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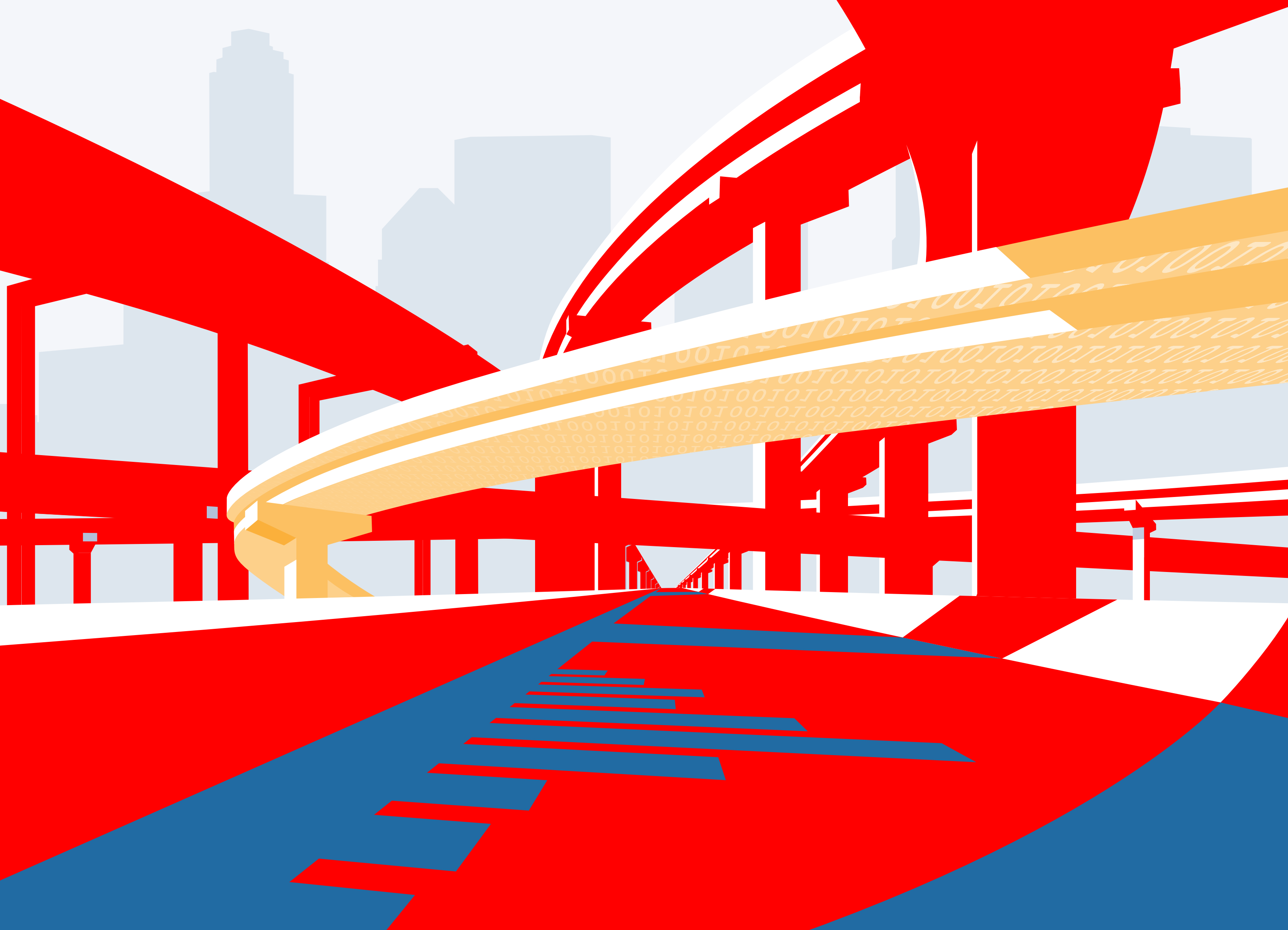

Driving Public Health in the *Fast* Lane

The Urgent Need for a 21st Century Data Superhighway

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Acknowledgements

The Council of State and Territorial Epidemiologists (CSTE) is an organization of member states and territories representing public health epidemiologists. CSTE supports effective public health surveillance and sound epidemiologic practice through training, capacity development, and peer consultation.

This report was funded by the **de Beaumont Foundation**. The Foundation advances policy, builds partnerships, and strengthens public health to create communities where people can achieve their best possible health. Opinions in this report do not necessarily reflect the views of the Foundation.

CRD Associates is a Washington, DC-based strategic communications and government relations consulting firm that was contracted by CSTE to develop this report in close consultation.

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Acronyms

AIMS: Association of Public Health Laboratories Informatics Messaging Services
AMD: Advanced molecular detection
APHL: Association of Public Health Laboratories
CDC: Centers for Disease Control and Prevention
CSTE: Council of State and Territorial Epidemiologists
eCR: Electronic case reporting
EDRS: Electronic death registration system
EHR: Electronic health record
ELR: Electronic laboratory reporting
HIE: Health information exchange
IT: Information technology
LIMS: Laboratory Information Management System
LRN: Laboratory Response Network
NCHS: National Center for Health Statistics
NMI: National Notifiable Disease Surveillance Modernization Initiative
NNDSS: National Notifiable Disease Surveillance System
NVSS: National Vital Statistics System

Glossary of Terms

Application: Software running on a platform that performs a specific analysis (output) from a raw data set (input).

Bioinformatics: In the context of public health surveillance, the field of data science that analyzes and compares whole genomes from organisms, showing temporality of infection and relatedness and allowing strong inferences about common sources of outbreaks and clusters. Bioinformatics relies on cloud computing with broadband internet connectivity, platforms with robust messaging capacity, and applications running sophisticated algorithms.

Clinical decision support: An application usually running in the electronic health record platform that assists the provider with patient care, such as medication interactions, allergies, immunization reminders, appropriate laboratory diagnostics, and public health case reporting.

Cloud computing: A federated data model that allows computer systems to send and receive data on common platforms for user sharing, comparisons, analytics, and visualization. The infrastructure for cloud computing is composed of many server computers connected by the internet.

Disease (or condition) notification: In the context of public health surveillance, disease cases that are voluntarily notified to CDC by the state or local health department. Notifiable disease and reportable disease lists have a great deal of overlap but are not necessarily the same.

Disease (or condition) reporting: In the context of public health surveillance, diseases that are required by state and local law and rule to be reported to the health department when suspected by a health care provider, hospital, or laboratory, and possibly others such as restaurant operators and school principals.

Electronic health record: The digital versions of patients' medical encounters, which can include patient demographics, diagnoses, vaccination status, medications, laboratory results, and more. Electronic health records are not routinely part of the public health surveillance domain, but are critical sources of health care data that enhance public health response.

Health information exchange: A public or private organization that governs a network of electronic health records from many providers onto a single platform using cloud computing. Any provider or health official with access rights can view or exchange the data in a patient record with another provider or entity.

Interoperability: The ability of computer applications, platforms, systems, and networks to communicate electronically with one another by using standardized nomenclature, language, and architecture.

Legacy system: An outdated or older computer system, programming language, or application software that is used until upgrades are available, or used instead of available upgraded versions (often as a result of resource constraints). "Legacy system" also may be associated with terminology or processes that are no longer applicable to current contexts or content.

Platform: Computer hardware and software needed to run an application that can receive inputs from, and send outputs to, multiple sources using common standardized messaging language.

Public health surveillance: The ongoing systematic collection, analysis, and interpretation of health data, closely integrated with the timely dissemination of these data to those responsible for preventing and controlling disease (or condition), exposure, and injury.

Situational awareness: In the context of public health preparedness, acquiring and analyzing data and the information about a known incident or event. Syndromic surveillance is a situational awareness tool.

Syndromic surveillance: A branch of public health surveillance that traditionally identifies syndromes rather than individual cases. Syndromes are based on a collection of symptoms and signs (e.g., headache and fever) rather than diagnostic codes and lab results. Syndromes are obtained from electronic health record emergency department chief complaints, triage notes, and other data elements, and from other points of care in the community such as urgent care centers, poison center calls, or emergency medical service runs. As diagnostics codes become available in the medical record, they are often incorporated.

Anne Schuchat, MD (RADM, USPHS, RET)
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Expert Testimonial

"Data are truly the engine of public health. Without appropriate data, we don't know how to chart the course ahead, how to know if we are headed in the right direction, or when and where we may have made a wrong turn. As data grow bigger, we need better systems and strategies to manage the flow of information and ensure access to the most timely content. There are so many fast-moving, complex public health challenges that require real-time or even predictive data for public health to fully comprehend and address them. So where are we now? Are we still puttering along the data superhighway in our Model T Ford, or are we speeding along in the latest electric car? **Spoiler alert:** we are likely closer to the former than the latter. What that means for the system's ability to address these complex challenges is that we are woefully behind. Yesterday's data systems must evolve to meet future public health challenges.

The opioid epidemic is one example where the factors driving the epidemic are changing over time. So far there have been three waves: The first wave of the epidemic began in 1999, caused by a rise in prescription drug use due to overprescribing by physicians who were under the misguided belief of no harm. The second wave of the epidemic came from increases in heroin use beginning in 2010. The third wave, a rise in synthetic opioids including illicitly manufactured fentanyl, began in 2013 and has increased rapidly. Without access to reliable data, we have been slow in recognizing changes and were also not able to get ahead of these shifts as quickly. It also means we may not see the next threats to our health coming until they are closer than we think. We know that 30 million American adults have diabetes but another 84 million have prediabetes, which can lead to development of the disease. Nine out of 10 adults don't know they have prediabetes. This is a major public health problem – what else is there in our blind spots? Old diseases are making a comeback and challenging our public health data systems to keep up. Measles was declared eliminated from the United States in 2000, yet in 2019 we saw 880 cases in the first five months of the year. Tracking this resurgence was more difficult than it would have been if our systems were ready.

Don't despair—the news isn't all bad and there are opportunities to strengthen and improve our data systems. We need a few things to do this: **Deep, growing data sets** that drive new analytics; the ability to **predict, model, and address** diseases based on data quality and currency; and modernizing the public health data platform, adding data resources that are **well-governed, fast, and flexible**. We may not be ready for self-driving cars in our public health data world yet, but there are an awful lot of 'driver-assist' features that public health really needs to make standard options in the immediate future.

Executive Summary

Every day—unbeknownst to most Americans—public health surveillance saves lives by detecting and coordinating the response to health threats. The nation's public health surveillance system protects the public from threats such as re-emerging vaccine preventable diseases like measles, emerging infectious diseases like Ebola and Zika, new threats like e-cigarettes that build on old threats like tobacco, natural disasters, antibiotic-resistant organisms, injury, environmental threats like lead, and more.

In a world where travel across the globe can be accomplished within 36 hours, the demands for public health surveillance have changed **dramatically** over the past several decades. Today, emerging health threats around the world pose a risk to the health of every American. Global health security depends on high-quality, immediate, population-wide, complete, and accurate detection and reporting of diseases and conditions of high public health consequence.

Yet, public health surveillance is falling behind.

The use of data is transforming the world. A 2018 report by the National Science Foundation positioned the United States as the global leader in science and technology.[1] Many industries—financial services, retail, logistics, communications, and health care—have harnessed the power of technology and electronic data exchange to streamline processes, reduce manual paper-based methods, increase accuracy, improve productivity, and achieve cost savings.[2] Despite the availability of new technologies to facilitate timely data exchange, public health departments struggle to take advantage of these advancements and continue to rely on sluggish, manual processes like paper records, phone calls, spreadsheets, and faxes requiring manual data entry.

These outcomes do not result from a lack of data or the limitations of today's technology; rather, these poor outcomes are due to inadequate resources. Public health has been unable to access existing data or implement advanced technologies necessary to improve the timeliness of public health surveillance. To be effective, public health surveillance must shrink the time interval between recognition of a problem and the response to it. To do so, health care providers and public health departments must facilitate more, better, and faster data exchange.

The consequences of slow data sharing are significant—delayed detection and response, lost time, lost opportunities, and lost lives.

1 National Science Foundation. Report shows United States leads in science and technology as China rapidly advances. ScienceDaily. www.sciencedaily.com/releases/2018/01/180124113951.htm. Published January 24, 2018.
2 Benefits of EDI. EDI Basics. https://www.edibasics.com/benefits-of-edi/. Accessed May 11, 2019.

Efforts to modernize public health surveillance and data systems have been made over the years, but the categorical, disease-specific approach to funding and implementing improvements have resulted in uneven progress. This has created a patchwork of "haves" and "have nots" across systems and jurisdictions, preventing transformative, cross-cutting, comprehensive upgrades. For example, the Centers for Disease Control and Prevention (CDC) has more than one hundred siloed public health surveillance data systems. State, territorial, local, and tribal health departments share data with CDC through these systems. Many of these systems are not interoperable, which results in duplicate and redundant data entry.

Therefore, to transform the nation's public health surveillance capacity, we must evolve from manual data sharing methods and disease or condition-specific silos towards building a core public health data infrastructure—**a "public health data superhighway"**—that facilitates automatic, interoperable data exchange. This foundational approach to improvement, or enterprise-wide approach, will support widespread and rapid access to public health data for all public health programs at all levels of government for all diseases and conditions. Just like a rising tide lifts all boats, a public health data superhighway improves all public health programs. Public health needs a coordinated and integrated approach to using data to deliver on mission, serve the public, and steward resources while respecting privacy and confidentiality.

