and their caregivers about risks that may be related to brain health; 2) an Educator Guide that provides additional information for presenters to share with audiences; 3) a one-page handout for older adults and caregivers called "Brain Health as You Age: You Can Make a Difference!"; and 4) a supplementary handout, "Brain Health as You Age: Key Facts and Resources," which includes basic information and resources for the topics covered in the presentation.

► Providing Links to Dementia Resources

Federal agencies like CDC and NIH/NIA are advancing new methods for disseminating free, up-to-date information to organizations interested in educating the public through their websites, apps, and other social media. Useful information and resources related to dementia are posted on specific federal agency websites, such as the [CDC Public Health Media Library](#) and the [HHS Storefront](#) (which includes information from NIA and other federal agencies). Organizations that “sign on” to use these sites gain immediate access to this current information. In addition, any update to the site made by the federal agency is automatically updated on the organizations’ sites. This innovation not only saves resources but also ensures consistency and accuracy of messaging.

► Designing Science-based Messaging

There is a need for the development of timely and coordinated messages about cognitive impairment that can be disseminated through public health channels. To address this need, CDC funded the University of Pennsylvania PRC to develop and disseminate science-based, culturally- relevant messages and strategies that promote awareness about cognition and cognitive impairment and ultimately lead to increased detection of cognitive impairment, including Alzheimer’s disease. They will assess perceptions about cognitive health and impairment among non-Hispanic white and African-American adults aged 50 or older living in the Philadelphia area. Based on the assessment, messages will be developed, pilot-tested, and evaluated for potential scalability to other populations and settings.

CDC ROAD MAP PRIORITY ACTIONS

The strengths and capacities of public health can be particularly valuable in advancing communication in four specific areas: advance care planning, recruitment into clinical trials and studies, younger-onset dementia, and abuse and exploitation. Public health can raise awareness and sensitivity about these issues, and work with aging services networks, healthcare provider networks, and other partners at state and local levels.

- **E-08** Promote appropriate partnerships and strategies to educate and increase local participation in clinical trials and studies on cognitive health and impairment.

► Recruiting Older Adults into Research (ROAR)

Efforts to learn more about Alzheimer's disease depend, in large part, on volunteers who participate in studies. There is an urgent need for adults of all ages and health levels to participate in research; currently at least 70,000 volunteers are needed to participate in more than 150 active clinical trials and studies in the U.S. that are testing ways to understand, treat, prevent, or cure Alzheimer's disease (<http://www.nia.nih.gov/alzheimers/publication/participating-alzheimers-research/introduction>).

CDC worked with an inter-agency team from NIH/NIA and ACL to approach the challenge of increasing clinical trial participation by bringing aging, public health, research networks, and related resources together. The effort, "Recruiting Older Adults into Research" (ROAR), seeks to raise research awareness and engagement among older adults, connect them with easy and actionable opportunities to participate, and ultimately expand the pool of older adults willing to participate in clinical studies and trials for Alzheimer's disease and other health conditions. As a result, a [ROAR Toolkit](#) was developed that provides easy and actionable ways for professionals to promote participation in research.



Information provided in the ROAR Toolkit

CDC ROAD MAP PRIORITY ACTIONS

As cognitive health continues to gain recognition as an important public health issue, state and local public health professionals will be called upon to translate current and emerging research into practice. Competency-based educational strategies and materials are needed to give the public health workforce the knowledge and skills for carrying out this vital role.

Healthcare providers are another important focus of needed education efforts related to dementia. Educational initiatives that maximize partnerships between academic institutions and practice and care partner organizations, and align with major competency-based efforts, can increase awareness, knowledge, and abilities of healthcare providers who interact with and support people with cognitive impairment and their care partners. By defining various providers' roles, offering formative and continuing education, preparing professionals, and providing practical tools and resources, strong partnerships can be forged in states and communities to enhance community-clinical capacity for effective detection, early diagnosis, referral, and care.

- **W-01** Develop strategies to help ensure that state public health departments have expertise in cognitive health and impairment related to research and best practices.
- **W-03** Support continuing education efforts that improve healthcare providers' ability to recognize early signs of dementia, including Alzheimer's disease, and to offer counseling to individuals and their care partners.

