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INSIGHT

COVID-19: U.S. Public Health Data and Reporting

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The daily updated counts of cases, deaths, and recoveries during the COVID-19 pandemic have served as important indicators throughout the crisis—informing policy decisions, research, and public awareness. Ongoing data collection, or *surveillance,* is a key component of public health practice. As the nation's lead public health agency, the Centers for Disease Control and Prevention (CDC) has sought to conduct surveillance within the U.S. system of federalism where many public health authorities are based in state law. Some observers have called for improved public health surveillance during the pandemic; this Insight provides an overview of the current systems and policy considerations for Congress.

Overview of U.S. Public Health Surveillance

In the United States, national public health surveillance is conducted through multiple multifaceted systems generally involving the federal, state, territorial, and local (jurisdictional) governments. Much of the original data, such as on COVID-19 virus test results and hospitalizations, are collected from disparate and often private organizations, such as laboratories, hospitals, and outpatient health care facilities. Jurisdictions can mandate the collection of certain data from private entities in jurisdictional law and can implement reporting systems. These data are then used to inform jurisdiction-level public health policy and actions. De-identified data are then usually provided voluntarily to CDC by the jurisdictions. CDC provides funding, sets data standards, and provides technical assistance to jurisdictions for surveillance systems. CDC may also conduct national-level public health surveillance by other means, such as through surveys or data collected directly from health care entities or other designated sites.

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Current COVID-19 Public Health Surveillance Systems

Throughout the COVID-19 epidemic, some have critiqued the adequacy of U.S. public health surveillance. Aside from well-known data issues related to diagnostic testing, some have critiqued the timeliness of reporting, the availability of additional demographic information on COVID-19 cases (such as on race/ethnicity), and the completeness of COVID-19 mortality data. These critiques point to some long-standing issues with U.S. public health surveillance, including differences in jurisdictional laws and systems for surveillance, such as for electronic reporting systems and requirements for the medical certification of deaths.

In the current COVID-19 pandemic, CDC and other federal agencies (such as the Federal Emergency Management Agency, FEMA) are collecting many types of data to inform the federal response and to better understand the disease and affected populations.

CDC has begun to publish a weekly surveillance report, COVIDView, with data related to COVID-19 outpatient visits, emergency department visits, hospitalizations, deaths, and laboratory data. These data draw upon multiple surveillance systems, including additions to the existing influenza surveillance systems, and mortality data collected through the National Vital Statistics System. A new module for hospital reporting in the National Healthcare Safety Network is also used to inform response efforts. These high-level data are intended as indicators for monitoring the pandemic and informing broad response decisionmaking.

CDC also collects more detailed data on COVID-19 cases through the National Notifiable Diseases Surveillance System (NNDSS). In this system, jurisdictions mandate the reporting of certain notifiable diseases from health care entities to jurisdictional health departments, and then voluntarily share de-identified data with CDC. 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." CDC, with the Council of State and Territorial Epidemiologists, publishes a list of diseases and conditions recommended to be reported by jurisdictions and supports electronic reporting systems. COVID-19 is a reportable disease in all jurisdictions, and CDC has developed a case reporting system. Jurisdictions can report preliminary data through the system and complete records over time as more information is gathered and the patient situation changes.

CDC has published some preliminary research using NNDSS data, including a report on severe outcomes among patients (February 12-March 16, 2020) and on underlying health conditions (February 12-March 28, 2020). These reports note how current reporting from jurisdictions is preliminary and often lacks details on cases. For example, the report on underlying health conditions stated,

> the analysis was limited by missing data related to the health department reporting burden associated with rapidly rising case counts and delays in completion of information requiring medical chart review; these findings might change as additional data become available.

Given limitations with NNDSS, CDC also operates COVID-NET, a surveillance system that collects detailed data on COVID-19 hospitalizations in 100 counties across the United States. Data from this system can allow for more robust analyses on subsets of COVID-19 cases, such as published in a recent CDC report.

Congressional and Administrative Actions

Recent legislative and executive actions have addressed public health reporting, with a focus thus far on laboratory data. Section 18115 of the CARES Act (P.L. 116-136) requires laboratories to report the results of COVID-19 tests to the HHS Secretary, as specified. This section repeals a provision related to laboratory reporting in the Families First Coronavirus Response Act (P.L. 116-127, Section 1702). Vice

President Michael Pence sent a letter on March 29 to hospital and academic laboratories requesting that data on laboratory results be sent daily to HHS, in addition to any jurisdictions that require reporting.

In addition, the first (P.L. 116-123), third (CARES Act; P.L. 116-136), and fourth (H.R. 266) coronavirus supplemental appropriations acts include funding that may be used for surveillance. The three acts include funding for cooperative agreements between CDC and jurisdictions for public health functions including surveillance—not less than $950 million in the first supplemental, not less than $1.5 billion in the CARES Act, and not less than $11 billion in H.R. 266. In addition, the CARES Act includes $500 million to the CDC for "public health data surveillance and analytics infrastructure modernization." Additional funding for CDC and transfers from other HHS accounts in these acts could also be used by the agency for surveillance purposes.

The Paycheck Protection Program and Health Care Enhancement Act (H.R. 266) includes several provisions in Division B that require reporting and analysis of data on COVID-19 cases, hospitalizations, and deaths, including a required HHS report on COVID-19 cases "disaggregated nationally by race, ethnicity, age, sex, geographic region, and other relevant factors."

Policy Considerations

As the COVID-19 pandemic progresses, better and timelier data could help support the nation's response as well as local-level public health decisionmaking, such as informing social distancing guidelines. At the same time, health care facilities and health departments face competing demands, as surges of patients can affect their ability to report data. Given these circumstances, Congress may consider the following:

- How the federal government can reduce reporting burden on health care entities and health departments while ensuring timely national data collection.
- How national-level data collection can better address issues related to health disparities during the COVID-19 outbreak, such as related to race/ethnicity, socioeconomic status, and urban/rural residence, given differences in jurisdictional surveillance.
- Whether electronic case reporting systems—systems that better link electronic records of providers, laboratories, and health departments for case reporting—could be more widely implemented across jurisdictions during the pandemic.
- Whether surveillance can be improved in a manner that does not run afoul of data privacy protections such as those in the Healthcare Insurance Portability and Accountability Act (HIPAA) and state health data laws.