Data Modernization for Public and Population Health

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RTI International

You can't manage what you can't measure.

Drucker

You can have data without information, but you cannot have information without data.

Moran

Above all else, show the data.

Tufte

In God we trust, all others bring data.

Deming

Data are just summaries of thousands of stories.

Heath

What is Data Modernization?

Data modernization is about making sure that the right data are available at the right time to drive action.

Technology, processes, and people come together to ensure that data can be transmitted, shared, integrated, and used to affect public and population health.
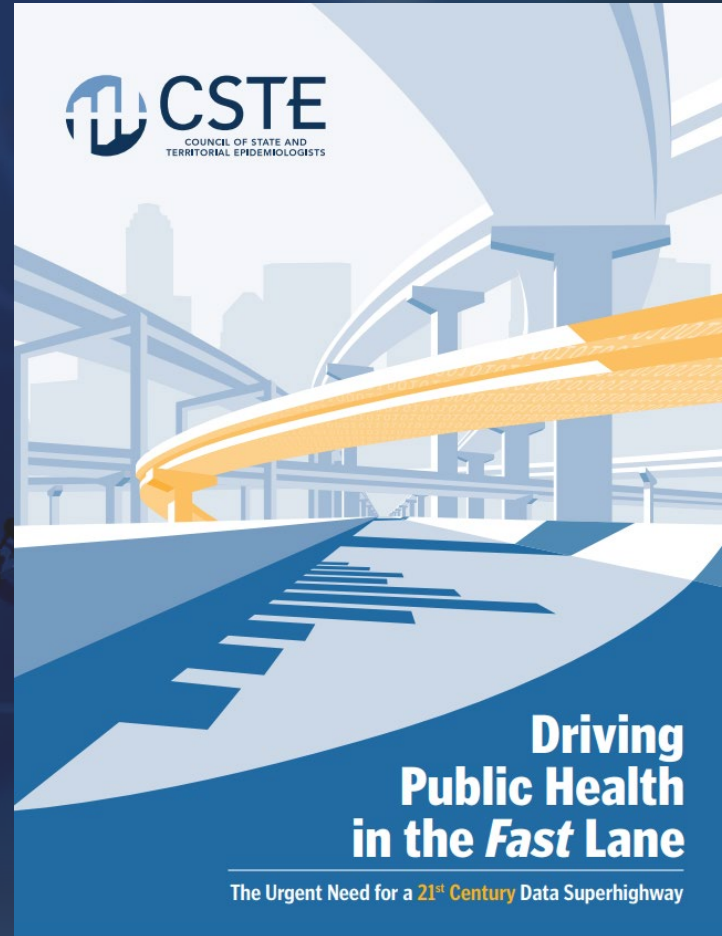
Relies on interoperability methods, strong governance, and trust relationships.

Alarm Was Being Raised

CSTE, NAPHSIS, APHL and HIMSS formed a coalition and launched **Data: Elemental to Health** in spring 2019.

"

The nation's public health data systems are antiquated and in dire need of security upgrades – paper records, phone calls, spreadsheets and faxes requiring manual data entry are still in widespread use and have significant consequences, including delayed detections and response, lost time, missed opportunities, and lost lives.

