

CODE

ENSURING THE FUTURE OF ESSENTIAL HEALTH DATA FOR ALL AMERICANS

A 2025 Report of the Center for Open Data Enterprise



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INTRODUCTION

Recent changes to the federal data landscape have put America's health data at risk. In response to these changes, the Robert Wood Johnson Foundation (RWJF)[1] is supporting an initiative by the Center for Open Data Enterprise (CODE)[2] and the National Conference on Citizenship (NCoC)[3] to ensure the availability of essential data for health and healthcare improvement now and into the future.

On July 9 and 10, 2025, CODE and NCoC co-hosted an online *Roundtable to Ensure the Future of Essential Health Data for All Americans.* By convening a diverse group of 78 subject-matter experts, this Roundtable identified data collections that may be impacted by federal policy changes, highlighted data that is especially important to health and healthcare, and discussed strategies for saving or improving key data on America's health and the factors that impact it. The project engaged data users, data providers, and policy and technical experts to envision the future of America's government, private, and community-based public health data. A list of participating organizations is in Appendix 3. CODE gathered additional insights by sending a pre-Roundtable survey to all participants and analyzed the responses to inform the Roundtable design and this report.

RWJF and CODE also held a public Webinar to set the stage for Roundtable discussions with brief talks from seven expert participants. Appendix 4 presents selected quotes from the Webinar; the full video is available here and the transcript is available here.[4, 5]

For the Roundtable, CODE facilitated 24 breakout sessions, each with three to eight participants. Most participants joined two of these breakout sessions on topics of their choosing. CODE also held a half-hour session at the end of the day for facilitators to present high-level findings to the full participating group.

This paper builds on the Roundtable and other research by CODE to describe the state of U.S. data related to public health, identify challenges, and present opportunities. It provides an overview of recent federal decisions that have impacted the government data and research landscape; implications of these actions for future research, data collection, and public health; and current opportunities for action. CODE is also simultaneously publishing an online Core Public Health Data Hub (https://bit.ly/public-health-data) with core federal datasets and other resources.[6]

CODE is now setting up small working groups to follow up on these and other opportunities. We hope that this next stage of work will develop new findings, tools, and strategies not only to preserve public health data, but to make the data even more complete, accurate, and useful than it may have been in the past.

EXECUTIVE SUMMARY

This paper includes three sections:

Background: The Current State of U.S. Health Data. This section reviews changes to public health data that have been made since the beginning of 2025 and their possible impact. These federal actions include changing data collections and publication through Executive Orders, taking down federal websites and datasets, cutting staff and funding for health agencies and health research, changing how health research is

overseen, and withdrawing from global health efforts. This section provides the context for analyzing current challenges in different areas of public health and the potential for cross-cutting solutions.

Results of an Expert Convening: Six Areas of Public Health Work. This next section, based primarily on discussions at the Roundtable, goes into greater depth on current issues and challenges in six areas of work in public health. It follows the structure of the Roundtable, which included breakout discussion sessions on each of these topics:

- Social Determinants of Health Data (SDOH)
- Disaggregated data (data on race and ethnicity, gender, and sexual orientation)
- National Institutes of Health (NIH) and scientific research funding
- Environmental and climate factors
- Healthcare access and quality
- Health risks and prevention

Cross-Cutting Recommendations for Action: Where the previous section is organized around *the kinds of work public health experts do*, this section is structured by *the kinds of actions they can take*. It describes strategies that emerged across the different topical breakout sessions, which could be applicable to different areas of public health work. These include:

- *Preserving core federal data and tools.* Strategies could include projects to analyze data priorities and data gaps, monitor changes to core datasets, and develop advisory bodies for data collections that operate outside of government.
- *Building state, local, and community capacity.* Here, there are opportunities to identify and publicize models of successful state and local health data projects, share data collection strategies, ensure funding and incentives for states to collect data, find new ways to use state data for national insights, and support community-level data projects.
- *Developing non-government resources for data and analysis.* This can include work on standards for health and medical records, development of nontraditional data sources, use of private data, and leveraging philanthropy to support new or existing data programs.
- *Messaging, communications, and advocacy.* Opportunities include analyzing target audiences and developing case studies, and developing strategies to influence policymakers and business leaders, impact public opinion, and support advocacy and legal action.
- *Rethinking and improving health data privacy.* With new risks to data privacy, there are timely opportunities to analyze the impact of new federal policies, review, strengthen, and adapt privacy safeguards, and address privacy-related issues of public trust.

In each of these areas, CODE has made several recommendations that we hope public health experts and practitioners will consider and act on.



BACKGROUND: THE STATE OF U.S. HEALTH DATA

A robust and inclusive federal health data ecosystem is essential to improving the health and well-being of all Americans. No matter the domain, accurate, reliable, and disaggregated public health data provides crucial evidence for targeted interventions, funding, and equitable policymaking.

Public health outcomes are significantly shaped not only by clinical care, but by a broader set of social, environmental, and structural factors referred to as the Social Determinants of Health, or SDOH. These factors, which contribute to roughly 80 percent of health outcomes[7] for individuals, include housing stability, food access, education, transportation, employment, and more.

Data sources also need to be disaggregated by race, ethnicity, and sexual orientation and gender identity (SOGI) factors, to make it possible to determine how health issues and the SDOH impact different groups. For example, climate and environmental factors may disproportionately impact communities of color. Women's health data is critical to tracking metrics on maternal mortality, reproductive outcomes, and intimate partner violence. Disaggregated LGBTQ+ health data allows researchers and policymakers to respond to disproportionate risks faced by that community, including mental health challenges and violence.

Several federal agencies play a foundational role in collecting and disseminating data critical to advancing health equity and informing public health research. These include agencies and bureaus within the U.S. Department of Health and Human Services (HHS)[8] and those that contribute health-related data from other agencies. Within the HHS, for example:

- The Centers for Disease Control and Prevention (CDC)[9] manages widely used tools such as the Behavioral Risk Factor Surveillance System (BRFSS)[10] and the Youth Risk Behavior Surveillance System (YRBSS)[11], which offer insight into chronic disease, mental health, violence, and disparities affecting LGBTQ+ youth.

- The National Center for Health Statistics (NCHS)[12], housed within the CDC, provides a wealth of vital statistics. These include statistics on births, deaths, infant mortality, and family growth trends; data for the leading causes of death and emerging causes of death; changes in health insurance coverage and related health outcomes; national nutrition guidelines and obesity rates; and much more.

- The NIH funds and supports a wide array of research, from cancer and aging to infectious disease and minority health.

- The National Institute on Minority Health and Health Disparities (NIMHD)[13] focuses on the root causes of health disparities affecting racial and ethnic groups and underserved communities.

> *Public health outcomes are significantly shaped not only by clinical care, but by a broader set of social, environmental, and structural factors referred to as the Social Determinants of Health, or SDOH.*

Outside of HHS, several other agencies provide important health-related data for the federal data ecosystem:

- The U.S. Census Bureau (Census)[14] supplies demographic and socioeconomic data via the American Community Survey and Decennial Census. Both are vital for understanding population-level health determinants and were frequently identified as essential data sources by Roundtable participants in breakout discussions and in our survey.

- The U.S. Department of Veterans Affairs (VA)[15] provides critical information on veterans' health.

- The U.S. Department of Agriculture (USDA)[16] provides data related to health and nutrition.

- The U.S. Environmental Protection Agency (EPA)[17] provides data on pollution exposure and environmental burdens across communities.

- The U.S. Department of Energy (DOE)[18] and the State Department provide data and tools related to climate change and its impacts on health.

Together, these and other data sources have collectively provided a comprehensive view of health in America. They inform decision-making, policy development, and public accountability, ensuring that health

interventions are effective, equitable, and grounded in evidence. Through the Roundtable and pre-Roundtable survey, CODE has identified a core set of dozens of public health datasets, presented in Appendix 2, that can form a basis for focusing on essential data resources.

FEDERAL ACTIONS AND PUBLIC RESPONSE

Since January 2025, the Trump Administration has made a number of changes that have impacted health research and federal data. These actions, many of them implemented through executive orders (EOs), include dismantling of Diversity, Equity, and Inclusion (DEI) efforts across federal agencies, defunding health and scientific research, and withdrawing American participation from global institutions. Many of these efforts are aligned with the *Make America Healthy Again Initiative* (MAHA)[19], a policy framework aimed at reforming federal public health agencies by emphasizing individual health responsibility, reducing federal involvement in health equity and community-based programs, and shifting greater authority to states and local governments.

During the government shutdown in October and early November, the administration took actions that made the future of America's health data even more uncertain. The administration attempted to fire large numbers of CDC staff including at the NCHS, developments that AcademyHealth said would "strike at the heart of the nation's *evidence infrastructure*.[20] Public health experts were particularly concerned about cuts to the staff for the National Health and Nutrition Examination Survey (NHANES) and the suspension of work, and potential firing, for staff of the Morbidity and Mortality Weekly Report (MMWR).[21, 22, 23, 24] Some firings at the CDC were quickly reversed by the administration, and in mid-October, a federal court ordered the administration not to implement any layoffs during the shutdown, including cuts to staff at HHS.[25, 26, 27] Despite this legal victory, now that the shutdown is over, it's reasonable to expect that the administration may try again to reduce the nation's public health staffing and data collections in the months ahead.

So far, the administration's policies have targeted data on maternal health, gender identity, HIV, DEI, sexual orientation and gender identity, environmental justice, the SDOH, and more. These actions have been met with a variety of reactions, including resistance from academic researchers and journals, lawsuits from state attorneys general, and efforts to track website changes and archive data. This section covers:

- President Trump's Executive Orders and their impact
- Removal of federal public health webpages and data
- Termination of federal staff and dismantling offices
- Research funding cuts
- Disbanding advisory committees
- Withdrawal from global health collaborations

EXECUTIVE ORDERS

Early on, President Trump rescinded several Executive Orders (EOs) that President Biden had used to improve data for equitable public health. These included the EOs on Advancing Racial Equity and Support for Underserved Communities Through the Federal Government[28], Protecting Public Health and the Environment and Restoring Science To Tackle the Climate Crisis[29], and Ensuring a Data-Driven Response to COVID-19 and Future Public Health Threats[30]. At the same time, President Trump issued several new EOs with a direct impact on minority populations and public health.

- EO 14173[31] directs federal agencies to terminate all offices, positions, programs, and contracts related to DEI.
- EO 14151[32] directs federal agencies to terminate all offices, positions, programs, and contracts related to environmental justice.
- EO 14168[33] declares that "[i]t is the policy of the United States to recognize two sexes, male and female" and explicitly rejects "gender ideology." Also directs agencies to enforce sex-based rights only as they relate to biological sex.
- EO 14243[34] grants federal officials unfettered access to data from all state programs receiving federal funding, unemployment, and payment records. While this EO is framed as a means to eliminate data silos, it could lead to federal influence on the way state data is collected - an important issue since national health data is collected at the state level.
- EO 14303[35], described in more detail below, has the stated purpose of "restoring a gold standard to science."
- EO 14332[36], "Improving Oversight of Federal Grantmaking," is also described in more detail below.

REMOVAL OF FEDERAL PUBLIC HEALTH WEBPAGES AND DATA

In February 2025, 8,000 federal webpages and more than 2,300 datasets related to critical public health issues went offline, including 3,000 webpages from the CDC.[37] Specifically, CDC guidelines for sexually transmitted infection (STI) treatment and birth control information for clinicians' use were altered or taken down. In the same period, health-relevant data and websites also disappeared from the U.S. Department of Energy (DOE), the U.S. State Department, the National Oceanic and Atmospheric Association (NOAA), and the EPA.

Many of these information sources were returned to the web - sometimes just days after being taken down, and in some cases later on as the result of legal challenges. Despite this, it is difficult to tell whether information has been distorted or removed, whether the websites still include all necessary documentation, or whether other changes may be made in the future.

Websites may also be restored with new language that undercuts the trustworthiness of their information. For example, a federal court order mandated that HHS restore the YRBSS, but the website now includes a notice that the CDC was "required to restore this website." It also notes that "Any information on this page promoting gender ideology is extremely inaccurate and disconnected from the immutable biological reality

that there are two sexes, male and female." A similar notice is now on the page for the CDC's Social Vulnerability Index (SVI)[38], which was also restored by court order.

In response to these changes, many individuals and organizations have started to archive data sources and websites that have been taken down, or have a high likelihood of being removed.[39] For example, a group of researchers at the Harvard T.H. Chan School of Public Health launched an initiative to preserve federal data related to health equity.[40] STAT News has been conducting live monitoring and storing of CDC data since January 31st.[41] The Data Rescue Project is aggregating information on various data archiving initiatives, and has created a Data Rescue Tracker to catalog these data rescue efforts.[42, 43] Public Environmental Data Partners (PEDP), which has been a model for collaborative action, rapidly recreated the Environmental Protection Agency's (EPA) EJScreen and the Climate and Economic Justice Screening Tool (CEJST) after they were removed.[44] Other groups are challenging data deletions in court, as described in the Recommendations section of this paper.

TERMINATION OF FEDERAL STAFF AND DISMANTLING OFFICES

Sweeping personnel and organizational changes across federal agencies have dramatically altered the U.S. health and health data landscape. Roughly 10,000 HHS staff were let go due to reductions-in-force (RIFs) from March through June 2025, including 2400 CDC staff.[45, 46] Among other impacts, HHS dismantled its team responsible for setting federal poverty guidelines and decimated the Agency for Healthcare Research and Quality (AHRQ), the lead federal agency for patient safety research.[47, 48] Roughly two-thirds of the AHRQ workforce has resigned or been given RIF notices this year, and in early September the House Appropriations Committee approved a proposed 2026 budget that would eliminate AHRQ entirely, describing the agency as "duplicative."[49, 50] The dismantling of this agency could impact healthcare by disrupting longstanding research and data collections, including research on prevention and the Medical Expenditure Panel Survey, which informs researchers and policymakers on critical healthcare issues.

At this point, the future of HHS funding is uncertain. In August, the Senate Appropriations Committee approved a budget that would preserve funding for some parts of HHS, but cut HHS funding by 6 percent overall and by 19 percent for the CDC[51]. The President's proposed budget also includes major cuts to the Substance Abuse and Mental Health Services Administration (SAMHSA), which provides essential data on mental health and substance abuse.[52]

Sweeping personnel and organizational changes across federal agencies have dramatically altered the U.S. health and health data landscape.

These sorts of cuts put a wide range of health data at risk, including vital SDOH data from multiple agencies other than HHS. Staffing levels at the USDA and the U.S Department of Education[53] have been drastically reduced, while key sources for environmental justice data have been discontinued.

