# U.S. House of Representatives
# Committee on Science, Space, and Technology
# Subcommittee on Investigations and Oversight

## Hearing Charter

*Data for Decision-Making: Responsible Management of Data during COVID-19 and Beyond*

Wednesday, September 23, 2020
11:00 a.m. EDT
Cisco WebEx

**Purpose**

The purpose of the hearing is to explore COVID-19 data management at the local, state, and Federal level, including how relevant stakeholders are collecting, analyzing, and reporting data that informs COVID-19 research and decision making. The Subcommittee will discuss how healthcare providers, scientists, and public health agencies can ensure the integrity, accuracy, and transparency of the data in the midst of the COVID-19 pandemic. The Subcommittee will explore how hospitals and researchers can be best served by the Federal government at this time and what investments in data infrastructure are needed to improve public health surveillance in the long term.

**Witnesses**

- **Dr. Lisa Lee, PhD**, Associate Vice President for Research and Innovation, Virginia Tech
- **Dr. Lisa Maragakis, MD, MPH**, Senior Director of Infection Prevention, Johns Hopkins Health System
- **Mr. Avik Roy**, President, Foundation for Research on Equal Opportunity
- **Ms. Janet Hamilton, MPH**, Executive Director, Council of State and Territorial Epidemiologists

**Overarching Questions**

- How can the Federal government ensure that COVID-19 data is accurate, secure, transparent, and accessible to relevant stakeholders?
- How is COVID-19 data used to inform decisions made by hospitals and clinics, state and local governments, and the Federal government?
- How has the recent switch from the Centers for Disease Control and Prevention's (CDC) National Healthcare Safety Network (NHSN) to the TeleTracking system contracted by the Department of Health and Human Services (HHS) affected hospitals' ability to report COVID-19 data and stakeholders' ability to use it?

- How can the Federal government invest in public health infrastructure and disease surveillance efforts beyond the current pandemic?

**The Need for Accurate, Objective, and Accessible COVID-19 Data**

Our ability to chart the progress of the pandemic and move towards vaccine deployment depends on the reliable collection and sharing of COVID-19 data. It is essential for understanding the spread of the disease, allocating sufficient resources to areas most at risk, and making prudent decisions regarding the safety of returning to pre-pandemic school, work, and social conditions. Decision-makers at every level—from individual hospitals up to the Federal government—need data that is current, complete, accurate, accessible, and provided on a timely basis.[1] With this, they can:

- Allocate drugs like Remdesivir to hospitals[2];
- Create state-specific lists mandating periods of self-isolation or negative COVID-19 test results for interstate travelers[3];
- Establish benchmarks for phased reopening at the local and state level[4];
- Manage overflow of patients from overwhelmed hospitals to nearby facilities,[5] and more.

Trained experts, including surveillance scientists and epidemiologists, are needed to produce objective data to inform this decision-making. It is not as simple as collecting and reporting information. Raw epidemiological data must be cleaned and validated for accuracy. It must be analyzed, interpreted, and translated for the intended application.

**Protecting Patient COVID-19 Data**

The importance of data in tracing, tracking, and preventing transmission has seen governments around the world turn to the expertise of private technology companies in gathering, storing, and processing information.[6] In the United States, the core Federal law restricting the use and protecting the disclosure of health data is the Health Insurance Portability and Accountability Act (HIPPA), enacted in 1996.[7] HIPAA has traditionally applied to the flow of information among healthcare providers, health plans, and healthcare clearinghouses.

