



Collaborating to Fill Emerging Federal Data Gaps

State Solutions for Health Data Continuity

June 23rd, 2026

Agenda

1 hour

Lines muted

- State Solutions for Health Data Continuity
 - Overview
 - Practical Solutions from the Data User Perspective
- Action-Oriented Workgroups
- Technical Assistance (TA)
- Next Steps

15 minutes (optional)

Lines unmuted

- TA Requests and Questions

State Solutions for Health Data Continuity

Ensure states have the robust data infrastructure needed for health policy, program evaluation, and health equity research.

Assess Vulnerabilities

Identify critical gaps in state-focused health data if **federal surveys** are eliminated or investments are reduced

Strategize Continuity

Develop actionable, **state alternatives** to ensure high-quality health data remains available for decisionmaking processes

Federal Surveys with Health Data



Survey Data Finder



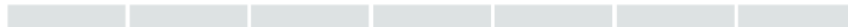
Which federal surveys have the data I need?

Instructions: To identify potential gaps in survey domains, open the drop-down menu below and select which surveys you want to include in your review.

Domains	Examples	Data Gap?	Surveys				
			American Community Survey (ACS)	Behavioral Risk Factor Surveillance System (BRFSS)	Current Population Survey Annual Social and Economic Supplement (CPS-ASEC)	Health and Retirement Study (HRS)	Medical Panel Survey (MPS)
Criminal Justice Involvement	Arrest & incarceration history	-	-	-	-	-	-
Health Behaviors	Exercise, diet, seatbelt use	-	-	✓	-	✓	✓
Health Care Access	Usual place of care, unmet need, cost-related barriers	-	-	✓	✓	✓	✓
Health Care Utilization	Provider visit in past year, SUD treatment	-	-	✓	✓	✓	✓
Health Conditions	Heart disease diagnoses, diabetes diagnoses	-	-	✓	-	✓	✓
Health Insurance	Health insurance costs, health insurance coverage type	-	✓	✓	✓	✓	✓
Health Limitations	Functional limitation, learning or developmental disabilities	-	✓	✓	✓	✓	✓
Health Screenings	Breast cancer screening, colon cancer screening	-	-	✓	-	✓	✓
Health Status & Characteristics	Self-reported health status, height & weight	-	-	✓	✓	✓	✓
Maternal-Child Health	Pregnancy, number of pregnancies, birthweight, breastfeeding duration	-	-	✓	-	-	-
Mental Health	Mental illness diagnoses, anxiety & depression symptoms	-	-	✓	-	✓	✓
Parenting Activities	Reading & singing with children, caregiving duties	-	-	-	-	-	-
Reproductive Health	Fertility treatment, sterilization, endometriosis	-	-	✓	-	✓	✓
Satisfaction	Individuals' satisfaction with their providers, health insurance coverage	-	-	-	-	✓	✓
Sexual Health & Behaviors	Contraceptive use, sexual activities	-	-	-	-	-	-
Social Determinants & Adverse Childhood Experiences (ACEs)	Food insecurity, bullying exposure	-	-	✓	-	✓	✓
Substance Use	Tobacco use, alcohol use, cannabis use	-	-	✓	-	✓	✓
Vaccinations	Flu shot in past year, up-to-date on childhood vaccines	-	-	✓	-	✓	✓

Instructions: Use scroll bar to view additional surveys.

Number of surveys with data on each domain based on above selection:



Additional Survey Details

Specifications	Surveys			
	American Community Survey (ACS)	Behavioral Risk Factor Surveillance System (BRFSS)	Current Population Survey Annual Social and Economic Supplement (CPS-ASEC)	Health and Retirement Study (HRS)
Demographics (e.g., age, education, race & ethnicity)	✓	✓	✓	✓
Economic Characteristics (e.g., income, home ownership, public assistance benefits)	✓	✓	✓	✓
Survey Focus (health focus)	Broad population survey (health insurance)	Health status, conditions, risks	Labor force survey (health insurance)	Aging issues among elderly and near-elderly adults
Population (i.e., sample frame)	Total population	Non-institutionalized civilian adults	Non-institutionalized civilians	Non-institutionalized adults, age 50+
Ages	Children	-	✓	-
	Non-elderly adults	✓	✓	✓ (age 50+)
	Elderly adults	✓	✓	✓
Geographies (representative)	National	✓	✓	✓
	State	✓	✓	-
	Sub-state	✓	-	-
Cross-sectional vs. Longitudinal	Cross-sectional	Cross-sectional	Longitudinal	Longitudinal
Survey Documentation	2023 ACS data dictionary	2023 BRFSS codebook	2024 CPS ASEC codebook	HRS codebooks
Website	ACS (U.S. Census Bureau)	BRFSS (CDC)	CPS-ASEC (U.S. Census Bureau)	HRS (University of Michigan)

Instructions: Use scroll bar to view additional surveys.