Janet Hamilton, Director of Science and Policy at Council of State and Territorial Epidemiologists
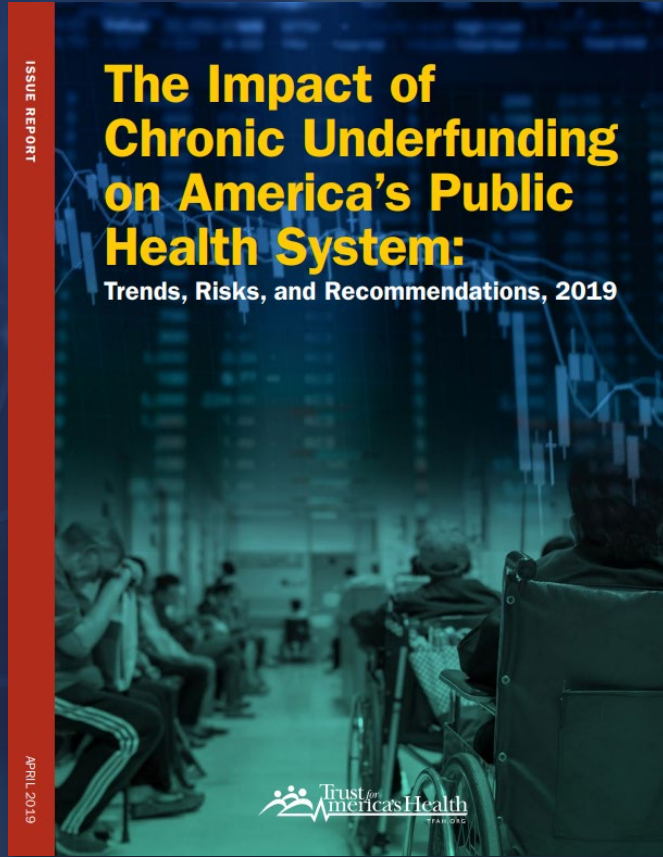
Speaking at Public Witness Day, Labor, Health and Human Services, Education and Related Agencies

116th Congress

Since 2008, reduction in more than **35,000** state and local public health jobs.

In 2009, **45%** of local health departments cut their budgets.

Federal funding has consistently been categorical and not infrastructure focused.

ISSUE REPORT

The Impact of Chronic Underfunding on America's Public Health System:
Trends, Risks, and Recommendations, 2019

Trust for America's Health
TFAH.ORG

APRIL 2019

Challenges to Public Health Reporting Experienced by Non-Federal Acute Care Hospitals, 2019

Chelsea Richwine, PhD, Carmelita Marshall, MS, PMP, Christian Johnson, MPH, Vaishali Patel, PhD, MPH

Amidst a global pandemic, the need for efficient exchange of electronic health information between hospitals and public health agencies has never been more critical. To ensure public health agencies have timely and complete data to improve their disease surveillance capabilities, the Centers for Medicare & Medicaid Services (CMS) has established policies that require hospitals to meet specific public health objectives as a condition for participation in the Promoting Interoperability (PI) program (1). These objectives include submission, and in some cases receipt of data, for the purposes of immunization registries, syndromic surveillance reporting, case reporting, and public health registry reporting. To understand the challenges hospitals faced with public health reporting in the year prior to the pandemic, this data brief uses nationally representative survey data from the 2019 American Hospital Association (AHA) Information Technology (IT) supplement to describe the number and types of challenges hospitals experienced when electronically reporting to public health agencies and how these challenges varied by state and hospital characteristics. While new challenges may have emerged or become exacerbated during the pandemic, this analysis identifies potential ongoing barriers to health information exchange among hospitals and public health agencies and provides insights into hospitals' readiness to support key public health activities prior to the pandemic.

HIGHLIGHTS

- In both 2018 and 2019, half of all hospitals reported a lack of capacity to electronically exchange information with public health agencies.
- In 2019, seven in ten hospitals experienced one or more challenges related to public health reporting.
- Small, rural, independent, and Critical Access hospitals were more likely to experience a public health reporting challenge compared to their counterparts.
- The types of public health reporting challenges experienced by hospitals varied substantially at the state-level.

