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Independent State Health Surveys: Responding to the Need for Local Population Health Data

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Abstract

Context—There is high demand for local-level population health data. A national system of state and local data collection would help improve both population health and health care delivery. The primary source of state-level population health data for adults is the Behavioral Risk Factor Surveillance System. However, many states need data on children and adolescents, racial and ethnic subpopulations, consistent estimates for localities, or more in-depth information on key topics than the Behavioral Risk Factor Surveillance System provides. Eleven state health surveys (SHSs) have emerged in an effort to address these gaps.

Design—Semistructured telephone interviews were conducted in 2009 with representatives of 9 SHSs. The interviews were recorded, and data were transcribed, organized, and analyzed according to the query structure. This analysis identified (1) the core elements of SHS that have been successful in meeting needs for local data and (2) the processes and strategies used by state officials in creating these surveys.

Results—Key findings include the following: (1) SHSs provide concrete data on local health issues that meet the needs of policy makers who wish to adopt evidence-based public health policies; (2) data from SHSs allow researchers to identify issues, apply for grants, and evaluate, assess, and track health indicators; (3) a “champion” is required to build the case for a survey and push through barriers to obtain funding and stakeholder buy-in; and (4) SHSs face challenges such as inconsistent funding and lack of uniform standards.

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Conclusion—Opportunities to support SHSs include (1) identifying sustained funding sources; (2) providing technical assistance and facilitating training to foster best practices, quality standards, and comparability across states; and (3) supporting an organization for SHS researchers to share resources, information, and experiences.

Keywords

Behavioral Risk Factor Surveillance System; community health needs assessment; evidence-based policy; health care reform; health surveys; independent state health; population health surveillance; state health surveys; surveys

There is broad agreement that public health policies and interventions at all levels of government should be evidence-based.^{1–4} Developing, monitoring, and evaluating evidence-based policies and programs require reliable data on population health that are comparable within and across states. To effectively promote evidence-based decision making, public health data must be easily accessible and usable to a broad range of stakeholders.

Improved awareness and understanding of the role multiple determinants play in public health fuel the growing demand for local population health data. In 2010, the Institute of Medicine echoed earlier reports concluding that the nation lacked appropriate measurement tools to track and assess the social, economic, and environmental factors that affect health outcomes and suggested that improving health data collection and measurement would help improve both population health and the health care system.^{5,6} Congress agreed: the 2010 Patient Protection and Affordable Care Act mandated that health data be collected and reported “at the smallest geographic level” to address health disparities based on race, ethnicity, and other social characteristics.⁷

The nonprofit Public Health Accreditation Board developed a voluntary, national accreditation program for public health departments with support from the Robert Wood Johnson Foundation and the US Centers for Disease Control and Prevention. Released in July 2011, the Public Health Accreditation Board Accreditation Standards and Measures require local health departments to “collect and maintain reliable, comparable, and valid data that provide information both on conditions of public health importance and on the health status of the population.”⁸ Recent studies conducted in Michigan, as well as in Mississippi, Missouri, New Jersey, Oregon, Pennsylvania, and South Carolina, also demonstrate the need for state-level population health data.^{9,10}

Since 1984, the primary source of state-level population health survey data on adults has been the Behavioral Risk Factor Surveillance System (BRFSS), the telephone survey established by the Centers for Disease Control and Prevention that interviews more than 350 000 adults annually.^{11–13} All 50 states, the District of Columbia, Puerto Rico, the US Virgin Islands, and Guam use BRFSS to collect information on health risk behaviors, preventive health practices, and health care access. Some states, such as New Hampshire and Massachusetts, added questions to the BRFSS in order to obtain substate data to guide planning and evaluation of public health policies or assess health insurance coverage.^{14,15} More recently, a variety of independent, state-level, comprehensive health surveys have

emerged largely independent of BRFSS.¹⁶ To learn more about independent state health surveys (SHSs), a 2-part study was conducted.

First, a systematic inventory documented the characteristics of comprehensive SHSs and any common features they share that supplement BRFSS. These findings are reported in the work of Brown et al.¹⁷ Next, the University of California Center for Health Policy Research conducted key informant interviews with the leaders who developed and implemented these independent SHSs. This study reports on the 2 primary outcomes of key informant responses from SHS leaders: (1) the core elements of the independent, comprehensive SHSs that reflect policy and research needs for local data; and (2) the evolving processes and strategies used in developing, funding, implementing, and disseminating the results of those surveys. The results provide other states with guidance for developing their own surveys, offer examples of innovative solutions to common problems, and suggest opportunities to harmonize the existing surveys into a broader national system that meets the need for state and local health data.

Methods

To be included in this study, surveys had to:

- be conducted within the previous 5 years;
- collect self-reported information from a probability sample of the civilian noninstitutionalized population;
- include questions on demographics, income, health status, health insurance, chronic conditions, and health behaviors or risk factors;
- produce state and at least 1 substate population estimate; and
- be repeated periodically.

