Congressional Research Service
Informing the legislative debate since 1914

Tracking COVID-19: U.S. Public Health Surveillance and Data

November 2, 2020

Congressional Research Service
https://crsreports.congress.gov
R46588

CRS REPORT
Prepared for Members and
Committees of Congress

Congressional Research Service
Informing the legislative debate since 1914

SUMMARY

R46588

November 2, 2020

Kavya Sekar
Analyst in Health Policy

Angela Napili
Senior Research Librarian

Tracking COVID-19: U.S. Public Health Surveillance and Data

Public health surveillance, or ongoing data collection, is an essential part of public health practice. Particularly during a pandemic, timely data are important to understanding the epidemiology of a disease in order to craft policy and guide response decisionmaking. Many aspects of public health surveillance—such as which data are collected and how—are often governed by law and policy at the state and subfederal level, though informed by programs and expertise at the Centers for Disease Control and Prevention (CDC).

The Coronavirus Disease 2019 (COVID-19) pandemic has exposed limitations and challenges with U.S. public health surveillance, including those related to the timeliness, completeness, and accuracy of data. This report provides an overview of U.S. public health surveillance, current COVID-19 surveillance and data collection, and selected policy issues that have been highlighted by the pandemic. **Appendix B** includes a compilation of selected COVID-19 data resources.

Current COVID-19 Surveillance and Data Collection

CDC's COVID-19 surveillance involves numerous surveillance systems that collect a variety of data, including on cases, testing positivity rates, hospitalizations, deaths, and emergency department visits. The multiple systems reflect an effort by CDC to strike a balance in surveillance—collecting different data types, with different measurement-related strengths and weaknesses that together can provide a picture of how the pandemic is affecting different populations in different locations. Other components of the Department of Health and Human Services (HHS) and other agencies also collect data to inform emergency response.

Congress has taken several related actions, including

- enacting a new authority in the CARES Act (P.L. 116-136, §18115) authorizing the HHS Secretary to impose data reporting requirements on clinical laboratories during the public health emergency;
- appropriating funding for grants to jurisdictions and tribal entities that can be used for surveillance;
- appropriating $500 million in the CARES Act (P.L. 116-136) for public health data modernization; and
- enacting several provisions in the Paycheck Protection Program and Health Care Enhancement Act (PPPHCEA; P.L. 116-139) requiring regular reports on COVID-19 data and epidemiology submitted from CDC to Congress.

Selected Policy Issues

Some Members of Congress and other observers have raised concerns about related policy issues highlighted by the pandemic, including the following:

- **Demographic data.** Available data show that COVID-19 has had a disproportionate health effect on certain groups, including certain racial and ethnic minority communities. Data gaps in demographic information on COVID-19 cases have affected the ability to analyze and understand related disparities. Congress and the Administration have taken actions to improve demographic data collection, though gaps remain.
- **Hospital capacity and utilization data.** While Congress has long recognized the need for "public health situational awareness" during a health emergency, including an ability to monitor health care utilization and supplies, no federal data collection system for relevant information existed for the pandemic. Such data have been sought to inform funding and supply allocation decisions. The Administration has created new systems, first through CDC and then through a new system with a private vendor, TeleTracking (among other data collection options). Some have critiqued these changes, for example, as being abrupt and burdensome for hospitals or potentially putting data quality at risk.
- **Data modernization.** Public health surveillance often relies on records provided by health care entities, such as laboratories and providers. CDC has been working to transition public data surveillance to more robust integrated electronic systems for decades; this process was incomplete when the COVID-19

pandemic began. Efforts to modernize public health data systems, while underway, are hindered by several challenges, including a lack of standards that enable data sharing between health care entities and public health departments.

Looking Ahead

During the COVID-19 pandemic, Congress and the Administration have taken arguably unprecedented actions related to public health data—for example, by imposing data requirements directly on health care entities for reporting to jurisdictions' health departments and the federal government. Moving forward, Congress may consider how to ensure oversight of federal agencies' data collection systems. Congress may also consider whether to continue to strengthen data requirements, beyond the pandemic, for jurisdictions or health care entities within the limits of its constitutional authority. In doing so, Congress may consider how such actions would affect the longstanding federal-state partnership for public health surveillance. Congress may also consider whether the entities involved have the adequate resources and technical capabilities for robust public health surveillance.

Contents

Overview of U.S. Public Health Surveillance 1
Legal Authorities 3
Current COVID-19 Data Collection 5
CDC Surveillance Systems 5
Ongoing Monitoring of the COVID-19 Pandemic 6
Other CDC Surveillance and Data Collection 15
Other Federal Data Collection 16
Relevant Congressional Actions During COVID-19 18
Clinical Laboratory Reporting Requirements 18
Funding 18
Reports to Congress 18
Selected Policy Issues and Considerations 19
Demographic Data 19
Background 20
COVID-19 Situation and Agency Actions 22
Issues for Congress 24
Hospital Capacity and Utilization Data 27
Background 27
COVID-19 Situation and Agency Actions 29
Issues for Congress 32
Data Modernization 33
Background 33
COVID-19 Situation and Agency Actions 36
Issues for Congress 37
Concluding Observations 39

Figures

Figure 1. Syndromic Surveillance: CDC ILINet and NSSP Data 14
Figure 2. CDC Graphical Presentation on COVID-19 Data, by Race and Ethnicity 20

Tables

Table 1. Current COVID-19 CDC Surveillance Systems 7

Appendixes

Appendix A. Acronyms Used in This Report 41
Appendix B. Selected COVID-19 Data Resources 44

Contacts

Author Information..... 51

Public health surveillance is defined as "the ongoing, systematic collection, analysis, and interpretation of health-related data essential to planning, implementation, and evaluation of public health practice."[1] Particularly during a pandemic, timely public health data are important to understanding the epidemiology of a disease—such as how it spreads and which populations are most vulnerable—in order to craft policy and guide response decision-making.

The Centers for Disease Control and Prevention (CDC) is the nation's lead public health agency. It conducts public health surveillance in the context of a U.S. system of federalism in which many laws governing public health and surveillance are based at the state, territorial, tribal, or local (jurisdiction) level.[2] Many aspects of public health surveillance—such as what data are collected and how—are governed by law and policy at the state and subfederal level, though informed by funding, data reporting systems, technical assistance, and guidance from CDC and other public health professional associations.[3] As a result, the federal government tends to play an assisting and coordinating role, though some surveillance occurs at a federal level. In this report, *jurisdiction* refers to a subfederal government or a nonfederal government affiliated with the United States, including states, territories, freely associated states, localities, and tribal governments.

The Coronavirus Disease 2019 (COVID-19) pandemic has exposed limitations and challenges with U.S. public health surveillance, including related to the timeliness, completeness, and accuracy of data needed to respond to the pandemic, as well as related to data sharing between various entities. This report provides an overview of U.S. public health surveillance, surveillance activities specific to COVID-19, and selected policy issues that have arisen during the pandemic. While electronic health record (EHR) and privacy issues are discussed, they are not a focus of this report. This report does not discuss infectious disease modeling or other public health research related to COVID-19, nor does it address international data collection on COVID-19 supported by CDC or other federal agencies.

Overview of U.S. Public Health Surveillance

Public health surveillance is the means of collecting health data that inform public health practice and research, and particularly data that can be used to better understand the *epidemiology* of a specific disease or health issue. Epidemiology can be defined as

> the study of the occurrence and distribution of health-related events, states, and processes in specified populations, including the study of the determinants influencing such processes, and the application of this knowledge to control relevant health problems.[4]

Surveillance and epidemiology studies are important for understanding the risk factors for a given disease or health issue and shedding light on how diseases and health issues affect different populations. Public health surveillance can also be used to identify a new or unusual health event.

---

[1] Centers for Disease Control and Prevention (CDC), "Public Health 101 Series: Introduction to Public Health Surveillance," https://www.cdc.gov/publichealth101/surveillance.html, (hereinafter, CDC, "Public Health 101 Series: Introduction to Public Health Surveillance").

[2] CDC, "Public Health 101 Series: Introduction to Public Health Surveillance."

[3] Lawrence O. Gostin and Lindsay F. Wiley, "Chapter Nine: Surveillance and Public Health Research: Privacy, Security, and Confidentiality of Personal Health Information," in *Public Health Law: Power, Duty, Restraint* (University of California Press, 2016), pp. 303-344, (hereinafter, Gostin and Wiley, *Public Health Law*)

[4] Dona Schneider and David E. Lilienfeld, "Chapter 1-Introduction to Epidemiology: Laying the Foundations," in *Lilienfeld's Foundations of Epidemiology*, 4th ed. (New York, NY: Oxford University Press, 2015), p. 3, (hereinafter, Schneider and Lilienfeld, *Foundations of Epidemiology).*

Especially during an infectious disease emergency caused by a novel pathogen like COVID-19, surveillance and epidemiology can provide critical scientific insights needed to inform policy decisions—including disease spread, the populations that are affected, the symptoms and severity of disease among those populations, common risk factors for disease among those populations, and related changes over time. In addition, evidence from surveillance and epidemiology can help experts evaluate the impact of certain polices, such as whether mask use or physical distancing measures lower COVID-19 spread and case counts.[5] Public health surveillance can also inform public health actions. For example, a cluster of new disease cases in a specific location could lead a local public health department to conduct an investigation and implement control measures. Some public health surveillance systems focus on a specific disease or class of diseases (e.g., influenza surveillance), whereas others focus on a type of surveillance data collected (e.g., mortality surveillance or health behavior surveys).

In the United States, national public health surveillance is conducted through multiple multifaceted systems that, in many cases, involve a partnership between the federal government and the jurisdictions.[6] Much of the original data, such as those related to laboratory results, hospitalizations, and deaths, are collected from disparate and often private organizations, including laboratories, hospitals, and outpatient health care facilities. Jurisdictions can mandate the collection of certain data from health care entities in law and can implement reporting systems. These data are then used to inform jurisdiction-level public health policy and actions. De-identified data (data records with all personal identifiers, e.g., names, removed) are typically provided voluntarily to the CDC by the jurisdictions. CDC provides funding, creates standardized national reporting systems, and offers technical assistance to jurisdictions for surveillance systems.[7] CDC also conducts national or subnational-level public health surveillance by other means, such as through surveys or data collected directly from health care entities[8] or other designated sites.[9]

Public health surveillance has been conducted in the United States for some time and is now a major component of CDC's programs. Mandatory reporting of disease cases at the state level dates back to before the country's independence. For example, a 1741 Rhode Island statute required "tavern keepers to report to local authorities any patrons known to harbor contagious diseases."[10] The federal government began publishing data reports on mortality and select infectious disease (e.g., plague, smallpox) in the 1800s. With the establishment and growth of the U.S. Public Health Service, and subsequently the CDC in the 1900s, public health surveillance efforts became a key component of vaccination programs, infectious disease control, environmental health programs, and monitoring the health status and behaviors of the population.[11] Today, CDC maintains over 100 surveillance systems for different uses. In 2016,

[5] Angela Ulrich, Joanne Bartkus, Kristine A. Moore, et al., "Part 5: SARS-CoV-2 Infection and COVID-19 Surveillance: A National Framework," in *COVID-19: The CIDRAP Viewpoint* (Center for Infectious Disease Research and Policy, 2020), hereinafter, "Ulrich et al., "COVID-19 Surveillance: A National Framework").

[6] CDC, *Public Health Surveillance: Preparing for the Future*, September 2018, https://www.cdc.gov/surveillance/pdfs/Surveillance-Series-Bookleth.pdf.

[7] Gostin and Wiley, *Public Health Law*, pp. 303-344.

[8] For an example of data collected directly from health care entities, see CDC, "National Hospital Care Survey," https://www.cdc.gov/nchs/nhcs/index.htm.

[9] For an example of data collected from designated sites, see CDC, "Centers for Birth Defects Research and Prevention (CBDRP)," https://www.cdc.gov/ncbddd/birthdefects/cbdrp.html.

[10] Gostin and Wiley, *Public Health Law*, pp. 308.

[11] Gostin and Wiley, *Public Health Law*, pp.303-344.

about one-third of CDC's grant awards supported surveillance-related programs, mostly at state and local health departments, and about one-quarter of CDC's staff conducted surveillance-related activities.[12]

Legal Authorities

As stated above, many legal authorities for public health surveillance—particularly those that require health care entities to report certain health data on individuals to health departments—are based at the state or territory level. States or territories may delegate this authority to the local level. Public health legal experts describe states' authorities for disease and other health reporting as an exercise of states' "police powers."[13]

At the federal level, CDC surveillance efforts (national surveillance systems, funding, technical capacity, administration, etc.) are generally authorized as part of the Public Health Service Act (PHSA; 42 U.S.C. §201 et. seq.), the compilation of statutes that authorize many of the activities of the U.S. Public Health Service (of which CDC is a component). Many public health surveillance programs are authorized by two broad and permanent PHSA authorities of the Department of Health and Human Services (HHS) Secretary, by delegation to CDC:

- **PHSA Section 301 [42 U.S.C. §241]:** RESEARCH AND INVESTIGATION, "The Secretary shall conduct in the Service, and encourage, cooperate with, and render assistance to other appropriate public authorities, scientific institutions, and scientists in the conduct of, and promote the coordination of, research, investigations, experiments, demonstrations, and studies relating to the causes, diagnosis, treatment, control, and prevention of physical and mental diseases and impairments of man…."

  PHSA Section 301 is listed as an authorization (sometimes the sole authorization) for public health surveillance grant programs on diverse topics, including those related to health behaviors, birth defects and developmental disabilities, and emerging infectious diseases.[14]

- **PHSA Section 317 [42 U.S.C. §247b]** PROJECT GRANTS FOR PREVENTIVE HEALTH SERVICES, "The Secretary may make grants to States, and in consultation with State health authorities, to political subdivisions of States and to other public entities to assist them in meeting the costs of establishing and maintaining preventive health service programs…."

  PHSA Section 317 is listed as an authorization (sometimes the sole authorization) for public health surveillance grant programs on diverse topics, including vaccine-preventable diseases, child development, emerging infectious diseases, and birth defects and developmental disabilities.[15] Many programs list subcomponents of PHSA Section

[12] CDC, *Public Health Surveillance: Preparing for the Future*, September 2018, https://www.cdc.gov/surveillance/pdfs/Surveillance-Series-Bookleth.pdf.

[13] Gostin and Wiley, *Public Health Law*, pp. 303-344.

[14] See authorities listed on assistance listings for CDC surveillance funding programs in beta.sam.gov, the federal assistance database: "Behavioral Risk Factor Surveillance System," https://beta.sam.gov/fal/10edcc5736244e968f9d58eba38994b5/view; "Birth Defects and Developmental Disabilities - Prevention and Surveillance," https://beta.sam.gov/fal/620e3e6ce1804db7b4d99b9374d67787/view; "Emerging Infections Sentinel Networks," https://beta.sam.gov/fal/a5557ea21d00445ba58d405c5aab1e92/view.

[15] See authorities listed on assistance listings for CDC surveillance funding programs in beta.sam.gov, the federal assistance database: "Birth Defects and Developmental Disabilities - Prevention and Surveillance,"

317 as authorizations, such as PHSA Section 317(k)(1), PHSA Section 317(k)(2), and PHSA Section 317(c).

Some CDC surveillance systems are specifically authorized. For example, surveillance related to maternal health is authorized in PHSA Section 317K.[16] The National Center for Health Statistics, the principal health statistics agency, and its data collection activities are authorized in PHSA Section 306 (see text box below).[17]

Annual federal appropriations can also affect the authorization and scope of CDC surveillance programs. CDC is funded by a combination of discretionary appropriations through the Labor-HHS-Education and Related Agencies (LHHS) appropriations bill and by several mandatory budget authorities.[18] CDC receives many disease and activity-specific budget lines through the annual appropriations process, particularly as specified in congressional documents (i.e., reports, explanatory statements) accompanying appropriations bills.[19] Some funding is designated for specific surveillance systems. For example, CDC has received specific annual appropriations in recent years for the National Violent Death Reporting System, a state-based system for collecting data on violent deaths (though the program is not explicitly authorized).[20] Other disease-specific budget lines are used to fund surveillance systems specific to those diseases (among other activities related to those diseases). For example, the broad "Influenza/Influenza Planning and Response" budget line funds the network of surveillance systems used to monitor influenza along with several other influenza prevention and control activities, such as public health awareness and vaccine-related efforts.[21]

National Center for Health Statistics (NCHS)

One CDC operating division, the National Center for Health Statistics (NCHS), is the principal health statistics agency—one of 13 principal statistical agencies in the federal government that produce official government statistics. NCHS is specifically authorized in PHSA Section 306 (42 U.S.C. §242k). NCHS collects and publishes a variety of health statistical information, including on

- births and deaths;
- health insurance coverage and health care services access;
- health care usage;
- health conditions, such as overweight and obesity, cholesterol, and hypertension; and
- health behaviors, such as smoking and physical activity.

NCHS is not the only CDC operating division that conducts surveillance activities; surveillance is a component of a number of CDC programs. For example, infectious disease case reporting systems are based in the Center for Surveillance, Epidemiology, and Laboratory Services (CSELS).

https://beta.sam.gov/fal/620e3e6ce1804db7b4d99b9374d67787/view; "Emerging Infections Sentinel Networks," https://beta.sam.gov/fal/a5557ea21d00445ba58d405c5aab1e92/view; "Child Development and, Surveillance, Research and Prevention," https://beta.sam.gov/fal/2064230419584d09857d2f5ec38b2e70/view; "Prevention and Public Health Fund (Affordable Care Act): Enhanced Surveillance for New Vaccine Preventable Disease," https://beta.sam.gov/fal/a909bebbb4244bf88f42b4b8a9896f9d/view.

[16] 42 U.S.C. §247b-12.

[17] 42 U.S.C. §242k.

[18] CRS Report R44916, *Public Health Service Agencies: Overview and Funding (FY2016-FY2018)*.

[19] See CDC Operating Plans, https://www.cdc.gov/budget/operating-plans/index.html.

[20] See CDC Operating Plans, https://www.cdc.gov/budget/operating-plans/index.html.

[21] CDC, *Justification of Estimates for Appropriation Committees: Fiscal Year 2020*, pp. 61-64, https://www.cdc.gov/budget/documents/fy2020/fy-2020-cdc-congressional-justification.pdf.

Source: See CDC, "Health Statistics: Measuring Our Nation's Health," March 2020, cdc.gov/nchs/about/factsheets/factsheet_health_statistics.htm.

Current COVID-19 Data Collection

As mentioned above, data are needed to understand many epidemiological aspects of the COVID-19 pandemic—where the virus is spreading, the level of transmission in a given community, which populations are affected, the severity of disease and health outcomes (e.g., deaths) in those populations, risk factors associated with outcomes, and how these aspects change over time. Data are also sought to inform decisions regarding how funding, personnel, and supplies are allocated to affected regions. CDC, HHS, and other federal agencies, such as the Federal Emergency Management Agency (FEMA),[22] are collecting many types of data to inform the federal response to the COVID-19 pandemic and to better understand the disease and affected populations.