Yet the vast amount of patient data collected as part of COVID-19 response efforts has raised new questions about protecting public health information.[8] For example, some public health agencies are developing apps to track COVID-19 patients and their contacts using technology built by Google and Apple.[9] However, data collected through apps, sensors, and online portals may not be subject to HIPAA requirements if the tech companies making the devices and

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[1] https://www.gao.gov/assets/670/665712.pdf
[2] https://www.healthcarefinancenews.com/news/hospitals-get-direct-shipments-covid-19-antiviral-drug-remdesivir-through-hhs-secured-supply
[3] https://www.aarp.org/travel/travel-tips/safety/info-2020/state-quarantine-guide.html
[4] https://www.whitehouse.gov/openingamerica/
[5] https://www.wsj.com/articles/hospitals-in-covid-19-hot-spots-are-filling-up-11594860223
[6] https://www.bmj.com/content/369/bmj.m1925
[7] https://www.wsj.com/articles/protecting-health-data-after-covid-19-more-laws-less-privacy-11599750100
[8] https://www.statnews.com/2020/05/20/health-data-patient-privacy-legislation-congress/
[9] Ibid.

analyzing the data operate outside the healthcare system.[10] A recent poll found that many Americans harbor doubts about whether tech companies would protect the privacy of their health data if they provided access to an infection-tracing app.[11] Individuals are more likely to trust public health agencies to handle and store their information over private companies.

Electronic health information, if improperly obtained, could be used to steal identities, commit fraud, and disrupt healthcare services.[12] The Government Accountability Office has previously found that HHS needs to strength its security and privacy oversight because its guidance on HIPAA compliance does not meet the cybersecurity elements called for by the National Institute of Standards and Technology.[13] The American Medical Association notes that the primary purpose of "boosting guardrails around data use" is to build public trust, not inhibit data exchange.[14]

## The National Healthcare Safety Network: A Crucial Source of COVID-19 Data

CDC's NHSN was established as a healthcare-associated infection tracking system. Over decades, NHSN has established relationships with over 25,000 healthcare facilities, including hospitals, long-term care facilities, nursing homes, and more. Facilities report to NHSN in part to comply with Centers for Medicare and Medicaid Services (CMS) infection reporting requirements.[15]

On March 29, 2020, Vice President Pence issued a letter on behalf of the White House Coronavirus Task Force to hospital administrators announcing the creation of a NHSN COVID-19 Patient Impact and Hospital Capacity Module and instructing the hospitals to file daily reports to the system.[16] As noted in the letter, most hospitals already submitted regular reports to NHSN on healthcare-associated infections. The COVID-19 data would be used to support CDC and Federal Emergency Management Agency efforts to understand disease patterns, develop policies, and support state and local public health authorities.

The CDC then made the COVID-19 data collected through NHSN publicly available on its website.[17] Data was validated by CDC epidemiologists and broken out by state, allowing public health officials across the country to view the data from neighboring states in order to develop a comprehensive picture of the spread of the disease beyond their own state's data collection efforts.

The CDC's handling of COVID-19 data has not been without difficulty or controversy. The expansion of NHSN's responsibilities with the addition of the COVID-19 Patient Impact and Hospital Capacity Module strained the already stretched resources of the NHSN, resulting in lags

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[10] https://www.wsj.com/articles/protecting-health-data-after-covid-19-more-laws-less-privacy-11599750100
[11] https://www.washingtonpost.com/technology/2020/04/29/most-americans-are-not-willing-or-able-use-an-app-tracking-coronavirus-infections-thats-problem-big-techs-plan-slow-pandemic/
[12] https://www.gao.gov/key_issues/health_information_technology/issue_summary
[13] https://www.gao.gov/products/GAO-16-771
[14] https://www.ama-assn.org/delivering-care/patient-support-advocacy/why-covid-19-tracking-will-flounder-without-privacy
[15] https://www.cdc.gov/nhsn/about-nhsn/index.html
[16] https://www.whitehouse.gov/briefings-statements/text-letter-vice-president-hospital-administrators/
[17] https://www.cdc.gov/nhsn/covid19/report-patient-impact.html

in reporting hospital data to the public. The CDC also came under criticism in May for its reporting of COVID-19 testing data, erroneously combining serology tests and diagnostic tests.[18]

**Switch to TeleTracking Database**

On April 6, HHS awarded a $10.2 million, 6-month contract to TeleTracking Technologies to collect data on available hospital beds, hospital capacity, COVID-19 patients, and deaths. The contract requires the company to set up a "COVID-19 rapid deployment plan for real-time healthcare system capacity reporting."[19] The data requested was information hospitals were already reporting to the CDC, and according to an HHS spokeswoman, the intent was to complement CDC efforts rather than compete. On April 10, HHS Protect, a streamlined data collection platform built by Palantir, went live.[20] HHS Protect compiled data that was being reported through TeleTracking, the CDC NHSN site, HHS, and individual hospital websites.

