

# Building Back Better

*Transforming U.S. public health data and infrastructure to protect health and achieve health equity*

April 2021

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## Acronyms

<b>AIMS</b>	APHL Informatics Messaging Service
<b>APHL</b>	Association of Public Health Laboratories
<b>CDA</b>	Clinical Document Architecture
<b>CDC</b>	Centers for Disease Control and Prevention
<b>CMS</b>	Centers for Medicare and Medicaid Services
<b>CODI</b>	Childhood Obesity Data Initiative
<b>DHIS2</b>	District Health Information Software 2
<b>DMI</b>	Data Modernization Initiative
<b>eCR</b>	Electronic Case Reporting
<b>EHR</b>	Electronic Health Record
<b>EHS</b>	Electronic Health System
<b>FEMA</b>	Federal Emergency Management Agency
<b>FHIR</b>	Fast Healthcare Interoperability Resources
<b>GIS</b>	Geographic Information System
<b>HIPAA</b>	Health Insurance Portability and Accountability Act
<b>HITECH</b>	Health Information Technology for Economic and Clinical Health
<b>HL7</b>	Health Level Seven
<b>HRSA</b>	Health Resources and Services Administration
<b>IIS</b>	Immunization Information System
<b>iPPRL</b>	Incremental Privacy-Preserving Record Linkage
<b>IT</b>	Information Technology
<b>JPHIT</b>	Joint Public Health Informatics Taskforce
<b>MedMorph</b>	Making EHR Data More Readily Available for Research and Public Health
<b>MENDS</b>	Multi-State EHR-based Disease Surveillance Network
<b>NSSP</b>	National Syndromic Surveillance Program
<b>ONC</b>	Office of the National Coordinator for Health Information
<b>PCORI</b>	Patient-Centered Outcomes Research Institute
<b>PCORnet</b>	Patient-entered Clinical Research Network
<b>PGHD</b>	Patient-Generated Healthcare Data
<b>PH</b>	Public Health
<b>PHCP</b>	Public Health Community Platform
<b>PHDSC</b>	Public Health Data Standards Consortium
<b>PHII</b>	Public Health Informatics Institute
<b>PHIN</b>	Public Health Information Network
<b>RCKMS</b>	Reportable Conditions Knowledge Management System
<b>RWJF</b>	Robert Wood Johnson Foundation
<b>STLT</b>	State, Tribal, Local and Territorial
<b>TSA</b>	Transportation Security Administration
<b>UNICEF</b>	United Nations International Children’s Emergency Fund
<b>USCDI</b>	U.S. Core Data for Interoperability
<b>WHO</b>	World Health Organization

## Executive Summary

The COVID-19 pandemic highlighted the need to rethink the way the U.S. public health system functions. It underscored the need for public health data and infrastructure to be timely, efficient, effective and equitable in its response to the next national emergency or global pandemic. To better understand how to transform public health data and infrastructure to protect health and achieve health equity, the Robert Wood Johnson Foundation (RWJF) commissioned the Public Health Informatics Institute (PHII) to conduct an environmental scan, host a series of interviews with thought leaders from the public and private sectors, and convene an advisory group to inform the development of this report and recommendations that are included herein.

The key findings are presented in two parts. The first part describes key insights thought leaders shared during interviews and advisory group meetings. The second part describes a number of initiatives and innovations thought leaders identified as laying the groundwork for transformation of public health data and infrastructure. While the first part focuses on challenges and opportunities, the second part highlights progress public health has already made (despite severe underfunding, workforce shortages and other challenges) and should provide encouragement that the exchange and use of public health data can be more functional, efficient and effective.

The resounding recommendation from thought leaders across multiple public and private organizations is that transformation of public health data and infrastructure *must occur now*. Despite the progress made by some previous initiatives and innovations, the COVID-19 pandemic has brought to the forefront that fractured parts of the current system still exist, and that short-term fixes will not suffice. It has provided the sense of urgency to undertake more overarching transformation.

