DATA FOR DECISION-MAKING: RESPONSIBLE MANAGEMENT OF DATA DURING COVID–19 AND BEYOND

HEARING

BEFORE THE

SUBCOMMITTEE ON INVESTIGATIONS AND OVERSIGHT

OF THE

COMMITTEE ON SCIENCE, SPACE, AND TECHNOLOGY

HOUSE OF REPRESENTATIVES

ONE HUNDRED SIXTEENTH CONGRESS

SECOND SESSION

SEPTEMBER 23, 2020

Serial No. 116–82

Printed for the use of the Committee on Science, Space, and Technology

Available via the World Wide Web: http://science.house.gov

U.S. GOVERNMENT PUBLISHING OFFICE
41–411PDF WASHINGTON : 2021

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C O N T E N T S

September 23, 2020

DATA FOR DECISION-MAKING: RESPONSIBLE MANAGEMENT OF DATA DURING COVID–19 AND BEYOND

WEDNESDAY, SEPTEMBER 23, 2020

HOUSE OF REPRESENTATIVES,
SUBCOMMITTEE ON INVESTIGATIONS AND OVERSIGHT,
COMMITTEE ON SCIENCE, SPACE, AND TECHNOLOGY,
Washington, D.C.

The Subcommittee met, pursuant to notice, at 11:03 a.m., via Webex, Hon. Bill Foster [Chairman of the Subcommittee] presiding.

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]

[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.

Chairman FOSTER. The hearing will now come to order. Without objection, the Chair is authorized to declare recess at any time.

Before I deliver my opening remarks, I wanted to note that, pursuant to House Resolution 965, today, the Subcommittees are meeting virtually. I want to announce a couple of reminders to the Members about conduct of this remote hearing. First, Members should keep their video feed on as long as they are present in the hearing. Second, Members are responsible for muting and unmuting their own microphones, so please keep your microphones muted unless you're speaking. And finally, if Members have documents that they wish to submit for the record, please email them to the Committee Clerk, whose email address was circulated prior to the hearing.

Well, good morning, and welcome to this virtual hearing on the Subcommittee of Investigations and Oversight of the House Science Committee. Today's hearing focuses on how data drives the decisionmaking at every level of response to COVID–19. Ensuring the integrity, transparency, and accuracy of this data, free from political interference, is crucial to keeping us safe and prepared. Accurate data is crucial to policy planners, to first responders and medical professionals, to epidemiologists and scientific researchers, to politicians, and to the general public. The American public should never have to doubt that Federal data collection and management efforts serve one purpose alone: informing public health decisions with the best available science.

COVID–19 has presented an unparalleled challenge to our Nation's public health infrastructure. Epidemiologists, hospital administrators, and government data scientists have worked tirelessly to adapt existing systems for the ever-evolving landscape. With the CDC's (Centers for Disease Control and Prevention's) National Health Safety Network's (NHSN's) COVID–19 module, which was launched in late March, an existing system was expanded to meet an urgent need at the peak of the initial COVID–19 crisis. Experienced CDC surveillance scientists collected, cleaned, and analyzed emerging data to produce region-specific reports on COVID–19 and published these reports publicly on the CDC website. Local and State health authorities, as well as hospitals and infectious disease modelers, were able to use these reports to gauge the severity of the crisis in their region and make decisions on resource management and disease control measures, and coordinating this with nearby cities and States. While it was not a perfect system—NSHN was reportedly overstretched and under-resourced for this huge task—hospitals had the benefit of working with CDC epidemiologists that they had cultivated relationships with over the years.

In April, with minimal if any consultation with Congress, HHS (Department of Health and Human Services) contracted with TeleTracking Technologies to institute a totally new system. This system would be entirely dedicated to the management of COVID–19 data. In July, reporting to the new system became mandatory. There is much to be said about the burden that this switch placed on hospitals, and our witnesses are—today are well-equipped to answer our questions about the effects of this transition over the past two months.

But beyond implementation issues, this switch away from the CDC has called into question the role of career scientists in overseeing the data quality of the TeleTracking system. The stakes could not be higher because it's so important that public trust in the COVID–19 data underlying public health decisions means so much to our country. Moving the Federal Government's primary data base from the CDC with its expert career epidemiologists to an HHS now dominated by short-term political appointees places this all-important data at risk of political manipulation.

And, unfortunately, concerns about political manipulation of COVID–19 information are not unfounded. We have repeatedly seen public attacks against CDC scientists for the sake of bolstering the President's questionable claim that he has successfully controlled the virus. Just this month, it was reported that HHS political officials have attempted to edit, delay, and prevent the publication of the CDC's *Morbidity and Mortality Weekly Reports*. Only under a cynical Administration hostile to science could these CDC analytical reports be considered "hit pieces" aimed at undermining the President unless somehow they see scientific truth as the enemy.

Now, there will always be a pressure to misreport public health information. This can come from top down from politicians at all levels who might benefit politically from misrepresenting to the public their success at controlling infectious diseases. It can come from industries, facilities, or groups who stand to benefit financially from misleading the public, or from the bottom up, from doctors, clinics, hospitals, or nursing homes that have an incentive to minimize public disclosure of the extent of spread of infectious diseases at their patient care facilities. And there are legitimate gray areas and a need for clear and consistent reporting standards such as differing standards for hospitalization, standards for reporting racial and ethnic information, or the reporting of the simple cause of death for patients with significant comorbidities.

As the pandemic continues to spread, we must ensure that COVID–19 data is protected from inappropriate influence and is transparent, accessible, and accurate. Unfortunately, we have seen firsthand the dangers and the cost to human lives of incorrect information being passed to decisionmakers when Governors, Mayors, hospitals, and local health officials were told to make plans based on faulty projections of the availability of testing, or PPE (personal protective equipment), or of sanitizer. Those plans inevitably fail, and tens of thousands of Americans died.

As a Member of the Select Subcommittee on the Coronavirus Crisis, and as Chairman of this Subcommittee, I'm committed to ensuring that decisionmakers at all levels across the United States have access to reliable data unmarred by political influence.

So I look forward to today's hearing, hearing from our witnesses about how we can best invest public health—in public health infrastructure and disease surveillance that can serve us through this pandemic and beyond.

[The prepared statement of Chairman Foster follows:]

Good morning, and welcome to this virtual hearing of the Subcommittee on Investigations and Oversight. Today's hearing focuses on how data drives the decisionmaking at every level of the response to COVID-19. Ensuring the integrity, trans-

parency, and accuracy of this data, free from political influence, is crucial to keeping us safe and prepared. The American public should never doubt that Federal data collection and management efforts serve one purpose alone: informing public health decisions with the best available science.

COVID-19 has presented an unparalleled challenge to our nation's public health infrastructure. Epidemiologists, hospital administrators, and government data scientists have worked tirelessly to adapt existing systems for the ever-evolving landscape. With the CDC's National Healthcare Safety Network's COVID-19 module, launched in late March, an existing system was expanded to meet an urgent need at the peak of the initial COVID-19 crisis. Experienced CDC surveillance scientists collected, cleaned, and analyzed emerging data to produce region-specific reports on COVID-19, and published the reports publicly on the CDC website. Local and state health authorities, as well as hospitals and infectious disease modelers, were able to use these reports to gauge the severity of the crisis in their region and make decisions on resource management, and disease control measures, and coordinating with nearby cities and states. While it was not a perfect system—NSHN was reportedly overstretched and under-resourced for this huge task—hospitals had the benefit of working with CDC epidemiologists they had cultivated a relationship with for years.

In April, HHS contracted with TeleTracking Technologies to institute a totally new system. This system would be entirely dedicated to the management of COVID-19 data. In July, reporting to the new system became mandatory. There is much to be said about the burden this switch placed on hospitals, and our witnesses today are well equipped to answer our questions about the effects of this transition over the past two months. Beyond implementation issues, this switch away from CDC has called into question the role of career scientists in the TeleTracking system. The stakes could not be higher, because it is so important that the public trust the COVID-19 data underlying public health decisions. Moving the Federal government's primary database from CDC—and its expert epidemiologists—to HHS places this all-important data at risk of political manipulation.

Unfortunately, concerns about political manipulation of COVID-19 information are not unfounded. We have repeatedly seen attacks against CDC scientists for the sake of bolstering the President's claim that he has successfully controlled the virus. Just this month, it was reported that HHS political officials have attempted to edit, delay, and prevent the publication of the CDC's Morbidity and Mortality Weekly Reports. Only under a cynical administration hostile to science could these CDC reports be considered "hit pieces" aimed at undermining the President.

There will always be political pressure to mis-report public health information, whether from politicians themselves or from industries or groups who stand to benefit from misleading the public about the risk posed to their bottom line or political message. As the pandemic continues to spread, we must ensure that COVID-19 data is protected from inappropriate influence and is transparent, accessible, and accurate. As a Member of the Select Subcommittee on the Coronavirus Crisis, and as Chairman of this Subcommittee, I am committed to ensuring that decision-makers at all levels, across the United States, have access to reliable data unmarred by political influence. I look forward to hearing from our witnesses today about how we can best invest in public health infrastructure and disease surveillance that can serve us through this pandemic and beyond.

Chairman FOSTER. And the Chair will now recognize the Ranking Member of the Subcommittee on Investigations and Oversight, Mr. Norman, for an opening statement.

Mr. NORMAN. Good morning and thank you, Chairman Foster. And I want to thank the witnesses for your participation today. I hope we can use this hearing as an opportunity not only to identify where data gaps exist, but also to identify potential solutions to help us all better understand the ongoing coronavirus pandemic and make well-informed decisions moving forward.

Over the past several months, we've seen life as we know it change within the blink of an eye. Cities across the country went into shut down, schools and nonessential businesses were closed, and stay-at-home orders were issued to limit the spread of the virus. We saw our economy come to a halt as millions of Americans lost their jobs and many businesses were forced to permanently shut their doors.

On a daily basis, health officials, healthcare providers, policymakers, and other leaders across the country have had to make difficult decisions about the health and safety of their communities. Decision-makers should rely on detailed and accurate data to advise and prioritize response efforts. Data issues are not a new public health problem, as data collection, management, and sharing have challenged the public health community since long before the coronavirus pandemic.

Unfortunately, the coronavirus pandemic increased the strain on public health infrastructure all across our country. Incomplete and at times inaccurate data is being reported to State and local health departments, which is then used to inform critical policy and operational decisions. The catastrophic impact the coronavirus has had on long-term facilities and nursing homes is just one example of how poor data management has led to detrimental consequences over the past few months. If better data had been available to policymakers, we would have known just how vulnerable the elderly are to this virus, and the countless deaths and hospitalizations could have been prevented.

One of the biggest data challenges affecting the coronavirus pandemic is that we do not know exactly how much of it is out there, and researchers must estimate its prevalence through data-driven disease forecasting and modeling. Predictions on the number of coronavirus cases, hospitalizations, and deaths help inform public decisionmaking by calculating the expected impact of the pandemic in coming weeks or even months.

Outdated public health systems are in desperate need of modernization. Currently, the virus is spreading faster than public health data and response efforts. This has been allowed due to a lack of integrating public health systems all across the State and local governments. We must consider how to incorporate new and innovative techniques to improve slow and static decisionmaking processes and this begins with modernization of our public health infrastructure.

We cannot afford to make bad policy decisions due to poor data during this pandemic and future public health emergencies. It is important we understand the gaps and challenges with the data that we have to best inform response efforts.

As policymakers, our decisions must be informed by data. The quality of those decisions is directly affected by the quality of the data we're using. I look forward to hearing more about how we can improve the timeliness, accuracy, and distribution of public health data.

I yield back.

[The prepared statement of Mr. Norman follows:]

Good Morning and thank you, Chairman Foster. And thank you to the witnesses for your participation today. I hope we can use this hearing as an opportunity not only to identify where data gaps exist, but also to identify potential solutions to help us all better understand the ongoing Coronavirus pandemic and make well-informed decisions moving forward.

Over the past several months, we've seen life as we know it change within the blink of an eye. Cities across the country went into shut down, schools and non-essential businesses were closed, and stay-at-home orders were issued to limit the spread of the virus. We saw our economy come to a halt as millions of Americans lost their jobs and many businesses were forced to permanently shut their doors.

On a daily basis, public health officials, healthcare providers, policymakers, and other local leaders across the country have had to make difficult decisions about the health and safety of their communities. Decision makers should rely on detailed and accurate data to advise and prioritize response efforts. Data issues are not a new public health problem, as data collection, management, and sharing have challenged the public health community since long before the Coronavirus pandemic.

Unfortunately, the Coronavirus pandemic increased the strain on public health infrastructure across the country. Incomplete and at times inaccurate data is being reported to state and local health departments, which is then used to inform critical policy and operational decisions.

The catastrophic impact the Coronavirus has had on long-term care facilities and nursing homes is just one example of how poor data management has led to detrimental consequences over the past few months. If better data had been available to policymakers, we would have known just how vulnerable the elderly are to this virus, and countless deaths and hospitalizations could have been prevented.

One of the biggest data challenges affecting the Coronavirus pandemic is that we do not know exactly how much of it is out there, and researchers must estimate its prevalence through data-driven disease forecasting and modeling. Predictions on the number of Coronavirus cases, hospitalizations, and deaths help inform public health decision-making by calculating the expected impact of the pandemic in coming weeks or even months.

Outdated public health systems are in desperate need of modernization. Currently, the virus is spreading faster than public health data and response efforts. This has all been allowed due to a lack of integrating public health systems across state and local governments. We must consider how to incorporate new and innovative techniques to improve slow and static decision-making processes amid this pandemic, and this begins with modernizing public health infrastructure.

We cannot afford to make bad policy decisions due to poor data during this pandemic and future public health emergencies. It is important that we understand the gaps and challenges with the data that we have to best inform response efforts.

As policymakers, our decisions must be informed by data. The quality of those decisions is directly affected by the quality of the data we're using. I look forward to hearing more about how we can improve the timeliness, accuracy, and distribution of public health data.

I yield back.

[The prepared statement of Chairwoman Eddie Bernice Johnson follows:]

Thank you, Chairman Foster, and thank you to our panel of witnesses for appearing before the Subcommittee today. The COVID-19 pandemic has claimed 200,000 lives in the United States. In my home state of Texas, there have been over 28,000 new cases reported in the past week alone. This is the highest number of any state in the nation. The country still faces many challenges in overcoming the pandemic including preparing for the upcoming cold and flu season, providing aid to businesses in this new coronavirus economy, and helping students navigate new learning environments. Experts agree that the virus will likely continue to circulate until there is a vaccine. It has never been more important to rely on the scientific community to guide our decision-making with the best available research and data.

However, over the past few months, we have seen an increasing number of attacks against career scientists and their work in responding to the pandemic. Most recently, we learned that political officials at HHS have routinely challenged the science behind the CDC's Morbidity and Mortality Weekly Reports, a vital and objective source of COVID-19 data, and tried to silence agency officials in order to paint the Administration's pandemic response in a better light. Last week, Assistant Secretary Michael Caputo even accused CDC scientists of "sedition" and of organizing a "resistance unit" against the President. As Members of the Committee on Science, Space, and Technology, we do not stand for such blatant disregard of scientific integrity in the Federal government.

Our ability to fight the pandemic depends greatly on accurate, objective, and accessible data. With it, the Federal government can efficiently distribute personal protective equipment, testing supplies, and therapeutics. We can better understand the spread of the disease and make prudent decisions about the economy. Without it, hospitals, patients, and state and local jurisdictions can be left in the dark, fighting on their own without critical supplies. The American people must be able to trust that decisions made at all levels are based on trustworthy data and unmarred by political influence.

We have the world's top scientists doing their best to respond to the pandemic. Yet if we allow their work and our public health institutions to be influenced by political games, we could lose the nation's trust at a critical time. Already, many communities of color do not trust the government's role in their health. Yet we know-from the CDC's own Morbidity and Mortality Weekly Reports, in fact-that these communities have been the hardest hit by the pandemic. As we get closer to the possibility of a COVID-19 vaccine, we must ensure that the Federal government is trustworthy and transparent in its decision making.

Thank you again to our witnesses for testifying today. I yield back.

Chairman FOSTER. Thank you. And at this time I would like to introduce our witnesses.

Our first witness is Dr. Lisa M. Lee. Dr. Lee is the Associate Vice President for Research and Innovation at Virginia Tech and holds a faculty appointment in the Department of Population Health Sciences. For 30 years, Dr. Lee has worked in public health and ethics at the local, State, and Federal levels, including 14 years at the CDC. She also served as the Executive Director of the Presidential Bioethics Commission and most recently as the inaugural Chief of Bioethics at Walter Reed Army Institute of Research.

