

STATE ALZHEIMER'S DISEASE PLANS: DATA COLLECTION

Recommendations to create a better system of data collection regarding Alzheimer's disease and its public health burden

Alabama	
Alaska	<ul style="list-style-type: none"> • Use existing Department of Health and Social Services (DHSS) data to identify the unduplicated number of people with Alzheimer's and other dementias served by DHSS programs each year, and quantify the cost per person served. Use this to project future baseline costs and fiscal implications of changes in service lines and policies. • Access CMS, private insurance and out-of-pocket costs to analyze cost of in-patient and out-patient services for Medicare beneficiaries for persons receiving Medicaid services across the continuum so that there is a complete picture of the total individual and collective health care costs for Alaskans. • Maintain funding to use the Behavioral Risk Factor Surveillance System (BRFSS) to collect health outcomes data for persons with Alzheimer's disease and other dementias. Use BRFSS to gather caregiver information. • Work with the Alaska Native Tribal Health Consortium (ANTHC) to identify the number of people served with Alzheimer's and other dementias. • Collaborate with tribal partners, National Resource Center on American Indians, Alaska Natives, and Hawaiian Alaska Native Elders Resource Center at the University of Alaska Anchorage and ANTHC to better understand the impact of Alzheimer's and other dementias among Alaska Native Elders and communities.
Arizona	<ul style="list-style-type: none"> • Include cognitive impairment, comorbidities/co-occurring disorders, stress and caregiving-related questions in the state's Behavioral Risk Factor Surveillance System (BRFSS) survey. Disseminate these findings for use in program and research development to respond to the needs of Arizona residents.
Arkansas	<ul style="list-style-type: none"> • Mandate that the Arkansas Department of Health utilize the Behavioral Risk Factor Surveillance System Cognitive Impairment module to capture statewide data that will provide state-specific information to better inform public health and policy audiences. • Work with service providers to create a coordinated and systematic way of collecting Alzheimer's and dementia-related data in Arkansas' Medicaid and Medicare programs.
California	<ul style="list-style-type: none"> • Increase surveillance of incidence of Alzheimer's disease and the impact of caregiving through the Behavioral Risk Factor Surveillance System, California Health Interview Survey, the Healthcare Effectiveness Data and Information Set, and other surveys. • Promote common data elements and uniform data collection to accurately capture the population with cognitive impairment eligible for or served by California's publicly funded aging and disability programs. • Reinstate data collection activities that have been eliminated as a result of budget cuts; for example, California Alzheimer's Disease Centers and the Family Caregiver Alliance. • Use available data to assist in program refinement, grant submissions, and implementation of California's Alzheimer's Disease State Plan.
Colorado	<ul style="list-style-type: none"> • Add an Alzheimer's module to the Colorado Behavioral Risk Factor Surveillance System to collect state-level data on the prevalence of Alzheimer's disease and associated characteristics such as living arrangements, family and caregiver needs, and responsibilities.
Connecticut	
Delaware	<ul style="list-style-type: none"> • Study other states' infrastructure for collection/analysis of data and quality assurance measures. • Identify existing sources of data and quality assurance measures (e.g. U.S. Decennial Census and/or American Community Survey, Alzheimer's Association, Minimum Data Set (MDS) 3.0, Behavioral Risk Factor Surveillance System (BRFSS), and others).

