

THE BEHAVIORAL RISK FACTOR SURVEILLANCE SYSTEM: FEDERAL-STATE RELATIONSHIPS AND ROLES

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I. Background

Begun initially in 15 states in 1984, the Behavioral Risk Factor Surveillance System (BRFSS) has grown to become the largest telephone-administered health survey in the world, with nearly 160,000 completed interviews in 1999 (Powell-Griner 1997; Nelson 1998; CDC 2000). Data are collected each year from adults in all 50 states, the District of Columbia, Puerto Rico, Guam, and the Virgin Islands on risk behaviors, health conditions, receipt of preventive clinical services, and health care access. Information from the BRFSS is used for planning, program, policy, evaluation, and research purposes at the local, state, and federal level.

From its onset, the system was designed to ensure that both states and the federal Centers for Disease Control and Prevention (CDC) had unique and well-defined responsibilities and roles. State health departments are responsible for selecting optional module and state-added questions, administering the survey instrument, collecting data, and producing state reports and other dissemination activities. CDC's responsibilities include developing and enforcing the protocol for sampling and data collection, making final decisions about core and optional module questions, data processing and weighting, producing standardized data reports, and making data more broadly available, e.g., through the Internet or CD-ROMs.

The BRFSS represents an example of a successful shared federal-state collaboration for the ongoing collection, processing, and distribution of health-related data. The nature of the BRFSS federal-state arrangement results in multiple benefits to both states and CDC, as well as creating certain tensions between these entities. These benefits and tensions are the subject of this paper, as they provide insights for agencies and other organizations who seek to develop and run collaborative surveys.

II. BRFSS Funding and Decision-Making

Funding. The BRFSS was designed to build state-level capacity to conduct and utilize survey data for state public health programs and to ensure that states had some ownership over their own data. An important part of CDC's strategy for the BRFSS was that CDC would only provide about half the funding for the system, expecting states to pick up the remainder of the financial obligations. A 1995 survey of state health department BRFSS coordinators found that this goal had been

achieved: on average, states provided 51% and CDC 49% of resources for the BRFSS (Adams 1997). However, the amount of state financial support for the BRFSS is not uniform. In some states, the CDC provides 100% of the funding, while in others, CDC provides a very small portion of overall resources. This disparate state financial support for the survey is reflected in sample sizes: states with few or no resources have annual sample sizes <2,000, while states with substantial resources have annual sample sizes that often exceed 5,000.

Because most state health departments chose to seek additional financial resources, new relationships have been formed between health department staff and other program or organizations that need data, e.g., local health districts, voluntary health organizations such as the American Cancer Society, substance abuse bureaus, and even highway departments. The extent of these relationships and provision of funding is highly variable among states. Some states have actively pursued such relationships and the BRFSS has become a highly visible and relied on source of data, while in other states, BRFSS data are virtually unknown outside of the department responsible for data collection.

Decision-Making. The nature and locus of control for decision-making for the system has changed over the nearly 20 years of the system's existence. During the 1980s, decisions about training, sampling, and questionnaire content were made almost exclusively by CDC staff. As the system expanded across states in the late 1980s and early 1990s, and as the number of required questions grew, states increasingly grew frustrated with their lack of input. In the early 1990s, states strongly recommended that CDC develop an operational plan to determine which topic areas would be included on the instrument throughout the remainder of the decade and that the number of CDC-required questions be capped. A state advisory group consisting of five state BRFSS coordinators was formed to provide a forum for state BRFSS coordinators to provide formal input to CDC on the operation of the system. This state advisory group process has continued, and state BRFSS representatives meet with CDC staff three times a year to review proposals, provide feedback, and make recommendations about the system. Through advisory votes at the annual BRFSS conference, state health department representatives also have an opportunity to provide formal feedback about proposed questions (e.g., deletions, changes, and additions). State input and recommendations about the BRFSS are taken seriously by CDC staff, although final

decisions about the system are made at the federal level.

III. Benefits to States and the Federal Government from the Shared BRFSS Relationship

The BRFSS arrangement, as evidenced by its long-standing nature, has many benefits for both states and the federal government. Aspects that are clearly beneficial to both parties include cost savings resulting from economies of scale (i.e., each state doesn't need to independently develop their own survey instrument, locate a sample provider, and finalize data files each year), comparability of data across states, and flexibility to make changes as demands and needs change over time. However, there are some specific benefits that can be categorized as primarily benefitting states or primarily benefitting the federal government.