Surveys of limited scope or content, such as those focused only on tobacco or health insurance and access to health care, were excluded. The study design was reviewed and approved September 23, 2009, by the UCLA South General institutional review board (#G09-08-073-01).

The 8 SHSs selected represent a range of approaches and innovations, as well as geographic, racial, and ethnic inclusiveness. Leaders from the New York City Community Health Survey (NYCCHS) were also invited to participate. Although it does not generate statewide estimates, NYCCHS is innovative, technically excellent, and covers the most densely populated area in the United States, which is also highly diverse racially, ethnically, and linguistically. For simplicity, this study includes NYCCHS when referring to SHSs. Characteristics of the participating surveys, including frequency, sampling frame, age groups, sample size, number of local strata, languages, and URL, are listed in Table 1.

None of the SHS contacted refused to participate in the key informant interviews, but not all SHSs could provide the information requested. The Hawaii Health Survey, for example, was first begun in 1968, and no one currently working on the survey had institutional memory going back to the survey beginnings. Because of personnel changes and differences in the

ways responsibilities were assigned at the different SHSs, multiple informants from one survey were sometimes contacted to obtain information comparable with that obtained from a single informant at the other surveys. Obtaining complete information from 9 key informants required contacting 16 individuals: 4 from New York City; 2 each from Arizona, California, Illinois, and North Carolina; and 1 each from Iowa, Missouri, Ohio, and Utah.

In 2009, each key informant answered 34 questions in a semistructured telephone interview designed to explore survey origins, common obstacles to initiating and conducting an independent health survey, strategies for overcoming obstacles, innovations used, and lessons learned. Table 2 presents the query structure, questions, and follow-up probes.

The interviews were recorded, and data were transcribed, organized, and analyzed according to the query structure. Key informants were given the opportunity to comment on or correct the transcripts. The quotations presented here were selected both to illustrate the wide variation among the state surveys and to reflect innovations used by particular states to meet their needs. When a key informant requested anonymity, quotations were attributed to “a state survey director” rather than to a specific state.

Findings

Need for state surveys

Despite the fact that all 50 states have a BRFSS, 11 states plus a number of cities, counties, and regions fielded new surveys distinct from BRFSS. These SHSs were developed in response to frequent requests for local population health data from state, county, and city governments and their partners. For example, local population health data were used to apply for grants (Iowa counties and California health agencies), evaluate a tobacco prevention initiative (Ohio foundation), assess health insurance coverage and access to health care (Utah legislature and California health agencies), track health indicators in racial and ethnic minorities (California health agencies), and track health data to respond to health crises (New York City).

The state data we were getting from Federal surveys was inadequate because what people really were interested in was the distribution of problems locally.
(California)

Mayor Bloomberg—all of them—were very data oriented. They wanted evidence, they wanted data; they wanted to be informed when they made decisions. And a lot of that didn't exist.” (New York City)

Another factor that prompted independent SHS development was the need for specific data on children and adolescents, since BRFSS surveys only adults. The National Survey of Children's Health (NSCH), also administered by the Centers for Disease Control and Prevention, is repeated only once every 4 years.¹⁸ Policy makers and advocates in 7 states (Arizona, California, Illinois, Iowa, New York City, North Carolina, and Ohio) found NSCH too infrequent to meet their needs. States also found that data on children and adolescents needed to be linked with data on parents (Arizona, California, Iowa, and North Carolina).

By doing [the North Carolina Child Health Assessment and Monitoring Program] CHAMP every year we can address issues specific to our state and look at cross tabulations across different behaviors. By doing it annually, we can look at time trends. (North Carolina)

States also found they needed data on topics not captured in BRFSS. Although BRFSS includes 1 or 2 questions on health insurance coverage, officials in Arizona, California, Illinois, Iowa, New York City, and Utah found these data insufficient. Other topics where states cited the need for additional data included chronic disease prevalence and risk factors (California, Illinois, Iowa, Missouri, and New York City), access to care (California, New York City, and Utah), health status (Arizona, New York City), tobacco prevention (Missouri, New York City), environmental factors (Arizona, New York City), and mental health (California, Illinois, Iowa, and New York City).

BRFSS questions on diet and exercise didn't go into enough detail to allow us to understand them. We were interested in things like ability to get out of the house for seniors, the availability of places for people to exercise—parks, sidewalks. Not just whether they did exercise. (Illinois)

Of the 9 SHSs represented by the key informants, 2 used their state BRFSS sampling frame to identify parents. Although BRFSS provides state-level data, some states found that differing goals, priorities, and organizational incentives at both the federal and the state levels made collaboration unworkable (Arizona, California, New York City). Four states reported that the state sample was not designed to produce representative substate and local estimates (California, Iowa, Missouri, and New York City). California also found that the state BRFSS sample was not large enough to produce estimates for ethnic and racial minorities. Illinois and North Carolina, the 2 states that did build on the BRFSS survey, said the collaboration worked because the BRFSS sample in their states was large and agencies administering BRFSS were willing to be flexible. Using parents from the BRFSS sampling frame, North Carolina administered an independent survey on child health and Illinois administered an independent survey on adolescent and child health.