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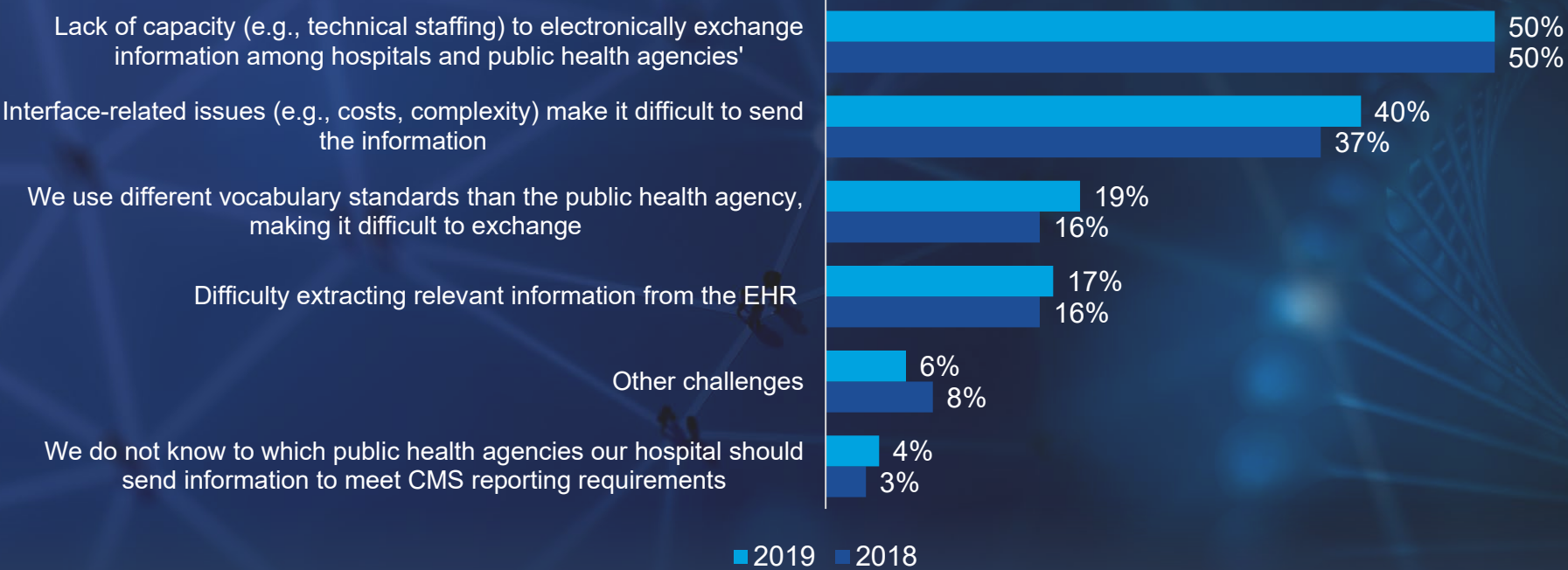
2019: Half of Hospitals Report Difficulty Electronically Exchanging Data With Public Health

Lack of capacity (e.g., technical staffing) to electronically exchange information among hospitals and public health agencies'
- 50% (2019)
- 50% (2018)

Interface-related issues (e.g., costs, complexity) make it difficult to send the information
- 40% (2019)
- 37% (2018)

We use different vocabulary standards than the public health agency, making it difficult to exchange
- 19% (2019)
- 16% (2018)

Difficulty extracting relevant information from the EHR
- 17% (2019)
- 16% (2018)

Other challenges
- 6% (2019)
- 8% (2018)

We do not know to which public health agencies our hospital should send information to meet CMS reporting requirements
- 4% (2019)
- 3% (2018)

■ 2019 ■ 2018

We Could Not Answer Basic Questions about COVID-19

How many people had COVID-19 at any given time?

Was our healthcare system holding up?

Where were patients going?

Who was most at risk and who were we missing?

- Lack of electronic data especially with new labs
- Duplicate data
- Missing information for patient matching
- Data arriving via secure email or fax and needing manual entry
- System crashes due to volume

Demographic information does not flow from EHRs to LIMS to public health. In many cases, it had to be gathered through contact tracing.

INVITED COMMENTARY

IDSA — Infectious Diseases Society of America

hivma — hiv medicine association

OXFORD

What the Coronavirus Disease 2019 (COVID-19) Pandemic Has Reinforced: The Need for Accurate Data

Simone Arvisais-Anhalt,[1] Christoph U. Lehmann,[2,3,4,5] Jason Y. Park,[1,6] Ellen Araj,[1] Michael Holcomb,[4] Andrew R. Jamieson,[4] Samuel McDonald,[2,7] Richard J. Medford,[2,8] Trish M. Perl,[8] Seth M. Toomay,[9] Amy E. Hughes,[5] Melissa L. McPheeters,[10,11,12] and Mujeeb Basit[2,13]