Benefits to states from the BRFSS model:

- ▶ CDC expertise on question design, sampling, data collection, and analysis
- ▶ Training for survey operations and analyses
- ▶ Direct input into BRFSS operations
- ▶ Weighting of state and sub-state estimates for all questions by CDC
- ▶ Availability of monthly cleaned and edited data for rapid analyses within states
- ▶ Ability to include state-added questions with no CDC input
- ▶ Ability to select standardized optional module questions on multiple topics
- ▶ Provision by CDC of annual state-specific and summary reports for all states
- ▶ Availability of selected annual and trend data on CDC's Internet Web site
- ▶ Networking with other states and federal staff (e.g., email addresses, list-servs)
- ▶ State health department staff development

Benefits to the federal government from the BRFSS model:

- ▶ Enhanced data quality and consistency
- ▶ Comparable state-specific data
- ▶ Ability to track and evaluate the impact of national health programs and policies at the state level
- ▶ Adequate national sample sizes from pooled state data for smaller population groups of interest, e.g., American Indians
- ▶ Availability of a rich and large data source for research on many health issues
- ▶ Ability to provide state- and federal-level data for federal agencies besides CDC, e.g., the Executive Branch, Congress, and other organizations
- ▶ Provide a population benchmark and source of questions for other surveys (e.g., HMO

behavioral surveys)

- ▶ Act as a model for other surveillance efforts, e.g., foreign countries or local health departments

IV. Tensions

Despite the benefits obtained by states and the federal government from the BRFSS model, there are inevitable tensions resulting from this arrangement. They can be classified as tensions from a state perspective or tensions from a federal perspective (Table 1).

Table 1. State and Federal Tensions Resulting from BRFSS Approach

<u>State</u>	<u>Federal</u>
Demand for uniformity	Requests for tailoring
Unequal balance of power/unilateral federal decision-making	Rogue state decision-making
Inadequate level of technical support from CDC	Excessive requests for technical support from states
Disparate state funding	Disparate state talent
Irrelevance of some measures at the state level	Difficulty persuading, enticing, or enforcing states to follow survey operation policies
Over-representation of certain topics on survey instrument (e.g., HIV)	Improper or late data submission
Use of questions primarily for individual scientists' research agendas	Insertion of state-added and optional module questions into core questionnaire

The first four tensions are mirror images of each other. There are great benefits from a federal processing and quality perspective to have states use a uniform approach for asking questions and submitting data for processing by CDC. Such a uniform approach minimizes errors and improves timeliness. However, states greatly value the opportunity to tailor the questionnaire to meet their individual needs. About 40% of states geographically stratify their sample, which requires separate weighting within each strata. For example, in one year Virginia used 35 geographic strata (one for each of their health districts). Having such localized data was of great value for Virginia, but processing and weighting of their state's data by CDC was substantially more time- and

resource-intensive than for a state without strata.

Although states appreciate having involvement and input into the BRFSS, final decision-making authority about BRFSS issues resides with CDC staff. This power imbalance issue occurs most commonly in the context of decisions about questions. The majority of states have, for example, been lukewarm or even opposed to the inclusion of questions on a specific topic, and yet the topic ultimately was added by CDC to the questionnaire because of internal CDC pressure. This has led to resentment by states, as they have felt that their objections have not been adequately heard. There have been states, though, that have made rogue decisions about questions or sampling. For example, one state refuses to ask HIV-related questions to persons older than age 45 years and uses a different set of alcohol questions than the rest of the states. This leads to comparability problems for these two measures and requires footnoting of data sets and reports by CDC.

Two closely-related tension issues are the level of technical support that CDC is expected to provide states for operations and analyses, and the disparities in state funding and state talent. The states vary greatly in their ability to conduct the survey and analyze data: some states have several staff members with doctoral degrees and many years of experience, while others have only a part-time BRFSS coordinator with minimal training, leading some state staff to ask CDC to analyze their data and produce state-specific reports. CDC's policy has been that such work is the state's responsibility, as CDC staff are concerned about being overwhelmed with technical requests (there are only a 4-5 project officers to handle all the states and territories). As a result, some states believe that CDC does too little for states, while some federal staff believe that the CDC does too much for states.

