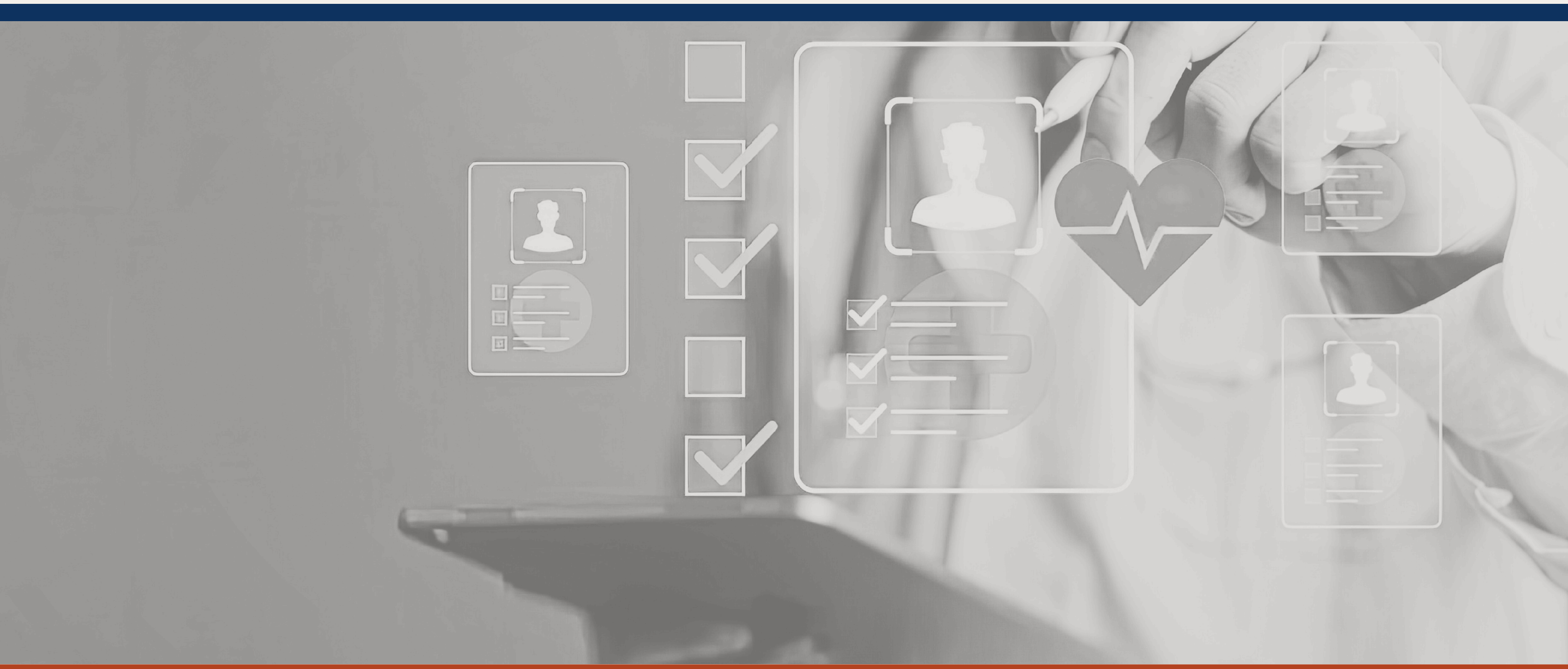
CIVITAS
Networks for Health®

Assessing the Changing Landscape of Public Health Data

FINAL REPORT

March 2026



CIVITAS
Networks for Health®

ABOUT

Civitas Networks for Health® (Civitas) is the leading voice and convener for organizations working to use data to improve health in communities across the country. By bringing together local implementers—Health Information Exchanges (HIEs), emerging Health Data Utilities (HDUs), Community Information Exchanges (CIEs), Regional Health Improvement Collaboratives (RHICs), All Payer Claims Databases (APCDs), Quality Improvement Organizations (QIOs), and other multistakeholder groups—we foster data-driven collaboration that creates national impact while staying rooted in local realities.

Civitas members serve as critical national infrastructure for health and include a wide range of organizations that work together at the local, regional, and state levels, providing vital support to the nation's health infrastructure. Our members invest in data-driven collaboration to enhance health by addressing cost, access, equity, quality, and safety. They are leading the way in every state through health data exchange, data analytics, adoption of technology, and the application of multi-stakeholder, cross-sector collaborations to develop sustainable solutions.

To learn more, visit the Civitas website at www.civitasforhealth.org.

TABLE OF CONTENTS

Support for this report was provided by the Robert Wood Johnson Foundation (RWJF). The views expressed here do not necessarily reflect the views of the Foundation.

EXECUTIVE SUMMARY

In early 2025, more than 8,000 federal webpages containing datasets, guidance, standards, and tools used by state and local public health agencies, health information exchanges (HIEs), and partner organizations were removed. Based on the findings from the Assessing the Changing Landscape of Public Health Data surveys, their removal created gaps in authoritative data and guidance, increased reliance on ad hoc workarounds, fragmented data flows, and reduced situational awareness, thus impairing timeliness, rigor, and credibility of public health decision-making.

A September 2, 2025, court settlement required restoration of “taxpayer-funded webpages, databases, and critical resources,” but uncertainty about completeness, integrity, update cadence, and long-term stewardship persisted. Concurrent reductions in federal staffing and technical assistance compounded concerns about maintenance and support, introducing ongoing operational risks for states and intermediaries.

For this effort, Civitas Networks for Health® (Civitas) aimed to assess these impacts and develop actionable recommendations to support continuity of access to critical public health data and guidance.

Civitas convened its State Health Technology Commons, a collaborative of state health technology leaders, and the Civitas Public Health Workgroup, a forum for Civitas member HIEs, all payer claims databases (APCDs), quality improvement organizations (QIOs), and regional health improvement collaboratives (RHICs) using data to support public health, to assess the scope and consequences of the federal webpage removals, document operational impacts and suggest potential solutions that are reflected in the recommendations. The project employed a mixed-methods design that integrated two structured quantitative surveys, targeted qualitative engagement (virtual learning community calls and facilitated workshops), systematic documentation of data availability, and a landscape review of archived and alternative sources.

Civitas approached this effort as an unbiased, fact-finding inquiry: stakeholders were engaged transparently, input was collected systematically and confidentially, and findings were driven by documented evidence and cross-validated data rather than advocacy positions. This neutral posture enabled Civitas to surface operational realities, aggregate diverse perspectives, and produce recommendations grounded in verifiable impacts and practical feasibility.

EXECUTIVE SUMMARY

Through the information gathering via surveys, workshops, and literature scan, the following examples were identified as high impacts resulting from the information removal:

- Disruptions to public health surveillance, maternal and child health programs, disease-specific guidance, and equity-focused initiatives.
- The removal or modification of datasets and guidance related to maternal health, sexual orientation and gender identity (SOGI), race and ethnicity, rural populations, and environmental justice constrained agencies' ability to monitor disparities, design targeted interventions, and communicate transparently with affected communities.
- Smaller rural and resource-constrained states were disproportionately harmed due to limited analytic capacity and reliance on federal sources.
- The loss of federal institutional infrastructure and knowledge, as well as technical assistance, increased staff burden and workforce training needs.
- Missing guidance related to interoperability standards, electronic health record (EHR) certification guidance, provider enumeration data, and federal reporting requirements impacted system development and operations.*
- Funding-related activities, including grant reporting, grant writing, and budget and strategic development were consistently identified as experiencing high levels of disruption.

The findings demonstrated that federal datasets, standards, and guidance function as core public health infrastructure rather than supplemental resources. Their removal exposed structural dependencies, increased administrative burden, and introduced risks to continuity, equity, and public trust. Moreover, the proliferation of archived datasets across multiple repositories, while well-intentioned, further complicated the landscape, requiring states and HIEs to expend significant effort to validate provenance, integrity, and fitness for use.

---

*This content was removed during the government shutdown; its absence nevertheless supports the report's thesis that removal of guidance undermines planning and operations.

EXECUTIVE SUMMARY

This report concludes that strengthening public health resilience requires not only restoring individual datasets, but also re-establishing confidence in the stability, governance, and stewardship of national public health infrastructure. To that end, Civitas offers a set of coordinated recommendations that provides a systematic approach for states, intermediaries, funders, and national partners to reduce future disruptions, stabilize public health data ecosystems, and ensure sustained access to the data and guidance necessary for effective, equitable public health action.

Recommendations include:

- Focusing on aligning and coordinating multi-funder efforts.
- Establishing a trusted resource directory and reusable vetting framework.
- Supporting neutral-entity-hosted, multi-state learning forums and regional maintenance consortia.
- Integrating resilience into state data strategies.
- Formalizing partnerships between public health agencies and local intermediaries to restore and maintain trust in data sharing.

BACKGROUND

In early 2025, a series of executive actions resulted in the removal of more than 8,000 federal webpages that contained data, guidance, and other resources widely used by state and local public health agencies.[1] Between January 21 and February 11, 2025, the Centers for Disease Control and Prevention (CDC) removed 203 datasets, which is 13 percent of its online datasets.[2] These resources support core public health functions including surveillance, program planning, research, policy development, and emergency response. The loss presented potential gaps in access to epidemiologic datasets, surveillance tools, and policy documents, which posed significant potential disruption to population health assessments and intervention design. Jurisdictions faced potential risks of increased reliance on ad hoc workarounds, fragmented data flows, and reduced situational awareness. These circumstances could also impact the timeliness and rigor of public health decision-making and, in some cases, public trust.

Given the potential threats and great concern, swift action for legal mitigation was deployed. A court settlement on September 2, 2025, mandated restoration of “taxpayer-funded webpages, databases, and critical resources,” but uncertainty remained about the timing, completeness, and maintainability of restored assets and the capacity of federal and partner agencies to update and support them.[3]

Recognizing the pending harm of the datasets being removed and altered, RWJF identified a need for a landscape assessment to better understand and test assumptions of the ramifications resulting from core public health data no longer being available.

---

[1] https://www.kff.org/hiv-aids/a-look-at-federal-health-data-taken-offline/
[2] https://scholarship.law.bu.edu/faculty_scholarship/4044/
[3] https://www.pbs.org/newshour/politics/trump-administration-agrees-to-restore-federal-health-data-and-websites-in-lawsuit-settlement

PROJECT OVERVIEW

In this context, Civitas Networks for Health® (Civitas) was awarded a grant to survey and learn from its members and key contributing partners across the United States. Civitas convened its State Health Technology Commons (Commons), a collaborative of state health technology leaders, and the Civitas Public Health Workgroup (PHWG), a forum for Civitas member HIEs, all payer claims databases (APCDs), quality improvement organizations (QIOs), and regional health improvement collaboratives (RHICs) using data to support public health, to assess the scope and consequences of the removals and to identify practical strategies to mitigate information loss.

This project aimed to document which of the removed federal resources were being relied upon, measure the operational impact on public health jurisdictions, capture existing local mitigation approaches, and develop actionable recommendations and a curated compendium of archived data sources to support continuity of access to essential public health information.

Civitas Networks for Health®

Civitas Networks for Health® is a national collaborative comprised of member organizations working to use health information exchange, health data, and multi-stakeholder, cross-sector approaches to improve health.

State Health Technology Commons

The State Health Technology Commons aims to foster cross-state agency and community partnerships to implement strategies, policies, and technologies that advance health information interoperability and reusable infrastructure.

Civitas Public Health Workgroup

The Public Health Workgroup provides a forum for Civitas members to convene on key topics of interest and workstreams within public health.