[1]Department of Pathology, University of Texas Southwestern Medical Center, Dallas, Texas, USA, [2]Clinical Informatics Center, University of Texas Southwestern Medical Center, Dallas, Texas, USA, [3]Department of Pediatrics, University of Texas Southwestern Medical Center, Dallas, Texas, USA, [4]Lyda Hill Department of Bioinformatics, University of Texas Southwestern Medical Center, Dallas, Texas, USA, [5]Department of Population and Data Sciences, University of Texas Southwestern Medical Center, Dallas, Texas, USA, [6]Eugene McDermott Center for Human Growth and Development, University of Texas Southwestern Medical Center, Dallas, Texas, USA, [7]Department of Emergency Medicine, University of Texas Southwestern Medical Center, Dallas, Texas, USA, [8]Department of Internal Medicine, Division of Infectious Diseases and Geographic Medicine, University of Texas Southwestern Medical Center, Dallas, Texas, USA, [9]Department of Radiology, University of Texas Southwestern Medical Center, Dallas, Texas, USA, [10]Department of Health Policy, Vanderbilt University, Nashville, Tennessee, USA, [11]Department of Biomedical Informatics, Vanderbilt University, Nashville, Tennessee, USA, [12]Center for Improving the Public's Health through Informatics, Vanderbilt University, Nashville, Tennessee, USA, and [13]Department of Internal Medicine, Division of Cardiology, University of Texas Southwestern Medical Center, Dallas, Texas, USA

Figure 1. Median and range of time (with possible sources of delay listed) for the stages from COVID-19 symptoms onset ...

COVID-19 symptoms to specimen collected

3 days (0-42 days)

Specimen collected to specimen resulted

32 hrs (<1–151 hrs)

Specimen resulted to data reported

29 hrs (2-157 hrs)

Data reported to data published by entity

?

Barriers:
- Inconvenient testing access
- Patient delays presenting for testing

Barriers:
- Testing platform used
- Testing capacity
- Patient priority category
- Courier time to laboratory (10 hrs, <1–92)

Barriers:
- Collecting missing reportable information
- Batching data
- Reporting mechanism downtime