In September, the USDA announced that it will discontinue the widely used survey on food insecurity and put about a dozen hunger researchers on leave.[54] As NPR has reported, discontinuing this survey will make it difficult to track the impact of upcoming cuts to food assistance programs in the U.S.[55] While the USDA cited the survey's cost as one reason for halting it, the website dataindex.us has pointed out that the survey costs only about one million dollars a year, and provides data to inform more than one hundred billion dollars in spending through the Supplemental Nutrition Assistance Program (SNAP).[56]

RESEARCH FUNDING CUTS

Both cuts in federal funding and constraints on what researchers can study are impacting the scientific and medical research communities. By May 2025 the NIH cut its provision of research and programmatic grants by an estimated $2.7 billion.[57] Grant Witness, a new site that tracks these changes, identified more than 5000 impacted NIH grants by late August, although about 20 to 25 percent of discontinued grants had been reinstated at that point.[58]

In addition to scaling back on new grants, the NIH has terminated a number of existing studies on subjects including aging, cancer, child health, and diabetes. For example, a $400,000 grant for a project studying maternal mortality and intimate partner violence was cancelled due to its connection to the term "equity."[59] After conflicting legal decisions, described in more detail later in this paper, the cuts to existing NIH grants have remained.

Additional cuts have resulted in the termination of long-term studies vital to understanding the health impacts of SDOH across the lifespan. For example, longitudinal research on topics such as COVID-19's effects during pregnancy, genetic links to substance use, and occupational exposure to radiation have been prematurely halted. These studies often generate disaggregated data and insights about vulnerable populations. Their loss leaves critical gaps in our understanding of how social and structural conditions contribute to long-term health inequities, and how to counter them for better outcomes.

The Trump Administration has also severely reduced federal funding to certain academic institutions, citing concerns about antisemitism, DEI, or other issues. In April the NIH canceled $110 million to Harvard and its associated hospitals.[60] Columbia University lost nearly $400 million in federal grants due to antisemitism concerns and was forced to lay off close to 180 staff who were paid by these grants. The cut impacted over 300 grants for scientific and medical research.[61]

Other funding cuts have impacted mental health, substance use, and neurological disorders, including research on neuroscience, Alzheimer's disease, and psychiatric epidemiology. For example, the NIH canceled a 5-year $676,000 contract for a study that stored and studies DNA samples to analyze genetic trends in alcohol and drug consumption with substance use and mental health disorders.[62]

State Attorneys General are providing a line of defense for preserving federal research and data collections. In April, a coalition of 16 states sued the NIH, challenging the termination of grants. Another coalition of Attorneys Generals has sued to reverse cuts to HHS.[63, 64] While only some lawsuits have been successful, legal action could help reinstate health data collections and other functions.

DISBANDING ADVISORY COMMITTEES

Federal scientific programs have long relied on expert councils and committees, including those that operate under the Federal Advisory Committee Act (FACA).[65] In his first day in office, President Trump reinstated an EO from his first-term directing agencies to terminate at least one-third of their FACA committees.[66] By April, agency heads eliminated many committees whose role was to ensure standards for scientific research and data collection and publication.[67] In the absence of formal advisory committees, political appointees may have greater control over agencies' research and published findings.

These cuts included three advisory committees to the U.S. Census, including the National Advisory Committee on Racial, Ethnic, and Other Populations.[68] Commerce Secretary Howard Lutnick said that the committees were eliminated because their purpose "had been fulfilled".[69] However, dozens of organizations have disagreed strongly with that assessment. In a letter to Secretary Lutnick sent by the Leadership Conference on Civil and Human Rights, these organizations argued that "The elimination of these committees both undermines transparency for the American public and threatens the ability of the Census Bureau to serve communities that have historically been undercounted in the census and under-represented in other surveys."[70, 71]

The administration's anti-DEI efforts are also reflected in other changes to federal advisory committees. An analysis of NIH scientific councils showed that 43 advisors had been let go as of mid-April 2025, and that 38 of those were female, Black, or Latino.[72]

Outside of the NIH, the removal of federal advisory committees for scientific health-related data, such as the EPA's Science Advisory Board and Clean Air Science Advisory Committee, illustrates the growing risk to data quality and utility.[73, 74] These panels have contributed expert insight into public data collections in vital areas, making sure they are methodologically sound, statistically valid, and relevant to current needs. With their reduced input, federal scientific data may become less reliable and less useful to the research community, reducing the overall integrity of the evidence base that underpins health science and policy.

An EO on "Restoring Gold-Standard Science" states that research used in policymaking must meet a range of quality standards, including reproducibility and transparency, peer review, and freedom from conflicts of interest.[75] However, as the Center for Open Science and others have pointed out, the EO gives federal agency heads the responsibility to determine whether these "gold-standard" principles are being followed.[76,77] The *New York Times* wrote that the order thus puts "political appointees in charge of vetting scientific research and gives them the authority to 'correct scientific information,' control the way it is communicated to the public and the power to 'discipline' anyone who violates the way the administration views science."[78]

A later EO, issued in early August, could have an even greater impact. This Order requires that a senior political appointee reviews all discretionary federal grants to ensure that they "demonstrably advance the President's policy priorities".[79] In addition to setting up a potential bottleneck that could slow down research funding dramatically, this EO takes control out of the hands of impartial grant review committees: It states that their findings should be considered advisory, but not final.[80]

WITHDRAWAL FROM GLOBAL HEALTH COLLABORATIONS

On his first day in office, President Trump withdrew the U.S. from the World Health Organization (WHO).[81] America's withdrawal from the WHO and other global health initiatives severs its access to certain early warning systems and collaborative frameworks that have historically informed domestic preparedness.[82] The U.S. has also stopped supporting the Demographic and Health Surveys (DHS) program, which many low- and middle-income countries rely on for shaping maternal and child health programs, and which also informs comparative health equity research in the U.S.[83, 84] The program is now operating with interim funding from other sources and some reduced functions.

Withdrawal from global partnerships may isolate U.S. scientists from international research networks and early-warning systems essential for addressing global health threats, weakening global solidarity and forfeiting the ability to anticipate and address emerging issues with timeliness and precision. If these trends continue, the U.S. risks falling behind not only in global scientific leadership, but in its ability to protect and promote the health of its own population through evidence-based research and rapid response.



RESULTS OF AN EXPERT CONVENING: SIX AREAS OF PUBLIC HEALTH WORK

The ongoing threats to health data demand a response from public health leaders, researchers, healthcare providers, data experts, and other groups concerned about ensuring health resources and improving health equity for all Americans. The July 2025 virtual Roundtable was designed to discuss the state of health data, identify risks and opportunities, and propose possible next steps.

Discussions at the Roundtable were broken into six topics covering the following areas of public health work:

- Social Determinants of Health (SDOH) data
- Disaggregated data (data on race and ethnicity, gender, and sexual orientation)
- Healthcare access and quality
- Health risks and prevention
- Environmental and climate factors
- NIH and scientific research funding

Each breakout session was structured to address critical issues in each topic area. CODE facilitated the sessions around questions including:

- What are the greatest threats to essential health data in these areas?
- What opportunities do we have to strengthen essential data sources?
- How are these different kinds of data being used for health policies and programs - and what are the possible impacts if data is lost?
- How can we respond?

This section presents CODE's synthesis of observations and challenges that emerged during Roundtable discussions in each topic area. As part of the discussion, each breakout session identified key data sources for public health and health equity, with a primary focus on federal sources. The Roundtable participants identified federal sources that are still intact, those that have been altered since the beginning of 2025, and those that are no longer available from the federal government. A list of these datasets is included in Appendix 2.

While each area of work poses unique challenges, the solutions that Roundtable participants proposed were generally cross-cutting and would advance work in more than one area. For example, participants across several topic areas suggested focusing on core federal datasets, state and local data capacity, data standardization, and messaging for advocacy as opportunities in their areas. CODE has synthesized these opportunities in the next section of this paper, *Cross-Cutting Recommendations for Action*.

SOCIAL DETERMINANTS OF HEALTH (SDOH)

OVERVIEW

The SDOH include a wide range of factors, which CODE has addressed in previous Roundtables with HHS and other partners. Because these factors are so diverse, research and action to improve the SDOH depend on an unusually large number of federal data sources both within and outside of HHS. These include:

- Census data[85], particularly the American Community Survey (ACS)[86]
- Centers for Medicare and Medicaid Services (CMS) data[87], including claims data and Medicaid data
- CDC data[88], particularly from the BRFSS and YRBSS
- Mental health data from SAMHSA[89]
- Data from the Bureau of Labor Statistics[90], including the American Time Use Survey[91]
- Data from federal agencies focused on different aspects of American life, including data on homelessness from the U.S. Department of Housing and Urban Development (HUD)[92], on incarceration from the Bureau of Justice Statistics[93], on food insecurity from USDA, and on education from the U.S. Department of Education.

If critical federal sources are seriously compromised or disappear, it would be very difficult to rebuild the nation's SDOH data infrastructure from the ground up.

Without reliable, up-to-date SDOH data to inform policy, allocate resources, and target interventions, it will be harder to equitably improve population health. For example, the loss of environmental justice data sources like the EPA's EJScreen will jeopardize the ability to track community-level exposure to environmental hazards such as air pollution, extreme heat, and climate-driven disasters.[94] These datasets and tools have historically been used to inform emergency response, target infrastructure investments, and support public health planning, particularly in low-income and historically marginalized communities.[95]

CHALLENGES

Public health experts are working to preserve federal sources of SDOH data, through advocacy and legal actions, when necessary, although these strategies can be time consuming and expensive. Public health professionals are also exploring alternatives to federal SDOH data, but these options have challenges as well. For example:

- *State data* can be a source of SDOH information, but states vary greatly in their data collection capacity – and state governments may be increasingly reluctant to share their data for fear of its misuse.
- *Community-level data* collected through surveys, for example with the help of community-based organizations (CBOs), is another option. But community-level data capacity is even more variable than state levels and existing privacy laws make it difficult for CBOs to undertake health data collections.
- *Survey-based data* related to the SDOH may be inaccurate due to low response rates. Responses to health-related and demographic surveys have already been dropping in recent years, and are likely to drop further as individuals worry about how the government or other authorities may use their data.
- *Gathering data from the healthcare system itself*, through electronic health records (EHRs), patient interviews, or other means, poses other difficulties related to data quality and interoperability. It has been difficult in the past to rely on health records for SDOH data. Physicians may also not be the best or most trusted source for gathering SDOH data through patient interviews or questionnaires.

DISAGGREGATED DATA

OVERVIEW

Disaggregated data is data that can be analyzed with regard to a range of characteristics and includes information on race, ethnicity, sexual orientation, gender identity, income and education, immigration status, individual health conditions, and more. It is a critical tool for improving health equity. Roundtable participants raised concerns that losing disaggregated data could have a negative impact on communities of color, migrants, low-income communities, and LGBTQ+ individuals, especially trans people. The Leadership

Conference Education Fund has established the Data Disaggregation Action Network (D-DAN) to preserve this kind of data, with a particular focus on race and ethnicity.[96]

Roundtable participants described how disaggregated data can:

- Enable different stakeholders to identify populations, target interventions, and generally support health policy
- Identify racial disparities in healthcare, insurance coverage, and treatment outcomes
- Identify cultural or language issues in communication
- Help states and cities understand their populations
- Track vaccine distribution and factors, such as social media disinformation, that may impact vaccination rates in some communities

While the federal government has removed some data on race and ethnicity – for example, removing it from the Office of Personnel Management's public records – most of that data has remained in place so far. Data advocates are watching the implementation of recent OMB revisions to Statistical Policy Directive 15 (SPD 15), released in March 2024, that provide for more precise collection of race and ethnicity data across government.[97] At this writing, the administration seems to be planning to implement the SPD 15 revisions: In June, the Acting Director of the U.S. Census Bureau reportedly stated that the Bureau is "still moving forward" with plans to make changes to update 2030 Census survey questions accordingly. [98] However, the Acting Director was relieved of that role in September, and it is not clear what course a new Census Director will take.[99] Federal agencies had faced a September 2025 deadline to develop action plans for their SPD 15 revisions, but at the end of September OMB extended the deadline by six months.

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In contrast to data on race and ethnicity, SOGI data has been systematically removed or changed in federal datasets. A July article in *The Lancet*, titled "Data manipulation within the U.S. federal government," examined 232 datasets from HHS, CDC, and the VA that had been updated in the first two months of the administration.[100] The authors found that nearly half of the datasets that had been updated were altered, most of them by changing the word "gender" to "sex" in data categories and descriptions – and usually without logging this as a change to the data. As the authors point out, this is a nontrivial alteration that "changes the accuracy of the dataset and the conclusions that can be drawn [and can] even invalidate the results themselves." A UCLA analysis has also stressed the importance of maintaining data on LGBTQ+

populations in federal surveys on health, nutrition, and other topics, and described the potential impact of losing that data in the future.[101]

Parts of the academic and publishing communities are resisting increasing government restrictions on language and content in health research. CDC officials have reportedly instructed their researchers to withdraw scientific papers submitted for academic publication to allow for review by the Trump Administration[102]. These papers will be reviewed to ensure they align with the administration's EO stating the government will only recognize two sexes. In response, the *American Journal of Public Health* has announced that it will apply heightened scrutiny to research submitted by government entities, particularly if they appear to be altered by political directives.[103] Major medical journals including the *New England Journal of Medicine* and the *Lancet* have reaffirmed they will not change their evaluation standards in line with political mandates.

Roundtable participants also noted a new, dual risk: Disaggregated data is both disappearing from public datasets and being weaponized against some American communities. Whole groups within the population now face the risks of erasure on the one hand, and discrimination and targeting on the other. As one Roundtable participant put it, "The focus has shifted from using data to expose disparities, to protecting people from how their data is used."

CHALLENGES

Roundtable participants described a number of challenges in maintaining disaggregated data and ensuring that it is not weaponized against individuals or communities. These include:

- *Loss of critical federal resources.* Some federal sources of disaggregated data would be very difficult to replace, and losing them could have a dramatic impact on health research. For example, the team overseeing the Pregnancy Risk Assessment Monitoring System (PRAMS)[104], a crucial source for identifying groups of women and infants that are at higher risk for poor health outcomes, has been placed on indefinite leave, and users can no longer request data access directly.[105] [106]This change will make the identification of groups at higher risk and understanding the drivers of maternal complications and mortality even more difficult, exacerbating this major public health concern.

- *Limited state and local data capacity.* While some states and large cities are now collecting disaggregated data and can fill some gaps in federal data, as described below, not all have the capacity to do so. Even large states like California rely on federal data to support their public health programs. The CalAIM program to improve Medi-Cal services and the California Health Care Foundation use federal data and analytic tools in their work.[107, 108] Smaller cities also generally rely on localized versions of federal data, which may not continue to be disaggregated in the ways they need. As one participant noted, "In many places, the only available data comes from the American Community Survey." In addition, collecting new kinds of data is an added burden for state and local governments that may already be strapped for resources.

- *Discontinuation of federally funded research.* Under this administration, NIH has canceled grants to study communities of color and LGBTQ+ individuals, as described below. Some institutions are being told to remove words like "diversity," "equity," or "climate change" from grant proposals, while others are having to sign certifications that they don't support DEI programs, leading to self-censorship and deprioritizing research on health equity.