PROCESS/METHODOLOGY

Overview

The project employed a mixed-methods design that integrated two structured quantitative surveys, targeted qualitative engagement (virtual learning community calls and facilitated workshops), systematic documentation of data availability, and a landscape review of archived and alternative sources. Activities were sequenced to:

(1) Identify impacts and data gaps through survey distribution,
(2) Validate findings with respondents,
(3) Compile and verify a curated resource inventory, and
(4) Produce consensus recommendations informed by survey results and stakeholder discussions.

Impact Assessment Survey

Survey respondents were drawn from the Commons and the Civitas PHWG. Two tailored surveys were administered electronically: one to Commons members to assess effects on state public health jurisdictions' access to and reporting of data, existing workarounds, alternative resources, and operational impacts; and a second to Civitas PHWG participants, and other targeted Civitas partners, to capture impacts on data sharing intermediaries, such as HIEs, and other research organizations. The full survey instruments are available in the Appendix of this report.

Reminder messages and follow-ups were used to maximize response rates. Survey responses were exported for quantitative analysis and coding of open-text responses.

Curated List of Removed datasets and Guidance Documents

Alongside survey development, a curated reference of archived sources and data aggregators was compiled to validate the accessibility of key public-health datasets and guidance. This effort entailed systematic searches of federal sites, web archives, partner repositories, and major aggregators to verify availability, locate archived copies or mirrors, and document access pathways and limitations. The result is a draft compendium cataloging removed datasets and guidance documents, with notes on accessibility status and archival locations. The curated list of datasets and alternative resources are available in the Appendix of this report.

Learning Community Calls and Facilitated Workshops

In December 2025, two virtual learning community calls were convened, one with Commons members and one with members of the Civitas PHWG, to present preliminary survey findings, clarify responses, and solicit real-time feedback and additional resource leads.

PROCESS/METHODOLOGY

Following these discussions, in January 2026, two facilitated virtual workshops, one with Commons members and one with members and additional partners of the Civitas PHWG, were held to review and further validate findings, identify the most impactful data needs, and co-develop pragmatic mitigation and restoration strategies. Inputs from the workshops were recorded, transcribed as needed, and mapped back to the draft recommendations to ensure recommendations reflected stakeholder priorities and operational realities.

Final Report and Recommendations

Quantitative survey responses were analyzed descriptively to characterize the scope and prevalence of reported impacts, while qualitative data from open-text survey items, the learning calls, and workshop outputs were coded thematically to identify recurring impacts, workaround strategies, and investment needs. These analyses are synthesized into this final report that summarizes findings and a prioritized set of actionable recommendations for jurisdictions, data aggregators, federal partners, and foundations interested in supporting continued work.

Project Limitations

While this project yielded many valuable insights, the findings reflect the perspectives of a limited subset of individuals affected by the removal of federal datasets and guidance documents. A primary challenge was identifying and engaging in the full range of impacted staff within each state public health agency. Organizational structures vary widely across states, and staff who rely on federal datasets and guidance are often distributed across multiple divisions and program areas. As a result, there is rarely a single individual with comprehensive visibility into all agency-wide impacts.

To address this challenge, Civitas relied on members of the Commons to identify and engage colleagues most likely to have experience with or knowledge of the removed federal webpages and to encourage broader participation within their agencies. Civitas also recommended that Commons members, many of whom work in Medicaid agencies, request that specific individuals at their state department of health such as epidemiologists, data modernization directors, public health informaticists, and data analysts complete the survey and participate in the facilitated workshop. In parallel, Civitas contacted each state's designated public health epidemiologist using the Council of State and Territorial Epidemiologists (CSTE) public directory and partnered with the Association of State and Territorial Health Officials (ASTHO) to distribute the survey through its Informatics and Data Modernization Network (IDMN).

FINDINGS

Survey Findings

As stated above, Civitas leveraged the Commons to survey state public health agencies and the Civitas PHWG to survey HIEs and other Civitas members and partners to identify the impact of federal webpage, guidance, and datasets that were removal in early 2025 as result of the Administration's executive orders.

Whereas the surveys were conducted in late November, shortly after an extended government shutdown, survey results reflect not only the impact of the intentional removal of datasets and guidance on federal websites but also the impact of not having access to information during the government shutdown. Additionally, since some datasets were restored because of the August 2025 Washington State Medical Association et al. v. Kennedy et al. lawsuit settlement, the surveys also gathered information on the integrity of the restored datasets.

Survey results reflect responses from 39 individuals representing 15 states (5 of which submitted responses by more than one individual), 11 HIEs (both nonprofit and state administered), 2 public health research organizations (with 2 responses from one organization), 1 territory and 1 federal partner.

Survey responses indicate that the removal of federal webpages, datasets, and guidance materials had widespread and operationally significant impacts across state health departments, HIEs, and public health partner organizations. Respondents consistently reported disruptions to core public health functions, including surveillance, health equity analysis, grant reporting, program planning, and standards-based interoperability work. Respondents also expressed uncertainty regarding the completeness, timeliness, and reliability of restored content, limiting their ability to resume normal operations.

The most frequently cited data losses involved foundational public health surveillance and equity datasets, including the Behavioral Risk Factor Surveillance System (BRFSS), the Social Vulnerability Index (SVI), Morbidity and Mortality Weekly Reports (MMWR), the Youth Risk Behavior Surveillance System (YRBSS), and the Pregnancy Risk Assessment Monitoring System (PRAMS). These resources are widely used across public health programs rather than within single initiatives, meaning their removal created compounding effects across multiple projects simultaneously. Additionally, most state public health agencies use numerous federal datasets like the ones mentioned above, resulting in widespread challenges across the agency.

Findings also highlighted that the impact extended beyond data access to include the loss of critical infrastructure and institutional knowledge. In several cases, respondents noted that some of the removed SharePoint sites, vocabularies, and repositories of standards (e.g., PRAMS documentation, PHINVADS, USCDI-related guidance) functioned as institutional infrastructure and operational systems

FINDINGS

that supported daily workflows, onboarding, and compliance. Their removal resulted in the loss of protocols, technical guidance, and historical context that could not be easily recreated due to the simultaneous reduction in federal staffing referred to as reductions in force (RIF).

The magnitude of impact varied by organization type. State health departments most frequently emphasized disruptions to surveillance systems, disease-specific guidance, maternal and child health data, and health equity resources, while HIEs and health IT partners reported greater impacts related to interoperability standards, provider enumeration data, EHR certification guidance, and federal reporting requirements. These differences reflect distinct operational dependencies but underscore a shared reliance on federal resources to support alignment, consistency, and accountability across the health system.

Smaller and more rural states reported disproportionate impacts, citing limited capacity to generate statistically valid state- or local-level data independently. For these states, federal datasets often serve as the primary or sole source for population health analysis, maternal health surveillance, and health equity monitoring. Respondents noted that data loss exacerbated existing resource constraints and reduced their ability to meet legislative, grant, and public reporting obligations.

Finally, respondents identified equity-related impacts as concerning and problematic. The removal or alteration of resources related to gender identity, racial and ethnic equity, and maternal health constrained the ability of agencies to monitor disparities, design targeted interventions, and communicate transparently with affected communities. Several respondents also reported a growing lack of trust in federal partners, driven by inconsistent communication, lack of confidence in restored datasets including the uncertainty around restoration timelines and quality of the data, and the reduced access to technical assistance.

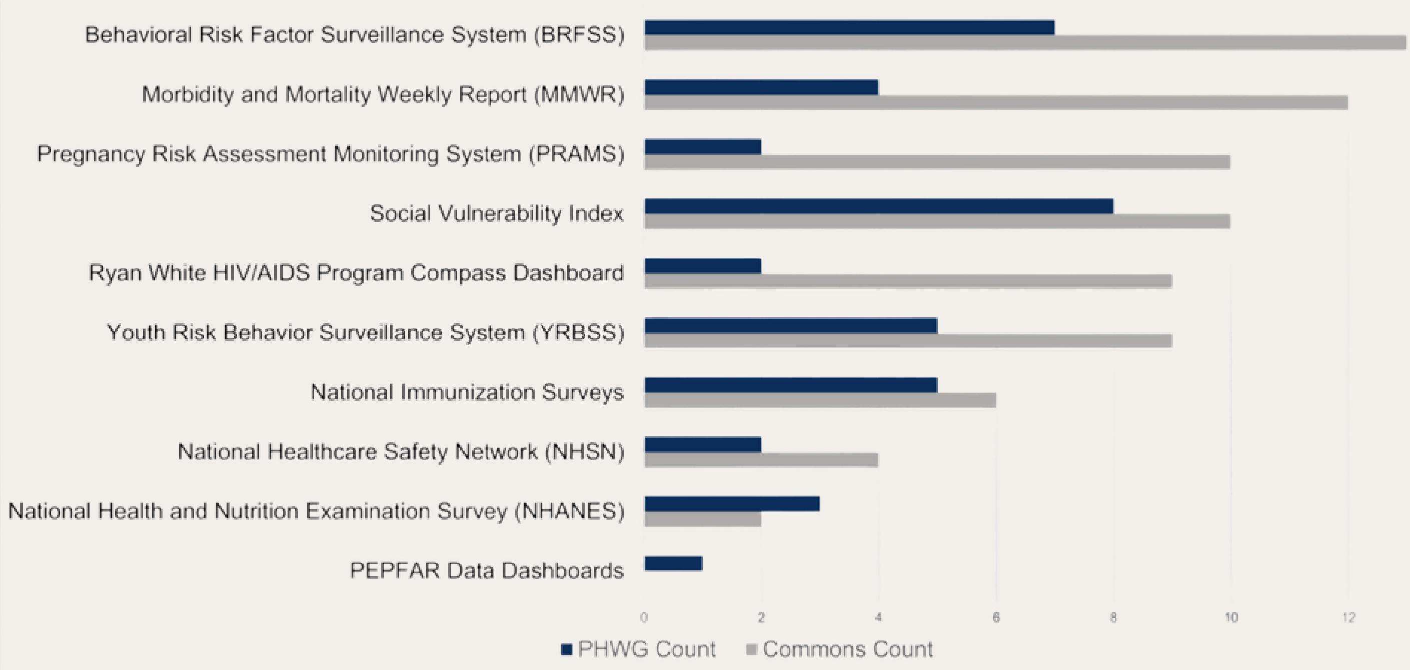
FINDINGS

Detailed Survey Findings

To begin assessing the impact of the removal of federal datasets, policy materials, and guidance documents on state public health agencies and HIEs, Civitas first sought to identify which specific resources respondents previously relied upon. As shown in the chart below, state respondents indicated that the removal of the Behavioral Risk Factor Surveillance System (BRFSS), Morbidity and Mortality Weekly Report (MMWR), Pregnancy Risk Assessment Monitoring System (PRAMS), Social Vulnerability Index (SVI), HIV program data, and Youth Risk Behavior Surveillance System (YRBSS) datasets had the most significant impact on their operations.

While fewer HIE respondents reported reliance on removed datasets, those that did identified a similar set of resources as critical, including BRFSS, SVI, YRBSS, and the National Immunization Survey (Figure 1).