Delaware (cont.)	<ul style="list-style-type: none"> • Explore the need for new data and quality assurance measures as a partnership with the Alzheimer's Association, Delaware Department of Health and Social Services, University of Delaware, Delaware State University, and others. • Coalesce the variety of data and quality assurance sources, analysis, and dissemination in a way that improves access and impact of these measures.
District of Columbia	<ul style="list-style-type: none"> • Implement the cognitive impairment module in the Behavioral Risk Factor Surveillance System (BRFSS) to 4,800 District of Columbia residents 18 years and older in all eight wards of the city. Provide BRFSS data findings to the Alzheimer's Association.
Florida	
Georgia	<ul style="list-style-type: none"> • In alternating years, utilize the Behavioral Risk Factor Surveillance System's (BRFSS) Cognitive and Caregiver Modules. • Link BRFSS data with health-related outcome and/or quality measures. • Provide surveillance data to state agencies, regional commissions and other planning agencies to encourage communities and agencies to adequately plan on growth in the number of people with Alzheimer's and other dementias. • Add co-morbidities to the death certificate to better enable tracking of dementia incidence.
Hawaii	<ul style="list-style-type: none"> • Identify opportunities for improved data collection and analysis on Alzheimer's disease and other dementias in Hawaii, with a key component of this surveillance being the Cognitive and Caregiver modules of the Behavioral Risk Factor Surveillance System (BRFSS).
Idaho	<ul style="list-style-type: none"> • Work with the Department of Health and Welfare to incorporate questions about cognitive health in its annual Behavioral Risk Factor Surveillance System (BRFSS).
Illinois	<ul style="list-style-type: none"> • Determine the most effective system (either the national Behavioral Risk Factor Surveillance System or a similar system) to collect data regarding prevalence, population trends, service needs, and the impact of Alzheimer's disease and other dementias on persons with the disease, their families, and their caregivers, and implement that system. • Review the data collected to prioritize those in greatest need of programs and services.
Indiana	<ul style="list-style-type: none"> • Improve brain health surveillance. • Improve state Alzheimer's data by adding the Caregiver Module and Cognitive Impairment Module to Indiana's Behavioral Risk Factor Surveillance System. • Secure funding to repeat these modules every 1-2 years. Produce report on findings and use the data for planning and program design. • Improve data collection on Alzheimer's disease and its public health burden (such as data on hospital admissions and mortality).
Iowa	<ul style="list-style-type: none"> • Modify the existing community needs assessment process to include questions that would identify and quantify at-risk people with Alzheimer's disease and other dementias. This would include the local public health community needs assessment, the Area Agency on Aging area planning process, and other agency activities that receive federal and state funding for services to Iowa's aging population.
Kentucky	<ul style="list-style-type: none"> • Require the Alzheimer's and Related Dementias Unit to coordinate a statewide effort to develop and implement a statewide data collection system. • Collect and monitor data on the prevalence of the disease, the capacity of the health care system (for example, availability of geriatric specialists and dementia-related services as well as the number of inpatient geriatric psychiatry beds), and the number of caregivers.
Louisiana	<ul style="list-style-type: none"> • Establish a dementia-specific initiative in the Office of Public Health to develop and implement the most effective system to collect data regarding prevalence, population trends, service needs, and impact of Alzheimer's disease and other dementias on the person, their caregivers, and families.
Maine	<ul style="list-style-type: none"> • Support and fund increased state-based surveillance through the Behavioral Risk Factor Surveillance System (BRFSS). Other state data sources should be considered to inform practices and policies. • Research the true financial cost of Alzheimer's and other dementias on individuals living with the disease, families, communities, and the state.
Maryland	
Massachusetts	
Michigan	<ul style="list-style-type: none"> • Develop a profile of Michigan's home-based dementia caregivers to aid planning and advocacy.