- *Loss of trust.* While community-level surveys could help fill data gaps in theory, they are becoming harder to carry out. Communities of color, Indigenous communities, and communities with large migrant populations are increasingly reluctant to provide data to the government or other organizations for fear that it will be misused.

- *Loss of a culture of disaggregation.* If disaggregated data is no longer the norm for health research, the nature of research and its application will change. This shift could potentially increase the imbalance of power between majority and minority groups. As one Roundtable participant put it, "Not having the data means you're erasing people… you're erasing their experience."

NIH AND SCIENTIFIC RESEARCH FUNDING

OVERVIEW

The status of the National Institutes of Health (NIH), the country's largest funder of medical research, has been in limbo for the entirety of 2025, depending on decisions in the courts and in Congress.[109] The future of NIH funding remains uncertain. The President's proposed budget would cut the NIH budget dramatically. However, those proposed cuts are meeting bipartisan resistance. In August, the Senate Appropriations Committee rejected the President's request to cut $18 billion from NIH in Fiscal Year 2026, and voted instead to increase the NIH budget by $400 million in a 26-3 vote.[110] While this latest Senate vote is a hopeful sign for the NIH, it's too early to tell how these conflicts will play out.

At the same time, individual physicians and researchers have opposed these cuts and organized on behalf of NIH.[111] In June, hundreds of NIH employees signed The Bethesda Declaration, a letter sent to the current NIH director to protest new government policy and urge him "to maintain NIH as the world leader of biomedical research."[112]

Cancelling or suspending longitudinal studies funded by NIH could have long-lasting consequences for the country's ability to sustain robust, inclusive, and forward-looking public health research. Many of these long-term studies focus on vulnerable or understudied populations and help inform policy, clinical care, and community interventions.

CHALLENGES

Beyond the evident funding threats to America's research enterprise, Roundtable participants and CODE's research surfaced many challenges that have less obvious impacts on the way research is conducted. These include:

- *A brain drain from NIH and other research organizations.* With scientific training and internship programs cut – and with research scientists considering moving their labs to other countries – American medical research will become less innovative, less advanced, and less efficient.

- *Major cuts to equity-related research.* The issues impacting disaggregated federal data, described above, impact the research enterprise as well. SOGI research, particularly research involving trans

people, is not being funded. Many researchers may also avoid conducting studies involving sensitive topics like race, gender identity, or reproductive health, not because the science doesn't require it, but because funding policies now discourage or penalize such focus areas.[113]

In April the NIH updated its Grants Policy Statement - which included the Civil Rights Act of 1964 - to overturn previous "Civil Rights Protections".[114] The new "Civil Rights Term" prohibits NIH grant recipients from studying topics related to, or seen as promoting DEI or "discriminatory equity ideology." This narrowing of scope threatens the quality and inclusivity of future research, particularly for populations already facing health disparities.

- *Uncertain access to restricted datasets.* There is a risk that researchers could lose access to restricted datasets that are not open to the public but are widely used by qualified researchers and others who are granted special access. An April report covering HHS found that nearly two dozen data repositories, on topics including COVID, HIV, and Alzheimer's disease, were "under review."[115] As of the end of September, almost all of these data repositories were still described online as "under review for potential modification in compliance with administration directives." These databases cannot be downloaded and archived since they can only be accessed under individual data use agreements (DUAs).

- *Potential loss of scientific independence* through the elimination or recasting of advisory committees, and through new rules on "gold-standard science" and grant approval described earlier in this paper.

ENVIRONMENTAL AND CLIMATE FACTORS

OVERVIEW

From the beginning, the current administration has discontinued data sources and tools that were designed to assess the impact of climate change, support environmental justice (EJ), and connect climate and environmental issues to health outcomes. In response, academic and civil society organizations quickly launched efforts - described earlier in this paper - to download and archive federal datasets and tools at risk of alteration or removal.

Climate data has continued to be particularly vulnerable as the administration and Congress have reversed the climate policies of the Biden administration. The One Big Beautiful Bill Act (OBBBA) rescinded any unobligated funds from two allocations approved through the Inflation Reduction Act (IRA): $200 million previously allocated to NOAA for climate forecasting and research, and more than $30 million for data programs run by the Council on Environmental Quality.[116, 117] NOAA is discontinuing its program to track billion-dollar disasters, a key source of information on the impact of extreme weather related to climate change.[118] An August report from the Environmental Data and Governance Initiative (EDGI), titled "Climate of Suppression," provides an in-depth analysis of changes to public environmental information so far under the current administration.[119, 120]

CHALLENGES

- *Continued dependence on federal data.* While groups like PEDP can recreate important federal environment and climate tools, they still rely on federal data, and their efforts will not be sustainable

if federal data sources are discontinued. The same is true of new tools like the U.S. Climate Vulnerability Index, developed by the Environmental Defense Fund (EDF) and Texas A&M. [121] [122]

- *Loss of quality in predictive models.* With the discontinuation of federal datasets, as well as potential cuts to the National Weather Service[123] (NWS), it may become more difficult to predict extreme weather events, fires, or floods. That, in turn, will make it harder to prepare for and manage the severe health impacts of those events.

- *Loss of expertise.* As with medical research, federal cuts and reductions in staff are eroding the base of expertise that supports government work on environmental and climate analysis.

HEALTHCARE ACCESS AND QUALITY

OVERVIEW

Federal health and related data help shape policies that govern healthcare access, public health interventions, resource distribution, and regulatory oversight. Removing data sources and reducing institutional expertise weaken the evidence base informing decisions that can impact healthcare access and quality.

Vital programs such as Medicaid expansion and maternal health initiatives rely heavily on accurate, complete, and up-to-date metrics to determine eligibility criteria, allocate funds, and evaluate impacts.[124] When demographic variables like race and geography are stripped from surveys, policies also risk overlooking or excluding those in need of the most support. And when web-based tools and platforms are taken down, it is harder for agencies and lawmakers to interpret information and develop actionable insights. The result can be a shift from data-driven policymaking to a process that is fragmented, less responsive, and less equitable. More immediately, anecdotal reports indicate that people are hesitant to use Medicaid services due to fear of sharing personal data.

CHALLENGES

While Roundtable discussions focused on current changes to federal data, participants noted other longstanding challenges to data for healthcare access and quality. These include:

- The fragmentation of data sources
- The need for better state-to-state data coordination
- The need for data standardization
- The need to analyze data on individuals together with data on the community and environment.

HEALTH RISKS AND PREVENTION

OVERVIEW

The biggest threat to data on health risks and prevention emerged after the July 2025 Roundtable: The current leadership upheaval at the CDC. Under the current Secretary of HHS, public health prevention has been severely disrupted, beginning with the controversial replacement of members of the vaccine advisory committee. In August, the head of the CDC was fired just a month after having been appointed by President Trump and confirmed by the Senate. Several top CDC officials resigned in the wake of her firing. Some Senators have called for oversight hearings, but at this writing the future of CDC leadership is uncertain.[125] It is also not clear whether the administration will try again to fire large numbers of CDC personnel, as it attempted to do early in the government shutdown that began in October 2025.

CHALLENGES

Even before the current political changes at the CDC, data on health risks and prevention faced ongoing challenges. Roundtable participants described challenges in:

- Maintaining critical health surveillance data
- Collecting and analyzing "real-world" data on health risks, particularly related to health-related social needs, from electronic records
- The absence of a centralized repository for data related to health risks and prevention – and the need to develop an effective decentralized system instead



CROSS-CUTTING RECOMMENDATIONS FOR ACTION

This Roundtable demonstrated the wide range of data that are essential to public health, and the many ways in which those datasets are at risk. CODE is now collaborating with RWJF to set up working groups in areas that cut across the topics discussed at the Roundtable. This section describes Roundtable findings that cut across topic areas to describe possible strategies for action.

PRESERVING AND IMPROVING CORE FEDERAL DATA AND TOOLS

Across all topical areas, Roundtable and survey participants identified essential data sources for their work as well as areas of high concern. The survey was not numerically representative of all participants. However, their responses generally tracked with key points from the breakout session discussions. Some key findings:

- Almost half of survey respondents came from the research and academic community. Nonprofit and government respondents each made up about 15 percent of respondents, with the rest coming from other sectors.

- The main uses for health-related data, in order, were for research, policy analysis and development, advocacy and public engagement, and program design, analysis, and evaluation.
- Almost all respondents use demographic data in their work. About half of respondents also said that they used data on the SDOH, with similar numbers using data on health outcomes and on health utilization and claims.
- Survey respondents cited the CDC (including NCHS) as their most important data source, followed by the Census, CMS, AHRQ, and NIH.

Through the July Roundtable, the pre-Roundtable survey, and related work, CODE has identified more than 70 federal data sources that are widely used by public health researchers and practitioners. Appendix 2 provides a table of these sources, including both those that have had continued government support and a small number that have been taken down or challenged by the current administration.

RECOMMENDATIONS

Conduct a landscape analysis. Roundtable participants described the need for a "national data gap analysis" to surface missing or deleted federal health data and identify areas where new investments, particularly from philanthropy, could help fill in the gaps. Experts in this field need to understand the status of core data sources in order to develop options for preserving, augmenting, or finding alternatives to endangered datasets. A landscape analysis could produce an expanded database of data sources, categorize them by their user groups and areas of application, and prioritize them based on their potential audience and impact. This review could also identify issues with data alterations, political challenges to data collections, inadequate funding or staffing of agencies responsible for the data, or other concerns.

Establish a monitoring system for health data. With so many relevant federal datasets at risk, the public health community needs a monitoring system to identify imminent threats to core sources of information. One option is to set up a tracking system like those used to track the health of species, to continually identify data sources that are vulnerable, endangered, or extinct. Another, complementary approach is to categorize the threats posed to the data, ranging from political targeting to insufficient funding, as a basis for advocacy. In addition, there is a need to monitor legal disputes over data availability, funding cuts that may endanger data sources, and other factors that impact data quality and use.

This work can be done through collaboration between organizations that now monitor the health of all federal data, such as dataindex.us, and health data experts with experience in the use of these data sources and their quality requirements. A monitoring project could also help prioritize federal health-related datasets to keep an especially close eye on those with the greatest value.

Consider launching shadow advisory committees. Advocates can tap the expertise of former federal data experts and former members of FACA committees. In some cases, they may want to assemble "shadow advisory committees" that can monitor and advise on federal data collections. The Union of Concerned Scientists has published a toolkit for setting up such committees.[126,127] In August, the Census Scientific Advisory Committee (CSAC) announced that it was reconstituting itself outside of government under the name I-CSAC, with the "I" standing for Independent.[128] These models could be adapted for some of the public health federal advisory committees that have been dismantled.

BUILDING STATE, LOCAL, AND COMMUNITY CAPACITY

With growing concerns about the completeness, accuracy, and usefulness of federal health data, public health experts are exploring how state, local, or community data can be collected and applied. A greater focus on subnational data could ultimately lead to a more decentralized, resilient, and inclusive health data infrastructure. In addition to state data, cities, and communities are finding new ways to collect and publish health-related data at a more local level than state data provides.

Roundtable participants noted a number of state and local government initiatives that could serve as models for other work. For example: the California Health Interview Survey[129] is the nation's largest state health survey; Maryland's program on case mix data[130] makes it possible to analyze inpatient and outpatient administrative data; Georgia's Occupational Health and Safety Surveillance Program[131] provides information on workforce-related injuries, illnesses, and fatalities; and Connecticut's program on Race Ethnicity and Language[132] is designed to identify and eliminate health disparities.

RECOMMENDATIONS

Celebrate and publicize successful state and city data programs. Across the country, state and city governments are experimenting with new approaches to data gathering that can serve as models for other locales. In addition to the examples above, several developing programs are focused on topical areas that can make them especially applicable models:

- Some cities and states have taken the lead in work on environmental justice (EJ) and its health impacts, often combining federal data with more local data. Detroit is creating an EJ tool for the city using indicators from the Environmental Defense Fund's Climate Vulnerability Index (CVI)[133], and California develops environmental tools with significant amounts of state data.

- States and cities have also developed programs for collecting disaggregated data, often with the help of the Leadership Conference Education Fund, which is encouraging its state partners to implement the revised SPD 15 guidelines. In the July 2025 report "Disaggregation Nation," the Fund describes how race and ethnicity data has been improved in four "case study states": California, Illinois, New York, and Oregon.[134]

- Some states are also passing laws that could serve as model legislation for data collections. In late 2024, for example, California passed the Latino and Indigenous Disparities Reduction Act, which established new requirements for collecting disaggregated data related to morbidity and mortality.[135] In California, the UCLA Latino Policy & Politics Institute is also working with statewide partners to support state level data collection efforts, identify data sets that are at risk of disruption, and study ways to fill the gaps.[136]

- New regional efforts are also providing new models for state collaboration. The Northeast Public Health Collaborative, a project developed with partnership from RWJF, has been launched as "a voluntary regional coalition of public health agencies and leaders, brought together to share expertise, improve coordination, enhance capacity, strengthen regional readiness, and promote and protect evidence-based public health."[137]

Share data collection strategies. Several states, and organizations including the Coleridge Initiative[138], are developing new ways to share and manage health data across state borders. Similarly, states have an opportunity to share information on data collection strategies. These could include strategies for collecting water and air quality data, state-level population surveys, the application and analysis of Medicare and Medicaid data for population insights, and the collection of disaggregated data. In collaboration with groups such as NASCIO[139], the State CDOs Network[140], and the National Governors Association,[141]state health leaders could work to categorize major challenges in health data collection, spotlight model solutions, facilitate interstate dialogue, and publish the results.

Ensure funding and incentives for state and local data. States and cities rely heavily on the federal government for public health data: About 80 percent of the CDC's budget goes to state, tribal, local, and territorial governments, including funding to support health data and the technology to maintain it.[142] Funding disruptions at the federal level are now rippling down to state and local systems, affecting local health data availability, sustainability, and the capacity to analyze health equity. The impacts include cuts to programs to modernize immunization tracking and the cancellation of NIH programs to support community-driven data gathering. Information on the impacts of these funding cuts could provide a basis for advocacy around increased government funding as well as funding from philanthropic or other sources.

At the same time, it's important to monitor the federal requirements that drive the collection of much state data. If federal data requirements are weakened or discontinued, states may no longer collect important information. A monitoring project could identify any changes to requirements for state health data collections, evaluate the impact of those changes,

Use state data at a national level. National health data already relies largely on aggregating and analyzing data from all 50 states. But the federal government does not have to be the only entity aggregating state and local data. Academic, nonprofit, or other research organizations could create national datasets from subnational data in the same way. The COVID pandemic gave us a successful test of this approach: When the CDC was not providing trusted statistics on the pandemic, both the Center for Government Excellence at Johns Hopkins University and the nonprofit USAFacts developed their own dashboards by aggregating data themselves.[143, 144] These and similar projects can be studied and cataloged to serve as models for using state data to develop national insights.