The following recommendations highlight the initial steps to transform the public health system into one that is equitable and can be effectively used to monitor, respond and improve the health and well-being of all Americans:

1. **Convene a multi-disciplinary group of thought leaders from the public and private sectors to develop a vision, strategy, road map, policy framework and call-to-action** for developing a nationwide strategy and common functional architecture to transform the way that significant public health data is gathered and used.
2. **Promote efforts to make equity the cornerstone of all public health activities** by incentivizing public health systems to implement approaches to gathering and using public health data that put communities at the center of decisions about what data are collected, how they are collected and how they are used.
3. **Sponsor the development of a nationwide requirements project** on a core public health information system, such as infectious disease surveillance, to translate business needs into data and systems requirements and demonstrate the benefits of a shared understanding of the actions, processes and capabilities needed to ensure the system is successful.
4. **Invest in the public health workforce** to ensure that public health continues to benefit from a workforce that has the appropriate technical skills and reflects diversity nationally.

## Introduction

The COVID-19 pandemic shined a bright light on public health data and infrastructure in the United States. It made painfully obvious what many people in the public and private health sectors already suspected: underinvestment in public health data and infrastructure left the country unprepared to launch a timely, efficient and effective response.

While federal, state and local public health agencies hurried to carry out core public health functions such as surveillance, laboratory testing and contact tracing, the pandemic disrupted lives, pushed hospitals to and beyond capacity, and took a toll on the U.S. economy. As of March 28, 2021, there have been more than 30.2 million confirmed COVID-19 cases and more than 549,000 deaths in the United States.<sup>1</sup>

Disadvantaged and minority communities continue to experience higher rates of infection and death from the disease. They also face greater economic impact because the social factors that typically create challenges in their communities are only amplified by a health crisis of COVID-19's magnitude (e.g., food insecurity, housing instability, social isolation).<sup>2</sup>

So, what role has public health data and infrastructure played in the U.S. response to the COVID-19 pandemic and, perhaps most importantly, what steps must be taken to ensure that the next public health crisis does not further exacerbate health inequities?

The Public Health Informatics Institute (PHII) set out to answer these questions as part of a collaborative project sponsored by the Robert Wood Johnson Foundation (RWJF). PHII conducted an environmental scan, facilitated interviews with thought leaders from the public and private sectors, and convened an advisory group to inform the development of this report and the recommendations that are included herein.

This report synthesizes key points made during discussions with thought leaders and proposes a pathway to reimagine the way that public health carries out its vital work. Ultimately, this report aims to become the basis for a “call-to-action” that underscores the need to strengthen the public health data and infrastructure and **build back better** so that the U.S. public health system is better prepared to promote health and health equity and protect against health threats.



The purpose of this report is to share foundational background and context, describe the approach that PHII used to gather data for the report, highlight key findings and share recommendations to RWJF.

<sup>1</sup> Johns Hopkins Coronavirus Resource Center. <https://coronavirus.jhu.edu/data/cumulative-cases>. (accessed March 28, 2021)