► Ensuring Expertise in Healthcare Professionals

CDC is represented on a National Advisory Panel for the Health Resources and Services Administration on the development of the Alzheimer's Disease (AD) Uniform Curriculum. Specifically, the panel is tasked to develop and pilot 15 to 35 modules, together with collateral training materials, to address high-priority issues related to the detection, management, and treatment of AD. The purpose of the curriculum is to build a workforce skilled in providing high-quality care, ensuring timely and accurate detection and diagnosis, and identifying high-quality dementia care guidelines and measures across care settings.

► Educating Healthcare Providers

A CDC representative served on the Gerontological Society of Aging Workgroup on Cognitive Impairment Detection and Earlier Diagnosis, together with other experts from public, private, and academic sectors. In its [2015 report](#), the Workgroup summarized efforts underway by national governmental and related organizations to identify evidence-based assessment tools for detecting cognitive impairment. The Workgroup also articulated how the Medicare Annual Wellness Visit can be used by primary care providers as a springboard for implementing evidence-based cognitive impairment assessment tools on a widespread basis.

In addition, with CDC funding and technical assistance, seven states designed and delivered educational initiatives to enhance healthcare providers' ability to recognize early signs of dementia and offer appropriate counseling and referral. Various methodologies— including webinars, Dear Colleague letters, and traditional classroom training—were employed to reach target audiences.

Sampling of States' Educational Activities

With CDC funding, NACDD provided support to a partnerships between the **Arizona** Department of Health Services and the Alzheimer's Association, Desert Southwest Chapter, to raise awareness about cognitive health concerns and provide training for public health professionals, including community health workers, working in underserved areas in the state. A system was also set up for health professionals to refer individuals in need of further consultation about Alzheimer's disease or related dementia.

The **Georgia** Department of Public Health and the Alzheimer's Association, Georgia Chapter, developed an educational webinar for physicians about dementia awareness, the importance of early detection and diagnosis of Alzheimer's disease, opportunities provided through the Medicare annual wellness visit, and appropriate assessment tools. More than 70 physicians and 75 nurse practitioners were trained initially, and the [Webinar](#) is available for viewing and CME on the Georgia Department of Public Health website through January 2016.

State health departments in **Hawaii**, **New York**, and **Wisconsin** developed Dear Colleague letters that were sent to physicians and other healthcare providers in their states to highlight assessment tools and the importance of detection.





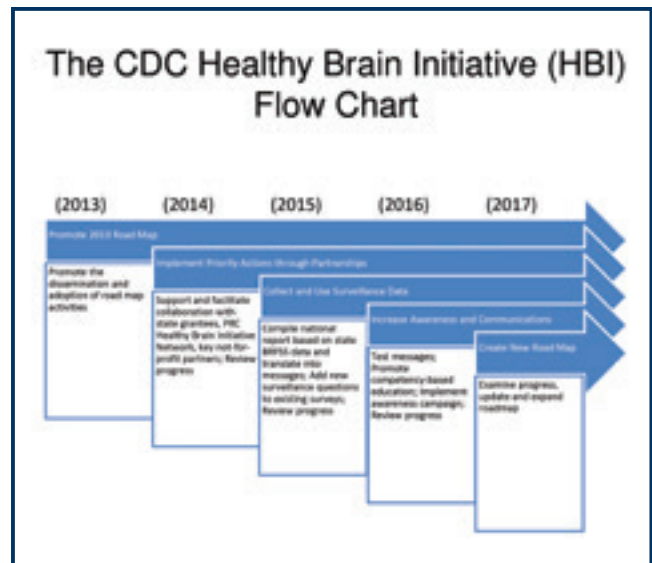
Looking Ahead

There is now tremendous visibility of Alzheimer's disease and related dementias at the national, state, and local levels. This area represents a new horizon for public health, one driven by growth in prevention science and increasing awareness of state and local roles for promoting initiatives that support cognitive health and functioning. Along with the tremendous visibility and investment come high expectations for continuous learning and its translation into action. It is our hope that this report will accelerate the pace of change, lead to stronger collaborative partnerships, and result in more rapid progress toward improving cognitive health for all.