CDC Surveillance Systems

CDC conducts public health surveillance activities for COVID-19 that include both ongoing monitoring of the pandemic and one-time and intermittent data collection efforts. Together, these activities help provide an understanding of the pandemic, as covered in the next two sections. In general, surveillance systems are classified as four key types:[23]

- **Passive surveillance.** Data are reported by institutions (such as health care providers), as required by law or policy or voluntarily, but are not actively sought. Data are often incomplete or prone to error but are relatively inexpensive to collect.
- **Active surveillance.** Data are actively sought or solicited by contacting institutions or persons (such as health care providers or patients) to obtain and evaluate records, or by analyzing electronic data (such as electronic health record data) to identify cases or events of interest. Active surveillance provides the most accurate type of data but is often more expensive than passive surveillance.
- **Sentinel surveillance.** Data are collected from a subset of reporting sites to gather more detailed data from those designated sites than would be gathered from all sites. Sentinel surveillance generally provides accurate data and is often less expensive than active surveillance, but it represents only a subset of all data of potential interest.
- **Syndromic surveillance.** Data of interest are identified by linking and scanning data systems for patterns (which does not require direct input from individuals), particularly to identify an unusual health event, for example, a cluster of emergency department visits for a pneumonia-like condition. Syndromic surveillance is moderately expensive, requires significant computing capabilities,

[22] Federal Emergency Management Agency, "Understanding Data & Prioritizing Resources," updated July 27, 2020, https://www.fema.gov/disasters/coronavirus/data-resources.

[23] Schneider and Lilienfeld, "Chapter 7: Morbidity Statistics," in *Lilienfeld's Foundations of Epidemiology* (Oxford University Press, 2015), pp. 123-126, and Centers for Disease Control and Prevention (CDC), "Public Health 101 Series: Introduction to Public Health Surveillance," last updated November 15, 2018, https://www.cdc.gov/publichealth101/surveillance.html.

and may overestimate health risks. See the "Syndromic Surveillance" section for further details.

Surveillance systems are generally judged to be effective if they help prevent or control the targeted health event, or if they help improve the public's knowledge about health.[24] In general, surveillance systems are not meant to collect all the data about a given disease or health issue that are possible to collect. Instead, to achieve their intended objectives, such systems balance attributes of simplicity, flexibility, data quality, acceptability, sensitivity (the ability to identify cases accurately),[25] positive-predictive value (probability of detecting true cases),[26] representativeness, stability, timeliness, and regularity of reporting.[27]

Surveillance for COVID-19 is inherently tied to other public health activities, such as testing and contact tracing. The availability of testing, the quality of tests available, and testing strategies to identify cases affect any surveillance data that rely on testing. Population-wide testing in targeted areas or types of institutions (e.g., long-term care facilities) may be conducted specifically to aid with surveillance as a part of a larger disease control strategy (referred to as "surveillance testing"). Contact tracing aids with actively identifying cases for surveillance. Limitations and issues with both testing and contact tracing, therefore, can affect the availability, completeness, and quality of COVID-19 surveillance data.[28]

Ongoing Monitoring of the COVID-19 Pandemic

As outlined in **Table 1**, CDC's COVID-19 surveillance involves many existing and new surveillance systems that collect *ongoing* data to inform public health policies and response, including data on cases, testing, hospitalizations, emergency department visits, and deaths. **Table 1** provides an overview of these systems—grouped by type of surveillance—including the name of the data collection platform(s) used for each type of surveillance, the type of primary data collected, the entities reporting data to CDC, and a summary of secondary (additional) data collected and the use(s) of each system in COVID-19 surveillance efforts.

[24] Ulrich et al., "COVID-19 Surveillance: A National Framework."

[25] Specifically, *sensitivity* is defined as "ability to accurately identify cases both in terms of diagnostic accuracy as well as the total count of the cases and their severity." See Denise M. Oleske, "Chapter 5: Screening and Surveillance for Promoting Population Health," in *Epidemiology and the Delivery of Health Care Services* (Springer Science, 2009), pp. 131-150.

[26] Specifically, *positive predictive value* is "the proportion of individuals identified as a case who actually do have the condition under surveillance." See Denise M. Oleske, "Chapter 5: Screening and Surveillance for Promoting Population Health," in *Epidemiology and the Delivery of Health Care Services* (Springer Science, 2009), pp. 131-150.

[27] Ibid. and CDC, "Updated Guidelines for Evaluating Public Health Surveillance Systems," 2001, https://www.cdc.gov/mmwr/preview/mmwrhtml/rr5013a1.htm.

[28] For background on testing and contact tracing, see CRS Report R46481, *COVID-19 Testing: Frequently Asked Questions*, coordinated by Amanda K. Sarata and Elayne J. Heisler, and CRS In Focus IF11609, *Contact Tracing for COVID-19: Domestic Policy Issues*, by Kavya Sekar and Laurie A. Harris.

Table 1. Current COVID-19 CDC Surveillance Systems

Surveillance System: Platform(s) and Type	Surveillance Type	Type of Primary Data	Reporting Entities	Summary
Case-Based Surveillance				
National Notifiable Diseases Surveillance System (NNDSS)	Passive and Active Surveillance	COVID-19 cases reported using a standardized case definition	State and other jurisdictions' health departments. (Laboratories and health care providers report to health departments.)	Demographic, health information, and exposure history for confirmed cases.
Virologic Surveillance				
COVID Electronic Laboratory Reporting (CELR)	Passive Surveillance	COVID-19 diagnostic (reverse transcription polymerase chain reaction) laboratory test results	State and other jurisdictions' health departments. (Laboratories report to health departments.)	Test result data allow for tracking infection rates over time, by location, and identifying groups of individuals at higher risk for infection.
Syndromic Surveillance				
U.S. Outpatient Influenza-like Illness Surveillance Network (ILINet)	Syndromic Surveillance	Emergency department visits for "influenza-like illness (ILI)."	Outpatient health care providers in all 50 states, Puerto Rico, the District of Columbia, and the U.S. Virgin Islands.	Helps monitor ILI illness trends and compare to prior years; serves as "early warning system" for outbreaks. ILI represents a symptom profile representative of both COVID-19 and flu spread.
National Syndromic Surveillance Program (NSSP)	Syndromic Surveillance	Emergency department visits for "COVID-19-like illness (CLI)" and ILI.	Subset of emergency departments and outpatient facilities in 47 states.	Gives early warning of where COVID-19-like illness is increasing and provides insights into shifts in the geographic areas, age groups, and population groups affected.
Hospitalization Surveillance				
COVID-19-Associated Hospitalization Surveillance Network (COVID-NET)	Sentinel Surveillance	Hospitalization data.	More than 250 acute care hospitals in 99 counties.	Detailed information on hospitalizations, including underlying health conditions, demographic information, and patient outcomes.

Surveillance System: Platform(s) and Type	Surveillance Type	Type of Primary Data	Reporting Entities	Summary
Long-Term Care Surveillance				
National Healthcare Safety Network (NHSN) LTCF COVID-19 Module	Passive Surveillance	Long-term care facility data (e.g., nursing homes).	All Centers for Medicare & Medicaid Services (CMS)-registered nursing homes and some state-regulated long-term care facilities (e.g., assisted living facilities).	Data collected include (1) counts of residents and facility personnel with suspected and laboratory positive COVID-19; (2) counts of suspected and laboratory-positive COVID-19-related deaths among residents and facility personnel; (3) staffing shortages; (4) status of personal protective equipment (PPE) supplies; and (5) ventilator capacity and supplies for facilities with ventilator dependent units.
Mortality Surveillance				
National Vital Statistics System (NVSS)	Passive Surveillance	COVID-19 mortality data based on death certificate data. NVSS also collects data on births, marriages, and fetal deaths.	State and other jurisdictions' vital records offices	Death records include demographic information, underlying cause of death, and contributing causes of death.

Source: CDC, "CDC Activities and Initiatives Supporting the COVID-19 Response and the President's Plan for Opening America Up Again," May 2020, https://www.cdc.gov/coronavirus/2019-ncov/downloads/php/CDC-Activities-Initiatives-for-COVID-19-Response.pdf; and CDC, "Coronavirus Disease 2019 (COVID-19)—COVIDView: A Weekly Surveillance Summary of U.S. COVID-19 Activity—Purpose and Methods," updated August 14, 2020, https://www.cdc.gov/coronavirus/2019-ncov/covid-data/covidview/purpose-methods.html.

Notes: Hospital capacity and utilization data collected through HHS Protect and TeleTracking are not shown here, as this system is not a CDC surveillance system. This table was reviewed by CDC for accuracy on September 30, 2020, and edited accordingly.

As shown in **Table 1**, CDC uses several surveillance systems to provide a total data picture for the COVID-19 pandemic. The data represent different severity of disease among the population: virologic data can help provide a picture of total infections identified by testing, outpatient and emergency department visits provide a view of mild/moderate illness, and hospitalization and death data help provide an understanding of severe illness.[29] Further, these surveillance activities

[29] CDC, "COVIDView: Key Updates for Week 43, ending October 24, 2020," https://www.cdc.gov/coronavirus/2019-ncov/covid-data/covidview/index.html.

seek to collect a variety of data types to balance out the different measurement-related strengths and weaknesses, that, summarily, can show how the pandemic is affecting different populations and in different locations. The different data collection systems reflect a balance in several ways:

- **Timeliness.** How quickly the data are reported and updated.
- **Representativeness.** Whether the data are representative of the population being measured.
- **Completeness.** Whether the details available in the records used for data collection in a particular system are complete, both at the time of collection and in general.
- **Bias.** Whether the data are subject to factors that can lead to overestimates or underestimates; for example, many COVID-19 cases that are mild or without symptoms may go undiagnosed, resulting in data that may disproportionately represent those with relatively more severe cases.
- **Uncertainty, and measurement and sampling error.** Whether there are inherent measurement issues with the data, such as related to test result error or uncertainty created by small sample sizes.
- **Geography.** The geographic areas covered by the data.

The inherent strengths and weaknesses of specific surveillance systems underscore the importance of collecting multiple types of data. For example, emergency department data in syndromic surveillance can be collected and updated in close to real-time, but such data are not typically representative of all cases. On the other hand, case-based reporting from laboratory results and clinical features, which takes the extra time to collect full details on each case, may be more representative of a larger number of COVID-19 cases and have more complete and verified information. Still, case data have been affected by limitations in testing capacity. Together, these systems are meant to optimize existing resources and capabilities of the entities involved (e.g., jurisdictions' health departments, health care providers) to provide sufficiently complete and actionable data to respond to the pandemic.[30] Additional data collected in prevalence surveys or other public health research can further inform an understanding of COVID-19 epidemiology, and therefore inform how ongoing surveillance data should be interpreted and limitations of such data. Despite CDC's efforts to collect multiple types of data, some observers argue that its existing surveillance capacities may not be adequate to provide the data required to address the pandemic.[31]

As described below, three surveillance systems play an especially important role in understanding disease cases and mortality, and in detecting and monitoring outbreaks: (1) case-based surveillance, (2) mortality surveillance, and (3) syndromic surveillance.

[30] National Academies of Sciences, Engineering, and Medicine 2020. *Evaluating Data Types: A Guide for Decision Makers using Data to Understand the Extent and Spread of COVID-19*, Washington, DC: The National Academies Press.

[31] Resolve to Save Lives and Vital Strategies, "Tracking COVID-19 in the United States From Information Catastrophe to Empowered Communities," July 21, 2020, https://preventepidemics.org/wp-content/uploads/2020/07/Tracking-COVID-19-in-the-United-States-Report-1.pdf; and Eric C. Schneider, "Failing the Test—The Tragic Data Gap Undermining the U.S. Pandemic Response," *New England Journal of Medicine*, vol. 383 (July 23, 2020), pp. 299-302.

Case-Based Surveillance

COVID-19 cases are reported to 60 U.S.-affiliated jurisdictions including the 50 states; the District of Columbia; New York City; the U.S. territories of American Samoa, Guam, the Commonwealth of the Northern Mariana Islands, Puerto Rico, and the U.S Virgin Islands; and three freely associated states (the Federated States of Micronesia, the Republic of the Marshall Islands, and the Republic of Palau). These jurisdictions then report to CDC.[32] CDC generally conducts case-based surveillance of certain notifiable infectious diseases and noninfectious conditions (e.g., lead poisoning) through the National Notifiable Diseases Surveillance System (NNDSS).[33] A notifiable disease or condition is one for which "regular, frequent, and timely information regarding individual cases is considered necessary for the prevention and control of the disease or condition."[34] In this case-based system, jurisdictions can mandate reporting of certain disease cases from health care entities to jurisdictional health departments, which voluntarily share de-identified data with CDC. CDC, with the Council of State and Territorial Epidemiologists (CSTE),[35] publishes a list[36] of diseases and conditions recommended to be reported by jurisdictions and supports electronic reporting systems.[37] CSTE represents state and territorial epidemiologists acting in official capacity for their jurisdictions. CSTE develops "case definitions" for the notifiable diseases—standard laboratory and clinical criteria for a given disease or condition case—and CSTE members vote to adopt these standardized case definitions as a part of national surveillance.[38]

In the case-reporting system, jurisdictions' health departments can collect and report data on laboratory-confirmed COVID-19 cases or those that are probable cases based on clinical criteria. Case-based surveillance can be both active and passive: reporting from laboratories or health care providers is a passive surveillance activity, whereas case finding through contact tracing is an active surveillance activity. Through the case-reporting system, jurisdictions can collect detailed information on COVID-19 cases, including on patient demographics (e.g., age, sex, race/ethnicity), health status and medical history, hospitalizations, and exposure history (e.g., a patient's work setting).[39] Though CDC implements standardized systems for jurisdictions to report to CDC, states and other jurisdictions are typically responsible for deciding what information to collect and share with CDC. Guidance issued pursuant to a provision in the CARES Act (P.L. 116-136, §18115) added new federal reporting requirements for laboratories

[32] CDC, "About CDC Data," last updated July 13, 2020, https://www.cdc.gov/coronavirus/2019-ncov/cases-updates/about-us-cases-deaths.html. COVID-19 is a reportable disease in all 60 jurisdictions, meaning that "it is mandatory that reportable disease cases be reported to state and territorial jurisdictions when identified by a health provider, hospital, or laboratory"; https://wwwn.cdc.gov/nndss/data-collection.html.

[33] CDC, NNDSS Modernization Initiative, "NMI Notes," updated July 10, 2020, https://www.cdc.gov/nmi/news.html.

[34] CDC, National Notifiable Diseases Surveillance System, "Data Collection and Reporting," updated September 28, 2018, https://wwwn.cdc.gov/nndss/data-collection.html.

[35] For more information about the Council of State and Territorial Epidemiologists (CSTE), see Council of State and Territorial Epidemiologists, "About CSTE," updated March 16, 2017, https://www.cste.org/page/About_CSTE.

[36] See list at https://wwwn.cdc.gov/nndss/conditions/notifiable/2020/.

[37] CDC, National Notifiable Diseases Surveillance System, "Integrated Surveillance Information Systems/NEDSS," https://wwwn.cdc.gov/nndss/nedss.html.

[38] Council of State and Territorial Epidemiologists (CSTE), "CSTE Position Statements," https://www.cste.org/page/2020PSLanding.

[39] CDC, "Instructions for Completing the Human Infection with 2019 Novel Coronavirus (COVID-19) Case Report Form," last updated May 1, 2020, https://www.cdc.gov/coronavirus/2019-ncov/downloads/COVID-19-Persons-Under-Investigation-and-Case-Report-Form-Instructions.pdf; and CDC, "Human Infection with 2019 Novel Coronavirus Case Report Form," https://www.cdc.gov/coronavirus/2019-ncov/downloads/pui-form.pdf.

submitting data to jurisdictions during the pandemic (as described in the "Demographic Data" section). Jurisdictions can report preliminary data from laboratories through the system, particularly to meet the minimum federal reporting requirements, and then complete records over time as more information is gathered and the patient situation changes, such as if the patient is later hospitalized. CDC has published several research reports using case report data; analyses in these reports have been affected by missing data issues, in which many of the reported cases lacked details necessary for analysis, such as on underlying health conditions or patient race/ethnicity.[40]

Mortality Data

Through the National Vital Statistics System (NVSS) based in NCHS, CDC compiles mortality data provided voluntarily by all vital records jurisdictions, including 50 states, the District of Columbia, and the territories. NVSS collects and publishes national data on all *vital statistics*, defined as births, deaths, marriages, divorces, and fetal deaths.[41] Data collected by NVSS are obtained solely from states and other jurisdictions' *vital records*, including records of deaths, births, marriages, collected by state and jurisdictional vital registration offices. These offices are responsible for collecting and maintaining vital records and then sharing de-identified records with NCHS that are used to calculate vital statistics.[42] As a part of the Vital Statistics Cooperative Program (VSCP), NCHS provides funding, coordination, and standards for vital records, while jurisdictions primarily have authority and management over vital records programs.[43]

Much of the death registration process—such as the format of and information collected on the legal certificate of death and process for completing the death certificate—is governed by laws at the jurisdictional level, rather than the federal level. NCHS works with states and other jurisdictions to issue a standard death certificate recommended for recording information about deaths. These jurisdictions may voluntarily adopt the standard certificate in whole or in part. All death certificates include a medical portion to be completed by a medical certifier—a physician, medical examiner, and/or coroner (depending on vital record jurisdictions' laws). The medical certifiers are to report the immediate cause of death, the chain of events or conditions that led to the immediate cause of death, and the underlying cause of death. The certifier may also include additional significant conditions that contributed to the death.[44] Information provided on these death certificates is coded by data personnel at state vital statistics offices and NCHS to be used for state and national statistics.[45] CDC often reports current year mortality data as "provisional,"

---

[40] See, for example, Erin K. Stokes, Laura D. Zambrano, Kayla N. Anderson, et al., "Coronavirus Disease 2019 Case Surveillance—United States, January 22–May 30, 2020," *Morbidity and Mortality Weekly Report (MMWR)*, vol. 69, no. 24 (June 19, 2020), pp. 759-765; CDC, Morbidity and Mortality Weekly Report, "Severe Outcomes Among Patients with Coronavirus Disease 2019 (COVID-19)—United States, February 12–March 16, 2020," March 27, 2020; and CDC, Morbidity and Mortality Weekly Report, "Preliminary Estimates of the Prevalence of Selected Underlying Health Conditions Among Patients with Coronavirus Disease 2019—United States, February 12–March 28, 2020," April 3, 2020, https://www.cdc.gov/mmwr/volumes/69/wr/mm6913e2.htm?s_cid=mm6913e2_w.

[41] CDC, "About the National Vital Statistics System," https://www.cdc.gov/nchs/nvss/about_nvss.htm.

[42] National Vital Statistics System, "Mortality Data," https://www.cdc.gov/nchs/nvss/deaths.htm.

[43] National Research Council, *Vital Statistics: Summary of a Workshop*, Washington, DC, 2009, pp. 35-48, https://www.nap.edu/catalog/12714/vital-statistics-summary-of-a-workshop.

[44] CDC, *Medical Examiners' and Coroners' Handbook on Death Registration and Fetal Death Reporting*, pp. 9-11, https://www.cdc.gov/nchs/data/misc/hb_me.pdf.