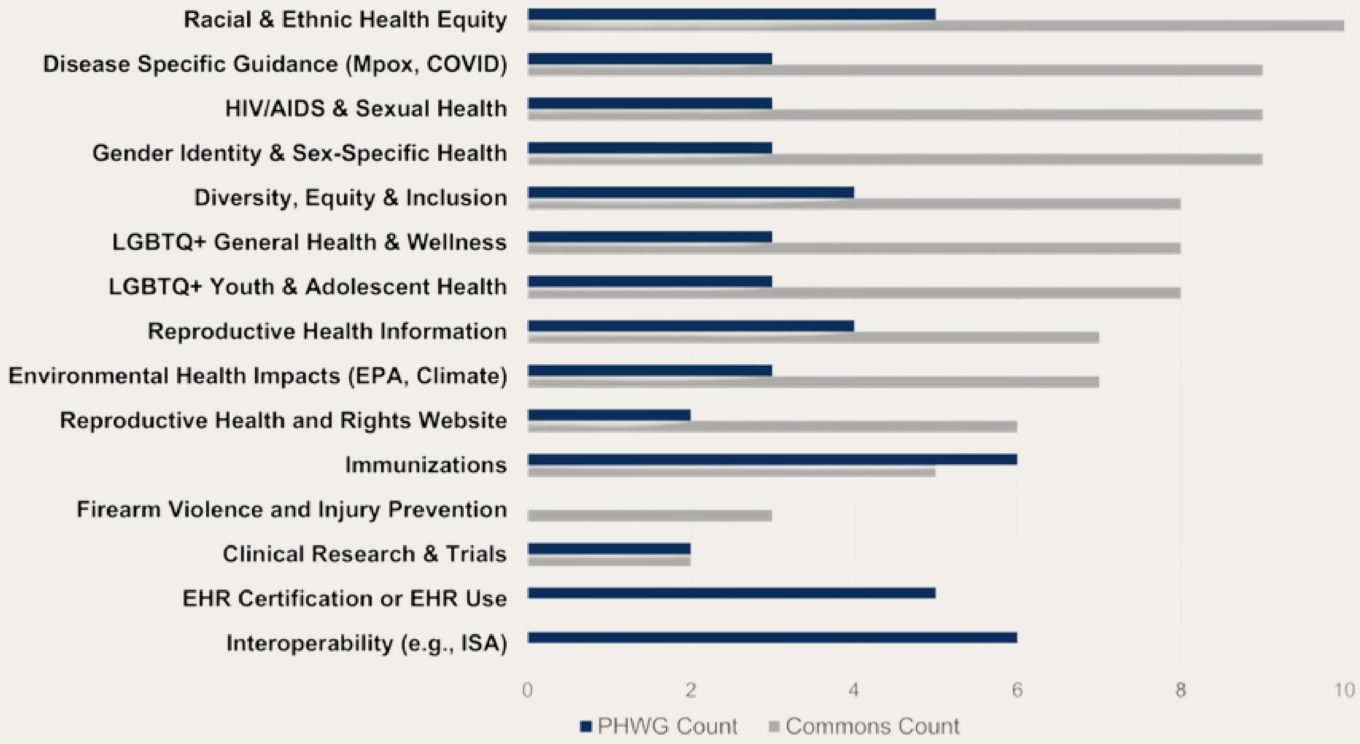
Figure 1: Which databases were removed that your department, programs, and users relied upon?



The removal of datasets was not limited to data assets alone. Respondents also reported the loss of federal policy and guidance documents as having notable operational impacts. State agencies most frequently relied on documents related to racial and ethnic health equity, diversity and inclusion, disease-specific guidance, HIV/AIDS, sexual health and gender identity, environmental health, and reproductive rights. In contrast, the documents most frequently used by HIEs were focused on immunizations, EHR certification standards and use, interoperability, and federal grant opportunities (Figure 2).

FINDINGS

Figure 2: Which removed policy or guidance pages did your organization or associated program previously rely upon?



Respondents were also asked to identify additional databases or guidance materials that had been removed and were relevant to their work. State respondents reported relying on resources from multiple federal agencies, including the CDC, Environmental Protection Agency (EPA), Department of Justice (DOJ), and U.S. Department of Agriculture (USDA). These resources spanned a wide range of use cases, including crime statistics related to LGBTQ+ populations and health equity, clinical guidelines for the treatment of sexually transmitted infections (STIs), syndromic surveillance data, documentation supporting electronic case reporting and electronic laboratory reporting, and environmental health risk data (Table 1).

FINDINGS

Table 1 – What other databases were removed that your organization relied upon that were not listed?

ACRONYM	FULL NAME	AGENCY/OWNER	PURPOSE & FUNCTION	IMPACT AREAS
NCVS	National Crime Victimization Survey	Bureau of Justice Statistics (DOJ)	Survey measuring crime victimization; includes SOGI (Sexual Orientation and Gender Identity) demographic items	Crime statistics victimization research, LGBTQ+ health equity data
PHINVADS	Public Health Information Network Vocabulary Access and Distribution System	CDC	Centralized system for accessing, searching, and distributing standardized vocabularies used in public health information systems	Syndromic Surveillance eCR (electronic Case Reporting), ELR (Electronic Laboratory Reporting)
STI	Sexually Transmitted Infections	CDC	Clinical treatment guidelines for sexually transmitted infections	STI prevention, treatment, protocols, clinical practice
IRIS	Integrated Risk Information System	EPA	Human health assessment program evaluating health effects from environmental contaminant exposure; contains ~570 chemical assessments with toxicity values	EPA regulations, state environmental programs, Superfund cleanups, RCRA hazardous waste decisions, toxic chemical exposure assessment
PPRTV	Provisional Peer-Reviewed Toxicity Values	EPA	Second-tier toxicity values for Superfund and RCRA programs when IRIS assessments unavailable; provides provisional reference doses and cancer risk values	Superfund site remediation, hazardous waste cleanup, drinking water contamination response, community exposure risk assessment
USDA Food Insecurity	USDA Food Insecurity Data Set	USDA Economic Research Service	National and state-level food security statistics measuring household access to adequate food	Food assistance programs (SNAP, WIC), nutrition policy, social determinants of health research

FINDINGS

Consistent with the findings above indicating that HIEs primarily seek data and guidance related to interoperability and data exchange, respondents identified several additional datasets and resources that had been removed. These included the United States Core Data for Interoperability (USCDI and USCDI+), the National Plan and Provider Enumeration System (NPPES), resources associated with the Federal Health Information Technology Advisory Committee (HITAC), and select national surveys focused on mental health and social needs (Table 2).

Table 2 – PHWG: What other databases were removed that your organization relied upon that were not listed?

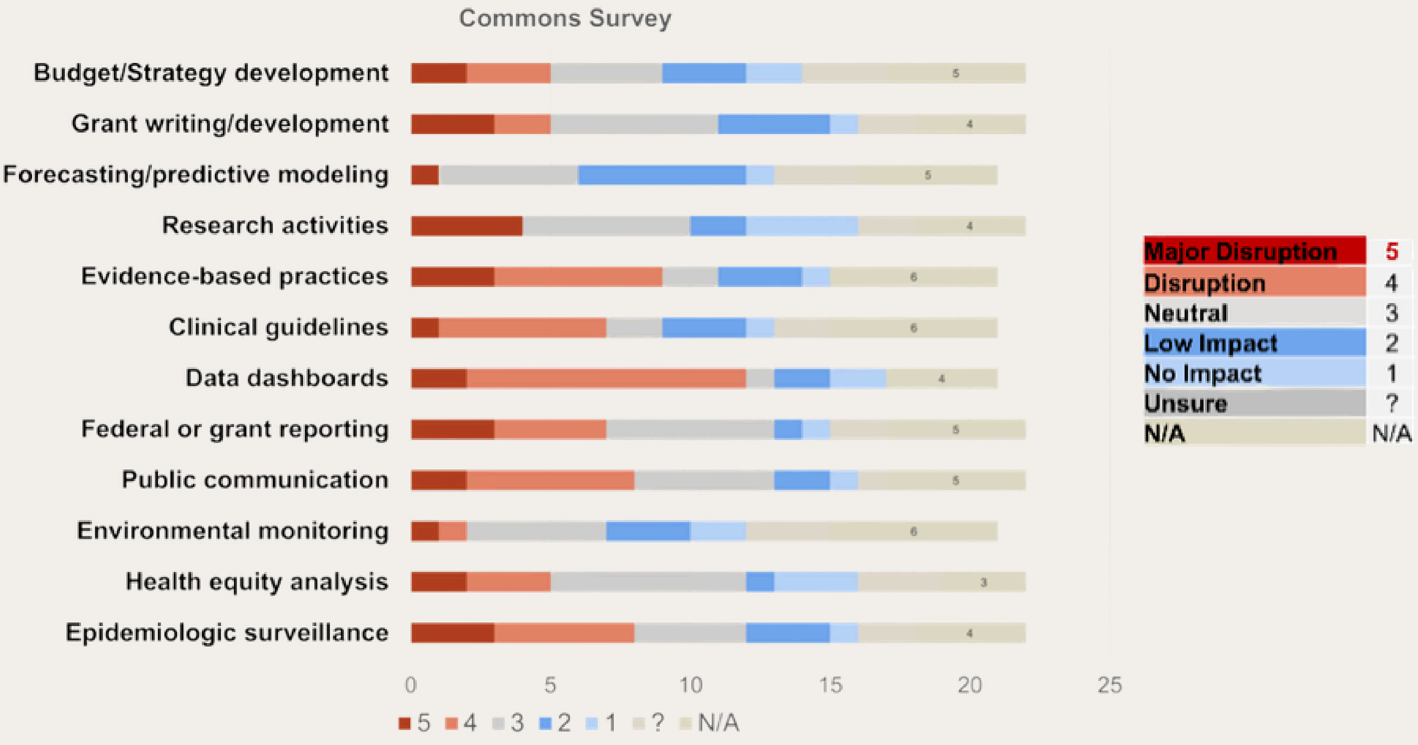
ACRONYM	FULL NAME	AGENCY/OWNER	PURPOSE & FUNCTION	IMPACT AREAS
NSDUH	National Survey on Drug Use and Health	SAMHSA (HHS)	Annual nationwide survey providing national and state-level data on substance use mental health and treatment	Substance abuse, epidemiology, mental health, surveillance, state planning, federal block grant allocations
ACS	American Community Survey	U.S. Census Bureau	Ongoing survey collecting detailed demographic social economic and housing data from U.S. households	Population health planning, health equity analysis, resource allocation, community health assessments, social determinants of health research
Census Population Data	Decennial Census & Population Estimates	U.S. Census Bureau	Official population counts and demographic data collected every 10 years plus annual population estimates	Federal funding allocation, public health denominators, epidemiological rates, health disparities analysis, resource planning
NPPES	National Plan and Provider Enumeration System	CMS (HHS)	System that assigns unique National Provider Identifiers (NPIs) to health care providers and maintains provider demographic data	Provider credentialing, claims processing, health care directory services, fraud prevention, HIE participant verification
USCDI	United States Core Data for Interoperability	ASTP/ONC (HHS)	Standardized set of health data classes and elements for nationwide interoperable health information exchange	EHR interoperability, health information exchange, clinical data exchange standards

FINDINGS

HITAC	Health Information Technology Advisory Committee	ASTP/ONC (HHS)	Federal advisory committee providing recommendations to the National Coordinator for Health IT on policy standards and implementation	Health IT policy development, interoperability standards, EHR certification criteria, nationwide health information network
USCDI+	United States Core Data for Interoperability Plus	ONC/Multiple Federal Agencies	Expanded data elements beyond USCDI for specific federal programs and use cases	Federal program reporting, specialized clinical quality measures, public health data exchange
USDA Food Insecurity	USDA Food Insecurity Data Set	USDA Economic Research Service	National and state-level food security statistics measuring household access to adequate food	Food assistance programs (SNAP, WIC), nutrition policy, social determinants of health research

In addition to identifying the datasets and documents on which states and HIEs depend, it is also important to understand the operational functions affected by the loss of access to these resources. State respondents reported significant disruptions to evidence-based practices, epidemiologic surveillance, public communications, and federal grant reporting (Figure 3).