Minnesota	<ul style="list-style-type: none"> • Use the Medicare Annual Wellness Visit cognitive assessment as a means of developing better statewide prevalence data on cognitive impairment by reporting the data to the Minnesota Community Measurement for further research, validation, and development of estimates.
Mississippi	<ul style="list-style-type: none"> • Recommend use of the Behavioral Risk Factor Surveillance System (BRFSS) to collect health outcomes data for persons with impaired brain function and Alzheimer's disease and other dementias, including the impact of cultural variances. • Review surveillance data on an ongoing basis to identify trends in brain health within the state. • Utilize surveillance data to inform the public and state government regarding the scope of brain function impairment in Mississippi.
Missouri	
Montana	<ul style="list-style-type: none"> • Implement a statewide data reporting system to improve data collection on the prevalence of Alzheimer's and other dementias in Montana and to keep an up-to-date inventory of dementia services across the state. • Implement and maintain the cognitive impairment and caregiver modules in the Behavioral Risk Factor Surveillance System (BRFSS) survey of Montana residents 18 years and older. Ensure that these modules are included often enough to provide accurate and salient data regarding the cognitive health and caregiver well-being of Montanans. Disseminate findings from the BFRSS for use in program and research development. • Enhance the state's role in creating and compiling health burden data on Alzheimer's and other dementias – for example, hospital admissions, mortality, adult protective service calls and cases, death certificate data, Medicare cognitive assessment data, Minimum Data Set (MDS) cognitive impairment data in nursing homes, and hospital records on dementia as a diagnosis. • Promote accurate death certificate completion, including Alzheimer's and other dementias as a cause of death, to ensure prevalence data is comprehensive. • Encourage health systems in Montana to use a cognitive assessment as part of the Medicare Annual Wellness visit as a means of enhancing data on cognitive impairment. This data should then be reported to DPHHS for further research and validation.
Nebraska	<ul style="list-style-type: none"> • Implement the Cognitive Impairment and Caregiver Modules in the Behavioral Risk Factor Surveillance System (BRFSS).
Nevada	
New Hampshire	
New Jersey	
New Mexico	<ul style="list-style-type: none"> • Study the incidence, impact, and other aspects of Alzheimer's disease and other dementias in New Mexico with a focus on underrepresented populations. • Identify and expand existing data sources and develop new data sources; determine how best to ensure analysis and use of the data.
New York	<ul style="list-style-type: none"> • Utilize various data to estimate numbers and costs associated with dementia policy and planning, such as data available through the Statewide Planning and Research Cooperative System, Medicaid, and the Outcome and Assessment Information Set. • Assess the function and value of data systems, discontinue those with low value, and better utilize those with value or achievable potential.
North Carolina	<ul style="list-style-type: none"> • Continue inclusion of cognitive impairment and caregiver modules in the Behavioral Risk Factor Surveillance System on a five-year interval. Resulting data should be used to inform public awareness campaigns and analyzed for potential connection with other behavioral and lifestyle risk factors tracked by the statewide survey.

North Carolina (cont.)	<ul style="list-style-type: none"> • Improve prevalence data through accurate death certificate completion by offering continued medical education training on the identification of Alzheimer's and other dementias as cause of death. Medical schools and residency programs should also offer education and training in this area. • Improve data on Alzheimer's disease and other dementias prevalence by implementing a statewide data reporting system.
North Dakota	
Oklahoma	<ul style="list-style-type: none"> • Include Alzheimer's-specific questions in the Behavioral Risk Factor Surveillance System.
Oregon	<ul style="list-style-type: none"> • Create a work group of stakeholders to identify existing data, identify gaps, and design and implement a system that ensures data can be collected, analyzed, and reported to guide policy and funding decisions related to dementia care in Oregon. • Increase public health surveillance and analysis of impacts of Alzheimer's disease and other dementias and caregiving in Oregon using the Behavioral Risk Factor Surveillance System cognitive impairment and caregiver modules. Explore use of other existing data sources available that are related to state-funded medical and long-term care services.
Pennsylvania	<ul style="list-style-type: none"> • Implement the Behavioral Risk Factor Surveillance System's (BRFSS) Cognitive Impairment and Caregiver modules. Use data to enhance awareness and action in statewide public health programming for Alzheimer's disease and other dementias.
Puerto Rico	<ul style="list-style-type: none"> • Increase by 50 percent the number of physicians and hospitals reporting cases to the Department of Health.
Rhode Island	<ul style="list-style-type: none"> • Encourage 211/"The POINT" to develop capacity to sort call-in data and the geographical breakdown of needs to better inform the state's awareness of Alzheimer's-related inquiries, including the needs of caregivers, areas in need of improvement, and gaps in services and support.
South Carolina	<ul style="list-style-type: none"> • Utilize existing health data dissemination infrastructure to integrate information on Alzheimer's disease and other dementias. • Expand the scope of data included in the Alzheimer's Disease Registry to include increased sources of data, resulting in greater capacity to identify gaps in services available.
Tennessee	<ul style="list-style-type: none"> • Partner with relevant agencies and organizations to design and implement a data system that is consistent statewide and to ensure that the data are analyzed and reported to support and guide decisions regarding Alzheimer's disease and other dementias. • Partner with the Tennessee Department of Health, Office of Health Statistics to determine if the existing system can collect the requested data. • Request the addition of questions related to Alzheimer's disease and other dementias on the Behavioral Risk Factor Surveillance System that will provide state information on: (1) the number of people with Alzheimer's disease and other dementias; (2) the number of family caregivers who are taking care of someone with Alzheimer's disease and other dementias; and (3) the age, income, living arrangements, health problems, and other characteristics of people with dementia and their family caregivers. • Collect data from existing sources, monitor existing data sets, and make the data available at the Tennessee Commission on Aging and Disability.
Texas	<ul style="list-style-type: none"> • Explore and secure funding sources to support Behavioral Risk Factor Surveillance System (BRFSS) survey questions. • Establish a workgroup to identify, develop, or use existing standardized BRFSS questions. • Work with the Department of State Health Services to prepare and submit BRFSS proposals to the BRFSS Coordinator. • Monitor status of BRFSS proposals and make necessary changes to questions based on feedback from the BRFSS Coordinator. • Create a statewide, multi-disciplinary group to identify Alzheimer's disease data and surveillance gaps in Texas. • Collaborate with partners to identify on-going data needs, collection methods, reporting formats, and funding sources.