[45] National Center for Health Statistics (NCHS), "National Vital Statistics System- Instruction Manuals," https://www.cdc.gov/nchs/nvss/instruction_manuals.htm.

or "preliminary," and therefore subject to change as more information is gathered and death records are completed.[46]

The completeness and quality of mortality data are affected by the death registration process, including the availability of information at the time of death (such as diagnostic testing results), the training of medical certifiers or other individuals involved in death registration, and the certifier's professional judgement regarding the cause of death and contributing factors.[47] In the case of COVID-19, an evolving medical understanding of the disease and the sometimes limited access to diagnostic testing has affected medical certifiers' ability to link a given death with COVID-19—affecting the overall quality and completeness of mortality data.[48] CDC has issued guidance on certifying deaths due to COVID-19.[49] Also, jurisdictions differ in the extent to which they include probable COVID-19 deaths along with laboratory-confirmed COVID-19 deaths in death counts. A death is classified as attributable to COVID-19, if COVID-19 is coded as an underlying or contributing cause of death.[50] Health experts widely view the reported death counts as undercounts of the true number of deaths linked to COVID-19, and therefore use measures such as "excess deaths" (covered in the textbox below) to understand mortality trends during the pandemic. [51]

Understanding Mortality Data: Death Counts vs. Excess Deaths

Because of known limitations with mortality data that can lead to undercounts in the number of deaths attributed to COVID-19, experts use a concept of *excess deaths* to compare total mortality from all causes of death combined (referred to as *all-cause mortality*) to what would be expected based on prior-year data during the same time period. Excess death calculations use a combination of comparisons with prior-year data averages and modeling; therefore, excess deaths calculations can differ based on methodology. Although excess deaths can be a useful measure for understanding the health impact of the pandemic, such calculations should not be interpreted as representing mortality attributable only to COVID-19. Per an October CDC report, as of October 15, 2020, 299,028 excess deaths occurred from late January through October 3, 2020 with 198,081 (66%) attributed to COVID-19. Excess deaths during the months of the pandemic are linked to a combination of both COVID-19 and secondary effects of the pandemic, such as delayed medical care and mental health issues. Distinguishing between deaths caused by COVID-19 and other causes can be challenging, as COVID-19 is known to cause a variety of complications throughout the body (e.g., heart and brain complications), and therefore a death actually linked to COVID-19 may be misclassified and therefore undercounted. Further, deaths attributable to certain causes appear to have declined during the pandemic, such as motor vehicle accidents, according to preliminary data. A more complete understanding of mortality during the pandemic and contributing factors may not be available for some time.

[46] See CDC, "Provisional Death Counts for Coronavirus Disease 2019 (COVID-19)," last updated October 30, 2020, https://www.cdc.gov/nchs/nvss/vsrr/covid19/index.htm.

[47] National Committee on Vital and Health Statistics (NCVHS), *Next Generation Vital Statistics: A Hearing on Current Status, Issues, and Future Possibilities*, 2018, https://ncvhs.hhs.gov/wp-content/uploads/2018/05/Summary-Report-Next-Generation-Vitals-Sept-2017-Hearing-Final.pdf.

[48] James R. Gill and Maura E. DeJoseph, "The Importance of Proper Death Certification during the COVID-19 Pandemic," *Journal of the American Medical Association*, vol. 324, no. 1 (2020).

[49] CDC, "Reporting and Coding Deaths Due to COVID-19," last updated May 20, 2020, https://www.cdc.gov/nchs/covid19/coding-and-reporting.htm

[50] As indicated by the International Classification of Diseases code used on the death record, U07.1, see CDC, "COVID-19 Death Data and Resources," September 1, 2020, https://www.cdc.gov/nchs/nvss/covid-19.htm#understanding-the-numbers.

Lauren M. Rossen, Amy M. Branum, and Farida B. Ahmad, "Excess Deaths Associated with COVID-19, by Age and Race and Ethnicity- United States, January 26-October 3, 2020," *Morbidity and Mortality Weekly Report*, vol. 69, no. 42 (October 23, 2020), pp. 1522-27.

[51] U.S. Government Accountability Office, *COVID-19: Data Quality and Considerations for Modeling and Analysis*, July 2020, https://www.gao.gov/assets/710/708527.pdf.

Sources: U.S. Government Accountability Office, *COVID-19: Data Quality and Considerations for Modeling and Analysis*, July 2020, https://www.gao.gov/assets/710/708527.pdf; and Jody W. Zylke and Howard Bauchner, "Mortality and Morbidity: The Measure of a Pandemic," *Journal of the American Medical Association*, vol. 324, no. 5 (July 1, 2020); and Lauren M. Rossen, Amy M. Branum, and Farida B. Ahmad, "Excess Deaths Associated with COVID-19, by Age and Race and Ethnicity- United States, January 26-October 3, 2020," *Morbidity and Mortality Weekly Report*, vol. 69, no. 42 (October 23, 2020), pp. 1522-27.

Syndromic Surveillance

Syndromic surveillance is a type of *biosurveillance* conducted by CDC. Biosurveillance is defined in PHSA Section 319D(j)[52] as "the process of gathering near real-time biological data that relates to human and zoonotic disease activity and threats to human or animal health, in order to achieve early warning and identification of such health threats, early detection and prompt ongoing tracking of health events, and overall situational awareness of disease activity." CDC's National Syndromic Surveillance Program (NSSP) specifically collects emergency department and outpatient data on patient symptoms to detect unusual levels of illness before clinical diagnoses are made, and to act as an "early warning signal" for outbreaks and help monitor the size and extent of ongoing outbreaks.[53]

Following the 9/11 terrorist attacks and the anthrax attacks in 2001, Congress enacted the Public Health Security and Bioterrorism Preparedness and Response Act of 2002 (P.L. 107-188), which introduced numerous reforms related to the nation's ability to respond to bioterrorism, including creation of CDC's syndromic surveillance program, or BioSense. This system was initially focused on detecting bioterrorism events by federal monitoring of data collected directly from emergency departments and shared with state and local governments. Through grant awards, CDC enabled certain state and local health departments to use BioSense for their own syndromic surveillance. Some states also created their own separate syndromic surveillance programs. The BioSense system has grown over time, and it is now used for other purposes, such as monitoring infectious disease outbreaks, opioid overdoses, and the health effects of natural disasters. The system is now a part of the larger National Syndromic Surveillance Program (NSSP) that integrates systems and expertise based at the federal, state and, local health departments.[54] Because this type of surveillance requires large volumes of data and specialized algorithms and analytical techniques to make sense of it, CDC and jurisdictions have had to build the necessary technical and analytical capacity.[55] Since program inception, CDC, jurisdictions' epidemiologists, and other health experts have worked to expand data types, improve data standards and quality, and develop new syndrome profiles and algorithms to expand the types of diseases and conditions monitored.[56]

For COVID-19, CDC uses syndromic surveillance to monitor disease activity and the extent of outbreaks—providing earlier data than may be available from diagnostic testing.[57] As

[52] 42 U.S.C. §247d-4(j).

[53] CDC National Syndromic Surveillance Program (NSSP), "What is Syndromic Surveillance?" https://www.cdc.gov/nssp/overview.html.

[54] Deborah W. Gould, David Walker, and Paula W. Yoon, "The Evolution of BioSense: Lessons Learned and Future Directions," *Public Health Reports*, vol. 132 (2017), pp. 7S-11S.

[55] Henry Rolka and Kara Contreary, "Chapter 1: Past Contributions," in *Transforming Public Health Surveillance: Proactive Measures for Prevention, Detection, and Response* (Elsevier, 2016), p. 19.

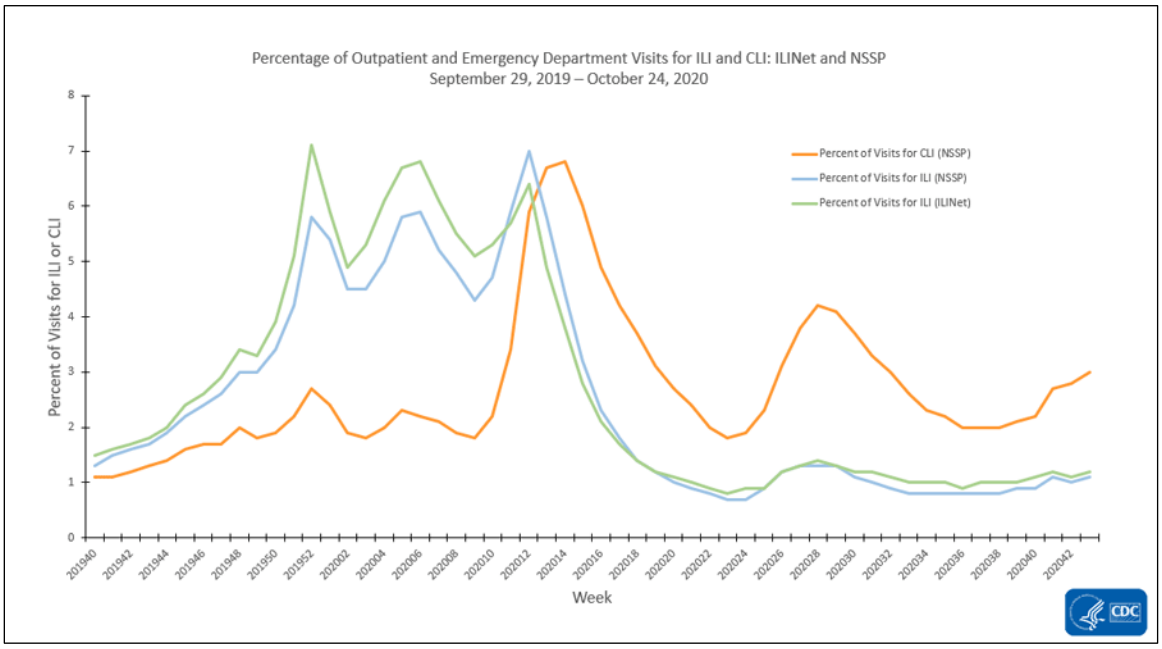
[56] Deborah W. Gould, David Walker, and Paula W. Yoon, "The Evolution of BioSense: Lessons Learned and Future Directions," *Public Health Reports*, vol. 132 (2017), pp. 7S-11S.

[57] CDC NSSP, "NSSP Supports the COVID-19 Response," August 2020, https://www.cdc.gov/nssp/covid-19-

summarized in **Table 1**, CDC uses two different syndromic surveillance systems for COVID-19: NSSP and ILINet (data shown in **Figure 1**). However, syndromic surveillance was unable to act as an early warning signal at the beginning of the outbreak. As published in a CDC report, though some evidence shows that COVID-19 began limited early spread in the United States in late January and early February, emergency department data collected through NSSP did not present warning signs. As stated in the report, "It is not known how many U.S. infections occurred during February and March, but overall disease incidence before February 28 was too low to be detected through emergency department syndromic surveillance data."[58] Technical challenges have hindered the ability of syndromic surveillance to serve as an early warning signal for new and unusual diseases; for example, emergency department data can be variable and error-prone, making it difficult to characterize a new disease event with such data. In addition, similarities between the symptoms of COVID-19 and common diseases such as influenza and pneumonia may have limited public health officials' ability to identify and characterize a new disease event.[59]

Figure 1. Syndromic Surveillance: CDC ILINet and NSSP Data

From COVIDView, week ending in October 24, 2020



Source: CDC, "COVIDView: A Weekly Surveillance Summary of U.S. COVID-19 Activity, Key Updates for Week 43, ending October 23, 2020," https://www.cdc.gov/coronavirus/2019-ncov/covid-data/covidview/index.html.

Notes: This image is provided for illustrative purposes only. Refer to CDC's website above for the most current data. The x-axis displays data by week, including year and two-digit week numbers.

response.html.

[58] Michelle A. Jorden, Sarah L. Rudman, and Elsa Villarino, "Evidence for Limited Early Spread of COVID-19 Within the United States, January–February 2020," *Morbidity and Mortality Weekly Report*, vol. 69, no. 22 (June 5, 2020).

[59] Mathew J. Thomas, Paula W. Yoon, James M. Collins, et al., "Evaluation of Syndromic Surveillance Systems in 6 US State and Local Health Departments," *Journal of Public Health Management and Practice*, vol. 24, no. 3 (2018), pp. 235-40, and Henry Rolka and Kara Contreary, "Chapter 3: Models of Public Health Surveillance," in *Transforming Public Health Surveillance: Proactive Measures for Prevention, Detection, and Response* (Elsevier, 2016), p. 41.

Other CDC Surveillance and Data Collection

CDC has other data collection systems, either in use or planned for future use, including (1) one-time or intermittent surveillance systems, (2) surveillance systems in development that may collect data in the future, and (3) surveillance systems that collect data related to secondary health impacts of the pandemic. These systems include the following:[60]

Other Data Collection Relevant to COVID-19 Science and Epidemiology

- **SARS-CoV-2 Sequencing for Public Health Emergency Response, Epidemiology and Surveillance (SPHERES).** CDC leads this national genomics consortium, with participation from clinical and public health laboratories, academic institutions, and the private sector, to coordinate SARS-CoV-2 sequencing across the United States. Virus samples are collected from a subset of laboratories and used to monitor genomic changes in the virus.[61]
- **COVID-19 Serology Surveillance.** CDC partners with public health and private entities to conduct seroprevalence surveys, or population-wide surveillance using antibody testing methods to estimate levels of prior COVID-19 infections. These surveys may be conducted across wide geographies (i.e., entire states or group of states), within smaller communities and geographies (e.g., counties), or among specific populations (e.g., health care personnel).[62] These surveys help inform an understanding of prior COVID-19 exposure within specific populations or geographies.
- **National Wastewater Surveillance System (NWSS).** CDC is working with other federal agencies, such as the Environmental Protection Agency (EPA), to enable jurisdictions to submit COVID-19 data collected from wastewater into a national database. Wastewater, or sewage, from households and other buildings can be tested for virus particles in human fecal waste. These data can inform an understanding of COVID-19 spread in a given community and help monitor related changes. According to CDC, these data can complement other public health surveillance data, but at this time, "it is not possible to reliably and accurately predict the number of infected individuals in a community based on sewage testing." NWSS is still in the early stages of implementation.[63]

Other Data Collection Relevant to Secondary Health Effects, Health Care, and Related Health Behaviors

- **Household Pulse Survey.** In partnership with the Census Bureau, NCHS has incorporated health-related questions into the Household Pulse Survey, an experimental household survey designed to track various social, economic, and

[60] This list was developed based on correspondence with CDC, September 30, 2020.

[61] CDC, "Coronavirus Disease 2019: SARS-CoV-2 Sequencing (SPHERES)," updated July 7, 2020, https://www.cdc.gov/coronavirus/2019-ncov/covid-data/spheres.htmll.

[62] CDC, "CDC Seroprevalence Survey Types," updated May 17, 2020, https://www.cdc.gov/coronavirus/2019-ncov/covid-data/seroprevalence-types.html.

[63] CDC, "National Wastewater Surveillance System (NVSS)," updated August 17, 2020, https://www.cdc.gov/coronavirus/2019-ncov/cases-updates/wastewater-surveillance.html, and Environmental Protection Agency (EPA), "Assessing SARS-CoV-2 Virus Levels in Sewage," https://www.epa.gov/healthresearch/assessing-sars-cov-2-virus-levels-sewage.

secondary health effects of the COVID-19 pandemic (previously weekly, now biweekly).[64] Health-related questions in the survey include those on anxiety and depression, mental health care, health insurance coverage, and reduced access to care.[65]

- **Research and Development Survey (RANDS) Platform.** RANDS is an ongoing survey platform used by CDC to test the use of commercial probability-based survey panels (preselected survey respondent populations) for health data collection.[66] During the COVID-19 pandemic, the RANDS platform has been used to collect data and test survey questions related to access to health care, use of telemedicine, and loss of work due to illness from COVID-19.
- **Behavioral Risk Factor Surveillance System (BRFSS)/Youth Risk Behavioral Surveillance System (YRBSS).** BRFSS and YRBSS are annual household surveys that collect data on health-related risk behaviors, chronic health conditions, and the use of preventive services among adults and youth, respectively. According to CDC, questionnaires for 2021 are expected to include COVID-19-related questions.[67] Some states and other jurisdictions already incorporate COVID-19-related questions into their BRFSS survey, such as on related health behaviors (e.g., face mask use). CDC has not been involved in developing these questions.[68]

In addition, CDC may conduct other one-time data collection efforts in targeted areas or among specific populations as a part of its research related to COVID-19.[69]

Other Federal Data Collection

Although CDC public health surveillance data can inform an epidemiological understanding of COVID-19 and related health issues, such data may not encompass all data types for responding to the pandemic. Alongside CDC, other federal agencies, such as HHS and the Federal Emergency Management Agency (FEMA), have taken steps to collect data for pandemic response.

HHS created an internal data repository in early April 2020 called HHS Protect to help inform federal response efforts.[70] As a part of HHS Protect, "200 disparate data sources are brought together into one ecosystem that integrates data across federal, state, and local governments and the healthcare industry."[71] During the early months of the pandemic, publicly available

[64] CRS In Focus IF11594, *New Census Bureau Products Track COVID-19's Effects*, and United States Census Bureau, "Household Pulse Survey Data Tables," https://www.census.gov/programs-surveys/household-pulse-survey/data.html.

[65] NCHS, "Health Care Access and Mental Health," last updated September 23, 2020.

[66] NCHS, "About RANDS," https://www.cdc.gov/nchs/rands/about.htm.

[67] CRS Correspondence with CDC, September 30, 2020.

[68] CRS Correspondence with CDC, September 30, 2020, and author's own experience participating in the District of Columbia BRFSS survey in August 2020.

[69] See CDC research reports related to COVID at CDC, "Morbidity and Mortality Weekly Report (MMWR)-Novel Coronavirus Reports," https://www.cdc.gov/mmwr/Novel_Coronavirus_Reports.html.

[70] Dave Nyczepir, "Inside the HHS System Informing White House Coronavirus Decisions," *FedScoop*, April 21, 2020, https://www.fedscoop.com/hhs-system-white-house-coronavirus-response-jose-arrieta/.

[71] HHS, "HHS Protect: Frequently Asked Questions," press release, July 20, 2020, https://www.hhs.gov/about/news/2020/07/20/hhs-protect-frequently-asked-questions.html.

information about HHS Protect was limited.[72] In July 2020, following media attention[73] and letters from Members of Congress,[74] HHS and CDC held a press conference to explain the data issues and the HHS Protect system.[75] Part of HHS Protect was made publicly available, and HHS published an FAQ on the system.[76] As a component of HHS Protect, HHS has implemented a new system through a private vendor, TeleTracking, to collect data related to hospital capacity and utilization, as discussed in the "Hospital Capacity and Utilization Data" section. As reported by the Government Accountability Office in September 2020, "[HHS Protect] is designed to provide a holistic view of the U.S. health care system to guide action for the COVID-19 response. Specifically, the former HHS Chief Information Officer said that HHS is using the platform to help identify pandemic hotspots in the United States and increase supplies to those areas most affected."[77]

In addition, the Centers for Medicare & Medicaid Services (CMS) has taken action to require data reporting from CMS-certified long-term care facilities, along with hospitals and clinical laboratories. Effective May 8, 2020, CMS-certified long-term care facilities (including nursing facilities and skilled nursing facilities) must report regular data, including data on suspected and confirmed COVID-19 infections among residents and staff; total deaths and COVID-19 deaths among residents and staff; and other data types relevant to bed capacity, medical supplies, and staffing. These data are to be submitted at least once every seven days through a new module in CDC's National Healthcare Safety Network (see **Table 1**).[78] On August 25, 2020, CMS made reporting by hospitals and critical access hospitals (CAHs) of specified COVID-19 data a Condition of Participation (CoP) for the Medicare and Medicaid programs.[79] Requirements for clinical laboratories are discussed in the "Demographic Data" section.

