STATE SOLUTIONS FOR HEALTH DATA CONTINUITY

Data Gap Strategy Brief Series

shadac STATE HEALTH ACCESS DATA ASSISTANCE CENTER

rwjf robert wood johnson foundation

Investment in State Surveys

In the wake of a dynamic environment for federal data infrastructure, state health policy professionals have grown concerned about whether they will continue to have access to data they need for evidence-based policymaking. Uncertainties include the potential cancellation or scaling back of critical surveys, reduced federal survey staffing that could undermine data quality or technical assistance, and the possibility that public data releases may be curtailed or restricted.

To identify strategies to fill potential data gaps caused by federal survey disinvestments, the State Health Access Data Assistance Center (SHADAC), as part of its State Solutions for Health Data Continuity project funded by the Robert Wood Johnson Foundation, conducted discussions with 46 diverse experts and stakeholders, including state data analysts, survey data collectors, researchers, and foundations. During these discussions, SHADAC was able to gather insights on people's top concerns about emerging and potential gaps in federal surveys, and explore various potential alternatives and strategies for filling state-level data gaps.

We have created a series of "Strategy Briefs" that review a selection of strategies or "alternatives" for filling federal data gaps, identified both through these discussions and from SHADAC's expertise.

This brief provides a high-level overview of the strategy: **Investment in State Surveys**. Along with a general description of this gap filling strategy, SHADAC experts will also summarize identified advantages, disadvantages, and implementation considerations for data users and other interested parties.

Complement, not Substitute

A recurring theme across our stakeholder discussions was the **potential for data from state surveys to fill emerging gaps**. However, we repeatedly heard that this strategy should be employed **to *complement*, rather than *substitute*, federal survey data**. State surveys cannot completely replace federal survey data, as federal survey data provide a standardized, U.S.-wide view that enables national benchmarking and cross-state comparability.

Critically, SHADAC experts stressed that state surveys often require or rely on data from federal surveys for methodological purposes, such as in calibration for weighting of survey data. In spite of this, discussants also universally agreed that state survey data sources could **help fill gaps** that might emerge as the federal government reduces investments in survey data and **complement federal health data** that is collected and released with additional state-level data.

Strategy Description

State health surveys collect data at the state level on topics including health insurance coverage, health behaviors, health care access and use, and affordability. State health surveys can be tailored to each state's unique communities and populations, collecting state-focused data that can inform decisionmaking and policy development.

For the purpose of this brief, we consider state surveys to be distinct from federal surveys that operate in partnership with states, such as the Behavioral Risk Factor Surveillance System (BRFSS). A forthcoming strategy brief will provide more detail on how federal surveys with state components can help fill data gaps.

SHADAC has long tracked state survey research activity. Some examples of long-established, state-level health-related surveys include:

- The California Health Interview Survey (CHIS)
- The Massachusetts Health Insurance Survey (MHIS)
- The Minnesota Health Access Survey (MNHA)
- The Ohio Medicaid Assessment Survey (OMAS)
- The Oregon Health Insurance Survey (OHIS)

State surveys have historically functioned as data sources that can provide state-specific data to policymakers to inform decisions on coverage, budget, health policy, and others, often complementing information from federal sources by filling information gaps or providing greater granularity than can be found in federal surveys.

A key historical driver of state surveys came in the late 1990s and early 2000s when Children's Health Insurance Program (CHIP) expansion efforts required states to report detailed data and documentation on progress in reducing children's uninsurance. A 2006 paper from SHADAC experts explains that many states would "struggle to meet these evaluation requirements" because the estimates states needed on the number of uninsured low-income children were not generally found in readily available data sources, such as administrative data and federal survey data.[1]

Federal surveys could be used to obtain some estimates, but those sources had limitations. While state surveys do not *replace* the need for or use of administrative data or federal survey sources, SHADAC's experts note that, "over time, many states have developed their own state household surveys to fill the gaps in federal data and produce a more detailed understanding of state populations, programs, and unmet insurance coverage needs."[1]

This example highlights that state surveys have long been used a gap-filling strategy in the face of federal survey and administrative data gaps, providing a proof-of-concept to demonstrate how they are suited to be applied in the current context.

Investment in state surveys as a strategy for filling data gaps could include two pathways, each with their own considerations, advantages, and disadvantages:

1. **Creating and fielding new state surveys** in states that do not currently field a state-level health survey
    a. This could be done by individual states, or in collaboration with multiple states.
2. **Expanding or continued investment in existing state surveys**
    a. Investment in an existing state survey could include revising a survey with updated methodology (e.g., over-sampling demographic subgroups), adding questions, or fielding additional or supplemental components of a survey to fill gaps.
    b. Groups of states could collaborate to align their survey methodology, entire instruments, or individual questions to enhance comparability of estimates—something that is not always possible with individual state surveys, which can differ in meaningful ways.