After Dr. Lee is Dr. Lisa L. Maragakis. Dr. Maragakis is an Associate Professor of Medicine and Epidemiology at Johns Hopkins University. She is the Senior Director of Infection Prevention at the Johns Hopkins Health System and the Hospital Epidemiologist for the Johns Hopkins Hospital. Dr. Maragakis also serves as the Executive Director of the Johns Hopkins Biocontainment Unit as Incident Commander for the Johns Hopkins Medicine COVID–19 Response and is the Co-Chair for—of the Centers for Disease Control and Prevention's Healthcare Infection Control Practices Advisory Committee.

Our third witness is Mr. Avik Roy, who serves as President and Co-Founder of the Foundation for Research on Equal Opportunity (FREOPP). He's also the Founder of Roy Healthcare Research. Mr. Roy is currently a Senior Advisor to the Working Group on Health Care Reform at the Bipartisan Policy Center and is a member of the Board of Advisors at the National Institute of Health Care Management. His recent writings include papers on reopening schools and colleges during COVID–19 and on developing strategies for returning people to work during the pandemic.

And our final witness is Mrs. Janet Hamilton—Ms. Janet Hamilton. Ms. Hamilton is the Director at the Council for State and Territorial Epidemiologists (CSTE). She's also—serves as a Board Member of the International Network for Epidemiology and Policy and has worked as a consultant on international influenza surveillance in Mexico, Ukraine, and Greece. While working for the Florida Department of Health's Bureau of Epidemiology, she saw surveillance—she oversaw surveillance programs for reportable diseases, hospital emergency department-based surveillance, outbreaks and natural disaster events, antimicrobial resistance, and influenza.

As our witnesses should know, each of you will have 5 minutes for your spoken testimony. Your written testimony will be included in the record for the hearing. And when you've all completed your spoken testimony, we will begin with questions. Each member will have 5 minutes to question the panel. And if there is time and interest, the Chair may entertain a second round of questions.

And we will start now with Dr. Lee for 5 minutes.

TESTIMONY OF DR. LISA M. LEE, ASSOCIATE VICE PRESIDENT FOR RESEARCH AND INNOVATION, VIRGINIA TECH

Dr. LEE. Thank you, Mr. Chairman and Members of the Subcommittee, for this opportunity to give voice to the critical issue of how the Nation collects, uses, and communicates health data during COVID–19 and beyond.

In my written testimony I addressed three key points in response to your questions, and these include, first, that public health surveillance is a vital health intelligence without which we experience loss of productivity and life; second, that public health surveillance is a set of activities, all of which must function both during and between public health emergencies; and third, that public health surveillance requires the public's trust. Without it, the system fails. Because of time, I refer you to my written comments, which provide a more complete description of my concerns.

And I'll use this time to highlight my last point: trust. Trust is the foundation of all public health practice. It is public health's currency. The public has to trust that their government leaders are acting in the public's best interest. This is especially important for health data, which, along with financial data, are the two things people most want to keep private. Public health professionals are ethically and legally bound to protect identifiable information about individuals for whom they provide services.

Another foundational principle of ethical data collection is that data are used for the purpose for which they are collected. The public must trust that the data they are being—that the data—their data are being used to improve health and for nothing else, not for profit for a private company, not for law enforcement, and not to cause them social, reputational, or financial harm. The public must also trust that the conclusions drawn from the data that they provide to the system are accurate, objective, and will result in benefits to them and their community.

In the case of moving COVID–19 hospital surveillance from CDC to the Office of the Secretary at HHS, trust is being tested in a number of important ways. First, the removal of CDC's public health surveillance experts who together have hundreds of combined years of experience in the complex process of public health surveillance. Removing them reflects the removal of the world's experts in this field. There is no equivalent of this expertise in the private sector.

CDC's surveillance experts work closely with State, local, tribal, and territorial health departments to coordinate public health surveillance for over 70 conditions. They've established a trusted, collaborative relationship with State and local partners over many decades. Their surveillance expertise is sought after by countries and multilateral health agencies across the globe. Removing CDC surveillance scientists from this process is like removing trusted NASA (National Aeronautics and Space Administration) engineers from sending a rocket to Mars.

Second, the public's trust is challenged by moving data collection to an office that is much more vulnerable to political pressure from the White House during this most volatile and important election

year. Moving data collection, though data collection alone is not equal to implementing a carefully planned, effective public health system. Nonetheless, moving the data collection to HHS is seen by many as a move that puts the data in great jeopardy not only due to the loss of that expertise but also because of lack of objectivity driven by political pressure.

Most Americans—68 percent in a recent poll—do not trust what the President says about the pandemic. The number of cases and deaths continue to rise with no coordinated Federal response insight. The President has suggested that the best way to reduce case numbers is to stop testing. Given this and other comments, many people find it hard to imagine that there's a great deal of support to ensure that COVID–19 data under the control of HHS will be complete and well-suited to direct public-health action.

Finally, the data collection contract awarded to a private for-profit company raises concerns. The White House has moved reporting from CDC to a private entity, but it's abundantly clear that public health surveillance is an inherently governmental activity. It is a good that creates a number of positive externalities and reduces important negative externalities. And a good with these characteristics is not responsive to what drives markets. When a private company takes on an inherently governmental activity like public health surveillance, there is a clear mismatch in mission. For-profit companies are driven to succeed in order to meet their obligation to ensure profits, as they should. But public health surveillance is not a profit-driven activity, and this mismatch creates a great deal of mistrust.

The American people have trusted the public health system to protect their communities from infectious diseases since before we were a country. The foundation of that system, the eyes and ears of public health, is public health surveillance. And without a well-functioning public health surveillance system, we would be unable to meet our fundamental duty to care for the health of our Nation. And if we cannot care for the health of our Nation, we cannot care for our country's prosperity. We cannot afford to fail.

Thank you, and I look forward to your questions.

[The prepared statement of Dr. Lee follows:]

Written testimony from Lisa M Lee to the U.S. House Committee on Science, Space, and Technology, Subcommittee on Investigations and Oversight, remote hearing titled "*Data for Decision-Making: Responsible Management of Data during COVID-19 and Beyond.*"

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

The statements below reflect my professional opinion and do not necessarily represent the views of my current or former employers, including Virginia Tech, the Department of Health and Human Services, or the Centers for Disease Control and Prevention.

Mr. Chairman and members of the Subcommittee,

Thank you for the opportunity to give voice to the critical issue of how the nation collects, uses, and communicates the meaning of health data during this global COVID-19 crisis and beyond.

I have been asked to provide testimony about two topics:

1) **The role of CDC epidemiologists in analyzing and validating data that is collected via the National Healthcare Safety Network (NHSN), and how hospitals, states, and researchers have traditionally interacted with the system, including the role of surveillance scientists, including local and state stakeholders, and, your opinion about the new TeleTracking system contracted by the Department of Health and Human Services to collect and host COVID-19 hospital data from around the country; and**
2) **How the federal government can invest in a long-term public health surveillance strategy beyond the COVID-19 pandemic, including a discussion of what a trustworthy data management system should look like, including how to ensure patient data is adequately protected and validated while making it readily accessible to researchers.**

Together, these two questions bring three points to the fore. First, public health surveillance serves as vital health intelligence, without which we experience loss of productivity and life. Second, public health surveillance is a *set* of activities, all of which must function both during and between public health emergencies. And, third, public health surveillance requires the public's trust; without trust, the system fails.

To address the first point, it is important to note that public health surveillance has served as the eyes and ears of the health system since 1741, when tavern keepers were required to report contagious conditions among their patrons to colonial leaders.[i] Public health

surveillance is the health intelligence that provides critical—and often early—warning about health threats. Contemporary public health surveillance is defined as "the ongoing, systematic collection, analysis, and interpretation of health-related data with the a priori purpose of preventing or controlling disease or injury, or of identifying unusual events of public health importance, followed by the dissemination and use of information for public health action."[ii]

Public health surveillance is a multi-layered system that includes health care providers, local and state health departments, the Centers for Disease Control and Prevention (CDC), which employs our federal public health experts, and in our increasingly connected world, the World Health Organization (WHO), which serves as the international body to coordinate multinational public health emergencies. All of these organizations work together to keep their eyes on the horizon and their ears to the ground to anticipate and respond to health threats both during epidemics and in times of good health.

Similar to other types of intelligence, a well-functioning public health surveillance system provides health intelligence that can anticipate and contain threats before they become catastrophic. For a public health surveillance system to motivate effective public health action, it must be accurate, objective, and its findings clearly communicated. A successful system requires consistent investment in technical infrastructure as well as human resources. It is often said that the public health system is working well when nothing happens, indicating that health threats were anticipated and mitigated. To make nothing happen, however, is not cost-free. It requires a skilled and prepared workforce as well as regularly updated technology. Chronic underfunding of the U.S. public health system over the past decade[iii] has led to underinvestment in the public health surveillance system at all levels.

Without consistent investment in a well-functioning public health surveillance system, governments are at risk for failing to meet their basic duty of caring for the health of their population.

The second point is that public health surveillance is a *set* of activities, not simply the collection of health data and posting of data files. Public health surveillance, especially for a highly-lethal, novel virus, is a complex system that includes numerous, interconnected activities. In addition to careful planning and efficient system design, data must be collected and collated—which includes ensuring they are valid, complete, timely, deduplicated, and reliable. Once the raw data are deemed accurate, the next steps are to analyze and interpret the data. To do this well, a surveillance scientist must know the characteristics of the data and how to use appropriate statistical methods to accurately analyze the data. In addition, the surveillance scientist must translate the findings into meaningful information for health officials, policy makers, and others who need the data to make decisions about actions. A

key characteristic of a public health surveillance system is the expectation that the data and findings are used to motivate public health *action* in the form of disease prevention, health promotion, and reduction of morbidity and mortality. Collection of health data in the absence of useful public action is not public health surveillance.

In the United States, we conduct public health surveillance on injuries, health-related behaviors, and over 70 conditions—some chronic, some infectious—as well as health events that might signal a new or unusual health threat. For each condition, we count a variety of what we call "sentinel events." These are events that occur over the duration of an injury or illness. For example, we often count the number of positive laboratory tests for a disease; the number of clinical diagnoses of a condition; if applicable, the number of persons who have recovered or are vaccinated and are now immune to the disease; and (almost always) the number of deaths related to a condition. Each of these events tells us something different about the disease or condition in question.

Because an estimated 75 percent of emerging pathogens that cause disease in humans are spread from animals, it is increasingly important to include disease surveillance in animals as part of a fulsome public health surveillance system. This approach, called One Health,[iv] is a resource that we have yet to meaningfully incorporate into the human public health surveillance system. If we did, however, our health intelligence would be greatly improved. We would see potential health threats much earlier and be poised to act to prevent them long before a large scale loss of human health and life.

Developing a useful public health surveillance system that measures the right sentinel events requires careful thought, planning, and coordination. In addition, it requires an understanding of the science and epidemiology of a condition, as well as what specific data will be needed for decision making.

For COVID-19, for example, we have made efforts to collect data on a number of sentinel events, or signals. We monitor the number of SARS-CoV-2 tests done because it is an important measure of how well we are *assessing the impact* of the disease in a community. We use the number or proportion of *positive* tests to measure the current spread of infection in a community, as an indicator of the completeness of our testing program, and to predict the number of additional cases we are likely to see in the coming weeks. We use the number of COVID-19 hospitalizations to tell us something about the number and characteristics of severe cases, and to estimate current and future care needs. We use the number of recovered cases, plus the number of antibody tests, to tell us about spread of disease from weeks or months before. And we collect information on the number of deaths as an indicator of delayed care seeking behavior, severity of infection, and effectiveness and equitable distribution of treatment.

Decisions about which events to include in a surveillance system are crucial because they help us describe what is happening with the particular condition; this, in turn, helps us decide how to appropriate and allocate resources, when and where to deliver which public health interventions, and to evaluate the success of the public health interventions we have used in combatting outbreaks. These important decisions about the design of the surveillance system should be made by public health surveillance scientists with training and experience with data, epidemiology, statistical analysis and interpretation, communicating complex data, and public health programming.

Since public health management is under the jurisdiction of the states in our country, a strong partnership between state and federal surveillance experts is critical. CDC has been cultivating partnerships with and among states since its founding in 1946. These partnerships, driven in large part by a long-standing partnership with the Council of State and Territorial Epidemiologists, have facilitated a national system of notifiable diseases that is the basis of the majority of public health intervention carried out by state public health professionals.

In my experience as a surveillance scientist who has worked over 30 years at the state, federal, and international levels, surveillance scientists in state health departments and at CDC are the most experienced and best positioned to think through these issues and design a system that will guide an effective, evidence-based response. This is not a task for administrators, or persons with a political agenda.

The third point is about trust. Trust is the foundation of all public health practice; it is public health's currency. The public has to trust that their government leaders are acting in its best interest. Trust is especially important for the kind of data that public health surveillance collects—data about people's health. The top two types of information people most want to keep private are financial data and health data.

The public must trust that their data are being used to improve their health and for nothing else—not for the profit of a private company; not for law enforcement; and not to cause them social, reputational, or financial harm. The public must also trust that the conclusions drawn from the analysis of the data they provide to the system are accurate, objective, and will result in benefits for them and their community. Without the public's trust, the public health system cannot function.

Each year, when asked about which government agencies Americans trust most, CDC consistently ranks near or at the top. One source of this trust is the U.S. public health system's exceptional track record of protecting privacy and confidentiality of patient data. To date, the U.S. public health surveillance system has proven to be especially trustworthy, with virtually no harm to individuals resulting from a breach of surveillance data. Even with a

highly stigmatized infectious disease like HIV, Americans trust the public health surveillance enterprise to collect, store, and use their data to benefit the public's health. Public health professionals are both ethically[v] and legally[vi] bound to protect identifying information about individuals to whom they provide essential services. One of the foundational principles of ethical data public health data collection is that data are used only for the purpose for which they are collected.[vii] Public health surveillance scientists have been protecting and making data useful for researchers for decades. There is no reason to doubt that they will continue to do so in the future.

In the case of moving COVID-19 surveillance from CDC to the Office of the Secretary at HHS headquarters, trust is being tested in a number of critical ways.

First, the removal of public health surveillance science experts from CDC, who together have hundreds of combined years of experience and expertise in the complex process of public health surveillance, reflects the removal of the world's experts in this field. There is no equivalent of this expertise in the private sector. CDC's public health surveillance experts work closely with state, local, tribal, and territorial health department personnel to coordinate public health surveillance for over 70 conditions. They have established trusted, collaborative relationships with state and local partners over decades. Their surveillance expertise is sought after by countries and multilateral health agencies across the globe. Removing CDC public health surveillance scientists from this process is like removing trusted NASA engineers from sending a rocket to Mars.

Second, the public's trust is challenged by moving the data collection to an office that is much more vulnerable to political pressure (direct or indirect) from the White House during the most volatile and important election year we have witnessed most certainly in my lifetime. Moving data collection (though, as I mentioned, data collection is not equal to implementing a carefully planned, effective public health surveillance system), to the HHS Secretary's office is seen by many to put the data in great jeopardy. Not only is there the dire loss of expertise, as I discussed above, but there is also an infusion of what many people worry will be a lack of objectivity driven by political pressure in the face of a national disaster in the midst of this volatile election year. Most Americans (68% in a recent poll[viii]) do not trust what the president says about the pandemic. The number of cases and deaths continue to rise with no coordinated federal response in sight. In a number of published news reports, the president has suggested that the best way to reduce case numbers is to stop testing. Given these and other comments, many people find it hard to imagine that there is a great deal of support to be sure that COVID-19 data under the control of the HHS Office of the Secretary are complete and well-suited to direct public health intervention. This increased political pressure raises serious concerns about reduced objectivity in both the collection and reporting of the data.

Finally, the data collection contract awarded to a private, for-profit company raises concerns. During the early 2000s, the Bush administration talked a great deal about whether federal employees were engaging in "inherently governmental" activities and, if not, there was a move to contract the activity out of federal agencies, from federal employees to contracts with private entities.

While the White House has moved COVID-19 hospital reporting activities from CDC to a private entity, specifically TeleTracking Technologies, it is abundantly clear that public health surveillance is as "inherently governmental" as one can imagine. It is not a good that responds to market forces. It creates a number of positive externalities (and reduces negative externalities); and a good with these characteristics is not responsive to what drives markets.[ix]

When a private company, such as TeleTracking Technologies, takes on an inherently governmental activity like public health surveillance, there is a clear mismatch in mission. TeleTracking Technologies is driven to succeed in order to meet its obligation to ensure profits, as are all for-profit entities. Public health surveillance, however, is not a profit-driven activity. This mismatch creates a great deal of mistrust.[x]

The American people have trusted the public health system to protect their communities from infectious diseases since before we were a country. The foundation of that system, the eyes and ears of public health, is public health surveillance. Without a well-functioning public health surveillance system, we will be unable to meet our fundamental duty to care for the health of our nation. And if we cannot care for the health of our nation, we cannot care for our country's prosperity. We cannot afford to fail.