Contingent on funding and CDC priorities, future activities of CDC’s Healthy Brain Initiative would include the following:

Monitor and Evaluate

- Promote the use of the BRFSS Cognitive Decline and Caregiver modules in states and territories, and work to prepare data, design innovative tools to facilitate access to data, and disseminate findings.
- Determine appropriate time intervals for collecting and disseminating data from the BRFSS Cognitive Decline and Caregiver modules.
- Develop mid-course data to track and monitor the national Healthy People 2020 objectives regarding “Dementias, including Alzheimer’s disease”.



Develop Policy and Mobilize Partnerships

- Create policy briefs and provide information to decision makers about the Healthy Brain Initiative findings and their implications, particularly in the areas of multiple chronic conditions, economic issues related to public health, and caregiving.
- Implement public health actions at state and local levels through the Funding Opportunity Announcement (FOA), “The Healthy Brain Initiative: Implementing Public Health Actions related to Cognitive Health, Cognitive Impairment, and Caregiving at the State and Local Levels”. The primary purpose of the FOA is to engage public health and their national, state, and local partners in a comprehensive and coordinated national approach to implement public health actions that promote cognitive health, address cognitive impairment including Alzheimer’s disease, and support the needs of care partners. Awardees, Alzheimer’s Association and The Balm In Gilead, Inc., were selected through a competitive application process, and their projects began in October 2015. The FOA provides a tremendous opportunity to build upon current efforts to implement Road Map action items and address additional items. Anticipated short-term outcomes within the next two years include:
 - ▷ Increased evidence for public health interventions;
 - ▷ Increased integration of cognition into organizational missions and planning;
 - ▷ Increased understanding among healthcare partners about assessment tools and the caregiver’s health and role in care management; and
 - ▷ Increased understanding of cognition and resources available among public health organizations and partners.

Educate and Empower

- Strengthen the reach of the Healthy Brain Research Network, its linkages to diverse partners, and its ability to leverage opportunities to conduct and translate evidence-based strategies to the public health community.
- Support efforts to identify and promote culturally-appropriate strategies designed to increase public awareness about dementia, including Alzheimer's disease; to reduce conflicting messages; decrease stigma; and promote early diagnosis.
- Continue to work with federal, state, and local partners to identify common areas for collaboration on Road Map actions as well as the IOM Report on Cognitive Aging and determine how to ensure engagement of the public health community.
- Identify opportunities to fill knowledge gaps concerning public health and aging services informational needs through applied research.
- Continue to disseminate results to relevant audiences through appropriate scientific peer-reviewed journals and presentations.

Assure a Competent Workforce

- Support the work of the Healthy Brain Research Network Scholars program and education in schools of public health and medicine.
- Work with partners to enhance education of healthcare providers, policy makers, and the general public.
- Identify and disseminate evidence-based caregiver strategies.

The Healthy Brain Initiative envisions a nation in which the public embraces cognitive health as a vital component of health and is committed to its inclusion in public health efforts. To achieve that vision, the long-term goal is to maintain or improve the cognitive performance of all adults.

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The Alzheimer’s Association, dedicated to eliminate Alzheimer’s disease through advancement of research; provide and enhance care and support for all affected; and reduce the risk of dementia through the promotion of brain health.

The Association of State and Territorial Health Officials, striving to transform public health within states and territories to help its members dramatically improve health and wellness.

The National Association of Chronic Disease Directors, providing support to over 5,000 specialized chronic disease practitioners working in every state and U.S. Territory public health department to prevent and control chronic disease.

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Related Publications and Presentations

CDC Website Features

- “November Is National Family Caregivers Month,” www.cdc.gov/features/caregivers-month [November, 2014]
- Disease of the Week CDC app for the iPad-focus on Alzheimer’s Disease [November, 2014]
- September is World Alzheimer’s Month: <http://www.cdc.gov/Features/WorldAlzheimersDay/>

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National Committee Activities (not identified in main report)

- 2015 Healthy Aging Summit
 - CDC representative on the HHS planning committee provides linkages to other CDC programs and initiatives
- White House Conference on Aging
 - CDC representative on the planning committee for the White House Conference on Aging provides linkages to the Health Brain Initiative and other CDC programs
- American Society on Aging (ASA)
 - Member of ASA's Healthcare and Aging Network