While we did work with our colleagues [at BRFSS] to add some questions, it was clear that the flexibility we wanted in terms of information captured, in terms of the neighborhood-level estimates [wasn't there]. The speed with which we wanted to have that information back to start making informed policy decisions was not a good fit with the BRFSS. (New York City)

Developing state surveys

States committed to developing an SHS responded to demand for local data, and this often involved building collaborations to gain support. Some health departments initiated the survey independently (New York City, North Carolina, Ohio, and Utah); others did so in collaboration with a university (California and Iowa), hospital (Illinois), clinic (Iowa), or foundation (Arizona). Survey champions needed to build a working coalition that included supervisors and colleagues, state and local agencies, politicians, funders, researchers, the media, and the general public. When the primary survey champion was not a government

employee, it was important to find strong supporters within government to ensure their support and funding.

There's one person in particular in the Department of Public Health who believes that it's important enough that she's going to do what she can to get the funding.
(Iowa)

The broad differences in the extent of needs assessment conducted prior to the 9 surveys in this study were primarily a function of constraints on funding and time. States used a wide variety of strategies to efficiently plan a survey that would be responsive to the needs of the population. Some states organized technical advisory boards (California and Illinois), legislative task forces (Illinois), and multiagency committees (North Carolina). Needs assessment included key informant interviews (Arizona, California, and Iowa), informal conversations with leaders (California, Iowa, and New York City), group brainstorming sessions (Arizona), and formal or informal surveys of potential users of data (California and Illinois).

The planning processes for SHSs also varied widely. Illinois had no planning budget at all and relied primarily on volunteer labor from knowledgeable and committed children's hospital staff, with input from only a few stakeholders to survey parents of children in the Illinois BRFSS sample. In contrast, the California Endowment awarded 2 consecutive 18-month survey planning grants to conduct a formal needs assessment, feasibility study, and planning process that solicited input from hundreds of stakeholders and built support for the fully independent California Health Interview Survey (CHIS), a multilanguage omnibus survey of adult, child, and adolescent residents in 50 000 California households.

Stakeholders who participated in the planning process included state health departments and agencies (Arizona, California, Iowa, and North Carolina); local health departments (Arizona, California, and Missouri); policy analysts, academics, foundations, and community-based organizations (Arizona and California); and advocacy organizations (California and Illinois). In 2 examples, funding opportunities precluded a formal planning process: one state survey director reported that a foundation was willing to support the survey if it were started in 2 months; and NYCCHS was started in 2002 with \$500 000 that had to be spent by the end of the year. In some cases, funding also affected the final content of a survey (Arizona and Iowa) and how results were disseminated (Iowa). Finally, barriers to developing SHSs needed to be overcome. These included securing stable, dedicated funding and accurately predicting costs; acquiring new expertise; and overcoming both active opposition to the survey and differences in organizational culture among partners.

We organized technical advisory committees and an advisory board. These became political support for our effort—particularly among ethnic and racial minority groups in California for whom data on their groups was important, but which prior to our survey was scarce or nonexistent. (California)

Funding state surveys

Generally, independent SHSs were funded through a complex network of partnerships with multiple public and private agencies that contributed both cash and in-kind resources such as

staff time. This complex funding structure, particularly the use of in-kind resources, along with the wide variety of SHS instruments and sample sizes, makes it challenging to determine the true cost of an individual survey or to estimate comparable costs across SHSs. Key informants reported that staff members usually worked on multiple projects, making it difficult to track hours spent on a particular survey (Arizona, Illinois, Iowa, Missouri, North Carolina, and Utah). Funding partners included federal health agencies (California and Utah), the state governor's office (Arizona), and non-health-related state agencies (Utah). Some states allowed agencies, organizations, or funders to support individual questions, blocks of questions, or additional samples (Arizona, California, Iowa, and North Carolina). Iowa also pieced together contributions from multiple grants that partnering organizations received for research or program evaluation.

The Department of Public Health took pieces and parts of wherever they could find appropriate funding.... We did offer local county health departments or regional empowerment boards the opportunity to buy in. If they wanted data specific to their county, we would oversample for them at a cost. We also offered different departments within the Department of Public Health the opportunity to buy questions. (Iowa)

California actively marketed the survey and forged partnerships with advocacy groups to better inform decision makers about the need for the survey.