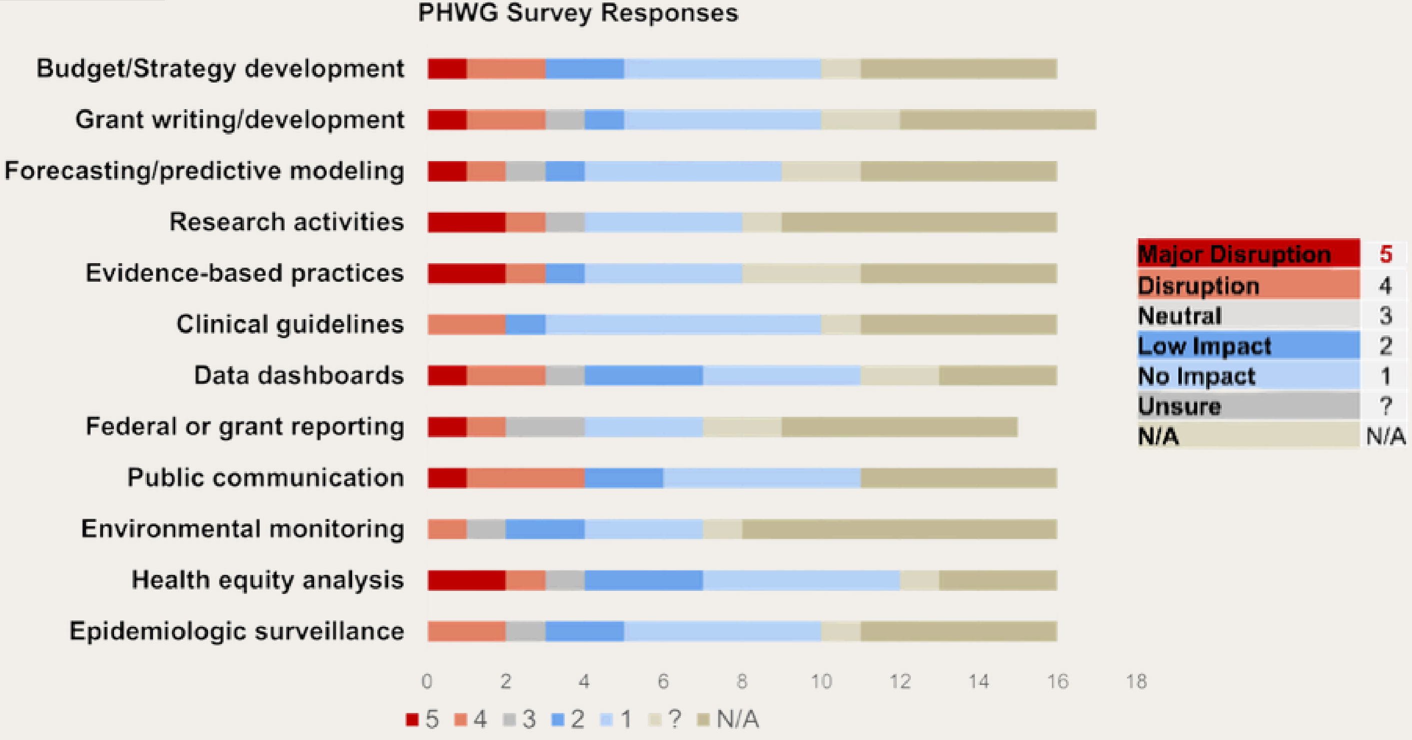
Figure 3 – Affected Functions: What was the level of impact from the removed datasets on these functions?



FINDINGS

HIE respondents, by contrast, indicated fewer overall disruptions. Among those reported, public communications experienced the greatest impact, followed by grant writing, budget development, and strategic planning activities (Figure 4).

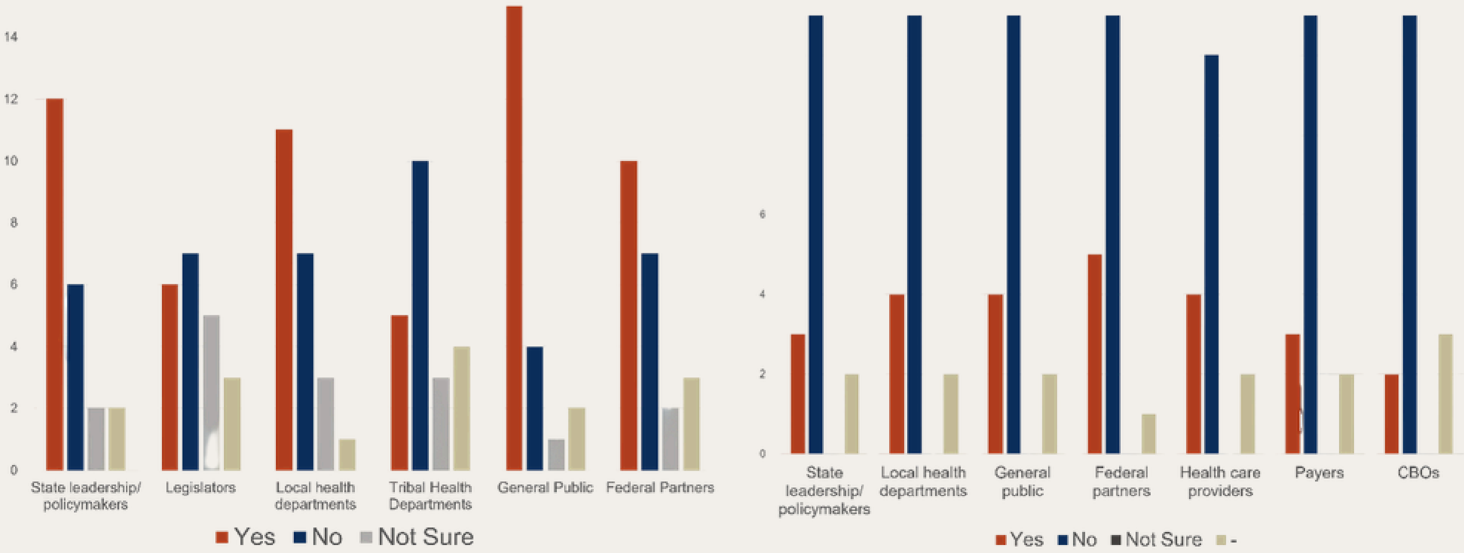
Figure 4 – PHWG: Affected Functions: What was the level of impact from the removed datasets on these functions?



Next, Civitas sought to assess the extent to which the removal of federal webpages affected respondents' ability to communicate effectively with key partners. State respondents reported the greatest impacts on communication with the public, state leadership and policymakers, local health departments, and federal partners. In contrast, HIE respondents reported substantially fewer communication challenges overall. Among the impacts identified by HIEs, communication with federal partners, providers, the public, and local health departments was most frequently cited (Figure 5).

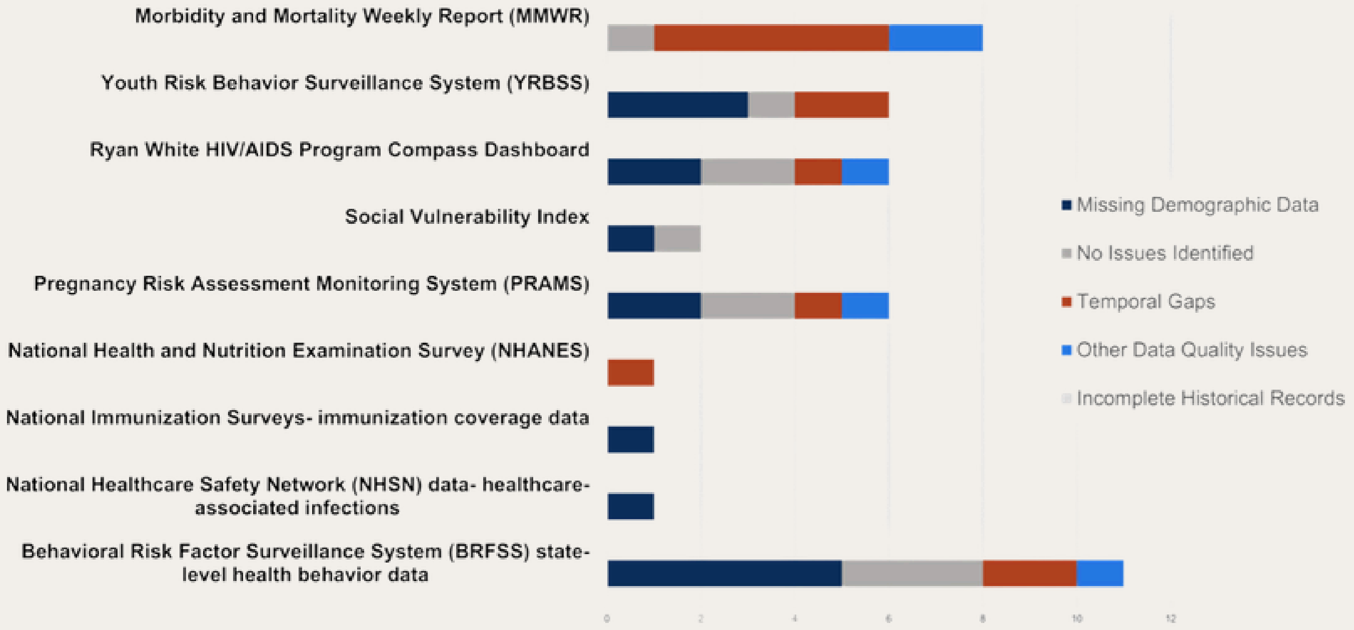
FINDINGS

Figure 5 – Did missing or altered webpages or data sectors affect your ability to communicate with specific partners?



Given the subsequent restoration of certain datasets following the August 2025 *Washington State Medical Association et al. v. Kennedy et al.* lawsuit settlement, it is critical to assess the integrity and completeness of the restored data. Respondents were asked to indicate whether restored datasets exhibited missing data elements, temporal gaps, declines in data quality, or incomplete historical records. Missing demographic data was identified as a concern across most of the datasets assessed, potentially reflecting federal policy changes related to the discontinuation of gender identity data collection. Respondents also noted temporal gaps in several datasets, as well as interruptions in the publication of the *Morbidity and Mortality Weekly Report (MMWR)* (Figure 6).

Figure 6 – What issues have you encountered with restored datasets?



FINDINGS

Industry Findings

As several widely used, large-scale national health surveys, datasets, and guidance went offline in January 2025, significant impacts were felt across the public and private sectors. The removal of public health data sources delayed or reduced access to routine CDC data sources and reports, including the MMWR, which had been in continual circulation since 1952.[4] This affects epidemiological modeling and forecasting where the loss of granular data sources can degrade the accuracy of disease outbreak predictions, intervention planning, research, and health policy.