Support and enhance community data-gathering. City governments and community-based organizations (CBOs) have an opportunity to collect community-level data through surveys or crowdsourcing. However, they face many obstacles in doing so. NIH grant programs to support community-level data have been canceled, and CBOs have seen reductions in their own funding. Communities are increasingly distrustful of government data collections. And CBOs all collect data differently, making it difficult to apply strategies from one community to another. Foundations, nonprofits, and other stakeholders can address these issues by developing new funding sources, developing best practices for community engagement in research design, standardizing community data collections, and in other ways.

Partnerships with CBOs can help gather data about their communities and its individuals' needs. In one well-known environmental project, for example, NOAA has worked with communities across the country to measure heat in the city and document the risk of urban heat islands in poor neighborhoods.[145] Developing partnerships like this requires trusted relationships and a clear understanding about how data can improve health and benefit the community. In some states, success may also depend on overcoming legal obstacles.

The state of Louisiana recently passed a law that only data from EPA-quality air pollution monitors, which are prohibitively expensive, can be made public. Environmental advocates are now suing the state.[146]

DEVELOPING NON-GOVERNMENT RESOURCES FOR DATA AND ANALYSIS

Even before the current challenges to public health data and analysis, a number of academic and nonprofit organizations had developed programs, tools, and data collections to support health-related work. In the current environment, their work and resources will become even more important.

Many Roundtable participants noted academic initiatives that they had used or were personally involved with. Some of these are specific to health data, while others work with public data more broadly. Most of these programs rely on federal, state, or county-level data, but provide platforms and dashboards that integrate the data to make it more usable. Examples include:

- The Inter-university Consortium for Political and Social Research (ICPSR)[147], based at the University of Michigan, has been a major source of data and research in the social sciences since the 1960s. ICPSR has developed programs specific to health and the SDOH, including the National Neighborhood Data Archive (NaNDA)[148] and the COVID Coordinating Center.[149]
- At Johns Hopkins University, the Bloomberg School of Public Health has developed a Measles Tracker using state and county data, while the Bloomberg Center for Government Excellence has used a range of federal data to build the City Data Explorer.[150, 151]
- The University of Pennsylvania's Actionable Intelligence for Social Policy (AISP)[152] initiative helps state and local governments apply data to improve lives.
- The University of Wisconsin produces the Area Deprivation Index[153], a validated measure of "neighborhood disadvantage" that can be analyzed to improve health.
- Texas A&M, in partnership with the Environmental Defense Fund, maintains the U.S. Climate Vulnerability Index (CVI), which shows the risk of climate impacts for more than 70,000 Census tracts.[154]
- The Yale School of Public Health has built PopHIVE, which uses both government and non-government data to "turn complex and siloed data into timely, clear, and actionable public health insights."[155]
- Many foundations and nonprofit organizations have also developed widely used platforms and dashboards for health-related data, including the Robert Wood Johnson Foundation, the Annie E. Casey Foundation[156], the Commonwealth Fund[157], and the Urban Institute[158].

One example of the last category is the City Health Dashboard, created by the NYU Grossman School of Medicine's Department of Population Health and with support from RWJF.[159] Spanning 1,225 cities, the City Health Dashboard provides neighborhood and city-level data on over 45 key metrics, helping communities and local leaders build healthier futures. This online resource enables community leaders in places with populations above 50,000 along with a growing set of smaller places to easily see where their cities or neighborhoods stand on key measures of health, such as diabetes and insurance coverage, and drivers of health, such as child poverty and rent burden. The Dashboard provides data that serve as a foundation for crafting tailored, informed solutions and advocating for impactful, data-driven policies.

While national health data resources can be invaluable, they may also be vulnerable where they depend on federal data. The Area Deprivation Index, for example, draws on data from the ACS; the CVI draws on 184 different data sets; and the Annie E. Casey Foundation's Kids Count[160] relies on Census support. In addition, academic programs that rely on federal grants may be in danger of losing funding for their work.

Some nonprofit organizations, with philanthropic support, have gone beyond analyzing government data to provide new, independent data sources. Roundtable participants pointed to a number of successful examples, including:

- KFF[161] (formerly the Kaiser Family Foundation), which produces its own data through polling and other means as well as curating state data.[162] KFF's research has covered several topics where other data sources may be difficult to find, including health marketplace premiums, Medicaid funding, and medical debt.[163, 164, 165]
- The Population Reference Bureau (PRB)[166], which plays a role in collecting as well as analyzing data, which is used in health-related platforms such as KidsData[167] in California.
- State-level programs like DataHaven[168], a nonprofit research group that conducts a large statewide probability sample survey across Connecticut.

Even before the current challenges to public health data and analysis, a number of academic and nonprofit organizations had developed programs, tools, and data collections to support health-related work. In the current environment, their work and resources will become even more important.

With government data sources becoming less reliable, several Roundtable participants discussed the prospects for aggregating individuals' data to understand public health. Many researchers are using data from hospital admissions, electronic records, and other sources, and studying the potential to use Health Data Utilities and Health Information Exchanges to provide real-world data. While promising, this approach poses challenges: It will require standards for managing and using these data sources, data adjustments to protect privacy, and ways to ensure that the data is representative of diverse populations.

Roundtable participants also discussed the potential to draw data from the private sector as a way to leverage data collections that already have a strong economic model. Private-sector data could include both actual medical data, such as medical imaging, and a wide range of data related to the SDOH. Using this data will require strategies to protect proprietary information and privacy while ensuring that the data and analysis are not biased by the priorities of the company that collected it.

Finally, several Roundtable discussions touched on the potential to develop new data from nontraditional sources. These include the use of AI to re-examine historical data and create powerful new tools; analysis of data from social media and search engines; and crowdsourcing for data collection at community level.

RECOMMENDATIONS

Establish and implement standards for clinical and other health data. Data can be aggregated from electronic health records more effectively as those records become more standardized. While HL7[169], USCDI[170], and ISO[171] provide frameworks and standards for healthcare data, most people, including many implementers, do not know how to use them effectively or securely. Data is collected inconsistently at a local level, making it difficult to analyze data from different local sources together. Continuing efforts to improve standardization of medical records, as well as analysis of administrative claims data, can open new potential for public health data as well.

Some recent initiatives have the potential to make rapid progress on data standardization. At the end of 2023, HHS operationalized the Trusted Exchange Framework Common Agreement (TEFCA) to accelerate and facilitate health data exchange.[172] Building on that progress, in July 2025 CMS announced a partnership with more than 60 companies to build a new Health Tech Ecosystem designed to coordinate patients' health records and make them available to them.[173] If successful, this major initiative could transform health data standardization and exchange.

Some standardization projects can be especially helpful in improving health equity. Standards for demographic data collection will make it easier to collect disaggregated data, make different data sources more reliable, and help improve data quality overall. In 2024 the Civitas Networks for Health[174], AHIP[175], and HL7 launched the Demographic Data Element Modernization (DEMo) Initiative[176] for that purpose. Efforts to standardize SDOH data, like the Gravity Project[177], can help make that data more useful as well.

Explore the potential of nontraditional data sources. With the rise of AI, data experts have become increasingly interested in nontraditional data sources (NTDs) that can be developed, analyzed, and made useful in new ways. These include unstructured data that AI can turn into structured, valuable data for the public. The GovLab at New York University recently categorized many of these NTDs, such as internet search data, mobile data, and social media data, and shared how these data sources can be used for health, humanitarian aid and disaster response, climate and environment and other applications.[178]

Data advocates are exploring the potential to crowdsource data, a well-established strategy for using large numbers of volunteers to gather data and share it publicly. A director at AcademyHealth has pointed to several health crowdsourcing projects, such as a flu-tracking project that fills gaps in CDC data and a global study of COVID systems.[179] She also notes, however, that "While the benefits of crowdsourcing health data are clear, it is important to recognize that this complements rather than replaces the essential role of government-collected data."

The next steps are to continuously improve methodologies, determine who should control these data sources and in what ways, and determine how best to make different NTDs useful as public goods. A landscape analysis could catalog and describe these potential data sources, identify major use cases for them, and highlight opportunities for philanthropic or other funding to support them. This analysis could also look at the potential role of AI in developing, maintaining, and improving data sources and tools.

Leverage private data sources. These may also be useful to public health researchers and practitioners. For example, the company Socially Determined[180] can provide SDOH data on a hyperlocal level, while other companies, like UniteUs[181] and Kaizen Health[182], can link patients to services for meeting health-related

social needs. Unlike public sources of data, however, the cost of these commercial services may be a consideration.

Determine priorities and potential for philanthropic support. Major philanthropies are meeting this moment by replacing government data sources or the government funding that supported research. RWJF supports a wide range of programs and projects to advance health and racial equity, including several projects on current challenges to the national public data infrastructure.[183] RWJF, for example, has put out a call for proposals to support researchers who have lost their federal funding.[184]

Foundations and private funders can't be expected to replicate the nearly $50 billion annual budget of the NIH.[185] But they can fill important gaps on a prioritized basis. For example, if overall NIH funding remains adequate but research on health equity is defunded, foundations can focus their grants on meeting that research need.

Foundations and nonprofits will need a collective effort to identify the most critical data gaps and the most efficient and effective ways to fill them. Some funders' collaboratives have been formed to coordinate support for scientific research and public data in general, and to identify opportunities for joint projects with pooled funding. As the landscape of public health data develops, a similar effort focused on health data funding could help allocate foundation resources.

MESSAGING, COMMUNICATIONS, AND ADVOCACY

Those who work with federal data know its unique value, and know how important it is to maintain high-quality, impartial data resources. Some of the administration's attacks on federal data have triggered a rapid response. When President Trump fired the Commissioner of the Bureau of Labor Statistics, op-ed and editorial writers across the country sounded an alarm and statistical organizations around the world protested the decision.[186] Public health experts and organizations also rallied quickly to protest major cuts to the CDC during the government shutdown.

However, there has been much less opposition to many of the other challenges to federal data described in this paper. For most Americans, data is an abstract commodity whose value is difficult to grasp. Participants in the health data Roundtable, like data and policy experts around the country, saw a pressing need to develop and communicate compelling messages for use in advocacy. As one participant put it, "It's a wonky topic. How do we explain to the public why data matters?"

Public health specialists can collaborate with data experts and communications professionals to promote the value of U.S. health data. Roundtable participants noted that researchers and data analysts may not be the best communicators, and will need to partner with others to develop compelling messages in plain language. Together they can develop messaging strategies for critical audiences.

Each audience will have different needs, both in the types of information they can use and the way that information is delivered. One Roundtable discussion, for example, explored different ways of presenting location-related information, which is critical to health issues ranging from environmental exposure to access to care. While it has become commonplace to map this kind of data, several participants believed that maps

are overused, and that policymakers can make better use of geospatial insights in simpler tabular format. As one put it, "Maps are not useful for decision making. Reports and spreadsheets are."

RECOMMENDATIONS

Identify and analyze critical audiences and key messages for them. Like any messaging strategy, communications to support federal data can begin by identifying core audiences, the goals of messaging campaigns to them, and the types of messages that are most relevant to different groups. Key audiences can include the general public and media, Congressional staffers, state and local governments, community groups, businesses, and others. Communication goals can range from encouraging individuals to complete government surveys, to increasing funding for key federal data programs. A project could identify critical audiences and relevant messages for public health data, through a literature review and consultation with public communication experts, and create a landscape analysis and mapping to avoid duplication and better leverage collective efforts. These efforts can address not only the value of public health data but the value of public health itself, at a time when established health programs such as vaccination are being questioned.

Communication strategies can also identify data collections that have a broad constituency including business, government, and civil society organizations. All these groups, for example, have a strong interest in the reliability of U.S. Census data, and various organizations are working now to ensure that the Census will produce accurate and useful data in 2030. Similarly, federal data from the EPA, NOAA, NASA, and other environmental and climate sources is critical for large and small businesses, city planners, developers, and many other stakeholders. Forming alliances with these stakeholders can bolster the case for preserving widely used resources like the EPA's Integrated Risk Information System[187] (IRIS) or the CDC's National Biomonitoring Program[188].

Develop case studies and a story bank for public health data. Several organizations and projects, such as America's Essential Data[189], are now collecting use cases for federal data of all kinds. Companies like mySidewalk[190] that work with city governments also have experience with the direct application of national data at a local level. Other organizations are collecting use cases for legal action. These and other organizations could collaborate in a targeted effort to create a story bank of use cases on the value of data for public health, written in plain language and demonstrating real-life impacts. Such use cases could include showing how accountability data on customer service can improve Medicaid services for working parents; how CDC data can help a person with asthma decide whether to "mask up" when traveling; or how journalists can use data from the CDC and Census to track changes in health insurance coverage.

Develop strategies to influence legislators and policymakers. Advocates for public health data can craft messages that will have particular impact for members of Congress, state legislators, or other elected officials. New groups advocating for federal health statistics and continuing research funding, such as Friends of NCHS[191] and the Coalition for National Science Funding (CNSF),[192] have high professional credibility. Since federal research grants flow to red as well as blue states, advocates can use localized information to press Congress for continued federal research funding. New resources for this information include the Impact Map, which shows the local impacts of federal policy changes including reductions in research support; Grant Witness, which tracks changes in NIH and NSF grants at a state level; and SCIMaP, which shows the impact of federal health research cuts. [193]

The recent Senate committee vote to increase NIH funding is a reminder that American medical and health research has a long history of bipartisan support. Various approaches to advocacy may have particular resonance with members of Congress and help preserve research funding.

Document the economic benefits of federal data programs. The financial benefits of federal data can be a major theme in data advocacy. Resources like the ACS are simultaneously critical sources for public health and valuable information sources for the business community. Businesses and trade organizations can be allies in advocacy for many data sources that serve their needs and also serve public health. At the same time, a communications strategy could document the economic harm of discontinuing data programs, including the negative impact on Congressional districts that lose NIH grants for local research and data collection. A project or report could analyze the ROI on data relevant to public health; draw on resources like the Impact Project to demonstrate the local economic harm of NIH cuts; and collaborate with businesses that use health-related government data to advocate for continued data collection.

Fight disinformation and rebuild trust in data. The COVID pandemic undermined the public's trust in the CDC. Now, under the current leadership of HHS, the CDC and other government entities may publish material that most scientists would recognize as disinformation. It's important to work with groups tackling disinformation to identify cases that misrepresent open, public health data, and jointly develop strategies to counter that misinformation. At the same time, public health experts can rebuild trust in health data by developing clear examples of the value of different data collections; addressing the management, security, and privacy of federal data; and working with trusted community organizations to improve data literacy.