---

[72] Dave Nyczepir, "Inside the HHS System Informing White House Coronavirus Decisions," *FedScoop*, April 21, 2020, https://www.fedscoop.com/hhs-system-white-house-coronavirus-response-jose-arrieta/.

[73] See, for example, Sheryl Gay Stolberg, "Trump Administration Strips C.D.C. of Control of Coronavirus Data," *New York Times*, July 14, 2020, https://www.nytimes.com/2020/07/14/us/politics/trump-cdc-coronavirus.html, and Adriel Bettelheim, "Trump's Covid-19 Data Reporting Switch Draws Outcry from Health Groups," *Politico*, July 15, 2020.

[74] See, for example, House Select Subcommittee on the Coronavirus Crisis, "Clyburn, Maloney, Krishnamoorthi Demand Information On Decision To Divert Coronavirus Data From CDC," press release, July 18, 2020, https://coronavirus.house.gov/news/press-releases/clyburn-maloney-krishnamoorthi-demand-information-decision-divert-coronavirus.

[75] HHS, "Prepared Remarks from HHS Media Call with CDC Director Redfield and CIO Arrieta on COVID-19 Data Collection," July 15, 2020, https://www.hhs.gov/about/news/2020/07/15/prepared-remarks-from-hhs-media-call-cdc-director-redfield-cio-arrieta-covid-19-data-collection.html.

[76] HHS, "HHS Protect: Frequently Asked Questions," press release, July 20, 2020, https://www.hhs.gov/about/news/2020/07/20/hhs-protect-frequently-asked-questions.html.

[77] U.S. Government Accountability Office, *Federal Efforts Could Be Strengthened by Timely and Concerted Actions*, GAO-20-701, September 21, 2020, https://www.gao.gov/reports/GAO-20-701/.

[78] CMS, "Centers for Medicare and Medicaid (CMS) COVID-19 NHSN Reporting Requirements for Nursing Homes," https://www.cdc.gov/nhsn/pdfs/covid19/ltcf/cms-covid19-req-508.pdf. For further information about CMS-certified facilities, see CRS In Focus IF11545, *Overview of Federally Certified Long-Term Care Facilities*.

[79] Centers for Medicare & Medicaid Services, *Medicare and Medicaid Programs, Clinical Laboratory Improvement Amendments (CLIA), and Patient Protection and Affordable Care Act; Additional Policy and Regulatory Revisions in Response to the COVID-19 Public Health Emergency*, August 25, 2020, https://www.cms.gov/files/document/covid-ifc-3-8-25-20.pdf., pp. B-B22.

Relevant Congressional Actions During COVID-19

Congress has taken several actions related to public health data and reporting during the COVID-19 public health emergency that include (1) establishing clinical laboratory requirements, (2) appropriating funding, and (3) requiring reports to Congress.

Clinical Laboratory Reporting Requirements

Section 18115 of the CARES Act (P.L. 116-136) requires that every clinical laboratory that performs or analyzes a test intended to detect or diagnose a possible case of COVID-19 report the test results to the HHS Secretary. Test results must be reported in such form and manner, and at such timing and frequency, as the Secretary may prescribe until the end of the Secretary's COVID-19 Public Health Emergency declaration (PHSA Section 319) or any extension of such declaration. The provision allows the Secretary to decide which laboratories must submit reports pursuant to that section and does not require the data to be made publicly available. (As discussed in the "Demographic Data" section, HHS subsequently issued guidance to implement this provision on June 4, 2020.) The CARES Act section repeals a provision related to laboratory reporting in the Families First Coronavirus Response Act (P.L. 116-127, §1702). The Families First provision would have required that state and local governments receiving funds pursuant to that act ensure that their respective State Emergency Operations Centers[80] receive from the state and local public health departments regular and real-time reporting on aggregated data on testing and results, as determined by the CDC Director, and that such data are transmitted to the CDC.

Funding

Congress has appropriated funding in several coronavirus supplemental appropriations acts for grants or cooperative agreements between CDC/HHS and jurisdictions and tribal entities for public health functions, including surveillance—not less than $950 million in the first supplemental (P.L. 116-123), not less than $1.5 billion in the CARES Act (P.L. 116-136), and not less than $11 billion in the Paycheck Protection Program and Health Care Enhancement Act (PPPHCEA; P.L. 116-139).[81] The CARES Act directs $500 million to the CDC for "public health data surveillance and analytics infrastructure modernization." CDC has received a total of $7.5 billion in supplemental appropriations for COVID-19, and $10.25 billion in grants for testing and other public purposes (including surveillance) in the PPPHCEA was awarded as a CDC grant to jurisdictions.[82] Additional funding for CDC and transfers from other HHS accounts in these acts may be used by the agency for surveillance purposes.

Reports to Congress

PPPHCEA, enacted April 24, 2020, also includes several provisions in Division B that require HHS reporting and analysis of COVID-19 data, including the following:

---

[80] State Emergency Operations Centers are state-based entities for coordinating an emergency response to a specific incident; see FEMA "Layer: State Emergency Operations Centers," gis.fema.gov/arcgis/rest/services/FEMA/State_EOC/FeatureServer/0.

[81] CDC, State and Local Readiness, "COVID-19 Funding," updated May 29, 2020 https://www.cdc.gov/cpr/readiness/funding-covid.htm.

[82] CDC, "Emerging Issues (E) Project: Funding for the Enhanced Detection, Response, Surveillance, and Prevention of COVID-19 Supported through the Paycheck Protection Program and Health Care Enhancement Act of 2020," https://www.cdc.gov/ncezid/dpei/pdf/elc-enhancing-detection-guidance.pdf.

- **Not later than 21 days after enactment,** report on COVID-19 testing, cases, hospitalizations, and deaths, including, in a de-identified and disaggregated manner, race, ethnicity, age, sex, geographic region, and other relevant factors of individuals tested for or diagnosed with COVID-19. Reporting should reflect the extent that such information is available to be submitted to the Committees on Appropriations of the House and Senate, to the Committee on Energy and Commerce of the House of Representatives, and to the Committee on Health, Education, Labor, and Pensions (HELP) of the Senate. Such reporting should be updated and resubmitted to such committees, as necessary, every 30 days until the end of the COVID-19 public health emergency (PHSA §319).
- **Not later than 180 days after enactment,** report on the number of positive diagnoses, hospitalizations, and deaths as a result of COVID-19, disaggregated nationally by race, ethnicity, age, sex, geographic region, and other relevant factors, including epidemiological analysis of such data.

Four reports submitted thus far have been made available publicly on the Senate HELP Committee website (see the **Appendix B**); results of the reports are discussed in the "Demographic Data" section.

Selected Policy Issues and Considerations

COVID-19 has exposed certain weaknesses in public health surveillance, particularly the nation's ability to collect the comprehensive, location-specific, and timely data needed to respond to the pandemic. The following sections provide an overview of three key data issues that have emerged during the pandemic: (1) demographic data, (2) hospital capacity and utilization data, and (3) data modernization. Each section includes background on prior related efforts, actions taken during the pandemic, and issues for Congress.

Part of the challenge with any national public health surveillance effort is the large and diverse number of independent entities involved—federal, state, territorial, tribal, and local governments, as well as thousands of mostly private and independent health care organizations, including laboratories, hospitals, and other health care providers. This multifaceted system has inherent structural challenges, such as differences in jurisdictions' laws, policies, and capacities for surveillance and different data types collected by different health care entities. These system-level issues and their implications are discussed in the context of the policy issues below.

Readers should note that while the below sections include a discussion of introduced and chamber-passed legislation relevant to these issues, these discussions are not comprehensive of all relevant introduced legislation. CRS has identified that there are hundreds of introduced bills potentially relevant to these issues. The discussion, therefore, focuses on bills passed by either chamber or introduced by relevant committee or other leaders in either chamber.

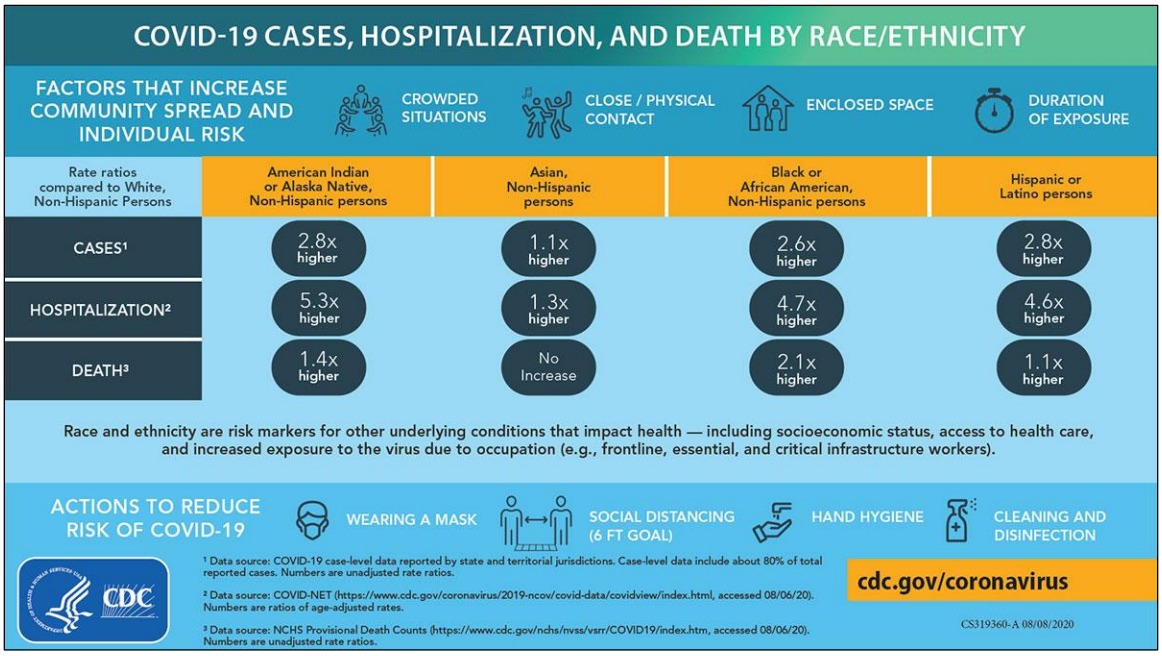
Demographic Data

Available data show that COVID-19 has had a disproportionate health effect on certain groups, including older adults and certain racial and ethnic minority communities. **Figure 2** provides an overview of racial and ethnic disparities in COVID-19 data, as of August 18, 2020 and includes known information about relevant risk factors.[83] However, data gaps in demographic information

[83] CDC, "COVID-19 Hospitalization and Death by Race/Ethnicity," last updated August 18, 2020,

on COVID-19 cases have inhibited a complete understanding of health disparities during the pandemic. Early in the pandemic, many states were not collecting or reporting data on race/ethnicity among COVID-19 cases. HHS has used its new laboratory reporting authority in the CARES Act to address this issue, as described below. However, missing data issues and data gaps remain. In addition, issues have arisen related to data on American Indian/Alaska Native (AI/AN) populations and the sharing of health data on tribal members between CDC, states, and tribes (as described in the text box below).

Figure 2. CDC Graphical Presentation on COVID-19 Data, by Race and Ethnicity



Source: CDC, "COVID-19 Hospitalization and Death by Race/Ethnicity," last updated August 18, 2020, https://www.cdc.gov/coronavirus/2019-ncov/covid-data/investigations-discovery/hospitalization-death-by-race-ethnicity.html.

Notes: This image is provided for illustrative purposes only. Refer to CDC's website above for the most current data.

Background

Prior to the pandemic, the federal government had sought to improve demographic information collection in health data, including public health surveillance, through various efforts. In 1999, as a part of ongoing efforts related to racial and ethnic disparities, HHS published *Improving the Collection and Use of Racial and Ethnic Data in Health and Human Services*, a comprehensive study of issues related to racial and ethnic data collection. The report noted gaps in the availability and quality of race/ethnicity data in a number of health data systems, including those related to mortality and infectious diseases.[84]

---

https://www.cdc.gov/coronavirus/2019-ncov/covid-data/investigations-discovery/hospitalization-death-by-race-ethnicity.html, and CDC, "COVID-19 Hospitalization and Death by Age," https://www.cdc.gov/coronavirus/2019-ncov/covid-data/investigations-discovery/hospitalization-death-by-age.html.

[84] HHS, *Improving the Collection and Use of Racial and Ethnic Data in Health and Human Services*, December 1, 1999, https://aspe.hhs.gov/report/improving-collection-and-use-racial-and-ethnic-data-hhs.

In 2000, the Minority Health and Health Disparities Research and Education Act (P.L. 106-525) directed the National Academy of Sciences (NAS)[85] to write a report on HHS's data collection systems and practices related to race/ethnicity and develop recommendations to improve the collection of such data. In its report *Eliminating Health Disparities: Measurement and Data Needs*, NAS's National Research Council (NRC) noted that the collection of race/ethnicity data in state-based public health data systems was "uneven and unstandardized." NRC recommended that states "require standard racial and ethnic data collection in their health data collection systems, but in a manner that provides states the flexibility to serve their own specific information needs," and with guidance and overall data standards set by the federal government. The panel noted that states faced challenges in collecting such data—for example, health care organizations may not collect information on race/ethnicity and patients may not report such information when completing medical forms.[86]

In 2010, the Patient Protection and Affordable Care Act (ACA, P.L. 111-148, as amended) established in Section 4302 demographic information collection standards for health data, including requirements to collect information on race/ethnicity (as PHSA §3101). Section 4302 stated that such standards are to apply to "any federally conducted or supported health care or public health program, activity or survey … to the extent practicable." In 2011, HHS issued implementation guidance for ACA Section 4302, which applied the policy to "population-based health surveys conducted or sponsored by HHS, in which respondents either self-report information or a knowledgeable proxy provides information about the person or responds for all persons in a household."[87] As indicated in the guidance, the policy would not apply to many public health surveillance systems as they are not applicable population-based health surveys.

Separately, one of the goals of the 2011 HHS *Action Plan to Reduce Racial and Ethnic Health Disparities* was to "increase the availability, quality, and use of data to improve the health of minority populations."[88] In the 2015 implementation progress report, HHS highlighted data collection efforts related to chronic diseases and health care quality.[89] The report did not emphasize infectious disease-related data collection.

In its public health surveillance programs, CDC's efforts in recent years to improve electronic reporting by states and to standardize data collection across different surveillance systems have improved timely collection of demographic data to some extent. With modernization efforts beginning in 2014, more states have been submitting public health data—such as death records or notifiable disease cases—electronically through CDC's standardized reporting systems.[90] To the extent that states and other jurisdictions are reporting demographic information through these systems, these efforts have improved the timeliness of such data collection. However, decisions regarding whether and how to collect and report such demographic data have been traditionally

[85] NAS is now called the National Academies of Sciences, Engineering, and Medicine. See https://www.nationalacademies.org/.

[86] Michele Ver Ploeg and Edward Perrin, *Eliminating Health Disparities: Measurement and Data Needs*, National Research Council, 2004, https://www.nap.edu/download/10979, p. 9-10.

[87] HHS, "Implementation Guidance on Data Collection Standards for Race, Ethnicity, Sex, Primary Language, and Disability Status," October 2011, https://aspe.hhs.gov/basic-report/hhs-implementation-guidance-data-collection-standards-race-ethnicity-sex-primary-language-and-disability-status.

[88] HHS, "HHS Action Plan to Reduce Racial and Ethnic Health Disparities," 2011, https://minorityhealth.hhs.gov/npa/files/plans/hhs/hhs_plan_complete.pdf.

[89] HHS, "HHS Action Plan to Reduce Racial and Ethnic Health Disparities: Implementation Progress Report 2011-2014," November 2015, https://aspe.hhs.gov/basic-report/hhs-action-plan-reduce-racial-and-ethnic-health-disparities-implementation-progress-report-2011-2014.

[90] CDC, "Public Health Surveillance: Preparing for the Future," https://www.cdc.gov/surveillance/pdfs/Surveillance-Series-Bookleth.pdf.

left to states' and other jurisdictions' discretion (see "Data Modernization" section for further background).

American Indian/Alaska Native (AI/AN) Communities and Public Health Data

COVID-19 has disproportionately affected AI/AN communities. According to available data, the hospitalization rate for AI/AN individuals is over five times greater than for White individuals. Moreover, the pandemic has revealed challenges in public health data sharing between tribes, states, and CDC; in some cases, certain states and CDC have refused or been unable to share public health data with tribes.

With support from the Indian Health Service (IHS), 12 Tribal Epidemiology Centers (TECs)—one in each of IHS's 12 service areas—serve as public health organizations for AI/AN Tribal and Urban Indian communities, conducting public health surveillance activities for these communities. Through annual appropriations, Congress supports TECs—a program first authorized in 1996. In ACA Section 10221, as a part of reauthorization of the Indian Health Care Improvement Act, the provision designated existing TECs as "public health authorities" under the Health Insurance Portability and Accountability Act of 1996 Privacy Rule. This designation allows covered entities such as health care providers to share Protected Health Information (PHI) without authorization with TECs for specified public health purposes. ACA Section 10221 also required that the HHS Secretary "grant to each epidemiology center described ... access to use of the data, data sets, monitoring systems, delivery systems, and other protected health information in the possession of the Secretary." Along with the ACA provisions, many CDC grants require that states and territories work with tribes for their public health programs.

In a 2015 issue brief, CDC noted that state privacy laws and misinterpretation of the Privacy Rule can inhibit data sharing with TECs. In addition, data sharing agreements between states and CDC may pose a barrier to CDC sharing state-collected data with tribes. Reporting gaps for race/ethnicity data have also hindered CDC's ability to share COVID-19-related data on AI/AN communities with TECs and tribal organizations.

Source: See CDC Public Health Law, "Tribal Epidemiology Centers Designated as Public Health Authorities Under the Health Insurance Portability and Accountability Act," 2015, https://www.cdc.gov/phlp/docs/tec-issuebrief.pdf., and Kate Conger, Robert Gebeloff, and Richard A. Oppel, "Native Americans Feel Devastated by the Virus Yet Overlooked in the Data," *The New York Times*, July 31, 2020.

COVID-19 Situation and Agency Actions

Throughout the pandemic, many jurisdictions have faced issues with incomplete data from laboratories on COVID-19 cases. Oftentimes, the testing data reported from laboratories were missing key patient information needed to contact the patient and conduct contact tracing. In addition, much of the early COVID-19 data lacked information about patient demographic characteristics, such as race and ethnicity,[91] which are not typically collected by laboratories or sent to laboratories by providers.[92] After a positive test result, public health departments typically have to follow up with patients and providers to obtain full details about the case—a difficult and time-consuming task, especially when cases rise rapidly.[93] These circumstances have affected jurisdictions' ability to collect and report race/ethnicity and other demographic data in a timely manner.

On June 4, 2020, HHS issued guidance to implement Section 18115 of the CARES Act. As a part of the guidance, the Secretary requires that all laboratories report data on a daily basis with a

[91] Kelly Servick, ""Huge Hole" in Testing Data Blurs Racial, Ethnic Disparities," *Science*, July 17, 2020, https://science.sciencemag.org/content/369/6501/237; and Amy Maxmen, "Why the United States is Having a Coronavirus Data Crisis," *Nature*, August 25, 2020.