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Lisa M Lee, PhD, MA, MS serves as Associate Vice President for Scholarly Integrity and Research Compliance at Virginia Tech. She also holds a faculty appointment in the Department of Population Health Sciences. Prior to joining Virginia Tech, she served as the inaugural Chief of Bioethics at Walter Reed Army Institute of Research where she served as IRB Chair, Research Integrity Officer, and Chair of the Bioethics Consultation Service. During the Obama administration, she was appointed to serve as Executive Director of the Presidential Bioethics Commission.

For 30 years, Lee has worked in public health and ethics at the local, state, and federal levels, including 14 years at the US Centers for Disease Control and Prevention. At CDC, she served in a number of leadership roles, including the agency's Assistant Science Officer, director of the Office of Scientific Integrity, and Chief Science Officer in the office of surveillance and epidemiology.

Lee is the lead editor of *Principles and Practice of Public Health Surveillance*, 3d edition (Oxford University Press). She has authored numerous publications in both science and ethics and serves as associate editor for the *Journal of Bioethical Inquiry, Public Health Reports*, and *Public Health Reviews*. The focus of Lee's current work is research ethics pedagogy and public health ethics. Dr Lee serves as Chair elect of the Executive Board of Association for Practical and Professional Ethics. In 2014 she was honored with the Pellegrino Medal for excellence in bioethics.

Lee holds a PhD from Johns Hopkins University School of Public Health, an MA in educational psychology and an MS in bioethics. She is an epidemiologist, bioethicist, and ethics educator.

Chairman FOSTER. Thank you. And next is Dr. Maragakis for 5 minutes.

TESTIMONY OF DR. LISA L. MARAGAKIS, SENIOR DIRECTOR OF INFECTION PREVENTION, JOHNS HOPKINS HEALTH SYSTEM

Dr. MARAGAKIS. Thank you. Good morning, Chairman Foster, Ranking Member Norman, and Members of the Committee. Thank you for the opportunity to appear before you today to discuss the experiences of experts in infection prevention and control across the United States who are on the frontlines of the pandemic response, leading hospitals and health systems in their efforts to accurately and effectively report and utilize COVID–19 data.

I am Dr. Lisa Maragakis. I serve as the Senior Director of Infection Prevention for the Johns Hopkins Health System. But today in my testimony I am here to represent the members of the Society for Healthcare Epidemiology of America, the professional society of experts in infection prevention. Our members work tirelessly to protect patients by detecting and preventing healthcare-associated infections and combating the threat of antimicrobial resistance organisms. Having access to accurate, timely, and transparent data from a variety of sources is vital to our infection prevention work. Accurate data helps us to detect infectious disease transmission in healthcare, understand the effectiveness of infection prevention interventions, and devise innovative solutions to prevent infectious disease transmission.

Our members serve a critical role on the frontlines of the COVID–19 pandemic response by collecting, analyzing, and utilizing data to inform critical decisions about policies, procedures, and hospital resource allocation to keep healthcare personnel, patients, and our community safe.

Healthcare epidemiologists and infection preventionists are highly skilled in utilizing data to detect and respond to infectious disease threats. Epidemiologists, public health officials, and career staff scientists share the common goal of wanting to make sure that accurate and timely information sent to the right hands at the right time for evidence-based strategic decisionmaking.

For decades, our experts have worked closely with and relied upon experts at the Centers for Disease Control and Prevention's National Healthcare Safety Network known as NHSN. This is a sophisticated data surveillance system that collects, analyzes, and reports healthcare-associated infection data. Our expert counterparts at the CDC and NHSN are indispensable in their expertise and understanding of the nuances and intricacies of validating and processing these consequential data.

The NHSN system works very well, and for my colleagues and me it seems natural for the CDC to build upon and expand the standardized and validated NHSN system to handle the COVID–19 surveillance data. The NHSN data reporting is largely automated, minimizing the burden on healthcare facilities to collect and report the data. It therefore was a shock when hospitals were abruptly informed in mid-July that they had to stop using NHSN for COVID–19 data reporting and instead use the TeleTracking system, a new system which was not automated and which was un-

familiar. The abrupt transition was made without working with hospitals, associations, or the electronic medical record vendors to automate the data reporting process.

Within 48 hours, all healthcare facilities had to scramble to manually report the data elements into the new system, find new data that had previously not been required, and create new workflow processes. This created chaos and confusion and diverted critical resources to accomplish the new reporting requirements. All of this occurred under a cloud of fear that critical Federal support could be withheld if hospitals failed to meet these new requirements.

Although the transition took place several weeks ago, chaos persists, and multiple changes to the system continue to occur. The data in the new system are not validated by CDC experts prior to being used to inform decisions made by the Coronavirus Task Force and HHS officials. Data irregularities and inconsistencies have been detected in the publicly reported data. My colleagues and I have concerns over the accuracy of the data that is being used for decisionmaking at the Federal and State levels.

I am here today to share the Society for Healthcare Epidemiology of America's colleagues and my experiences and to ask for your help to ensure that our country, our hospitals, our researchers, and the public have access to accurate, timely, and transparent data to help guide our COVID–19 response.

Thank you, and I look forward to your questions.

[The prepared statement of Dr. Maragakis follows:]

Testimony of Lisa L. Maragakis, MD, MPH,

On behalf of

The Society for Healthcare Epidemiology of America

House Science, Space, and Technology – Subcommittee on Oversight and Investigations

September 23, 2020

Good morning Chairman Foster, Ranking Member Norman, and members of the committee. Thank you for the opportunity to appear before you to discuss the experiences of experts in infection prevention and control across the United States who are on the front lines of the pandemic response, leading hospitals and health systems in their efforts to accurately and effectively report and utilize COVID-19 data.

I am Dr. Lisa Maragakis and I serve as the Senior Director of Infection Prevention for the Johns Hopkins Health System. Today, in my testimony, I represent the members of the Society for Healthcare Epidemiology of America, the professional society of experts in infection prevention. Our members work tirelessly to protect patients by detecting and preventing healthcare-associated infections and combating the threat of antibiotic-resistant organisms. Having access to accurate, timely, and transparent data from a variety of sources is vital to our infection prevention work. Accurate data helps us detect infectious disease transmission in healthcare settings, understand the effectiveness of infection prevention interventions, and devise innovative solutions to prevent infectious disease transmission.

Our members serve a critical role on the frontlines of the COVID-19 pandemic response by collecting, analyzing, and utilizing data to inform critical decisions about policies, procedures, and hospital resource allocation to keep healthcare personnel, patients, and our communities safe. Healthcare epidemiologists and infection preventionists are highly skilled in utilizing data to detect and respond to infectious disease threats. Epidemiologists, public officials and career staff scientists share the common goal of wanting to make sure accurate and timely information gets into the right hands at the right time for evidence-based, strategic decision-making.

For decades, our experts have worked closely with and relied upon experts at the Centers for Disease Control and Prevention's National Healthcare Safety Network, known as NHSN. This is a sophisticated data surveillance system that collects, analyzes, and reports healthcare-associated infection data. Our expert counterparts at the CDC and NHSN are indispensable in their expertise and understanding of the nuances and intricacies of validating and processing these consequential data.

The NHSN system works very well and, for my colleagues and me, it seemed natural for the CDC to build upon and expand the standardized and validated NHSN system to handle COVID-19 surveillance data. The NHSN data reporting was largely automated, minimizing the burden on healthcare facilities to collect and report the data. It therefore came as a shock when hospitals were abruptly informed in mid-July that they had to stop using NHSN for COVID-19 data reporting and instead utilize the Teletracking System, a new data collection system that was not automated and which was wholly unfamiliar.

The abrupt transition was made without working with hospitals, associations, or the electronic medical record vendors to automate the data reporting process. Within 48 hours, all healthcare facilities had to scramble to manually report the COVID-19 data elements into the new system, find new data that had previously not been required, and create new workflow processes to accommodate the reporting. This created immediate chaos and confusion, and diverted critical resources to accomplish the new reporting requirements. All of this occurred under a cloud of fear that critical federal support could be withheld if hospitals failed to meet the new requirements. Although the transition took place several weeks ago, this chaos persists and multiple changes continue to occur.

The data in the new system are not validated by CDC experts prior to being used to inform decisions made by the Coronavirus Task Force and HHS officials. Data irregularities and inconsistencies have been detected in the publicly reported data. My colleagues and I have concerns over the accuracy of the data that is being used for decision making at the federal and state levels. I am here today to share SHEA colleagues' and my experiences and to ask for your help to ensure that our country, our hospitals, researchers, and the public has access to accurate, timely, and transparent data to help guide our COVID-19 response.

Thank you. I look forward to your questions.

Lisa Maragakis, M.D., M.P.H., FSHEA, FIDSA is an associate professor of medicine and epidemiology at Johns Hopkins University School of Medicine and the Johns Hopkins Bloomberg School of Public Health. Dr. Maragakis is the Senior Director of Infection Prevention, at The Johns Hopkins Health System and the Hospital Epidemiologist for The Johns Hopkins Hospital. In these roles, she is responsible for the conceptualization, planning, implementation, and development of the Johns Hopkins Health System's infection control and prevention program. Her research interests are the epidemiology, prevention and control of healthcare-acquired infections and antimicrobial-resistant gram-negative bacilli. Dr. Maragakis serves as the Executive Director of the Johns Hopkins Hospital Biocontainment Unit and as Incident Commander for the Johns Hopkins Medicine COVID-19 response. She also serves as the IDSA Co-Chair for the 2014 and 2020 Updates of the Compendium of Strategies to Prevent Healthcare-Associated Infections, and as the Co-Chair of the Centers for Disease Control and Prevention's Healthcare Infection Control Practices Advisory Committee (HICPAC).

Chairman FOSTER. And thank you for that exquisitely timed oral presentation.

The—after Dr. Maragakis is Mr. Roy for 5 minutes.

TESTIMONY OF MR. AVIK ROY, PRESIDENT, FOUNDATION FOR RESEARCH ON EQUAL OPPORTUNITY

Mr. ROY. Chairman Foster, Mr. Norman, Members of the Investigations and Oversight Committee—Subcommittee, it's good to see many of you again, and thanks for inviting me here today.

As you mentioned, Mr. Chairman, the Foundation for Research on Equal Opportunity or FREOPP for short is a nonpartisan think tank that focuses exclusively on ideas that can improve the lives of Americans on the bottom half of the economic ladder. I welcome the opportunity to discuss how better data collection, reporting, and analysis can help all Americans weather this pandemic.

My written statement contains a more detailed discussion of this topic, but in my oral remarks, I'm going to focus on three subjects. First, I'll discuss how poor data reporting led to needless deaths of vulnerable seniors in our nursing homes and assisted living facilities. Second, I'll discuss a critical flaw in the way that we are reporting and interpreting coronavirus PCR (polymerise chain reaction) testing data. Third, I'll discuss the value of real-time data aggregation and analysis in solving these two problems and also in distributing potentially lifesaving medications to severely ill COVID patients.

Many of you are familiar with our research on the tragedy taking place in our nursing homes and assisted living facilities. Zero-point-six percent of Americans live in long-term care facilities, and yet within this 0.6 percent of the population lies 42 percent of all deaths from the novel coronavirus, 42 percent. A major contributor to this problem, as Mr. Norman mentioned, has been a lack of consistent data on long-term care infections and mortality.

In the spring, New York and other States ordered nursing homes to accept patients being discharged from hospitals with active COVID infections. At the time that these orders were issued, New York wasn't even collecting data on COVID deaths in nursing homes. Today, the State systematically undercounts its nursing home deaths in ways that make it harder to protect those who remain. CMS (Centers for Medicare & Medicaid Services) now requires nursing homes to report COVID fatalities directly to them, but if hard-hit States in the spring had collected this data in real-time, we could've delivered more PPE and testing supplies to long-term care facilities in need.

A second very large problem was recently identified by Apoorva Mandavilli of the *New York Times* relating to the way in which we're administering and reporting PCR test results for SARS-CoV–2, the novel coronavirus. PCR is in theory the most accurate test that we have for identifying people with active viral infections, but as I detail in my written testimony, it turns out that many laboratories have been overamplifying PCR test samples by a factor of as much as 1,000. The experts interviewed by Mandavilli were shocked to learn of this, and many said that over half of the positive PCR test results in their regions were likely to be false positives based on this information.

This is no mere technical detail because many States and school districts are using test positivity rates, case counts, and case-based forecasts to determine whether or not to reopen schools and their economies. It is essential for PCR lab companies to immediately begin including amplification data in the form of CT (cycle threshold) values when reporting a positive result.

The good news is that public health officials are beginning to gain the capabilities to better analyze nursing home data, PCR test results, and many other types of information essential to reducing the spread of COVID–19. One of these new capabilities is HHS Protect. HHS Protect is helping the government reduce—distribute remdesivir, the FDA (Food and Drug Administration)-approved drug that has shown signs of reducing mortality in hospitalized COVID patients. Without detailed real-time information from all U.S. hospitals on COVID–19 patients, it wouldn't be possible for authorities to distribute limited supplies of remdesivir to patients who can most benefit from its use.

The CDC chose to help build HHS Protect precisely because it's traditional decades-old system, the National Healthcare Safety Network, would have taken months to be upgraded to the same level. Dr. Redfield has been vocal in his—in espousing the value of this new system, and I refer you to his remarks that I've quoted in my written testimony.

The transition to HHS Protect has had understandable challenges. It's a bit like changing an airplane's engine in midflight. And the concerns raised by my colleagues today regarding disruption and trust are important ones to address so that Americans can have full confidence in the new system. But HHS Protect does have significant benefits. It's dynamic approach to data aggregation will enable public health authorities to analyze detailed PCR testing data so we can better understand whether or not patients with very high CT values are at risk for illness or transmission. And CDC Director Redfield has said that the availability of HHS Protect will free up NHSN personnel to apply greater focus on protecting vulnerable seniors in nursing homes. As I noted earlier, nearly half of all deaths in the United States from COVID–19 have taken place in long-term care facilities.

There's much more to say, let me stop there. I look forward to our discussion today. Thank you very much.

[The prepared statement of Mr. Roy follows:]

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TESTIMONY BEFORE THE UNITED STATES CONGRESS

House Science, Space, & Technology Committee
Subcommittee on Investigations & Oversight

DATA FOR DECISION-MAKING

Responsible Management of Data During COVID-19 and Beyond

AVIK S. A. ROY

President, The Foundation for Research on Equal Opportunity

September 23, 2020

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INTRODUCTION

The performance of U.S. public health infrastructure during the COVID-19 pandemic has been, in large part, a problem of data. Gaps in the collection, reporting, and analysis of data have driven many of the critical policymaking challenges faced at the federal, state, and local levels.

- ***Long-term care facilities.*** 42% of all U.S. deaths from COVID-19 have taken place in long-term care facilities, such as nursing homes and assisted living facilities, that house 0.6% of the U.S. population.[1] However, as recently as May, 11 states were not reporting long-term care deaths as a distinct category.[2] Reporting of this data only improved after the Centers for Medicare & Medicaid Services began requiring that nursing homes report such deaths directly to CMS.
- ***Misleading data from coronavirus PCR testing.*** The most reliable method of detecting an active SARS-CoV-2 infection (i.e., a "case") is through amplification of coronaviral RNA in a sample taken from a nasal or throat swab using the *reverse transcriptase polymerase chain reaction* method (RT-PCR). There is considerable evidence that misuse and/or misinterpretation of RT-PCR test results has led policymakers to misapprehend COVID-19 case data and thereby to enact overly aggressive economic restrictions.[3]
- ***Delivering potentially life-saving treatments to critically ill patients.*** In May, remdesivir was approved by the FDA for emergency use after clinical trials showed that the drug reduced mortality in hospitalized COVID-19 patients. Antiquated data systems at the CDC had made it difficult to route supplies of the drug to regions facing spikes in hospitalized patients, limiting patients' ability to benefit from this new treatment. Earlier in the pandemic, similar problems had made it difficult to route supplies of personal protective equipment and ventilators to facilities in need.

Congress has been trying to upgrade America's public health surveillance infrastructure for more than a decade, with limited results. Fortunately, we are finally seeing progress on multiple fronts, and more progress will be possible as the pandemic subsides.