On April 21, hospitals were instructed to make a one-time report of COVID-19 admissions and intensive care unit beds to TeleTracking in order to receive payment from the $110 billion allocated by the CARES Act.[21] Congress had approved the funding with no such preconditions.[22] At this time, hospitals still had the choice between TeleTracking and the CDC for their daily COVID-19 reports, and few opted for the TeleTracking database. In June, the Administration's effort to push hospitals to use TeleTracking intensified, with Remdesivir allocation tied to reporting.[23]

On July 10, HHS made reporting to TeleTracking mandatory. Hospitals were instructed to cease filing daily reports through NHSN and begin sending data to TeleTracking instead.[24] The HHS announcement stated that this daily reporting to TeleTracking would now be the sole mechanism used to calculate the distribution of Remdesivir and other treatments and supplies. HHS established a deadline of July 15 – only five days later – for hospitals to come into compliance with this new requirement.

This new requirement and abrupt timeline placed significant stress on hospitals. Pivoting to a new system required hospital administrators to learn how to use an entirely new database, with many datapoints that had not been previously requested by the CDC. Experts who spoke with Committee staff estimated that the new system asked for approximately 50 percent more datapoints. Furthermore, multiple experts expressed that the terminology used in the TeleTracking system was ill-defined, leading to confusion over what exactly was being requested. When hospitals sought clarification on these terms, they were unable to reach experts at TeleTracking or HHS. Experts who spoke to Committee staff had not seen any updated guidance documents clarifying these terms issued by HHS since the July 10 announcement.

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[18] https://www.nytimes.com/2020/05/22/us/politics/coronavirus-tests-cdc.html
[19] https://www.washingtonpost.com/health/growing-friction-between-white-house-cdc-hobbles-pandemic-response/2020/05/15/0e63978e-9537-11ea-82b4-c8db161ff6e5_story.html
[20] https://www.theverge.com/2020/4/21/21230453/palantir-coronavirus-trump-contract-peter-thiel-tracking-hhs-protect-now
[21] https://www.beckershospitalreview.com/data-analytics/hhs-tied-billions-in-covid-19-aid-to-reporting-data-through-teletracking-7-details.html
[22] https://www.nytimes.com/2020/08/23/us/politics/coronavirus-data.html
[23] https://www.nytimes.com/2020/08/23/us/politics/coronavirus-data.html
[24] https://www.hhs.gov/sites/default/files/covid-19-faqs-hospitals-hospital-laboratory-acute-care-facility-data-reporting.pdf

The CDC NHSN public website stopped publishing COVID-19 data on its website on July 14.[25] Immediately following the switch, the historical data was removed from the CDC website.[26] Since then, data have been made available via the HHS Protect Public Data Hub.[27] Experts have expressed concerns to Committee staff that the data put out by HHS is not validated, as the CDC NHSN data was by in-house epidemiologists. Adding to some experts' mistrust of TeleTracking data is that unlike with the CDC NHSN system[28], administrators cannot correct or update errors in data inputs retroactively.

The Administration continues to ramp up its efforts to compel hospitals to report through TeleTracking. On August 25, the Administration announced that CMS funding would be contingent on reporting COVID-19 data to HHS. This would be especially challenging for under-resourced hospitals, who are struggling to adapt to the new system and rely heavily on CMS reimbursements. The Wall Street Journal reported in early September that the Administration is planning to publicize a list of hospitals that have not come into full compliance with the TeleTracking reporting requirements.[29] The same article notes that HHS Protect has made labelling errors and glitches that have misidentified hospitals as non-reporting. These errors jeopardize hospitals' access to Remdesivir, among other resources and supplies. Representatives from a state health agency who spoke with Committee staff described an instance of misallocation of Remdesivir to their state. In this case, the allocation of Remdesivir had little to no relation to the hospital- and state-level data submitted to HHS. Hospitals in this state had also been inaccurately classified by HHS as non-compliant for approximately four weeks after the state confirmed full participation in the TeleTracking system.