[92] U.S. Government Accountability Office, *Federal Efforts Could Be Strengthened by Timely and Concerted Actions*, GAO-20-701, September 21, 2020, https://www.gao.gov/reports/GAO-20-701/.

[93] Darius Tahir, "Virus Hunters Rely on Faxes, Paper Records as More States Reopen," *Politico*, May 10, 2020; and Council of State and Territorial Epidemiologists (CSTE), *Driving Public Health in the Fast Lane: The Urgent Need for a 21st Century Data Superhighway*, September 2019, https://cdn.ymaws.com/www.cste.org/resource/resmgr/pdfs/pdfs2/Driving_PH_Display.pdf.

minimum set of required elements to state or local public health departments that will then report to CDC. The minimum required data elements that must be reported for each test include, among other things, patient age, race, ethnicity, sex, zip code, and county. The guidance also provides that laboratories should report patient contact information to state and local public health departments, such as the patient's address and phone number, along with other information, but should not share this information with CDC. Laboratories were required to meet the reporting requirements no later than August 1, 2020.[94] HHS published further implementation guidance with specific categories to be used for race/ethnicity on July 31.[95] The press release accompanying the June 4, 2020, guidance stated,

> HHS and the entire Trump Administration are deeply concerned that COVID-19 is having a disproportionate impact on certain demographics, including racial minorities and older Americans," said HHS Secretary Alex Azar. "High quality data is at the core of any effective public health response, and standardized, comprehensive reporting of testing information will give our public health experts better data to guide decisions at all levels throughout the crisis.[96]

On August 25, the Centers for Medicare & Medicaid Services announced new rules to enforce the laboratory reporting requirements, among other things. Per the announcement, "If a laboratory does not report the required information, CMS will impose a civil monetary penalty in the amount of $1,000 a day for the first day, and $500 for each subsequent day. Labs will have a one-time, three-week grace period to begin reporting required test data."[97] The rule amends the Clinical Laboratory Improvement Amendments of 1988 (CLIA) regulations to require, for the duration of the COVID-19 Public Health Emergency, laboratories to report all SARS-CoV-2 testing results.[98] This requirement allows existing penalties available under the CLIA statute to be imposed for violations of this requirement.[99] According to a September GAO report, CDC officials have conducted outreach to provider organizations to offer education and assistance on collecting testing data, to aid in the collection of demographic data.[100]

On June 4, 2020, during a Labor, Health and Human Services, Education, and Related Agencies (LHHS) Appropriations Subcommittee hearing in the House, CDC Director Robert Redfield apologized for the agency's inadequate reporting on racial and ethnic disparities among COVID-19 patients.[101] CDC has since developed a health equity strategy for COVID-19, *COVID-19*

---

[94] HHS, "COVID-19 Pandemic Response, Laboratory Data Reporting: CARES Act Section 18115," June 4, 2020, https://www.hhs.gov/sites/default/files/covid-19-laboratory-data-reporting-guidance.pdf.

[95] HHS, "COVID-19 Lab Data Reporting Implementation Specifications," https://www.hhs.gov/sites/default/files/hhs-guidance-implementation.pdf.

[96] HHS, "HHS Announces New Laboratory Data Reporting Guidance for COVID-19 Testing," press release, June 4, 2020, https://www.hhs.gov/about/news/2020/06/04/hhs-announces-new-laboratory-data-reporting-guidance-for-covid-19-testing.html.

[97] Centers for Medicare and Medicaid Services (CMS), "Trump Administration Strengthens COVID-19 Surveillance with New Reporting and Testing Requirements for Nursing Homes, Other Providers," press release, August 25, 2020, https://www.cms.gov/newsroom/press-releases/trump-administration-strengthens-covid-19-surveillance-new-reporting-and-testing-requirements.

[98] The CLIA regulations are codified at 42 CFR Part 493 and specify standards and conditions required to maintain CLIA certification, a requirement for performing any clinical testing with return of results in the U.S..

[99] See PHSA §353 [42 U.S.C. §263a] generally, and PHSA §353(h), "Intermediate sanctions."

[100] U.S. Government Accountability Office, Federal Efforts Could Be Strengthened by Timely and Concerted Actions, GAO-20-701, September 21, 2020, https://www.gao.gov/reports/GAO-20-701/.

[101] Brianna Ehley, "CDC Head Apologizes for Lack of Racial Disparity Data on Coronavirus," *Politico*, June 4, 2020, https://www.politico.com/news/2020/06/04/coronavirus-robert-redfield-racial-disparity-cdc-301223. See actual statement at House Appropriations Committee, "Hearing Video: COVID-19 Response," *YouTube*

Response Health Equity Strategy, with a priority strategy to "expand the evidence base." For this priority strategy, CDC plans to "build on plans for collecting and reporting timely, complete, and representative data on testing, incidence, vaccination, and severe outcomes among other populations of focus," and to conduct relevant analyses and special studies related to health equity issues, among other actions.[102] The Government Accountability Office (GAO), in September 2020, reported several shortcomings of the health equity strategy, including that the strategy (1) "does not assess whether having the authority to require states and jurisdictions to report race and ethnicity information is necessary to ensure CDC can collect such data" and (2) "does not specify how it will involve key stakeholders, such as health care providers, laboratories, and state and jurisdictional health departments." [103] Specifically, GAO issued data-related recommendations, as described in the text box below.

Pursuant to requirements in the PPPHCEA, CDC has been submitting reports on individuals tested for or diagnosed with COVID-19 disaggregated by "race, ethnicity, age, sex, geographic region and other relevant factors of individuals tested for or diagnosed with COVID-19, to the extent such information is available." CDC has submitted reports to the required congressional committees. Four publicly available reports have been identified thus far (see **Appendix B**). Updates to the reports note some progress in the collection of demographic data, with gaps remaining. The report from August 2020, notes that 97% of case reports include documented sex and age. As for race/ethnicity data, from April 2, 2020, to August 11, 2020, the proportion of case reports with complete information on race increased from 21% to 60%; on ethnicity, from 18% to 50%; and on race and ethnicity, from 14% to 48%.[104] CRS was unable to identify a publicly available report for September or October.

Issues for Congress

With the requirements on laboratories pursuant to the CARES Act, the Administration has taken action to require reporting of demographic data on COVID-19 cases. Congress may consider whether and how to further expand demographic data collection—either by addressing demographic data gaps in other systems, such as those collecting data on mortality or vaccination rates, or by further supporting states and health care entities in improving capacity for demographic data collection. GAO has issued several recommendations for demographic data collection, including giving CDC the authority to require states and other jurisdictions to collect race and ethnicity data, as outlined in the text box below. Congress may also consider whether differences in health care access among certain demographic groups may affect COVID-19 data collected related to those groups. For example, media reports indicate that testing sites may be less prevalent in some predominately racial and ethnic minority communities; therefore, cases in those communities may be more likely to go undetected.[105] Congress may also continue oversight

at https://www.youtube.com/watch?v=q1MrujFlXOs&t=1h19m50s&ab_channel=HouseAppropriationsCommittee

[102] CDC, "CDC COVID-19 Response Health Equity Strategy: Accelerating Progress Towards Reducing COVID-19 Disparities and Achieving Health Equity," last updated August 21, 2020, https://www.cdc.gov/coronavirus/2019-ncov/community/health-equity/cdc-strategy.html.

[103] U.S. Government Accountability Office, *Federal Efforts Could Be Strengthened by Timely and Concerted Actions*, GAO-20-701, September 21, 2020, https://www.gao.gov/reports/GAO-20-701/.

[104] CDC, *Report to Congress on Paycheck Protection Program and Health Care Enhancement Act Disaggregated Data on U.S. Coronavirus Disease (COVID-19) Testing: 3rd 30 day Update*, August 2020, https://www.help.senate.gov/imo/media/doc/FY2020%20CDC%20RTC%20on%20COVID-19%20Testing%20Data_3rd%2030%20Day%20Update%20-%20final%20for%20signature_encrypted.pdf.

[105] Kelly Servick, "'Huge Hole' in Testing Data Blurs Racial, Ethnic Disparities," *Science*, July 17, 2020, https://www.sciencemag.org/news/2020/07/huge-hole-covid-19-testing-data-makes-it-harder-study-racial-disparities,

of the Administration's ongoing efforts, such as CDC's COVID-19 Response Health Equity Strategy.

GAO Recommendations Related to COVID-19 Data by Race and Ethnicity

- "As the Centers for Disease Control and Prevention (CDC) implements its COVID-19 Response Health Equity Strategy, the Director of the Centers for Disease Control and Prevention should determine whether having the authority to require states and jurisdictions to report race and ethnicity information for COVID-19 cases, hospitalizations, and deaths is necessary for ensuring more complete data, and if so, seek such authority from Congress.
- As CDC implements its COVID-19 Response Health Equity Strategy, the Director of the Centers for Disease Control and Prevention should involve key stakeholders to help ensure the complete and consistent collection of demographic data.
- As CDC implements its COVID-19 Response Health Equity Strategy, the Director of the Centers for Disease Control and Prevention should take steps to help ensure CDC's ability to comprehensively assess the long-term health outcomes of persons with COVID-19, including by race and ethnicity."

Source: U.S. Government Accountability Office, Federal Efforts Could Be Strengthened by Timely and Concerted Actions, GAO-20-701, September 21, 2020, https://www.gao.gov/reports/GAO-20-701/.

Recently proposed and House-passed legislation would expand and strengthen the collection and reporting of the demographic information associated with COVID-19 surveillance.

Heroes Act (H.R. 925)

The House-passed Heroes Act (H.R. 925) includes several provisions related to demographic data collection. Demographic data collection and health disparities are mentioned throughout the bill with respect to various populations and institutions (e.g.., occupational groups, nursing facilities). Key broad provisions include the following:

- Section 572 would amend the requirement for the monthly CDC reporting on demographic data from the PPPHCEA. The amended requirement would include providing technical assistance to state, territorial, and local public health departments to improve the collection of such data, and, if such data is not collected, explaining why the health department has been unable to collect or provide such information. The section would also require the CDC to make its monthly data report publicly available on its website.
- Section 573 would require the HHS Secretary to work with six designated federal agencies, including CDC and the National Institutes of Health (NIH), to support the modernization of data collection methods and infrastructure at such agencies to increase data collection related to health inequities, such as racial, ethnic, socioeconomic, sex, gender, and disability disparities. The section would authorize $4 million in appropriations to each designated federal agency to carry out the requirements in this section.
- Section 574 would require the HHS Secretary, acting through the CDC Director, to award grants to state, territorial, and local health departments to support data modernization and infrastructure not later than six months after enactment. The grants would support modernization of data collection methods and infrastructure to increase data related to health inequities, such as racial, ethnic, socioeconomic,

and Soo Rin Kim, Matthew Vann, and Laura Bronner, "Which Cities Have The Biggest Racial Gaps In COVID-19 Testing Access?," *FiveThirtyEight*, July 22, 2020, https://fivethirtyeight.com/features/white-neighborhoods-have-more-access-to-covid-19-testing-sites/.

sex, gender, and disability disparities. The CDC Director would be required to provide guidance and technical assistance to grantees, as specified, and track grantees' performance. Not later than one year after the grants are awarded, the CDC Director would be required to submit a report to designated congressional committees on (1) best practices for health departments to collect and transmit data related to health inequities; (2) nationwide trends that hinder the collection and transmission of health inequities data; (3) federal best practices for working with states and localities to ensure culturally competent, accurate, and increased data collection and transmission; and (4) recommended changes for legislative or regulatory authority to help improve and increase health inequities data collection. A final report would be required to be submitted not later than three months after the end of the COVID-19 public health emergency (PHSA Section 319). The section would authorize $100 million to remain available until expended.

- Section 575 would require the IHS Director to conduct and support field studies to improve understanding of health inequities among AI/AN communities, in coordination with the tribal epidemiology centers and appropriate federal agencies, including CDC and NIH. Not later than 60 days after enactment, the Director is to establish a nationally representative panel of tribal leaders to establish processes and procedures for the research and field studies. The section includes required reports on related activities, including an initial report to be submitted not later than one year after expending all funds available to carry out the section, and a final report is to be submitted not later than three months after the end of the COVID-19 public health emergency (PHSA Section 319). The section authorizes $25 million in appropriations to remain available until expended.
- Section 576 would require the HHS Secretary, acting through the CDC Director, to complete field studies to better understand health inequities that are not currently tracked by HHS, including analyses related to the impacts of socioeconomic status, disability status, language preference, factors contributing to disparities in COVID-19 health outcomes, and other topics related to health disparities as determined by the Secretary. The Secretary would be required to submit an initial report not later than December 21, 2021, and a final report not later than three months after the end of the COVID-19 public health emergency (PHSA Section 319). The section authorizes $25 million in appropriations to remain available until expended.
- Section 577 the would require the Secretary to submit a report to designated congressional committees, not later than 30 days after enactment, that shows COVID-19 testing, positive diagnoses, hospitalization, intensive care admissions, and mortality rates disaggregated by race, ethnicity, age, sex, gender, geographic region, and other relevant factors as determined by the Secretary. The report is to include proposals for evidence-based response strategies to reduce disparities. The Secretary is to submit a final report not later than three months after the end of the COVID-19 public health emergency (PHSA Section 319). This reporting requirement is to be coordinated with those in the PPPHCEA.

Senate Proposals

As a part of the Senate-introduced Safely Back to School and Back to Work Act (S. 4322), included as a part of the Senate "HEALS" package,[106] Section 106 "Modernizing Infectious Disease Data Collection," would require HHS to develop several data-related strategies in consultation with other experts and health officials, including "strategies to improve the collection and reporting of appropriate, aggregated, deidentified demographic data to inform responses to public health emergencies, including identification of at-risk populations and to address health disparities."

Hospital Capacity and Utilization Data

Federal data collection related to COVID-19 hospital capacity and utilization reflect an effort to rapidly assemble new data systems needed to respond to the pandemic. Although Congress has long recognized the need for "public health situational awareness" during a public health emergency, including an ability to monitor health care utilization and supplies, no such federal data collection system existed prior to the pandemic, as described below. Such data have been sought to inform the allocation of funding dollars and supplies to health care facilities treating COVID-19 patients. Since the pandemic began, agency roles and responsibilities for such data collection have shifted among the Assistant Secretary for Preparedness and Response (ASPR), CDC, the HHS Office of the Chief Information Officer (OCIO), and the White House, explained further below. Some observers have found the data collection requests and changes to be abrupt and burdensome; other observers are concerned about data quality and the lack of transparency regarding data collection decision-making. Some of these issues may be inherent to implementing a new data system at scale during a pandemic.

Background

Starting with the Pandemic and All-Hazards Preparedness Act of 2006 (PAHPA; P.L. 109-417. Congress has required HHS to

> establish a near real-time electronic nationwide public health situational awareness capability through an interoperable network of systems to share data and information to enhance early detection of rapid response to, and management of, potentially catastrophic infectious disease outbreaks and other public health emergencies that originate domestically or abroad.[107]

As reported by GAO, by 2010, HHS had not developed a comprehensive plan for a public health situational awareness network.[108] As a part of reauthorization in 2013, the Pandemic and All-Hazards Preparedness Reauthorization Act of 2013 (PAHPRA; P.L. 113-5)[109] Section 2014 required HHS to submit a detailed strategy and implementation plan to Congress.

The HHS Secretary designated the ASPR to serve as the lead for coordinating strategy and implementation of a cross-cutting situational awareness network. In 2014, ASPR and the HHS

---

[106] Senate Republican Policy Committee, "Update on the Coronavirus Response: HEALS Act," July 28, 2020, https://www.rpc.senate.gov/policy-papers/update-on-the-coronavirus-response-heals-act.

[107] P.L. 109-417, §202.

[108] U.S. Government Accountability Office, *Public Health Information Technology: Additional Strategic Planning Needed to Guide HHS's Efforts to Establish Electronic Situational Awareness Capabilities*, GAO-11-99, December 17, 2010, https://www.gao.gov/products/GAO-11-99.

[109] P.L. 113-5, §204.

Secretary submitted *Public Health and Medical Situational Awareness Strategy* to Congress, followed by a subsequent implementation plan (2015-2018) in 2015.[110] Both plans defined "Public Health and Medical Situational Awareness (PH&M SA)" as

> a knowledge state that results from the process of active information gathering (both domestic and international) with appropriate analysis, integration, interpretation, validation, and sharing of information related to health threats and the health of the human population, as well as health system and human services resources, health-related response assets, and other information that could impact the public's health to inform decision making, resource allocation, and other actions.[111]

As described in the definition above, the situation awareness system was to include health system resources, health response assets, and information to inform decision-making and resource allocation. The implementation plan tasks HHS and its subagencies (such as CDC) to work with other federal agencies and jurisdictions' health departments in defining and implementing a situational awareness system.[112]

GAO reported that, as of May 2017, HHS had made limited progress in implementing its situational awareness plan. HHS reported challenges in identifying the minimum data elements required for such a system and in establishing standards for the network. GAO noted that HHS's implementation plan lacked specificity and measures to track progress, and that, as a result, "the implementation plan's usefulness for ensuring that needed information is available to be shared in a standardized format and can be used by public health officials throughout the nation is diminished."[113] GAO also noted that, according to federal IT standards, the HHS Chief Information Officer (CIO) should play a key role in any electronic data collection effort.[114]

HHS has reported some data collection capabilities related to situational awareness for health emergencies, as listed in the 2017 GAO report.[115] ASPR has established and maintained the Secretary's Operation Center for synthesizing public health and medical information for emergency response.[116] Another example, the HHS emPOWER map, enables health officials to monitor the location of Medicare beneficiaries reliant on electricity-dependent medical equipment, which helps locate these individuals in the event of an extreme weather event or a power outage.[117] ASPR's *2017-2022 Health Care Preparedness and Response Capabilities* mentions "situational awareness" throughout, and tasks ASPR-funded regional-level health care coalitions (HCCs)[118] with defining essential elements of information (EEI) for health emergency

---

[110] U.S. Government Accountability Office (GAO), *Public Health Information Technology: HHS Has Made Little Progress toward Implementing Enhanced Situational Awareness Network Capabilities*, GAO-17-377, September 2017, https://www.gao.gov/assets/690/686971.pdf (hereinafter, GAO, *Public Health Information Technology*)

[111] Assistant Secretary for Preparedness and Response (ASPR), "The National Public Health and Medical Situational Awareness Strategy Implementation Plan (2015-2018)," 2015, https://www.phe.gov/about/OPP/Documents/phm-sa-ip-sept2015.pdf.

[112] ASPR, "The National Public Health and Medical Situational Awareness Strategy Implementation Plan (2015-2018)," 2015, https://www.phe.gov/about/OPP/Documents/phm-sa-ip-sept2015.pdf.

[113] GAO, *Public Health Information Technology*, p. 24.

[114] GAO, *Public Health Information Technology*, p. 29.

[115] GAO, *Public Health Information Technology*, pp. 37-38.

[116] ASPR, "ASPR's Vision for Building Readiness: Sustaining Robust and Reliable Public Health Security Capabilities," August 2018, phe.gov/ASPRBlog/Lists/Posts/Post.aspx?ID=314.

[117] HHS, "HHS emPOWER Map 3.0," 2020, https://empowermap.hhs.gov.