LTC FACILITIES: 42% OF COVID-19 DEATHS, BUT 0.6% OF THE POPULATION

The most underappreciated aspect of the novel coronavirus pandemic is its effect on a specific population of Americans: those living in nursing homes and assisted living facilities.

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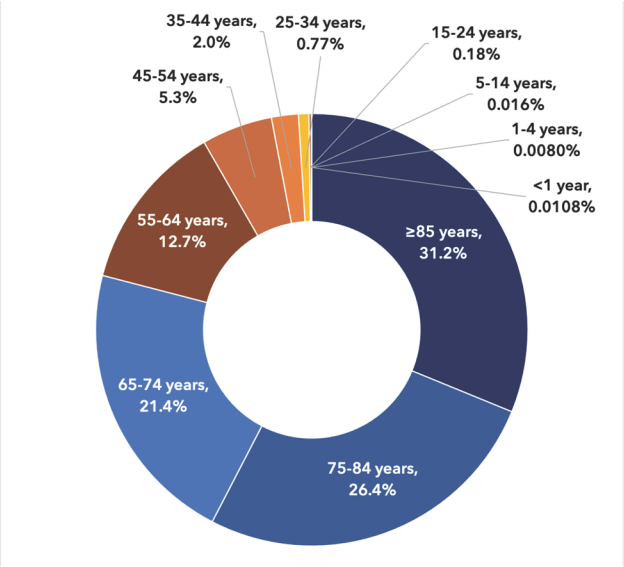
[1] G. Girvan and A. Roy, Nursing Homes & Assisted Living Facilities Account for 42% of COVID-19 Deaths. The Foundation for Research on Equal Opportunity. 2020 May 7: https://freopp.org/the-covid-19-nursing-home-crisis-by-the-numbers-3a47433c3f70?source=collection_home---1------0----------; accessed September 21, 2020.
[2] A. Roy, The Most Important Coronavirus Statistic: 42% of U.S. Deaths Are From 0.6% Of The Population. *Forbes*. 2020 May 26: https://www.forbes.com/sites/theapothecary/2020/05/26/nursing-homes-assisted-living-facilities-0-6-of-the-u-s-population-43-of-u-s-covid-19-deaths/#232a01f074cd; accessed September 21, 2020.
[3] A. Mandavilli, Your Coronavirus Test Is Positive. Maybe It Shouldn't Be. *The New York Times.* 2020 Aug 29: https://www.nytimes.com/2020/08/29/health/coronavirus-testing.html; accessed September 21, 2020.

The disease caused by SARS-CoV-2 affects the elderly far more severely, on average, than younger individuals. 79% of U.S. deaths from COVID-19 have occurred in individuals aged 65 and over, whereas 1% have occurred among those under 35. Among those who are elderly, deaths are concentrated even further among those living in long term care facilities.

Figure 1. Share of COVID-19 Fatalities by Age Bracket



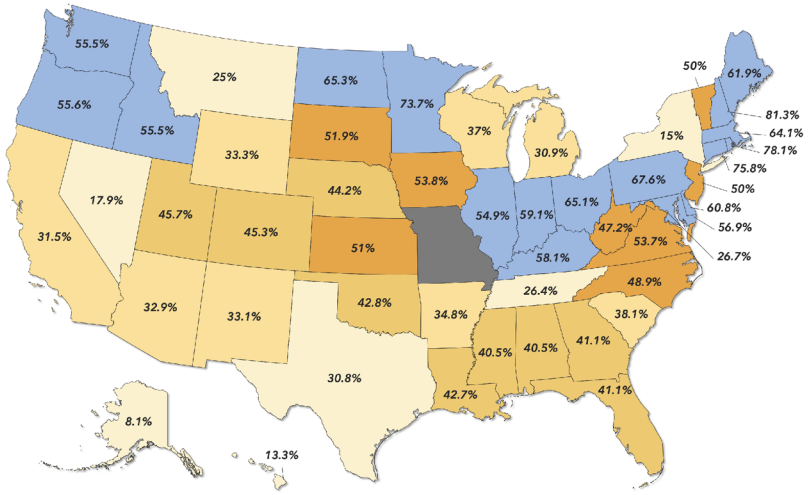
79% of U.S. COVID-19 deaths have occurred in people over 65. Those under 35 years of age represent 1 percent of deaths. *(Sources: CDC, FREOPP analysis)*

Nursing homes serve disproportionately poor individuals, with a large number of Medicaid enrollees. Vulnerable seniors residing in such long-term care facilities represent 42 percent of U.S. COVID-19 fatalities, while residents of such facilities only account for 0.6 percent of the total U.S. population.[4]

[4] G. Girvan and A. Roy, Nursing Homes & Assisted Living Facilities Account for 42% of COVID-19 Deaths. The Foundation for Research on Equal Opportunity. 2020 May 7: https://freopp.org/the-covid-19-nursing-home-crisis-by-the-numbers-3a47433c3f70?source=collection_home---1------0----------; accessed September 21, 2020.

In part this is due to disastrous decisions taken by some state governors to force nursing homes to accept COVID-infected patients who had been discharged from a hospital, including New York, New Jersey, and Michigan.[5] This catastrophic policy helped spread COVID-19 in long-term care facilities, leading to needless deaths and additional hospitalizations that we then asked our health care personnel to take on.

Figure 2. COVID-19 Deaths in Long-Term Care Facilities as a Share of Total COVID-19 Deaths (as of August 31, 2020)



0.6% of Americans live in long-term care facilities that account for 42% of all COVID-19 deaths. In some states, this tragedy was compounded by policies that forced nursing homes to accept patients infected with the novel coronavirus SARS-CoV-2. *(Source: G. Girvan and A. Roy, FREOPP.org)*

Importantly, these policy mistakes were driven by poor data. In the spring, too many policymakers were unaware of the fact that residents of long-term care facilities were especially vulnerable to COVID-19, and did not take adequate precautions to limit the spread of the coronavirus in these facilities. For example, New York only began to track

[5] A. Roy, The Most Important Coronavirus Statistic: 42% of U.S. Deaths Are From 0.6% Of The Population. *Forbes*. 2020 May 26: https://www.forbes.com/sites/theapothecary/2020/05/26/nursing-homes-assisted-living-facilities-0-6-of-the-u-s-population-43-of-u-s-covid-19-deaths/#232a01f074cd; accessed September 21, 2020.

nursing home deaths in mid-April. Michigan only began reporting such deaths in mid-May. These states and others should have done more to route testing supplies and personal protective equipment to LTC facilities early on, and restrict visitation from relatives in affected communities.

Some states continue to produce misleading data regarding nursing home cases and fatalities. For example, New York counts deaths of nursing home residents that occur in a hospital as hospital deaths, not as nursing home deaths, resulting in a significant undercount of the severity of the pandemic in long-term care facilities.[6]

MISLEADING DATA FROM COVID-19 PCR TESTING

There are three principal categories of COVID-19 tests available in the U.S. Antibody tests, sometimes called serology tests, detect the presence of anti-SARS-CoV-2 antibodies in a patient's serum, indicating that a patient has likely been infected by the coronavirus in the recent past. Antigen tests detect the presence of certain viral proteins in a patient sample, indicating an active infection. RT-PCR tests detect the presence of viral genetic material in a patient sample, also indicating an active infection.

While we do not know how many tests of each type are being performed in the U.S.—itself an important gap in COVID-19 data—a critical problem has emerged with RT-PCR testing, which is considered to be the most accurate and reliable method for detection of an active infection.

An investigation by Apoorva Mandavilli of the *New York Times* found that a critical piece of data is missing from most PCR test results: the cycle threshold, or Ct, needed to detect SARS-CoV-2 RNA.[7]

RT-PCR works by amplifying a targeted sequence of viral RNA. Each cycle of amplification roughly doubles the amount of viral genetic material in a given sample. Hence, ten cycles of amplification yields a roughly 1,000-fold amplification ($2^{10} = 1{,}024$), and 20 cycles yields a roughly million-fold amplification. (The precise amount of amplification can vary based on a number of factors.)

Much like turning up the volume on a quiet musical recording, the amount of viral genetic material in a given sample is inversely proportional to the number of amplification cycles needed to detect it. That is: the more amplification required, the fewer copies of the virus are in the sample. Higher concentrations of viral particles in a patient's serum may correlate to more severe illness and/or a higher probability of viral transmission, though in the case of SARS-CoV-2 this is not well understood.

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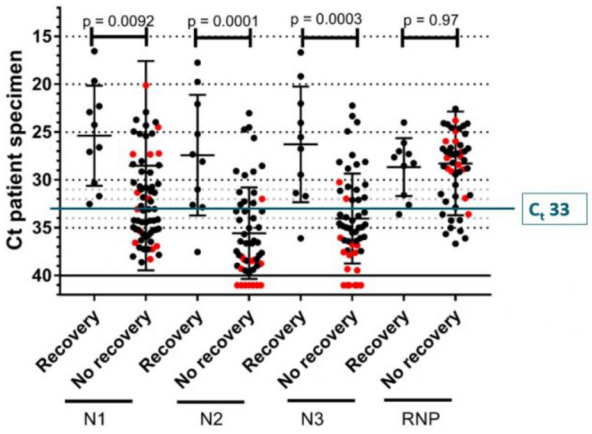
[6] J. Vielkind et al., In Worst-Hit Covid State, New York's Cuomo Called All the Shots. *The Wall Street Journal*. 2020 Sep 11: https://www.wsj.com/articles/cuomo-covid-new-york-coronavirus-de-blasio-shutdown-timing-11599836994; accessed September 21, 2020.

[7] A. Mandavilli, Your Coronavirus Test Is Positive. Maybe It Shouldn't Be. *The New York Times*. 2020 Aug 29: https://www.nytimes.com/2020/08/29/health/coronavirus-testing.html; accessed September 21, 2020.

Nonetheless, research by the U.S. Centers for Disease Control & Prevention found that above 33 cycles of amplification (i.e., a cycle threshold, or Ct, of 33), the probability of detecting viral particles that are capable of replicating is very low.[8]

Figure 3. PCR Cycle Thresholds Required to Detect Replication-Competent SARS-CoV-2



Replication-competent SARS-CoV-2 is rarely found above Ct 33. CDC data indicates that replication-competent coronavirus was recovered from patient samples where SARS-CoV-2 was detected in 33 amplification cycles or fewer. *(Source: CDC)*

Similarly, research from the Robert Koch Institute—the German equivalent of the CDC—found a "loss of cultivability in cell culture [of SARS-CoV-2] corresponded to a Ct value > 30."[9] The European Centre for Disease Prevention and Control warns that "a high Ct value (e.g. >35) could be due to…contamination of reagents" and such samples should be re-

[8] Centers for Disease Control & Prevention. Duration of Isolation and Precautions for Adults with COVID-19. 2020 Sep 10: https://www.cdc.gov/coronavirus/2019-ncov/hcp/duration-isolation.html; accessed September 21, 2020.
[9] Robert Koch Institute. Instructions for testing patients for infection with the novel coronavirus SARS-CoV-2. 2020 Aug 11: https://www.rki.de/DE/Content/InfAZ/N/Neuartiges_Coronavirus/Vorl_Testung_nCoV.html; accessed September 21, 2020.

tested with a "second gene target."[10] A meta-analysis of 25 studies published in the pre-print journal medRxiv found that "a cut-off of RT-PCR Ct > 30 was associated with non-infectious samples."[11]

While exact thresholds will vary by test, then, it appears that individuals for whom SARS-CoV-2 genetic material can only be detected above 30-35 cycles are unlikely to be at high risk of severe COVID-19 illness, and their test results may even be falsely positive in many cases.

In her investigation of U.S. PCR testing practices, however, the *New York Times*' Mandavilli found that it was most common for laboratories to deploy 40 cycles, with some labs amplifying for 37 cycles. "I'm shocked that people would think that 40 could represent a positive," said Juliet Morrison, a virologist at the University of California, Riverside. Morrison agreed that a Ct cutoff of 30-35 would be more reasonable.

At Mandavilli's request, New York state's Wadsworth Center examined 872 positive PCR test results it had obtained in July, after amplification for 40 cycles. "With a cutoff of 35," Mandavilli reported, "about 43 percent of those tests would no longer qualify as positive. About 63 percent would no longer be judged as positive if the cycles were limited to 30." In Minnesota, of 300 positive tests from a state lab, roughly half were positive at 30 cycles or fewer.[12]

Michael Mina, a Harvard epidemiologist, told Mandavilli that the cutoff should be 30 "or even less," and indicated that 85 to 90 percent of those testing positive in Massachusetts in July at 40 cycles would have been classified as negative at a cycle threshold of 30. "I would say that none of those people should be contact-traced, not one." Other experts interviewed by Mandavilli were "stunned" or "shocked" to learn of this information.

Obviously, if between 63 and 90 percent of PCR tests are falsely positive, due to a cycle threshold of 40 instead of 30, this has significant implications for the U.S. COVID-19 policy response.

For example, in California's four-tier system of economic restrictions, "many non-essential indoor businesses are closed" in counties with a test positivity rate of more than 8%, or with more than 7 new cases per 100,000 residents. As of September 21, 2020, the majority of California counties were above one or more of these thresholds.[13]

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[10] European Centre for Disease Prevention and Control. Questions and answers regarding laboratory topics on SARS-CoV-2. https://www.ecdc.europa.eu/en/all-topics-z/coronavirus/threats-and-outbreaks/covid-19/laboratory-support/questions; accessed September 21, 2020.

[11] T. Jefferson et al., Viral cultures for COVID-19 infectivity assessment–Systematic review. medRxiv. 2020 Sep 3: https://www.medrxiv.org/content/10.1101/2020.08.04.20167932v3; accessed September 21, 2020.

[12] J. Olson, Minnesota's broad COVID-19 testing under microscope. *Minneapolis Star-Tribune*. 2020 Sep 12: https://www.startribune.com/broad-covid-19-testing-under-microscope/572396572/; accessed September 21, 2020.

[13] State of California. Blueprint for a Safer Economy. 20 Sep 2020: https://covid19.ca.gov/safer-economy/; accessed September 21, 2020.

Economic restrictions are harmful enough on their own, and have a disproportionate impact on low-income and minority populations.[14] But they are doubly harmful if they are excessive or unwarranted, for example if positivity rates and case rates are being inflated by overamplification of RT-PCR samples. In California's case, a summer breakdown in the state's infectious disease monitoring system made it even more difficult to develop an effective policy response.[15]

DELIVERING LIFE-SAVING TREATMENT TO SERIOUSLY ILL COVID-19 PATIENTS

Remdesivir, an antiviral drug manufactured by Gilead Sciences, received Emergency Use Authorization from the FDA in May, after a double-blind, randomized, placebo-controlled trial indicated that hospitalized COVID-19 patients treated with remdesivir recovered four days earlier, on average, on treatment, with a 40% reduction in mortality.[16]

Gilead expects to be able to meet world demand for remdesivir later this year. However, at present, supply of the drug is subject to manufacturing constraints. Hence, directing scarce remdesivir inventory to facilities with high numbers of hospitalized COVID-19 patients is literally a matter of life or death.

The National Healthcare Safety Network, a surveillance system managed by the CDC, is the traditional source of such data. However, of the 6,200 hospitals in the U.S., only 3,000 regularly report COVID-19-related data through NHSN. This meant that NHSN lacked visibility into the remdesivir needs of more than half of all U.S. hospitals. In addition, NHSN ran on antiquated software and hardware that makes it difficult to modernize or upgrade.

Indeed, on four separate occasions this century, Congress has passed laws requiring HHS and CDC to modernize their situational awareness network capabilities. Until now, none of these statutes have been effective:

- In **2006**, Congress passed the Pandemic and All Hazards Preparedness Act (PAHPA), which required HHS to "establish [by 2008] 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." In 2010, the U.S. Government Accountability Office concluded that HHS

[14] A. Roy et al., *A New Strategy for Bringing People Back to Work During COVID-19*. The Foundation for Research on Equal Opportunity. 2020 Apr 14: https://freopp.org/a-new-strategy-for-bringing-people-back-to-work-during-covid-19-a912247f1ab5?source=collection_category---1------1----------; accessed September 21, 2020.
[15] A. Barry-Jester & A. Hart, California's Data Failures Stymie Efforts to Curb the Virus. Kaiser Health news. 2020 Aug 21: https://khn.org/news/californias-data-failures-stymie-efforts-to-curb-the-virus/; accessed September 21, 2020.
[16] J. Beigel et al., Remdesivir for the Treatment of COVID-19—Preliminary Report. New England Journal of Medicine. 2020 May 22: https://www.nejm.org/doi/full/10.1056/NEJMoa2007764; accessed September 21, 2020.

had not done so, nor had it even developed a "comprehensive strategic plan [as] required by PAHPA."[17]

- In **2013**, Congress passed the Pandemic and All Hazards Preparedness Reauthorization Act (PAHPRA), this time requiring HHS to submit a comprehensive strategy within 180 days. This did not happen. GAO in 2017 concluded that HHS had not taken "measurable steps for completing and tracking the status of the activities required by the law."[18]
- In **2019**, Congress passed the Pandemic and All-Hazards Preparedness and Advancing Innovation Act (PAHPAIA), building on the previous mandates. CDC has stated that it has not hired new biosurveillance specialists in accordance with the statute.[19]
- In **2020**, Congress passed the Coronavirus Aid, Relief, and Economic Security Act (CARES), which authorized $1 billion for modernizing public health data infrastructure, and required CDC to develop a plan by April 30. The plan has yet to be published.