Our partnership with advocacy organizations, with an emphasis on getting good data on racial and ethnic minorities, helped apply political pressure and get funding. No partner was more forceful than the Asian advocacy groups who wanted a multiple language survey. (California)

Yet, an informant from New York City cautioned that some funders have unrealistic expectations, requiring too much effort in exchange for too little funding.

Key informants identified 2 events that prompted midstream changes in funding: reallocation of state funds and economic recession. North Carolina and Missouri relied on tobacco Master Settlement Agreement funds to begin their surveys, but they were forced to find alternative funding when the states reallocated the tobacco funds. Recession-driven cutbacks in foundation funding and government budgets also impacted SHSs in Illinois, Missouri, New York City, North Carolina, and Utah.

The Foundation would like to replicate [the survey]. We're attempting to look at 2010—however ... their investment income was hurt by the downturn in the financial markets and so they don't have the resources. (A state survey director)

Rigor and quality of state survey data

The technical knowledge of key informants varied, but most addressed some aspects of validity, reliability, and representativeness of their survey estimates. All informants agreed that using pretested survey questions improves the validity and reliability of survey questions and the comparability of data across surveys. All states used at least some questions drawn from federal or other SHSs, such as BRFSS (Illinois, New York City, and Missouri), the Youth Risk Behavior Surveillance System,¹⁹ the Survey of Children with

Special Health Care Needs²⁰ (Illinois and New York City), the National Health Interview Survey²¹ (California, Iowa, and New York City), Consumer Assessment of Healthcare Providers and Systems²² (Iowa), National Adult Tobacco Survey²³ (Missouri and Ohio), NSCH (New York City and North Carolina), the Colorado Health Access Survey (North Carolina),²⁴ and CHIS (Arizona, Illinois, New York City, and Utah). States also crafted their own questions, which were tested to varying degrees and met with mixed success (California, Illinois, Iowa, New York City, and Ohio).

Some SHSs created opportunities to obtain a more specialized sample at little or no cost. In California, the large sample size, coupled with extensive demographic and behavioral questions, allowed CHIS to select respondents from very low-prevalence populations, such as American Indian women who report problems with alcohol or people with cancer who use complementary and alternative therapies. Once identified, targeted individuals could be recontacted to participate in a follow-up study at a fraction of the cost it would have required to generate an equivalent sample from scratch. The New York City Community Health Survey designed a unique poststratified random-sampling methodology to produce neighborhood and citywide estimates. The NYCCHS sampling frame and call-back surveys were used to identify relatively low-prevalence groups. To improve response rates, NYCCHS conducted the second interview immediately after the initial interview or scheduled the callback with the same interviewer to avoid a loss of rapport.

This study found no uniform standards on data quality for SHSs, and states had diverse policies on data release. North Carolina used technical notes to warn users about small sample sizes and large confidence intervals, both of which contribute to data instability, but released as much data as possible. Iowa did not release data for estimates based on small sample sizes, whereas California and Utah restricted data if the coefficient of variation was larger than one-third of the estimate (consistent with NCHS policy). All of the surveys studied released local area estimates. Statewide samples rarely represent the population of each county or region. Representatives of all of the SHSs reported that the demand for local data prompted them either to use analytic methods that will provide representative estimates for small areas or populations or to gather large samples.

When samples are small you can't drill down and have statistical significance. Your analysis is very superficial and you can't do regression or anything that would provide more robust information. (Arizona)

In 2003, they had to combine the small-county data so it wasn't county-specific. In 2007, we completed 50,000 interviews. Four hundred each in 107 of the rural counties; 800 each in five of the counties that are metropolitan statistical areas, and we stratified by rural/urban in those five counties; and then 800 each in Kansas City and St. Louis City. (Missouri)

Comparing response rates across states was not possible because not all SHSs calculated response rates, some key informants did not know the response rate for their survey, and the SHSs that did calculate response rates used different formulas. The reported response rates ranged from 30% to nearly 80%. Key informants from Ohio and Utah reported using cell phones as well as landlines to increase response rates. States reported a number of technical

obstacles to collecting survey data, including low response rates, especially among linguistically isolated groups, lack of technical support, errors by survey vendors, respondent fatigue, and the tendency of respondents to give socially desirable responses. No participating state survey collected personal identifying information that would allow direct linkage of survey and administrative data. Some SHS directors developed unique solutions to overcome some of these obstacles. For example, Iowa survey leaders observed that the state's Hispanic-Latino population comprised several subpopulations, whose characteristics varied widely depending on the length of residency and immigration status, and that this was correlated with language of interview. This insight led the state to develop a unique way to analyze their data from this low-prevalence population.