Barriers:
- Data aggregation (manual vs automated, in house vs outsourced)
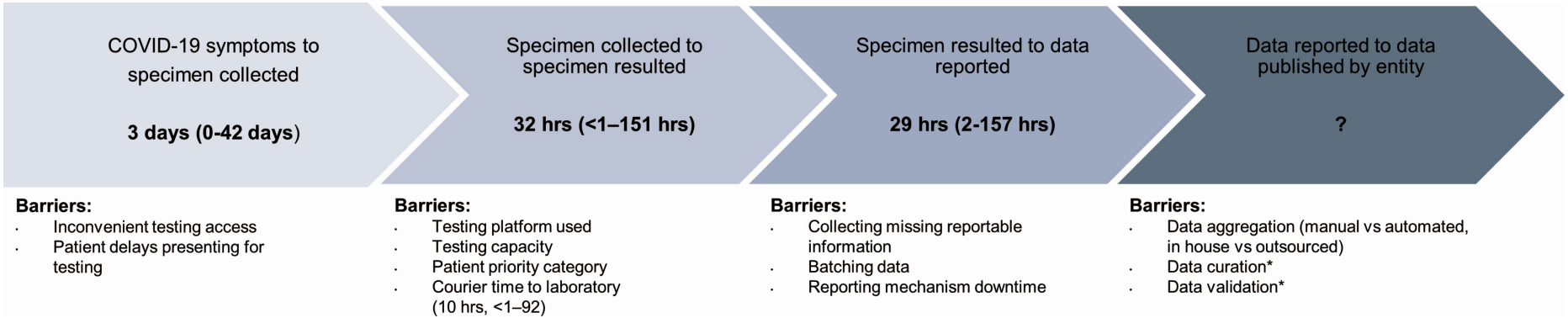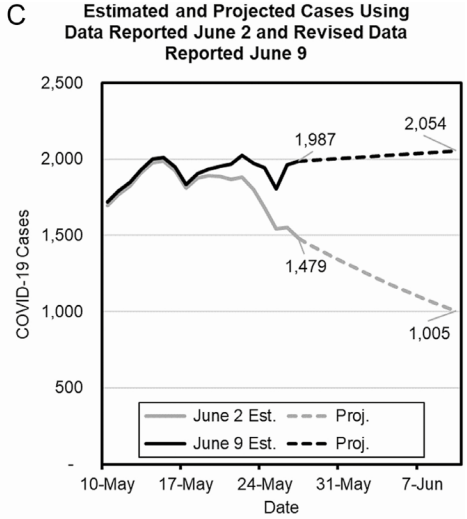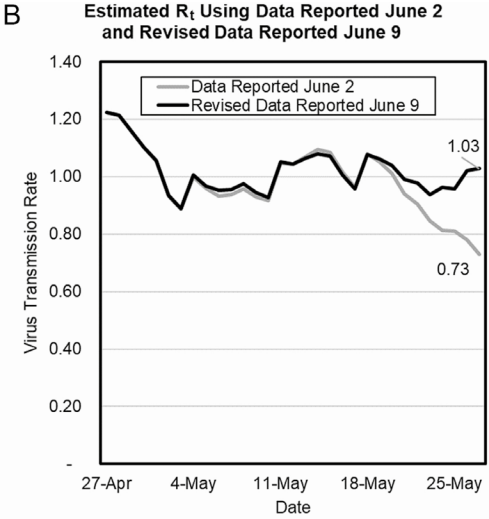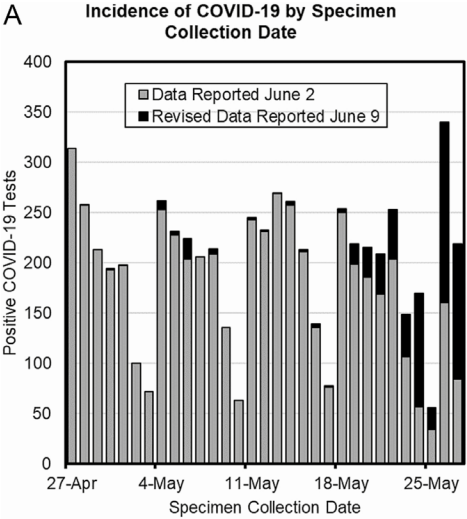- Data curation*
- Data validation*

Figure 2. A, Daily incidence of COVID-19–positive cases reported by the Dallas County Health Department based on …

Key Lessons and Their Impact

Interoperability was spotty at best:

- Lab data was unavailable electronically or delayed.

- In many states, surveillance and investigation systems did not communicate within health departments.

Our data system was an **underfunded patchwork.**

Lack of strong relationships and data agreements between entities to be built upon.

We Must Make Critical Changes

Faxes to electronic laboratory reporting

Spreadsheets to HL7 standards

Siloed public health databases to integrated ones

Whiteboards to dashboards

Administration Priorities COVID Plan Briefing Room Español MENU

BRIEFING ROOM

Executive Order on Ensuring a Data-
Driven Response to COVID-19 and
Future High-Consequence Public
Health Threats

JANUARY 21, 2021 • PRESIDENTIAL ACTIONS

Health Information Technology Advisory Committee
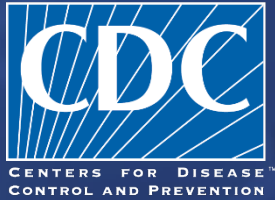The Office of the National Coordinator for Health Information Technology

Public Health Data Systems Task
Force 2021
Report to the Health Information
Technology Advisory Committee

July 14, 2021

ONC's
CURES ACT FINAL RULE

HealthIT.gov/CuresRule

CDC
CENTERS FOR DISEASE
CONTROL AND PREVENTION

A comprehensive strategy to modernize data, technology, and workforce capabilities—together and at once. This initiative supports public health surveillance, research and, ultimately, decision making.

NIH

...New ways to optimize technology-intensive research will inform decisions regarding future policies, approaches, and business practices, and will allow NIH to adopt more cost-effective ways to capture, access, sustain, and reuse high-value biomedical data resources....