The public health data superhighway transformation will:

- Inform decision-making by providing access to data sources that were previously unavailable or burdensome to retrieve;
- Enable coordinated responses to emerging public health threats without developing multiple stand-alone systems for specific diseases or conditions;
- Ensure that data systems are interoperable within public health, as well as with external health care providers;
- Support sophisticated data analytics, thereby allowing public health professionals and policymakers to make smarter, faster decisions and get ahead of chronic, emerging, and urgent threats;
- Support federal, territorial, tribal, state, and local public health needs;
- Establish effective security and privacy protections to limit data breaches and minimize their impact.

This report explores the challenges with data sharing within the current public health surveillance system and demonstrates the need to create an efficient and modern 21st century public health data superhighway.

According to focus group conversations with public health subject matter experts, key challenges include:

- Manual paper-based methods remain a prominent mode of data exchange;
- Systems improvements to date have been limited to specific programs, resulting in siloed benefits;
- A vast disconnect remains between health care and public health;

- Limited resources, data science, and informatics expertise are available to support public health systems.

Developing the public health data superhighway requires confronting the new landscape of health data collection, storage, and sharing. As the public health community, stakeholders, and policymakers seek to transform the nation's public health surveillance system, key principles must be considered.

Five Key Principles to Transforming the Nation's Public Health Surveillance System

1. **Enterprise approach to data systems modernization**
   with new federal funding to enable CDC and state, territorial, local, and tribal health departments to develop a core data exchange infrastructure. Funding must be sustained to maintain and upgrade the public health data superhighway;
2. **Interoperable data systems**
   within public health, and between public health and health care to seamlessly exchange data on the public health data superhighway;
3. **Security to protect patient data**
   by adopting policies, transparent privacy practices, and security measures to defend and prevent cyberattacks;
4. **Workforce that is prepared for the Information Age**
   to build, implement, maintain, and use the data systems that comprise the public health data superhighway;
5. **Partnership & Innovation with the public and private sectors**
   to build and maintain the public health data superhighway and establish leading-edge public health data systems and processes.

High-quality and timely data give us a blueprint to address public health threats, pinpoint action to protect the health of the nation, and are essential to solve the health problems our nation faces. We can no longer afford to let public health threats outpace the limits of our public health surveillance system. The technology is available to develop the public health data superhighway, but new approaches and sustained investments are needed to get public health out of the slow lane and to improve the health of the nation.

Introduction

The Public Health Enterprise

Today, it is common for consequential public health threats to dominate news headlines: a record-breaking number of measles cases in the first four months of 2019; the deadly, drug-resistant superbug *Candida auris* becoming an untreatable health threat; steep rises in fentanyl-linked overdose deaths; and lead contamination in public water systems. While diverse in their origins and public health impact, these **public health threats have one thing in common**: effective response and prevention efforts rely on a strong, timely public health surveillance system.

Public Health Surveillance: Moving Data to Action

CDC defines public health surveillance as the ongoing systematic collection, analysis, and interpretation of health data, closely integrated with the timely dissemination of these data to those responsible for preventing and controlling disease (or condition), exposure, and injury.[3] It enables population-level measurements of disease burden and allows for evaluation of broad interventions and prevention measures.

Gathering and exchanging data defines the foundation of public health surveillance. Starting at the point of patient care, health-related information is collected and sent to the territorial, tribal, state, and/or local health department so epidemiologists—also known as disease detectives—can measure the health status of the population and evaluate and implement control measures. To provide a nationwide perspective of disease burden, health departments share de-identified data with CDC, which ultimately informs national public health responses, prevention initiatives, and policy. The value and quality of the nation's public health surveillance system relies on efficient and accurate data flow from source to the agencies to make evidence-based decisions.

> *"My colleague in Pennsylvania, working in concert with CDC and the Agency for Toxic Substances and Disease Registry, is responding to a manufacturing plant 'bad actor' that has released lead into the air.* ***The community understandably wants answers about their health:*** *What are our blood levels? How many people and children have been tested? How do they compare to other communities? Does my child need to be tested? Unfortunately, those questions can't be answered with today's data, because while health care facilities have data stored in electronic medical records, data are sent on paper to the health department and the stacks take time to enter and process."* [4]
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> **Janet Hamilton, MPH**
> **Council of State and Territorial Epidemiologists**

3 German RR, Lee LM, Horan JM, et al. Updated guidelines for evaluating public health surveillance systems: Recommendations from the guidelines working group. MMWR. 2001;50(13):1-35. https://www.cdc.gov/mmwr/preview/mmwrhtml/rr5013a1.htm. Published July 27, 2001.
4 Hamilton, J. FY20 LHHS Testimony Hamilton. Oral. CSTE. https://cste.sharefile.com/share/view/sc5e20318a5a49a1a. Published April 24, 2019.

Core Pillars of Public Health Surveillance

National public health surveillance has been built through a strong, long-standing partnership with CDC and state, territorial, local, and tribal public health departments. There are five core pillars and processes that serve as the foundation for modernization of the nation's public health surveillance system. (More detailed descriptions can be found in Appendix A.)

1. **Electronic case reporting (eCR)**
   - eCR is the automatic submission of disease reports directly from clinical care electronic health records (EHRs) at clinical care organizations to state, territorial, local, and tribal health departments.
   - eCR implementation is under development and has the potential to transform data exchange between health care providers and public health departments.
2. **Laboratory information management systems (LIMS), including electronic laboratory reporting (ELR)**
   - LIMS are computer applications that form the backbone of laboratory data collection, management, storage, and sharing.
   - ELR is used to electronically report laboratory results from LIMS (private laboratory or public health laboratory) to public health epidemiologists.
3. **Syndromic surveillance**
   - Syndromic surveillance uses near real-time data collection from hospital emergency department visits and data sources from other points of care in the community, such as urgent care centers, poison center calls, or emergency medical service runs for continuous monitoring of community health.
   - This system has evolved to include more data sources and advanced detection analytics.
4. **Electronic vital records systems**
   - The electronic vital records system is a national system of 57 state and territorial vital records jurisdictions that provide secure electronic collection of birth and death data from hospitals, funeral homes, health care providers, and medical examiners.
   - Electronic death registration systems (EDRS) provide mortality data.
5. **National Notifiable Disease Surveillance System (NNDSS)**
   - NNDSS is the national disease system that collects, aggregates, and analyzes individual case investigations of reportable diseases and conditions from state, territorial, local, and tribal public health agencies from hospitals, health care providers, and laboratories.

The Public Health Enterprise

Effective prevention, detection, response, and policy development rely on coordinated efforts between public health agencies at all levels of government—federal, state, territorial, local, and tribal—working together with health care providers, the private sector, and the public. This collective effort to protect and promote the public's health is the "public health enterprise." As stakeholders work to modernize public health data systems, improvements and investments must be understood and advanced at the "enterprise level." Modernizing public health data systems at the enterprise level will benefit all public health programs at all levels of the government for all diseases and conditions.

Building the Interoperable Public Health Data Superhighway

To advance public health and enable timely and accurate exchange of data for all public health programs at all levels of government for all diseases and conditions, the public health community must modernize its data systems and implement existing technologies to better protect the public's health. It is time to reframe the traditional siloed approach to public health surveillance and adopt a progressive, enterprise-wide mindset. An enterprise-wide investment to modernize public health surveillance will build an interoperable core data exchange infrastructure—the "public health data superhighway."

Effective public health surveillance requires the five core data pillars—or "lanes" of the superhighway—to seamlessly share data across the public health enterprise. However, the diversity of systems that are available to exchange data makes this challenging. Within a state, the health department's data system may not integrate or interoperate with the health care provider's system or the laboratory's system. Furthermore, a state health department's data system may not be able to seamlessly share data with federal partners. As a result, the public health enterprise has been slowed by error-prone, manual, paper-based data exchange.

Compounding the slow exchange of data, traditional disease and condition-specific approaches to public health surveillance has resulted in more than **100 separate, disease and condition-specific, stand-alone surveillance systems at CDC**. Data input is not standardized across the agency, creating a burden on the public health professionals to keep track of duplicative, non-harmonized, non-standardized data requirements for each program.[5]

> **"...From the frontlines of the E. coli lettuce outbreak... public health professionals took pictures of their computer screens to share via text messages images of lab reports from implicated food samples identifying the linkage to human illness. Why? Because key electronic data systems storing epidemiologic and laboratory data had no way to seamlessly share the information and speed the response."** [6]
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> **Janet Hamilton, MPH**
> **Council of State and Territorial Epidemiologists**

5 Office of Public Health Scientific Services. CDC Public Health Surveillance Strategy Report: 2014-2018. cdc.gov. https://www.cdc.gov/surveillance/pdfs/Surveillance-Series-Bookleth.pdf. Published September 2018.

6 Hamilton, J. FY20 LHHS Testimony Hamilton. Oral. CSTE. https://cste.sharefile.com/share/view/sc5e20318a5a49a1a. Published April 24, 2019.

> ***"CDC is dedicated to unlocking the full potential of data for disease detection, prevention, and elimination. For over 70 years, CDC has used the best available science and data to make public health decisions. We must continue to be bold and innovative to eliminate disease, protect Americans from health threats, and improve the human condition."***
>
> **Robert R. Redfield, MD**
> **Director, CDC and Administrator, ATSDR**

Lack of interoperability between data systems, reliance on manual, paper-based methods of data sharing, and a siloed approach to public health surveillance slow responses to significant public health threats, allowing diseases to spread and delaying detection of health conditions.

Interoperability is critical to the public health data superhighway because it allows different technology systems and software within and across organizational boundaries to communicate, exchange information, and use data in a coordinated manner.[7] This would allow coordinated and comparable data exchange, eliminating the need to create hundreds of individual surveillance systems for each disease and enabling state, territorial, local, and tribal jurisdictions to exchange any public health data seamlessly between each other and with CDC.

This enterprise approach is crucial to the future of public health surveillance because the public health data superhighway will:

- Inform decision-making by providing access to data sources that are currently unavailable or burdensome to retrieve;
- Enable coordinated responses to emerging public health threats without developing multiple stand-alone systems specific to diseases or conditions;
- Ensure that data systems are interoperable within public health as well as with external health care providers;
- Support sophisticated data analytics, thereby allowing public health professionals and policymakers to make smarter, faster decisions and get ahead of chronic, emerging, and urgent threats;
- Support federal, state, territorial, local, and tribal public health needs;
- Establish effective security and privacy protections to limit data breaches.

7 What is Interoperability? himss.org. https://www.himss.org/library/interoperability-standards/what-is. Accessed April 23, 2019.

Examining the Barriers of the Current Public Health Surveillance System

As the public health community looks to modernize public health surveillance, CSTE conducted a review of key challenges currently faced by the United States public health surveillance system for this report. Two focus groups of public health subject matter experts—including state and local epidemiologists, state and local public health laboratorians, state vital record registrars, and health care providers—convened in April 2019 to discuss the current landscape of data sharing through the public health surveillance system, and identify barriers to integrated, interoperable data exchange on the public health data superhighway.

To frame the discussion, participants in the focus groups were asked to describe how data is shared and moved through today's public health surveillance system for four public health threat case studies. Discussion questions can be found in Appendix B. While all public health threats rely to varying degrees on the five core pillars of public health surveillance—and would benefit from enterprise-wide improvements—experts discussed specific pillars in each case study to highlight principle functionality in monitoring the specific health threat. Thus, the case studies are illustrative, and not exhaustive, of the challenges of the current system and the opportunities to build a public health data superhighway.

While an effort was made to capture a diverse set of experiences and locations when selecting the subject matter experts, this report provides a snapshot of the difficulties and barriers experienced by public health departments, public health laboratories, and health care providers from predetermined jurisdictions and geographical areas, and is thus not generalizable to every jurisdiction. Indeed, each jurisdiction's experience is unique given the fragmented, uneven approach to systems modernization nationwide.

That said, the common themes that emerged across the diverse representations of subject matter experts highlight mutual challenges that can be addressed **by improving the core public health data infrastructure at an enterprise level.** This report summarizes the barriers that obstruct the timely and efficient transfer of public health data, and demonstrates the need to establish an interoperable, secure, and automated public health data superhighway that protects the health of all Americans.

Public Health Authority to Receive and Protect Confidential Data

Public health's ability to collect identifiable, patient information is necessary to respond to public health threats effectively and is a critical aspect to protect the nation's health. Below are descriptions of public health's authority to collect and protect patient information:

- Public health has broad authority to collect data to prevent and control disease and protect public health; [1]
- State and Local Health and Sanitary Codes authorize receipt and investigation of reportable disease data by public health. The ability to collect identifiable patient information is necessary to respond effectively, codified primarily by state and local laws and regulations;
- The Health Insurance Portability and Accountability Act (HIPAA) of 1996 permits public health information disclosure to public health without patient consent; [2]
- Confidentiality is rigorously protected by public health laws at all times; information use is limited to the purpose for which it was collected; [3]
- Information that could result in the identification of an individual is not released.