When we're looking at the Hispanic-Latino population, we've got some [respondents] that are going to be third generation and some that are going to be first generation, some that are longstanding and others that are here illegally—and we end up throwing them all together. So we looked at the Latino population that answered in Spanish separately from the Latino population that answered in English ... there were significant differences between those two groups. (Iowa)

North Carolina developed a unique solution to correct inaccurate data about body mass index in children. Interviewers used preinterview instructions, precise probes during the interview, and scheduled callback surveys to improve data collection. During the telephone interview, parents were asked how they obtained their children's height and weight. If parents did not know their children's height and weight, reported estimating the data, or said that the exact measurement was taken more than 3 months earlier, the interviewer made an appointment to call the parent back within a week, allowing parents time to measure their children and provide both current and accurate measures.

Disseminating state survey data

Key informants reported that their surveys provided data that were used locally, regionally, and statewide to make policy decisions (California, Iowa, New York City, North Carolina, and Utah), develop and evaluate programs (Arizona, California, Missouri, New York City, North Carolina, and Utah), and analyze health trends (California, Missouri, New York City, North Carolina, and Utah). Data were also used in academic research (Arizona, California, Iowa, New York City, North Carolina, and Ohio), reports on specific health topics (Arizona, California, North Carolina, and Utah), conference presentations (California, Missouri, and New York City), grant applications (California, New York City, and Utah), and media outreach (California, Missouri, New York City, and Ohio). New York City Community Health Survey data were combined with data from vital statistics, hospitalization records, and Census data to provide a composite profile of aggregate zip code–defined neighborhoods. These profiles were disseminated to community advocates and used in epidemiology courses and health department grand rounds. The California Health Interview Survey created data maps for counties, fact sheets, policy briefs, research briefs, policy reports, and monographs, which were disseminated to a large mailing list that included all California local, state, and federal legislators. Missouri developed county profiles, and California, New York City, and North Carolina issued health “report cards” or progress reports.

We're able to generate very quickly highly policy-relevant data that was used, really, within months. (New York City)

There's a stark difference in tobacco prevalence between '03 to '07, [29 and 23 percent, respectively]. There's a way that we can map that on our website. We're really making a difference here and we need these kinds of data to help us continue to make the case for what we're doing. ... I looked at counties where we actually have had Tobacco Control Coalitions, there is a stark difference in the support for clean air ordinances. (Missouri)

The primary mode of dissemination for SHSs was the Internet, making data widely available and eliminating printing costs. Survey data were housed in state health agencies (Iowa, Missouri, New York City, and North Carolina), universities (Arizona, California, Iowa, and Ohio), foundations (Arizona and Missouri), and a hospital research center (Illinois). States published reports of findings, policy briefs, data maps, community health profiles, and public use data sets on their Web sites. Three states offered Web-based query tools on their Web sites (Arizona, California, and New York City), 4 had public use data sets available for download (California, New York City, North Carolina, and Ohio), and 3 offered confidential data sets that researchers could access through a formal application process (Arizona, California, and Ohio). The California Health Interview Survey developed its own online data analysis tool, *AskCHIS*, which has become a model for many other state and federal surveys.

I had tried out a couple of query systems, which seemed to be highly regarded, and I thought they were cumbersome—not easy to use.... I had the idea that we were going to have a query system which would be user friendly, didn't require a program to be downloaded to a local computer, and would give the user the ability to craft their own query for the data and generate tables that would meet their needs. ... and we said, "well, let's build our own." (California)

Reflecting the tremendous variation in states' investments in dissemination (ranging from zero in Illinois to \$1.5 million over 9 years in California), assessment of dissemination needs, planning, and practices varied widely.

Anyone can go to www.NYC.gov/epiquery and do increasingly sophisticated analyses so that we don't have to respond to data requests one by one. We also have a unit that does process data requests and provides public use data sets. (New York City)

We don't have any formal dissemination process and we haven't done any needs assessment. Maybe there is a need out there that we're not meeting and we just don't know it yet. (Utah)

We don't actually hear and we may never know [who uses our data] ... wish we had a little better sense of how the data were being used. (Iowa)

Most states interacted with and could identify many data users by category, including funders (Arizona and California), university researchers (Arizona, California, Iowa, New York City, North Carolina, and Ohio), local public health agencies (California, Missouri, New York City, Ohio, and Utah), state health agencies (Arizona, California, Missouri, New

York City, Ohio, and Utah), community-based organizations and advocacy groups (California, New York City, North Carolina, and Utah), health coalitions and taskforces (Missouri, New York City, and North Carolina), the media (California, Missouri, New York City, and Ohio), health care reform task forces (Utah), city councils (New York City), and the state legislature (Arizona, California, Illinois, Iowa, New York City, and Utah). Only CHIS formally tracked data users by requiring registration and login from users who access the Web-based query system or the public use data files. Its 28 000 registered users have made more than 350 000 successful queries since *AskCHIS* was launched in 2002. Ohio innovatively encouraged the academic community to use data from the Ohio Family Health Survey by offering competitive research grants to Ohio students and faculty for conducting a project with policy implications.