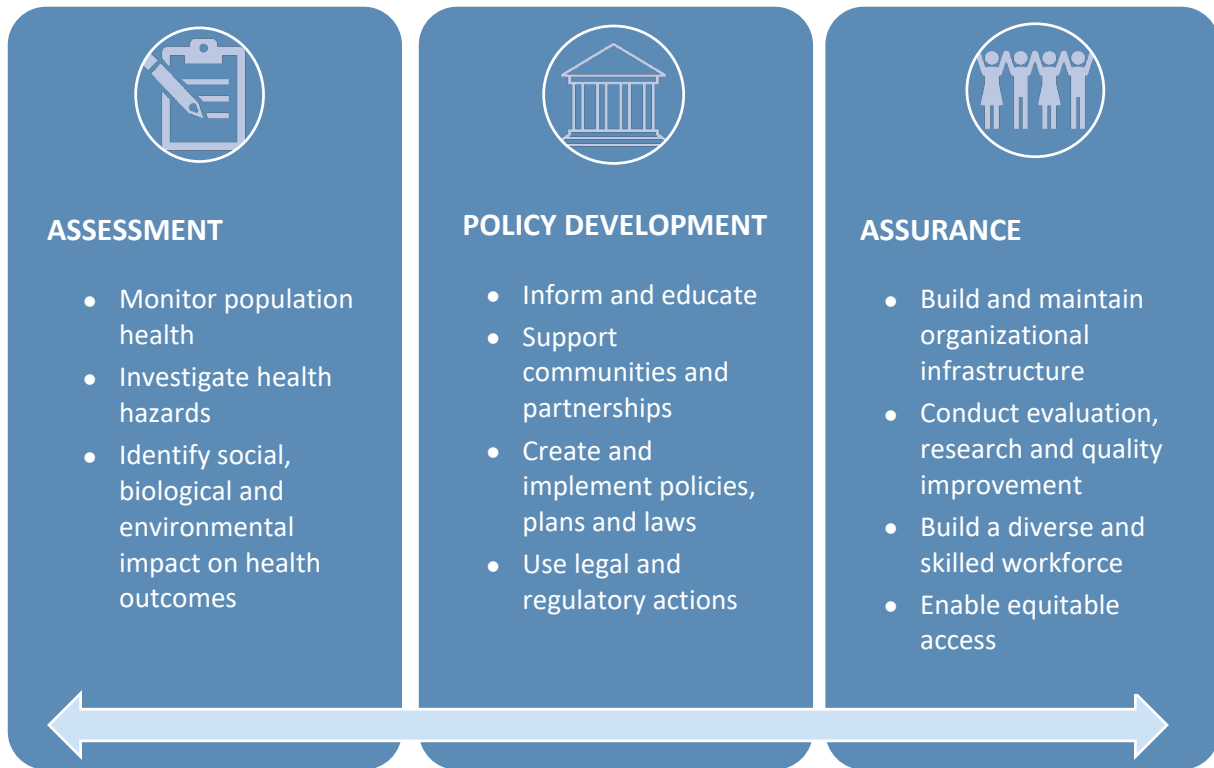
<sup>2</sup> CDC. COVID-19 Racial and Ethnic Health Disparities. <https://www.cdc.gov/coronavirus/2019-ncov/community/health-equity/racial-ethnic-disparities/index.html> (accessed March 28, 2021)

## Background

To understand how to transform public health data and infrastructure to protect health and achieve health equity, it is necessary to understand public health functions and challenges, as well as opportunities for improvement.

### What is the work of public health?

In its simplest form, public health can be defined as the science of protecting the safety and improving the health of communities and individuals. Fortunately, this critical function is not the sole responsibility of any one agency or sector of society. Rather, it is a function and responsibility shared by governmental public health agencies (e.g., national, state, tribal, local and territorial), the healthcare delivery system, academia, community-based entities (e.g., schools, organizations, religious congregations), businesses and employers, and the media.<sup>3</sup> As part of the larger ecosystem invested in protecting and promoting the public’s health, governmental public health agencies play an important role and serve as the backbone of the public health system. Public health departments exist in all 50 states, eight U.S. territories, the District of Columbia and approximately 3,000 cities and counties across the country. All public health agencies perform the following core set of functions and services:



Source: CDC, <https://www.cdc.gov/publichealthgateway/publichealthservices/essentialhealthservices.html>

Despite performing many common functions and services, no nationwide set of standards or protocols defines the way that public health agencies should carry out these functions and services. Instead, public

<sup>3</sup> Institute of Medicine. 2003. The Future of the Public's Health in the 21st Century. Washington, DC: The National Academies Press. <https://www.nap.edu/catalog/10548/the-future-of-the-publics-health-in-the-21st-century> (accessed April 3, 2021)



health agencies at the state, tribal, local and territorial (STLT) levels are left to develop or adopt and implement approaches specific to their needs and the needs of the populations they serve.