Today, data privacy concerns have become a pressing issue for many patients as they interact with the health care and public health communities. Although public health surveillance activities benefit patients at both the individual and population level, patients often find the term "surveillance" threatening. This negative perception persists for several reasons. To start, health data includes some of a patient's most confidential information, such as diagnoses (e.g., HIV status, addiction) that may be used to stigmatize or discriminate against vulnerable populations. Because most patients do not understand where health data are stored and protected, the functions of public health surveillance and how public health authorities use the data, a pervasive "fear of the unknown" breeds distrust of the public health surveillance system. While public health data is both a strategic asset and a critical national resource to protect our democracy, American patients have historically disfavored government-led surveillance initiatives, so essential public health surveillance mechanisms may be incorrectly interpreted as an unreasonable overreach into individual patients' lives instead of beneficial.[4] Finally, the increasing threat of sophisticated health data system security breaches exacerbates patient concerns about health data misuse. Cyber vulnerabilities such as hacking, malware, ransomware, and phishing attacks impact millions of patients each year, and cost the industry $6.2 billion annually.[5, 6] Moreover, these cyberattacks also disincentivize patients—who fear becoming victims of health data misuse—from honestly and fully disclosing essential health information to providers.[7]

Health data privacy and security issues are addressed by a complex web of federal and state regulations with variable standards for health data protection and usage within the public health surveillance system. Traditionally, public health data collection and transmission processes have been manual, such as faxing reports from a clinical laboratory to a public health department. In addition to being slow and riddled with data errors, these manual processes are also especially vulnerable to security threats, lack audit trails, and risk misplacement of paper documents or transmission to the wrong place. On the other hand, electronic data systems promote timeliness and improve data quality, but must meet rigorous data security standards.[8,9] As the public health community shifts to electronic public health surveillance, it must have adequate resources and leadership to respond to privacy and cybersecurity challenges facing the public health community, and continue to prioritize strong cybersecurity infrastructure to adequately defend against breaches or attacks on any public health data system.

1 Whalen v Roe. law.cornell.edu (Burger Court 1977). https://www.law.cornell.edu/supremecourt/text/429/589.
2 Permitted Uses and Disclosures: Exchange for Public Health Activities. Healthit.gov. https://www.healthit.gov/sites/default/files/12072016_hipaa_and_public_health_fact_sheet.pdf. Published December 2016.
3 Section 308(d) of the Public Health Service Act (42 U.S.C. 242m). cdc.gov. https://www.cdc.gov/rdc/Data/b4/section308.pdf.
4 Geiger AW. How Americans have viewed government surveillance and privacy since Snowden leaks. Pew Research Center. https://www.pewresearch.org/fact-tank/2018/06/04/how-americans-have-viewed-government-surveillance-and-privacy-since-snowden-leaks/. Published June 4, 2018.
5 The Rampant Growth of Cybercrime in Healthcare. Workgroup for Electronic Data Interchange. https://www.wedi.org/docs/publications/cybercrime-issue-brief.pdf?sfvrsn=0. Published February 8, 2017. Accessed May 9, 2019.
6 Ronquillo JG, Winterholler JE, Cwikla K, Szymanski R, Levy C. Health IT, hacking, and cybersecurity: national trends in data breaches of protected health information. JAMIA Open. 2018;1(1):15-19. https://academic.oup.com/jamiaopen/article/1/1/15/5035928. Published June 11, 2018.
7 Ibid.
8 Privacy, Security, and Electronic Health Records. hhs.gov. https://www.hhs.gov/sites/default/files/ocr/privacy/hipaa/understanding/consumers/privacy-security-electronic-records.pdf.
9 Kruse CS, Smith B, Vanderlinden H, Nealand A. Security Techniques for the Electronic Health Records. J Med Syst. 2017;41(8): 127. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5522514/. Published July 21, 2017.

Infographics

The Public Health Data Superhighway

When thinking about an interoperable public health data superhighway, consider an **interstate highway**. What are the characteristics of an interstate highway that allows different cars to get to different destinations?

- The interstate highway provides a common infrastructure for rapid, efficient movement of cars regardless of the destination;
- The interstate highway supports all makes and models of cars;
- The interstate highway allows for bidirectional travel within as well as between states;
- Roads that make up the interstate consist of multiple, bidirectional lanes;
- There are standard signs, road markings and layout;
- On ramps and off ramps allow some cars to enter and exit at different points on the interstate highway depending on their origin and destination.

Similarly, what are the characteristics of an **interoperable public health data superhighway**?

- The superhighway provides a common infrastructure for rapid, timely data exchange regardless if it is sent to public health departments, public health laboratories, vital records registrars, or federal agencies;
- The superhighway supports efficient movement of diverse types of data for different diseases and conditions;
- The superhighway allows for bidirectional data exchange within states, within CDC, and between states and CDC;
- Disease-specific surveillance systems that make up the superhighway work simultaneously, sharing the same infrastructure;
- Data has a standard format;
- Data can be accessed by different entities along the superhighway; data can be added to enhance existing data in the superhighway.

*Data move **securely** and **seamlessly** between three main actors:*

Patients

Patients provide health data when seeking medical care

Health Care

Electronic health records generated by health care providers contribute patient medical records to the public health surveillance system

Public Health

Epidemiologists (disease detectives) in state, territorial, local, and tribal departments conduct investigations to control public health threats, while laboratory results confirm diagnoses and support rapid responses. These data are shared with CDC, advancing national health protection

But other sources play a role, too:

Non-Traditional Sources

Data sources from the environment, pharmacies, schools, and prescription drug monitoring programs supplement public health surveillance data

Vital Records

Detailed information is collected to keep track of the births and deaths that occur each year

The Public Health 21st Century Surveillance SUPERHIGHWAY

Collected at the point of contact with health care providers, health data have a long journey ahead before informing public health prevention and intervention efforts. In the digital world, this path is instantaneous and seamless—one that eschews disease-specific silos in favor of enterprise-wide interoperability to provide high-quality and timely information.

DESTINATION

Health Protection

Secure, enterprise, interoperable public health data systems rapidly and seamlessly share data, protecting Americans from public health threats of all types—acute, chronic, and emerging

Walter G. Suarez, MD, MPH
Executive Director, Health IT Strategy and Policy
Kaiser Permanente

Expert Testimonial

"Public health surveillance saves thousands of lives every year in the United States. We have the potential to save even more lives and to better and more effectively detect and prevent the spread of diseases, with the implementation of a fully integrated, interoperable, secure electronic public health surveillance system.

Public health surveillance has been called the cornerstone of public health practice and a critical function and responsibility of the entire health care ecosystem. Spanning from federal, state, and local public health agencies to health care providers, clinical laboratories, health plans, social service agencies, and others, its primary purposes could not be more important to society at large: actively monitor and serve as an early warning system to detect diseases when and where they occur; stop diseases from spreading; track effectiveness and impact of interventions; inform and respond to shifting public health priorities; and ultimately keep people healthy.

In today's rapidly evolving digital economy, the foundational principles of public health surveillance—**continuous, systematic collection, analysis and interpretation of health-related data for planning, implementing and evaluating public health actions**—remain unchanged. What is undergoing a fundamental transformation is how public health surveillance is achieved.

Twenty years ago, at the dawn of the information technology era, most health care and public health activities relied on paper, phones, faxes, and manual processes. Today, when we are at the brink of what some have called the Fourth Industrial Revolution, we are building on information technology advances to improve the speed, accuracy, reliability, effectiveness and interoperability of health information collected and used in public health surveillance.

Significant progress has been made in the past 15 years to improve the nation's public health surveillance systems, and more changes are needed to achieve the vision of a seamless, integrated, interoperable electronic public health surveillance system for the nation. Among them:

- Timeliness: be able to collect surveillance data in real or near-real time;
- Data Quality: ensure data being captured and collected is as complete and reliable as possible;
- Structured Data: strive to capture data that is structured for automated handling;
- Interoperable Standards: adopt and use electronic interoperable technical standards for data collection and exchange;
- Information Infrastructure: modernize public health information infrastructure and data systems;
- Advanced Analytics: pursue the use of advanced descriptive and predictive analytic tools, including artificial intelligence and machine learning;
- Interconnectivity: ensure that public health surveillance systems are interconnected with other systems in the community via electronic health information exchanges;
- Improved Access to Data Sources: pursue expanded access to electronic health record systems and other health information systems and data sources in the community;
- Integrating Workflows: explore improving the integration of public health and clinical workflows to ensure that data captured in the clinical space is rapidly identified for, and reported to public health;
- Registries: avoid the proliferation of one-off public health and clinical registries by pursuing a new national integrated registry framework;
- New Technologies: harness new technologies such as cloud computing, social networks, patient-generated health data, and mobile medical devices;
- Multi-Directional Communication: establish surveillance systems that interactively communicate back actionable information to key actors in the health care system.

The future of public health surveillance is inextricably connected to the future of health and health care. We continue to move away from a "sick" economy that focuses on diseases, and into a new economy that focuses on the health and well-being of individuals and the communities they live in. Our efforts should be aimed at delivering the highest-quality, most-affordable personalized health care, while at the same time addressing the social needs and determinants of health of individuals and communities. This supports a public health surveillance system that proactively addresses both traditional and non-traditional public health emergencies and population health needs, using advanced health information technology tools and resources.

Case Studies

Challenges of Today's Public Health Surveillance System

Opioid Overdose

The nation is in the midst of a devastating opioid use epidemic. The most recent national data available from CDC based on state vital records shows approximately 68 percent of the 70,200 overdose deaths reported in 2017 involved an opioid.[9] In past years, the epidemic was driven by prescription opioid-related overdose deaths, but starting in 2013, illicitly manufactured and synthetic opioids such as fentanyl and carfentanil began to rise. Today, the opioid epidemic is fast moving and fueled by these highly potent synthetic substances. The consequences of the opioid epidemic are devastating to communities and families and create a complex public health problem. Staying ahead of the epidemic requires identifying emerging synthetic drugs, usage trends, creating early warnings to alert communities of overdose spikes, and evaluating the effectiveness of control strategies, programs and policy. This requires accurate and timely overdose data to inform responses at the local, state, and national level.[10]

CDC has made significant investments within 32 states through the Enhanced State Opioid Overdose Surveillance Program and the National Syndromic Surveillance Program to increase timeliness of reporting fatal and non-fatal opioid overdoses.[11] This investment has allowed these states to start providing more comprehensive data to CDC by enhancing their surveillance systems, and begin linking data sources from medical examiners and coroners, emergency rooms, hospitals, and toxicology reports. Developing early warning systems for drug overdoses, diagnostics tests, and quantifying the number of deaths from fentanyl analogs have been early successes of the effort. CDC has also funded the implementation of EDRS to enhance reporting of fatal opioid overdoses—and all causes of death—from funeral homes to the vital records registrar and ultimately to NCHS. As of December 2018, 49 of the 57 vital statistic jurisdictions have implemented EDRS.[12]

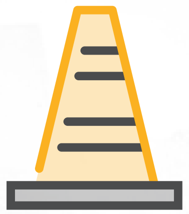
However, there continue to be many significant barriers within states to provide timely opioid surveillance data to both their health departments for local and state responses and to CDC for national responses. A comprehensive public health surveillance system requires uninterrupted data exchange from the health care system to the public health department and CDC.

Follow the Data

Currently, in the event of an opioid overdose death, the decedent's EHR and past medical history collected at the point of care are not linked to the EDRS. To access this information, there are significant and time-consuming administrative burdens. Medical examiners and coroners must manually access the health care provider's health information exchange (if available) or EHR and prescription drug monitoring

9 Understanding the Epidemic. cdc.gov. https://www.cdc.gov/drugoverdose/epidemic/index.html. Updated December 19, 2018. Accessed April 11, 2019.
10 Landen M. Nonfatal Opioid Overdose Standardized Surveillance Case Definition. cste.org. https://cdn.ymaws.com/www.cste.org/resource/resmgr/ps/2019ps/Nonfatal_Opioid_Overdose_011.pdf. Updated 2018.
11 Connecting Data Helps Combat the Opioid Crisis. cdc.gov. https://www.cdc.gov/drugoverdose/epidemic/index.html. Updated August 23, 2018. Accessed April 11, 2019.
12 Information Systems for Vital Records Stewardship. naphsis.org. https://www.naphsis.org/systems. Published 2014. Accessed May 11, 2019.

databases to get comprehensive data around the overdose death. As medical examiners and coroners work to determine the cause of death, they create a record that is unique to their system (some are paper/file systems) where toxicology laboratory results, patient history, additional records, and documents are stored. This medical examiner record is not linked to the health care system's EHR and is not accessible to the public health department, vital records registrar, or the EDRS. If an epidemiologist needs data to help inform decision making to address a local outbreak, a manual request must be made over the phone or through email to the medical examiner or coroner. The information is then faxed to the health department for manual input into another database. There are no national consensus-based standards for how the data should be stored in the EHR or shared with public health.



Road block! Progress has been made to improve public health surveillance, but in a very limited scope, often focusing on just one component of the system

Compare this approach to improvement to the interstate analogy: If the interstate needs five miles of repaving, but only one mile is fixed, the cars' progress toward the destination will still be impeded and delayed despite the improvement.