The urgent necessity of improving surveillance data, especially from hospitals, first arose during supply constraints related to the distribution of PPE and ventilator equipment. In response to this problem, and in anticipation of supply challenges with emerging therapies, CDC and the U.S. Department of Health & Human Services established HHS Protect, which aggregates data from NHSN as well as from state public health agencies, private vendors, and hundreds of other data sources.

In July, CDC and HHS required that states the report data to HHS Protect do so through a system developed by TeleTracking, a private-sector vendor. The new system enabled public health officials to gain access to COVID-19 data from an additional 3,100 hospitals: 2,000 who report directly to HHS or to state governments; and 1,100 using TeleTracking.[20] As a result, HHS Protect now has access to COVID-19 data from over 90% of U.S. hospitals: a substantial improvement from the legacy NHSN system.

While some have claimed that HHS Protect "sidelines" the CDC and the NHSN, CDC Director Robert Redfield has directly contradicted those claims:

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[17] U.S. Government Accountability Office. Public Health Information Technology: Additional Strategic Planning Needed to Guide HHS's Efforts to Establish Electronic Situational Awareness Capabilities. 2010 Dec 17: https://www.gao.gov/products/gao-11-99; accessed September 21, 2020.

[18] U.S. Government Accountability Office. Public Health Information Technology: HHS Has Made Little Progress toward Implementing Enhanced Situational Awareness Network Capabilities. 2017 Sep 6: https://www.gao.gov/products/GAO-17-377; accessed September 21, 2020.

[19] J. White & D. Badger, In Order to Defeat COVID-19, the Federal Government Must Modernize Its Public Health Data. The Heritage Foundation. 2020 Sep 3: https://www.heritage.org/health-care-reform/report/order-defeat-covid-19-the-federal-government-must-modernize-its-public; accessed September 21, 2020.

[20] J. Arrieta, Prepared Remarks from HHS Media Call with CDC Director Redfield and CIO Arrieta on COVID-19 Data Collection. HHS Press Office. 2020 Jul 15: 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; accessed September 21, 2020.

> As many of you know, CDC operates a system called the National Health Safety Network. This is an important surveillance system in our nation's hospitals, which focuses on fighting antibiotic resistance.
>
> In April, HHS leaders, with input from CDC, created a new system, called HHS Protect, that allows us to combine data through systems like NHSN, as well as other public and private sources. The data reported from hospitals that went into HHS Protect either came through the NHSN, directly to HHS Protect from the states, or through a system called TeleTracking.
>
> What we have now asked is that, going forward, states provide data from hospitals directly through the TeleTracking system or directly to the HHS Protect system.
>
> First, this reduces the reporting burden—it reduces confusion and duplication of reporting. Streamlining reporting enables us to distribute scarce resources using the best possible data.
>
> 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.[21]

Importantly, the new reporting system requires hospitals to report more details regarding patient demographic and clinical characteristics, so that remdesivir can be sent to hospitals with patients who will benefit from treatment. "No one is taking access or data away from CDC," said Redfield. "The new infrastructure we have now actually provides our CDC team with easier access to a much broader variety of data sets than they would have without it. Approximately 1,000 CDC experts have, and continue to have access to the raw data collected in HHS Protect—in addition to thousands of other public health professionals across HHS."

THE BENEFITS OF A MODERNIZED COVID-19 DATA SYSTEM

Switching to a new reporting system in the middle of a pandemic is difficult to do, of course, and HHS and CDC have acknowledged that they could have done better in communicating the reporting change to hospitals. But the new system should save lives, and not just due to more effective delivery of remdesivir.

According to CDC Director Redfield, HHS Protect frees up personnel at NHSN "to increase its focus on…nursing home and long-term care facility reporting needs…streamlining the hospital reporting system allows NHSN to concentrate its COVID-19 activity on the high-priority area of protecting the vulnerable in nursing homes."

In addition, a modernized data aggregation system could compile detailed RT-PCR lab results, especially from large commercial lab companies that are able to report Ct values. A more systematic analysis of Ct values, through HHS Protect, should yield important insights into the true COVID-19 caseload, and discover any correlations between SARS-CoV-2 viral

[21] R. Redfield, Prepared Remarks from HHS Media Call with CDC Director Redfield and CIO Arrieta on COVID-19 Data Collection. HHS Press Office. 2020 Jul 15: 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; accessed September 21, 2020.

load, illness severity, and transmission. These insights could prove important in the treatment and management of COVID-19, and in reducing the spread of the coronavirus.

Avik S. A. Roy

President and Co-founder, The Foundation for Research on Equal Opportunity

Avik S. A. Roy co-founded The Foundation for Research on Equal Opportunity (FREOPP) in July of 2016. The non-partisan think tank researches policy that affects those below the average median income in the U.S. FREOPP has recently conducted studies on COVID-19 policy entitled "Reopening America's Schools and Colleges During COVID-19" and "A New Strategy for Bringing People Back to Work During COVID-19."

Avik has had a career in finance, journalism, and public policy. He worked as an analyst and portfolio manager at the investment firms Bain Capital and JPMorgan Chase before he left to found a healthcare-focused hedge fund. In early 2012, Roy founded Roy Healthcare Research, a health care policy research firm and worked as the principle.

His career in journalism began in 2009 with his blog *The Apothecary*, which focused on healthcare policy and the Affordable Care Act. In 2011 he became a senior fellow at the Manhattan Institute with a focus on health care policy. In 2013 he published his book *How Medicaid Fails the Poor*. Through the Manhattan Institute he authored a proposal for health care entitled *Transcending Obamacare: A Patient-Centered Plan for Near-Universal Coverage and Permanent Fiscal Solvency* and *The Case Against Obamacare*. He worked at Forbes as a contributor in 2010, an opinion editor in 2014, and since 2018 has been a policy editor. He has made appearances as a commentator on Fox News, Fox Business, MSNBC, CNBC, Bloomberg Television, PBS's Newshour, and HBO's Real Time with Bill Maher.

His political and policy career includes work on Romney for President in 2012 as part of the Health Care Policy Advisory Group. Avik helped formulate Governor Romney's national health reform plan and advised the campaign on other health care-related matters, including Medicare & Medicaid reform. Avik was a senior policy advisor for Perry for President in 2015. He led major policy initiatives on economic opportunity for all Americans, reforming Wall Street, and defeating Islamic jihad.

His current policy work, in addition to his role as president at FREOPP, includes membership of the board of advisors for both the National Institute for Health Care Management and at the Center for Advancing the American Dream. Additionally, Mr. Roy is a senior advisor for the working group on health care reform at the Bipartisan Policy Institute. Avik earned a B.S. in biology from MIT and attended the Yale University School of Medicine.

Chairman FOSTER. Thank you. And next is Ms. Hamilton for 5 minutes. And I think you—yes, there's a muting problem perhaps.

TESTIMONY OF MS. JANET HAMILTON, EXECUTIVE DIRECTOR, COUNCIL OF STATE AND TERRITORIAL EPIDEMIOLOGISTS

Ms. HAMILTON. Are you able to hear me now?

Chairman FOSTER. OK.

Ms. HAMILTON. OK. Chairman Foster, Ranking Member Norman, and Members of the Subcommittee, thank you for the privilege to appear before you today. I am Janet Hamilton, Executive Director of the Council of State and Territorial Epidemiologists. CSTE represents public health epidemiologists nationwide working on the front lines to respond to COVID–19.

Our hearing subject today is one of the most important issues we need to tackle as a country. After years of neglect, our public health data infrastructure is on crutches, antiquated, and in dire need of security upgrades. Sluggish paper records, phone calls, spreadsheets, and faxes, requiring data entry remain in widespread use and have significant consequences: delayed detection and response, lost time, lost opportunities, and lost lives.

COVID–19 has taken advantage of gaps in our current system. First, we do not have a seamless interoperable way for healthcare to communicate with public health. Our Nation needs electronic case reporting. It's that simple. We need to ensure that when providers see patients in any setting, patient demographics, clinical information, and test results for reportable conditions like COVID–19 are rapidly shared with State and local public health and then incorporated into CDC's National Notifiable Disease Surveillance System.

Second, we need an electronic lab test ordering process that supports the collection of information to launch a rapid public health response. The fax machine shouldn't be the standard of care. Imagine the time it takes a busy health department to sort through thousands of faxed records, decipher, and digitize them daily.

Third, nearly 1/3 of all emergency department visits are not reported to the National Syndrome Surveillance System.

And lastly, death certificates are sometimes filed on paper. Deaths surpassing 200,000 tragically tells just part of the human cost from COVID–19.

It takes weeks to uncover and link the death data with case, laboratory, and medical examiner data without which we cannot understand the racial and ethnic disparities exacerbated by COVID–19. The absence of information leaves us blind to the truth about the pandemic. State and local public health departments indicate initial COVID–19 lab reports are missing street address and phone number as much as 50 percent of the time. And data for race and ethnicity are missing as much as 85 percent of the time, despite that these data are already stored in electronic health records.

I have personally felt frustration and anguish and seen my colleagues suffer, too, when we want to provide answers to community members. Despite wanting to help, we can't because our public health data system arteries are clogged. How many cases of COVID–19 are there in my area? Where will the next hotspot be?

When can schools open safely? We can't answer these questions without data.

We have started to implement solutions, but it will take a coordinated, sustained approach between State and local public health, CDC, Congress, and the Federal Government, as well as our healthcare partners. We need to move now. We need to move fast. And most importantly, we need to do all of this with public health: CDC with their State partners leading.

CSTE is part of the data elemental to health campaign. Before COVID–19, we called on Congress to provide first-ever dedicated funding for public health data systems to build a 21st-century public health data superhighway. As I've outlined today, the coordinated systems for this infrastructure already exist. We do not have a science problem. We have a resource problem. With sustained resources, all jurisdictions could come online with the core systems, and CDC could build its own secure platform to receive electronic data from States. So far, a $550 million down payment has been allocated for the data modernization initiative at CDC. This funding is critical, but it cannot be a one-off. The Federal Government must commit to long-term, annual, base-budget funding to CDC.

To close, CDC, together with State and local public health officials, have led every public health response to date. In this response, we have seen inconsistent Federal and State coordination. State public health leaders must have direct regular access to Federal officials to help contain the virus in their regions. We cannot and should not make essential policy decisions without CDC and public health experts on the ground who fully understand the data-collection challenges and strengths.

Thank you for the opportunity to testify before the Subcommittee today.

[The prepared statement of Ms. Hamilton follows:]

Written Testimony
House Committee on Science, Space, and Technology
Subcommittee on Investigations and Oversight
Data for Decision-Making: Responsible Management of Data During COVID-19 and Beyond
September 23, 2020

Statement of Janet Hamilton, MPH
Executive Director, Council of State and Territorial Epidemiologists

Chairman Foster, Ranking Member Norman, and distinguished members of the Subcommittee, thank you for allowing me the privilege to appear before you today. I am Janet Hamilton, Executive Director of the Council of State and Territorial Epidemiologists (CSTE). I am an epidemiologist with over fifteen years of experience in public health, formerly serving in the Florida Department of Health where I oversaw disease surveillance programs, both the epidemiologic scientific content and the surveillance systems that support them. I now head CSTE, an organization of 56 member states and territories representing applied public health epidemiology that serves as the professional home for 2,000 applied public health epidemiologists or "disease detectives" nationwide. Like in other outbreaks, we are the epidemiologists in state, territorial, local, tribal health departments on the front lines of the COVID-19 response. CSTE and its members work tirelessly to respond to and protect the public's health, a role that has never been more important than it is today. Thank you for the opportunity to testify before the Subcommittee regarding "Data for Decision-Making: Responsible Management of Data During COVID-19 and Beyond," an issue of incredible importance to CSTE, our partners, and the American people.

COVID-19 has exposed deadly gaps in our nation's public health data infrastructure. Now more than ever it is critical for the Centers for Disease Control and Prevention (CDC) and state and

local health departments across the country to have a strong national public health surveillance system that detects and facilitates the immediate response to and containment of emerging health threats. Unfortunately, that is not the case today. The COVID-19 pandemic demonstrates many of the issues we face are due to a *consistent failure over many years* to invest in the public health infrastructure. Whether it's influenza, measles, pertussis, Ebola, dengue, Zika, lead, hepatitis A, human papillomavirus (HPV), wildfires, tornados, hurricanes, e-cigarette or vaping product use-associated lung injury (EVALI), or now COVID-19, public health threats are persistent and constantly evolving here at home and overseas. Effective prevention and efficient, timely responses rely on an interactive network of governmental public health agencies at the federal, state, territorial, local, tribal (STLT) levels working with health care providers and the public and private sector. Every day, this cooperative network saves lives by detecting and responding to COVID-19 and other health threats.

Existing gaps include:

- A lack of seamless interoperable data sharing to public health from health care and across public health;
- Absence of a robust process to order COVID-19 laboratory tests electronically that supports 'at the time of test order' collection of even the *minimal* information needed to initiate a rapid public health response;
- Laboratories are unfamiliar with electronic laboratory reporting and are faxing paper results instead of sending files in electronic machine-readable formats or are changing formats multiple times without communicating with the health department—leading to unusable files and test results;

- Nearly absent electronic case reporting to share data between health care and public health at the STLT;
- Emergency departments not participating in public health syndromic surveillance systems; and
- Death certificates not being filed electronically.

Months into this response, these gaps lead to slow, cumbersome and incomplete data exchanges, resulting in sluggish efforts to respond effectively with the speed and intensity the COVID-19 pandemic demands. The absence of information is a very dangerous thing. It leaves public health officials blind to the pandemic.

To respond successfully to COVID-19—or a future pandemic—we need a vastly improved data infrastructure that ensures information moves to public health at pace with the spread of disease. In a time when many industries have transitioned quickly to working digitally, the United States is operating an antiquated public health system that relies on *sluggish* paper records, phone calls, faxes, and spreadsheets that often require manual data entry. All of this has allowed the disease to outpace our response—the disease is moving faster than the data.

A robust, interoperable public health data system is the key to responding to any public health emergency, particularly a pandemic of the magnitude of COVID-19. State laws governing and requiring disease reporting and receipt of these data during a pandemic like COVID-19 is how state public health officials know where the virus is surging and who is most impacted and most at risk. Public health officials in your home states are asking the same questions you and your

constituents are asking. How many cases of COVID-19 are there in my area? Where will the next hotspot be? When can we open schools safely? Are there cases in my children's school? Are hospitalizations in children or pregnant women increasing? As some schools re-open, are there also increases in Multisystem Inflammatory Syndrome in Children (MIS-C)? Where are the types of places that people most likely to be exposed and then become infected? Are we starting to see cases of re-infection? Are there so many infections occurring in my community that activities are no longer safe? Your state public health officials need access to data to understand how the virus is progressing and to make the decisions necessary to contain it. In order for these questions to be answered, the data must flow from the health care setting (doctor's offices, laboratories, and outbreak settings) into public health at the STLT level. Disease detectives conduct interviews to learn detailed information about when and how people became infected and identify their contacts. Additionally, the reports are aggregated from *all* these settings, de-duplicated, de-identified and then passed onto CDC and federal partners for national policy setting. Data security is paramount to the infrastructure.

Tragically, many reports are missing valuable information, delayed or in many instances never made. For example, many jurisdictions indicate laboratory reports have three major problems:

1. Illegible, hand-written results—these often come from point of care testing locations using rapid tests. These tests have no infrastructure deployed with them to ensure the results can be reported electronically; some health departments report hiring more than 50 staff just to handle incoming data entry and decipher records, yet still have lags handling tens of thousands of reports daily.