[Click here to return to the main dashboard](#)

SHADAC's interactive "Survey Data Finder" Tool

Building Practical Solutions from the Data User Perspective

- **State Perspective:** State policymakers, analysts, and state survey data collection teams
 - Collected insights from 10 states: **AR, CA, CO, IN, KY, MD, MN, MS, OR, WV**
- **Research and Technical Experts:** Academic and non-academic researchers, former federal agency staff, and data collectors
- **Strategic Stakeholders:** Advocates, associations, and survey research firms
- **Philanthropy:** National and state-based foundations

No Replacement for Federal Surveys and Federal Survey Experts

- Serves as the **gold standard**, creating standardized data across all 50 states, enabling true comparability and national benchmarking
- Serves as a **methodological anchor** for the entire industry, offering technical methods and design approaches that states and other organizations adopt
- Provides **foundational estimates** that function as critical building blocks for decisionmaking
 - Acts as the primary data source for developing representative survey weights
 - Supports statistical models used to analyze the effects of state policy changes
 - Supplies data that providers rely on for community needs assessments
- Supports **robust, stable funding** to sustain the complex, long-term data collection efforts involved

The math does not work on philanthropy replacing government. Government has trillions of dollars, philanthropy has billions.

- Philanthropist

[When we collect data,] we want to use a validated survey instrument, and we don't have the capacity to test and validate our own questions.

- State Data Collector and User of Federal Survey Data

Primary Concerns

Data Loss

Full survey elimination and removal of content

Elimination of Summary Data

Loss of tools, tables, or reports that make data more accessible

Erosion of Data Quality and Transparency

Increasing data anomalies, vanishing technical documentation

Loss of Institutional Knowledge and Expertise

Loss of staff and access to technical assistance

Data Manipulation

Data tampering, public messaging and website banners

Uncertainty

Unclear timelines and changes to federal data landscape

*Some [federal officials] have been working with data for decades, and they are **THE** expert on that topic and that survey. The institutional knowledge that has been lost is vast. And that means that there's a potential for unintentionally introducing bias into the surveys.*

- Non-Academic Researcher

Strategic Considerations for Data Continuity

- Decisionmakers are not always aware of the role of federal survey data in state-level policy development, assessment, and monitoring
- There is a fundamental tension between implementing immediate stopgap measures to bridge federal survey gaps and committing resources to build entirely new state-level data infrastructure
- Current challenges come after years of disinvestment and declining response rates—solutions must prioritize efforts to modernize and innovate
- Solutions must be viable for all 50 states, regardless of their political climate, budget constraints, or technical sophistication

The red states are going to feel the pain with the lack of data and the impact of that as much or more than any other state in the country. And, if you can make it [data collection] work in a red state, it's probably going to work in a blue state...we need to understand how to create solutions that will endure [in all states].

- Philanthropist

Gap-Filling Challenges

- Expense and financial sustainability
- Identifying trusted and authoritative convenors
 - Unclear who has the authority to establish shared goals and methodological standards
 - Lack of consensus about who is trusted to lead the effort across diverse stakeholders
- Determining the precise moment to invest
 - Avoiding premature over-investment while ensuring data users are not caught flat-footed

One researcher we spoke with tried to get ahead of a data gap by contacting individual states to secure data typically collated by a federal agency. Ultimately, the data system came back online and that effort was wasted...

The system went live again. So that represented a couple months of work and chaos and delays...

- Academic Researcher

Action in the Face of Uncertainty

Varying appetite for immediate state primary data collection, but a universal desire to stay connected, share information, and start coalescing around solutions and priorities.