While public health laboratories do not provide post-mortem testing, some are starting to gain the capacity to provide testing in cases of non-fatal overdoses. Test requests to the public health laboratory are often done through a phone call from the ordering health care provider followed by a paper-based (or rarely, an electronic) test requisition form. Depending on whether the laboratory has an electronic reporting system to epidemiologists, the test results will either be sent through this system or provided in a spreadsheet via fax or email. Test results sent back to the ordering health care provider are almost entirely via phone call, or a faxed or mailed paper report. Some toxicology testing, however, may be conducted by a private reference laboratory in which test results are mailed, faxed, or emailed back to the public health laboratory. These test results are not captured within the LIMS, and therefore often never get to the health department as reportable data, leaving a significant data gap.

Throughout the process of data sharing from patient care to the health department, there are many manual processes that could be streamlined by connecting existing databases and automating data transfer. Dependence on phone calls, faxes, and emails obstruct real-time information from guiding important decisions made by health care providers and public health departments. On a national level, the mortality statistics released annually to the public by CDC are at least one year old; in 2019, the best data available at the national level is from 2017. With this delay, the opioid epidemic continues to march ahead of the nation's manual public health surveillance capability.

Foodborne Outbreak

Illnesses caused by foodborne disease agents are commonplace in the United States with approximately 48 million people getting sick, resulting in 128,000 hospitalizations and 3,000 deaths per year.[13] In the event of a multi-state foodborne outbreak, timely, complete, and accurate exchange of data between public health agencies at the federal, state, territorial, local, and tribal level is critical to identify and remove the source of contamination and prevent further illness.

Since 1996, **PulseNet**—a national network of 83 laboratories that uses DNA "fingerprints" to identify bacteria causing foodborne illness—has facilitated the exchange of data to mitigate local and multi-state outbreaks. People who have been sickened by bacteria with similar DNA fingerprints can be linked to other people who consumed the same contaminated food. This allows public health professionals to identify a foodborne outbreak, determine its cause, and take actions such as a food recall to prevent further illness. PulseNet relies on standardized methods and a secure online database that allows for the real-time exchange of data between public health laboratories and federal agencies such as CDC, the Food and Drug Administration, and United States Department of Agriculture, revolutionizing the ability to detect and respond to foodborne outbreaks quickly and efficiently. Essential to the vitality of PulseNet is the timely exchange of standardized data.[14] And while linkages of the laboratory data have been crucial to detect outbreaks, the system is not linked to the epidemiological data systems that store the information necessary to determine the likely cause of the outbreak.

Advanced molecular detection (AMD) has also integrated new technologies and disciplines, such as next generation sequencing (NGS) and bioinformatics, into traditional disease investigation methods. By providing a greater level of detail and information on the genetic makeup of pathogens, NGS enables public health professionals to detect the occurrence of related illnesses—signaling a cluster or outbreak—and respond to public health threats more rapidly and effectively. Highly specialized data scientists in bioinformatics use high performance computing methods to analyze vast quantities of genetic data. When epidemiologists investigate foodborne outbreaks, they can now leverage AMD to quickly link genetically related clusters of illness to contaminated food.[15] AMD is replacing the less accurate PulseNet technology developed in the 1990s for foodborne outbreak detection and response. However, like PulseNet data, AMD data cannot not stand on its own. It still needs to be linked to other epidemiological data such as case interviews and environmental tests in order to pinpoint the cause or source of the outbreak and implement optimal control measures. A comprehensive public health response will require interoperable data systems between the public health laboratory and epidemiologists.

Road block! PulseNet is only one of the 14 enteric illness public health surveillance systems used by CDC.

Currently, the same data from one case of salmonella must be reported through seven separate surveillance systems at CDC because each system has been built separately and is not interoperable.

Follow the Data

While the exchange of data from local and state public health laboratories to federal agencies has been well established, substantive limitations in overall data exchange during foodborne outbreaks still exist. In addition to sending data to federal agencies, the public health laboratory must also share that data with epidemiologists in their local jurisdictions. Food exposure information, which is necessary to link disease clusters to the contaminated food source, is collected in the field through case interviews and requires data exchange between epidemiologists, laboratories, and federal agencies. Although some public health laboratories have set up electronic systems to exchange foodborne data to epidemiologists, this is not widespread. Public health laboratories still rely heavily on time-consuming manual data entry into spreadsheets, phone calls, faxes and emails. In some instances, an epidemiologist will drive to the public health laboratory twice per week to physically pick up lab reports and bring them back to the health department for manual data entry. As a result, real-time data are not exchanged, creating a traffic jam of information. Anecdotes from the field have also highlighted situations where the quickest way to share outbreak-related data was to email a cell phone photo of a computer screen because the software and system between the sender and receiver were not interoperable, and thus incapable of data exchange. When time is of the essence in a foodborne outbreak for both preventing further illness and not adversely impacting or implicating the wrong industry, these methods delay responses and leave important health information vulnerable to human error such as inaccurate transcription, keying errors, duplicated or incomplete data entry, or no information.

> In some instances, an epidemiologist **will drive to the public health laboratory** twice per week to physically pick up lab reports and bring them back to the health department for manual data entry.

Measles Resurgence

The nation is in the midst of a massive measles resurgence and cases are at the highest since the United States eliminated the disease in 2000. A vaccine-preventable disease, measles is a highly contagious infection that causes high fever, coughing, conjunctivitis, and rashes. Complications can range from mild to severe, including ear infections, pneumonia, encephalitis, and death. Since one infected person can spread the disease through coughing and sneezing to **90 percent of unvaccinated people around them**—even two hours after leaving a room or defined air space—a timely and swift public health response to a measles outbreak is critical.

13 Estimates of Foodborne Illness in the United States. cdc.gov. https://www.cdc.gov/foodborneburden/2011-foodborne-estimates.html. Updated November 5, 2018. Accessed April 16, 2019.
14 Boxrud D, Monson T, Stiles T, Besser J. The role, challenges, and support of PulseNet laboratories in detecting foodborne disease outbreaks. Public Health Rep. 2010;125(Suppl 2):57–62. doi:10.1177/00333549101250S207

15 Advanced Molecular Detection: An In-Depth Look. cdc.gov. https://www.cdc.gov/amd/pdf/amd-indepth-look-P.pdf..

Measles is a nationally notifiable disease, meaning state, local, tribal, and territorial public health departments voluntarily submit de-identified, public health patient data to CDC via NNDSS. A public health surveillance system that monitors 120 diseases nationwide, NNDSS allows CDC to use public health data to determine disease trends, monitor outbreaks, and evaluate prevention and control efforts to protect Americans from serious public health threats.[16]

Follow the Data

During large nationwide outbreaks, including the recent rise of measles spurred by vaccine refusal, improvement efforts through NMI have helped to expedite public health control and prevention efforts. However, these improvements are limited to data exchange between health departments and CDC, and many barriers still remain at the territorial, tribal, state, and local levels—ultimately slowing down responses.

> In a non-outbreak scenario, the public health laboratory prints and **manually faxes** anywhere between 100-200 infectious disease test reports to health care providers daily. This estimate increases exponentially during an outbreak.

As part of the epidemiologic investigation by the health departments, rapid, immediate case identification and contact tracing are critical steps to mitigate a measles outbreak. Currently, this is a labor intensive and time-consuming process where 24/7 call centers are established to broker information about potential measles cases between health care providers and the public health department. If a measles case is suspected, it is necessary for epidemiologists to collect clinical care characteristics, risk exposures, and demographics to initiate follow up. While this information is collected in an EHR by the health care provider at the point of care, it is not automatically or electronically exchanged with public health professionals. If a phone call or fax is delayed or neglected to be sent to the health department, health and epidemiologic data remain incomplete, hindering a comprehensive response to the outbreak. As a result, contagious patients or their exposed contacts may not be identified in a timely manner, allowing them to perpetuate the outbreak by spreading the disease to other vulnerable people.

Similar health data access challenges exist for public health laboratories. Information such as vaccine status and symptom onset date help provide an accurate laboratory interpretation to health care providers and epidemiologists. While the health department epidemiologists may have gathered this information through phone calls, the inability of the laboratory to electronically access these data from either the health department or EHR leaves information inaccessible for a time. The public health laboratory often needs to call the health care provider for the same clinical information previously requested by the health department epidemiologist, or receive emailed or faxed spreadsheets from epidemiologists relaying this information. In a measles outbreak, the magnitude of the public health investigation results in massive amounts of information shared through manual data entry, and often requires removing critical public health employees from response duties to physically transport results and data between health care providers, the laboratory, and epidemiologists.

Due to the fast-paced nature of a measles outbreak and the need for rapid test results, the large volume of testing can overwhelm the capacity of the public health laboratory to provide diagnostic information

16 National Notifiable Diseases Surveillance System (NNDSS). cdc.gov. https://wwwn.cdc.gov/nndss/. Updated March 13, 2019. Accessed April 29, 2019.

to both the epidemiologists and health care providers. With the lack of infrastructure for bidirectional electronic test ordering and reporting between health care providers and the public health laboratory, manual faxes and emailed data are the burdensome means of communication. Test reports can stack up on fax machines, delaying clinical interventions, and mailed test results can take several days to move through the postal system. An example shared from our focus groups crystallizes the time-consuming burden of manual methods: in a non-outbreak scenario, the public health laboratory prints and manually faxes anywhere between 100 to 200 infectious disease test reports to health care providers daily. This volume increases exponentially during an outbreak.

Finally, although NMI has made substantial improvements to NNDSS, gaps still remain. In non-outbreak situations, data are sent to CDC through NNDSS on a weekly basis. However, this weekly frequency becomes inadequate during a response to an outbreak when data are needed as quickly as possible. Due to this limitation, CDC will often ask jurisdictions to call or manually provide spreadsheets of data to expedite the data sharing process. This, however, does not supplant the need for jurisdictions to continue to report data through NNDSS as the outbreak data sharing processes do not link with the regular, less timely established processes; therefore, the same data is sent multiple times to CDC through different systems. This itself is error prone and results in additional processes needed to complete reconciliation.

Highly contagious infectious diseases like measles move quickly and indiscriminately through unimmunized communities, and an effective public health response requires public health data exchange to outpace the spread of the disease. Better, faster, accurate data exchange through an interconnected and interoperable public health data superhighway will help track and stop ongoing public health threats.

Natural Disasters

Recent natural disasters, such as Hurricane Florence in North Carolina, Hurricane Harvey in Houston, tornadoes in Mississippi and Alabama, and the 2018 California wildfires, show the impact of natural disasters on the public's health. Damage to a community's infrastructure, injuries, physical and mental illness, and death during or after a natural disaster are important indicators to determine the need for public health interventions, resource allocation, and prevention of further morbidity and mortality. Public health surveillance and the real-time nature of syndromic surveillance help provide situational awareness during the acute phase of a disaster response. This allows for rapid needs assessments that can determine where people are at the highest risk for illness or injury and where limited medical resources should be deployed. In the long term, public health data can be used to assess chronic health consequences that result from a natural disaster and can help provide information for future planning, preparedness, mitigation, and response activities.

Follow the Data

Death statistics are one key indicator of a natural disaster's impact; however, due to the strain a natural disaster puts on emergency systems and public health resources, registering deaths and issuing new birth certificates to individuals that lost theirs during the disaster is a challenge. In the fall of 2017 as Puerto Rico was in the immediate aftermath of Hurricane Maria, the country's paper-based death registration quickly hit the limits of its utility when funeral homes could not reach the deceased because parts of the island were physically unreachable and isolated due to flooding.[17]

17 National Association for Public Health Statistics and Information Systems. Hurricane Maria and Puerto Rico Vital Records – The Difficulties of Death Registration During a Natural Disaster. naphsis.org. https://www.naphsis.org/single-post/2018/03/23/Hurricane-Maria-and-Puerto-Rico-Vital-Records-%E2%80%93-The-Difficulties-of-Death-Registration-During-a-Natural-Disaster. Published March 23, 2018. Accessed April 30, 2019.

In another example, when Hurricane Sandy caused record-breaking storm surge on the coast of New Jersey and New York City, the infrastructure of EDRS was successfully leveraged to collect near real-time mortality data despite major disruptions to power and displacement of public health staff.[18] The existing EDRS structure allowed for the flexibility to rapidly reconfigure the collected information so it would capture immediate information on hurricane-related deaths that otherwise would not have been possible through a paper-based system. In any natural disaster, preparedness and continuity of operations are critical to ensure the continued and uninterrupted collection of vital statistics.

EDRS also have advantages over paper-based systems in that vital record registrars are able to take laptops out into the field, input information into the system, and issue the necessary certificates in the matter of minutes instead of days. Close to the source of information collection, electronic systems also increase accuracy in data collection and provide real-time information on death tolls.

With federal support, **49 of the 57 vital statistic jurisdictions have implemented EDRS**, as of December 2018.[19] However, these funding initiatives have been mostly focused to enhance death data quality and timeliness for statistical and administrative uses of death data—*not* surveillance and more immediate or real-time decision making at the federal, state, territorial, local, and tribal level. A fully functional vital records infrastructure that supports real-time surveillance and is interoperable with other surveillance systems requires concerted investment and attention to upgrade legacy systems that have been in place for almost two decades and to keep pace with the rapid evolution of technology.