We had this RFA process where researchers affiliated with Ohio universities could apply for small grants to do something with the data. It had to have policy implications. They would do an analysis, write up a report, and hopefully a publication, and then also write up a policy brief. We had a meeting in June for the researchers to present their results to the public. (Ohio)

Survey organizers and stakeholders found the dissemination of SHS data challenging. The amount of data could be overwhelming, and resources often were inadequate to support effective analysis and dissemination. Some stakeholders did not know how to use the data, lacked the capacity to analyze large data sets by themselves, or had unrealistic expectations about the specificity of data. California and Iowa trained potential end users on how to access, use, and interpret survey data. Online tutorials and community training workshops make the data accessible to constituents with low technical capacity. Similarly, NYC-CHS conducted community outreach, presented data generated by the surveys outside the department, and promoted the data internally to health department colleagues. Arizona, California, and New York City each created user-friendly, online query systems. Stakeholders needed to be continually reengaged, because some were tempted to suppress or discredit data that did not support their political goals or preconceived notions about a topic.

There is a huge amount of data. It took much, much, much longer to define the questions you want to ask. It's not enough to just say, "Oh, I want to know everything," because everything is completely overwhelming. (Arizona)

The Health Department sees some of the worst cases of different conditions that are measured by the survey. They were surprised to find rates lower [than they expected].... Health status [estimates] might not be as bad or the unmet need rates might not be as bad as what they see. So then they would dismiss the [estimates].... (Iowa)

States with robust dissemination plans, such as California, Iowa, and New York City, reported that most end users prefer simple, user-friendly analyses rather than complex research reports.

Really emphasize policy briefs that are simple, short, graphically interesting and target issues that many policymakers and advocates would be keenly interested in. (California)

Study Limitations

Funding and Office of Management and Budget survey burden limitations made it impossible to include representatives from every independent SHS, so the study was limited to 8 SHSs plus NYCCHS. Equivalent information was not always available for all of the surveys. On some topics, key informants reported on events that occurred many years in the past, which introduced the possibility of recall bias. Not all key informants responded to every question with equal detail. When a key informant was not prepared to address questions on a given topic, the interviewer focused on other aspects of the survey and asked the key informant to suggest additional respondents. This might give the impression that a finding associated with an individual state is not also true for other states; however, it may be a reflection of the different expertise, experiences, and priorities of the key informants. In addition, all the data were self-reported and not independently verified.

Lessons Learned and New Opportunities

Lessons learned

This study suggests several important lessons for states planning an SHS, along with strategies for existing surveys to address funding, technical issues, and dissemination. The SHSs studied were developed in response to demands for population health data at the state, regional, and local levels, especially on children, adolescents, and topics either not covered or insufficiently covered in federal surveys. State and local policy makers, advocates, and researchers use these data to build an evidence base for appropriate public health action. To meet these local data needs in a timely manner, survey leaders reported that they required more control over the survey content, time frame, frequency, sample design, and data files than offered by BRFSS or the National Health Interview Survey.

Each survey had at least 1 individual who aggressively built the case for a survey and pushed through barriers to obtain funding and buy-in from stakeholders. It seems clear from this study that other states seeking to develop their own local survey initiatives will need a persistent champion.

Funding and time constraints resulted in dramatically different planning processes, survey content, and dissemination of results. Obtaining funding, sustaining funding, and adapting to midstream funding changes are constant concerns for state survey directors, and some partnered with stakeholders and advocacy groups to increase political support and access to funding. Several have joined forces to advocate for future federal funding for independent SHSs, and these efforts may benefit from parallel efforts to integrate and harmonize survey data on state and local public health spending.²⁵

All states used at least some questions drawn from other state or federal health surveys and several crafted their own questions, which were tested to varying degrees and met with mixed success. Survey planners seeking to collect data on children or adolescents reported significant technical issues and challenges. This study did not ask, and it is not known, whether most items across SHSs are consistent and comparable.

No uniform standards on goals, survey design, items, or release of stable estimates for SHSs were found. No participating state survey collected identifying information that would allow direct linkage of survey data with administrative data, although some surveys are exploring this possibility. Clearly, states are eager to meet the demand for local data by releasing data on local areas as small as possible to extend the scope of evidence available for policy, program, and research purposes. Each state survey set its own standards for data reliability and validity, balancing SHS funding and demand for local data with release of estimates based on small sample sizes with large confidence intervals. States used different methods to calculate response rates, so response rates across states could not be compared.

States had diverse policies on data release. Investments in dissemination ranged from zero to \$1.5 million over 9 years. At a minimum, every state survey posted raw data and, in some cases, findings on a Web site.

New opportunities to support state health surveys

This study suggests opportunities for public and private agencies to support the development of SHSs. Identifying, and possibly providing, consistent funding sources would be ideal. To make funding a priority, SHS leaders and advocates will need to demonstrate ways in which SHSs provide data that will improve public health and reduce health care costs. Although this study found diversity in goals, survey design, items, and estimate stability, it did not explore this diversity in any detail. This area is ripe for further investigation.