Identify and utilize effective legal strategies. Several organizations have sued the federal government, with some success, to oppose changes that impact health research and data. Many of these lawsuits require use cases and case studies to establish which organizations and individuals have standing to sue. As these cases proceed, advocates can study them to determine which legal strategies are most likely to be effective and where they can be applied. Several organizations have brought lawsuits or used legal leverage to protect data and research. Some examples include:

- *Restoring pages to federal websites*. At the start of September, AcademyHealth announced that HHS had agreed to settle a lawsuit that they had joined in May[194]. Under the terms of the settlement, HHS agreed to restore federal webpages removed from the NIH, CDC, and Food and Drug Administration (FDA) sites earlier this year. The missing pages covered LGBTQ+ health, gender and reproductive health, clinical trials, vaccine guidance, HIV/AIDS research, and other essential topics. Dr. Aaron Carroll, president and CEO of AcademyHealth, called the agreement "a clear win for evidence".[195]

- *Enforcing legal requirements for data gathering*. In February 2025, the *Washington Post* reported that SOGI data had been removed from the Census Bureau's National Crime Victimization Survey (NCVS).[196, 197] A group of almost a hundred advocacy organizations protested the change on the basis that some of the SOGI data in that survey is required under the Hate Crimes Statistics Act (HCSA)[198]. The survey has now resumed publishing that data.[199]

- *Restoring research funding*. In June, in response to a lawsuit brought by the American Public Health Association and others, a federal judge ordered the NIH to restore many of the grants that it had canceled, ruling that the funding cuts were illegal and reflected "racial discrimination and discrimination against America's L.G.B.T.Q. community."[200, 201] In early August, the Government Accountability Office (GAO) also determined that the cuts to NIH grants violated the law by

"impounding" funds allocated by Congress.[202] Later that month, however, the U.S. Supreme Court reversed the lower court's decision and allowed cuts to NIH grants to proceed, citing the President's emergency powers.[203] Since the Supreme Court is ruling on this and some similar cases through emergency orders - unsigned opinions issued quickly without hearing oral arguments - it can be difficult to interpret what precedents the Court intends to set.[204]

RETHINKING AND IMPROVING HEALTH DATA PRIVACY

The current administration has taken unprecedented steps to promote data sharing among federal agencies, including the IRS, the Social Security Administration, and the Department of Homeland Security. This has caused concern across the political spectrum, with the ACLU arguing that the administration's data linkage programs run afoul of the Privacy Act of 1974,[205, 206, 207] and a privacy expert at the American Enterprise Institute arguing against synthesizing data on individuals into a single "master file."[208]

Some of the most contentious examples have involved health-related data. In June, the Associated Press reported[209] that CMS had shared data on millions of Medicaid recipients with the Department of Homeland Security (DHS)[210], raising the risk that U.S. Immigration and Customs Enforcement (ICE)[211] could use the information for its immigration crackdown. As one Roundtable participant put it, "CMS sharing data with DHS blew open a longstanding trust agreement." A group of 20 state Attorneys General sued the government, claiming that this data sharing violated the Health Insurance Portability and Accountability Act (HIPAA)[212] and other federal laws. In August, a federal judge issued a preliminary injunction ordering CMS to stop sharing this data with DHS.[213] The National Health Law Program (NHeLP) has also filed a Freedom of Information Act request for documents relating to this CMS action.[214, 215]

State data leaders have been concerned about the possible consequences of a March 2025 Executive Order on "eliminating information silos."[216] This EO could improve data sharing, coordination, and analysis between the federal and state governments. However, the EO also requires federal agency heads to "ensure the Federal Government has unfettered access to comprehensive data from all State programs." Depending on how that access is used, the EO could cause data privacy concerns, as well as a loss of trust in government surveys or federal pressure on states to change the ways they collect their data.

Finally, plans for the new CMS Health Tech Ecosystem has raised some privacy concerns. Health data interoperability has been a longstanding goal, and there is a clear logic to linking an individual's data from different sources. However, the involvement of private tech companies, and the speed of the effort, are raising questions about the ability to carry out this work with strong privacy protections[217].

RECOMMENDATIONS

Analyze the impact of new federal policies on data privacy. Federal decisions and programs like those described above have the potential to rapidly change accepted norms around health data privacy. Privacy experts, advocates, and lawyers should continue to monitor these developments, flag potential risks to data privacy, and examine legal options where necessary.

Review, strengthen, and adapt existing health privacy safeguards. HIPAA, the basic framework for maintaining health data privacy, may be due for reform. As it is now written and implemented, HIPAA could be an impediment to appropriate forms of data sharing to consolidate individuals' health records. It is also an obstacle to CBOs, which are not allowed to collect data from the people they serve. At the same time, HIPAA may be inadequate to the privacy challenges posed by current federal plans for data consolidation and the use of AI, and the ability to use AI to reidentify individuals' data. Experts in data privacy protection, health data, and HIPAA could collaborate to review HIPAA and other privacy laws in the light of current issues and recommend reforms.

Address trust issues in health data privacy and security. Fears about data privacy and security can reduce response rates to the Census and other surveys, including health-related surveys, at a time when response rates have already been dropping. In a circular process, low response rates can further undermine trust in the data the federal government publishes. Equally troubling, there are anecdotal reports that use of Medicaid services may be dropping as Medicaid-eligible individuals worry about revealing data that could lead to immigration enforcement. A new project could collect and evaluate data on survey undercounts, reduced use of Medicaid services, and other indicators of mistrust, as a way of demonstrating the need to develop more trustworthy data practices.

CONCLUSION

The July 2025 Roundtable and ongoing research have demonstrated the risks to federal data that cut across many areas of public health. At the same time, more and more public health experts are advocating or suing to preserve important data, exploring alternatives to federal data sources, evaluating frameworks for data governance, and working in other ways to ensure that the country has accurate, reliable data to improve the nation's health.

The work summarized in this report is only the beginning. CODE is setting up working groups to build on the recommendations in this paper or other actions that may advance the field. CODE welcomes collaborative opportunities, inquiries, or ideas for this work through contact@odenterprise.org. By working together, we can develop a path forward that preserves the best of America's health data and creates new data sources for the future.

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ABOUT CODE

The Center for Open Data Enterprise (CODE) is an independent 501(c)3 nonprofit organization based in Washington, D.C. CODE's mission is to harness the power of open and shared data for the public good, by working with government agencies, businesses, nonprofits, and researchers who are both data providers and data users. Since it was founded in January 2015, CODE has held over 40 Open Data Roundtables and workshops with the White House, a dozen different federal agencies, and independent partners in the U.S., and has implemented several international projects. CODE also partners with private-sector companies, foundations, and other nonprofit organizations to fulfill its mission.

In addition to its current project with RWJF, CODE has conducted extensive work on using data to improve health and healthcare, with a particular focus on Social Determinants of Health data. CODE has held a dozen Roundtables on health topics, most of them in partnership with HHS, and has published the results in reports on CODE's website. CODE has also focused on changes to the federal data landscape across domains through a Report on America's Data Future and a recent *Roundtable on Building the Data Ecosystem America Deserves*.

CREATIVE COMMONS

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APPENDIX 1: ACRONYMS

ACLU	American Civil Liberties Union
ACS	American Community Survey
AHRQ	Agency for Healthcare Research and Quality
AI	Artificial Intelligence
AISP	Actionable Intelligence for Social Policy
BRFSS	Behavioral Risk Factor Surveillance System
CBO	Community Based Organization
CDC	Centers for Disease Control and Prevention
CEJST	Climate and Economic Justice Screening Tool
CMS	Centers for Medicare and Medicaid Services
CNSF	Coalition for National Science Funding
CODE	The Center for Open Data Enterprise
CVI	Climate Vulnerability Index
D-DAN	Data Disaggregation Action Network
DEI	Diversity, Equity, and Inclusion
DEMo	Demographic Data Element Modernization (DEMo) Initiative
DHS	Demographic and Health Surveys *or* Department of Homeland Security
DOE	Department of Energy
DUA	Data Use Agreement
EDF	Environmental Defense Fund
EDGI	Environmental Data and Governance Initiative
EHR	Electronic Health Record
EJ	Environmental Justice
EJScreen	Environmental Justice Screening and Mapping Tool
EO	Executive Order
EPA	Environmental Protection Agency

FACA	Federal Advisory Committee Act
FDA	Food and Drug Administration
GAO	U.S. Government Accountability Office
HCSA	Hate Crimes Statistics Act
HHS	U.S. Department of Health and Human Services
HIPAA	Health Insurance Portability and Accountability Act
HL7	Health Level Seven
HUD	U.S. Department of Housing and Urban Development
ICE	U.S. Immigration and Customs Enforcement
ICPSR	Inter-university Consortium for Political and Social Research
I - CSAC	Independent Census Scientific Advisory Committee
IRA	Inflation Reduction Act
IRIS	Integrated Risk Information System
ISO	International Organization for Standardization
LGBTQ +	Lesbian, Gay, Bisexual, Transgender, and Queer
MAHA	Make America Healthy Again Initiative
MMWR	Morbidity and Mortality Weekly Report
NaNDA	National Neighborhood Data Archive
NCoC	National Conference on Citizenship\
NCHS	National Center for Health Statistics
NCVS	National Crime Victimization Survey
NHANES	National Health and Nutrition Examination Survey
NHeLP	National Health Law Program
NIH	National Institutes of Health
NIMHD	National Institute on Minority Health and Health Disparities
NASA	National Aeronautics and Space Administration
NOAA	National Oceanic and Atmospheric Administration
NPR	National Public Radio

NTD	Nontraditional Data Source
NWS	National Weather Service
OBBBA	One Big Beautiful Bill Act
PEDP	Public Environmental Data Partners
PRAMS	Pregnancy Risk Assessment Monitoring System
PRB	Population Reference Bureau
RIF	Reduction in Force
RWJF	Robert Wood Johnson Foundation
SAMHSA	Substance Abuse and Mental Health Services Administration
SDOH	Social Determinants of Health
SNAP	Supplemental Nutrition Assistance Program
SOGI	Sexual Orientation and Gender Identity
SPD 15	Statistical Policy Directive No. 15
SVI	Social Vulnerability Index
STI	Sexually Transmitted Infection
TEFCA	Trusted Exchange Framework and Common Agreement
USCDI	United States Core Data for Interoperability
USDA	United States Department of Agriculture
VA	Department of Veterans Affairs
WHO	World Health Organization
YRBSS	Youth Risk Behavior Surveillance System

APPENDIX 2: CORE FEDERAL PUBLIC HEALTH DATA

The following table includes 72 federal datasets that Roundtable participants identified as especially important to their work. It includes both datasets that are housed within federal agencies and those that are supported by federal funding, primarily from NIH. In two instances - the CEJST and EJScreen tools - federal websites have been taken down, and the links provided here go to tools that have been recreated by the group Public Environmental Data Partners.

Several federal websites on this list may be the subject of litigation, or may be at risk of potential alteration, discontinuation, or underfunding. CODE plans to continue to monitor the status of these resources and risks and changes to them. CODE's online Core Public Health Data Hub includes URLs and descriptions for the datasets in this table as well as additional resources in the field.[218]

Name	Agency
Healthcare Cost and Utilization Project (HCUP)	AHRQ
Medical Expenditure Panel Survey	AHRQ
National Healthcare Quality and Disparities Report Data Tools	AHRQ
Social Determinants of Health Database	AHRQ
Environmental Justice Index	ATSDR/CDC
Social Vulnerability Index	ATSDR/CDC
Survey of Inmates in Local Jails (SILJ)	Bureau of Justice Statistics
Behavioral Risk Factor Surveillance System (BRFSS)	CDC
Birth Defects Tracking	CDC
CDC WISQARS - Web-based Injury Statistics Query and Reporting System	CDC
CDC WONDER	CDC
Environmental Public Health Tracking Program	CDC
Morbidity and Mortality Weekly Report (MMWR)	CDC
National Biomonitoring Program	CDC
National Health Interview Survey	CDC
National Health And Nutrition Examination Survey (NHANES)	CDC
National Survey of Family Growth (NSFG)	CDC
National Vital Statistics System (NVSS)	CDC
NWSS Wastewater Monitoring in the U.S.	CDC
PLACES: Local Data for Better Health	CDC
PRAMS (Pregnancy Risk Assessment Monitoring System)	CDC
STI Surveillance Network (SSuN)	CDC
Tracking Heat Events	CDC
VaxView Vaccination Coverage	CDC
American Community Survey (ACS)	Census
Current Population Survey (CPS)	Census
Decennial Census of Population and Housing	Census
Household Trends and Outlook Pulse Survey	Census

OnTheMap for Emergency Management	Census
Survey of Income and Program Participation (SIPP)	Census
Climate + Economic Justice Screening Tool (CEJST) (formerly CEQ)	CEQ (former)
Consumer Information and Insurance Oversight	CMS
Data.Medicaid.gov	CMS
Federally Qualified Health Center All Owners	CMS
Fee-for-service (FFS) Data	CMS
Hospitals - Patient-reported outcomes	CMS
Marketplace 2025 Open Enrollment Fact Sheet	CMS
Medicare Claims Synthetic Public Use Files (SynPUFs)	CMS
Civil Rights Data	U.S. Department of Education
The Nation's Report Card (NAEP)	U.S. Department of Education
American Time Use Survey	U.S. Department of Labor
National Agricultural Workers Survey	U.S. Department of Labor
Air Quality Index (AQI)	EPA
Enforcement and Compliance History Online	EPA
EnviroAtlas	EPA
Integrated Risk Information System	EPA
Smart Location Database - Catalog	EPA
Toxics Release Inventory (TRI) Program	EPA
EJScreen (formerly EPA)	EPA
National Risk Index	FEMA
Area Health Resources Files	HRSA
Health Center Program Uniform Data System (UDS) Data	HRSA
Health Professional Shortage Areas (HPSAs)	HRSA
Homelessness Data - HUD Exchange	HUD
Surveillance, Epidemiology, and End Results Program	NCI
United States Renal Data System (USRDS)	NIH
All of Us Research Program	NIH
ClinicalTrials.gov	NIH
Value Set Authority Center (VSAC)	NIH
National Longitudinal Study of Adolescent to Adult Health (Add Health)	NIH (funder)
National Health and Aging Trends Study (NHATS)	NIH (funder)
NaNDA (National Neighborhood Data Archive)	NIH (funder)
National Survey of Children's Health	NIH (funder)
Nurses' Health Study	NIH (funder)
Climate Mapping for Resilience and Adaptation (CMRA) Assessment Tool	NOAA
National Weather Service	NOAA
National Survey on Drug Use and Health	SAMHSA
Demographic and Health Surveys program	USAID
HHS Poverty Guidelines for Affidavit of Support	USCIS/HHS

Food Access Research Atlas	USDA
Food Security in the U.S. - Key Statistics & Graphics	USDA
USDA FoodData Central	USDA

APPENDIX 3: ROUNDTABLE PARTICIPATING ORGANIZATIONS

- AcademyHealth
- AltaMed Health Services Corporation
- American Statistical Association
- Annie E. Casey Foundation
- Association of Public Data Users (APDU)
- Bloomberg Center for Government Excellence
- Blue Cross Blue Shield Association
- CDC
- Center for Government Excellence at Johns Hopkins
- Center for Improving Value in Health Care
- Center for Open Science
- City Health Dashboard
- Civitasforhealth
- Commonwealth Fund
- Connecticut Area Health Education Center Network
- Consultant
- COPAFS
- CRISP
- Data Haven
- Environmental Defense Fund
- Episcopal Health Foundation
- Esri
- Feeding America
- First 5 California
- Flywheel
- George Washington University

- George Washington University, Milken Institute School of Public Health
- Georgetown University
- Harvard Kennedy School: Shorenstein Center on Media, Politics, and Public Policy
- Harvard T.H. Chan School of Public Health
- HealthBegins
- HIMSS
- ICPSR
- KFF (Kaiser Family Foundation)
- Koss on Care LLC
- Leadership Conference on Civil and Human Rights
- Local Initiatives Support Corporation
- Massive Data Institute
- MyHealth Access Network
- National Coalition STD Directors
- National Conference on Citizenship
- National Health Law Program
- PEDP
- Population Reference Bureau
- Public Health Informatics Institute
- Radiant Earth Foundation
- Robert Wood Johnson Foundation
- SciLine
- Supportive Housing Network of NY
- The George Washington University Milken Institute School of Public Health
- UC Berkeley Goldman School of Public Policy
- University of California at Los Angeles (UCLA)
- University of Connecticut
- University of Michigan

- Urban Institute
- USAging
- Vanderbilt University Medical Center
- Wisconsin Collaborative for Healthcare Quality
- Yale School of Medicine
- Yale University
- ZeOmega

APPENDIX 4: ROUNDTABLE WEBINAR EXCERPTS

On July 9, 2025, CODE held a public webinar with seven public health experts concerned about the state of federal data. A video of the webinar is available here, and the full transcript of the webinar can be found at this link.[219, 220] Their diverse perspectives provided a multifaceted view of the current state of public health data. Below are excerpts from their remarks, which have been edited for brevity.