Paper-based death registration quickly hit the limits of its utility when funeral homes could not reach the deceased because parts of the island were physically unreachable and isolated due to flooding.

18 Howland RE, Li W, Madsen AM, et al. Evaluating the Use of an Electronic Death Registration System for Mortality Surveillance During and After Hurricane Sandy: New York City, 2012. Am J Public Health. 2015;105(11):e55–e62. doi:10.2105/AJPH.2015.302784

19 Information Systems for Vital Records Stewardship. naphsis.org. https://www.naphsis.org/systems. Published 2014. Accessed May 11, 2019.

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Expert Testimonial

"Data are essential to preserving and protecting the public's health. Nothing demonstrates this need quite like a public health emergency. Our efforts in addressing the opioid epidemic are a prime example of needing up-to-date medical records, pharmacy data, and mortality data.

Historically, IT systems have been built in silos. Programs requested, implemented, and managed them alone. Because of siloed funding streams, there was little to no flexibility in connecting these systems. At our agency, we have over 378 existing applications and 50 systems.

Silos mean that information, effort, and technology are redundant and expensive. Requirements for entities who collect and share data with the department are too difficult and complex, and we aren't providing the level of service we should to our partners: tribes, local health, and non-governmental organizations.

Since 2011, Washington Department of Health has been working to transform "Data at Health." Instead of thinking about separate surveillance systems, we are considering the business needs: what data do we need, how do we use it currently, and how do/will we need to use data in the future?

Our mission is to improve population health through timely and actionable information. Our vision in this work is to revolutionize health through data. Our goals are to:

- Develop well-designed, usable, and maintained information systems;
- Improve efficient and effective intra- and inter-partner data exchange and data use;
- Analyze and disseminate data and information that is timely, ethical, open, and transparent;
- Create a multidisciplinary Information Governance framework;
- Develop Informatics leadership and workforce.

We are currently documenting patterns in our data collection, use, and reporting to help guide and design future technologies that fulfill our vision of a sustainable and productive public health surveillance system. This includes looking to reduce the number of systems we must maintain by allowing systems to share common capabilities like collecting data.

We are developing a bidirectional electronic information exchange between electronic health record systems and the department. We are using national interoperability standards and the state's health information exchange (a common data collection capability) to facilitate the use of data submitted by external organizations. The Health Information Exchange allows us to use one connection point and one data use agreement to exchange a multitude of health data sets with clinical partners for one annual flat cost. These data are taken in to our internal routing system (another common capability) and sent to the correct database for each data set.

An example is our **Prescription Monitoring Program (PMP)**. Integrating the PMP into electronic medical record systems allows us to provide seamless access to important data for addressing the opioid epidemic. This integration allows providers to more easily review the prescription history of a patient and make a more informed decision when prescribing opioids. We are seeing almost immediate results from this improvement with over 20 million queries of the PMP last year, almost twice the number of prescriptions dispensed. We have seen improved prescribing practices from our state's efforts and can share these data at the state and local level through a shared tool for data visualization that many programs use. For the PMP, prescribing practices are tracked using six different metrics we calculate each calendar quarter. With the PMP, we are not only collecting pharmacy data to perform public health surveillance—we are also giving it back to our health care partners at the patient level to improve care. It highlights what you can do when you share capabilities for exchange and visualization and turn it into information.

The number, size, and complexity of our current surveillance data systems, as well as the complexity of our funding structure, make it unlikely that we can implement changes all at once for the many systems we have. Instead, we envision a roll out of components over time. To do so requires a unique funding model with cost allocation to the programs and populations that benefit. We will need to use existing funding in combination with new funding opportunities and federal matching to strategically purchase reusable, configurable, modular components, which will meet multiple surveillance needs. This is all collectively worked on in our agency as Data@Health and the Foundational Public Health Services.

Our investments will need to take advantage of 21st century technological solutions and shared platforms to help keep pace with information system innovations. The hope is that by advancing and keeping pace with standards and our health care partners, we may be able to apply these enhancements in the shared service module rather than each program bearing the cost of upgrading each and every silo. **Such development is critical** to maximally leverage the surveillance and related data we collect to inform disease tracking, case management, clinical decision-making, access to services, intervention effectiveness, and return on investment—both for the Department and our partners.

Key Findings

Progress Made, but Silos Remain

In-depth conversations with public health subject matter experts, combined with extensive research of current literature, identified several key findings in the current state of the nation's public health surveillance system.

Improvements: Paving the Way

Public and private sector collaboration and leadership have improved current systems and implemented limited disease or condition specific electronic data exchange.

1. CDC Surveillance Strategy

Over the years, as technology has advanced, there have been investments to build the nation's public health data superhighway. CDC continuously works strategically to improve the exchange of data within its own programs and within the states. Launched in 2014 after recognition that the nation's public health data systems were inefficient and falling behind, a strategy was developed and implemented to improve public health surveillance. The elements of the strategy focused on four areas: NNDSS, syndromic surveillance, mortality reporting, and ELR to establish data standards, decrease redundancies and reporting burdens on state and local health departments, and reduce the number of siloed, disease-specific systems.[20] Between 2014 and 2018, significant progress and achievements have been made:

- Mortality reports electronically collected from states within ten days of death increased from 7 percent in 2014 to 63 percent in 2018;
- A modernized electronic messaging system was implemented to receive notifiable disease cases;
- 60 percent of emergency department visits are reported electronically to health departments;
- 80 percent of laboratory reports are now sent electronically to state health departments.[21]

CDC has also sought to use innovation to enhance the collection of data, and are working to establish a secure, cloud-based platform to centralize where health departments and public health laboratories can send data. Ultimately, the Surveillance Data Platform will reduce the burden of duplicative data entry, sending the same data multiple times to different disease program areas, increase coordination between the states and CDC, and provide new opportunities to perform advanced data analytics including predictive analyses.

20 Office of Public Health Scientific Services. CDC Public Health Surveillance Strategy Report: 2014-2018. cdc.gov. https://www.cdc.gov/surveillance/pdfs/Surveillance-Series-Bookleth.pdf. Published September 2018.
21 Ibid.

2. Advanced Molecular Detection Program

CDC has also led advanced molecular detection efforts within the agency and continues to support state and local health departments to adopt next generation sequencing technologies. The agency's commitment to improve the availability of AMD technologies has revolutionized public health laboratory and epidemiological science to address public health threats, including (but not limited to) **antibiotic resistance, foodborne illnesses, health care associated infections, vaccine preventable diseases, and vector-borne disease.** The AMD program's successful outcomes include faster and more accurate tests to diagnose infections, improved vaccines, identifying emerging pathogens, mapping disease transmission sooner, and responding to outbreaks.[22] CDC has also recognized the importance of investing in the bioinformatics workforce to ensure that highly specialized genomic expertise exists in public health departments. Through a partnership with the Association of Public Health Laboratories (APHL) and CSTE, CDC supports bioinformatics training programs for public health professionals. Through the investments and efforts of the AMD program, CDC and public health laboratories are now leading laboratory innovation to respond to public health threats.

3. APHL Informatics Messaging Services: A Public Health Information Exchange for Lab Data

Frustrated by the need for public health laboratories to develop and maintain multiple electronic data exchange connections for every public health partner that required laboratory data, APHL developed the APHL Informatics Messaging Services (AIMS) platform in 2007. This platform is a secure, interoperable, cloud-based data hub that aids in the transport, validation, translation, and routing of electronic laboratory data, eliminating the need for multiple connections. Now, instead of sending disease and condition-specific data through multiple unique data systems, laboratories can link their LIMS to the AIMS platform where their critical public health data is automatically routed and made available to partners like CDC, hospitals,

22 Advanced Molecular Detection. cdc.gov. https://www.cdc.gov/amd/pdf/amd-at-a-glance-final-508.pdf.

Building the Public Health Workforce: AMD Leading the Way

AMD is driven by a modern public health workforce proficient in three unique areas: laboratory science, epidemiology, and bioinformatics. Bioinformaticians are primarily data scientists trained to analyze and interpret large data sets as applicable to public health. It is important to recognize the specialized skill set of bioinformaticians—one not encompassed by traditional laboratory or epidemiology training—which includes in-depth computational and statistical analysis, the application of bioinformatics to conduct research on huge molecular data sets such as those generated by AMD technologies, and the development of computer tools to track patterns of outbreaks. Working together, public health laboratorians, epidemiologists, and bioinformaticians can harness new technologies to facilitate more, better, and faster public health data.

Advancements in technology have revolutionized public health laboratory and epidemiological science by generating a wealth of data on the genetic makeup of pathogens. Traditionally, public health laboratorians and epidemiologists have not been trained in the field of bioinformatics. However, as these advanced laboratory techniques become the norm, public health has a growing need for a highly trained bioinformatics workforce that can maximally leverage these technologies' benefits. Currently, there is a large bioinformatics workforce gap in public health that must be addressed. Two programs—APHL and CDC's Bioinformatics Fellowship, which trains and prepares bioinformaticians to apply their expertise within public health, and CDC, CSTE, and APHL's AMD Academy, which trains epidemiologists and public health laboratorians in bioinformatics—must be expanded and replicated. Investments in fellowships, training programs, job creation and professional development must be prioritized for public health to leverage and stay ahead of advances in technology.

health care providers, private laboratories, and other public health partners within the laboratory's jurisdiction. Today, the AIMS platform connects more than 200 health care organizations, and nearly every state is exchanging some data through the AIMS platform. This is moving public health data to the fast lane. However, AIMS' current functionality is limited to the diseases and conditions that have program-specific funding, and is not employed broadly for enterprise-wide public health surveillance. While AIMS provides the infrastructure necessary for laboratory data exchange, investments are needed to speed up public health data at all levels of government to benefit all public health programs.

4. Jurisidictional Improvement

State, territorial, local, and tribal jurisdictions have all increased efforts to move from paper-based data collection and entry to automated, interoperable, and integrated electronic systems. Focus group members each had examples where their health department took steps toward interconnected data exchange. Some examples include:

- Software development to enable automated data transfer from vaccine registries;
- Implementation of electronic test ordering and reporting for laboratory results to priority health care facilities;
- Barcodes on specimens to transfer patient demographic information directly into LIMS;
- Social media platforms and symptom-related key word searches on the internet that can be leveraged by public health to identify health event trends in communities and pulled syndromic surveillance databases;
- Implementation of eCR at two sites (Houston and Utah), with five additional sites positioned to onboard.

Challenges: Stuck in the Slow Lane

Despite progress in moving surveillance into the 21st century, antiquated, fragmented, and siloed data sharing systems continue to impede public health action.

1. Manual Methods of Data Exchange: An Administrative Burden

Despite the progress in electronic data exchange, our focus groups revealed that the nation's public health surveillance system still heavily relies on manual processes, like paper-based data sharing, phone calls, and faxes. The case studies highlight areas where reliance on these processes inhibits timeliness, accuracy, and completeness. In one example, electronic systems support the exchange of opioid use data between the public health laboratory and epidemiologists. Yet, data reported by reference laboratories through email and fax are not integrated into the broader opioid use surveillance data. This particular example highlights the consequences of modernizing only one data system within the larger public health system. While comprehensive data exists and is reported to the health department, the mechanical difference in data exchange results in a significant data set being left unintegrated, and thus unable to inform the public health response to the opioid epidemic.

In addition to data gaps, manual processes are incredibly burdensome to health departments and health care providers. It is confusing to simply keep track of which diseases and conditions are still using manual reporting versus electronic reporting. Additionally, the amount of paperwork that must be processed is time-consuming and inefficient. For public health laboratories, often two laboratory reports have to be exchanged: one to epidemiologists for public health purposes, and one to the ordering health care provider for clinical diagnostic purposes. There is little infrastructure that allows the bidirectional flow of test ordering or result reporting from health care providers to public health laboratories, therefore, phone calls and faxes are heavily relied on. A focus group member shared that the biggest bottleneck in their process is manually faxing 100-200 infectious disease test results back to health care providers each day. This task not only ties up a highly trained public health workforce in administrative activities, but also detracts from time that could be dedicated to public health interventions. The pressure of this burden becomes acute during an outbreak or public health emergency, when test volume is high and the public health workforce is stretched.

Highlights of other manual administrative burdens shared by the focus groups are listed below:

- If specimens are sent to CDC for testing, tests cannot be ordered electronically, and results cannot be returned electronically. Any information shared back to jurisdictions are contained in spreadsheets or individual PDF documents and have to be reformatted and manually entered into the health department's database.

- During outbreaks, CDC will often set up ad hoc disease-specific surveillance systems that have different data requirements than the routine surveillance system. This results in **duplicative, manual data entry**: one entered into NEDSS and one into the outbreak system. Due to different requirements, the health department must reformat the data several times to satisfy the needs of its own database *and* the multiple databases at CDC.

Manual data entry and paper-based data exchange through phone calls, faxes, and emails impede timely responses, perpetuate outbreaks, and can potentially cause loss of life.

- Disparate software systems between epidemiologists and public health laboratories prevent electronic data exchange; therefore, public health staff must create and manually enter data into spreadsheets.
- Epidemiologists must retrieve copies of laboratory reports in-person from the public health laboratory multiple times per week because electronic systems are not available to exchange data.
- Vital records registrars, epidemiologists, and public health laboratorians must call health care providers to request patient medical history, records, and other documents, which are then faxed to the health department.