Perhaps, the most important first step would be to document and compare the items used to collect data in each of the SHS. Creating a question bank of pretested survey items, such as the one available through the UK Data Service,²⁶ would facilitate collaboration among SHS leaders and funders, particularly in harmonizing items and establishing best practices and minimum quality standards. This concept has been endorsed by SHS leaders and outside experts who participated in informal meetings and a National Institutes of Health Office of Behavioral and Social Sciences Research workshop.

Another opportunity for technical assistance would be to develop an online data query tool that SHSs could use to pool their data and conduct analyses across surveys. The California *AskCHIS*, the Arizona *AHS Answers*, and the New York City *epiquery* tools provide outstanding models. Additional studies have reviewed a variety of approaches to implementing Web-based data query systems adopted by other states and may prove useful in planning new data query systems.^{27,28}

An emerging National Network of State and Local Health Surveys is providing technical assistance and training for state statisticians, epidemiologists, and health services researchers who are working to develop and advance state and local health population health surveys. Funded by a 2011 grant to UCLA from the Robert Wood Johnson Foundation, the network grew out of a series of informal “Breakfast of Champions” meetings, cosponsored by UCLA and the National Cancer Institute. The network, which held its first meeting in October 2011 prior to the American Public Health Association annual meeting, has developed a Web site (<http://statelocalhealthsurveys.net>) and plans to convene an annual meeting, produce an e-newsletter, and work with partners to support the Public Health Systems and Services

Research program sponsored by the Robert Wood Johnson Foundation. The network will focus primarily on technical support and disseminating data and results.

In summary, this study showed that successful and enduring SHSs are characterized by a persistent “champion,” state and local advocates, consistent funding, a plan for data collection, a strong and committed staff, and creative dissemination of raw data and findings (which can, in turn, help generate advocates). The new National Network of State and Local Health Surveys is positioned to assume a leadership role in developing national guidance and standards to advance systematic collection of population health data at the state and local levels, especially by promoting a survey question bank. Federal assistance, through both funding and technical support, would accelerate this process consistent with new health care legislation and evidence-based policy and practice.

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We dedicate this article to E. Richard (Rick) Brown, a nationally recognized public health leader who advocated for health care reform and pioneered the collection and broad dissemination of health survey data to influence policy.

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TABLE 1

Characteristics of Participating State Health Surveys

Survey Name	URL ^a	Frequency	Sampling Frame	Age Groups	Sample Size	Number of Local Strata	Languages
Arizona Health Survey	http://www.arizonahealthsurvey.org/	Biennial since 2008	New	Statewide	4000 adults	2	English
				18	600 children	Maricopa County Balance of state	Spanish
				Maricopa County only	200 adolescents		
				0–11			
				12–17			
California Health Interview Survey	http://www.CHIS.ucla.edu	Biennial since 2001	New	18	50 000 adults	44	English
				0–11	10 000 children	41 counties	Spanish
				12–17	4000 adolescents	3 multicounty regions	Chinese
				18			Vietnamese
Illinois Health Survey	http://www.illinoishealthsurvey.org/Home.php	2008 ^b	BRFSS	0–11	500 households with children	Chicago	Korean
				12–17			English
				18			Spanish
Iowa Child and Family Household Survey	http://ppc.uiowa.edu/2010-ihhs	Every 5 y since 2000	New	0–4	4000 children	8 regions	English
				5–9			
				10–14			
				15–17			
Missouri County-Level Survey	http://health.mo.gov/data/cis/	2003	New	18	50 000 adults	115	English
		2007				114 counties St Louis	
New York City Community Health Survey	http://www.nyc.gov/html/doh/html/data/survey.shtml	Annual since 2002 ^c	New	18	10 000 adults	42 neighborhoods	English
				0–12	3000 children		Spanish
							Russian
							Mandarin
							Translation service ^d
North Carolina Child Health Assessment and Monitoring Program	http://www.schs.state.nc.us/units/stat/champ/	Annual since 2005	BRFSS	0–17	4000 children	28	English
						25 largest counties	Spanish
						3 regions	

Survey Name	URL ^a	Frequency	Sampling Frame	Age Groups	Sample Size	Number of Local Strata	Languages
Ohio Family Health Survey	http://grc.osu.edu/omas/	1998 2004 2008 2010	New	0–17 18	50 000 adults 13 000 children	88 Counties	English Spanish
Utah Health Care Access Survey	http://health.utah.gov/opha/OPHA_UHAS.htm	1991 1996 2001	New	18 Limited data on children	9000 adults in 3000 households	12 Local health districts	English
		Annual since 2003 ^e		5–17			

Abbreviation: BRFSS, Behavioral Risk Factor Surveillance System.

^aAll URLs were accessed July 26, 2012, and these URLs were updated at that time.