Alonzo Plough, PhD, MPH, Chief Science Officer and Vice President, Research-Evaluation-Learning, Robert Wood Johnson Foundation



"The crisis of the elimination of critical public health data has quickly emerged as a top priority for the Foundation to address. We've moved to see who is archiving data and support some of these reactive approaches to the immediacy of the problem. Now our focus has begun to change to what it is going to mean to develop sustainable alternative or ancillary data systems to make up for the missing federal data support at state, local, and regional levels.

The good news is that there is a great convergence and interest in the philanthropic sector around the data issue in health and other areas. How can we not just react but think about this crisis as an opportunity? I would say there are four lanes: Classic public health surveillance data, hospital related and healthcare data, environmental data, and then the entire lane of social and economic determinants, such as housing. I think it's time to disaggregate a bit and think about some of the specific work that's happening in each of those streams. And that's how the philanthropic funders are thinking about it."

Denice Ross, former U.S. Chief Data Scientist and Senior Advisor, Federation of American Scientists



"We've noticed three main themes in the patterns of what's happening. The first is the targeted removal of data elements that are not aligned with this administration's priorities. The second pattern is the large-scale degradation of the federal data apparatus. This includes staffing cuts and canceled contracts and the disbanding of scientific advisory committees. The third area is trust in government. Trust impacts whether people will fill out forms and surveys, especially questions about demographics and other characteristics that might make them feel vulnerable. Another trust issue is whether people believe the data that are released by the federal government.

So with that in mind, there are three things that we can do to help shore up the flow of federal data. The first one is to identify the public health data sets that you deem most essential. The second, once you've identified those essential data sets, is to keep an eye on those data for any changes or opportunities for public input. And the third recommendation I have is to be sure to tell the story about how these data benefit American lives and livelihoods."

Charles Rothwell, former Director, National Center for Health Statistics



"The National Center for Health Statistics or NCHS is one of 13 principal federal statistical agencies in our country's very decentralized federal statistical system. It collects data directly through its own surveys with in-person interviews, as well as through actual physical exams and associated lab testing. These data are then used to measure the health of people across our country and important subgroups within our population and monitor trends in their health conditions and behaviors and characteristics. The data guide public policies and programs and track the impact of policy changes.

Clearly, the decentralized federal statistical system is in peril. In my opinion, it's not so much by design as by unintended consequences of broader moves in parallel departments. Now is the time to make constructive changes that make sense to all parties interested in a more recognized source of useful and trusted data, monitoring the outcomes through shared data of our very interconnected and complex society."

Anne Schuchat, M.D., former Principal Deputy Director and Director of the National Center for Immunization and Respiratory Diseases, CDC



"I want to focus on the more active part of public health surveillance, and that really starts at the local and state health department level. The local and state health departments need linkage with their communities, and they need linkage with the healthcare sector. About 80 percent of CDC's budget goes to state and locals, and a lot of the state health department's budget comes from the federal government.

The ability to update the systems to take advantage of technology is threatened right now. The federal surveillance systems are really not federal. They are aggregations of state and local jurisdictions who have to agree on what they will report, when they will report it, and how they will report it. When the federal government decides that the federal agencies shouldn't communicate with states, this really interrupts the governance process. We have a saying: What gets measured gets done. And what you stop measuring is probably going to get undone. The progress that we've made may really be threatened when we stop looking."

Meeta Anand, Senior Director, Census & Data Equity, Leadership Conference on Civil and Human Rights



"The Data Disaggregation Action Network (D-DAN) works at both the federal and state levels to improve the collection and dissemination of data disaggregated by race and ethnicity. We're focused largely on Statistical Policy Directive number 15, or SPD15, released by the Office of Management and Budget in March 2024. We're watching how SPD15 will be implemented in federal agencies and in the U.S. Census. We are trying to advocate for that at the federal level, and we're encouraging our state partners to go full speed ahead in implementing SPD15, especially looking at implementing requirements for disaggregated data.

I think we all need to come together and start establishing a framework of data governance and data principles that we can all agree to in understanding what privacy and confidentiality mean in this context. Until we restore

public trust, all of us can work in our silos, but we all know that the issues we have are not going to be solved until everyone starts having trust and belief in the importance of public data and that it be used for the public good."

Margot Brown, DSc, Senior Vice President, Justice and Equity, Environmental Defense Fund



"Without data, we would have not been able to reveal the deep and often devastating connections between climate change and human health. We know at the Environmental Defense Fund that data has been transformational. It's driven climate solutions, it has saved lives and created public health interventions, and it has sparked action from city halls to Capitol Hill.

To advance really meaningful environmental and climate justice work, especially for frontline communities and historically overburdened communities, we need data that has three parts to it: It must be comprehensive, localized, and accessible. We need to look at cumulative environmental burden data and public health outcomes, at socioeconomic vulnerability and climate risk factor projections. And we're looking at community knowledge and really uplifting and upholding lived experience. In 2023 at the Environmental Defense Fund, we created the U.S. Climate Vulnerability Index (CVI), which reveals where risk of climate change intersects with the most severely socially and economically vulnerable communities. It shows how we can help policymakers and communities take targeted data-informed action."

Silvia R. González, PhD, Director of Research, Climate Change, EJ, and Health, UCLA Latino Policy and Politics Institute



"At the Latino Policy and Politics Institute, we focus a lot on narrative change, particularly around disaggregated data. We always say that the Latino community is not a monolith, that we have so many different communities and different experiences. Data preservation isn't just some abstract idea. We are at a time when Latino communities, when immigrant communities are being persecuted through fear and being forced to be invisible. So the politically motivated erasure of data on health, on environmental justice, on disaster preparedness, on immigration status, on race - it's all very personal to the work that we do.

Our team has been very proactive in advocacy to inform state level responses. We've initiated discussions with various state agencies and elected officials around two specific issues: One, proactively to start identifying data sets that are at risk of disruption, and then two, prioritizing data sets that do not have local backups. We found that most state agencies have not been thinking about data preservation, and so we need to ensure that states are investing in that."

REFERENCES

[1] https://www.rwjf.org/

[2] https://www.opendataenterprise.org/

[3] https://ncoc.org/

[4] Webinar video: https://www.dropbox.com/scl/fi/dh6xv501wk1la86fe9a5y/2025-CODE-Roundtable-Essential-Health-Data-Public-Webinar.mp4?rlkey=t79bm0mc74p00lwo6ayu4zmoe&st=c7xrapf4&dl=0

[5] http://reports.opendataenterprise.org/RWJF_Webinar_Transcript.pdf

[6] https://bit.ly/public-health-data

[7] https://pubmed.ncbi.nlm.nih.gov/37203650/

[8] https://www.hhs.gov/

[9] https://www.cdc.gov/index.html

[10] https://www.cdc.gov/brfss/index.html

[11] https://www.cdc.gov/yrbs/index.html

[12] https://www.cdc.gov/nchs/index.html

[13] https://www.nimhd.nih.gov/

[14] https://www.census.gov/

[15] https://www.va.gov/

[16] https://www.usda.gov/

[17] https://www.epa.gov/

[18] https://www.energy.gov/

[19] The White House. "MAHA." The White House. May 23, 2025. https://www.whitehouse.gov/maha/

[20] "AcademyHealth Warns of 'Collapse in the Nation's Health Evidence Infrastructure' Following Cuts to the National Center for Health Statistics." *Academyhealth.org*. October 15, 2025. https://academyhealth.org/blog/2025-10/academyhealth-warns-collapse-nations-health-evidence-infrastructure-following-cuts-national-center-health-statistics

[21] "CDC Firings Endanger the National Health and Nutrition Examination Survey - American Society for Nutrition." *American Society for Nutrition*. October 15, 2025. https://nutrition.org/cdc-firings-endanger-the-national-health-and-nutrition-examination-survey/

[22] "National Health and Nutrition Examination Survey." Centers for Disease Control and Prevention. December 30, 2024. https://www.cdc.gov/nchs/nhanes/index.html

[23] Fiore, Kristina. "'Voice of CDC' Goes Silent." *Medpagetoday.com*. October 16, 2025. https://www.medpagetoday.com/special-reports/exclusives/117978?xid=nl_mpt_Onthecase_2025-10-16&mh=306b2400107fce658138ba3aa169913c&zdee=gAAAAABoIe47RRtSJseomeYIBa5xaLCISLcgPmIaj2EKtaB22aF0xwvRAEPPSxwVcsdgGsmcj7zod7Peb14nrZp1TwMGzB7evD6kH_t__GpBRj5eB4_ZL-c%3D

[24] "Morbidity and Mortality Weekly Report (MMWR) ." CDC. 2019. https://www.cdc.gov/mmwr/index.html

[25] Faust, Jeremy. "Hundreds of CDC Layoffs Reversed." *Medpagetoday.com*. October 13, 2025. https://www.medpagetoday.com/opinion/faustfiles/117915?xid=nl_mpt_DHE_2025-10-13&mh=306b2400107fce658138ba3aa169913c&zdee=gAAAAABoIe47RRtSJseomeYIBa5xaLCISLcgPmIaj2EKtaB22aF0xwvRAEPPSxwVcsdgGsmcj7zod7Peb14nrZp1TwMGzB7evD6kH_t__GpBRj5eB4_ZL-c%3D

[26] Katz, Eric. “Judge Blocks Shutdown Layoffs after Finding Trump’s Actions Are Likely Illegal.” *Government Executive*. October 15, 2025. https://www.govexec.com/management/2025/10/judge-blocks-shutdown-layoffs-after-finding-trumps-actions-are-likely-illegal/408828/?oref=ge-skybox-post

[27] Katz, Eric. “Trump Admin Vows to Follow Court Order on Layoffs, but Some Cuts May Still Be Imminent.” *Government Executive*. October 17, 2025. https://www.govexec.com/workforce/2025/10/trump-admin-vows-comply-court-order-layoffs-some-cuts-may-still-be-imminent/408888/?oref=govexec_news_alert_nl&utm_source=Sailthru&utm_medium=email&utm_campaign=GovExec%20Alert:%20Oct.%2017%2C%202025&utm_term=newsletter_ge_alert

[28] Federal Register.. “Advancing Racial Equity and Support for Underserved Communities through the Federal Government.” Federal Register. January 25, 2021. https://www.federalregister.gov/documents/2021/01/25/2021-01753/advancing-racial-equity-and-support-for-underserved-communities-through-the-federal-government

[29] Biden, Joe. “Protecting Public Health and the Environment and Restoring Science to Tackle the Climate Crisis.” *Federal Register*. January 25, 2021. https://www.federalregister.gov/documents/2021/01/25/2021-01765/protecting-public-health-and-the-environment-and-restoring-science-to-tackle-the-climate-crisis

[30] “Ensuring a Data-Driven Response to COVID-19 and Future High-Consequence Public Health Threats.” *Federal Register*. January 26, 2021. https://www.federalregister.gov/documents/2021/01/26/2021-01849/ensuring-a-data-driven-response-to-covid-19-and-future-high-consequence-public-health-threats

[31] The White House. “Ending Illegal Discrimination and Restoring Merit-Based Opportunity.” January 21, 2025. https://www.whitehouse.gov/presidential-actions/2025/01/ending-illegal-discrimination-and-restoring-merit-based-opportunity/

[32] The White House. “Ending Radical and Wasteful Government DEI Programs and Preferencing.” January 20, 2025. https://www.whitehouse.gov/presidential-actions/2025/01/ending-radical-and-wasteful-government-dei-programs-and-preferencing/

[33] Trump, Donald. “Defending Women from Gender Ideology Extremism and Restoring Biological Truth to the Federal Government.” The White House. January 20, 2025. https://www.whitehouse.gov/presidential-actions/2025/01/defending-women-from-gender-ideology-extremism-and-restoring-biological-truth-to-the-federal-government/

[34] Trump, Donald. “Stopping Waste, Fraud, and Abuse by Eliminating Information Silos.” The White House. March 21, 2025. https://www.whitehouse.gov/presidential-actions/2025/03/stopping-waste-fraud-and-abuse-by-eliminating-information-silos/

[35] “Restoring Gold Standard Science.” *Federal Register*. May 29, 2025. https://www.federalregister.gov/documents/2025/05/29/2025-09802/restoring-gold-standard-science

[36] “Improving Oversight of Federal Grantmaking.” *Federal Register*. August 12, 2025. https://www.federalregister.gov/documents/2025/08/12/2025-15344/improving-oversight-of-federal-grantmaking.