Much of the funding that flows to STLT public health agencies is earmarked for specific programs that exist within categories (e.g., chronic disease prevention and health promotion, environmental health, immunization and respiratory diseases) and sub-categories (e.g., diabetes, asthma, influenza). Over time, this categorical approach to funding public health work has led to the development and implementation of numerous disparate and siloed public health data and information systems that are tasked with functions related to data collection, management, use and exchange.

### **What challenges are posed by the way public health currently does its work?**

There are numerous challenges posed by the way public health currently functions. Funding for public health programs is typically controlled at the national and state levels, yet the work of public health occurs at the local level. This poses a challenge because data must not only be useable at the national and state levels but must also be relevant at the local level to identify problems and measure progress. In addition, the lack of agreed-upon standards or protocols for carrying out common public health functions has led to variation in the quality, efficiency and effectiveness of public health services jurisdictions offer. There is also growing recognition that some of the ways that public health data are collected, interpreted and used can ignore community needs and inadvertently exacerbate racism and inequities in health and other outcomes. Although some variation across public health jurisdictions is arguably necessary to allow agencies to improve their responsiveness to the communities they serve, there are undoubtedly many opportunities to increase efficiency, effectiveness and equity by encouraging the nationwide adoption of best practices and promising approaches.

#### **Lack of interoperability**

The categorical and siloed nature of public health programs, funding streams and information systems at all levels rarely support agency-wide solutions or information system enhancements, let alone interagency or cross-jurisdictional solutions. Instead, it is common for public health agencies to use many different information systems that each support a specific program (e.g., vital records, immunizations, newborn screening, syndromic surveillance).<sup>4</sup> Rarely are these various information systems designed to be interoperable with other information systems within the agency or across jurisdictions (e.g., between states). Information systems that are not interoperable lack the ability to communicate with one another, to exchange data accurately, effectively and consistently, and to use the information that has been exchanged. Lack of interoperability creates general fractures in complete and accurate data collection. It also leads to missed opportunities to fully identify and understand communities that are often underrepresented in surveillance and more prone to get lost between these systems. Therefore, these siloed programs, funding and information systems impede interoperability needed for a comprehensive approach to community health and make it difficult to have meaningful disaggregated data at the local level. As a field that uses data, science and funding to drive investments in communities, public health needs to understand that those who are underrepresented in our data systems are also at risk in being underrepresented in accessing resources they need. Interoperable systems will make it more likely that information is captured and shared in a way that yields a comprehensive picture of the individual or community and enables timely identification of patterns of

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<sup>4</sup> CDC. Public Health Surveillance: Preparing for the Future. <https://www.cdc.gov/surveillance/pdfs/Surveillance-Series-Bookleth.pdf> (accessed April 3, 2021)



inequities. Better and more accurate data engenders trust in the public health system and greater participation in vital health initiatives. Efforts at interoperability must include, at its start, local public health agencies, their partners and the communities they serve.

#### Governance, policy and regulatory constraints

Public health agencies at all levels are challenged in their efforts to share data within their agency, between agencies or across jurisdictions. Data sharing laws, policies and regulations are different at all levels (e.g., national, state, local) and across jurisdictions.<sup>5</sup>As a result, public health practitioners are often unfamiliar with navigating such issues. Legal and regulatory restrictions, such as the Health Insurance Portability and Accountability Act (HIPAA), are often a reason public health agencies cite for not sharing or exchanging data. While regulations do pose restrictions on certain types of data sharing, they do not prohibit the sharing of all types of health data. The fear of breaching such laws and regulations, combined with data that exist in siloed, non-interoperable systems, poses significant challenges to data sharing and exchange.

#### Persistent health inequities

Traditionally, public health data are collected and interpreted without significant input or guidance from the communities that are in most need of public health and other resources (e.g., housing, education, social services). The social and psychological implications of representative data are important in mobilizing local communities and achieving health equity. Although public health data are often collected at the local level, they are most often interpreted at the state and national levels. When public health data are not collected, interpreted and used in a manner that puts communities in the center, it can intensify health and other resource inequities. For example, when data sources are not interoperable, it can make it difficult to see how variables from different sources come together to affect people's lives. When community members are not involved in data governance, it decreases the likelihood that data will be collected, shared and used in a manner that adequately reflects the needs and perceptions of the communities themselves. These types of issues can contribute to public health data and service delivery infrastructure that reinforce systemic racism by unintentionally failing to meet the needs of communities. As a result, the inequitable distribution of public health services and other resources is worsened, and the perceptions of individuals and communities who rely on public services are distorted.