Investment in State Surveys: Strategy Advantages

- **Tailoring Survey Questions to State- or Data-Specific Needs**
  State-level health surveys allow states to collect data on public health topics, address critical data gaps with tailored questions, and target specific populations that are relevant to a state. This localized approach can be especially compelling for state policymakers and who require state-specific insights to guide effective decisionmaking.

- **Authority Over Survey Methodology, Sampling**
  State surveys also allow each state to choose methodology that suits their needs and resources. For instance, a state particularly interested in public coverage could integrate a specific Medicaid sampling frame drawn from administrative data; a state could develop a panel to repeatedly survey a sample of respondents on emerging topics; or it could conduct a longitudinal survey to assess the impact of a policy over time.

Investment in State Surveys: Strategy Disadvantages

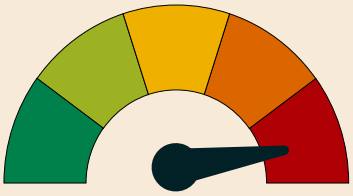
- **High Resource Intensity**
  Creating or expanding state health surveys can be a costly process. It often takes substantial funding, time, and staffing, as well as specialized expertise to perform the work associated with a survey. This work includes engaging stakeholders, designing the instrument and methodology, fielding the survey, analyzing the data, and disseminating results. Alongside these investments, there are also ample monetary and time costs associated with data governance, security, sharing, and storage. While there may be some economic efficiencies from states collaborating on surveys, such collaborations and associated complexities are also likely to increase costs in other ways.

- **Comparability and Benchmarking**
  A number of federal surveys allow for state-level estimates and comparison between states (or the U.S. average), as well as supporting the ability to compare data over time. Each of these would be challenging, and in some cases nearly impossible, to accomplish with state-level surveys. While states collaborating on a shared survey or aligned surveys would have opportunities to design for comparability, supporting U.S.-level or 50-state estimates would entail a major undertaking with substantial resources. Additionally, many state surveys use federal survey data for benchmarking and weighting, meaning that state surveys would still likely be reliant on federal surveys for such purposes.

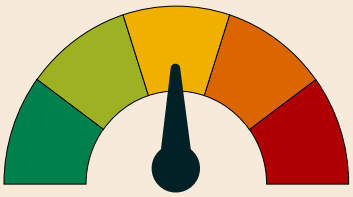
- **Response Rates and Respondent Trust**
  Survey response rates have broadly been declining for years, with Americans' trust in government and other institutions that conduct surveys also in decline.[2,3] There is some evidence that bringing a survey to a more proximate level of government, such as a respondent's own state, could help gain trust from respondents.[4] But that approach is unlikely to mitigate all the reasons people might be unwilling to answer an entire survey or individual survey questions. For instance, asking questions on politically charged issues, other sensitive topics, and certain personal demographic information could result in reduced response rates and biased data. Long survey instruments can also burden respondents in ways that reduce survey data completeness and quality; states attempting to fill many data gaps with a single, lengthy survey may face these challenges in prioritizing data collection.

- **Survey Sustainability**
  Surveys are often most useful when conducted consistently over a period of time, allowing for trend analyses to detect changes over time, such as changing rates of uninsurance or eroding affordability of health care. To support a survey on an ongoing basis for many years, stewards must make investments in engaging stakeholders and maintaining those relationships. This includes funders or potential funders—including state agencies and legislatures, and non-governmental entities, such as philanthropies—as well as those who rely on the survey for its data to serve their purpose. Survey stewards will need to consider the advantages and disadvantages of different models, such as having a single major sponsor versus many partners. For instance, having many partners could risk creating a long and complex survey and process, whereas a single sponsor could pose sustainability risks if that funder were to reduce or eliminate support.

Resource Intensity



New State Survey
High



Continued Investments in Existing Survey
(e.g., adding questions, alignment with other states, etc.)
Medium

Actors

State data collectors and users

Policymakers

Vendors

Funders

Timeline

If state survey already exists, additional or expanded investment could act as stopgap for loss of certain federal data

Establishing a new survey, or aligning an existing survey across states, would take significant time, funding, dedicated staffing, and collaboration, making it a longer-term alternative

Investment in State Surveys: Examples and Implementation Considerations

As mentioned previously, state-level surveys have often been used as a data gap filling strategy; such surveys have the potential to provide informative data on issues specific to individual states, populations, and regions. Continued or increased investment in state health surveys can help to solidify them as essential health data sources for states, both by continuing to field and analyze state-level data as well as providing opportunity for survey expansion or revisions as needed to fill data gaps.

For states that *do not* currently field their own survey, this strategy could involve **establishing a new survey**. Establishing and fielding a new state survey would be a large, resource-intense undertaking, requiring ample funding and personnel. In-house survey expertise varies, making the feasibility of this strategy dependent on a state's resources.

States could leverage technical assistance (TA) options to help them as they start the process of creating or investing in their own survey. Organizations such as SHADAC offer support in survey development, execution, and analysis, with years of experience providing practical guidance. States could also choose to rely more heavily on external vendors to field and analyze the survey if they do not have the in-state capacity to do so themselves, although this comes with expense.