[37] Goldman, Maya. “Trump Health Info Blackout Shocks Providers.” *Axios*. February 3, 2025. https://www.axios.com/2025/02/03/trump-health-data-removal-alarm-vaccines

[38] Centers for Disease Control and Prevention. “Social Vulnerability Index.” Place and Health - Geospatial Research, Analysis, and Services Program (GRASP). October 22, 2024. https://www.atsdr.cdc.gov/place-health/php/svi/index.html

[39] Majstorovic, Sebastian. “The Data Rescue Tracker.” Data Rescue Project. February 12, 2025. https://www.datarescueproject.org/data-rescue-tracker/

[40] Miller, Naseem S. “Researchers Rush to Preserve Government Health Data.” The Journalist’s Resource. January 31, 2025. https://journalistsresource.org/home/researchers-rush-to-preserve-federal-health-databases-before-they-disappear-from-government-websites/

[41] Parker, J Emory. “STAT Is Backing up and Monitoring CDC Data in Real Time: See What’s Changing.” *STAT*. February 14, 2025. https://www.statnews.com/2025/02/14/tracking-cdc-data-changes-trump-executive-order-targets-gender/?_hsenc=p2ANqtz--nyFYYQ3nciPOetFfa2Npu8J4vwGwcFj_5JVIMtHVaIhggHha9OMTqoMeluoljjyuKsfc65cJYh1r4rAfq85ZITPhk2g&_hsmi=347437006&utm/

[42] https://www.datarescueproject.org/

[43] https://www.datarescueproject.org/data-rescue-tracker/

[44] "Public Environmental Data Partners." Data + Screening Tools. 2025. https://screening-tools.com/

[45] Pifer, Rebecca. "HHS Staffers Sue over 'Hopelessly Error-Ridden' Layoffs." *Healthcare Dive*. June 4, 2025. https://www.healthcaredive.com/news/hhs-layoffs-lawsuit-paperwork-errors-doge-trump/749760/

[46] "Hundreds of Laid-off CDC Employees Are Being Reinstated." *NBC News*. June 12, 2025. https://www.nbcnews.com/health/health-news/hundreds-laid-cdc-employees-are-reinstated-rcna212561

[47] Allen, Arthur. "Trump HHS Eliminates Office That Sets Poverty Levels Tied to Benefits for at Least 80 Million People." *KFF Health News*. April 11, 2025. https://kffhealthnews.org/news/article/aspe-hhs-federal-poverty-guidelines-level-team-fired-medicaid-snap-wic/

[48] https://www.ahrq.gov/

[49] "What's Lost: Trump Whacks Tiny Agency That Works to Make the Nation's Health Care Safer." *CNN*. April 4, 2025. https://www.cnn.com/2025/04/04/health/health-care-cuts-agency-kff-health-news

[50] Minemyer, Paige. "House Republicans Propose 6% Budget Cut to HHS for 2026 Fiscal Year." *Fierce Healthcare*. September 2, 2025. https://www.fiercehealthcare.com/regulatory/house-republicans-propose-6-budget-hhs-fiscal-year-2026

[51] Ibid.

[52] "New Analysis: CDC's Budget Would Be Reduced by 53 Percent If the Administration's Proposed FY 2026 Budget Is Adopted; over Sixty CDC Programs Would Be Eliminated." *TFAH*. September 16, 2025. https://www.tfah.org/article/new-analysis-cdcs-budget-would-be-reduced-by-53-percent-if-the-administrations-proposed-fy-2026-budget-is-adopted-over-sixty-cdc-programs-would-be-eliminated/

[53] https://www.ed.gov/

[54] Luhby, Tami. "Trump Administration Puts Hunger Researchers on Leave after Canceling Food Insecurity Report." *CNN*. September 23, 2025. https://www.cnn.com/2025/09/23/politics/usda-hunger-researchers-on-leave

[55] Smith, Jordan-Marie. "USDA Cancels Survey Tracking How Many Americans Struggle to Get Enough Food." NPR. September 22, 2025. https://www.npr.org/2025/09/22/nx-s1-5549115/usda-food-insecurity-survey-hunger

[56] Dick, Chris and Beth Jarosz. "Forsaking Food Security." 2025. Dataindex.us. 2025. https://dataindex.us/newsletter/article/0e1a7dbb-47d1-4019-abb2-c1b7ef6c81f1

[57] "HEALTH, EDUCATION, LABOR and PENSIONS COMMITTEE Bernard Sanders, Ranking Member Minority Staff Report Trump's War on Science." 2025. https://www.sanders.senate.gov/wp-content/uploads/HELP-Committee-Minority-Report-Trumps-War-on-Science.pdf

[58] Grant Witness. https://grant-witness.us/. Accessed August 25, 2025.

[59] McShane, Julianne. "Domestic Violence and Maternal Mortality Are Rising. The NIH Just Defunded a Project to Study Both." *Mother Jones*. March 24, 2025. https://www.motherjones.com/politics/2025/03/domestic-violence-and-maternal-mortality-are-rising-the-nih-just-defunded-a-project-to-study-both/

[60] "More than $110 Million in NIH Grants to Harvard, Affiliated Hospitals Terminated since Late February." *Thecrimson.com*. 2025. https://www.thecrimson.com/article/2025/4/11/funding-canceled-nih-trump/.

[61] Otterman, Sharon. "Columbia Lays off Nearly 180 People because of Trump Research Cuts." *The New York Times*, May 6, 2025. https://www.nytimes.com/2025/05/06/us/politics/columbia-layoffs-trump-research-cuts.html

[62] Molteni, Megan. "From Pandemic Preparedness to Precious Frozen Spit, NIH Contract Terminations Cut Deep." *STAT*. May 9, 2025. https://www.statnews.com/2025/05/09/trump-ordered-nih-contract-terminations-cut-deep/

[63] "Commonwealth of Massachusetts v. Kennedy, Jr., 1:25-Cv-10814 - CourtListener.com." *CourtListener*. 2025. https://www.courtlistener.com/docket/69843493/commonwealth-of-massachusetts-v-kennedy-jr/

[64] Boone, Rebecca, and Amanda Seitz. "19 States Suing over Cuts to US Health and Human Services Agency." *AP News*. May 5, 2025. https://apnews.com/article/lawsuit-hhs-kennedy-attorneys-general-health-794d685fdb4e9855bc0840125677c372

[65] https://www.gsa.gov/policy-regulations/policy/federal-advisory-committee-management

[66] "Federal Advisory Committee Act (FACA) Management Overview." n.d. Www.gsa.gov. https://www.gsa.gov/policy-regulations/policy/federal-advisory-committee-management

[67] "A Backward March: Another Month of Attacks on Federal Science." *The Equation*. April 2, 2025. https://blog.ucs.org/jules-barbati-dajches/a-backward-march-another-month-of-attacks-on-federal-science/

[68] "LWVUS Sends Letter Opposing the Elimination of Census Committees | League of Women Voters." Lwv.org. April 3, 2025. https://www.lwv.org/census/lwvus-sends-letter-opposing-elimination-census-committees

[69]Schneider, Mike. "Census Bureau under Trump Cuts Loose Expert Advisers Who Work for Free." *AP News*. March 4, 2025. https://apnews.com/article/census-bureau-commerce-department-howard-lutnick-3a56003b790aedce6e6c8ddd7c6b6943

[70] Letter to Honorable Howard Lutnick, May 7, 2025. https://civilrights.org/wp-content/uploads/2025/05/Updated-Final-LCCHR-Census-Advisory-Committee-Letter-.pdf

[71] https://civilrights.org/

[72] Johnson, Carolyn Y. "Women, Minorities Fired in Purge of NIH Science Review Boards." *The Washington Post*. April 16, 2025. https://www.washingtonpost.com/science/2025/04/16/women-and-minorities-fired-nih-board-science/

[73] Sybinsky, Andrea. "Trump Administration Officially Disbands Census Advisory Committees - the Census Project." *The Census Project*. June 10, 2025. https://thecensusproject.org/2025/06/10/trump-administration-officially-disbands-census-advisory-committees/

[74] Borunda, Alejandra. "Why Members of Two of EPA's Influential Science Advisory Committees Were Let Go." *NPR*. January 29, 2025. https://www.npr.org/2025/01/29/nx-s1-5278637/why-members-of-two-epa-science-advisory-committees-were-let-go

[75] "Restoring Gold Standard Science." *The White House*. May 23, 2025. https://www.whitehouse.gov/presidential-actions/2025/05/restoring-gold-standard-science/

[76] "COS Statement on 'Restoring Gold Standard Science' Executive Order." *Center for Open Science*. May 29, 2025. https://www.cos.io/about/news/cos-statement-on-restoring-gold-standard-science-executive-order

[77] Johnson, Carolyn Y. "Why Trump's Push for 'Gold-Standard Science' Has Researchers Alarmed." *The Washington Post*. May 31, 2025. https://www.washingtonpost.com/science/2025/05/31/trump-science-gold-standard-politics/

[78] Sengupta, Somini. "The White House Gutted Science Funding. Now It Wants to 'Correct' Research." *The New York Times*, June 3, 2025. https://www.nytimes.com/2025/06/03/climate/executive-order-gold-standard-science.html

[79] Executive Order. "Improving Oversight of Federal Grantmaking." The White House. https://www.whitehouse.gov/presidential-actions/2025/08/improving-oversight-of-federal-grantmaking/. August 7, 2025.

[80] Katz, Eric. "Federal grants must 'demonstrably advance' Trump's agenda, President orders." *GovExec*. https://www.govexec.com/management/2025/08/federal-grants-must-demonstrably-advance-trumps-agenda-president-orders/407335/?oref=govexec_today_nl&utm_source=Sailthru&utm_medium=email&utm_campaign=GovExec%20Today:%20Aug.%2011%2C%202025. August 8, 2025.

[81] "Withdrawing the United States from the World Health Organization." *The White House*. January 20, 2025. https://www.whitehouse.gov/presidential-actions/2025/01/withdrawing-the-united-states-from-the-worldhealth-organization/

[82] Cheng, Maria, and Will Weissert. "Trump Wants to Pull the US out of the World Health Organization Again. Here's What May Happen Next." *AP News*. January 21, 2025. https://apnews.com/article/trump-withdraws-from-world-health-organization-697bbd79a95ae0b6a5d47fa4131f6329

[83] https://dhsprogram.com/

[84] Grown, Caren, and Fred Dews. 2025. "The US Government Data Purge Is a Loss for Policymaking and Research." *Brookings*. March 21, 2025. https://www.brookings.edu/articles/the-us-government-data-purge-is-a-loss-for-policymaking-and-research/

[85] https://data.census.gov/

[86] https://www.census.gov/programs-surveys/acs/data.html

[87] https://data.cms.gov/

[88] https://data.cdc.gov/

[89] https://www.samhsa.gov/

[90] https://www.bls.gov/data/

[91] https://www.bls.gov/tus/

[92] https://www.hud.gov/

[93] https://bjs.ojp.gov/

[94] https://pedp-ejscreen.azurewebsites.net/

[95] "Environmental Justice Index Community Engagement Report Responses to Feedback from Environmental Justice Index 2022 Community Engagement Acknowledgements." n.d. https://www.atsdr.cdc.gov/place-health/media/pdfs/2024/10/EJI-Community-Engagement-Report-508.pdf

[96] https://civilrights.org/edfund/data-disaggregation-action-network/

[97] "U.S. Office of Management and Budget's Statistical Policy Directive No. 15: Standards for Maintaining, Collecting, and Presenting Federal Data on Race and Ethnicity" U.S. Office of Management and Budget, March 28, 2024. https://spd15revision.gov/

[98] Hansi Lo Wang., NPR, June 2025. Linkedin.com. https://www.linkedin.com/feed/update/urn:li:activity:7336785580560740352/

[99] Wang, Hansi Lo. "The Census Bureau Is Now Headed by a Trump Official in an Acting Position." *KPBS Public Media*. September 19, 2025. https://www.kpbs.org/news/politics/2025/09/19/the-census-bureau-is-now-headed-by-a-trump-official-in-an-acting-position

[100] Freilich, Janet, and Aaron S Kesselheim. "Data Manipulation within the US Federal Government." *The Lancet*, July 2025. https://doi.org/10.1016/s0140-6736(25)01249-8

[101] Meyer, Ilhan H., Bouton, Lauren J.A., "Impact of Executive Orders on Access to Federal Data." Williams Institute. February, 2025. https://williamsinstitute.law.ucla.edu/publications/access-federal-lgbt-data/

[102] Steenhuysen, Julie, and Nancy Lapid. "US CDC Orders Pullback of New Scientific Papers Involving Its Researchers, Source Says." *Reuters*, February 2, 2025. https://www.reuters.com/world/us/us-cdc-orders-pullback-new-scientific-papers-involving-its-researchers-source-2025-02-02/

[103] Goldman, Maya. "Academic Journals Push Back on Trump's Changes to Health Data." *Axios*. February 6, 2025. https://www.axios.com/2025/02/06/academic-journals-push-back-on-trump

[104] https://www.cdc.gov/prams/index.html

[105] Malhi, Sabrina, and Meryl Kornfield. "Fertility and Maternal Health Programs Slashed, Alarming Experts." *The Washington Post*. April 19, 2025. https://www.washingtonpost.com/health/2025/04/19/cdc-cuts-maternal-mortality-fertility/

[106] "PRAMS Data." Pregnancy Risk Assessment Monitoring System (PRAMS). CDC. May 20, 2024. https://www.cdc.gov/prams/php/data-research/index.html

[107] https://www.dhcs.ca.gov/CalAIM/Pages/CalAIM.aspx

[108] https://www.chcf.org/

[109] Ollstein, Alice Miranda, and Sophie Gardner. "RFK Jr., DOGE Gutted Legally Required Offices. Courts May Undo It All." *Politico*. May 11, 2025. https://www.politico.com/news/2025/05/11/trump-transforms-congressionally-mandated-health-offices-into-ghost-towns-00340176

[110] "Senate Committee Advances Appropriations Bill." American Hospital Association, *AHA News*. August 1, 2025. https://www.aha.org/news/headline/2025-08-01-senate-committee-advances-appropriations-bill

[111] Oxman, David. “We Need a New Playbook to Oppose Trump’s War on Medical Science.” *The Hill*. February 27, 2025. https://thehill.com/opinion/healthcare/5165773-we-need-a-new-playbook-to-oppose-trumps-war-on-medical-science/

[112] “STAND up for SCIENCE.” STAND up for SCIENCE. 2025. https://www.standupforscience.net/bethesda-declaration

[113] Heidt, Amanda. “US Health Agency Seeks to Cut Gender-Related Terms from Scientific Papers.” *Nature*, February 2025. https://doi.org/10.1038/d41586-025-00367-x

[114] “NOT-OD-25-090: Notice of Civil Rights Term and Condition of Award.” 2025. Nih.gov. 2025. https://grants.nih.gov/grants/guide/notice-files/NOT-OD-25-090.html

[115] Cole, Samantha. “Massive, Unarchivable Datasets of Cancer, Covid, and Alzheimer’s Research Could Be Lost Forever.” *404 Media*. April 4, 2025. https://www.404media.co/nih-archives-repositories-marked-for-review-for-potential-modification/

[116] “Text - H.R.1 - 119th Congress (2025-2026): One Big Beautiful Bill Act.” *Congress.gov*. 2025. https://www.congress.gov/bill/119th-congress/house-bill/1/text. Pages 161 and 211.