2. Thousands of results that don't have enough information for the state/local health department to act upon—a name and a positive/negative result and that is all—no street address, county of residence, zip code, phone number, race or ethnicity.
3. Thousands of results from laboratories unfamiliar with reporting through structured electronic reporting formats, and changing and updating file types without communicating with public health, structures creating data mis-matchings and they can't be read or processed. (This is like putting the bank routing number in a different place, or reversing it with the account number—the machine cannot process the info and it errors out). Mismatched and duplicative data must be rapidly identified and corrected by public health. All of these facilities need support and training from the health department staff, and staff time to consult with facilities providing information to correct file submissions and mitigate further errors.

Jurisdictions report missing street address and phone number as much as 50% of the time, and data for race and ethnicity are missing as much as 80-85% of the time—despite state laws that require providers to report these data and require them to be stored in electronic health records. Because the nation's public health infrastructure is so fragmented and antiquated, even when health care providers already have the data stored and collected in electronic health records they cannot rapidly share these health data with public health. This environment leads to increased challenges on fatigued, exhausted providers to report—or delays and failures to report—and inefficiency and frustration on the part of patients, care providers and public health professionals.

In any outbreak, time matters—whether the issue is vaccine and prophylactic treatment following meningococcal exposure, which needs to be rapidly disseminated, or measles and COVID-19 cases who need to be isolated to prevent others from becoming infected, or where vaccine effectiveness to prevent pertussis needs to be evaluated for both children and adults, or where COVID-19 which threatens the lives of minorities in greater proportion and highlights longstanding racial health disparities—time matters—and data needs to be at the fingertips of public health. Further policy levers, similar to those implemented by the Centers for Medicare and Medicaid Services (CMS) to encourage providers to use electronic health records are needed now to incentivize the transmission of data from health care to public health in the form of an electronic case report. Electronic case reporting, or eCR generates information directly from the patient's electronic health record and with no additional clicks by providers, sends that information to public health with test results. Since EHRs include complete patient information entered by providers, it includes information not only about race and ethnicity, but pregnancy status, treatments, co-morbidities, and vaccination status—all critical information state/local public health departments need to gather when conducting case investigations to pass data onto CDC. Electronic case reporting is the transformation public health needs—and has been requesting for years.

Death certificates were one of the first sources of public health surveillance data. When we look at COVID-19 mortality data, every death certificate tells a story. COVID-19 mortality data when viewed collectively, uncover health disparities, inform policy and funding decisions, and improve outbreak and disaster response efforts. Sadly, in some states, death certificates are still filed on paper, and nationally it still takes as much as 1 – 8 weeks or more for death certificates

to be submitted to CDC for national aggregation. The estimated number of excess deaths alone, now over 200,000, tragically tells the story of the devastating impact of COVID-19 (https://www.cdc.gov/nchs/nvss/vsrr/covid19/excess_deaths.htm). But it can take weeks to uncover and link the death information with case data, laboratory data or medical examiner information in order to communicate meaningful information to policymakers, the media, the public, and providers who need answers to questions—where did the deaths occur and what populations are most vulnerable? What immediate steps can be taken to prevent more deaths based on today's data? Unfortunately, because of the lag in paper-based data systems and lags caused by the non-integration of key public health data systems, public health officials are hampered to provide fast, high-quality answers the public wants, needs, and expects in our technologically capable world.

As the nation's leading public health agency, CDC is charged with protecting the nation's health. CDC has been at the forefront of responding to every major public health crisis since its founding—including COVID-19. CDC's experience with data collection, analysis, and dissemination is an essential part of our nation's effective response to COVID-19. CSTE supports CDC's coordinated approach incorporating data providers and public health. It is adaptable and can accommodate new data elements, that meet important criteria including being assessed for feasibility and burden, and ensuring there is an actionable public health reason for collecting the data. The sudden change in hospital capacity reporting announced earlier this summer did not adhere to our guiding principle to coordinate across the response and to strengthen our public health infrastructure at all levels – STLT, CDC and data needs within HHS. Any further changes should be adequately vetted with STLT input to avoid confusion in

responding to a public health emergency that is managed in many aspects at the state level. It is not about the technology we are using; it is about the process and we must ensure that process includes public health rather than ignoring them. If we are going to implement new technology and new IT platforms, we should include public health and ensure the transition is done with input from STLT and CDC.

In our response to COVID-19 we have seen an unfortunate lack of engagement between federal and state officials. State and local public health officials have been key parts of every public health response to date serving on key task forces and work groups, in pre-decisional capacities, and most importantly, as part of the planning for future responses. Different levels of data are needed at different levels of government in this response. At the STLT, personally identifiable information is needed for accurate counting and de-duplication prior to passing this information onto the federal government. For example, in the case of point-of-care COVID-19 test results STLT public health need access to the identifiable results – to conduct case counting and de-duplication, case interviews, contact tracing etc., to identify where the tests were performed and if they were part of an outbreak, assess health disparities; the federal-level needs de-identified data in aggregate. State public health officials must have direct and regular access to federal officials to help effectively contain the virus in their regions and ensure that decisions to collect necessary data are informed by those who will use it across all levels of the response. We cannot (or should not) make essential policy decisions without input from experts on the ground to fully understand the data collection, aggregation and analyses gaps, challenges, or strengths.

An essential part of communication in a public health emergency are data and data transmission. Before COVID-19 public health data was a little known and little thought about challenge outside of the public health world. As evidenced by the topic of this hearing, data is finally being recognized outside public health as a keystone for public health, but unfortunately, our years of neglect for this essential infrastructure have left us debilitated during the COVID-19 pandemic.

Finally, our focus today is on COVID-19 data challenges, but as a public health professional who works across disciplines, I must reflect these public health data challenges are broad and systemic and hamper our public health responses beyond COVID-19 to other critical but non-infectious disease threats. When I reflect upon some of the recent public health emergencies, such as Zika, fungal meningitis, the opioid epidemic, and EVALI, one of the common critical stumbling blocks to rapid response has centered on data collection, data management, and data sharing. I fear that this will continue and worsen, unless investment in data infrastructure occurs across all of public health. Data sharing with public health is slow and cumbersome but they are also vulnerable. With sophisticated cybersecurity threats, it is critical that public health systems are equipped to prevent and respond to cyberattacks. Health care providers are required to report diseases and conditions to public health departments at STLT. These health records contain sensitive personal information—required to be reported and protected by state laws—and they demand significant care in handling to protect the privacy and safety of patients, particularly since such systems are frequently the target of hackers.

Fortunately, there are solutions and we can (and have) started to implement them, but this will take a coordinated, sustained approach between state and local public health, the CDC, Congress

and the federal government. We need to move now, we need to move fast, and most importantly, we need to do all of this with public health in the lead.

CSTE and our partners—the Association for Public Health Laboratories (APHL), the National Association for Public Health Statistics and Information System (NAPHSIS), and the Healthcare Information and Management Systems Society (HIMSS)—together with more than 90 other institutions representing patients and consumers, public health professionals, health care providers, and health systems have been working to increase funding to build a public health data super highway of the 21st Century to speed the seamless exchange of data for all diseases and conditions, to *predict* and *prevent* public health threats before they occur and to allow rapid response when they do occur. This interstate system of systems will seamlessly and securely collect sensitive data about diseases and conditions from health care providers and report it automatically to public health departments, link it to other key data—including birth and death records and immunization registries—and where required to be reported nationally, share that data seamlessly and securely with CDC.

We started our work *before* COVID-19, and the system we build must live beyond COVID-19, but we are faced with an emergency to which we must respond now. For COVID-19 and beyond it is critical that we transform our existing public health data infrastructure. There are five key pillars necessary to transform the nation's public health surveillance system—some of them are already under way, some of them are already showing progress, each of them builds on existing systems and platforms, but ALL of them are essential to a completely interoperable public health data system. Each of these pillars will play a key role in moving the United States from an

outdated and burdensome system to a 21st Century public health data system that provides accurate, instantaneous data. The five key pillars are:

1. ***The National Notifiable Disease Surveillance System (NNDSS)***, which collects vital individual case investigation data at state, local, tribal, and territorial public health agencies from hospitals, physicians, and labs, then sends this data to CDC to create a national understanding of disease burden. This information is used to respond to public health outbreaks and is the first line of health security defense.
2. ***Electronic Case Reporting (eCR)***, which is the automatic, seamless submission of disease reports directly from electronic health records at clinical care organizations to state, local, tribal, and territorial health departments. eCR dramatically improves disease/condition reporting and reduces physician burden in fulfilling their legal responsibility to report, which leads to early implementation of public health interventions and limits further spread of infectious agents.
3. ***Syndromic Surveillance***, which provides near real-time data on every hospital emergency department visit for hourly detection and continuous monitoring of community health incidents plus the impact of natural disasters (including hurricanes), flu pandemics, and opioid overdoses. It gives public health professionals the ability to monitor the pulse of the community and identify health threats as they emerge.
4. ***The Electronic Vital Records System***, which is a national system of 57 vital records jurisdictions that provide secure electronic collection of birth and death data from hospitals, funeral homes, physicians, and medical examiners. It allows for timely and accurate reporting of birth outcomes and causes of death, which serve to monitor and

respond to public health crises as they arise in communities, including reducing preventable deaths and infant and maternal mortality rates.

5. ***Laboratory Information Systems***, which are the backbone of how laboratory data is collected, managed and shared to inform public health decision-making. The Laboratory Response Network (LRN) is comprised of specialized laboratories that can respond to biological/chemical threats and other public health emergencies with advanced testing capabilities. Electronic Laboratory Reporting (ELR) is the electronic reporting of laboratory results from *private* and public labs to disease detectives and investigators in state, local, tribal, and territorial public health departments.

For further information about the need to modernize the public health data systems and workforce, please see CSTE's report, "Driving Public Health in the Fast Lane: The Urgent Need for a 21st Century Data Superhighway" at http://resources.cste.org/data-superhighway/mobile/index.html.

We are not out to reinvent the wheel. The core data systems for this infrastructure already exist, have demonstrated value, and are used to varying degrees in state and local health departments. We do not have a science problem; we have a resource problem. With the proper, sustained resources all jurisdictions could come online with the core systems and CDC could build its own secure platform to receive electronic data from the states.

To achieve a modernized public health data infrastructure requires significant federal investment and a commitment by Congress to see the project through in the long term. CSTE and our

partners have been advocating for several years now for funding for these pillars—both for regular, sustained annual funding at the CDC as well as supplemental funding to help us move more quickly during the COVID-19 response.

Between Fiscal Year 2020 funding and the Coronavirus Aid Relief and Economic Security (CARES) Act, Congress has provided $550 million for the Data Modernization Initiative (DMI) at the CDC. We are grateful for this foundational investment that will allow the agency to begin to allocate funding towards the five pillars and to states and local health departments to make initial upgrades to their systems. This existing funding is critical, but I must emphasize that it cannot be a one-time investment. States will simply not be able to adopt fully upgraded public health data systems with just one injection of federal funds. For the current system to truly evolve, the federal government must commit to long-term funding to complete essential system upgrades both federally and at the state and local level and to maintain these upgrades annually as technology improves. The Data: Elemental to Health campaign commits to continued advocacy for robust, sustained funding to complete and sustain the DMI well into the future and Congress must do the same.

Equally important: we must ensure that federal funding allocated to DMI is spent on DMI. While it is true that certain improvements are urgent and some funds must be spent on issues related to COVID-19, we understand Congress' intent in providing $550 million was to support long-term public health data improvements. CDC must use this money both to make immediate investments to upgrade the systems necessary to bring the pandemic to an end **and** to deliver the

necessary funding to the five pillars and facilitate a true transformation of America's public health data system.

Both chambers of Congress have recognized the importance of completing the DMI and, separately, have passed legislation authorizing the project. Language included in the House-passed Health and Economic Recover Omnibus Emergency Solutions (HEROES) Act would authorize the essential comprehensive improvements to our public health data systems that I have discussed today. The Senate passed similar language as part of the Lower Health Care Costs Act in 2019.

Over the past six months we have witnessed the failures of an outdated public health data infrastructure. We need to act now to make changes that will help us emerge from the ongoing COVID-19 pandemic and we need to make certain that we prepared for the next threat we face. COVID-19 will not be our last public health crisis.

Again, thank you for the opportunity to testify before the Subcommittee today.

Janet Hamilton, MPH

Executive Director, Council of State and Territorial Epidemiologists

Janet Hamilton, MPH, assumed the role of CSTE's Executive Director in April 2020. As Executive Director, Janet works directly with the Executive Board and senior management team to lead and shape CSTE's mission of advancing the field of applied public health epidemiology in the U.S. Janet received her Master of Public Health in Epidemiology from the University of Michigan and is a graduate of the American Medical Informatics Association (AMIA) 10 X 10 program. She was a member of CSTE's Executive Board, serving from 2011 to 2015 as the Surveillance and Informatics Steering Committee Chair and was CSTE President from 2017-2018.

Janet is an epidemiologist with over 15 years of public health work experience at the national, state, local, tribal, and territorial levels overseeing policy development and liaising with CSTE members and strategic partners. She started her career as fellow in the Florida-based Epidemic Intelligence Service with the Florida Department of Health in 2003 where she focused primarily on conducting outbreak investigations. Prior to her selection as Executive Director, Janet served as CSTE's Senior Director of Science and Policy, leading organizational efforts to strategically combine applied epidemiology science with policy efforts to advance public health and applied epidemiologic public health practice. One focus of her work at CSTE has been to lead public health surveillance data modernization through the "Data: Elemental to Health" campaign, which seeks to secure $1 billion in federal funding over 10 years to support this foundational need.

In her previous role with the Florida Department of Health, Janet played leadership roles in Florida's response to 2009 H1N1, MERS-CoV, Zika, fungal meningitis, Deep Water Horizon Gulf oil spill, 11 major hurricanes including the 2004 season where the state was impacted by four major storms, the threat of imported Ebola from West Africa in 2014 and other outbreaks and public health events. She oversaw

both the design, development and maintenance of the disease/condition surveillance systems themselves, as well as the rules and regulations to support data collection efforts. Additionally, she oversaw Meaningful Use activities for the Florida Department of Health in the areas of electronic laboratory reporting and syndromic surveillance. Her efforts developing and running the Florida Department of Health's infectious disease surveillance systems made Florida a leader in innovation in both reportable disease and syndromic surveillance.

Janet's work has been recognized in 2011 with the receipt of the Healthcare Information and Management Systems Society (HIMSS) Davies Award for positively impacting population health by optimizing health information technology. She has also been actively involved in numerous national committees to advance public health surveillance. At CSTE, she continues her work to support effective public health surveillance and sound epidemiologic practice through training, capacity development, and peer consultation.

Chairman FOSTER. Thank you. And at this point we will now begin our first round of questions, so the Chair will now recognize himself for 5 minutes.

Dr. Lee, we know that surveillance science is more complex than simply collecting data and posting it on a website. The data often needs to be cleaned and validated for accuracy, and anomalous—anomalies must be tracked down, errors corrected. Epidemiologists then search for trends and meaning behind the raw numbers. They translate their findings into actionable advice for decisionmakers. And I'm very concerned that we've lost a lot of institutional knowledge by requiring hospitals to report critical data to TeleTracking directly instead of through the CDC.

So, Dr. Lee, in your opinion, does HHS have the in-house expertise to handle the data collected by TeleTracking and use it to make decisions about resource allocations? And perhaps if you could also give some examples of the sort of, you know, data cleaning and error correction that have to take place.

Dr. LEE. Thank you, Mr. Chairman, for that great question. As I mentioned in my testimony, both written and oral, my—you know, I do not think that, you know, there is expertise anywhere except at CDC in terms of the complex set of activities that it takes to actually develop and implement a system. There is expertise, but it's—it lies squarely at CDC. As I said, there's hundreds of years of experience there.

I think the point really is to recognize that developing a system that measures sentinel events requires careful thought. It requires an understanding of science and epidemiology. It requires a sense of what specific data will be needed for decisionmaking. So for COVID–19, for example, we've made efforts to collect data on a number of events or signals. We monitor the number of tests to assess how well we're actually measuring the impact of the disease. We use the number of proportion of positive tests to measure the current spread of infection. We use the number of hospitalizations to say something about the number and characteristics of severe cases. We also collect data on the number of deaths as an indicator of both delayed care and severity of infection but also on the effectiveness and equitable distribution of treatment.

So these kinds of decisions that—about which events to include in a surveillance system are critical because they help us describe what's happening. And, you know, we have to make sure that when we have the data, we are deciding how to appropriate and allocate resources to decide when and where to deliver public health interventions, so—and also to evaluate when these interventions are useful and have helped us to combat outbreaks.

So these important decisions about the design of a system should be made by public health surveillance scientists with the training and experience in data management, epidemiology, statistical analyses and interpretations, as well as a good handle on how to communicate risky—risk and—risk data and complex data and, you know, data that are not complete—incomplete data. And since——

Chairman FOSTER. Well, thank you. I should—I have to——

Dr. LEE. Sure.

