

FACTSHEET

APRIL 2017

alz.org®

Data Collection and the Behavioral Risk Factor Surveillance System (BRFSS)

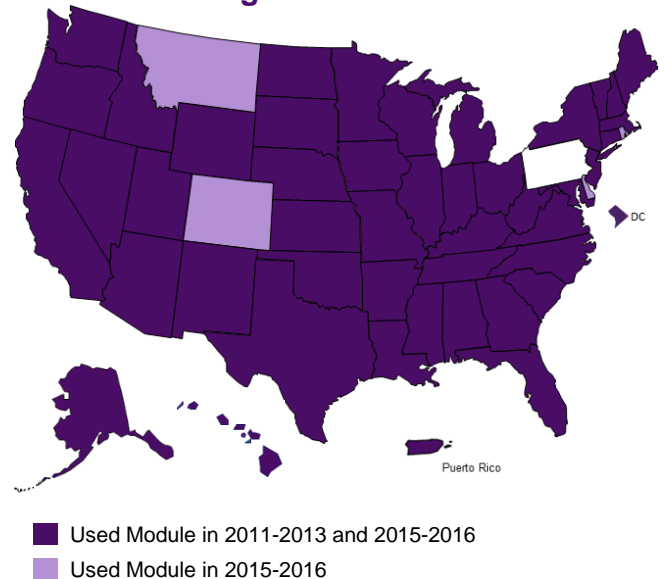
Data collection – known as “surveillance” – is a fundamental and essential public health tool.

- Surveillance is used to develop data on the prevalence of disease, health risk factors, preventive health behaviors, and burden of particular diseases and conditions as well as the health status of a population.
- Common topics of surveillance include cardiovascular disease, diabetes, disability, exercise, alcohol consumption, and access to health care.
- Data gathered from regular surveillance can be used to support the development of strategies to reduce disease risk and to devise effective interventions to lessen the burden of a disease.

Surveillance is needed to understand the impact and burden of Alzheimer’s disease and cognitive decline on the state level.

- Very little state-level population-based data on subjective cognitive decline, Alzheimer’s disease, and caregivers. And there are no state-level data that would allow for the analysis of trends over time.
- Effective surveillance would provide information about the impact and burden of subjective cognitive decline and caregiving, including the demographics, health status, and other characteristics of those experiencing increasing memory problems and of Alzheimer’s caregivers.

States Using the BRFSS Cognitive Module



Information gathered through surveillance can be used to:

- Identify the potential difficulties and burden that subjective cognitive decline and caregiving impose, and craft appropriate interventions.
- Make informed decisions in the development of plans and policies with regard to efforts such as increasing public awareness about Alzheimer’s, promoting early detection and diagnosis of the disease, and including cognitive health in other public health campaigns.
- Evaluate efforts at the state and local levels to address the crisis.

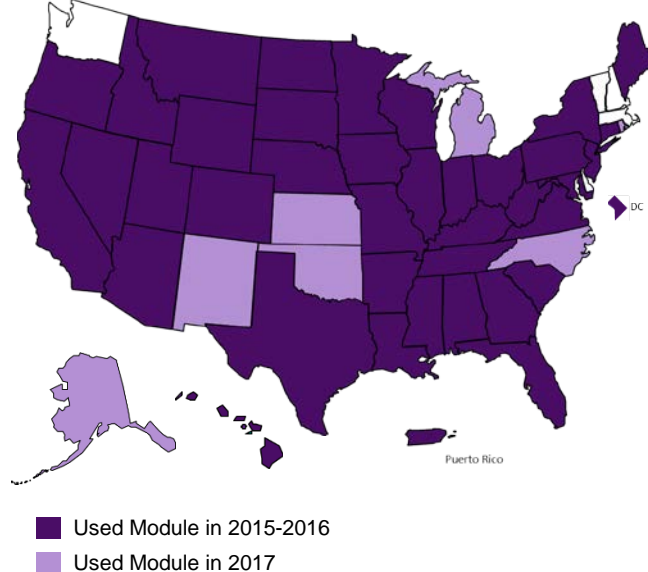
The Behavioral Risk Factor Surveillance System (BRFSS) is a proven data collection tool used in every state, the District of Columbia and the U.S. Territories.

- The BRFSS is a telephone survey conducted annually by state health departments. It was established in 1984.
- Financial, technical and methodological assistance for the BRFSS survey is provided to states by the Centers for Disease Control and Prevention (CDC).
- The BRFSS has three components:
 - the core questions, which are asked either annually or on a rotating basis
 - optional modules, each of which covers a particular topic in more detail and is developed by the CDC
 - state-added questions, determined by each state based on the health and data needs of that state

Two BRFSS modules have been developed to help understand Alzheimer's disease and other dementias on the state level.

- The *Cognitive Module* asks about increased confusion or memory loss ("subjective cognitive decline"), the potential difficulties it may cause with everyday activities, and whether individuals have discussed their memory problems with a health care professional.
- The *Caregiver Module* includes questions about a care recipient's health problems and greatest care needs as well as the impact of providing care on the caregiver.

States Using the BRFSS Caregiver Module



Use of these modules has been growing, providing valuable information in the fight against Alzheimer's.

- In 2009, five states – California, Florida, Iowa, Louisiana, and Michigan – served as pilot states for the Cognitive Module.
- From 2011-2013, 45 states, the District of Columbia and Puerto Rico used the Cognitive Module. In 2015-2016, 49 states, the District of Columbia and Puerto Rico used the Module. This makes it the most rapidly adopted module outside the core CDC program since the creation of the BRFSS.
- In 2015-2016, the Caregiver Module has been used in 38 states plus the District of Columbia and Puerto Rico. An additional seven states are using the Module in 2017.