Examples include:

- **Research Data Access** – Harvard T.H. Chan School of Public Health experts noted an unprecedented situation for researchers from losing access to data they have had access to their entire careers.[5] The uncertainty creates cascading effects across academic centers and state health departments. Programs scrambled to preserve data before additional removals occurred, diverting resources from actual public health work. To continue work, researchers are bypassing official government sources.
- **Data Gaps and Reduced Reliability** – Due to multiple legal challenges and legal settlements, HHS was required to restore more than 100 datasets and webpages deleted from federal websites. However, the landscape remains unsettled. Some data remains offline, documentation gaps persist, and future collection efforts may be altered. In some cases, data files were restored, but supporting documentation was not, making the data difficult to analyze. In other instances, variables were replaced (e.g., gender replaced with sex), fundamentally altering the analytical utility of decades-old datasets.
- **Evidence Based Health Policy and Resource Allocation** – Resource allocation, public health policy, and decision-making will lack the data informed and evidence-based modeling efforts without NHSN, ILINet, MMWR, and NOAA data. Additionally, there remains a sustainability risk of preserving the public evidence base for health policy from federal agencies to independent researchers and archivists.

---

[4] https://www.kff.org/hiv-aids/a-look-at-federal-health-data-taken-offline/
[5] https://hsph.harvard.edu/news/as-health-data-disappear-from-government-websites-experts-push-back/

FINDINGS

The following outlines a sample of the removed, paused, or current datasets and information from specific public health areas (Table 3). [6]

Table 3 – Sample of Public Health datasets Status of Paused/Removed/Current

SOLUTION TYPE	SUMMARY
Vaccine Tracking (paused)	• 35+ datasets covering COVID-19, influenza, and RSV vaccination are paused, most with last updates between January and April 2025. • Paused series include weekly and monthly coverage for adults, children, Medicare beneficiaries, and pregnant women, with race/ethnicity breakdowns. • RSV-specific pauses include maternal vaccination, nirsevimab receipt in infants under 8 months, and coverage intent among adults 75 and older. • The National Immunization Survey Adult COVID Module (NIS-ACM) paused as of late April 2025. • No vaccine tracking databases were current at time of analysis.
Pathogen Tracking	• RSV burden estimates and RSV hospitalization counts by week stopped updating in May 2025. • Provisional drug overdose death counts (VSRR) paused as of April 2025. • Respiratory conditions treated in emergency departments show a last update of August 2025.
Surveillance Data	• Wastewater surveillance (NWSS) for SARS-CoV-2, influenza A, RSV, mpox, and avian influenza H5 are current through September 2025. • NHSN hospital respiratory data, COVID-NET, and RSV-NET hospitalization surveillance are current through September to October 2025. • NSSP emergency department visit data for COVID-19, flu, and RSV are current through September 2025. • COVID-19 death rates, provisional death counts, variant proportions, and NNDSS weekly data are current through September to October 2025. • AtlasPlus, a 20-year aggregated source of surveillance data on HIV, viral hepatitis, sexually transmitted infections, and tuberculosis was temporarily removed. Users can access limited historical data via provided CSV and PDF files.
Injury and Behavioral Health	• Mapping Injury, Overdose, and Violence databases at national, state, county, and census tract levels are current through September 2025. • NSSP Mental Health-Related ED Visit Rates last updated August 2025. • Provisional drug overdose death counts paused as of April 2025 (also noted above under Pathogen Tracking).

---

[6] Unexplained Pauses in Centers for Disease Control and Prevention Surveillance: Erosion of the Public Evidence Base for Health Policy Annals of Internal Medicinehttps://doi.org/10.7326/ANNALS-25-04022

FINDINGS

Sample of Community-Driven Approaches to Address the Information Gap

Industry reliance on federal data infrastructure has depended on the assumption that the government will maintain data collection, standardization, and access as a public good. Academia, organizations, and individuals acted to preserve and archive data independently through the following solutions.

Table 4 – Community-Driven Approaches to Address the Information Gap

SOLUTION TYPE	APPROACH	STRENGTHS	LIMITATIONS	EXAMPLES
Web Archive	Point-in-time snapshot of federal websites	Free, comprehensive capture, verifiable provenance	Not actively maintained; no version control; outdated immediately	Archive.org End-of-Term, Internet Archive Wayback Machine, CDC Restored
Alternative Resources	Downloads of secure datasets prior and after information removal	Direct access; copies secured	Scattered across sources; no central index; variable quality and inconsistently updated	Academic downloads, journalist archives, individual organization downloads
Secondary Aggregators	Platforms that curate and index data from multiple sources	Platforms that curate and index data from multiple sources	Quality variable by aggregator; sustainability uncertain; fitness-for-use varies	Harvard Dataverse, Environmental Data & Governance Initiative, Data Rescue Tracker

See the Appendix for a curated list of resources in each solution type.

IMPACTS FROM REMOVAL OF FEDERAL DATASETS AND GUIDANCE

The removal of federal datasets, web-based systems, and guidance documents had wide-ranging and interrelated impacts on state public health agencies and HIEs. Across both surveys, the impacts extended beyond the loss of discrete data assets to include disruptions to infrastructure, institutional knowledge, program operations, funding activities, and trust in federal partners. The effects were particularly pronounced for smaller and rural states, equity-focused programs, and organizations engaged in active projects at the time of removal.

Highest impact areas were observed in federal, state and grant reporting, grant writing and development, and budget or strategic planning. Epidemiologic surveillance and public communication were also notably affected, while research and environmental monitoring showed more variable impacts

IMPACTS FROM REMOVAL OF FEDERAL DATASETS AND GUIDANCE

depending on organizational missions. Numerous respondents also cited project delays, inability to train staff due to training materials being removed, use of outdated or archived datasets, and emergency workarounds that increased staff burden and introduced quality risks.

Public Health Programs, Services, and Surveillance Activities

Public health programs experienced significant operational disruptions due to the loss of both data and supporting guidance. In many cases, the removal affected not only access to content but also the institutional infrastructure that programs depend on for day-to-day operations.

- **Epidemiological surveillance** activities were moderately to highly impacted, particularly where federal datasets served as foundational inputs for analysis. States reported delays to the 2025 BRFSS data collection cycle, with uncertainty around survey start dates and data update timelines; at the time of reporting, the 2023 BRFSS dataset remained the most recent finalized data available.
- **Training and workforce development** efforts were also impacted. States reported being unable to provide training to newly hired staff because federally hosted STI training materials were removed, and program implementation slowed due to the absence of authoritative federal guidance. Examples include:
    - The PRAMS, YRBSS, and SVI datasets are often used simultaneously across multiple studies and programs. For example, SVI is frequently used as a covariate in research and program planning; its removal affected numerous projects at once, including county-level dashboards and vulnerability mapping.
    - Surveillance impacts were particularly acute for equity populations, including LGBTQ+ communities due to the loss or modification of SOGI data, racial and ethnic populations due to coding and update barriers, rural populations that rely heavily on federal surveys, and maternal health programs that depend on PRAMS for state, regional, and national comparisons.
- **Loss of technical assistance and institutional knowledge** coincided leaving state staff without subject matter experts to consult. This causes increased reliance on existing staff.

Staff Burden

The biggest challenge for state public health agencies has been staff burden. While the impact varies by program and overall capacity, agencies must spend substantial additional staff time compensating for unavailable federal datasets, systems, and resources—hindering core public health functions and potentially putting lives at risk.

- **Increased Administrative and Workload Burden** – State staff have absorbed substantial additional workload in trying to locate, validate, and reconcile alternative data sources after the removal of authoritative federal datasets and guidance. This includes time spent searching

IMPACTS FROM REMOVAL OF FEDERAL DATASETS AND GUIDANCE

archived websites, documenting data provenance, responding to internal and external questions about data validity, and IT security to identify viable alternative datasets to use. In addition, respondents specifically noted the significant burden associated with individually negotiating data access agreements with multiple entities and researchers for programs, characterizing this process as a “huge burden.” Collectively, these activities have displaced staff time previously devoted to core responsibilities, including data analysis, program implementation, and stakeholder engagement, resulting in growing work backlogs and delayed deliverables.

- **Manual Workarounds and Redundant Effort** – In the absence of centralized federal infrastructure, staff have been required to recreate some functions previously supported by federal systems, such as compiling datasets from multiple sources and maintaining local documentation of standards and protocols. This has resulted in redundant work across states, with multiple teams independently reconstructing similar datasets or guidance, decreasing efficiency and consistency nationwide.
- **Delays to Program Timelines and Deliverables** – The removal of datasets and guidance during active projects has led to delays in surveillance cycles, reporting deadlines, dashboard updates, and analytic products. Staff reported needing to pause work at times resulting from issues such as lack of access to data, inability to submit new data, re-scope analyses due to missing or altered variables, and awaiting clarification on reporting requirements or grant funding. These delays have downstream effects on program planning, policy development, and funding accountability.
- **Training and Workforce Development** – States reported being unable to provide training to newly hired staff because federally hosted STI training materials were removed, and program implementation slowed due to the absence of authoritative federal guidance. In environmental health, the cessation of publication of Environmental Health Perspectives (EHP) by NIEHS represented a substantial loss of peer-reviewed scientific evidence that state agencies rely on to inform policy and regulatory decisions, including the development of standards for contaminants such as PFAS in drinking water.
- **Disproportionate Impact on Small and Resource-Constrained States** – The burden has been most acute for smaller, rural, and under-resourced states that rely heavily on federal datasets to generate statistically valid insights and meet reporting requirements. Limited analytic staff capacity makes it more difficult to absorb additional validation, documentation, and workaround activities, widening existing disparities in public health capacity across jurisdictions.

IMPACTS FROM REMOVAL OF FEDERAL DATASETS AND GUIDANCE

CASE STUDY - PRAMS

One program that has been most affected is PRAMS. PRAMS serves as the only national long term state level maternal and child health surveillance system and is used to inform state prenatal and postpartum policies and programming initiatives. In early 2025, the software system to collect PRAMS data was shut down while states were in the middle of surveying mothers who gave birth in 2024. In August of 2025, CDC indicated that while states could not contact any more mothers, the data that states had already collected would be processed though the timeline is uncertain given that the team responsible for PRAMS was terminated. Additionally, the removal of the PRAMS SharePoint resulted in the loss of protocols, procedures, and institutional knowledge that could not be easily reconstructed, particularly after the termination of CDC PRAMS staff.

PRAMS is also frequently used by researchers across the nation to assess perinatal health care and outcomes and produce regional and national comparisons. Since the PRAMS Automated Research file, an online portal used by researchers which provides a single coordinated process for accessing PRAMS across states is no longer available, researchers are having to sign and comply with separate data sharing agreements for each state (over 45 participating jurisdictions) to obtain the data. This is not only time consuming and burdensome for researchers but also for states. Respondents reported an increased burden on program staff to address researcher needs, especially in states that are continuing to collect PRAMS data without the technical support of CDC.

Reporting and Public Communication

Federal and grant reporting emerged as one of the highest-impact areas. States reported unclear or missing guidance for required reporting, including the Ryan White HIV/AIDS Program Services Report, resulting in delays and uncertainty in compliance. Public communication efforts were also disrupted, as agencies lacked current, authoritative data to support messaging to the public, policymakers, and partners.

These challenges were exacerbated by mid-project disruptions, where organizations lost access to

IMPACTS FROM REMOVAL OF FEDERAL DATASETS AND GUIDANCE

critical datasets or guidance during active reporting or analytic cycles. Respondents described delays to report releases, quality control issues, and the need for emergency mitigation strategies such as relying on archived datasets or seeking alternative sources that were less current or authoritative.

Health Information Exchanges

Although HIEs reported fewer overall impacts than states, the effects on HIE operations were nonetheless meaningful, particularly in areas tied to standards, interoperability, and reporting. HIEs reported delays in confirming race and ethnicity codes, difficulties tracking Uniform Data Set (UDS) measures, and challenges completing population landscape assessments due to aged or unavailable datasets.

