

FACTSHEET

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

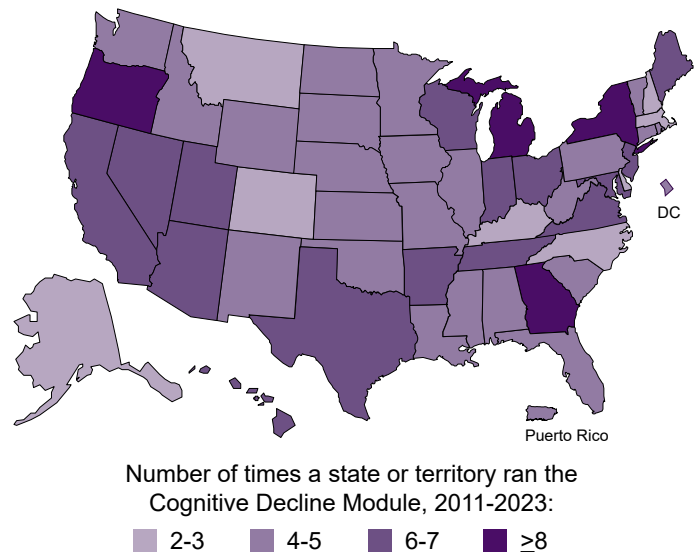
Data collection — known as “surveillance” — is a fundamental and essential public health tool.

- Surveillance is used to develop data on the prevalence of disease, health risk factors, protective health behaviors, the burden of particular diseases and conditions, and the health status of a population.
- Common topics of surveillance include cardiovascular disease, diabetes, disability, physical activity, tobacco use, 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.

- Effective surveillance provides 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.
- Regular collection of this data allows for the analysis of trends over time. This is crucial as the Alzheimer’s crisis continues to escalate with the aging of the baby boom generation.

States Using the BRFSS Cognitive Decline Module



Alzheimer’s-related 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.

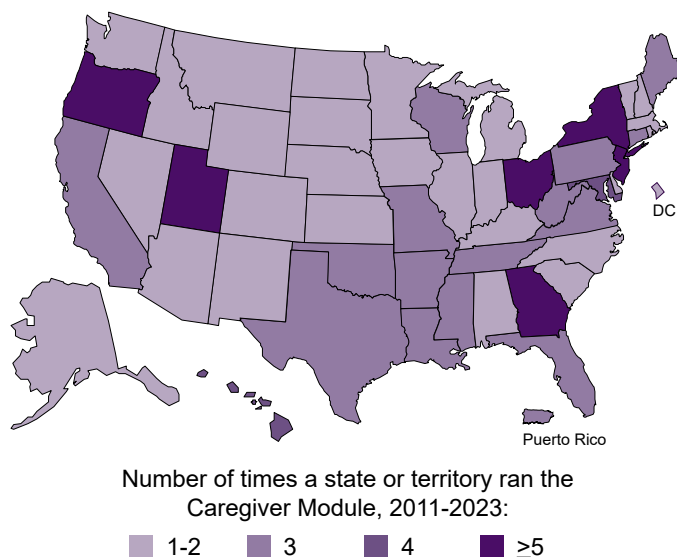
The Behavioral Risk Factor Surveillance System (BRFSS) is a proven data collection tool used in every state, the District of Columbia, and the U.S. Territories.

- 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



Both dementia-related modules are among the most widely adopted additional and optional modules in BRFSS.

- In 2009, five states served as pilot states for the Cognitive Decline Module. In 2012, 38 states had run the Cognitive Decline Module.
- Since 2015, every state, DC, and Puerto Rico have run both modules at least once — and all but three states have run both modules at least twice. Several states have elected to run one or both of the modules on a near annual basis.
- Between 2019-2020, 47 states, DC, and Puerto Rico used the Cognitive Decline Module. Between 2021-2022, 47 states and Puerto Rico collected Caregiver Module data.
- States are encouraged to run each of the two dementia-related modules at least once every four years in order to keep available data on cognitive and caregiver health up to date.