CMS
CENTERS FOR MEDICARE & MEDICAID SERVICES

CMS's data-driven strategy strives to make CMS data more accessible and usable in a secure manner… unleashing the power of data to drive system transformation – enhancing efficiency, improving quality and reducing cost.

FDA

As technology becomes more sophisticated and our world becomes more connected, data from many new sources can help us understand how medical products are performing, pinpointing the source of food-borne illness, or understand emerging public health threats.
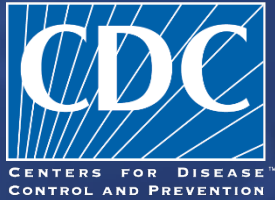
Common themes: Interoperability, integration, new data sources, workforce development, and advanced methods of using and visualizing data

surveillance, research and, ultimately, decision making.

will allow NIH to adopt more cost-effective ways to capture, access, sustain, and reuse high-value biomedical data resources...

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performing, pinpointing the source of food-borne illness, or understand emerging public health threats

FY 2020: $130M Cares Act Funding for "Enhancing CDC Services and Systems for Ongoing Data Modernization"

FY 2021: $200M for system-to-system interoperability for scalable responses and cloud-based data lakes for rapid detection and response

Total of **$500M** to expand public health surveillance infrastructure

CDC Data Modernization Initiative | A Roadmap of Activities and Expected Outcomes

ACTIVITIES If we (CDC and partners) do this …	SHORT-TERM OUTCOMES … then we expect these changes to occur …	INTERMEDIATE OUTCOMES … which will lead to …	LONG-TERM OUTCOMES … our ultimate goals.
COORDINATE PEOPLE AND SYSTEMS Create interoperable systems: federal, state, local, and healthcare Coordinate investments, decisions, and policies across CDC and with partners Make data sharing easier through common policies, practices, and standards Advance academic and private partnerships	**Increased collaboration, communication, and messaging** among CDC and partners **Reduced data collection and reporting burden** at state, tribal, local, and territorial levels Improved **data sharing and interoperability** through common standards like HL7® FHIR® Increased capacity to **quickly analyze, interpret, and act on data**	**Effective coordination** on complex health and emergency response challenges Timely and complete **data reporting to CDC** Efficient, secure **data access and exchange between systems** across the country **A more comprehensive picture** to improve decision-making and protect health for all	**CDC can rapidly identify and effectively mitigate emerging threats** **Trusted data promotes evidence-based behaviors, interventions, and solutions to protect health**
ACCELERATE DATA FOR ACTION Identify data for priority public health needs Upgrade and modernize IT infrastructure Strengthen the data science workforce Adopt open standards and tools while protecting data security Translate data into evidence-based recommendations	**Increased electronic reporting** and specific enhancements to flagship CDC surveillance systems **Stronger workforce** in data science, analytics, modeling, and informatics **Targeted real-time communication** of data and results	Real-time, linked systems that **recognize threats early** to inform timely response **A highly skilled workforce** that applies state-of-the-art data skills and tools **High-quality information and guidance** to protect people's health	**Every American has equal opportunity to attain the highest level of health possible** **All people have the right information at the right time to make decisions**
SUPPORT STRATEGIC INNOVATION Seek partner-driven data solutions Develop next-generation tools (e.g., modeling, visualization, predictive analysis, machine learning) Strengthen predictive analytics and forecasting	Integration and use of data from **new or non-traditional sources** Improved pathways to explore, develop, and **deploy next-generation technologies** Quick, continued data analysis with **adjustment of modeling in real time**	**Open-source, enterprise-level technologies** and coordinated systems New approaches to **address present and future threats**	**Our country is better prepared for, and protected from, all types of public health threats**

Overarching Themes and the Way Forward

Technology AND people

Connecting disparate systems with different priorities

Partnerships are critical

Policy alignment with goals

New and innovative types of data

Integration within data systems

Rigorous process for implementation and evaluation

Next Up Today…

On-the-ground experience at the state level

The role of implementation science

NIH Implementation science research perspective