States establishing a new survey could also look to other states or examples of recently established state surveys for guidance on overall process and to understand questions that need to be asked and answered, who to engage with, and more in the current landscape. This SHADAC resource provides an annually updated repository of State Survey Research Activity, indicating which states field a household survey, employer survey, or both relating to health insurance coverage and access—states could consider seeking assistance from other states that already have established surveys to leverage their learnings and expertise.

One example of a recently established state health survey is West Virginia's Mountain State Assessment of Trends in Community Health (MATCH) survey, a biennial survey first fielded in 2021. Operating as a partnership between West Virginia Department of Human Services (DoHS) and the West Virginia University Health Affairs Institute, MATCH is funded by a combination of state and federal funds.[5] Survey development, implementation and dissemination planning, and testing occurred in phases over a multi-year period.[6] In developing this health survey, the MATCH survey team engaged in TA, received input from state agencies such as the West Virginia Department of Health, and looked to other already established state surveys (such as the California Health Interview Survey and the Ohio Medicaid Assessment Survey) to help inform the MATCH survey.[7]

Recently, various regional collaboratives or coalitions have formed amongst states, such as California, Hawaii, Oregon, and Washington's West Coast Health Alliance and the Northeast Public Health Collaborative that includes states such as Massachusetts, New York, and Rhode Island. Leveraging these collaboratives to share information on surveys and data collection could help as states seek to promote evidence-based public health policy and decisionmaking. Additionally, such collaboratives could also be useful for coordination and alignment of survey questions between and across states to allow for comparability of data.

Further investment in already existing surveys would be another strategy to continue to provide quality, state-level health data to researchers, policymakers, and more. For example, in 2025, Minnesota conducted a survey to understand Minnesotans' opinions on Medicaid as new program policies were being considered at the federal level.[8] The survey was conducted with a "panel" of people who agreed to be recontacted after participating in the Minnesota Health Access Survey (MNHA). This allowed researchers and policymakers to better understand state-level perspectives on an important and policy-relevant topic in the moment.

State surveys can also address gaps left by federal sources, such as food security data no longer collected through the Current Population Food Security Supplement, or questions on sexual orientation and gender identity (SOGI) that have been removed or altered on a number of federal sources.[9,10] However, as noted earlier, states should consider how adding questions could influence respondent burden or potentially contribute to bias in estimates.

Some state surveys, like the Minnesota Health Access Survey (MNHA), are mandated and consistently funded by state law. However, this approach may not be possible in all states, and a single funder can pose risks. An alternative model requires engagement with multiple funders. For example, the Colorado Health Access Survey (CHAS) has been fielded biannually since 2009 and is funded by a mix of health foundations (such as The Colorado Health Foundation), state government agencies (such as the Colorado Department of Health Care Policy and Financing) and other supporters (such as the Colorado Hospital Association).[11,12]

Additionally, states should consider the extent to which funders, partners, and collaborators might be able to influence the direction of a survey. With the Colorado example, the CHAS website states that while funders and partners are not able to influence the "survey process, analysis, or presentation of results," they may fund specific areas of the survey process (e.g., supporting data analysis, dissemination support), or they could sponsor specific questions or request analysis of a certain subset of the data.[11] Securing multiple external funding sources requires states to establish clear protocols for partner input. This prevents the survey from expanding too broadly, growing excessively long, or losing annual trend consistency, while ensuring all collaborators remain mission-aligned.

Other investments to state surveys could be **working to align state health survey questions or form collaborations across neighboring states or regions**. This could help to promote information and expertise sharing, allow for cross-state comparisons of data, and provide researchers, analysts, and policymakers with more overall data on topics or populations that are at risk of being lost in federal data sets.

With all the benefits of investing in state level surveys, there are barriers to utilizing this alternative as a gap-filling strategy. For example, many states lack the in-house expertise or capacity to create or field state health surveys on their own. This means many states would likely need to work with survey vendors or other external entities for successful implementation, which can be costly and logistically difficult, especially as many states face tight budgets or lack staffing or capacity to maintain additional relationships.

Additionally, every option within this strategy requires a significant investment in time. Initiating a new survey can take months or even years. This timeline excludes the additional months required to field the survey, collect, clean, analyze, and disseminate the findings before any data gaps can actually be filled. Adding questions to an existing survey is likely be the best stopgap option within this strategy, especially if that process is already set up or a state has leveraged other states or TA to implement new or aligned questions or topic-specific panels.

Continued monitoring, experimentation, and technical support for data users are essential parts of implementing data gap filling alternatives and strategies; SHADAC plans to continue research and provide technical assistance in this area—contact us with questions or feedback.

Interested in learning about other alternatives and strategies for filling potential data gaps? Find and read the other iterations of SHADAC's Strategy Briefs here.

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