Manual processes like these leave room for error. Inaccurate data entry, reports that are delayed or never submitted, reports faxed to the wrong entity, incomplete data reporting—these all compromise data quality and impede timely data exchange. Because data exchange relies on paper records, phone calls, spreadsheets, and faxes, public health threats are moving faster than the nation's current public health surveillance system. The consequences of inefficient and slow data sharing are significant: delayed detection and response, lost time, lost opportunities, and lost lives.

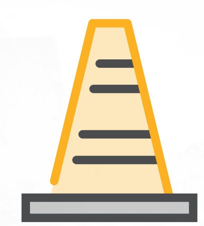
2. Siloed Systems: The Need for an Enterprise-Wide Approach

Public health surveillance systems traditionally have been created to serve specific programmatic needs. The evolution of these systems has arisen because funding to establish and maintain surveillance systems is allocated to one disease agent, such as influenza. Within the federal government, siloed funding streams have created more than one hundred disease-specific surveillance systems at CDC. Focus group members shared that within their own health departments, some diseases and conditions are set up for electronic data exchange while others are not, because funding mechanisms are program-specific and hamper efforts to make systematic improvements.

The lack of enterprise-wide improvements and sustainable funding creates interoperability challenges at two levels: **1)** within a health department, individual surveillance systems are not able to exchange information with each other; and **2)** health department systems cannot exchange information with CDC and vice versa. As long as investments are made to siloed public health surveillance systems, the barriers to seamless and timely data exchange will persist.

3. Absence of EHR Integration with Public Health: A Time Burden for All

EHR implementation throughout the health care community has increased rapid access to medical records, and has benefited patient care significantly by improving care coordination, enhancing privacy and security of health data, and reducing medical errors. Information such as patient demographics, laboratory diagnoses, risk factors, prescriptions, immunizations, previous treatments, and health care provider notes are stored in EHRs. In addition to clinical decisions, these valuable data can inform epidemiologic investigations and be de-identified to provide information on the health of communities, cities, and states. Despite the efforts and success to standardize and implement EHRs within the health care community, a wide gap remains connecting health care data to the public health surveillance system. **Data standards are different** between clinical care, CDC, and public health agencies, hindering the ability to efficiently share data across the clinical and public health sectors. Therefore, to share data with public health, health care providers must field redundant calls and resort to manual data sharing of critical health information that is otherwise available in the EHR. This results in major inefficiencies, lost time, and a diversion of clinical resources from patient care. Additionally, this approach diverts public health resources—technologies to support public health surveillance should facilitate more time for epidemiologists to focus on epidemiologic functions, or for laboratorians to perform testing.



Road block! Building disease-specific surveillance infrastructure is redundant and inefficient.

This is akin to constructing interstates that only allow a specific model of car. Each interstate has common infrastructure, yet efforts have not been made to utilize a foundational infrastructure to allow one interstate with lanes for multiple types of vehicles.

Christine Steward
Health Protection Director,
Sedgwick County Health Dept.
Wichita, KS

Expert Testimonial

"Local health departments make it easier for people to be healthy and safe. The Sedgwick County Health Department (SCHD) in Wichita, Kansas improves the health of more than 513,000 county residents by preventing disease, promoting wellness, and protecting the public from health threats. Every day, SCHD works with the state health department, Kansas Department of Health and Environment (KDHE), and local partners that use multiple inter-and intra-agency data systems to track and report their work. SCHD must have a **trained data workforce and enhanced infrastructure**, such as interoperable data systems automated to exchange information, to quickly and effectively gather and apply data to improve local health outcomes.

A workforce trained in data collection and analysis is critical for SCHD as it positions itself as a data warehouse, information distributor and technical advisor to local partners working to show community health program effectiveness. Compared to most local health departments in Kansas, SCHD has greater data analysis capacity and expertise. However, the large amount of work requested of data staff means projects have to be prioritized. Students working on data-oriented projects enhance data analysis capacity at SCHD.

Federal, state and local public health entities are linked together through state statutes and local ordinances, common population health purpose, and funding. Due to internally and externally siloed program management through the years, multiple software systems used by all levels of public health for managing work and reporting to each other have created **inefficient processes**—such as duplicate data entry—and are a barrier to advancing population health. SCHD is no exception. A 2018 internal SCHD survey counted 85 software systems, spreadsheets, and databases in use to manage and report data generated and received by SCHD.

Federal disease surveillance funding to CDC benefits local public health through enhancing federal software systems that state and local health departments use, and also through opportunities for state and local health departments to create automated, interoperable, and secure systems for rapid implementation of disease control measures.

- In Kansas, under public health statutes and guidelines, local health departments like SCHD contact residents diagnosed with certain notifiable diseases, such as whooping cough. SCHD staff record disease investigation information in EpiTrax, a secure, internet-based system maintained by KDHE. While not interoperable with other SCHD systems, EpiTrax does allow real-time collaboration on disease investigations by SCHD and KDHE.
- A new notifiable disease system developing nationally but not yet available to SCHD is a massive undertaking to standardize and implement Electronic Case Reporting (eCR). This system automatically pulls specific disease reports from electronic health records at clinical care organizations, and reports to public health without manual intervention. This improves medical provider-required disease reporting timeliness. In Kansas, KDHE implementation of eCR will benefit SCHD by decreasing the time to begin disease investigations and control measures.
- Through KDHE, SCHD participates in the National Syndromic Surveillance Program (NSSP) BioSense Platform, and is a Kansas leader in analysis of emergency department trends and evaluation of new processes to track health issues such as measles and opioid overdose. Sedgwick County would benefit from expansion of NSSP to include urgent care and outpatient clinics to gain a greater community-wide picture of disease trends.
- Although maintained by KDHE, Vital Records System data—composed of birth, marriage, divorce, stillbirth, and death records—is used extensively by SCHD for monitoring health outcomes, including suicide and infant mortality. For suicide prevention in Sedgwick County, the current state Vital Records System does not supply enough information and the data is not timely. Therefore, throughout each year, SCHD performs manual full case file reviews from multiple sources, manually entering that information into an internally-created database. An electronic Vital Records System that automates and standardizes reporting of hospital, medical provider, and medical examiner records to public health would speed availability of the data to SCHD to decrease the number of people who die by suicide.

Resources to build a trained data workforce and non-siloed, interoperable data systems at public health agencies are important for SCHD as it works with partners and continually strives for timely and effective disease surveillance and reporting. Investment to modernize the public health surveillance enterprise will ensure effective internal processes and external collaboration with partners to protect the health of communities across the United States.

Recommendations

Changing from the Slow Lane to the Fast Lane

With advancements in IT and the proliferation of computer-based record keeping over the past few decades, the barriers to building an interoperable public health data superhighway are not driven by a lack of data or insufficient technology. The public health data superhighway does not necessitate originating new data, but instead requires adequate resources to access timely, quality data from multiple existing sources utilizing modern technology and analytical methods. The recommendations below offer principles that policymakers and stakeholders must consider to successfully build an interoperable public health data superhighway.

Recommendation 1: ENTERPRISE Approach to Data Systems Modernization

Progress to move individual disease-specific surveillance systems to electronic exchange is helpful, but improvements have been isolated in siloed systems, and may only address one specific component of the data exchange process. Segregated systems create redundant infrastructure and huge inefficiencies, wasting resources in a field that is already underfunded. Public health must take an enterprise approach to improve public health surveillance, rather than relying on the traditional program-specific approach. The public health community and health care providers should agree to utilize **a common core data infrastructure**. Public health leadership and policymakers should also create **new and sustained funding opportunities** to support the development and maintenance of the core public health data superhighway.

A transformative, enterprise approach of this magnitude will require a commensurate level of investment. Substantial, predictable, and sustainable federal funding over time would allow CDC, state, territorial, local, and tribal health departments to move from siloed, sluggish, manual, paper-based data collection to seamless, automated, interoperable, and secure data systems that yield critical health information in real time. This funding would also support efforts to continually modernize both these data systems as technology evolves over time, and develop the public health workforce by training, recruiting (e.g., student loan repayment and fellowships), and retaining skilled data scientists.

> The public health data superhighway does not necessitate originating new data, but requires **adequate resources** to access timely, quality data from multiple existing sources utilizing modern technology and analytical methods.

This enterprise approach to data modernization is new, but the core surveillance systems themselves are not. The data systems that feed this public health information superhighway already exist, have demonstrated value, and are used to varying degrees in all state and local public health departments. It is critical to bring all jurisdictions online with these systems and modernize receiving, sharing, and connecting data that exists in silos. In addition, CDC needs its own secure data platform to receive data electronically from the states through NNDSS. While this may seem like a daunting shift, efforts made today are a down payment towards the health of future generations.

Recommendation 2: INTEROPERABLE Data Systems

The public health data superhighway must be built on the foundation of interoperable data systems and shared data standards. Many of the current challenges facing today's public health surveillance system are rooted in the discrepant public health data systems that cannot communicate with one another or external, private sector health care providers. Interoperability will drive more, better, and faster public health data.

More Data

Enhancing and improving public health surveillance requires better access to existing data sources. Increased access can be accomplished in two ways. First, it is paramount to access the wealth of data in EHRs. With the advancement and proliferation of EHRs, the public health and health care communities have an opportunity to increase efficient data transfer and enhance the quality, accuracy, completeness, and depth of the data contributed to public health surveillance. Seamless delivery of EHR data to public health will result in high-value data to public health surveillance efforts and create several efficiencies by reducing redundant manual request for clinical information.

Second, as the public health data superhighway is constructed, it should include electronic access to non-traditional data sources such as medication-assisted treatment programs, pharmacies, social media, disease registries, and prescription drug monitoring programs to supplement traditional data sources. Automated access to non-traditional data sources combined with traditional data sources will bring additional value and depth to public health activities.

Better Data

The paper-based methods of data collection and sharing are vulnerable to errors and mistakes. Transcription and translation errors, duplicate entries, and incomplete information reduce the quality of public health data. Reports can be entirely missed and never submitted, or there might be confusion about what and how to report. Investments should be made to automate data collection from multiple sources to reduce errors, remove the administrative burden of data collection, and increase data quality.

Additionally, efforts to standardize public health data are critical to harmonize data exchange from multiple sources. Public health and health care data standards are a key component of the overall interoperability of the public health data superhighway, because they allow individual data systems to contribute compatible and comparable information to be used in the aggregate.

Faster Data

Public health surveillance is hindered by slow, manual data exchange mechanisms. As elucidated in the case studies, paper reports stack up next to the fax machine waiting to be sent and received. Once received, reports need to be efficiently, processed, organized, and analyzed to turn raw data into information useful to policymakers and the public. Whether the public health department is operating under normal conditions, or during response to a public health outbreak or emergency, paper-based methods and manual data entry create a bottleneck in a timely public health response. To get data faster, investments must be made to build the public health data superhighway to enable *any* type of public health data to be electronically shared quickly and efficiently. By utilizing a core infrastructure, public health can then apply enterprise-level advanced data analytics, predictive analytics, and artificial intelligence to produce curated and precise real-time reporting from multiple data sources.

Recommendation 3: SECURITY to Protect Patient Data

Public health data are required by law to be reported, thereby making the public health community stewards to sensitive personal health information. Electronic data systems present new challenges to ensure security against **hacking**, **misuse**, or **identity theft**. With advances in cybersecurity threats, the public is increasingly aware of data security and privacy issues. Public health must adapt to uphold its reputation of protecting personal health information. If health care data security and privacy are neglected, the public health community risks losing the public's support despite efforts to improve their health—hence data moves at the speed of trust.[23] To prevent undercutting the benefits of public health surveillance, we should consider opportunities to establish chief privacy officers, or at a minimum add privacy laws to the scope of practice of the public health law community. This would address privacy and security issues within health departments. Additionally, it is necessary to educate the public on the value of public health surveillance, offering concrete examples or stories of the public and individual benefits.

If health care data security and privacy are neglected, the public health community risks losing the public's support.[23]

Recommendation 4: WORKFORCE that is Prepared for the Information Age

Data and workforce are the lifeblood of public health action. A capable workforce that uses data well ensures critical public health action to save lives. As technology advances and is incorporated into public health practice, more, better, and faster data will enable the public health workforce to solve tough public health problems.

Technology's potential can only be realized if public health professionals are equipped to harness it. Thus, a highly trained data science and informatics workforce is necessary to create, maintain, use, and update the public health data superhighway. Not to be confused with information technology (IT) workforce, **public health informatics** as defined by CDC is the systematic application of information, computer science, and technology to public health practice, research, and learning.[24] Funding for specific education, fellowships, and training in data science and informatics are required to develop this unique category of the public health workforce.

Currently, public health departments struggle to recruit data scientists and informaticians because they are often lured away by higher-paying jobs in the private sector. These personnel are often shared across many programs and divisions, which can be limiting during public health emergency or outbreaks. Fresh approaches such as increased salary caps to recruit and retain staff, professional development, succession planning, post-graduate fellowships, and on-the-job training are required to build the public health informatics workforce of the future.