While some of the challenges are similar to those experienced by states, HIEs identified several consequential operational, technical, and strategic challenges that HIEs face.

The impact has been most evident in three areas:

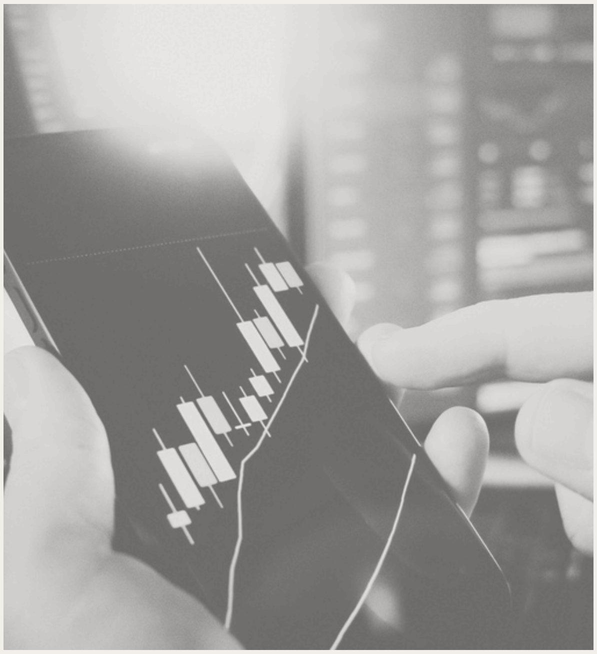
- **Service Delays Resulting from Interoperability and Standards Alignment** – Federal standards such as USCDI, USCDI+ and ISA serve as foundational references for interoperability planning and implementation. Due to the absence of these authoritative sources, HIE product development cycles, and reporting capabilities such as releasing dashboards and updating landscape assessments, were disrupted and in some cases paused. Several HIEs specifically noted impacts on dashboards and analytics, including missing or outdated social vulnerability data.
- **Grant Development, Performance Measurement, and Reporting Burden** – HIEs were challenged in meeting grant-funded deliverables and performance reporting requirements. Staff also described difficulty developing proposals and demonstrating compliance because federal measures, benchmarks, or reference materials were removed or outdated. For example, the removal of USCDI and USCDI+ guidance resulted in delaying an HIE in submitting health department reports, and the inability to access and compare UDS measures resulted in an HIE having to use archived data when developing a proposal related to quality measures. Additionally, HIE grant-funded interoperability efforts, such as behavioral health transitions of care work aligned with USCDI+, were delayed due to system unavailability and broader federal disruptions
- **Constraints on Equity-Focused Data Capture and Analysis** – The modification or removal of federal guidance related to SOGI, race, and ethnicity questions and data constrained HIEs' ability to support equity-focused analytics and future data capture. Respondents expressed concern that concurrent state-level changes to data collection could further limit HIEs' capacity to capture, exchange, and track disparities and support equity-driven initiatives over time.

CROSS-CUTTING IMPACTS

Across all categories, respondents emphasized broad systemic consequences, including the loss of institutional knowledge, increased administrative burden, and a growing lack of trust in federal partners. The removal of datasets and guidance documents—often without clear communication or replacement—significantly reduced confidence in the reliability and stability of federal systems, availability of technical assistance and overall trust in the federal government.

- **Strategic Planning, Funding Alignment, and Grants Management** – Funding-related activities, including grant reporting, grant writing, and budget and strategic development were consistently identified as experiencing high levels of disruption. States and HIEs reported delays in receiving active grant awards and having submission deadlines extended, both of which resulted in funding delays. In some cases, grants were eliminated entirely, such as an HIV stigma CDC grant that would have generated data to inform programs addressing stigma among people living with HIV. Several respondents noted delays in foundation funding decisions and postponed program launches, particularly in behavioral health and interoperability initiatives, due to uncertainty about data standards and federal direction.
- **Standards and Benchmarks** – The absence of federal standards and benchmarks, including UDS measures and USCDI guidance, impaired organizations' ability to develop competitive proposals, align projects with national priorities, and demonstrate comparability. There was also increasing reliance on older datasets for required analytics.
- **Erosion of Trust in Federal Systems** – Finally, state staff have reported frustration and declining trust related to removals, inconsistent communication, and uncertainty about restoration timelines. This has contributed to reduced confidence in federal systems as reliable infrastructure and increased skepticism when planning future programs or aligning with national standards.
- **Fragmented Information Landscape** – The removal of federal datasets from official platforms prompted multiple organizations to independently archive and maintain copies, creating a fragmented data landscape that is difficult to navigate. State and HIE staff now face the added burden of identifying what archived resources exist, determining which are appropriate for specific purposes, and assessing whether they are sufficiently current and reliable to use with confidence.
- **Point-in-Time Snapshots vs. Actively Maintained Resources** – When datasets are preserved as static snapshots rather than living resources, users face uncertainty about version control, update frequency, and completeness.
- **Variable Archiving Practices and Data Reliability** – Inconsistency in how datasets are archived, documented, and refreshed increases the risk of analytic errors, misinterpretation, and misalignment across jurisdictions and programs.
- **No Single Authoritative Source** – Without a central reference point, organizations must independently validate data provenance, reconcile discrepancies, and assess fitness for use, diverting resources from core public health activities and complicating cross-state comparisons, longitudinal analyses, and compliance reporting.

CROSS-CUTTING IMPACTS



- **Loss of Federal Documentation and Technical Guidance** – The removal of data dictionaries, technical documentation, and interpretive guidance that accompanied federal datasets has compounded navigation challenges. Without these resources, users lack the context needed to correctly interpret variables, apply appropriate methodologies, and ensure consistent use across programs and jurisdictions, increasing the risk of analytical errors and reducing confidence in findings.
- **Fragmented Research Efforts Underway Documenting Impact** – Several initiatives (e.g. Pew Charitable Trust, SSRS, AcademyHealth) have been launched to assess the impact of the removal of federal datasets and guidance documents. Some of these efforts have overlapped objectives and do not appear to have not been coordinated. This can lead to duplication of work and funding efforts, additional burden on public health staff, inefficient use of resources, and a fragmented understanding of system-wide impacts.

Taken together, the challenges for both state public health agencies and HIEs extend well beyond technical inconvenience or isolated access barriers. The impacts include sustained increases in workload that strain workforce capacity, heightened operational risk, and delays in critical public health and health information exchange activities. For public health agencies and HIE organizations, whose core missions depend on stable, authoritative federal data, standards, and guidance, these disruptions undermine the ability to carry out core public health functions as well as improve interoperability and data sharing within the health ecosystem.

CONCLUSION

The removal of federal public health datasets, guidance, and standards in early 2025 revealed a structural vulnerability that had long gone unrecognized: the nation's public health system is heavily dependent on federal data infrastructure that was assumed to be stable and permanent. When that infrastructure was disrupted, the consequences were not isolated or temporary. Surveillance cycles slowed, equity monitoring was reduced, maintaining grant compliance grew more challenging, and staff across the country absorbed extra responsibilities to restore removed functions. Smaller and rural states, already operating with limited analytic capacity, bore the greatest burden. The September 2025 court-mandated restoration provided partial relief, but incomplete documentation, altered variables, and the loss of the federal workforce that maintained these systems mean that the damage has not been fully reversed.

The archiving and aggregation efforts that emerged in response demonstrated both the commitment of the public health community and the limits of decentralized, ad hoc preservation. A fragmented landscape of point-in-time snapshots and variable-quality aggregators is not a substitute for authoritative, maintained federal infrastructure.

Sustained recovery requires deliberate investment in the systems, partnerships, and governance structures that can reduce dependency on any single point of failure and ensure that essential public health data remains accessible, reliable, and equitable regardless of federal policy shifts. While there are many projects underway to preserve and recover public health data, the lack of coordination among them has led to duplicated efforts, making it difficult for Public Health Authorities and HIEs to determine which resources to use.

The removal also had an important effect on confidence in the stewardship of national public health information. That reduced confidence can make data sharing and coordinated responses more challenging, particularly with communities that have historically been cautious about data use. At the same time, there is an opportunity to rebuild trust from the ground up by partnering with locally rooted intermediaries, such as HIEs and other data organizations, that already have relationships, governance practices, and operational experience that position them to support trustworthy data sharing. Strengthening and formalizing these local partnerships—with federal coordination, reliable funding, and clear accountability—can help accelerate recovery, improve resilience to future disruptions, and restore the public confidence needed for equitable, effective public health data sharing.

The following recommendations outline a practical path forward.

RECOMMENDATIONS

Based on analysis of archived and aggregated websites, survey findings, State Health Technology Commons and Public Health Workgroup calls and facilitated workshops, Civitas offers the following recommendations for consideration.

ALIGNMENT & COORDINATION

1 Convene Multi-Funder Meeting

Key Actions	Potential Impact
• Convene a 1-2 day in-person multi-funder meeting bringing together philanthropies, federal agencies, and organizations that have funded or are considering funding data infrastructure preservation and resilience work. • Provide a structured forum to share findings across initiatives, identify gaps and overlaps, and develop a consensus-based coordinated funding framework. • Develop a shared funding roadmap that sequences investments across the recommendations above, prioritizing those with the broadest cross-state impact. • Establish ongoing coordination mechanisms to prevent duplication and leverage existing investments.	• Aligns funding strategies to maximize collective impact. • Reduces duplication of effort across independently funded initiatives. • Accelerates progress by coordinating sequencing and complementary investments. • Creates a more coherent and sustainable funding ecosystem for public health data infrastructure.

INFORMATION INFRASTRUCTURE

2 Establish a Trusted Resource Directory

Key Actions	Potential Impact
• Identify, curate, and vet repositories containing archived or aggregated federal datasets and guidance documents. • Indicate which resources are current and actively maintained vs. point-in-time snapshots. • Create a shared, searchable directory accessible to state public health agencies, HIEs, and partners. • Standardize directory entries to include: dataset name and owning agency; resource type; provenance method; coverage period and update cadence; data integrity checks; security parameters; licensing terms and access constraints; recommended use cases.	• Reduces duplicative effort across states and HIEs independently locating and validating the same resources. • Saves staff time and redirects capacity to core public health services. • Enables confident, consistent resource selection. • Supports equitable access regardless of state capacity.

RECOMMENDATIONS

3 Develop a Reusable Resource Vetting Rubric

Key Actions	Potential Impact
• Create a checklist or scoring framework that state IT, security teams, and program owners can apply to evaluate archived or aggregated resources. • Rubric criteria should assess: clarity of data provenance; transparency of update practices; version control and availability of change logs; data integrity validation methods (hashing, diff logs); baseline hosting and security controls; sustainability and stewardship plans including responsible entity and funding horizon.	• Enables consistent, repeatable assessments across organizations. • Reduces uncertainty and legal/compliance risk when adopting alternative sources. • Promotes confident use of non-federal data sources. • Reduces need for each state to independently develop evaluation criteria.

OPERATIONAL RESILIENCE

4 Leverage Existing Multi-State Public Health Forums

Key Actions	Potential Impact
• Leverage an existing, neutral-entity-hosted forum with national reach (e.g., Civitas State Health Technology Commons) for ongoing peer-to-peer learning on practical mitigation strategies. • Structure sessions around priority operational issues including PRAMS access and burden, BRFSS data collection delays, data standards alignment, and use of restored resources. • Document and disseminate effective practices, lessons learned, and implementation challenges across participating states. • Establish standing agenda items for emerging data disruptions and rapid-response coordination.	• Reduces duplication of effort as states independently solve the same problems. • Accelerates adoption of proven mitigation strategies. • Builds cross-state solidarity and shared problem-solving capacity. • Creates an early warning system for emerging data disruptions.