Chairman FOSTER [continuing]. Get into other questions here.

Dr. LEE. OK.

Chairman FOSTER. You know, I'm concerned about, you know, the way that the TeleTracking requirement was implemented. You know, this is—Dr. Maragakis mentioned, it was actually more than a fear that payments would be suspended. Secretary Azar mentioned—emailed hospitals on April 21st and said please be aware that submitting data through TeleTracking is a prerequisite to payment, which is not what you want to hear when you—you're, you know, trying to deal with an ongoing emergency and then you have to divert personnel to learn a whole new system and work through its deficiencies.

And so do you know—you know, can you comment, Dr. Maragakis, about some—how hospitals may have been overwhelmed and under-resourced, you know, in trying to respond to this when that requirement came down?

Dr. MARAGAKIS. Yes, thank you, Mr. Chairman. It was extremely disruptive. The nature of the transition between systems really led to what was largely a manual process, whereas previously we had automated ways that had been constructed to extract the data from electronic medical systems and to report these data. As I mentioned in my opening testimony, manual processes had to be implemented. Many new data elements were required. The reporting frequency was escalated to daily. And so this has been a very large burden on hospitals and healthcare facilities across the Nation, and many are under-resourced to meet that challenge.

Chairman FOSTER. Thank you. My time is expired, and I now recognize the Ranking Member, Mr. Norman, for five minutes.

Mr. NORMAN. Thank you, Chairman Foster.

Mr. Roy, in your testimony you identified that 42 percent of all U.S. deaths from COVID–19 have occurred in long-term facilities. Namely, New York City has been publicized as one of the worst for the deaths. You go on to explain how some State Governors made disastrous decisions to force long-term facilities to accept COVID–19-infected patients due to poor data on how the virus disproportionately affects the elderly. You then indicate that some States are also producing misleading data on the number of deaths occurring in these facilities. In your opinion, how did we allow inaccurate data reporting to occur, and how can we ensure better reporting in the future?

Mr. ROY. Thank you, Mr. Norman. So the big problem here was that at the very beginning of the pandemic when we did not know very much about SARS-CoV–2, the novel coronavirus, so there's obviously a lot we still don't know, but in the beginning we knew even less. And a lot of the playbooks that the policymakers started using at the State and local levels and at the Federal level to some degree were based on influenza pandemics. But coronaviruses are not—do not necessarily behave in the same way as influenza viruses.

And so one of the ways in which this played out was the biggest concern that you saw, for example, in New York and other States like New York that adopted this policy was, well, we've got to keep people out of the hospital because we see all the pictures from Italy of the hospitals being overwhelmed. That's the thing we've got to avoid. We've got to avoid hospitals being overwhelmed. And you,

nursing homes, are going to have to take these patients because all we care about is avoiding hospitals being overrun.

The problem is that in coronavirus pandemics a big problem is how lethal SARS-CoV–2 in this case is in vulnerable seniors because compared to influenza, SARS-CoV–2 is much more deadly in the elderly relative to influenza, which affects the young as well to a more significant degree than COVID–19 does. So, as a result, they basically forced these infected patients in nursing homes and not—weren't even aware of how the nursing homes were spreading SARS-CoV–2 and COVID–19 illness. And until, again, you know—until it was effectively too late, they didn't start pulling that data.

And to this day, New York State what they do now is they—if you die in a hospital but you got infected in a nursing home, they are counting it as a hospital death, not a nursing home death, so we still don't have clear visibility into how many people in New York State and New York City have died in long-term care facilities. So all this to say these are some of the problems early on.

Now, CMS is starting to require this data to come in directly to CMS, and that's helping, but this is an example of the way faulty theories and, you know, led to mismanagement, and we could've used data to correct those faulty theories and we didn't.

Mr. NORMAN. Thank you. And, you know, you mentioned that Congress has been attempting to upgrade the American public health infrastructure for the last decade. What other steps can Congress take to modernize sluggish public health data systems so that we are better prepared for public health emergencies?

Mr. ROY. Well, as I mentioned in my written testimony, as you know, Mr. Foster, there have been numerous attempts by Congress to upgrade public health surveillance infrastructure. Until very recently, none of those efforts by Congress, even though they were well-funded and had mandates and GAO (Government Accountability Office) reports and inspections, led to any change in the modernization of that surveillance infrastructure. So it's good that we're starting to see that difference, and I think it will be very important for Congress to deploy its authority to see the difference or the improvement if there is an improvement from HHS Protect and learn how to use HHS Protect as a more 21st-century approach to public health surveillance.

Mr. NORMAN. OK. And we're running short on time, but can you expand on some of the consequences of overestimating the number of positive cases that exist?

Mr. ROY. Yes. So as I mentioned in my oral and written testimony, the—one of the big issues right now is you have a number of States that are locking down or closing schools based on test positivity rates and cases per 100,000 residents. But if a number of those positive test results are based on PCR tests, it turns out that in many parts of the country roughly half of the positive PCR tests appear to be false positives based on this reporting around CT values or the level of amplification of the PCR samples that lab companies are using. So it's incredibly important that we have a better understanding of what's going on in terms of the actual level of positivity from a CT value standpoint of these PCR tests. That may be part of the reason why—while we're seeing positive cases here and in Europe, we're not seeing—or particularly here, the

same level of deaths per positive case that we saw early on in the pandemic. There are other reasons as well, but that may be one of them. But most importantly, because of the harm from economic restrictions and from school closures, it's incredibly important that we are accurately understanding the true extent of the spread of the virus.

Mr. NORMAN. Great. Thanks so much. I yield back.

Chairman FOSTER. Thank you. And I'll now recognize my colleague from Oregon, Ms. Bonamici, for 5 minutes.

Ms. BONAMICI. Thank you, Chairman Foster and Ranking Member Norman. But thank you to our witnesses. And I know we're talking about data today, but I really appreciate the acknowledgment that lives are represented by this data. And you've articulated why accurate, reliable data and our ability to understand and learn from it is so important to save lives and protect public health. And now we're at this 200,000-lives-lost threshold, and each of those individuals was more than a statistic, and we have to keep that in mind as we're learning today and how are we going to apply the hard lessons over the last several months.

And I want to start with Dr. Maragakis. As you referenced in your testimony, HHS made reporting to TeleTracking mandatory on July 10 and stated that hospitals had five days to come into compliance with this requirement, also announced—HHS also announced TeleTracking reporting would now be the sole mechanism to calculate distribution of treatment and supplies for COVID–19. And I understand this new system included many data points that had not previously been requested by CDC, and the terminology used in TeleTracking was unclear, leading to confusion about what exactly was required.

So will you please explain the importance of standardized data and what it would mean if there are differences in how COVID data is compiled and reported? For example, if New York City is reporting probable COVID deaths but New York State is reporting only confirmed deaths, what does that mean? Describe what challenges that might lead to. And I also want to follow up on my colleague Mr. Ranking Member Norman's question. If you would respond, what is the consequence of underestimating the number of positive COVID cases as well?

Dr. MARAGAKIS. Thank you for the question. As you note, standardization of definitions is critical so that when we are counting and looking at the data, we are comparing apples to apples. That is ideally represented by Federal, national, standardized definitions that then can be trickled down through the State health departments, and facilities can follow this guidance and accomplish accurate reporting so that we are sure when we are looking at the numbers that we know precisely what is being measured. This is so critical in the case of the COVID–19 data.

And, as you mentioned, the switch from NHSN, which is a well-established, validated system with experts that are used to measuring these kinds of data elements, it led to poorly defined data elements, a lot of confusion, no user manual, difficulty getting the answers, and manual reporting of data. And so junk in, junk out, unfortunately. If we don't have good data and good definitions, we can't rely on what comes out the other end.

Ms. BONAMICI. And so all of these issues that you have described, have the—all the entities, hospitals and others that are reporting to TeleTracking, have they—has HHS been responsive to concerns that have been raised? Have they responded to feedback in the months since the switch?

Dr. MARAGAKIS. The implementation of this new system has been extraordinarily rocky. It's put an incredible burden on hospitals across our Nation. In the earliest days there was no guidance. This has gotten slowly better over time, but it has been very difficult to get the answers that health systems and hospitals need in order to accomplish the reporting.

Ms. BONAMICI. And do you agree that based on all those issues and concerns there is a possibility that there could be serious consequences from underreporting COVID–19?

Dr. MARAGAKIS. Absolutely. I feel—and we have to remember that this is not just about the cases of COVID–19 but about critical data elements that have to do with our response, so personal protective equipment on hand, staffing levels, and other data elements that are vital to our response and knowing how to prepare ourselves and allocate our resources.

Ms. BONAMICI. Thank you. And I wanted to get in a question to Ms. Hamilton as well. Thank you for your testimony. You raised similar concerns about mismatch and duplicative data in your reporting, and we know how important that accurate data is. State public health officials are operating under enormous strain during the pandemic, as you noted, but if the Federal data reporting and management system fails to perform competently, the States are forced to react and try to fill some of that gap. How are State public health agencies reacting to concerns about the lack of validation and transparency for data from TeleTracking? And are they taking steps to strengthen their own data collection capabilities? And why—what can they do to improve short-term data reporting and management at the State level? How important it is for them to collaborate on subsequent changes?

Ms. HAMILTON. Yes, those are great questions, and changes that affect healthcare affect public health because we work in such collaboration and coordination. I think the first thing is that our guiding principle needs to be to strengthen our public health infrastructure and ensure that data flows from healthcare to State local public health and then onto the Federal Government, so it should be flowing through the public health system, not around the public health system.

And when we saw a change like this, I mean, it was confusing. I think you've heard that very well. And it was confusing for public health as well. And States have then gone and worked very closely with their healthcare providers to figure out what kinds of intermediaries can be put in place so that the right data is available at the local level for that important decisionmaking.

You know, I also feel like I want to comment on something that has come up already, which is funding for public health. And I heard a comment that there had been a lot of funding. And I really want to make clear that public health has never had dedicated funding for surveillance system data modernization and improvement. And that's a really critical piece. We need that foundational

core funding, and it needs to happen on an annual basis. There has been——

Chairman FOSTER. And I'm afraid I must——

Ms. BONAMICI. The time is expired but——

Chairman FOSTER. I must interject——

Ms. BONAMICI [continuing]. Thank you. Thank you, Mr. Chairman. Thank you for your——

Chairman FOSTER. Thank you.

Ms. BONAMICI [continuing]. Testimony and——

Chairman FOSTER. And for Members that are interested, I will entertain having a second brief round of questions to follow up on anything—issues that have come up.

I now recognize my colleague from Virginia, Mr. Beyer, for 5 minutes.

Mr. BEYER. Mr. Chairman, thank you very much. I really appreciate your doing this. And I'm so glad that we're here to talk about COVID–19 data and data management and specifically about strengthening the public health infrastructure. This has really been one of the key weaknesses in the U.S. response.

I had a conversation with Dr. Chris Murray back in April I guess, who is the founder, the leader of the Institute for Health Metrics Evaluation, the first website I check every morning. And he was so frustrated by the lack of data. And to that end we put together the *Improving COVID Data Transparency Act*, which I'm sure that Chairman Foster and Ms. Wexton, and Ms. Bonamici are already on.

I come back to the only computer stuff, GIGO, the garbage in, garbage out. If you don't know what you're doing, it's very difficult to manage it. Werner Heisenberg, Dr. Foster is our only Ph.D. physicist in the Congress, who understands that anytime you measure anything, you inevitably change it. And if you measure it well, we're going to change it well.

But let me give you the information framework though because we have unfortunately—I don't mean this to be political, but this is the reality. We have a President who's undermining the role of our Federal institutions. He has a list of the intelligence agencies but rather would listen to foreign dictators. He undermines the scientific standards at the EPA (Environmental Protection Agency) so they can pollute unabated. And he undermines the credibility of our health agencies by censoring or convoluting the messaging for political reasons.

Early in the Trump Administration I raised concerns about the odd precedent of politicizing basic CMS correspondence to the medical community, so Seema Verma then hires image consultants. But we didn't imagine that the same narcissism in our health system response would hold true during a pandemic that placed image over American lives. And we've seen the CDC and Dr. Fauci be hamstrung in briefing to the public on the epidemic, and we've seen these coronavirus hearings turn into functional Trump campaign rallies.

So responding to this worry, the point of this bill is to depoliticized CDC communication. To have noncareer—nonpolitical rather, nonpolitical career CDC staffers brief the public on the *Morbidity and Mortality Weekly Reports*. These are the gold standard, a week-

ly epidemiology digest published by the CDC to share the latest information. And now we understand that the Trump officials actually interfere with these reports, too.

So, Dr. Maragakis, what's the danger in this type of political review or efforts to intimidate the author's reports other than 200,000 American lives?

Dr. MARAGAKIS. Thank you for your question. You know, we are in such a crisis in this country due to the pandemic, and there are terrible effects, both health and non-health effects, but we all really need to use these data and the guidance from the CDC to be able to trust that it is scientifically based, that it is evidence-based because we have enough work to do on our plates even if we had that clear guidance. And so manipulation or confusion or unclear messaging really just dilutes the message, it confuses the public, and it makes it more difficult for us to take the steps that we need to do to prevent viral transmission and to diagnose and care for the patients who are afflicted with this disease.

Mr. BEYER. Thank you very much. Dr. Hamilton, as I understand it, only one electronic healthcare record company can currently do electronic case reporting immediately to local health departments. Can you talk about the benefit of electronic case reporting and why that would help us to respond faster?

Ms. HAMILTON. Yeah, absolutely. That's a great question. And from the public health perspective, when we look at data modernization, we feel that this is probably the single biggest transformation that we need, and we just have not seen the commitment to fund this and invest in it.

I have some great colleagues across the country that have started to implement electronic case reporting. Most specifically, I would report from the Florida Department of Health, who has recently implemented it. And their comments in terms of data improvement from review of the initial data thus far is, amazingly, things like missing information is—that gap has really been closed, so the address information is missing less than 1 percent of the time, phone number as well. I mean, these are huge improvements when we look at the ability to identify hotspots and contact patients. The race and ethnicity information also dramatically improves going down to just missing for a few percentage points.

So, you know, it's the reports that come in, and then that allows public health to act in an immediate way to contact the patient, to identify contacts rapidly, and then even before you can reach someone, you can start aggregating it and identifying community-based hotspots, as well as health disparities based on that race and ethnicity data.

Mr. BEYER. That's great, thank you. And, Mr. Chair, I yield back with a comment I have a couple of children who are form-phobic, but when you do it on the internet it won't let you go forward until you put in your address. It really helps.

Chairman FOSTER. Thank you. And I will now recognize my other colleague from Virginia, Ms. Wexton, for 5 minutes.

Ms. WEXTON. Thank you, Mr. Chairman, and thank you to the witnesses for joining us here today.

You know, following up on the questions of my colleague from Virginia, I would ask of all the witnesses, what can we in Congress

do to protect our public health infrastructure from political pressure? Is there anything we can do or are we just out of luck?

Dr. LEE. Well, I'll start by saying that we have to rely on evidence, and we have to rely on the experienced public health professionals who have been doing public health surveillance before we were even a country. In 1741 was the first rules around tavernkeepers were, you know, being required to report contagious diseases to the colonial leaders. And I think the more that we can rely on the expertise and the experience of our State, local, and Federal health officials, the public health officials and keeping it out of the opportunity to spin, to make data, you know, a political pawn or a political tool is going to be critically important. And I can't agree with you more that what we need is Congress to fund—consistently fund public health surveillance and to ensure that that—experts who have experience are the ones who develop and maintain and implement these systems.

Ms. WEXTON. So through our funding function and our oversight function I guess is how we can do it. Thank you, Dr. Lee.

Now, my colleague from Virginia and I, we are very proud that our Commonwealth was the first State in August to rollout the COVIDWISE app. And people are putting it on their phones. I've got it on mine. Don has it on his. And, you know, it's a very convenient way to do contact tracing. It'll let you know if there—you've been in prolonged contact with a person who ultimately tests positive. But in order for it to work, we need people to actually have it on their phones. And because it has Bluetooth—it operates under Bluetooth technology instead of location data, it helps limit some of the privacy concerns that a lot of people have. So what can we as public officials do to help support our local health departments to get more people to put these apps on their phones? Because if we have 150,000 people who have downloaded it on our phones in Virginia, that's great, but in a State with a population of over 8 million, it's still just a small proportion of people. So what can we do to support those efforts? Dr. Lee, do you have any thoughts on that?