[117] “Text - H.R.1 - 119th Congress (2025-2026): One Big Beautiful Bill Act.” Congress.gov. July 4, 2025. https://www.congress.gov/bill/119th-congress/house-bill/1/text

[118] Dzombak, Rebecca, and Hiroko Tabuchi. “U.S. Government to Stop Tracking the Costs of Extreme Weather.” *The New York Times*, May 8, 2025. https://www.nytimes.com/2025/05/08/climate/noaa-billion-dollar-disasters.html

[119] https://envirodatagov.org/

[120] “Climate of Supression: Environmental Information Under the Second Trump Administration.” *Environmental Data and Governance Initiative*. August 6, 2025. https://envirodatagov.org/publication/climate-of-suppression-environmental-information-under-the-second-trump-administration/

[121] https://climatevulnerabilityindex.org/

[122] https://www.edf.org/

[123] https://www.weather.gov/

[124]Hinton, Elizabeth and Amaya Diana, “”Medicaid authorities and options to address social determinants of health.” Kff.org. Jan. 29, 2024. https://www.kff.org/medicaid/medicaid-authorities-and-options-to-address-social-determinants-of-health-sdoh/

[125] Newhouse, Sean Michael. 2025. “Bipartisan Senators Call for CDC Oversight Following Firing of Agency’s Director.” Government Executive. August 29, 2025. https://www.govexec.com/management/2025/08/bipartisan-senators-call-cdc-oversight-following-firing-agencys-director/407804/?oref=govexec_today_nl&utm_source=Sailthru&utm_medium=email&utm_campaign=GovExec%20Today:%20Sept.%202%2C%202025&utm_term=newsletter_ge_today

[126] *Union of Concerned Scientists*. https://www.ucs.org/.

[127] Finucane, Melissa., Ekwurzel, Brenda., Frey, H. Christopher. “Running an Independent

Science Advisory Committee” *Union of Concerned Scientists*. May 2025. https://www.ucs.org/sites/default/files/2025-05/Scientist%20Advisory%20Committees_final_rev_1.pdf

[128] Allison Plyer. https://www.linkedin.com/feed/update/urn:li:activity:7364724937946820609/. Accessed August 25, 2025

[129] https://healthpolicy.ucla.edu/our-work/california-health-interview-survey-chis

[130] https://hscrc.maryland.gov/Pages/data.aspx

[131] https://dph.georgia.gov/epidemiology/georgia-occupational-health-and-safety-surveillance-program

[132] https://portal.ct.gov/ohs/home/hit-work-groups/race-ethnicity-and-language?language=en_US

[133] https://climatevulnerabilityindex.org/

[134] "Disaggregation Nation." Leadership Conference Education Fund. https://civilrights.org/edfund/wp-content/uploads/sites/2/2025/07/DisaggregationNation2025.pdf. July 2025

[135] "Bill Text - SB-1016 Latino and Indigenous Disparities Reduction Act." n.d. Leginfo.legislature.ca.gov. https://leginfo.legislature.ca.gov/faces/billTextClient.xhtml?bill_id=202320240SB1016

[136] https://latino.ucla.edu/

[137] "Several Northeastern States and America's Largest City Announce the Northeast Public Health Collaborative - NYC Health." Nyc.gov. September 18, 2025. https://www.nyc.gov/site/doh/about/press/pr2025/announce-northeast-public-health-collaborative.page

[138] https://coleridgeinitiative.org/

[139] https://www.nascio.org/

[140] https://beeckcenter.georgetown.edu/projects/state-cdo-network/

[141] https://www.nga.org/

[142] Johnson, Mykaela. "Health Coalition Members Urge Congress to Fund CDC's Critical Work in Local Communities" Big Cities Health Coalition. April 10, 2025. https://www.bigcitieshealth.org/cdc-coalition-asks-for-fy26-cdc-funding/

[143] https://coronavirus.jhu.edu/

[144] https://usafacts.org/visualizations/coronavirus-covid-19-spread-map/

[145] "NOAA and Communities to Map Heat Inequities in 11 States | National Oceanic and Atmospheric Administration." Www.noaa.gov. April 14, 2021. https://www.noaa.gov/media-release/noaa-and-communities-to-map-heat-inequities-in-11-states

[146] Heimbinder, Michael. "Louisiana's Ban on Community Air Monitoring Is an Attack on Science & Free Speech." HabitatMap Environmental Tech & AirBeam. August 15, 2025. https://www.habitatmap.org/blog/louisiana-s-ban-on-community-air-monitoring-is-an-attack-on-science-and-free-speech

[147] https://www.icpsr.umich.edu/sites/icpsr/home

[148] https://www.icpsr.umich.edu/web/ICPSR/series/1920

[149] https://www.icpsr.umich.edu/sites/sbeccc/about/overview

[150]https://publichealth.jhu.edu/ivac/resources/us-measles-tracker

[151] https://cde.govex.jhu.edu/

[152] https://aisp.upenn.edu/about-us/

[153] https://www.neighborhoodatlas.medicine.wisc.edu/

[154] https://climatevulnerabilityindex.org/
[155] https://www.pophive.org

[156] https://www.aecf.org/

[157] https://www.commonwealthfund.org/

[158] https://www.urban.org/

[159] https://www.cityhealthdashboard.com/

[160] https://www.kff.org/

[161] https://www.kff.org/

[162] https://www.kff.org/state-health-facts/

[163] "How Much and Why ACA Marketplace Premiums Are Going up in 2026 - Peterson-KFF Health System Tracker." Peterson-KFF Health System Tracker. August 6, 2025. https://www.healthsystemtracker.org/brief/how-much-and-why-aca-marketplace-premiums-are-going-up-in-2026/

[164] "How Might Federal Medicaid Cuts in the Enacted Reconciliation Package Affect Rural Areas?" KFF. July 24, 2025. https://www.kff.org/medicaid/how-might-federal-medicaid-cuts-in-the-enacted-reconciliation-package-affect-rural-areas/

[165] "Polling on Medical Debt Illustrates the Challenges That Blocked Credit Reporting Rule Sought to Address." KFF. July 23, 2025. https://www.kff.org/quick-take/polling-on-medical-debt-illustrates-the-challenges-that-blocked-credit-reporting-rule-sought-to-address

[166] https://www.prb.org/

[167] https://www.kidsdata.org/

[168] https://www.ctdatahaven.org/

[169] https://www.hl7.org/

[170] https://www.healthit.gov/isp/united-states-core-data-interoperability-uscdi

[171] Villa-Gallón, Jazmín Eliana, Jorge Alberto Valencia-Bernal, and Yeison Alberto Garcés-Gómez. "ISO Standards in Healthcare Organizations: Research Evolution and Trends from a Bibliometric Analysis." *Publications* 12 (3): 27. 2024. https://doi.org/10.3390/publications12030027

[172] Olsen, Emily. "TEFCA Goes Live in 'Big Bang' for Health Data Exchange." *Healthcare Dive*. December 12, 2023. https://www.healthcaredive.com/news/tefca-goes-live-health-data-sharing-interoperability/702280/

[173] "White House, Tech Leaders Commit to Create Patient-Centric Healthcare Ecosystem." Cms.gov. July 25, 2025. https://www.cms.gov/newsroom/press-releases/white-house-tech-leaders-commit-create-patient-centric-healthcare-ecosystem

[174] https://civitasforhealth.org/

[175] https://www.ahip.org/

[176] https://civitasforhealth.org/demographic-data-standards/

[177] https://thegravityproject.net/

[178] Verhulst, Stefaan and Adam Zable, "Unlocking Public Value with Non-Traditional Data: Recent Use Cases and Emerging Trends." Open Data Policy Lab. April 9, 2025. https://opendatapolicylab.org/articles/new-blog-post-unlocking-public-value-with-non-traditional-data-recent-use-cases-and-emerging-trends/

[179] Dungan, Rachel. "The Role of Crowdsourcing as Researchers Respond to Loss of Public Health Data." Academyhealth.org. May 12, 2025. https://academyhealth.org/blog/2025-05/role-crowdsourcing-researchers-respond-loss-public-health-data

[180] https://www.sociallydetermined.com/

[181] https://uniteus.com/

[182] https://kaizenhealth.org/

[183] RWJF rapid response summary.pdf. "RWJF Rapid Response Summary.pdf." Google Docs. 2019. https://drive.google.com/file/d/1LDRdPIuOQw-dxbPULqy03E2xD3MR-8vh/view

[184] "Rapid Response: Reinvesting in Racial and Indigenous Health Research." *Robert Wood Johnson Foundation*. https://www.rwjf.org/en/grants/active-funding-opportunities/2025/rapid-response-reinvesting-in-racial-and-indigenous-health-equity-research.html. Accessed August 25, 2025.

[185] "Budget." National Institutes of Health (NIH). April 29, 2025. https://www.nih.gov/about-nih/organization/budget

[186] Niedzwiadek, Nick, and Sam Sutton. "Trump Fires Statistics Chief after Soft Jobs Report." *Politico*. August 2025. https://www.politico.com/news/2025/08/01/trump-firing-bureau-labor-statistics-chief-jobs-report-00488960

[187] https://www.epa.gov/iris

[188] https://www.cdc.gov/biomonitoring/index.html

[189] https://essentialdata.us/

[190] https://www.mysidewalk.com/

[191] https://www.friendsofnchs.org/

[192] Coalition for National Science Funding. https://www.cnsf.us/

[193] See: The Impact Map https://theimpactproject.org/the-impact-map/; Grant Witness. https://grant-witness.us/; and SCIMaP https://scienceimpacts.org/ all accessed August 25, 2025.

[194] "Lawsuit Settlement Restores Public Health Data: Key Facts and Resources | AcademyHealth." *Academyhealth.org*. September 4, 2025. https://academyhealth.org/publications/2025-09/lawsuit-settlement-restores-public-health-data-key-facts-and-resources

[195] "Victory for Public Health Data: AcademyHealth and Partners Secure Restoration of Vital Federal Webpages." *Academyhealth.org*, September 2, 2025. https://academyhealth.org/blog/2025-09/victory-public-health-data-academyhealth-and-partners-secure-restoration-vital-federal-webpages

[196] Dam, Andrew Van. "This Data May Vanish under Trump, so We Charted It." The Washington Post. February 14, 2025. https://www.washingtonpost.com/business/2025/02/14/this-data-may-vanish-under-trump-so-we-charted-it/

[197] https://bjs.ojp.gov/data-collection/ncvs

[198] Letter to Ron Jarmin et al, June 5, 2025, https://www.lgbtmap.org/file/06.09.2025_NCVS%20Letter_Final.pdf

[199] "National Crime Victimization Survey - OMB 1121-0111." OMB. 2025. https://omb.report/icr/202504-1121-001

[200] https://www.apha.org/

[201] Montague, Zach. "Trump's Cuts to N.I.H. Grants Focused on Minority Groups Are Illegal, Judge Rules." The New York Times, June 16, 2025. https://www.nytimes.com/2025/06/16/us/politics/trump-nih-grants-cut.html

[202] Romm, Tony. "Trump Administration Illegally Withheld N.I.H. Funding, Watchdog Finds." New York Times. https://www.nytimes.com/2025/08/05/us/politics/trump-gao-nih-funding.html. August 5, 2025.

[203] Schonfeld, Zack. "Supreme Court allows Trump to gut DEI linked NIH grants." The Hill. https://thehill.com/regulation/court-battles/5464453-supreme-court-allows-trump-to-gut-dei-linked-nih-grants/. August 21, 2025.

[204] Montague, Zach. "Judge Apologizes to Conservative Justices in Case over N.I.H. Cuts." *The New York Times*, September 2, 2025. https://www.nytimes.com/2025/09/02/us/politics/judge-apology-conservative-justices.html

[205] American Civil Liberties Union. https://www.aclu.org/

[206] "Data Silos, Dossiers, and Surveillance: The Unintended Risks of Federal Data Consolidation | American Civil Liberties Union." American Civil Liberties Union. April 28, 2025. https://www.aclu.org/documents/data-silos-dossiers-and-surveillance-the-unintended-risks-of-federal-data-consolidation

[207] "Privacy Act of 1974." U.S. Department of Justice. October 4, 2022. https://www.justice.gov/opcl/privacy-act-1974

[208] Tews, Shane. "The Dangerous Road to a 'Master File'–Why Linking Government Databases Is a Terrible Idea." *American Enterprise Institute - AEI*. April 18, 2025. https://www.aei.org/technology-and-innovation/the-dangerous-road-to-a-master-file-why-linking-government-databases-is-a-terrible-idea/

[209] Kindy, Kimberly and Amanda Seitz. "Trump Gives Data of Immigrant Medicaid Enrollees to Deportation Officials." *AP News*. June 13, 2025. https://apnews.com/article/medicaid-deportation-immigrants-trump-4e0f979e4290a4d10a067da0acca8e22

[210] https://www.dhs.gov/

[211] https://www.ice.gov/

[212] U.S. Department of Health & Human Services. "Health Information Privacy." HHS.gov. 2020. https://www.hhs.gov/hipaa/index.html

[213] Alder, Steve. "Federal Judge Blocks HHS from Sharing Medicaid Data with ICE." *The HIPAA Journal*. August 18, 2025. https://www.hipaajournal.com/federal-judge-blocks-hhs-sharing-medicaid-data-ice/

[214] https://healthlaw.org/

[215] DiAntonio, Andy. "National Health Law Program Files FOIA Request for Documents Related to Immigrant Data Sharing by the Medicaid Agency and Immigration Enforcement." *National Health Law Program*. July 9, 2025. https://healthlaw.org/news/national-health-law-program-files-foia-request-for-documents-related-to-immigrant-data-sharing-by-the-medicaid-agency-and-immigration-enforcement/

[216] "Stopping Waste, Fraud, and Abuse by Eliminating Information Silos." The White House. March 21, 2025. https://www.whitehouse.gov/presidential-actions/2025/03/stopping-waste-fraud-and-abuse-by-eliminating-information-silos/

[217] Olsen, Emily. "White House Data Sharing Plan Boasts Big Ambitions, but Has Scant Details." *Healthcare Dive*. August 21, 2025. https://www.healthcaredive.com/news/cms-data-sharing-initiative-lacks-detail-data-security-provider-resources-challenges/757951/

[218] https://bit.ly/public-health-data

[219] Video link: https://www.dropbox.com/scl/fi/dh6xv501wk1la86fe9a5y/2025-CODE-Roundtable-Essential-Health-Data-Public-Webinar.mp4?rlkey=t79bm0mc74p00lwo6ayu4zmoe&st=c7xrapf4&dl=0

[220] http://reports.opendataenterprise.org/RWJF_Webinar_Transcript.pdf

CODE

The Center for Open Data Enterprise (CODE), a 501(c)3 nonprofit organization based in Washington, DC, was founded in January 2015. CODE's mission is to harness the power of open and shared data for the public good. We achieve our mission by working with government agencies, businesses, nonprofits, and researchers who are both data providers and data users.

We support the application of fully open data – free, publicly available data that anyone can access and use, without limitation – as well as strategies for sharing and exchanging data that requires privacy or security restrictions. CODE welcomes ideas and opportunities for collaboration at contact@odenterprise.org.