[118] ASPR promotes and supports Health Care Coalitions (HCC) through its grant programs, which are "groups of individual healthcare and response organizations – such as hospitals, EMS providers, emergency management organizations, public health agencies, and more – working in a defined geographic location to prepare for and respond

data collection and with developing relevant situational awareness capabilities in their regions.[119] In addition, ASPR's *National Health Security Strategy 2019-2022* included a broad goal to "Improve Threat and Situational Awareness."[120]

Funding may be a key limitation for creating a situational awareness system. Though Congress authorized $138 million in appropriations for each of FY2014 through FY2018 in PAHPRA Section 204, funding had not been appropriated specifically to carry out this section. According to budget documents for the Public Health and Social Services Emergency Fund account (PHSSEF, an account that provides annual funding to ASPR), ASPR's situational awareness strategy and implementation efforts have been funded by several accounts for broad purposes, such as the "Policy and Planning" and "Preparedness and Emergency Operations" accounts—it is unclear how much funding from these accounts has been specifically designated for ASPR's situational awareness efforts, and whether related activities have been a priority for the agency among its competing other health emergency priorities.[121]

As specified in the Pandemic and All-Hazards Preparedness and Advancing Innovation Act of 2019 (PAHPAIA; P.L. 116-22), Congress added requirements for HHS to meet certain standards and implementation steps for enhancing situational awareness and data capabilities. However, many of the relevant deadlines in the act are set for 18 months after enactment on June 24, 2019, and therefore may not have been completed by the agency—particularly by the time the COVID-19 emergency began.

COVID-19 Situation and Agency Actions

Though ASPR was tasked with leading "situational awareness" efforts, it generally lacks IT and data collection expertise.[122] CDC has expertise in public health surveillance and existing relationships with jurisdictions and health care providers to facilitate hospital data collection; however, these efforts are typically focused on data relevant to disease epidemiology rather than on data needed for emergency response, such as hospital capacity and utilization. Meanwhile, the HHS OCIO has data collection and information management responsibilities, particularly across HHS subcomponents.[123] When the pandemic began, no HHS agency had a data collection capability for hospital utilization and capacity for all relevant health care providers across the country.

During the pandemic, the White House Coronavirus Task Force and FEMA have taken an active role in coordinating resource allocation efforts. They have also taken a lead in efforts to collect data to inform allocation decisions. An existing CDC system for hospital data collection was initially used to fill the data gap. However, this system, the National Healthcare Safety Network (NHSN), was determined to be inadequate for meeting the data needs of the pandemic. HHS and

---

to disasters and emergencies." See https://www.phe.gov/Preparedness/planning/hpp/Pages/find-hc-coalition.aspx.

[119] ASPR, "2017-2022 Health Care Preparedness and Response Capabilities," November 2016, https://www.phe.gov/Preparedness/planning/hpp/reports/Documents/2017-2022-healthcare-pr-capablities.pdf.

[120] ASPR, "National Health Security Strategy," https://www.phe.gov/Preparedness/planning/authority/nhss/Pages/default.aspx#:~:text=The%202019%2D2022%20National%20Health,recover%20from%20disasters%20and%20emergencies.

[121] Based on historical Public Health and Social Services Emergency Fund (PHSSEF) account budget documents available internally at the Library of Congress. For publicly available budget documents, see "HHS Budget and Performance," https://www.hhs.gov/about/budget/index.html.

[122] U.S. Government Accountability Office, *Public Health Information Technology: HHS Has Made Little*, GAO-17-377, September 2017, p. 24, https://www.gao.gov/assets/690/686971.pdf.

[123] HHS, "About OCIO- What We Do," https://www.hhs.gov/about/agencies/asa/ocio/about-ocio/what-we-do/index.html.

the White House switched to a new data collection module through TeleTracking, a private vendor, yet this system did not have the same existing data collection mechanisms and relationship with hospitals as the CDC system. These data were initially requested from hospitals for voluntary reporting on a daily basis (though tied to funding and resource allocations). As announced on August 25, 2020, however, data submissions are now required as a Condition of Participation in the Medicare and Medicaid programs. A chronology of events and agency roles are outlined below; all dates are in calendar year 2020.

- On March 29, Vice President Michael Pence sent a letter to hospital administrators requesting that daily data be sent to HHS, including "in-house" hospital test results by email and hospital capacity and supply data through a new COVID-19 module in CDC's National Healthcare Safety Network (NHSN). These data were to be submitted to HHS in addition to any jurisdictions that required reporting. Per the letter, the "data will help us better understand disease patterns and develop policies for prevention and control of health problems related to COVID-19." [124]
- Subsequently, on April 10, HHS Secretary Alex Azar sent a letter to hospital administrators to expand upon the earlier letter sent by the Vice President. The letter gives hospitals many options to meet the same reporting requests, including through their states, through a module in CDC's National Healthcare Safety Network, and through a new portal established by an HHS vendor, TeleTracking. [125]
- According to May statements by the American Hospital Association (AHA), one-time data submissions through TeleTracking had been used for targeted distributions of the CARES Act Provider Relief Fund[126] and allocations of Remdesivir, the antiviral drug available under a U.S. Food and Drug Administration (FDA) Emergency Use Authorization (EUA).[127]
- In updated guidance on July 10, HHS removed CDC's NHSN module as one of the reporting options for hospital capacity and utilization data. The updated guidance gave hospitals several options for reporting the data, including through their states, the TeleTracking-based system as a part of HHS Protect, or directly to the HHS Protect System. Per the guidance, "the data will be used to inform decisions at the federal level, such as allocation of supplies, treatment, and other resources."[128]

[124] Letter from Michael R. Pence, Vice President, to Hospital Administrators, March 29, 2020, https://www.cms.gov/files/document/32920-hospital-letter-vice-president-pence.pdf.

[125] FEMA, "Coronavirus (COVID-19) Pandemic: HHS Letter to Hospital Administrators," https://www.fema.gov/news-release/20200520/coronavirus-covid-19-pandemic-hhs-letter-hospital-administrators.

[126] American Hospital Association (AHA), "Special Bulletin: UPDATE: HHS Requests Data from Hospitals to Help It Allocate Funding to COVID-19 High-impact Areas," April 23, 2020, https://www.aha.org/special-bulletin/2020-04-23-special-bulletin-update-hhs-requests-data-hospitals-help-it-allocate.

[127] AHA, "Next Deadline for HHS-requested Data to Inform Remdesivir Distribution is Monday, May 18," May 18, 2020, https://www.aha.org/special-bulletin/2020-05-15-next-deadline-hhs-requested-data-inform-remdesivir-distribution-monday.

[128] HHS, "COVID-19 Guidance for Hospital Reporting and FAQs For Hospitals, Hospital Laboratory, and Acute Care Facility Data Reporting Updated July 10, 2020," https://web.archive.org/web/20200714201056/https:/www.hhs.gov/sites/default/files/covid-19-faqs-hospitals-hospital-laboratory-acute-care-facility-data-reporting.pdf.

- At a July 15 press conference, CDC Director Robert Redfield and HHS Chief Information Officer Jose Arrieta explained the change, stating that it would reduce the reporting burden on hospitals and that, "TeleTracking also provides rapid ways to update the type of data we are collecting—such as adding, for instance, input fields on what kind of treatments are being used. In order to meet this need for flexible data gathering, CDC agreed that we needed to remove NHSN from the collection process, in order to streamline reporting."[129]
- HHS issued updated guidance again on July 29 maintaining the same reporting options for hospitals, along with additional information and resources for data issues.[130]
- On August 25, the Centers for Medicare & Medicaid Services announced enforcement rules for the reporting of hospital capacity and utilization data. The rules make reporting a requirement for participation in the Medicare and Medicaid programs.[131]
- HHS issued updated guidance again on October 6 maintaining the same reporting options for hospitals and including further instructions and information about data reporting. The new guidance added fields for submitting data related to influenza, as a part of optional reporting. [132]

Some observers have critiqued the data collection changes. They have argued that the data collection changes have been abrupt for hospitals.[133] Several stakeholders, including members of the federal Healthcare Infection Control Practices Advisory Committee (HICPAC) and the Infectious Diseases Society of America, have voiced concerns about the new HHS-run data system, stating that it has placed unexpected reporting burdens on hospitals, put data quality at risk, and may affect the uniformity of data between states.[134] Analyses have found discrepancies between the federal data and state-collected hospital data, suggesting reporting errors and data quality issues.[135] Data issues may have affected federal shipments of supplies to states. For example, the *Wall Street Journal* has reported that missing state-submitted data from the federal

[129] HHS, "Prepared Remarks from HHS Media Call with CDC Director Redfield and CIO Arrieta on COVID-19 Data Collection," July 15, 2020, https://www.hhs.gov/about/news/2020/07/15/prepared-remarks-from-hhs-media-call-cdc-director-redfield-cio-arrieta-covid-19-data-collection.html.

[130] HHS, "COVID-19 Guidance for Hospital Reporting and FAQs For Hospitals, Hospital Laboratory, and Acute Care Facility Data Reporting Updated July 29, 2020," https://www.hhs.gov/sites/default/files/covid-19-faqs-hospitals-hospital-laboratory-acute-care-facility-data-reporting.pdf%3C.

[131] CMS, "Trump Administration Strengthens COVID-19 Surveillance with New Reporting and Testing Requirements for Nursing Homes, Other Providers," press release, August 25, 2020, https://www.cms.gov/newsroom/press-releases/trump-administration-strengthens-covid-19-surveillance-new-reporting-and-testing-requirements.

[132] HHS, "COVID-19 Guidance for Hospital Reporting and FAQs For Hospitals, Hospital Laboratory, and Acute Care Facility Data Reporting" updated October 6, 2020, https://www.hhs.gov/sites/default/files/covid-19-faqs-hospitals-hospital-laboratory-acute-care-facility-data-reporting.pdf

[133] Robbie Whelan, "Covid-19 Data Reporting System Gets Off to Rocky Start," *Wall Street Journal*, August 11, 2020; Nicholas Florko and Eric Boodman, "How HHS's New Hospital Data Reporting System Will Actually Affect the U.S. Covid-19 Response," *STAT*, July 16, 2020.

[134] Sheryl Gay Stolberg, "Health Experts Warn About Perils of New Virus Data Collection System," *New York Times*, August 12, 2020, https://www.nytimes.com/2020/08/12/us/politics/health-experts-warning-coronavirus-data.html; and Infectious Diseases Society of America (IDSA), "Response from IDSA President to New COVID-19 Data Reporting Protocol," July 14, 2020,

[135] Rebecca Glassman and Betsy Ladyzhets, "Hospitalization Data Reported by the HHS vs. the States: Jumps, Drops, and Other Unexplained Phenomena," *The COVID Tracking Project*, August 11, 2020, https://covidtracking.com/blog/hospitalization-data-reported-by-the-hhs-vs-the-states-jumps-drops-and-other.

hospital database may have affected the number of shipments of Remdesivir to North Carolina.[136] Some of these challenges may be inherent to implementing a new nationwide data collection system in the midst of a pandemic, and may be addressed as more hospitals adjust and HHS refines the new system.[137]

Issues for Congress

Moving forward, Congress may consider how to ensure that adequate data systems are in place and clear agency roles and responsibilities are delineated to help collect necessary hospital data during a public health crisis. Given that CDC already has data collection relationships with health care entities and health departments, one policy option is to consolidate all public health and health emergency data activities through CDC. Yet, CDC is generally not the primary agency that makes health emergency response allocation decisions based on such data. Generally, ASPR advises and coordinates on health emergency response. In the current situation, the White House, HHS OCIO, and FEMA have taken the lead in informing response-related data collection and decision-making. Another policy option is to strengthen the health emergency data capabilities and responsibilities of another agency, such as ASPR or HHS OCIO. Congress may also consider whether to facilitate a partnership between agencies or delegate related responsibilities to a new federal entity. Separately, Congress may also consider how to ensure that stakeholders—such as hospitals and public health agencies—are adequately engaged and notified of changes when new federal health data systems are created, and that any such changes are made in a transparent manner.

Several introduced and House-passed pieces of legislation would address the issue of hospital utilization and capacity data.

House-passed Legislation

A section of the Heroes Act (Section 511 in H.R. 925) would require the President to appoint a Medical Supplies Response Coordinator who, among other responsibilities, would be required to establish a national database of hospital capacity that would include information on variables such as beds, ventilators, personal protective equipment, medical devices, drugs, and vaccines. The House-passed FY2021 LHHS appropriations bill (H.R. 7617) Section 613 states,

> None of the funds made available by this Act may be used to require hospitals, hospital laboratories, and acute care facilities to report COVID–19 data using the "teletracking.protect.hhs.gov" website that was announced by the Department of Health and Human Services in the document titled "COVID–19 Guidance for Hospital Reporting and FAQs For Hospitals, Hospital Laboratory, and Acute Care Facility Data Reporting Updated July 10, 2020.'"

Senate Proposals

As for the Senate, S. 4328 introduced by Senator Schumer would require GAO to conduct a study of the hospital data collection changes during the pandemic. An amendment proposed by Senator Scott (S.Amdt. 2552) to Senate-introduced coronavirus legislation that received a vote but did not pass (S. 178) would have required the development of electronic reporting standards for public health and clinical data sharing, including for hospital capacity data. Legislation has been

[136] Melanie Evans and Alexandra Berzon, "Why Hospitals Can't Handle Covid Surges: They're Flying Blind," *The Wall Street Journal*, September 30, 2020.

[137] Robbie Whelan, "Covid-19 Data Reporting System Gets Off to Rocky Start," *Wall Street Journal*, August 11, 2020.

introduced in the Senate to broadly improve data sharing between public health agencies and hospitals (among other health care entities), but do not specifically address the issue of hospital capacity and utilization data (related bills are summarized in the next section).

Data Modernization

Public health surveillance often relies on records provided to public health agencies by health care entities, such as laboratories and providers. Historically, many of these records have been submitted by paper or fax to public health departments and shared between federal and state agencies by inefficient means such as Excel spreadsheets.[138] Although CDC has been working to transition public health data surveillance to more robust integrated electronic systems for decades, this process was incomplete when the COVID-19 pandemic began.[139] Health care entities still use paper and fax records to share data with public health departments, which hinders timely and complete data collection on COVID-19.[140] Moreover, information sharing is also hindered by incompatible data systems. GAO reported in September 2020 that "electronic systems that share data between providers, laboratories, and state and jurisdictional public health departments are often not compatible."[141] As mentioned above, Congress provided $500 million in the CARES Act for public health data modernization. Efforts to modernize public health data systems, while underway, are hindered by several structural challenges, including a lack of common standards used for health information exchange by health care providers and public health departments, jurisdiction-level laws and policies, and the technical capacities of public health departments in terms of workforce and IT systems.

Background

In recent decades, several efforts have been made to modernize public health data systems. Starting in the 1990s, CDC began the National Electronic Disease Surveillance System (NEDSS), which was designed to integrate and transmit electronic data on infectious diseases from multiple sources, including jurisdictions' health departments, laboratories, and health care organizations. Through this effort, CDC established common data and technical standards and created electronic systems for sharing public health data. According to CDC, "NEDSS helps public health agencies accept electronic data exchanges from healthcare systems and enables health departments to create and send standards-based case notifications to CDC for NNDSS."[142] However, adoption of the system has been slow and uneven across states. By 2012, 19 states and the District of Columbia were using the basic components of the system. [143] Currently, all 50 states use a

[138] Council of State and Territorial Epidemiologists (CSTE), "Driving Public Health in the Fast Lane: The Urgent Need for a 21st Century Data Superhighway," September 25, 2019, https://www.debeaumont.org/news/2019/white-paper-driving-public-health-in-the-fast-lane/.

[139] CDC, "Public Health Surveillance: Preparing for the Future," https://www.cdc.gov/surveillance/pdfs/Surveillance-Series-Bookleth.pdf; and Henry Rolka and Kara Contreary, "Chapter 1: Past Contributions," in *Transforming Public Health Surveillance: Proactive Measures for Prevention, Detection, and Response* (Elsevier, 2016), p. 18.

[140] Darius Tahir, "Virus Hunters Rely on Faxes, Paper Records as More States Reopen," *Politico*, May 10, 2020; Sarah Kliff and Margot Sanger-Katz, "Bottleneck for U.S. Coronavirus Response: The Fax Machine," *New York Times*, July 13, 2020, https://www.nytimes.com/2020/07/13/upshot/coronavirus-response-fax-machines.html.

[141] U.S. Government Accountability Office, *Federal Efforts Could Be Strengthened by Timely and Concerted Actions*, GAO-20-701, September 21, 2020, https://www.gao.gov/reports/GAO-20-701/.

142 CDC, "National Notifiable Diseases Surveillance System (NNDSS): Integrated Surveillance Information Systems/NEDSS," https://wwwn.cdc.gov/nndss/nedss.html.

[143] Henry Rolka and Kara Contreary, "Chapter 1: Past Contributions," in *Transforming Public Health Surveillance: Proactive Measures for Prevention, Detection, and Response* (Elsevier, 2016), p. 18.

compatible system to transmit infectious disease case data to CDC, but many states or other jurisdictions have not fully implemented electronic public health data sharing within their jurisdictions.[144]

Electronic Health Record Implementation and Interoperability Requirements[145]

As noted above, public health data surveillance often relies on the electronic transfer of clinical information from electronic health records to public health departments. This transfer is sometimes conducted via a Health Information Exchange (HIE), which enables secure health data exchange between health care entities. With the Health Information Technology for Economic and Clinical Health Act of 2009 (HITECH, P.L. 111-5), Congress enacted reforms to encourage health care organizations to adopt interoperable EHR systems that permit the secure exchange of electronic health data. As a result, EHR systems have been broadly implemented within the health care system, with nearly all hospitals[146] and 80% of office-based health care providers[147] reportedly using certified EHR systems in 2017.

Building on this near universal adoption, efforts have been made to improve interoperable health information exchange—health information technology (HIT) systems that "enable the secure exchange of electronic health information with, and use of electronic health information from, other health information technology without special effort on the part of the user."[148] Interoperability has been and continues to be an ongoing challenge in the electronic exchange of health information despite nearly universal adoption of EHR systems by health care providers and hospitals. For example, a 2018 report by the HHS Office of the National Coordinator for Health Information Technology (ONC) measures health care providers' interoperable health information exchange capability in terms of the ability to send, receive, find, integrate and use health information from outside sources. The report notes that hospitals outperform office-based clinicians, but that poor performance on measures of finding, integrating, and using electronic health information persists.[149] Interoperability is a multifaceted concept and includes various components, including foundational (e.g., basic inter-connectivity requirements for exchange); structural (e.g., format, syntax, and organization of data exchange); semantic (e.g., common underlying models and codification of the data including the use of data elements with standardized definitions); and organizational (e.g., governance, policy, social, legal, and organizational considerations to facilitate the secure, seamless, and timely communication and use of data) levels.[150]

---

[144] CDC, "National Notifiable Diseases Surveillance System (NNDSS): Integrated Surveillance Information Systems/NEDSS," https://wwwn.cdc.gov/nndss/nedss.html.

[145] Amanda Sarata, CRS Specialist in Health Policy, contributed to this section.

[146] Office of the National Coordinator for Health Information Technology, "Percent of Hospitals, By Type, that Possess Certified Health IT," https://dashboard.healthit.gov/quickstats/pages/certified-electronic-health-record-technology-in-hospitals.php.