RECOMMENDATIONS

⑤ Develop a Dataset Continuity Playbook

Key Actions	Potential Impact
• Develop a concise operational guide for responding when a federal dataset or guidance resource becomes unavailable. • Include immediate response actions: capturing relevant URLs; downloading, documenting, and validating the last known authoritative version; notifying key internal stakeholders. • Provide guidance on identifying and assessing alternative data sources using the vetting rubric. • Include recommended practices for secure local storage and version management. • Provide standardized communication templates for local health departments and partners that clearly articulate what is known, what data are being used, and which resources should not yet be relied upon. • Include a decision framework for determining when reliance on third-party sources is appropriate. • Address legal, IRB, and data-sharing considerations for reconstituted datasets.	• Enables faster, more consistent crisis response across states. • Reduces staff burden and decision fatigue during active disruptions. • Improves communication quality with partners and the public. • Reduces risk of using unreliable data due to unclear decision criteria. • Particularly valuable for smaller states with limited legal and analytic capacity.

⑥ Pilot Regional Maintenance Consortia

Key Actions	Potential Impact
• Identify a small set of high-priority, widely used federal datasets and guidance resources that are no longer actively maintained or where states have developed divergent aligned policies. • Priority candidates include de-identified PRAMS extracts, selected STI and environmental health guidance collections, and key equity-focused datasets. • Test shared governance, cost-sharing, and maintenance models across a small group of participating states. • Document findings to support replication and inform broader stewardship frameworks.	• Establishes a proof-of-concept for decentralized, sustainable data stewardship. • Reduces single points of failure by distributing maintenance responsibility. • Generates replicable governance models applicable to other datasets and regions. • Demonstrates feasibility of state-led data infrastructure to funders and policymakers.

RECOMMENDATIONS

7 Support State Data Resilience Strategies

Key Actions	Potential Impact
• Help states identify approaches to strengthen standardized local data ecosystems and reduce dependency on federal systems as single points of failure. • Support development or enhancement of state data lakes enabling secure storage and integration of multiple data sources. • Enable secure cross-agency data linkage to support public health analytics that do not depend on a single federal source. • Assist states in clarifying statutory authority and governance frameworks for public health data use, including privacy protections. • Prioritize capacity-building in smaller and rural states with the greatest vulnerability to federal disruptions. • Advocate for preservation and continued collection of SOGI, race, and ethnicity data elements as a condition of any future federal restoration or data governance framework.	• Reduces state vulnerability to future federal data disruptions. • Strengthens local analytic capacity, particularly in under-resourced states. • Supports more timely surveillance and reporting independent of federal update cycles. • Addresses the disproportionate burden on smaller states documented in survey findings.

PARTNERSHIPS AND INTERMEDIARIES

8 Foster the Development and Formalization of Partnerships between Public Health Agencies and Trusted Local Intermediaries in Data Stewardship

Key Actions	Potential Impact
• Support development of formal partnerships between state public health agencies and trusted local intermediaries, including HIEs and similar data organizations with a demonstrated commitment to public health as highlighted in the results of the 2025 National Health Information Organization (HIO) Survey (Appendix). • Define specific intermediary functions based on state context and existing relationships, which may include: aggregating and maintaining continuity of critical data streams; preserving documentation of previously available federal datasets and guidance; developing implementation guides and data dictionaries that translate federal standards into operational state-level use cases; maintaining shared data assets; providing technical translation support for program staff. • Encourage public health agencies to leverage HIEs as neutral, community-trusted intermediaries and conveners: use them to broker data sharing agreements, mediate disputes over appropriate use, harmonize consent and access policies, and provide transparent audit trails that increase public confidence. • Advocate for capacity building and sustainable funding for HIEs and other intermediaries to support governance, privacy compliance, secure infrastructure, and community outreach needed to restore and maintain trust. • Recognize variation in state-HIE relationships and develop flexible models that reflect different levels of existing integration and policy constraints. • Work with HIEs to develop local data capture strategies that reduce dependence on federal equity data collection, improve completeness and granularity, and ensure culturally appropriate engagement and consent practices.	• Strengthens resilience by distributing data stewardship across a broader network. • Leverages existing HIE infrastructure and relationships to support public health continuity and rebuild public confidence. • Reduces the burden on state agencies to independently maintain all data assets. • Ensures continuity of data exchange in states where HIEs serve as the primary conduit for analytics.

APPENDIX

Acronym List

IT	Information Technology
LGBTQ+	Lesbian, Gay, Bisexual, Transgender, Queer/Questioning, and more
MMWR	Morbidity and Mortality Weekly Report
NCVS	National Crime Victimization Survey
NHANES	National Health and Nutrition Examination Survey
NHSN	National Healthcare Safety Network
NIEHS	National Institute of Environmental Health Sciences
NIH	National Institutes of Health
NIS-ACM	National Immunization Survey Adult COVID Module
NOAA	National Oceanic and Atmospheric Administration
NPI	National Provider Identifier
NPPES	National Plan and Provider Enumeration System
NSDUH	National Survey on Drug Use and Health
NSSP	National Syndromic Surveillance Program
NWSS	National Wastewater Surveillance System
PAMS	Provider Assisted Measurement System
PEPFAR	President's Emergency Plan for AIDS Relief
PFAS	Per- and Polyfluoroalkyl Substances
PHINVADS	Public Health Information Network Vocabulary Access and Distribution System
PPRTV	Provisional Peer-Reviewed Toxicity Values
PRAMS	Pregnancy Risk Assessment Monitoring System
QIO	Quality Improvement Organization
RCRA	Resource Conservation and Recovery Act
RDAP	Research Data Archiving Platform
RHIC	Regional Health Improvement Collaborative
RIF	Reduction in Force
RSR	Ryan White HIV/AIDS Program Services Report
RSV	Respiratory Syncytial Virus
RWJF	Robert Wood Johnson Foundation
SAMHSA	Substance Abuse and Mental Health Services Administration
SNAP	Supplemental Nutrition Assistance Program
SOGI	Sexual Orientation and Gender Identity
STI	Sexually Transmitted Infection

APPENDIX

SVI	Social Vulnerability Index
USAID	U.S. Agency for International Development
USCDI	United States Core Data for Interoperability
USCDI+	United States Core Data for Interoperability Plus
USDA	U.S. Department of Agriculture
VSRR	Vital Signs Rapid Release
WIC	Women, Infants, and Children
YRBSS	Youth Risk Behavior Surveillance System

Alternate Data and Information Resources

The following tables outline examples of available alternatives to removed datasets and guidance. The resources focus primarily in public health, but resources are also available from other sectors and agencies. The aggregators serve as another reference for important information. However, there needs to be information provided on data integrity, validity, and reliability for reusability.

Web/Data Archive Resources

ORGANIZATION	RESOURCE NAME	TYPE	DESCRIPTION	NOTES
Internet Archive	Archive.org End of Term 2024	Web Crawl Archive	End of Term 2024 web crawls collection.	Downloadable data
Library of Congress Consortium	End of Term Web Archive	Federal Archive	Federal website preservation (.gov, .mil, etc.).	Can suggest databases
EDGI	Environmental Data and Governance Initiative	Climate Archive	Federal climate and environmental database preservation.	Can suggest databases
Immunization Action Coalition	Immunize.org	Guidelines Archive	Archives of CDC Vaccine Information Statements.	Free access
Internet Archive – Wayback Machine	Internet Archive CDC Datasets	Web Archive and Dataset Archive	Internet archive for preserving websites CDC datasets uploaded before January 28, 2025.	Free access and download

CDC Restored	Original www.cdc.gov site from January 6, 2025	CDC web archive	Volunteer based, unfunded project developing code to pull CDC pages archived prior to January 20, 2025.	Free access, additional resources
CDC Archive	End of Term Web Archive	CDC web archive	Archived web material for CDC.gov is preserved on the CDC Archive Site. Note that the content on this site is for historical purposes only and is no longer being updated. The information here may be outdated and links may no longer function.	Free access, not updated

Alternative Resources: Non-profits, media, journalism organizations

ORGANIZATION	RESOURCE NAME	TYPE	DESCRIPTION	NOTES
MuckRock/ Big Local News	Data Liberation Project	Database Archive	Database preservation project.	Can suggest databases
The 19th	The 19th Preservation Project	Document Archive	Government documents including CDC maternal mortality and abortion data.	Free access
Kaiser Family Foundation (KFF)	Disappearing Federal Data: Implications for Addressing Health Disparities	Journalism and Resource Archive	KFF review of major federal health datasets as of August 2025 shows that certain sociodemographic variables have been removed from some datasets or reports, including racial and ethnic and gender identity data.	Linked data sources

APPENDIX

Secondary Aggregators

ORGANIZATION	RESOURCE NAME	TYPE	DESCRIPTION	NOTES
RDAP, and members of the Data Curation Network	Data Rescue Tracker	Coordination Project	Cataloging ongoing public data rescue efforts in a clearinghouse for data rescue-related efforts and data access points for public US governmental data that are currently at risk. We want to know what is happening in the community so that we can coordinate focus. Efforts include data gathering, data curation and cleaning, data cataloging, and providing sustained access and distribution of data assets.	Includes web archives, datasets, and information from
Boston University/ Harvard University Independent Journalist	Public Environmental Data Project	Database Archive	Federal environmental and health databases archive that includes CDC, SVI, and EJI.	Volunteer member coalition
	CAFÉ Collection on Harvard Dataverse	Community of Practice	Research Coordinating Center for Climate and Health.	Free public access
Harvard University	Harvard Dataverse	Repository	Large publicly available research data repository.	Free public access
Harvard Library	Harvard Library Innovation Lab Datasets	Repository	311000+ datasets harvested in 2024-2025.	Free access
Johns Hopkins University	Johns Hopkins Public Health Resources	Resource Collection	Collection of public health resources.	University access

Inter-university Consortium for Political and Social Research (ICPSR)	ICPSR – Data Lumos	International consortium of 800+ academic and research bodies	Archive of social science data for research.	Access varies by dataset
Investigative Reporters & Editors	IRI Data Library	Academia Consortium	120+ federal datasets downloaded: • Alternate Data Library Sources Documentation • Alternate Data Library Sources Spreadsheet	Data Library Sunsetting (as of January 30, 2026)
University of California San Francisco (UCSF)	Population Health and Health Services Research Datasets	Repository	Population Health and Health Services Datasets, including: • Missing government data – 2025 • UCSF Population Health Data • Centers for Medicare and Medicaid Services (CMS) • Claims (Health Care Cost Institute HCCI, Optum, IBM Market Scan) • Demographic (Bureau of Labor Statistics, IPUMS, National Death Index, NVSS, US Census Health Statistics • Economic (Nielsen) • Geographic (County Health Rankings) • health care Cost & Quality (APCD, AHA, AHD, HCMA) • Health Equity (Compendium of Federal Datasets addressing Health Disparities) • Health Policy • Public Health & Social Services (ACS, BRFSS, CDC Wonder, HRS, LSOA)	Researchers interested in accessing these datasets should submit a Population Health and Health Services Data Consultation request

APPENDIX

Survey Questions: State Public Health Operations Impact from Federal Webpage and Dataset Removals