#### Emphasis on data collection vs. data use

National public health agencies like the Centers for Disease Control and Prevention (CDC) rely on STLT public health agencies to collect the data that are necessary to carry out some core public health functions, such as disease surveillance. At the same time, STLT agencies are often focused on gathering the data that they need to conduct their own state- or local-level public health activities. The effect is that STLT agencies spend a large amount of their energy and resources on being data *gatherers*—identifying, developing or procuring, and maintaining the information systems that allow them to gather and provide the data that is required from them and by them. The limited workforce and resources in most health departments means that insufficient time and resources are available for developing their skills as expert data *users* capable of extracting to inform daily decisions that effectively serve their communities and target populations.

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<sup>5</sup> Network for Public Health Law. Legal Bibliography. <https://www.communitycommons.org/entities/7cbb456d-007a-4e71-a76f-c2dc5cd3c183> (accessed March 28, 2021)

Insufficient investment in the workforce

The way that STLT agencies are funded and the approach many are taking to house their information technology (IT) departments also poses challenges related to human resources and procurement. For example, state and local governments are moving toward more centralized approaches to IT. Personnel with skills in informatics or IT are housed within a central IT department rather than within public health program offices. Central IT staff typically does not understand the complex system requirements for programmatic information systems. When making IT procurement decisions, this lack of understanding can lead IT to focus on the low-cost bidder versus the acquisition of a system that meets requirements. Additionally, many public health jurisdictions face barriers in their ability to hire staff with informatics expertise. In some jurisdictions, budgets are so limited that they cannot afford to hire informatics staff, and some jurisdictions face legislative restrictions on the number of full-time equivalent (FTE) staff that they can employ. Even when funding is available to cover an FTE through grants, cooperative agreements or other mechanisms, the agency might be unable to hire permanent staff. Therefore, they have to rely on contractors to perform some core functions, including those related to data and IT. The combination of centralized IT functions and increased reliance on contractors strips public health departments of in-house informatics expertise and can lead to an over-reliance on technology vendors. In addition, the public health workforce must include not only those with technical skills but also those who can ensure that equity is a central focus of all efforts to improve the ways that public health data are collected, interpreted and used to inform practice and policies.

**What are the opportunities to reimagine and improve the way public health does its work?**

Given that public health agencies have much in common when it comes to their work and challenges, there are significant opportunities to reimagine and improve public health processes. The table below highlights a few public health processes and compares the *current* approach many agencies use with a *reimagined* approach.

Table 1. Reimagining public health processes

Public Health Processes	Current Approach	Reimagined Approach
Employ data and information to guide actions and decision-making	Public health officials design, build, deploy, manage and use information systems in 50 states and ~3,000 counties.	Public health officials are expert users of readily accessed secure, relevant, timely, interoperable and community-centered information systems built by professionals to meet public health specifications and the needs of the communities that they are intended to serve.
Manage a set of well-known public health programs (e.g., immunization, maternal and child health, environmental health)	Jurisdictions develop their own ways of managing public health programs, unless federal or other funding requires specific programmatic activities and processes.	A common standards-based data/information architecture or model that allows participating organizations to maintain physical and operational control over their data exists to manage programs that do the same thing (based on a common IT