[147] Office of the National Coordinator for Health Information Technology, "Office-based Physician Electronic Health Record Adoption," https://dashboard.healthit.gov/quickstats/pages/physician-ehr-adoption-trends.php.

[148] PHSA §3000(9)(A); 42. U.S.C. §300jj.

[149] ONC, "2018 Report to Congress: Annual Update on the Adoption of a Nationwide System for the Electronic Use and Exchange of Health Information," December 2018, https://www.healthit.gov/sites/default/files/page/2018-12/2018-HITECH-report-to-congress.pdf.

[150] HIMSS, "Interoperability in Health Care," https://www.himss.org/resources/interoperability-healthcare.

These efforts to improve interoperability leverage both ONC's voluntary Health IT Certification Program[151] and the CMS EHR Incentive Programs (now the Promoting Interoperability Programs), which encourage the adoption and meaningful use of EHR technology by health care entities. The CMS Promoting Interoperability Programs (PIP), and the EHR Incentive Programs before them, require the use of ONC-certified EHR technology (CEHRT), which in turn involves certain inoperability requirements. As a result, the adoption of CEHRT has been strongly incentivized, and requirements supporting interoperability, such as open Application Programming Interface (API) functionality, have been facilitated. The current version of CEHRT, the 2015 Edition, has been updated with additional requirements to support interoperability. These requirements are the result of recent rulemaking pursuant to provisions in the 21st Century Cures Act (P.L. 114-255) that aim to address ongoing issues that have hindered interoperability and patient access to their health information.

The ONC Health IT Certification Program identifies technical standards and implementation specifications required for the program's certification criteria. The 2015 Edition CEHRT includes certification criteria for public health reporting, which includes enabling interoperability for syndromic surveillance, transmission of data to immunization registries, electronic case reporting, and electronic laboratory reporting.[152] CMS Promoting Interoperability Programs, as well as its Quality Payment Program (QPP) for health care providers, include requirements related to health care providers and hospitals using their CEHRT for the electronic reporting of public health information (e.g., electronic case reporting, syndromic surveillance). In this way, the ONC certification criteria and technical standards for public health reporting and the public health reporting quality measures under the CMS programs align to support public health reporting functionality in EHRs.

Implications for Public Health Surveillance

Public health departments can ideally take advantage of the generally broad implementation and standardization of EHRs in the health care system and access that data for use in public health surveillance programs. In certain cases, they have been able to do so. However, issues may arise because the data standards used in CEHRT—and therefore largely used throughout the health care system—are not always the same as those used by public health departments or the CDC, "hindering the ability to efficiently share data across the clinical and public health sectors."[153] For example, according to a recent study, hospitals reported that a lack of common vocabulary standards is a barrier to reporting electronic surveillance data to public health departments, with almost 15% of hospitals reporting this as a barrier.[154] Further, there are issues with *process interoperability,* or organizational practices and governmental policies that drive how data are collected and shared that affect data sharing between health care entities and public health agencies.[155]

---

[151] See ONC, "About The ONC Health IT Certification Program," https://www.healthit.gov/topic/certification-ehrs/about-onc-health-it-certification-program.

[152] 45 C.F.R. §170.315(f).

[153] Council of State and Territorial Epidemiologists (CSTE), "Driving Public Health in the Fast Lane: The Urgent Need for a 21st Century Data Superhighway," September 25, 2019, https://www.debeaumont.org/news/2019/white-paper-driving-public-health-in-the-fast-lane/, p. 38.

[154] AJ Holmgren et al, "Barriers to Hospital Electronic Public Health Reporting and Implications for the COVID19 Pandemic," *Journal of the American Medical Informatics Association*, vol. 27, issue 8, August 2020, https://academic.oup.com/jamia/article/27/8/1306/5842141

[155] Ramesh Krishnamurthy and J Mark Conde, "Chapter 20: Art and Science of Interoperability to Create

Starting in 2014, CDC initiated a new surveillance strategy to further modernize several types of public health surveillance, including mortality data, laboratory reporting, case reporting, and syndromic surveillance. Between 2014 and 2018, CDC made progress in implementing these electronic reporting systems. For example, death records electronically collected from states within 10 days of death increased from 7% in 2014 to 63% in 2018.[156] The program had also begun to pilot new systems for real-time data sharing between public health departments and health care organizations—particularly through the Digital Bridge program.[157] In FY2020, Congress provided its first specific appropriations of $50 million to CDC for "Public Health Data Surveillance/IT Systems Modernization" (related efforts were previously funded by other budget lines).[158] However, by the time of the pandemic, several challenges remained—particularly that many public health departments still relied on manual and paper-based processes to exchange data with health care entities. In addition, the siloed systems for different data types and diseases created duplication and hindered reporting.[159]

COVID-19 Situation and Agency Actions

The COVID-19 pandemic has demanded larger volumes of health data at greater speeds than has been required in previous public health emergencies. During the 2009-2010 H1N1 influenza pandemic, data were reported weekly by CDC and the states.[160] During the COVID-19 pandemic, data are being collected and shared daily. This data collection has faced many challenges, including errors, missing data, and delays in reporting.[161] Some see a modernized public health surveillance system as a solution to such issues.

With the $500 million provided in the CARES Act, CDC has undertaken efforts to modernize public health data—both for COVID-19 and for the long-term. CDC has expanded automated reporting of COVID-19 test results from laboratories to health departments and then to CDC, with 46 jurisdictions having converted to electronic systems as of October 16, 2020.[162] CDC is also helping implement electronic case reporting systems that will enable automated real-time data exchange between health care providers and public health agencies.[163] Looking to the future,

---

Connections," in *Transforming Public Health Surveillance: Proactive Measures for Prevention, Detection, and Response*, ed. Scott JN McNabb, J Mark Conde, Lisa Ferland, et al. (Elsevier, 2016), pp. 267-68.

[156] Council of State and Territorial Epidemiologists (CSTE), "Driving Public Health in the Fast Lane: The Urgent Need for a 21st Century Data Superhighway," September 25, 2019, https://www.debeaumont.org/news/2019/white-paper-driving-public-health-in-the-fast-lane/.

[157] Digital Bridge is a multi-sector collaboration for improving data exchange between health care and public health, involving several private and non-profit organizations as well as federal agencies, such as CDC and the HHS Office of the National Coordinator. See Digital Bridge, "Past Projects," 2020, digitalbridge.us/past-projects.

[158] U.S. Congress, House Committee on Appropriations, Subcommittee on the Departments of Labor, Health and Human Services, Education, and Related Agencies, *Division A- Departments of Labor, Health and Human Services, and Education, and Related Agencies Appropriations Act, 2020- Explanatory Statement*, committee print, 116th Cong., 1st sess., December 16, 2019, p.. 37.

[159] Council of State and Territorial Epidemiologists (CSTE), "Driving Public Health in the Fast Lane: The Urgent Need for a 21st Century Data Superhighway," September 25, 2019, https://www.debeaumont.org/news/2019/white-paper-driving-public-health-in-the-fast-lane/.

[160] Colin Wood, "For Public Health and Economy, States are Turning to Data," *StateScoop*, August 12, 2020.

[161] Benjamin Freed, "Coronavirus Data Errors Reveal 'Uncharted Water for States,'" August 18, 2020, https://statescoop.com/coronavirus-data-errors-reveal-uncharted-waters-for-states/.

[162] CDC, "COVID-19 Electronic Laboratory Reporting Implementation by State," August 24, 2020, https://www.cdc.gov/coronavirus/2019-ncov/lab/electronic-reporting-map.html

[163] CDC, "eCR Now: COVID-19 Electronic Case Reporting," updated July 28, 2020, https://www.cdc.gov/coronavirus/2019-ncov/php/electronic-case-reporting.html.

CDC is working with ONC to ensure that new interoperability rules for EHRs, enforceable in 2022, will facilitate public health data modernization.[164]

Technical challenges remain. Not all jurisdictions' public health departments have the IT infrastructure and capacity to handle automated data exchange with health care organizations, and many health care entities lack data sharing relationships with public health agencies. According to an August 2020 study, hospitals report that the most significant barrier to electronic reporting of surveillance data is that public health agencies "lacked the capacity to electronically receive data, with 41.2% of all hospitals reporting it [as a barrier]"—a reflection of "the policy commitment of investing in information technology for hospitals without a concomitant investment in IT infrastructure for state and local public health agencies."[165] A response by public health experts questioned some of the study's conclusions, noting that many public health agencies do have capacity for electronic data exchange, despite infrastructure needs. The authors noted that health care providers are often reluctant to exchange data with public health agencies, and that the variable nature of hospital data contributions to public health agencies presents a key challenge. The authors recommend "increasing support for public health agencies to enhance their ability to exchange (both *receive* and *send*) information while health care systems receive support to *send* data."[166]

In addition, some stakeholders are concerned that current efforts to modernize public health data vary among jurisdictions, with different systems and standards used in different places. Another concern is that the current challenges with sharing public health data—such as policy and system differences between jurisdictions, and the inability to share data rapidly between entities—may persist despite ongoing efforts.[167]

Issues for Congress

With the funding provided in the CARES Act, CDC is continuing to modernize public health data systems. Congress may consider conducting oversight of these efforts and whether to improve or expand upon these efforts in further legislation.

Recent proposed or House-passed legislation contains provisions that would modernize and improve existing public health data systems, as well as create new infrastructure for the compilation and storage of public health data.

House-passed Legislation

The House passed the Heroes Act (H.R. 925) on October 1, 2020, which included several provisions related to data modernization. Section 548 of the act would authorize $450 million in appropriations for CDC to "conduct activities to expand, enhance, and improve applicable public health data systems" and to award grants to state, local, tribal, and territorial public health departments to help improve their respective public health data systems. As a part of this effort, CDC would be required to designate data and technology standards for public health data, in

[164] Correspondence with CDC, August 24, 2020.

[165] AJ Holmgren et al, "Barriers to Hospital Electronic Public Health Reporting and Implications for the COVID-19 Pandemic," *Journal of the American Medical Informatics Association*, vol. 27, issue 8, August 2020, https://academic.oup.com/jamia/article/27/8/1306/5842141.

[166] Catherine J. Staes, James Jellison, Mary Beth Kurilo, et al., "Response to Authors of "Barriers to Hospital Electronic Public Health Reporting and Implications for the COVID-19 Pandemic," *Journal of the American Medical Informatics Association*, October 1, 2020.

[167] John R. Lumpkin and Andrew Wiesenthal, "A Digital Bridge to Real-Time COVID-19 Data," *HealthAffairs*, July 31, 2020.

consultation with ONC, and may not award a grant unless an applicant agrees to meet the standards. Section 548 would require the Secretary to submit a coordinated strategy and implementation plan not later than 180 days after enactment. It would also require a report to Congress on (1) any barriers to the implementation of interoperable public health data systems and electronic case reporting, and (2) the potential public health impact of the implementation of interoperable public health data systems and electronic case reporting, along with a description of the data modernization efforts. Section 550 would establish and authorize $6 billion in appropriations for a Core Public Health Infrastructure grant program for jurisdictions' health departments to address infrastructure needs, as identified by a voluntary public health department accreditation process. The section defines "core public health infrastructure" to include disease surveillance, among other functions. Section 562 would require CDC to award grants[168] to state, local, tribal, and territorial health departments to, among other activities, improve their respective existing public health surveillance systems, as a part of a National Testing and Contact Tracing Initiative. Division A, Title VIII, of the Heroes Act (H.R. 925) would provide a total of $13.7 million in appropriations to CDC including no less than $200 million "for public health data surveillance and analytics infrastructure modernization,"$1 billion is for Public Health Emergency Preparedness cooperative agreements pursuant to PHSA Section 319C-1, and an additional $1 billion for the core public health infrastructure program authorized in Section 550 of that act, with not less than $100 million for tribes and tribal organizations of that $1 billion.

The House-passed FY2021 LHHS appropriations bill (H.R. 7617) would provide $9 billion in new emergency funding for CDC (along with regular CDC appropriations in Title VI). Of this total, $3 billion would be designated for public health grants with jurisdictions,[169], $150 million for public health grants with tribal organizations, $400 million would be designated for "public health data surveillance and analytics infrastructure modernization," and $200 million would be designated for public health workforce development.

Senate Proposals

In the Senate, Title VIII of the Senate-introduced Coronavirus Response Additional Supplemental Appropriations Act, 2020 (S. 4320), introduced as a part of the "HEALS" package,[170] would provide $3.4 billion in total appropriations for CDC, of which not less than $1.5 billion would be for public health grants/cooperative agreements with jurisdictions and tribal organizations (those that can support surveillance, among other purposes) and not less than $200 million would be "for public health data surveillance and analytics modernization." The bill would also require the CDC to annually update[171] the public health data surveillance and IT systems modernization report to the House and Senate Appropriations Committees. As another component of the "HEALS" package, Section 106 of the Safely Back to School and Back to Work Act (S. 4322), "Modernizing Infectious Disease Data Collection," would make various amendments to data-related requirements in PAHPAIA. Among these requirements would be directing HHS to develop several new data-related strategies in consultation with experts and health officials,

[168] The number and size of these grants would be "subject to the availability of appropriations."

[169] Out of the $3 billion, $2 billion is designated for Public Health Emergency Preparedness cooperative agreements authorized by PHSA Section 319C-1 and $1 billion is designated for Epidemiology and Laboratory Capacity cooperative agreements authorized by PHSA Section 2821.

[170] Senate Republican Policy Committee, "Update on the Coronavirus Response: HEALS Act," July 28, 2020, https://www.rpc.senate.gov/policy-papers/update-on-the-coronavirus-response-heals-act.

[171] Until the associated funds for public data modernization, as described in Title VIII of the Coronavirus Response Additional Supplemental Appropriations Act, 2020 (S. 4320), are expended.

including "strategies to improve the electronic exchange of health information between State and local health departments and health care providers and facilities." Section 106 also amends the authorization for the Epidemiology and Laboratory Capacity grant program[172] to include "supporting activities of State and local public health departments related to biosurveillance and disease detection." These provisions were not incorporated into a version of a bill that received a vote in the Senate (S. 178 as amended by S.Amdt. 2652) but did not pass. For the Public Health and Social Services Emergency Fund (PHSSEF) account, S. 178 as amended by S.Amdt. 2652 included $16 billion in flexible funding available for public health purposes to prevent, prepare for, and respond to COVID-19 (including surveillance), of which $15 billion would be for grants to jurisdictions and tribal organizations.

Concluding Observations

Public health surveillance is complex. It involves over 100 surveillance systems; over 50 state and other jurisdictions with different laws, policies and capacities; and thousands of health care entities. Congress may consider the best ways to facilitate changes in this complex system to improve the continued response to the COVID-19 pandemic and to ensure that the nation is prepared for the next public health threat.

CDC has long taken a cooperative approach to public health surveillance by engaging jurisdictions through its grant programs—implementing standardized surveillance systems, encouraging the collection of certain data, promoting data standards, and facilitating technical capacity for data collection. CDC's surveillance efforts have been informed by congressional public health surveillance priorities, particularly through annual appropriations to CDC through which the agency receives many disease and activity-specific budget lines.

During the COVID-19 pandemic, when data gaps and issues arose, Congress and the Administration took arguably unprecedented actions related to public health data, such as by imposing data requirements directly on laboratories and hospitals for reporting to jurisdictions' health departments and the federal government. In addition, the pandemic has revealed certain data collection gaps, such as the lack of a federal system for monitoring hospital capacity and utilization. Though some issues related to the availability, timeliness, and completeness of data may be addressed by current data modernization efforts, these activities are ongoing and may not be completed until 2022 or thereafter. Moving forward, Congress may consider how to ensure oversight of federal agencies' data collection activities and systems so that relevant capabilities exist when an emergency arises. Key considerations are that data collection needs may vary for each public health emergency, and that such needs can be difficult to anticipate for a novel pathogen like COVID-19.

In addition, Congress may seek to assess how annual appropriations to CDC and ASPR might affect the surveillance systems and data capabilities of the agencies. CDC receives many disease- and activity-specific funding lines annually, which may affect the agency's ability to create broad surveillance capabilities that can be adapted for new threats like COVID-19. Both CDC and key stakeholders, such as the Council of State and Territorial Epidemiologists, have identified that disease-focused surveillance systems have hindered the creation of integrated public health surveillance capabilities that can adapt to new diseases and reduce duplication and reporting

[172] CDC's Epidemiology and Laboratory Capacity cooperative agreement program provides annual grant funding for a variety of public health laboratory and surveillance activities related to infectious diseases. Since 2012, funding has been provided to 64 jurisdictions, including all 50 states, several large localities, territories, and freely associated states. See https://www.cdc.gov/ncezid/dpei/epidemiology-laboratory-capacity.html.

burdens.[173] ASPR has not received specific appropriations to carry out its responsibilities for ensuring public health and medical situational awareness.

Congress may consider whether to evaluate and reconsider the federal governments' role in public health surveillance to avoid future data issues. Within the limits of its constitutional authority, Congress may consider whether to impose more stringent data standards and requirements on jurisdictions receiving grant funding for public health surveillance as a condition of such grants. Congress may also consider whether and how to continue some of the federal reporting requirements on health care organizations, such as those on laboratories and hospitals. In doing so, Congress may consider how such actions will affect the longstanding federal-state partnership for public health surveillance, where many aspects of public health surveillance are governed by laws and policies at the state level. Congress may also consider whether the entities involved have the adequate resources and technical capabilities for robust public health surveillance.

[173] Council of State and Territorial Epidemiologists (CSTE), "Driving Public Health in the Fast Lane," 2019, https://cdn.ymaws.com/www.cste.org/resource/resmgr/pdfs/pdfs2/Driving_PH_Display.pdf, and CDC, *Public Health Surveillance: Preparing for the Future*, September 2018, https://www.cdc.gov/surveillance/pdfs/Surveillance-Series-Bookleth.pdf.

