## 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

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| Arkansas    | • 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  | • 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    | • 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. |
| Illinois    | • 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. |
| Iowa        | • 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    | • 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   | • 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. |
| Maryland    | • Increase data collection capabilities.  
<p>| Michigan    | • Develop a profile of Michigan’s home-based dementia caregivers to aid planning and advocacy efforts. |
| Minnesota   | • Use the new cognitive assessment that is part of the Medicare Annual Wellness Visit 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 |<br />
| Missouri    |                                                                                                                                                  |</p>
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| New York   | • 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 Dakota |                                                                                                    |
| Oklahoma   | • Include Alzheimer's-specific questions in the State Health Department's Behavioral Risk Factor Surveillance System. |
| South Carolina | • 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  | • 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      | • 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 questions 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.  
• 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       | • 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    | • Implement the Caregiver Module and Cognitive Impairment module of the Behavioral Risk Factor Surveillance System. |
| Virginia   | • 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. |
| Virginia (cont.) | • 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. |
| West Virginia | • 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. |