**Action-Oriented Workgroup
Convenings**



**Customized Technical
Assistance**

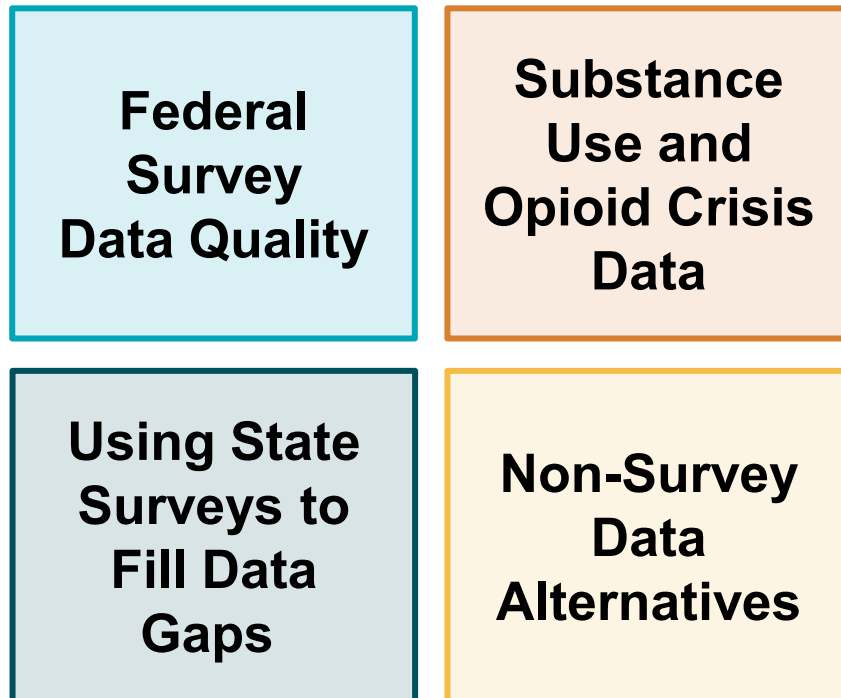


Action-Oriented Workgroups

- **Focus:** Targeted content, designed to troubleshoot technical barriers, identify pressing concerns, and generate standardized, scalable solutions
- **Format:** Virtual, interactive, and SHADAC-led, with guest subject-matter experts as needed
- **Frequency:** Varied, one-hour sessions, no more than quarterly
- **Safe Space:** To encourage frank conversations about state challenges, these will be invite-only and conversations will remain private to the workgroup

Shaping Our Workgroup Priorities

Potential Workgroups



Time to give feedback!

Vote in the Live Polls

After we present potential workgroup topics, an on-screen poll will ask you to indicate whether you think this is a priority for the field.

Use the Chat

Have a specific survey data concern you want to see addressed? Drop your content suggestions, unique state data challenges, or questions directly into the chat.

Sign up for a workgroup invitation list

If a specific topic is of interest and you want to participate, we will ask you to indicate this at the end.

Workgroup: Federal Survey Data Quality

A collaborative, action-oriented forum for state survey data users navigating increasing uncertainty regarding the quality, consistency, and transparency of federal health datasets.

Potential discussion topics:

- **Trend-break detection:** Identifying unusual shifts in trend data versus typical year-over-year variation.
- **Weighting and variance audits:** Monitoring for unexpected changes in standard errors and checking for consistent variance across sub-populations.
- **Sample size and geography tracking:** Assessing the loss of geographic granularity and its impact on sub-state or small-population estimates.
- **Imputation monitoring:** Tracking item nonresponse rates and opacity of federal imputation models.
- **Cross-survey/cross-data source validation:** Developing frameworks to cross-check federal estimates against state administrative data or alternative surveys.
- **Metadata and documentation audits:** Evaluating the transparency, timeliness, and completeness of federal codebooks and user guides.

Workgroup: Substance Use and Opioid Crisis Data

Exploring strategies for continued and improved availability of data for measuring drug-based public health risks, guiding the deployment of interventions, and evaluation of efforts to mitigate the opioid crisis and other substance use issues.

Potential discussion topics:

- **Risk assessment:** Identifying level of risk—both level of likelihood and impact—of emerging federal gaps in substance use data sources (e.g., NSDUH, YRBSS).
- **Leveraging existing data:** Assessing options for better using existing data (e.g., health care claims, EHR data) to fill potential data gaps.
- **New data collection:** Expanding on innovative measurement efforts (e.g., street-drug testing surveillance, waste water testing).
- **Improvements in state data infrastructure:** Enhancing existing state data sources (e.g., BRFSS, vital statistics mortality data) by adding new questions/variables, improving granularity of data collection and reporting.
- **Data for the future:** Existing data sources on substance use already had gaps and limitations; how can new data sources improve on, rather than reproduce, shortcomings of legacy data?