Appendix A. Acronyms Used in This Report

Acronym	Definition
ACA	Patient Protection and Affordable Care Act (P.L. 111-148)
AHA	American Hospital Association
AI/AN	American Indian/Alaska Native
API	Application Programming Interface
APSR	Assistant Secretary for Preparedness and Response and The Office of the Assistant Secretary for Preparedness and Response
BRFSS	Behavioral Risk Factor Surveillance System
CAH	Critical Access Hospital
CARES Act	Coronavirus Aid, Relief, and Economic Security Act (P.L. 116-136)
CBDRP	Centers for Birth Defects Research and Prevention
CDC	Centers for Disease Control and Prevention
CEHRT	Certified Electronic Health Record Technology
CELR	COVID-19 Electronic Laboratory Reporting
CIDRAP	Center for Infectious Disease Research and Policy
CIO	HHS Chief Information Officer
CLI	COVID-19-Like Illness
CLIA	Clinical Laboratory Improvement Amendments of 1988
CMS	Centers for Medicare & Medicaid Services
CoP	Condition of Participation
COVID-19	Coronavirus Disease 2019
COVID-NET	COVID-19-Associated Hospitalization Surveillance Network
CSELS	Center for Surveillance, Epidemiology, and Laboratory Services
CSTE	Council of State and Territorial Epidemiologists
EEI	Essential Elements of Information
EHR	Electronic Health Record
EIP	Emerging Infections Program
EPA	Environmental Protection Agency
EUA	Emergency Use Authorization
FDA	Food and Drug Administration
FEMA	Federal Emergency Management Agency
GAO	Government Accountability Office
HCC	Health Care Coalition
HEALS Act	Health, Economic Assistance, Liability Protection, and Schools Act
HELP	Health, Education, Labor, and Pensions
Heroes Act	Health and Economic Recovery Omnibus Emergency Solutions Act (H.R. 925)

Acronym	Definition
HHS	Department of Health and Human Services
HICPAC	Healthcare Infection Control Practices Advisory Committee
HIE	Health Information Exchange
HIT	Health Information Technology
HITECH	Health Information Technology for Economic and Clinical Health Act of 2009 (P.L. 111-5)
ICU	Intensive Care Unit
IHS	Indian Health Service
IHSP	Influenza Hospitalization Surveillance Project
ILI	Influenza-Like Illness
ILINet	U.S. Outpatient Influenza-like Illness Surveillance Network
IT	Information Technology
LHHS	Labor, Health and Human Services, Education, and Related Agencies
LTCF	Long-Term Care Facility
MMWR	Morbidity and Mortality Weekly Report
NAS	National Academy of Sciences
NCHS	National Center for Health Statistics
NCVHS	National Committee on Vital and Health Statistics
NEDSS	National Electronic Disease Surveillance System
NHSN	National Healthcare Safety Network
NIH	National Institutes of Health
NNDSS	National Notifiable Diseases Surveillance System
NRC	National Research Council
NSSP	National Syndromic Surveillance Program
NVSS	National Vital Statistics System
NWSS	National Wastewater Surveillance System
OCIO	HHS Office of the Chief Information Officer
ONC	HHS Office of the National Coordinator for Health Information Technology
PAHPA	Pandemic and All-Hazards Preparedness Act of 2006 (P.L. 109-417)
PAHPAIA	Pandemic and All-Hazards Preparedness and Advancing Innovation Act of 2019 (P.L. 116-22)
PAHPRA	Pandemic and All-Hazards Preparedness Reauthorization Act of 2013 (P.L. 113-5)
PH&M SA	Public Health and Medical Situational Awareness
PHI	Protected Health Information
PHSA	Public Health Service Act (42 U.S.C. §201 et. seq.)
PHSSEF	Public Health and Social Services Emergency Fund
PIP	Promoting Interoperability Programs
PPE	Personal Protective Equipment
PPPHCEA	Paycheck Protection Program and Health Care Enhancement Act (P.L. 116-139)

Acronym	Definition
QPP	Quality Payment Program
RANDS	Research and Development Survey
SPHERES	SARS-CoV-2 Sequencing for Public Health Emergency Response, Epidemiology and Surveillance
TEC	Tribal Epidemiology Center
VSCP	Vital Statistics Cooperative Program
YRBSS	Youth Risk Behavioral Surveillance System

Appendix B. Selected COVID-19 Data Resources

This appendix lists frequently cited resources for public health data on COVID-19 in the United States. It begins with CDC data sources, followed by non-CDC data sources. The appendix also lists a few resources that analyze data gaps and describe different data types' strengths and limitations. This appendix is not a comprehensive list but is intended as a starting point for research.

Different resources use different methodologies: readers should inspect websites' data notes and caveats, and should use caution when comparing data across sources, time frames, or geography. Websites often remove data, revise data methods and presentations, and change URLs; this list reflects available links and data at the time of this writing.

CDC has a dedicated email for congressional COVID-19 questions, including congressional requests for data: CDCWNCoVResponse@cdc.gov, or call CDC's Washington's office, 202-245-0600.

For a list of key data repositories related to COVID-19 testing, see Appendix C in CRS Report R46481, *COVID-19 Testing: Frequently Asked Questions*.

Selected Data Sources

CDC Data Sources

CDC COVID Data Tracker: Maps, Charts, and Data Provided by the CDC

https://covid.cdc.gov/covid-data-tracker

A compilation of COVID-19 data collected by the CDC. Some of the data are presented in sortable tables (click a column header to sort), trend charts (use the pull-down menu to change geography), or interactive maps (hover over a state). Data may not be complete or available for all jurisdictions. Examples of available data include the following:

State-level and national data on—

- Cases, including totals, cases per 100,000 population, and 7-day moving averages,
  https://covid.cdc.gov/covid-data-tracker/#cases_casesper100k
  https://covid.cdc.gov/covid-data-tracker/#trends_dailytrendscases
- Deaths, including totals, deaths per 100,000, and 7-day moving averages,
  https://covid.cdc.gov/covid-data-tracker/#cases_deathsper100k
  https://covid.cdc.gov/covid-data-tracker/#trends_dailytrendsdeaths
- Laboratory testing, including percent positive and tests per 100,000
  https://covid.cdc.gov/covid-data-tracker/#testing_testsperformed
- Emergency department visits for COVID-19-like illness, shortness of breath, pneumonia, and influenza-like illness
  https://covid.cdc.gov/covid-data-tracker/#ed-visits
- Correctional and detention facilities cases and deaths
  https://covid.cdc.gov/covid-data-tracker/#correctional-facilities
- Forecasts of cumulative deaths
  https://covid.cdc.gov/covid-data-tracker/#forecasting

County-level data on—

- Cases, including totals, percent of state's cases, cases per 100,000, three-day averages, and number of days declining in the past two weeks
  https://covid.cdc.gov/covid-data-tracker/#county-map
  https://covid.cdc.gov/covid-data-tracker/#pandemic-vulnerability-index
- Deaths, including death totals and deaths per 100,000, three-day averages, number of days declining in the past two weeks
  https://covid.cdc.gov/covid-data-tracker/#county-map
  https://covid.cdc.gov/covid-data-tracker/#pandemic-vulnerability-index
- Mobility trends, overlaid with trends in incidence, cases, and deaths
  https://covid.cdc.gov/covid-data-tracker/#mobility
- Pandemic Vulnerability Index, including measures of infection rates and predictions of future deaths and cases
  https://covid.cdc.gov/covid-data-tracker/#pandemic-vulnerability-index
- Underlying medical conditions that put people at increased risk for severe COVID-19 illness
  https://covid.cdc.gov/covid-data-tracker/#underlying-med-conditions

Noncomprehensive national data on—

- Cases and deaths by race, ethnicity, and age. ("These data only represent the geographic areas that contributed data on race/ethnicity. Every geographic area has a different racial and ethnic composition. These data are not generalizable to the entire U.S. population.")
  https://covid.cdc.gov/covid-data-tracker/#demographics
- Health care personnel cases and deaths
  https://covid.cdc.gov/covid-data-tracker/#health-care-personnel

COVID-19 Death Data and Resources (CDC, National Center for Health Statistics)

https://www.cdc.gov/nchs/nvss/covid-19.htm

These sources contain provisional counts of deaths due to COVID-19 and explain how to understand provisional death counts and death certificate data. Provisional data are incomplete, and death counts should not be compared across states. The technical notes state that "COVID-19 death counts shown here may differ from other published sources, as data currently are lagged by an average of 1–2 weeks." Examples of available data include the following:

State and national data on—

- Disparities by race and Hispanic origin. Charts compare the distribution of COVID-19 deaths with the distribution of the population
  https://www.cdc.gov/nchs/nvss/vsrr/covid19/health_disparities.htm
- Excess deaths. An interactive dashboard can produce estimates by week, age, race and ethnicity, and selected causes of death
  https://www.cdc.gov/nchs/nvss/vsrr/covid19/excess_deaths.htm
- Deaths from all causes, presented as the number of deaths and as a percentage of expected deaths. ("Percent of expected deaths is the number of deaths for all causes for this week in 2020 compared to the average number across the same

week in 2017–2019.”)
https://www.cdc.gov/nchs/nvss/vsrr/covid19/index.htm

- Deaths involving COVID-19
https://www.cdc.gov/nchs/nvss/vsrr/covid19/index.htm
- Deaths involving COVID-19, by age and by sex, for the nation and by sex (spreadsheet)
https://www.cdc.gov/nchs/nvss/vsrr/covid_weekly/index.htm#AgeAndSex

  State data in spreadsheet:
https://data.cdc.gov/NCHS/Provisional-COVID-19-Death-Counts-by-Sex-Age-and-S/9bhg-hcku
- Deaths involving COVID-19 by race and Hispanic origin and by age (spreadsheet)
https://data.cdc.gov/NCHS/Deaths-involving-coronavirus-disease-2019-COVID-19/ks3g-spdg
- Weekly counts of leading causes of deaths (spreadsheets)
https://www.cdc.gov/nchs/nvss/vsrr/covid_weekly/index.htm#StateCountyData

County-level data on—

- Deaths from all causes and deaths involving COVID-19 (spreadsheet)
https://www.cdc.gov/nchs/nvss/vsrr/covid_weekly/index.htm#StateCountyData

COVIDView: A Weekly Surveillance Summary of U.S. COVID-19 Activity (CDC)

https://www.cdc.gov/coronavirus/2019-ncov/covid-data/covidview/index.html

Summarizes key trends nationally, with some regional analyses. Data may be preliminary or incomplete. Examples of available national data include the following:

- Hospitalizations, including hospitalization rates by age, race, and ethnicity. Data are collected in select counties that participate in the Emerging Infections Program (EIP) and the Influenza Hospitalization Surveillance Project (IHSP). COVIDView includes additional data on symptoms at admission, underlying medical conditions, interventions (e.g. mechanical ventilation, intensive care unit), and discharge diagnoses, by age, sex, and race/ethnicity, https://gis.cdc.gov/grasp/COVIDNet/COVID19_5.html.
- Percentage of deaths attributed to pneumonia, influenza, or COVID-19, including trend data.
- Laboratory test trends, by laboratory type, including percentages of specimens testing positive. Data for public health laboratories and commercial laboratories have age data. “Commercial and clinical laboratory data represent select laboratories and do not capture all tests performed in the United States.”
- Outpatient and emergency department visits for illnesses compatible with COVID-19. Trends are also presented for age groups and for states.

COVID-19 Nursing Home Data (CDC)

https://data.cms.gov/stories/s/COVID-19-Nursing-Home-Data/bkwz-xpvg

- *Preliminary* national, state, and nursing home-level data on resident cases and deaths, including cases and deaths per 1,000 residents. Data are reported by nursing homes to the CDC's National Healthcare Safety Network (NHSN) system.

Non-CDC Data Sources

Hospital Capacity Data (HHS Protect Public Data Hub)

https://protect-public.hhs.gov/pages/hospital-capacity

State and national estimates of the number and percent of inpatient beds occupied by COVID-19 patients, and the number and percentage of inpatient and ICU beds occupied by all patients.

The COVID Tracking Project (The Atlantic)

https://covidtracking.com/

Compilations of data from the websites of state, local, and territorial public health authorities. Data might not be complete or reported in all jurisdictions. Examples of available COVID-19 data include the following:

National data on—

- Deaths per 100,000 population by race and ethnicity
  https://covidtracking.com/race
- Trends in tests, cases, hospitalizations (including currently in ICU and currently on ventilator), and deaths. Includes seven-day averages and historical data
  https://covidtracking.com/data#summary-charts
  https://covidtracking.com/data/national
- Long-term care facility deaths, including long-term care facilities' share of all reported COVID-19 deaths
  https://covidtracking.com/data/longtermcare

State-level data on—

- Tests (including antibody test data when available), cases, hospitalizations, and deaths, including trends and seven-day averages. For each state, click "Where this data comes from" for links to the current data source(s)
  https://covidtracking.com/data
  https://covidtracking.com/data/charts/all-metrics-per-state
- Race and ethnicity. For each group, a dashboard shows the percentage of the population, the percentage of cases, and the percentage of deaths. Likely disparities are flagged. For each state, the dashboard also shows the shares of cases and deaths where race and ethnicity are known and reported
  https://covidtracking.com/race/dashboard
- Week of single day record cases for each state
  https://covidtracking.com/data/charts/week-of-single-day-record-of-cases-per-state
- Long-term care facility deaths, including long-term care facilities' share of all reported COVID-19 deaths. https://covidtracking.com/data/longtermcare

County-level data on—

- The counties with the 20 highest infection rates and the counties with the 20 highest death rates, and the largest racial or ethnic group in each of those counties https://covidtracking.com/race

Coronavirus Resource Center (Johns Hopkins University & Medicine)

https://coronavirus.jhu.edu/

Aggregates COVID-19 data from various sources, including state and local public health authorities. A daily "COVID-19 Data in Motion" video shows key national highlights. Examples of available data include the following:

State-level data on—

- Cases and deaths, including new cases and deaths from the past day, past week, and past month, along with dates of record highs in new cases and deaths https://coronavirus.jhu.edu/region
- Trends in confirmed cases per 100,000 population https://coronavirus.jhu.edu/data/new-cases-50-states
- Trends in tests per 1,000 population and percent positive https://coronavirus.jhu.edu/testing/tracker/overview

County data
https://coronavirus.jhu.edu/us-map

Click the county on the map, then click the resulting Infographic for

- fatality rates (total deaths divided by confirmed cases)
- cases per 100,000 population
- new cases since the previous day and
- population and health care facts, including insurance, ICU beds, poverty, and demographics

Also lists top counties ranked by confirmed cases and number of deaths.

Compilations of Data Sources

COVID-19 Curated Data, Modeling, and Policy Resources (Mathematica)

https://www.mathematica.org/features/covid-19-curated-data-modeling-and-policy-resources

An annotated collection of resources for data, among other COVID-19 topics. Includes a section of sources on "Case count and testing rates." For more detailed information about each source, such as update frequency, see the spreadsheet *COVID-19 Data and Resources*.
https://mathematica-mpr.github.io/covidinfo/data_sources.html

COVID-19 Resource Tracker: A Guide to State and Local Responses (Urban Institute)

https://www.urban.org/policy-centers/health-policy-center/projects/covid-19-resource-tracker-guide-state-and-local-responses

A guide to resources that track, among other things, state and local data on COVID-19. In the spreadsheet, look for *data* in the "Type" column.

Analyses of Data Issues

- *Evaluating Data Types: A Guide for Decision Makers using Data to Understand the Extent and Spread of COVID-19* (National Academies of Sciences, Engineering, and Medicine, June 11, 2020)
  https://www.nap.edu/catalog/25826/evaluating-data-types-a-guide-for-decision-makers-using-data

  A brief overview of COVID-19 data types and their strengths and weaknesses. Data types include confirmed cases, hospitalizations, emergency department visits, confirmed deaths, excess deaths, fraction of viral tests that are positive, and representative prevalence surveys.
  Includes an interactive summary: https://www.nap.edu/resource/25826/interactive/

- *COVID-19: Federal Efforts Could be Strengthened by Timely and Concerted Actions* (Government Accountability Office, September 21, 2020)
  https://www.gao.gov/reports/GAO-20-701/

  Discusses data issues and makes recommendations. Includes sections on "HHS Efforts to Collect COVID-19 Data by Race and Ethnicity," "Lesson: Need to Collect and Analyze Adequate and Reliable Data to Drive Future Decisions," "Nursing Home Data," "Nationwide COVID-19 Data System," "COVID-19 Testing Data," and "Health Disparities."

- *COVID-19: Data Quality and Considerations for Modeling and Analysis* (Government Accountability Office, July 30, 2020)
  https://www.gao.gov/products/GAO-20-635SP

  Discusses limitations of COVID-19 surveillance data on cases, hospitalizations, and mortality.

- *COVID-19: Brief Update on Initial Federal Response to the Pandemic* (Government Accountability Office, August 31, 2020)
  https://www.gao.gov/assets/710/709033.pdf

  Data issues are discussed under "Key Health Care and Economic Indicators": Positivity Rate for COVID-19 Testing, Contact Tracing Performance, Proportion of Intensive Care Unit Beds Available, Higher than Expected Deaths from All Causes.

- *COVID-19: Opportunities to Improve Federal Response and Recovery Efforts* (Government Accountability Office, June 25, 2020)[174]
  https://www.gao.gov/assets/710/707839.pdf

  Discusses data issues in "CDC's Efforts to Collect Testing Data" and "Indicators to Facilitate Monitoring of Recovery Following the Federal Pandemic Response."

[174] Section 19010 of the CARES Act (P.L. 116-136, March 27, 2020) requires the Government Accountability Office to report on its COVID-19 monitoring and oversight efforts within 90 days of enactment, and every other month thereafter until a year after enactment. This is the first of these required reports. Future updates may be posted at https://www.gao.gov/coronavirus/.

- *Master Question List for COVID-19 (caused by SARS-CoV-2)* (Department of Homeland Security, Science and Technology Directorate) https://www.dhs.gov/publication/st-master-question-list-covid-19

  This frequently updated report summarizes what is known and not known about the science of COVID-19. It discusses and cites current data and research on, for example, fatality rates, disproportionate effects on particular population groups, forecasting models and methods, and transmissibility ("How easily is it spread?").

- *Tracking COVID-19 in the United States From Information Catastrophe to Empowered Communities* (Resolve to Save Lives, July 21, 2020) https://preventepidemics.org/covid19/resources/indicators/

  Researchers examined COVID-19 data dashboards for 50 states and DC. They identified best practices and evaluated whether and how the dashboards presented certain "essential" indicators.

- *LitCovid* (National Library of Medicine) https://www.ncbi.nlm.nih.gov/research/coronavirus/

  A curated database of scholarly COVID-19 citations, including articles that discuss and analyze data. Search the database for keywords related to particular data topics (e.g., disparities, excess deaths).

- Reports to Congress on Paycheck Protection and Health Care Enhancement Act Disaggregated Data on U.S. Coronavirus Disease 2019 (COVID-19) Testing (CDC)

  These reports describe data limitations and activities to improve the completeness of race and ethnicity data in COVID-19 surveillance and laboratory reporting. They also present selected data and trends.

  - Initial report (May 2020): https://www.help.senate.gov/imo/media/doc/FY%202020%20CDC%20RTC%20on%20COVID-19%20Testing%20Data%20-%20CDCfinalclean.pdf
  - Initial 30-Day Update (June 2020): https://www.help.senate.gov/imo/media/doc/FY2020_CDCRTC_COVID19Testing_First30DayUpdate_SignedR3%20(003).pdf
  - Second 30-Day Update (July 2020): https://www.help.senate.gov/imo/media/doc/FY%202020%20CDC%20RTC%20on%20COVID-19%20Testing%20Data_2nd%2030%20Day%20Update%20-%20for%20Transmittal.pdf
  - Third 30-Day Update (August 2020): https://www.help.senate.gov/imo/media/doc/FY2020%20CDC%20RTC%20on%20COVID-19%20Testing%20Data_3rd%2030%20Day%20Update%20-%20final%20for%20signature_encrypted.pdf

Author Information

Kavya Sekar
Analyst in Health Policy

Angela Napili
Senior Research Librarian

Disclaimer

This document was prepared by the Congressional Research Service (CRS). CRS serves as nonpartisan shared staff to congressional committees and Members of Congress. It operates solely at the behest of and under the direction of Congress. Information in a CRS Report should not be relied upon for purposes other than public understanding of information that has been provided by CRS to Members of Congress in connection with CRS's institutional role. CRS Reports, as a work of the United States Government, are not subject to copyright protection in the United States. Any CRS Report may be reproduced and distributed in its entirety without permission from CRS. However, as a CRS Report may include copyrighted images or material from a third party, you may need to obtain the permission of the copyright holder if you wish to copy or otherwise use copyrighted material.