Dr. LEE. Thanks. I do actually. I think Ms. Hamilton will have some more State and local perspective, but I think the—as I said in my testimony, the primary concern here for folks is that the data are being used for the reasons they were collected. If people do not trust that that's the case, if they think that the data might be used to call ICE (Immigration and Customs Enforcement) or to cause some other kind of harm or to track their location for other reasons, people will not trust the app.

So we have to make sure that we go back to first principles of what ethical data collection is for public health, and that means you collect the least amount of data necessary, you use them for the purposes for which they were collected only, and that you protect the privacy and identifiability of the data. Public health has been doing that for decades, for centuries, so I think we have a pretty good track record.

Ms. WEXTON. Thank you very much. Dr.—Ms. Hamilton, do you have anything to add to that?

Ms. HAMILTON. Yes, I mean, I think at the core we need the public's trust, and the more that we can support that with leader-

ship and recognition that public health has been the longest-standing steward of protected health information. We have done this since our inception, and we have done it well, securely, and safely, and we will continue to do that. And this is about people protecting themselves and their families.

And I think we have to recognize as well that traditional contact tracing, because of trust issues right now, is really suffering. You know, I hear from State colleagues they're identifying one or fewer contacts per case because people are not providing that information because of the erosion of trust that we have seen. And so we really need voices to lead and talk about how much experience public health has in this space and how critical it is to use all of the resources that we have available to us in order to really halt the spread of this virus.

Ms. WEXTON. Thank you very much. And with that I'm going to yield back because I see my time is almost up, so thank you so much for your responses.

Chairman FOSTER. Well, thank you. And I guess there is some Member interest in a quick second round of questions, and so with that, I will recognize myself for 5 minutes for actually a single question.

You know, there—I—Ms. Hamilton and others have mentioned the benefits of automating this in conjunction with the electronic health record systems. And one of the big issues in any of the automation and cross-operability is the lack in the United States of a unique patient identifier. And this is something that's been a longstanding problem in our country. It was one of the things that enabled the opioid epidemic. The fact that there was not a unique patient identifier made it impossible to identify a patient who was getting multiple opioid prescriptions from multiple doctors in—potentially in multiple States.

And so—and this has been—actually it's Congress' fault. There was—25 years ago, my former colleague Ron Paul adopted a policy rider, got a policy rider adopted that banned HHS from promulgating a unique patient identifier. And so this has been killing, by many estimates, tens of thousands of Americans every year due to preventable medical errors, due to patient misidentification. And of course with the COVID crisis, you know, there—additional flaws in a system without a unique patient identifier have been made clear, you know, everything from getting, you know, uniform death record reportings to just combining the healthcare records.

Zeke Emanuel in his recent study of many different countries identified this as a huge problem in the United States that isn't present in advanced countries where even in countries where there are multiple providers of electronic health records, there is a unique identifier so you show up and say, OK, here is my patient ID number, and then you can bring in the records from many medical providers.

And so, you know, I am very proud that we're able at least in the U.S. House to start fixing this problem. You know, faced with this, my Republican partner Representative Kelly and I put—got a floor vote last summer, and a strong bipartisan vote in favor of repealing that ban and so to finally allow a unique patient identifier for patients that wish one.

And second, we, just a month or two ago, got it adopted unanimously in the U.S. House, and so we're now really—this is something where the Senate can act by simply concurring with the House and save thousands of American lives.

So I was wondering if you can comment on the importance of being able to simply avoid a patient misidentification in this. You know, Ms. Hamilton or any one of our panelists.

Ms. HAMILTON. You know, I'll just say that de-duplication of records is a huge issue. And, you know, I provided for you all as part of my testimony today some of the lab reports that health departments currently receive in the thousands, and I hope that you'll be able to have those not easily viewable on screen, but please do look at some of those handwritten reports. I mean, we're deciphering these things, and it does create issues and problems. It creates issues identifying the right individual, and we get multiple reports on individuals. People are tested multiple times. Some of the lab reports only include a name and a date of birth with nothing else at all, so matching is certainly an issue with important consequence and one that we address very carefully within public health to do that matching.

Chairman FOSTER. Yes, well, I——

Mr. ROY. Mr. Chairman, I just want to add that I share this concern very much, and I'm happy to be helpful to you and the Committee in trying to find ways to advance policies that would achieve a unique patient identifier.

Chairman FOSTER. Yes. It is—I think the ground has shifted on that politically on both sides of the aisle certainly in the U.S. House. There's just unanimous recognition, you know, from the opioid issue if for no other reason. And so this is—it's rare that Congress can do something that will cost negative money and save thousands of lives, but this is certainly an opportunity.

Anyway, I understand also that Representative Beyer is interested in another round of questions, so I'll recognize him for 5 minutes.

Mr. BEYER. Mr. Chairman, thank you very much.

Following up on our last conversation with Dr. Hamilton, one of the things I've been impressed with is 15 years ago I learned that when you drive through Taco Bell, if they change the price on the—you know, the chalupa by five cents that the data immediately goes right to Taco Bell corporate in Atlanta or wherever it is, and they are able to figure out what the elasticity of demand is based on that. If they can do that at fast food restaurants, wouldn't that be nice to be able to do that with major health issues? So thank you for pushing forward on this.

I also want to shout out Dr. Maragakis for being part of SATA, which is in Arlington, Virginia. You see Virginia leads once again. And then Dr. Lee, who was part of Virginia Tech, an outright Hokie. So—I know you're upset, but Illinois was once part of Virginia back before the—1776, so we include you.

My bill that we talked about, which I'd love to compare to what Ms. Hamilton—Dr. Hamilton has in terms of this national infrastructure bill. It tries to restore trust in the CDC but also the value of the outsourcing of the modeling because most of the current

modeling is not being done by the CDC. And a lot of the States are hiring expensive outside consulting firms to do this.

So, Dr. Lee, can you talk about the importance of public health confidence in the CDC and any concerns about the outsourcing of information?

Dr. LEE. Thank you, excellent question. And I think that, you know—I think we've all stated over the last hour and a half about the importance of CDC expertise. I think one of the things that matters a lot to public health system is that the data that we collect and use to address public health issues are available not only to experts within CDC but that those data become safely available to other very smart people in our country who can help us with modeling, who can help with a number of different approaches to using the data to best prevent infections and, you know, help us mitigate risk for this particular infection.

So I think that, again, I will say that without the public's trust in our system to collect the data, we're not going to have that for anyone else to use, so we really need to be thinking carefully about how we can collect the data that is, you know, accurate and valid, how we can safely share those data with other really talented researchers in our region, in our country, in our world to help us fight this epidemic.

Ms. HAMILTON. Yes. I mean, I just——

Mr. BEYER. Thank you. We had a Joint Economic Committee meeting yesterday with Dr. Ashish Jha, head of the Public Health at Brown who was just terrific. And he again emphasized that access to information is the single best tool that Americans have to protect themselves from the virus.

Dr. Hamilton, I was impressed that less than one contact person is identified in the contact tracing because of fears of public trust. Can you tell me, what do they think is going to happen? Do they think that the person they identified will be arrested in the middle of the night?

Ms. HAMILTON. You know, when we don't reach people, we don't know what it is, right? I mean, I think that there's been a lot of concerns that are raised when it comes to what and how the data could be used. And unfortunately, it's—when it's not clear exactly how data is being used and we have confusing, mixed messaging, then there are a number of reasons, I'm sure, why people no longer want to provide certain kinds of information, fear of stigmatization, potential fears for loss of work, fears that arise in terms of, you know, will their children be able to go back to school. And unfortunately, we've seen some really divisive things happen in this pandemic, and I think that's why it's so important that we do hold up our public health leaders and partners and are clear in terms of how the data is being used so that we can really provide that information to the public to do our job saving lives.

Mr. BEYER. That's great. Thank you very much. And, Chairman Foster, I yield back.

Chairman FOSTER. Well, thank you. And before we bring the hearing to a close, I just want to thank our witnesses for testifying before the Committee today. I also want to thank you personally for your concern about data-quality issues in medicine. My daughter Christine does healthcare data analytics for the Commonwealth

of Massachusetts and regularly complains to me about low-quality data and incomplete data that she has to wrestle with. And so I think the things you have mentioned toward a better path forward in our country, that Congress should pay attention to that.

The record will remain open for 2 weeks for additional statements from the Members and any additional questions the Committee may ask of the witnesses. The witnesses are now excused, and the hearing is now adjourned.

[Whereupon, at 12:16 p.m., the Subcommittee was adjourned.]

Appendix

Additional Material for the Record

LETTER SUBMITTED BY THE PREMIER INC. HEALTHCARE ALLIANCE

PREMIER TRANSFORMING HEALTHCARE TOGETHER

Statement for the Record

Submitted by

The Premier Inc. healthcare alliance

House Science, Space, & Technology
Subcommittee on Investigations and Oversight

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

September 23, 2020

The Premier healthcare alliance appreciates the opportunity to submit a statement for the record on the House Science, Space, & Technology Subcommittee on Investigations and Oversight hearing titled "*Data for Decision-Making: Responsible Management of Data During COVID-19 and Beyond*" scheduled for September 23, 2020. We applaud the leadership of Chairman Foster, Ranking Member Norman and members of the Subcommittee for holding this hearing to examine the nation's management of data in response to the COVID-19 pandemic.

The Premier healthcare alliance is a leading healthcare improvement company, uniting an alliance of more than 4,100 U.S. hospitals and health systems and approximately 200,000 other providers and organizations to transform healthcare. With integrated data and analytics, collaboratives, supply chain solutions, and consulting and other services, Premier enables better care and outcomes at a lower cost. Premier plays a critical role in the rapidly evolving healthcare industry, collaborating with members to co-develop long-term innovations that reinvent and improve the way care is delivered to patients nationwide.

COVID-19 has exposed one of healthcare's fundamental weaknesses: the fragmented and siloed nature of care delivery and the lack of centralized coordination when it comes to managing and preventing disease spread. The public health system continues to rely on flawed data and obsolete technology that consistently fails to accurately identify and track current cases, monitor disease progression, or predict future surges. Not only do these blind spots create opportunities for the disease to spread, they also undermine the ability to safely plan for economic recovery and re-opening of the country.

America needs to modernize its public health surveillance process using the existing HIT infrastructure

The COVID-19 public health emergency has heightened the awareness of the need to modernize our public health surveillance capabilities. America needs an automated, near real-time means to collect this symptom and confirmed case information consistently and comprehensively so that it can be shared between and among multiple stakeholders, including federal, state, local, and tribal public health agencies and authorities. Existing health IT infrastructure and policies governing interoperability, standards and electronic health records (EHRs) can be leveraged to achieve effective and efficient public health systems modernization. The modernized public health infrastructure should include the following components.

- ***Collection and reporting of standardized and consistent data for use by federal, state, local and tribal health agencies and authorities.***

  One of the biggest shortcomings in today's public health data collection process is that states are collecting data in different ways and formats. This can be remedied by establishing a consistent set of data elements and collecting them through America's current data infrastructure. This will enable a consistent collection of public health information from across the nation that can be used

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as each state sees fit but in a manner that can provide a national picture of virtually any public health threat.

Over the last decade, tens of billions of dollars have been invested in building an interoperable health information technology infrastructure in America. This infrastructure should be leveraged nationally to comprehensively collect this syndromic and confirmed case information. Virtually all hospitals and most all physicians use electronic medical records (EMR) systems. Due to the requirements in the *21st Century Cures* legislation, app developers can create applications that work across the EMRs to collect this syndromic and confirmed case information. Unlike the current public health data collection system, a system using EMRs can be implemented with minimal physician burden and can be scaled to the majority of our nation's clinicians.

Any legislation modernizing America's public health data collection process should include language that calls for:

- Collecting, exchanging, reporting and using a uniform set of data elements from electronic patient encounter data across the nation; and
- Designating, adopting, recognizing and implementing data and technology standards (including standards for data transmission, data content and interoperability) for public health data collection systems, with deference given to standards published by consensus-based standards development organizations and with priority given to standards adopted by the Office of the National Coordinator for Health Information Technology.

- ***Ensure that nationwide syndromic surveillance is achieved by beginning with the collection of signs and symptoms data and add confirmed cases as testing results become available.***

  The data collection process from ambulatory/outpatient settings and providers should include syndromic surveillance (pre-test signs and symptoms) and then confirm the cases as they are identified. Symptoms are the earliest indicator that a surge or flare is occurring. This is especially critical when diagnostic test results can lag 1 to 4 days after the test was performed and are often inaccurate. If health systems and communities wait for confirmed cases, containment and mitigation strategies may be up to 7 days later than they might be and therefore less ineffective.

  It is critical, however, that symptoms are accurately identified. Because more than half of the information needed to accurately identify a symptom is in free text in the EHRs, it is important that the data collection use health IT tools such as machine learning (ML) and natural language processing (NLP) to obtain unstructured data from the full EHR. EHRs can also collect the confirmed test results, which can further build out and create a confirmed case report beyond the earlier identification of persons with symptoms. Once deployed, this public health information collection system could be used for virtually any public health threat. Moreover, such a data collection system can be used to project resource and staffing needs resulting from a surge in a public health threat.

- ***Provide clinical decision support (CDS) to help clinicians follow the latest evidence-based guidelines at the point of care.***

  An application that collects data from ambulatory physicians can also be used to alert physicians to the latest clinical evidence using CDS. CDS provides information and alerts in near real-time to clinicians in the workflow. This information will assist frontline providers in the identification of patients who are most at risk for severe illness, provide care management guidance, and inform physician decisions based on the latest evidence-based information. These alerts and insights will help improve patient outcomes by applying best practices and clinical guidelines at a time this evidence is rapidly evolving.

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Inaccurate patient matching is widespread, disrupts the coordination and quality of care during the COVID-19 pandemic, can cause serious safety events and is costly to the healthcare system

One of the most significant challenges impeding the safe, secure and efficient electronic exchange of health information is the lack of a consistent, national approach to patient data matching. As our nation's healthcare providers innovate care to test, treat and prevent the spread of COVID-19, patient identification and data matching errors have become exponentially more problematic and dangerous. These challenges stem from a narrow interpretation of archaic language that has been included in Labor-HHS Appropriations bills since FY 1999 that prohibits spending federal dollars to promulgate or adopt standards for a national unique patient identifier (UPI).

The Government Accountability Office found that inaccurate, incomplete or inconsistently formatted demographic information in patients' records can pose challenges to accurate matching. When records for different patients are mistakenly matched, or records for the same patient are not matched, it can adversely affect the patient's care. A Pew Charitable Trusts study found that patient matching rates can fall as low as 80 percent, leaving as many as one in five patients not matched to the correct record when receiving care from different providers.

The problem is so serious in fact, that the ECRI Institute, a widely respected national safety patient organization, ranked patient misidentification as one of the top ten patient safety concerns for healthcare organizations. Moreover, misidentification costs the average healthcare facility $17.4 million per year in denied claims and potential lost revenue.

COVID-19 elevates the urgency to remove the ban that threatens the lives of Americans

As patients' information is exchanged among various types of providers—including hospitals, primary care physicians, specialty physicians, pharmacies, and laboratories—it's imperative that the healthcare information belonging to the same patient is correctly matched. This has never been so critical than during the current public health emergency. With patients getting tested for COVID-19 in different settings such as drive-through and other makeshift testing sites and being treated in field hospitals, ensuring that healthcare records follow the right patient has become extremely problematic.

Providers treating COVID-19 patients in hospitals or other facilities urgently need current and accurate information about patients' laboratory or other diagnostic test results, their medication history and any comorbidities or diagnosed medical conditions to inform their treatment decisions. Public health experts must similarly rely on accurate and timely information on patients to conduct contact tracing and track outbreaks to stem the spread of the disease. Once a vaccine is developed, records must be accurately matched to the correct patient in order to identify who has been infected, who has been vaccinated, and what are the clinical outcomes.

Implementing unique patient identifiers will also help the nation address the disparate impact of COVID-19 that the Administration has identified during the pandemic. According to OCHIN, the Black, Hispanic / Latino, homeless and migrant population make up a disproportionate share of those who experienced duplication of healthcare records.

Premier urges Congress to remove the ban to finally address the impediment to patient matching and identification which is putting patients at risk, increasing costs to the healthcare system, perpetuating inefficiencies in care delivery and coordination, and undermining efforts to achieve nationwide interoperability.

Conclusion

In closing, the Premier healthcare alliance appreciates the opportunity to submit a statement for the record on the House Science, Space, & Technology Subcommittee on Investigations and Oversight hearing titled "Data for Decision-Making: Responsible Management of Data During COVID-19 and

Beyond." Premier is available as a resource and looks forward to working with Congress as it considers policy options to continue to address this very important issue.

If you have any questions regarding our comments or need more information, please contact Duanne Pearson at duanne_pearson@premierinc.com.

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