The remaining 3 tension issues from a state perspective concern question selection. Some topics are perceived by many BRFSS coordinators as either being of low concern in their states or that the sample size is inadequate for conducting meaningful state analyzes. An example of the former would be smokeless tobacco use, which is a major concern in certain western and southern states but much less of an issue in the northeast. An example of the small size problem is collecting data on pregnant women. No state has enough pregnant women in their samples for analyses of this population, yet when pooled across states, the BRFSS has proven to be an important source of data on risk behaviors for this population (Ebrahim, 2000). Finally, there have been several instances when a representative from a CDC program has proposed including questions that would be used for his or her own research agenda, leading to resentments among states that the BRFSS is perceived by CDC as primarily for the benefit of researchers.

From a federal perspective, the last 3 items in Table 1 involve data processing and quality. Getting all

states to consistently comply with data quality standards can be challenging, given that data collection is decentralized. Sometimes the problem is ignorance of CDC quality standards. Most issues are resolved when problems are brought to the attention of the states by CDC staff. There have been occasions, however, when a state was informed of a problem and did not act to correct it (e.g., the percentage of respondents >65 years of age from one interviewer in a state was consistently much higher than in any other state but no action was taken by the state BRFSS coordinator). Similarly, there are problems each year with a few states who are late in submitting their data or correcting problems identified by CDC during processing. Such delays hold up the entire system and prevent completion of summary reports and data placement on CDC's Web site. Recently, this problem has been dealt with more forcefully by CDC through the imposition of mandatory deadlines and threats to exclude states with late data from summary reports. As a result, data availability has improved considerably: the final weighted data set for 2000 data was completed by April 2001 for all states.

Every year several states request to include additional state-added questions or optional module questions into the core instrument. For example, the BRFSS asks only a couple of questions in the core instrument about health insurance coverage, but suppose an individual state wants to include 7 additional state-added questions about this topic. Should these questions be inserted into the core after the standard BRFSS questions, or should they used only after all the BRFSS core questions have been asked? Insertion of questions into the core makes the interviewing easier and keeps respondents focused on one topic, but including them after all core questions have been asked insures that all states are using the same instrument in an identical manner and prevents the addition of new variable fields that have to be accounted for in processing.

V. Conclusion

The BRFSS has several unique aspects that make it invaluable to both states and to the federal government. The distinct federal and state responsibilities ensures that both parties have an active stake in the operation and improvement of the system. The federal-state interaction has resulted in the BRFSS being able to meet multiple needs, but the shared operational and resource responsibilities results in some inevitable tensions. The ongoing dialogue between CDC staff and state health department representatives, and the genuine federal-state sharing of power, has allowed both parties to better understand each other's needs, increased the level of trust, and resulted in satisfactory compromises. No state has "seceded" or even threatened to secede from the BRFSS, and CDC has not withheld funding or ever threatened to withhold state funding for the system. Perhaps the greatest

compliment about the BRFSS model is that it has been adopted by other countries such as China and Mexico.

VI. References

Adams M, Fitzgibbon G, Huffman S, Johnson C, Lane M, Maylahn C. *Behavioral Risk Factor Surveillance System Costs and Operational Issues. A Report of the 1995-1996 State Working Group*. Atlanta, GA: Centers for Disease Control and Prevention, 1997.

CDC. *1999 BRFSS Summary Prevalence Report*. Atlanta, GA: Centers for Disease Control and Prevention, 2000.

Ebrahim SH, Floyd RL, Merritt RK 2nd, Decoufle P, Holtzman D. Trends in pregnancy-related smoking rates in the United States, 1987-1996. *JAMA*. 2000;283:361-366.

Nelson DE, Holtzman D, Waller M, Leutzinger C, Condon K. Objectives and design of the Behavioral Risk Factor Surveillance System. In: *Proceedings of the 1998 American Statistical Association Section on Survey Research Methods*; 1998:214-218. August 1998, Dallas, TX.

Powell-Griner E, Anderson JE, Murphy W. State- and sex-specific prevalence of selected characteristics—Behavioral Risk Factor Surveillance System, 1994 and 1995. *CDC MMWR Surveill Summ* 1997; 46:1-31.