Public Health Processes	Current Approach	Reimagined Approach
		infrastructure that is informed by and responsive to community needs).
<b>Ensure equitable access to the individual services and care needed to be healthy</b>	Jurisdictions collect and interpret data with limited input or guidance from the communities that are in most need of public health and other resources	Public health collaborates closely and holistically with communities and community organizations to ensure that their input and guidance is at the center of activities related to data collection, interpretation and use.
<b>Detect and control infectious disease outbreaks and other public health emergencies</b>	Jurisdictions work within their boundaries, regardless of the scale of the outbreak or emergency.	Cross-border outbreaks and other public health disasters are made an exception to staying within boundaries, and changes to current data sharing laws enable exchange that maximizes health outcomes and equity.
<b>Ensure data are securely managed</b>	Jurisdictions makes their own decisions about security measures.	Cybersecurity is managed and driven by national professionals and standards.
<b>Procure information systems</b>	Procurement is jurisdiction-driven.	Procurement using federal funding requires use of market-proven solutions (when available), and the federal government shares national standards to guide local procurement when it is merited.

As part of reimagining the ways to do its work, public health should seek opportunities to network states as a strategy for easing the burden associated with sharing information across jurisdictions and to inform interventions for cross-border outbreaks and pandemics at the national level. Furthermore, agencies like the Centers for Medicare and Medicaid Services (CMS), the Federal Emergency Management Agency (FEMA) and the Transportation Security Administration (TSA) use standardized, nationwide approaches to work processes that public health can use as a model for opportunities to improve its own. More than a half a million Americans have died as a result of the COVID-19 pandemic, underscoring the need for an efficient national public health system prepared to withstand threats across all populations effectively and equitably.

Moreover, there are also lessons in global health that the U.S. public health system can benefit from. For example, District Health Information Software 2 (DHIS2) is an open source, web-based platform for collecting, analyzing, visualizing and sharing data. DHIS2 is the world’s leading Health Management Information System (HMIS), currently being used in more than 100 low- and middle-income countries (LMICs). Most recently, DHIS2 has been used to accelerate case detection, situation reporting, active surveillance and response for COVID-19 in LMICs. It has also been used by the World Health Organization (WHO), the United Nations International Children’s Emergency Fund (UNICEF) and Gavi, the Vaccine Alliance to improve national immunization program coverage through better data

collection, analysis and use with standardized tools. DHIS2 provides an example of a platform for data collection and sharing that can be used by multiple agencies or jurisdictions at a range of levels for a variety of purposes.

## Methods

To develop this report and recommendations for the Robert Wood Johnson Foundation (RWJF) and its commission, the Public Health Informatics Institute (PHII) conducted an environmental scan, hosted a series of interviews with thought leaders and convened an advisory group.



The purpose of the environmental scan was two-fold: 1) to document key activities and initiatives related to public health data and infrastructure that lay the groundwork for where we are today, and 2) to identify thought leaders from the public and private sectors to participate in an interview and/or on an advisory group to provide insights and recommendations for strategies that could address current limitations in data collection, sharing and use.

Identified individuals were invited to participate in a one-hour interview using teleconferencing technology. A total of 14 interviews were conducted in February of 2021. Ten of the interviews were conducted with one thought leader, and four were conducted in groups with two or more thought leaders from the same organization. A total of 22 thought leaders participated in an interview. All interviews were audio recorded (with the permission of the interviewees), audio files were transcribed, and qualitative data analysis techniques were used to identify key themes. In addition to the 14 interviews, two of the thought leaders completed a “white boarding activity” to further explore and describe the work of public health, current approaches, and ideas about how current approaches could be reimagined to better protect and promote health.

Eleven of the thought leaders were also invited to be members of the advisory group convened to further inform the development of this report. The first advisory group meeting was held virtually on February 25, 2021. In addition to the 11 interviewees, three additional thought leaders, the RWJF project officer overseeing this project, and four observers from the RAND Corporation and Schmidt Futures attended the advisory group meeting. The agenda for the initial meeting included an overview of the key findings from the interviews with thought leaders, an exercise to stimulate a reimagining of the way public health functions and a review of draft recommendations for RWJF’s Commission on Public Health Transformation. After the first advisory group meeting, an initial draft of this paper was circulated to the group members for feedback. The second advisory group meeting was held on March 29, 2021. The agenda for the second meeting included the opportunity to provide additional feedback on the initial draft of this paper, a discussion about the meaning of transformation and identification of next steps, and action items to ensure implementation of the recommendations included in this report.