23 Report Details Public's Hopes, Fears About Using Data to Improve Health. Robert Wood Johnson Foundation. https://www.rwjf.org/en/library/articles-and-news/2015/04/report-highlights-publics-hopes-fears-about-using-data-to-improve-health.html. Published April 2, 2015. Accessed May 10, 2019.
24 Introduction to Public Health Informatics. cdc.gov. https://www.cdc.gov/publichealth101/informatics.html. Updated November 15, 2018. Accessed May 10, 2019.

The Digital Bridge

A unique forum that brings together decision makers in health care, public health, and health information technology, the Digital Bridge aims to address the challenges surrounding data exchange and the use of electronic health data between the health care and public health communities. The goals of the Digital Bridge are to:

- Ease the burden and costs for all stakeholder groups through a unified approach to information exchange;
- Advance greater standards-based information exchange across public health and health care;
- Lay the foundation for greater bidirectional exchange of data so that clinicians can be more informed about population health, environmental risks, and outbreaks.[25]

As its inaugural project, the Digital Bridge partners are collaborating to build a national framework for eCR. eCR harnesses the power and information stored in EHRs. The partners have developed processes that automatically flag potential disease cases from data in a patient's EHR, and create a report that is electronically sent to public health for analysis. This reduces burdensome manual, paper-based processes for both health care providers and public health professionals, ultimately improving timely outbreak response.

The Digital Bridge has positioned seven sites across the country that pair a health care entity with a government public health agency to demonstrate eCR implementation. Each demonstration site is a collaboration between a public health agency, a health care provider, and a data provider/EHR vendor. Two sites—Houston (Houston Methodist Hospital and the Houston City Health Department) and Utah (Intermountain Healthcare and the Utah Department of Health)—are actively in production with eCR. Designed to be scalable and standardized, the other five sites are positioned to move into the production phase. Given adequate funding, eCR is feasible nationwide.

25 Current State of Data Exchange. digitalbridge.us. https://digitalbridge.us/infoex/about/.

Recommendation 5: PARTNERSHIP & INNOVATION with the Public & Private Sectors

Protecting population health through public health surveillance begins at the bedside, as health care providers in the private sector diagnose and treat individual patients and provide data on reportable diseases and conditions to governmental public health departments. Public health is reliant upon the health care sector to generate the public health data that informs prevention and response efforts. Indeed, public health cannot effectively address public health threats without the health care sector. Similarly, the health care sector—including patients—stands to greatly benefit from bidirectional information sharing about public health threats, as well as efficiencies and reductions to provider burden associated with automated data exchange.

Enabling data exchange between the health care sector and the public health sector requires all entities—health care providers, CDC, and state, territorial, local, and tribal public health departments—to use the same meaningful data standards. Without this, interoperability is impossible. For health care and public health to benefit from the wealth of data available in EHRs, a consensus-based standards process must develop data standards that will support both clinical care and public health.

Ongoing public-private partnerships, such as the **Digital Bridge** *(see left)*, bring together governmental public health, health care providers, health care systems, and IT vendors. This is essential to public health surveillance transformation, and must continue. Though it has been challenging for public health to keep pace with emerging technologies, many of these technological advancements have been used for years by the private sector, and the public health community should seek partnerships to leverage the private sector's experience and expertise.

By working together, the health care and public health sectors can advance both fields by collaborating on efforts similar to the Digital Bridge and developing consensus-based data standards. Future technological advances will continue to transform data exchange, and long-term partnerships between public health and the private sector will help public health prosper from technological advancements and innovation.

Chris Alban, MD, MBA
Vice President, Clinical Informatics
Epic

James Doyle
Research & Development Product Lead
Epic

Expert Testimonial

"As a national leader in health information technology for large health care systems and providers, Epic strives to integrate data entry and clinical decision support seamlessly into the workflow of busy providers' electronic medical records. Our clients tell us of the added time to their day needed for electronic processes, and it is in our business interest to lessen this burden. When we work with our clients on projects that involve integration with government public health agencies—like disease reporting—we often hear that the public health agency is not ready to receive automated electronic reports due to public health's technical and workforce capacity challenges.

On behalf of Epic, we support the **Digital Bridge collaborative** and the eCR initiative. It's the first step in achieving the Digital Bridge's vision for the future of public health surveillance: a centralized system and repository that all provider organizations and public health agents integrate with to facilitate the bidirectional flow of data, knowledge, and guidance—and doing this all by lessening the burden for clinicians and epidemiologists.

A fully interoperable electronic public health surveillance system would improve public health outcomes via several contributing factors. First, it will provide easy access to reportable data for epidemiologists, leading to a greater understanding of the spread of disease and how it can be reduced. Specifically in the case of outbreaks, it will enable early detection for a rapid response and the prevention of a broader spread. Second, the ability to provide in-workflow clinical guidance to clinicians will make it easier for them to do the right thing, and reduce the chance any patients or steps in a clinical guideline are missed. Finally, it will allow for operations that are significantly more efficient. In health care provider organizations, there will be less time spent on manual reporting and communication, or on the implementation of clinical guidelines. Public health agencies will save time currently spent on gathering and standardizing data for analysis.

While most of this work is theoretically possible with our current system that is dependent on manual data gathering and communication, time and resource constraints prevent much of it from happening with a reasonable turnaround time. This system will enable **everyone involved (particularly epidemiologists, clinicians, and their staff)** to do more of this important work. With a fully interoperable connection between health care delivery organizations and public health, the prospect of real-time alerting, decision support, and analysis of trends comes that much closer to reality.

Conclusion

The Future of Public Health is Now

The use of data is transforming the world. In April 2019 at the 16th Annual World Health Care Congress, the United States Department of Health and Human Services Chief Data Officer, Mona Siddiqui, stated that the lack of timely data is the biggest barrier to creating health policy. In her remarks, Siddiqui stated: "We have a lot of data from 18 months to two years ago. Imagine trying to make policy decisions based on data that is two years old."[26] Public health threats rapidly evolve, and do not wait for public health to receive, store, and process data before causing more illness and death. It is frustrating when public health professionals cannot provide their community timely and relevant information about their health, or implement policies that help protect them. The nation's public health data systems are becoming impediments, not catalysts, to public health action.

Today, public health is on the precipice of a tremendous opportunity to implement cutting edge data systems to strengthen and safeguard the health of the nation. The public health data superhighway requires adequate and sustained funding to CDC and state, territorial, local, and tribal public health departments to build, upgrade, and maintain electronic data systems. Proper resources will expand and update vital records systems, support electronic laboratory ordering and reporting, expand the number of hospitals conducting syndromic surveillance, automate disease reports directly from electronic health records, develop highly skilled data science and informaticians, and improve data security. Without this investment, public health will continue to fall behin, while advancements in technology render opportunities to improve public health inaccessible.

Technology's potential can only be realized if public health professionals are equipped to harness it.

High quality, reliable data has always been the cornerstone of public health surveillance. Today, the tools and mechanisms to build the public health data superhighway are at our fingertips. Modernization will require new ways of thinking and moving away from traditional program-based approaches and manual methods. The nation must build and maintain the public health data superhighway to protect Americans from the public health threats of tomorrow. **The future of public health is now.**

26 HHS Chief Data Officer: Lack Of Timely Data Is A Barrier To Policy. Inside Health Policy. https://insidehealthpolicy.com/vitals/hhs-chief-data-officer-lack-timely-data-barrier-policy. Published April 30, 2019.

Appendix A

Core Pillars of Public Health Surveillance

In the United States, the public health surveillance system spans across federal, state, territorial, local, and tribal jurisdictions to support detection, response, and prevention of public health threats. While public health surveillance is recognized as an important component to protect the nation from public health threats, it is under-resourced. Much of the current funding for public health surveillance is reallocated from Centers for Disease Control and Prevention (CDC) to state, territorial, local, and tribal health departments to strengthen their respective surveillance systems, but gaps remain.[1] The nation's public health surveillance system is plagued by data quality and timeliness issues that inhibit the individual data systems and the public health surveillance system as a whole. To address the challenges facing the public health surveillance system, an in-depth understanding of each of the individual data systems is necessary.

Electronic Case Reporting (eCR)

Case reporting is a key component of public health, and occurs when reporting entities such as hospitals and health care providers submit patient disease information to public health authorities pursuant to jurisdictional laws. An initial case report to public health departments includes health data from the time of suspected disease onset and pre-disease confirmation, which is then updated with all relevant data post-disease confirmation.[2]

Unlike traditional case reporting, eCR systems can generate and transmit case reports through a semi- or fully-automated application—known as clinical decision support—that pulls reportable patient data from an electronic health record (EHR) or an intermediary system such as an health information exchange.[3] The Reportable Condition Knowledge Management System reduces the administrative burden on health care providers and public health professionals to manually identify and extract reportable disease/condition data from patient EHRs and manually generate a case report. This automated process mitigates the risk of data entry, transmission errors, or failures to report at all. With more accurate disease data, eCR systems can promote more timely notifiable disease reporting and optimize public health surveillance functionality throughout the system, supporting rapid public health responses and implementation of control measures.

Today, nearly all case reports continue to be submitted to public health authorities via manual processes such as faxes, emailed PDFs, and mailed paper forms. However, a few jurisdictions have implemented an eCR system through participation in the Digital Bridge—a public-private partnership that supports the electronic and interoperable processes that help modernize the public health surveillance system.[4]

1 Office of Public Health Scientific Services. CDC Public Health Surveillance Strategy Report: 2014-2018. cdc.gov. https://www.cdc.gov/surveillance/pdfs/Surveillance-Series-Bookleth.pdf. Published September, 2018.
2 Hamilton JJ, et al. Electronic Case Reporting (eCR). cste.org. https://cdn.ymaws.com/www.cste.org/resource/resmgr/2016PS/16_SI_02.pdf.
3 Public Health Informatics Institute. Advancing Electronic Case Reporting of Sexually Transmitted Infections. https://www.phii.org/sites/default/files/resource/pdfs/ECRofSTIGuidance_v3%20%281%29.pdf. Updated March 15, 2018.
4 Current State of Data Exchange. digitalbridge.us. https://digitalbridge.us/infoex/about/.

Laboratory Information Systems and Electronic Laboratory Reporting

Public health laboratories play a key role in public health surveillance, and are uniquely positioned to provide laboratory testing and training to support population-wide health. Functioning at the federal, state, territorial, local, and tribal level, governmental public health laboratories provide highly technical and specialized testing for diseases and conditions of public health consequence, and have a core function to support disease prevention, control, and surveillance. Additionally, through the structure of the Laboratory Response Network (LRN), public health laboratories provide coordinated and rapid responses to epidemics, biothreats, and environmental hazards including radiologic and chemical hazards. Key to the LRN and the broader public health surveillance system is accurate and timely laboratory testing to measure, track, and prevent the spread of public health threats.

Public health laboratories primarily provide test results to epidemiologists to support outbreak detection and public health investigations. Secondarily, diagnostic information can be shared back to health care providers to inform clinical care which requires bidirectional data exchange, and can create a burden when reporting mechanisms and requirements differ between the public health and health care communities. Advances in laboratory informatics—the specialized application of information technology to laboratories—have streamlined data management in public health laboratories and enabled quicker data exchange. Laboratory Information Management Systems (LIMS), the computer applications that form the backbone of laboratory data collection, management, storage, and sharing, can eliminate the need for manual and paper-based specimen accessioning, data management, and result recording. This allows public health laboratories to electronically track specimens and workflows, and store laboratory data in a central, secure location.[5] However, not all public health laboratories have implemented all these features within their LIMS.

Electronic management systems such as LIMS enable electronic laboratory reporting (ELR) to public health partners from both clinical and public health laboratories. Jurisdictional laws require laboratories to report test results of reportable diseases to public health authorities and state health departments in order to initiate case investigations. Laboratories generate secure laboratory reports and submit reportable data either manually or electronically with ELR. While manual laboratory data reporting methods are paper-based and impose significant administrative burdens, ELR can:

- Identify and extract reportable condition data from laboratory reports;
- Reduce data inaccuracies and improve data quality;
- Electronically transmit reportable condition data from laboratories to public health agencies.[6]

Initially, as laboratories moved from manual-based systems to ELR, there were challenges surrounding the lack of standardization of messaging formats, technical expertise in implementation, and appropriate policies. In 2010, CDC partnered with the Council of State and Territorial Epidemiologists (CSTE) and the Association of Public Health Laboratories to: create an ELR task force to develop, evaluate, and endorse standards for ELR requirements; coordinate federal and state ELR implementation efforts; and conduct needs assessments to identify state-specific ELR strategies.[7]

5 McPhillips-Tangum C, Saarlas K, Renahan-White A. The LIMS Project: Summary of Evaluation Findings. Public Health Informatics Institute. https://www.phii.org/sites/default/files/resource/pdfs/LIMS%20Evaluation%20-%20website-FINAL-2.pdf. Published June 2007. Accessed May 3, 2019.
6 Electronic Laboratory Reporting (ELR). cdc.gov. https://www.cdc.gov/EHRmeaningfuluse/ELR.html. Updated May 19, 2016.
7 Electronic Laboratory Reporting (ELR) Task Force Overview. cdc.gov. https://www.cdc.gov/EHRmeaningfuluse/ELRtf.html. Updated August 23, 2016.