Respondent(s) Information

- State/Territory
- Role/Title
- Division/Program Area
- Contact for Follow-Up

Awareness and Identification

1. Were you or your department aware that federal webpages or datasets were removed or made temporarily unavailable in early 2025?
2. If yes, which databases were removed that your department, programs, and users relied upon? (Select all that apply):

   Data/Survey/Surveillance Systems:
   - Behavioral Risk Factor Surveillance System (BRFSS) state-level health behavior data
   - National health care Safety Network (NHSN) data — health care-associated infections
   - National Immunization Surveys — immunization coverage data
   - National Health and Nutrition Examination Survey (NHANES)
   - PEPFAR Data Dashboards
   - Pregnancy Risk Assessment Monitoring System (PRAMS)
   - Social Vulnerability Index
   - Ryan White HIV/AIDS Program Compass Dashboard
   - Youth Risk Behavior Surveillance System (YRBSS)
   - Morbidity and Mortality Weekly Report (MMWR)
   - Others? Please specify:
3. If yes, which Policy or guidance pages that you rely on that were removed? (Select all that apply):

   Resources/Websites/Guidance on Topics Related to:
   - LGBTQ+ Youth & Adolescent Health
   - LGBTQ+ General Health & Wellness
   - HIV/AIDS & Sexual Health
   - Clinical Research & Trials
   - Disease specific guidance (e.g., Mpox, COVID)
   - Diversity, Equity & Inclusion
   - Gender Identify & Sex-Specific Health
   - Immunizations
   - Reproductive Health Information
   - Racial & Ethnic Health Equity
   - Reproductive Health and Rights Website

APPENDIX

- Firearm Violence and Injury Prevention
- Environmental and health impacts (e.g., EPA, climate, climate/health agency)
- Others? Please specify:

4. Please describe the most significant data source or webpage your department lost access to and how it was used in your work.

Impact

5. To what extent has the removal of datasets and guidance impacted the public health department's ability to carry out its mission?
6. **Affected Public Health Functions** - For each function below, indicate the level of impact from the removal of datasets and guidance. (Select N/A if your department does not perform this function).

FUNCTION	N/A	UNSURE	1 - NO IMPACT	2	3	4	5 - MAJOR DISRUPTION
Epidemiologic surveillance							
Health equity analysis							
Environmental monitoring							
Public communication							
Federal or grant reporting							
Data dashboards							
Clinical guidelines							
Evidence-based practices							
Research activities							
Forecasting or predictive modeling							

Forecasting or predictive modeling							
Grant writing or development							
Budget or Strategy development							
Other, please explain:							

7. Can you describe a specific example of an activity or report that was delayed or modified due to missing federal data?
8. **Alternate Data Sources** - If so, did the public health department identify an alternative data source(s) (e.g., academia, 3rd party aggregators, HIE) to use? Please describe the alternative data sources or methods you used.
9. **Create alternative sources** - Did your agency create alternative datasets for your population?
10. What partners were involved in creating the alternative data sources (regional, statewide, state-to-state, regional, private/public)?
11. **Communication** - Did missing or altered federal webpages or datasets affect your ability to communicate finding to the following partners/stakeholders?

Partners/Stakeholders	YES	NO	UNSURE
State leadership or policymakers			
Legislators			
Local health departments			
Tribal health departments			
General public			
Federal Partners			
Others? Please specify:			

APPENDIX

12. **Program/Policy Impact** - Please describe any specific programs (e.g., maternal health, infectious disease, environmental health) and/or policies affected by missing datasets, resources, or guidance.

13. Please describe any other impact.

Restored Datasets and Resources - Reliability and Usability

14. If you used any restored datasets or guidance from restored websites, please assess their quality compared to the original versions.

    Overall comparability in scope and usability to the originals:

    - Fully comparable
    - Partially comparable
    - Not comparable
    - Unsure/did not use restored datasets

15. What Issues have you encountered with restored datasets? These can include things like:
    - Temporal gaps in data (e.g., missing data from the period when databases were unavailable)
    - Missing demographic data elements that were previously available
    - Incomplete historical records
    - Other data quality issues

    Select all that apply.

	N/A	No issues identified	Temporal gaps	Missing demographic data	Incomplete historical records	Other data quality issues
Behavioral Risk Factor Surveillance System (BRFSS) state-level health behavior data						
National health care Safety Network (NHSN) data-health care-associated infections						
National Immunization Surveys- immunization coverage data						
National Health and Nutrition Examination Survey (NHANES)						

PEPFAR Data Dashboards						
Pregnancy Risk Assessment Monitoring System (PRAMS)						
Social Vulnerability Index						
Ryan White HIV/AIDS Program Compass Dashboard						
Youth Risk Behavior Surveillance System (YRBSS)						
Morbidity and Mortality Weekly Report (MMWR)						
Others? Please specify.						

16. Describe your experience reintegrating or validating restored datasets. Were there differences in format, documentation, completeness, or trustworthiness?
17. Did your department continue to rely on alternative sources after restoration?
18. Please share any additional thoughts and comments.

Survey Questions: Federal Webpage and Dataset Removals Impact to HIE and Other Data Organizations

Respondent(s) Information

- Organization
- State/Region(s) Served
- Role/Title
- Contact for Follow-Up

Respondent(s) Information

1. Were you or your organization aware that federal webpages or datasets were removed or made temporarily unavailable in early 2025?

APPENDIX

2. If yes, please indicate **which removed datasets** your organization or associated programs previously utilized. (Select all that apply):

   Data/Surveys/Surveillance Systems
   - Behavioral Risk Factor Surveillance System (BRFSS) state-level health behavior data
   - National health care Safety Network (NHSN) data — health care-associated infections
   - National Immunization Surveys — immunization coverage data
   - National Health and Nutrition Examination Survey (NHANES)
   - PEPFAR Data Dashboards
   - Pregnancy Risk Assessment Monitoring System (PRAMS)
   - Social Vulnerability Index
   - Ryan White HIV/AIDS Program Compass Dashboard
   - Youth Risk Behavior Surveillance System (YRBSS)
   - Morbidity and Mortality Weekly Report (MMWR)
   - Others? Please specify:

3. If yes, **which removed policy or guidance pages** did your organization or associated programs previously rely upon? (Select all that apply):

   Resources/Websites/Guidance on Topics Related to:
   - EHR Certification or EHR use
   - Interoperability (e.g., ISA)
   - LGBTQ+ Youth & Adolescent Health
   - LGBTQ+ General Health & Wellness
   - HIV/AIDS & Sexual Health
   - Clinical Research & Trials
   - Disease specific guidance (e.g., Mpox, COVID)
   - Diversity, Equity & Inclusion
   - Gender Identify & Sex-Specific Health
   - Immunizations
   - Reproductive Health Information
   - Racial & Ethnic Health Equity
   - Reproductive Health and Rights Website
   - Firearm Violence and Injury Prevention
   - Environmental and health impacts (e.g., EPA, climate, climate/health agency)
   - Others? Please specify:

4. Please describe the most significant data source or webpage your organization lost access to and how it was used in your work.

Impact

5. To what extent has the removal of datasets and guidance impacted the public health department's ability to carry out its mission?

APPENDIX

6. **Affected Functions -** For each function below, indicate the level of impact from the removal of datasets and guidance. (Select N/A if your organization does not perform this function).

FUNCTION	N/A	UNSURE	1 - NO IMPACT	2	3	4	5 - MAJOR DISRUPTION
Epidemiologic surveillance							
Health equity analysis							
Environmental monitoring							
Public communication							
Federal or grant reporting							
Data dashboards							
Clinical guidelines							
Evidence-based practices							
Research activities							
Forecasting or predictive modeling							
Grant writing or development							
Budget or Strategy development							

7. Can you describe a specific example of an activity or report that was delayed or modified due to missing federal data?
8. **Alternate Data Sources** - If so, did the public health department identify an alternative data source(s) (e.g., academia, 3rd party aggregators, HIE) to use? Please describe the alternative data sources or methods you used.

APPENDIX

8. **Alternate Data Sources** - If so, did your organization identify an alternative data source to use? Please describe the alternative data sources or methods you used.
   a. Was your organization asked to be an alternate data source? If so, for what data and function?
9. **Communication** - Did missing or altered federal webpages or datasets affect your ability to communicate findings to the following partners/stakeholders?

Partners/Stakeholders	YES	NO	UNSURE
State leadership or policymakers			
Local health departments			
General public			
Federal partners			
Health care providers			
Payers			
CBOs			
Others? Please specify:			

10. **Program/Policy Impact** - Were any specific HIE or data exchange services and/or policies affected by missing datasets, resources, or guidance? Please describe.
11. **Funding and Reporting** - Were any grant deliverables, performance measures, or reporting deadlines impacted? If yes, please provide a brief description.

Restored Datasets and Resources - Reliability and Usability

12. If you used any restored datasets or guidance from restored websites, please assess their quality compared to the original versions.

    Overall comparability in scope and usability to the originals:
    - Fully comparable
    - Partially comparable
    - Not comparable
    - Unsure/did not use restored datasets

APPENDIX

13. What issues have you encountered with restored datasets? These can include things like:
    - Temporal gaps in data (e.g., missing data from the period when databases were unavailable)
    - Missing demographic data elements that were previously available
    - Incomplete historical records
    - Other data quality issues

    Select all that apply.

	N/A	No issues identified	Temporal gaps	Missing demographic data	Incomplete historical records	Other data quality issues
Behavioral Risk Factor Surveillance System (BRFSS) state-level health behavior data						
National health care Safety Network (NHSN) data-health care-associated infections						
National Immunization Surveys- immunization coverage data						
PEPFAR Data Dashboards						
Pregnancy Risk Assessment Monitoring System (PRAMS)						
Social Vulnerability Index						
Ryan White HIV/AIDS Program Compass Dashboard						
Youth Risk Behavior Surveillance System (YRBSS)						

APPENDIX

Morbidity and Mortality Weekly Report (MMWR)						
Other data quality issues? (please specify):						

14. Describe your experience reintegrating or validating restored datasets. Were there differences in format, documentation, completeness, or trustworthiness?
15. Did your organization continue to rely on alternative sources after restoration?
16. Did your organization continue to supply data/information as an alternative source after restoration?
17. Please share any additional thoughts and comments.

2025 National Health Information Organization (HIO) Survey – HIO Connectivity to Public Health Agencies

Civitas supports the nationwide survey of Health Information Organizations (HIOs) in collaboration with the University of California, San Francisco (UCSF), and the Assistant Secretary for Technology Policy (ASTP).

The survey offers critical insights into the state of health information exchange in the U.S. and the evolving role of HIOs in advancing regional, state, and national interoperability. Key findings from the 2025 National HIO Survey related to HIO connectivity to public health include the following:*

- 73% of HIOs reported being connected to a state public health agency, 58% reported being connected to a local public health agency, and 17% reported being connected to a tribal or territorial agency. Among these:
    - 60% support syndromic surveillance reporting
    - 60% support immunization registry reporting
    - 54% support electronic lab reporting
    - 40% support public health registry reporting
- There is an average of 19 unique public health agencies connected to an HIO in any way and an average of 5 public health agencies who engage in bi-directional exchange with the HIO to which they are connected.
- Additional services provided by HIOs to public health include dashboarding and data visualization, analytic and data quality support, bi-directional data sharing, outbreak monitoring and alerting, and public health policy impact monitoring.

*These results have not yet been officially published. Once published, the information will be available on the Civitas website at www.civitasforhealth.org/health-information-organization-national-survey/