## Key Findings

This section of the report consists of two parts. The first part describes key insights thought leaders shared during interviews and advisory group meetings. The second part describes a number of initiatives and innovations thought leaders identified as laying the groundwork for transformation of public health data and infrastructure. While the first part focuses on challenges and opportunities, the second part highlights progress public health has already made (despite severe underfunding, workforce shortages and other challenges) and should provide encouragement that the exchange and use of public health data can be more functional, efficient and effective.

### Insights from thought leaders

The discussions with thought leaders yielded many compelling insights and ideas about the challenges and opportunities related to public health data and infrastructure.

#### COVID-19 as a horrific event and enormous opportunity

Nearly all the thought leaders expressed that the COVID-19 global pandemic provides a critical and time-limited opportunity to highlight the challenges posed by siloed, non-interoperable public health data systems. For example, some thought leaders pointed out that state and local public health agencies in the U.S. have been unable to conduct needed contact tracing during the pandemic due in part to antiquated public health systems that are not interoperable across jurisdictional lines (e.g., between one state and another). The pandemic has also exposed the inability of our national, state and local public health agencies to effectively gather and use data in a timely manner to identify and strategically respond to communities disproportionately affected by COVID-19. Although many of the weaknesses of the U.S. public health system, data and infrastructure existed prior to COVID-19, the pandemic emphasized those related to inability to mount a timely and effective response.

*“The COVID-19 pandemic provides a transformational moment for the U.S. public health system to build back better.”*

As a use case, the COVID-19 pandemic can provide a better understanding and help communicate the challenges of non-interoperable systems. Moreover, it can reveal where and how to bridge gaps in the public health system. This means not only rebuilding existing data and infrastructure to be more responsive and timely, but reimagining and retooling these systems in a way that supports equitable and evidence-based promotion of health and effective protection against health threats.

#### Focus on equity

Health equity means that everyone has the opportunity to be as healthy as possible. When policies, programs and systems that support health are equitable, poor health outcomes can be reduced and health disparities can be prevented, benefitting all communities. There are many data sources that could be used to promote health equity by identifying, preventing and responding to health disparities. Thought leaders noted that data on race, ethnicity, education level and income can be used to identify disparities, but other important data are also needed from sources such as laboratories, public health, social services, housing and transportation.

When data from multiple sources are used to identify disparities, there is a greater chance that the interventions designed around those data sources will meet the needs of vulnerable populations and

*“Not only can we not get consistent race and ethnicity data, but we might also have some biases in the way that we develop algorithms and use technology.”*

build on the intrinsic strengths of each unique community. However, data needed to help identify, prevent and respond to disparities are not collected and stored in a standardized manner across agencies and jurisdictions. For example, during the COVID-19 pandemic, lack of consistently-collected and -standardized data on race and ethnicity contributed to a delay in identifying that some racial and ethnic minority groups are disproportionately affected by COVID-19. It also made it challenging to document that some racial and ethnic minority groups are also unequally affected by the

unintended economic, social and secondary health consequences of COVID-19 mitigation strategies such as social distancing. Any new nationwide strategy and common data architecture will need to include effective approaches to mitigate these challenges and achieve health equity—not only by improving public health data systems but also by expanding access to care, establishing equitable care models and adequately addressing social determinants of health.

#### Need for a nationwide strategy

Thought leaders highlighted the need for an overarching nationwide strategy to modernize public health information infrastructure in a way that can set a unified strategic direction for all levels of public health and technologies. One key benefit is defining the critical intersections between federal, state and local public health agencies and working to standardize and improve fluidity of data sharing between them. Without this strategy, public health agencies at the state, tribal, local and territorial levels are left to come up with their own data sharing strategies and approaches. This can result in technologies that fail to meet the needs of public health, and public health being left with information systems that are siloed and incapable of supporting the exchange of data across agencies or jurisdictions. Several thought leaders spoke specifically about the need to convene the public and private sectors to build a vision and road map for developing and implementing a nationwide architecture for collecting, managing, exchanging and using public health data.