^bPilot; plans for biennial.

^cChild survey began in 2009 and repeated subject to funding.

^dTranslation service was available until 2008.

^eMerged with BRFSS in 2009.

TABLE 2

Semistructured Interview Questions and Follow-up Probes

Origin of the Survey	Technical Aspects	Funding Sources and Strategies	Dissemination and Data Use	Support for Future Surveys
<i>Why did your state choose to conduct a state health survey in addition to the BRFSS?</i>	<i>Do you feel comfortable answering technical questions about the survey?</i>	<i>Who are the financial partners supporting the survey now and who were they in the past?</i>	<i>Do you use a planning process for dissemination of results or findings?</i>	<i>How did you settle on the (particular survey model used by this state as identified prior to the interview)? What worked and what didn't?</i>
What gaps did it fill?	If no, skip to question 15 in the section on funding sources and strategies.			Where applicable, ask about survey-specific innovations (these innovations will be researched and identified for each state prior to the interview), collaborations, survey organization, sample design, measurement or methods, and dissemination.
Why did you choose not to work with BRFSS?				
<i>Who initiated the survey?</i>	<i>Where did you get your survey questions?</i>	<i>What was the total cost of the most recent survey you have conducted?</i>	<i>How were the data disseminated?</i>	<i>One goal of this project is to foster a community of like-minded researchers to provide support for high-quality survey research at the state and local levels. What would that look like for you? What kinds of support would be most helpful?</i>
Was this effort spearheaded by a particular individual?	Were they standard questions used in national surveys?	Did that include data collection and cleaning, and data analysis?	Modes?	Best practices?
Which organizations sparked this effort?	If not, were they pretested?	Cost per interview?	Target audience?	Sharing resources and information?
Was it initiated as a result of a particular event or need?			Focus on certain topics?	Establishing quality standards?
				Technical support?
				Fostering comparability across surveys?
<i>Was a needs assessment conducted, and if so, what kind?</i>	<i>Do you have criteria for releasing stable estimates? If so, what are they?</i>	<i>What was the dissemination budget?</i>	<i>For what purposes have the data been used?</i>	<i>Is there anything else you would like to share about support that would be helpful to your survey?</i>
If so, was it a survey, key informant interviews, or some other method?		<i>Who funded it?</i>	For example, surveillance, program development, policy, program evaluation, health trends over time, academic research?	
<i>Was there a participatory planning process with stakeholders?</i>	<i>For which geographic areas can you produce representative estimates? Did this require pooling multiple years of data?</i>	<i>How are you able to sustain funding? What obstacles do you face?</i>	<i>Who has used the data?</i>	
If so, who or which organizations were represented at the table?	If the sample wasn't stratified for localities, did they develop weights at the back end?	Does the budget change much from survey to survey?	For example, advocacy groups, the media, policy makers, researchers, not-for-profit organizations, businesses, etc?	
How was it conducted?	Small area estimates?	Do you have plans to field surveys in the future?		

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Origin of the Survey	Technical Aspects	Funding Sources and Strategies	Dissemination and Data Use	Support for Future Surveys
<p>How did you build commitment among stakeholders?</p> <p>Did the stakeholder planning process have influence on the final survey?</p> <p>If so, did it influence the focus, topics, sample design, or dissemination plans?</p>	<p><i>What was your response rate and how was it calculated?</i></p>	<p><i>What are some of your strategies for working within a limited budget?</i></p>	<p><i>Do you track the number and type of individuals who used the data? How?</i></p>	<p>Public use data sets, confidential data sets, Web query engine?</p>
<p><i>Where did the initial funding come from?</i></p>	<p>Please see the attached document to select from one of many common formulas.</p>	<p><i>What lessons have you learned about securing funding?</i></p>	<p><i>Has the data met the needs of the policy audience? If not, what would you change?</i></p>	
<p><i>What obstacles did you encounter and how did you overcome them?</i></p>	<p><i>Do you, or can you, link survey data to administrative data?</i></p>	<p>Survey development? Implementation? Reporting?</p>	<p>Do you collect Social Security numbers or some other specific identifying information needed to link these data?</p>	
<p><i>What were the lessons learned from the planning process?</i></p>	<p><i>Is there anything else you would like to share about the technical aspects of the survey?</i></p>	<p><i>Is there anything else you would like to share about funding?</i></p>	<p><i>Who houses the data and how was that decision made?</i></p>	
<p><i>Is there anything else you would like to share about how the survey came about?</i></p>			<p>If there is a confidential data set: Who is the data custodian?</p>	
			<p>If there is a query engine: On whose Web site is the query engine hosted?</p>	
			<p><i>What were the main obstacles to dissemination?</i></p>	
			<p><i>What lessons have you learned from the dissemination process?</i></p>	
			<p><i>Is there anything else you would like to share about the dissemination process?</i></p>	

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