Data Collection and the Behavioral Risk Factor Surveillance System (BRFSS)
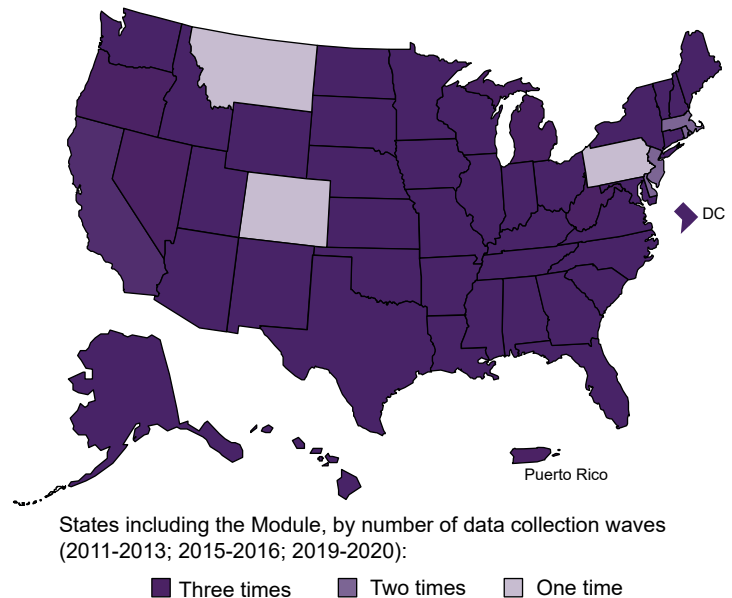
Data collection — known as "surveillance" — is a fundamental and essential public health tool.

- Surveillance is used to develop data on the prevalence of disease, health risk factors, protective 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.

- State-level data is growing, but gaps remain on subjective cognitive decline, Alzheimer's disease, and caregivers. Regular collection of these data is needed to 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 Decline Module

DC

Puerto Rico

States including the Module, by number of data collection waves (2011-2013; 2015-2016; 2019-2020):

- Three times
- Two times
- One time

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.
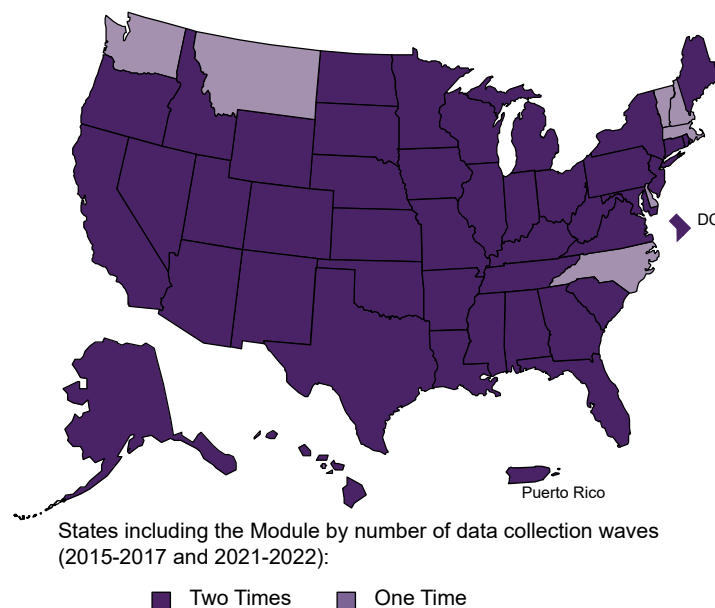
- The BRFSS is a telephone survey conducted annually by state health departments. It was established in 1984.

- 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 Decline Module asks about difficulties in thinking or memory ("subjective cognitive decline"), the potential challenges it may cause with everyday activities, and whether individuals have discussed their thinking or memory problems with a health care professional.

- The Caregiver Module includes questions about a care recipient's health problems and care needs as well as the impact of providing care on the caregiver.

States Using the BRFSS Caregiver Module

States including the Module by number of data collection waves (2015-2017 and 2021-2022):

■ Two Times   ■ One Time

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 Decline Module.

- From 2011-2013, 45 states, the District of Columbia (DC), and Puerto Rico used the Cognitive Decline Module. In 2015-2016, 49 states, DC, and Puerto Rico used the module. Between 2019 and 2020, 47 states, DC, and Puerto Rico used the Cognitive Decline Module.

- In 2015-2018, the Caregiver Module was used in 45 states, DC, and Puerto Rico. In 2021-2022, 49 states, DC, and Puerto Rico used the module.

- Both modules are among the most widely adopted modules since the creation of the BRFSS.