Texas (cont.)	<ul style="list-style-type: none"> • Continue to assimilate current data, monitor trends, track programs and policies, and recommend actions for improvement. • Support ongoing use of the BRFSS to collect and analyze Alzheimer's disease data. • Disseminate data and encourage partners/stakeholders to promote Alzheimer's disease data collection in their program activities.
Utah	<ul style="list-style-type: none"> • Collect and use data to drive public health service development and delivery. • Increase surveillance of incidence of Alzheimer's disease and the impact of caregiving through the Behavioral Risk Factor Surveillance System and other surveys. • Mandate that death certificate data include information obtained through postmortem diagnostic examinations.
Vermont	<ul style="list-style-type: none"> • Implement the Caregiver Module and Cognitive Impairment module of the Behavioral Risk Factor Surveillance System.
Virginia	<ul style="list-style-type: none"> • Require the Virginia Dementia Services Coordinator to develop, implement, and coordinate a state-wide data collection system (including use of the Behavioral Risk Factor Surveillance System) through the Virginia Alzheimer's Commission AlzPossible Initiative, which could provide a clearinghouse of links to the state agencies or groups with relevant, up-to-date, and available data on dementia. • Have the Dementia Services Coordinator collect and monitor data on the prevalence of the disease, the capacity of the health care system (for example, the availability of geriatric specialists, dementia-related services, and inpatient geriatric psychiatry beds), the number of caregivers, and the costs of caring for someone with dementia. • Use the Behavioral Risk Factor Surveillance System to collect health outcomes data for persons with Alzheimer's disease and dementia.
Washington	<ul style="list-style-type: none"> • Implement the Behavioral Risk Factor Surveillance System (BRFSS) cognitive and caregiver modules at least once every three years. • Advocate for the collection, documentation, and dissemination of the prevalence of individuals with cognitive impairment and dementia in clinical practices and health systems. • Analyze data from public and private sources regarding prevalence of complications and coexisting conditions such as falling, accidents, overmedication, hearing or vision loss, anxiety, depression, financial exploitation, abuse/neglect, fraud, etc.
West Virginia	<ul style="list-style-type: none"> • Maximize use of the Behavioral Risk Factor Surveillance System to collect data on the prevalence and impact of Alzheimer's disease on people with the disease and their caregivers. • Explore the creation of an independent Alzheimer's disease-focused social indicator survey. • Support the West Virginia Alzheimer's Disease Registry to improve the collection of actual Alzheimer's incidence information.
Wisconsin	<ul style="list-style-type: none"> • Identify data elements and sources for developing baseline measures. • Develop and employ metrics for measuring progress in achieving a dementia-capable system of care. • Collect and analyze data to determine baseline and quality improvement.

Updated January 2017