Workgroup: Using State Surveys to Fill Data Gaps

Cross-state collaboration and action to use, align, or expand stand-alone or federally supported state health surveys to fill data gaps.

Potential discussion topics:

- **Survey expansion:** Expanding existing stand-alone state health survey efforts (i.e., new items, new geographies).
- **Item harmonization:** Aligning on a particular survey item or supplement in either stand-alone and/or federally supported state health surveys (e.g., BRFSS).
- **Coordinated data processing:** Collaborating on processing of data elements no longer supported by the federal government.
- **Adaptive sampling:** Sharing survey sampling methods for reaching hard-to-reach populations.
- **Alternative weighting:** Identifying methodological alternatives if federal surveys are no longer available for survey weighting.
- **Funding solutions:** Highlighting promising practices for sustaining state-level primary data collection over time.
- **New surveys:** Launching a new, stand-alone primary data collection effort.

Workgroup: Non-Survey Data Alternatives

Assess and access non-survey data (e.g., administrative data, clinical data) for use alongside survey data for health care and public health monitoring, research, and decision support.

Potential discussion topics:

- **APCD utilization:** Accessing and using state All-Payer Claims Databases.
- **Administrative data alignment:** Identifying other administrative data collected routinely by states for cross-state harmonization and reporting.
- **T-MSIS:** Leveraging state Medicaid and CHIP enrollment data or data stored in the CMS Transformed Medicaid Statistical Information System (T-MSIS).
- **Clinical records access:** Overcoming barriers to using clinical data, including sharing EHR data validation techniques and documentation.
- **Data linkages:** Exploring linkages to non-survey data in primary data collection to reduce respondent burden.

What Topics Are Missing?

***Are we missing any workgroup topics
you'd like to see?***

Individualized Technical Assistance (TA)

Who We Support

- We can provide customized, complimentary TA to health data professionals, researchers, and policymakers who:
 - Rely on federal survey data for state-level work
 - Engage in or manage state-specific survey data collection
 - Conduct state health policy work, program design (like Medicaid), or public health interventions that rely heavily on robust data

How We Can Help

- Data Navigation: Identify alternative data sources if federal data is delayed or terminated
- Primary Data Collection: Support for designing and implementing state, local or program-specific survey efforts
- Quality and Methodology: Data quality assurance and navigating complex methodological shifts
- Analysis and Coding: Hands-on assistance with programming and data analysis
- Access and Compliance: Navigate secure data access requirements

Are there questions or technical assistance topics you want to share with us privately?

Closing and Next Steps

Stay Connected:

- Stay in the Zoom Room: We are holding an optional 15-minute Q&A at the end of this call to discuss workgroups or your specific TA needs
- Connect Online: Submit a question or technical assistance request at shadac.org/contact-us

Related Resources



Stay Up-to-Date: [Follow Us on LinkedIn!](#)

- [State Solutions for Health Data Continuity: Project Webpage](#)
- [Survey Data Finder, Interactive Tool](#)
- Brief Series: [Actionable Strategies for State Data Professionals Navigating Federal Data Gaps](#)

This series of briefs is designed to provide data users with alternatives for filling potential emerging data gaps; each brief provides a high-level roadmap of an alternative data strategy, including its advantages, disadvantages, and implementation considerations. The gap-filling strategies we describe in these briefs include:

- Investment in State Surveys
- Leveraging Electronic Health Record Data to Complement Data from Federal Surveys
- Leveraging Health Insurance Claims Data to Complement Data from Federal Surveys
- A Selection of Additional Project Publications:
 - [Sexual Orientation and Gender Identity \(SOGI\) Data Collection and Availability in Federal Health Surveys and Beyond](#) (February 2026)
 - [Examples of Federal Health Data Preservation Efforts Across the U.S.](#) (January 2026)
 - [Taking the Pulse of the Nation's Households: The Value of Real-Time Survey Data During an Era of Rapid Policy Change](#) (January 2026)
 - [The Landscape of Major Federal Health Survey Data Releases in 2025](#) (November 2025)
 - [Navigating a Path Forward Through Health Data Uncertainty](#) (August 2025)

Optional: TA Requests and Questions

- Optional session (15 minutes)
- Stay on the line
- Lines will be unmuted

Do you have questions about the project, workgroups, or technical assistance?