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.