On August 20, Dr. Deborah Birx, the Administration's Coronavirus Response Coordinator, announced to government officials in Arkansas that CDC would soon take over COVID-19 data collection efforts once again, referring to TeleTracking as an "interim system."[30] Later that day, HHS Assistant Secretary for Public Affairs Michael Caputo denied the report.[31]

**MMWRs: Another Key COVID-19 Data Source**

Since 1930, the Morbidity and Mortality Weekly Report (MMWR) series has been the CDC's primary vehicle for "scientific publication of timely, reliable, authoritative, accurate, objective, and useful public health information and recommendations."[32] These reports have been a valuable tool during the COVID-19 pandemic, conveying new data and the latest analyses and helping inform officials in every state in the country what they might be facing.[33] Since February, the CDC has published over 100 MMWRs on the novel coronavirus. The MMWR series has more than 190,000 electronic subscribers; its readership consists of physicians, nurses,

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[25] https://www.cdc.gov/nhsn/covid19/report-overview.html
[26] https://www.cnbc.com/2020/07/16/us-coronavirus-data-has-already-disappeared-after-trump-administration-shifted-control-from-cdc-to-hhs.html
[27] https://healthdata.gov/dataset/covid-19-estimated-patient-impact-and-hospital-capacity-state
[28] https://www.cdc.gov/nhsn/pdfs/newsletters/nhsn-nl-mar20-508.pdf
[29] https://www.wsj.com/articles/white-house-to-target-hospitals-for-uneven-covid-19-data-reporting-11599044400
[30] https://www.wsj.com/articles/troubled-covid-19-data-system-returning-to-cdc-11597945770
[31] https://www.wusa9.com/article/news/health/coronavirus/covid-19-cdc-data-collection/507-0bc1a893-8865-476a-956b-a44b52d66a5c
[32] https://www.cdc.gov/mmwr/about.html
[33] https://www.scientificamerican.com/article/we-cant-allow-the-cdc-to-be-tainted-by-politics/

public health practitioners, epidemiologists and other scientists, researchers, educators, and laboratorians.[34]

According to recent reports, communications officials at HHS have sought to change, delay, and prevent the publication of various MMWRs over the past 3.5 months.[35] For example, officials delayed the publication of a MMWR[36] that addressed how doctors prescribe hydroxychloroquine, the malaria drug touted by President Trump as a COVID-19 treatment despite a lack of evidence for its efficacy.[37] These officials also claimed that the timing of a MMWR[38] published in August about coronavirus spread among children was an attempt to undermine the President's call for schools to reopen in person.[39] Despite the fact that these independent scientific publications undergo rigorous vetting — often with multiple drafts to check data and methodology — one HHS official claimed that career scientists were using these reports to plot against the President.[40] CDC Director Robert Redfield denied this, as well as claims of a CDC "resistance unit," during a hearing before the Senate Appropriations Committee on September 16.[41]

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[34] https://www.cdc.gov/mmwr/about.html
[35] https://www.politico.com/news/2020/09/11/exclusive-trump-officials-interfered-with-cdc-reports-on-covid-19-412809
[36] https://www.cdc.gov/mmwr/volumes/69/wr/pdfs/mm6935a4-H.pdf
[37] https://www.washingtonpost.com/health/2020/09/12/trump-control-over-cdc-reports/
[38] https://www.cdc.gov/mmwr/volumes/69/wr/pdfs/mm6931e1-H.pdf
[39] https://www.washingtonpost.com/health/2020/09/12/trump-control-over-cdc-reports/
[40] https://thehill.com/homenews/administration/516677-cdc-director-pushes-back-on-caputo-claim-of-resistance-unit-at-agency
[41] Ibid.