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 required to understand Alzheimer’s disease and cognitive impairment on the state level.

- There currently are no state-level population-based data on cognitive impairment, Alzheimer’s disease, dementia and caregivers of individuals with these conditions.

- Effective surveillance would provide information about the impact of cognitive decline; the number of family members who are caring for someone with Alzheimer’s or another dementia; and the age, income, living arrangements, health problems and other characteristics of those experiencing cognitive decline and their caregivers.

- Information gathered through surveillance can be used in support of efforts to:
  - Increase public awareness about Alzheimer’s and other dementias as well as its societal impact.
  - Promote the early detection and diagnosis of Alzheimer’s and other dementias.
  - Identify the burden that cognitive decline and caregiving imposes – and craft appropriate interventions.
  - Include Alzheimer’s and other dementias as part of public health campaigns on other medical conditions such as diabetes and stroke.
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 10-question BRFSS modules have been developed to help understand Alzheimer’s disease and other dementias on the state level.

- The Cognitive Impairment Module asks about memory loss, its impact on activities of daily living, and whether individuals have discussed 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 difficulties faced by caregivers.

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

- From 2011-2013, 45 states, the District of Columbia and Puerto Rico used or are using the Cognitive Impairment Module. This makes it the most rapidly adopted module outside the core CDC program since the creation of the BRFSS.
- Since 2005, the Caregiver Module has been used in 27 states plus the District of Columbia. In 2012 and 2013, 13 unique states asked or are asking the 10 caregiving questions.