As of 2018, 80 percent of laboratory reports are received electronically by health departments, greatly reducing the manual administrative burden of paper-based laboratory reporting.[8] However, limitations still exist when exchanging reportable data between the laboratory and health care providers, and few laboratories within CDC have implemented ELR. As a result, manual reporting methods such as phone calls, emails, and faxes are still relied upon heavily.

Syndromic Surveillance

The 9/11 terrorist attacks and the subsequent anthrax attack using the United States Postal Service demonstrated a strong need for non-traditional public health surveillance methods that provided early detection of emerging public health threats. The process of identifying a potential case, submitting a clinical sample to public health laboratories, conducting testing, and reporting a result can be long and drawn out. In many instances, by the time a diagnosis is confirmed through conventional data sharing the outbreak has likely spread. To stay ahead of public health threats, the advent of syndromic surveillance created a faster, near real-time early warning system that provided data based on clinical symptoms prior to a definitive diagnosis.[9]

By relying on clinical indicators, syndromic surveillance systems collect data from hospital emergency departments and urgent care, or can be used with other data sources such as school or work absenteeism, over-the-counter medicine sales, emergency medicine service runs, poison center calls, and spikes in keywords used in social media or internet searches such as "flu" and "fever." Although originally developed to monitor bioterrorism events, it has become a tool to monitor outbreaks, drug overdoses, environmental conditions, natural disasters, and other public health threats. This enables early situational awareness to federal, state, territorial, local, and tribal public health agencies.

Many public health departments have adopted syndromic surveillance as a part of their broader public health surveillance strategies because it serves a vital role in population health monitoring, as well as emergency preparedness and response efforts.[10] While syndromic surveillance can enhance public health surveillance, it comes with limitations and thus cannot supplant traditional methods. Despite these limitations, syndromic surveillance adds valuable public health data and can be incredibly useful in an overall response.

Electronic Vital Records Systems

The National Center for Health Statistics (NCHS) within CDC is responsible for overseeing and coordinating the National Vital Statistics System (NVSS). NVSS collects detailed information from the vital records jurisdictions—50 states, five territories, the District of Columbia, and New York City—that are legally responsible for tracking the millions of births and deaths that occur each year. These data enable public health authorities to track key indicators of population health status such as life expectancy, infant and maternal mortality rates, pregnancy rates, and health disparities at the federal, state, territorial, local, and tribal levels.[11]

8 Office of Public Health Scientific Services. CDC Public Health Surveillance Strategy Report: 2014-2018. cdc.gov. https://www.cdc.gov/surveillance/pdfs/Surveillance-Series-Bookleth.pdf. Published September, 2018.
9 Henning K. Overview of Syndromic Surveillance What is Syndromic Surveillance? MMWR. 2004; 53(Suppl):5-11. https://www.cdc.gov/mmwr/preview/mmwrhtml/su5301a3.htm. Published September 24, 2004. Accessed May 1, 2019.
10 Ibid.
11 Ventura SJ. The U.S. National Vital Statistics System: Transitioning into the 21st century, 1990–2017. Vital and Health Statistics. 2018;1(62). https://www.cdc.gov/nchs/data/series/sr_01/sr01_062.pdf. Published March 2018.

Specifically, public health authorities use vital records data to:

- Identify at-risk populations and rare causes of death;
- Monitor deaths in an important cohort under public health surveillance (e.g. HIV-infected cases);
- Plan programmatic activities;
- Implement programs and policies to address health disparities.

Timely, accurate death data reporting is necessary to promptly assess and respond to emerging public health threats with high mortality rates such as natural disasters.[12] Within the last 20 years, there has been a shift from manual, paper-based vital statistics data collection methods to electronic means such as an electronic death registration system (EDRS).[13] EDRS enables automated death data processing—such as electronic data entry and transmission to the NVSS—which facilitates data reporting and improves death data quality by providing real-time scanning processes that highlight data entry errors such as missing or inaccurate information.[14]

Because EDRS promote timely, accurate death data collection and reporting, NCHS encourages all jurisdictions to adopt an EDRS.[15] However, for the many jurisdictions that implemented EDRS over 15–20 years ago, systems and software have not been maintained or upgraded, leaving them out of date and not interoperable with other systems.

National Notifiable Diseases Surveillance System (NNDSS)

To effectively monitor and respond to public health threats, the nation's public health surveillance system relies upon timely disease reporting and notification systems.[16] Disease reporting is the series of events that begins with infection or exposure—whether it is an infected person or environmental hazard including insect and tick vectors—and concludes with case reporting to the health department at the territorial, tribal, state, or local level. With diseases that are deemed notifiable, voluntary case notification to CDC occurs.[17] In the United States, notifiable diseases are those that require regular, frequent, and timely information about individual cases of communicable conditions, such as tuberculosis and E. coli, and noncommunicable conditions such as lead poisoning.[18]

Pursuant to jurisdictional laws and regulations, health care providers, hospitals, laboratories, and other individuals are required to report cases of designated conditions to health departments within a certain timeframe.[19] Working in coordination with the CSTE, CDC recommends which conditions and data elements are recommended to be sent to the federal level.[20]

12 Howland RE, Li W, Madsen AM, et al. Evaluating the Use of an Electronic Death Registration System for Mortality Surveillance During and After Hurricane Sandy: New York City, 2012. Am J Public Health. 2015;105(11):e55–e62. doi:10.2105/AJPH.2015.302784
13 Electronic Death Reporting System Online Reference Manual. cdc.gov. https://www.cdc.gov/nchs/data/dvs/edrs-online-reference-manual.pdf. Published December 2016.
14 Ibid.
15 Howland RE, Li W, Madsen AM, et al. Evaluating the Use of an Electronic Death Registration System for Mortality Surveillance During and After Hurricane Sandy: New York City, 2012. Am J Public Health. 2015;105(11):e55–e62. doi:10.2105/AJPH.2015.302784
16 Swaan C, van den Broek A, Kretzschmar M, Richardus JH. Timeliness of notification systems for infectious diseases: A systematic literature review. PLoS One. 2018;13(6):e0198845. Published June 14, 2018. doi:10.1371/journal.pone.0198845
17 Ibid.
18 Office of Public Health Scientific Services. CDC Public Health Surveillance Strategy Report: 2014-2018. cdc.gov. https://www.cdc.gov/surveillance/pdfs/Surveillance-Series-Bookleth.pdf. Published September, 2018.
19 Swaan C, van den Broek A, Kretzschmar M, Richardus JH. Timeliness of notification systems for infectious diseases: A systematic literature review. PLoS One. 2018;13(6):e0198845. Published June 14, 2018. doi:10.1371/journal.pone.0198845
20 National Notifiable Diseases Surveillance System (NNDSS). cdc.gov. https://wwwn.cdc.gov/nndss/. Updated March 13, 2019. Accessed May 1, 2019.

These data are necessary to:

- Identify disease and population trends (e.g. the patterns and spread of disease within a community);
- Monitor at-risk populations (e.g. monitoring hepatitis C infection rates in an IV drug rehabilitation center);
- Conduct case investigation and implement disease-specific control measures to prevent further spread;
- Prevent and contain outbreaks;
- Promote disease testing and education initiatives;
- Evaluate control measures, programs, and policy.[21]

Nationally notifiable disease notification often relies on a laboratory-confirmed diagnosis, which can create significant process-level delays in data transmission as a result of the elapsed time between disease onset and physician consultation, the physician ordering the test, and the laboratory conducting testing and reporting confirmed results.[22] These manual reporting burdens exacerbate the process-level delays at the state and local level, and thus serve as barriers to the NNDSS functionality.

As part of CDC's Surveillance Strategy, NNDSS is undergoing a transformation to keep pace with evolving technology and data exchange standards. This overhaul—known and the NNDSS Modernization Initiative (NMI)—aims to enhance timely and accurate data for public health decision making through interoperability and standardized data exchange mechanisms. Working closely with public health departments and public health laboratories, NMI has helped implement case notification messages to CDC. Continued improvements like NMI must be prioritized to ensure timely data exchange from state, territorial, local, and tribal jurisdictions to CDC.

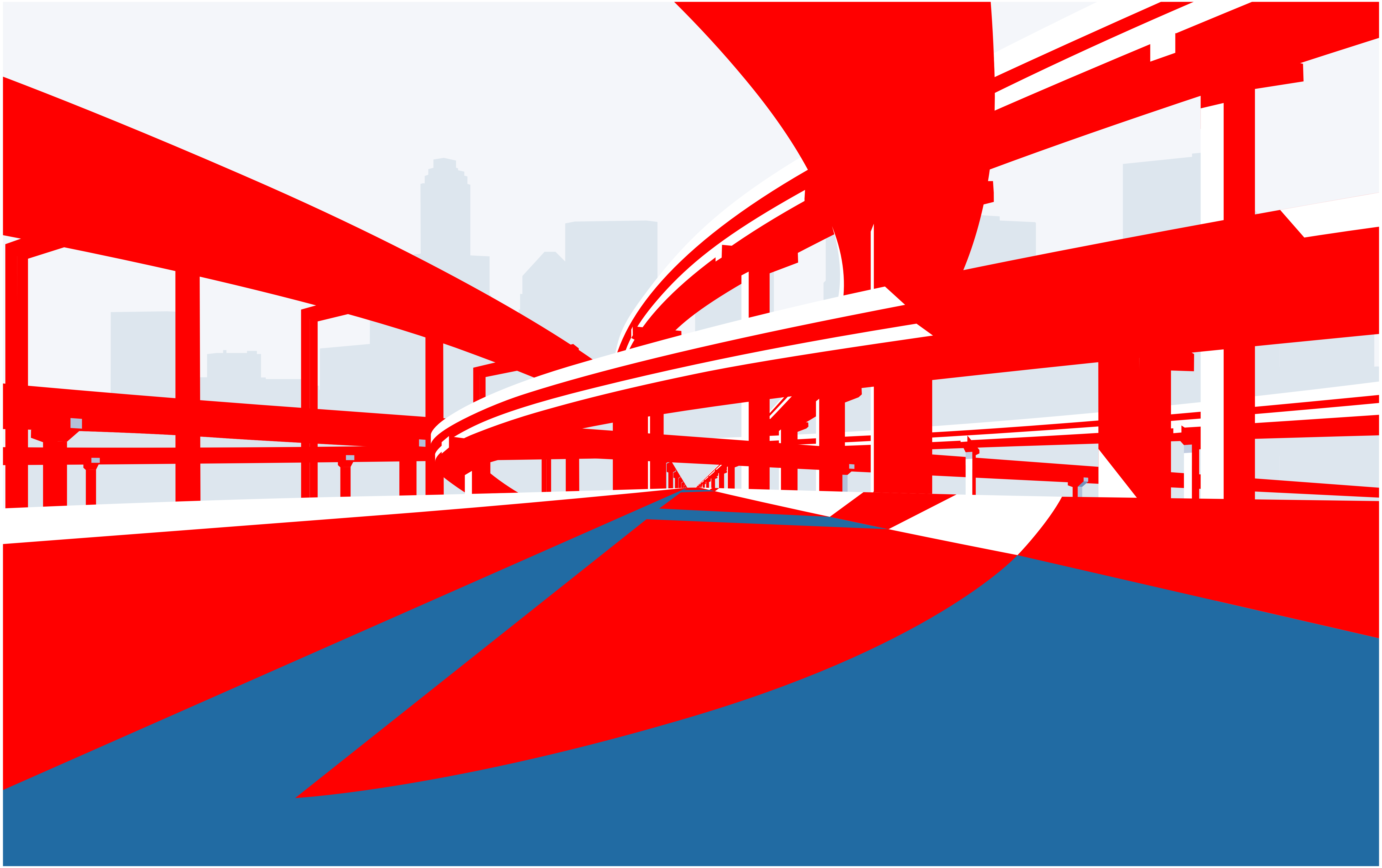
21 Swaan C, van den Broek A, Kretzschmar M, Richardus JH. Timeliness of notification systems for infectious diseases: A systematic literature review. PLoS One. 2018;13(6):e0198845. Published June 14, 2018. doi:10.1371/journal.pone.0198845
22 Ibid.

Appendix B

Questions to Frame Focus Group Discussions

Focus groups of public health subject matter experts discussed four public health threats—an opioid overdose, a foodborne outbreak, a measles resurgence, and a natural disaster—and described how data is shared throughout the current public health surveillance system. The following discussion questions were developed to guide conversations:

1. **Explain how health data currently flows through this scenario to contribute to public health surveillance.**
    - Are you relying on manual/paper-based processes to support some or all of the efforts? Faxing? Phone calls?
    - What, if any, systems are interoperable with each other?
2. **What are the barriers and challenges to current data flow?**
    - Where does the data get stuck with either sending or receiving? And why? For example, lack of standards for sharing information effectively?
    - How do these barriers and challenges make your job harder?
    - What opportunities are lost because of antiquated systems?
    - Are the data more vulnerable to breach? If so, why?
3. **How can integration or interoperability of the data systems be improved?**
4. **What are the benefits of having a fully interoperable, integrated surveillance system?**
    - External: Patient outcomes? Health outcomes? Patient privacy?
    - Internal: Workflow efficiencies? Cyber security?
5. **What are your workforce challenges?**
    - What skills will your workforce need to utilize electronic systems?



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