*“Outdated and inefficient public health data systems provide an existential threat to our country.”*

#### Importance of a common data architecture

Many thought leaders described the need for a common functional architecture and technology platform, standardizing like public health functions. This framework would support two needs: translating business needs into data and system requirements and managing data and its flow through the entire public health system—across jurisdictional lines and among authorized users (e.g., public health agencies, private healthcare providers, social service agencies, patients). Additionally, establishing a unified structure at the federal level invites state and local jurisdictions into a national network that would enable key data sharing at every level. In the future, this common framework could serve as a blueprint for how public health agencies at all levels of government can use information

*“We need a common structure that passes on the minimally necessary data for the next data user to engage. That would provide us with an effective public health data and system architecture that is sensitive to privacy issues.”*



technology, treat data as a shared asset, facilitate improved system interoperability, reduce duplication of system development and help ensure the best possible outcomes related to health and equity. One thought leader expressed that this moment calls for putting more effort into defining the capabilities of a nationwide public health data platform and describing what can be implemented separately in each state and local jurisdiction using national standards.

Thought leaders also shared several principles that should be at the foundation of a common data architecture for public health, including:

- Eliminating data silos.
- Enabling interoperability.
- Promoting appropriate access to data that are nationally significant but relevant to communities.
- Maintaining security.
- Sharing a common vocabulary.
- Mandating the use of common data standards.

Several thought leaders also noted that a legal framework is needed to simplify decision support and handle data in a manner that protects privacy. It should also enable and accelerate adoption of the common functional architecture for sharing critical data, such as those related to widespread outbreaks and pandemics.

#### Public health agencies are all special, but they're not unique

Although each public health agency must meet the unique needs of its population, much of the work of public health is the same from one agency to another. For instance, almost all federally-funded public health programs require specific functions be performed, and many of these are related to information. The way these tasks are implemented and reflected in information system functionality is most often determined jurisdiction by jurisdiction, with little or no collaborative efforts to define processes and system requirements in consistent and replicable ways.

The absence of standardized approaches can lead to unique, homegrown approaches that can be detrimental to the goals of public health. For example, in most jurisdictions there are populations (e.g., economically disadvantaged, lower education level, rural) that are less likely to be engaged with governmental decision-making and more apt to be missed by the system<sup>6</sup>. An unintended consequence of non-standardized approaches is that processes, systems and standards are never developed for those who are categorically missed by the current system. Many jurisdictions serve these populations based

*“All of public health needs to perform very similar, if not identical, functions. It doesn’t make sense for every state and local agency to develop their own infrastructure, platforms and technical standards.”*

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<sup>6</sup> Association of American Medical Colleges. Health Disparities Affect Millions in Rural U.S. Communities. <https://www.aamc.org/news-insights/health-disparities-affect-millions-rural-us-communities> (accessed April 15, 2021)

on personal relationships versus public health standards. As the public health workforce ages and turns over, those relationships and connections will be lost.

### Enhance the informatics capacity of the public health workforce

Thought leaders expressed a strong need to build the capabilities of the public health workforce to

*“We should start thinking about public health practitioners – not as data gatherers – but as expert data users. And this will require a different set of skills.”*

effectively use data and information technology. There is a growing need for public health practitioners trained as data scientists or informaticians, individuals who are able to take complex data and make it understandable and actionable for decision-makers and the public. Some thought leaders noted the importance of ensuring that each public health agency has a chief health strategist who is adept at using data to guide public health decision-making.

Furthermore, some noted the need to focus on recruiting, training and retaining a skilled public health workforce. While trained data scientists and informaticians are in short supply, it might be beneficial to provide public health agencies with access to these skillsets through a regionalized approach: those with experience serve a public health region rather than only one public health agency. One thought leader also suggested that accreditation boards could play a role by ensuring that accredited public health agencies implement programs that train staff to analyze and use data for decision-making. Alternatively, there is a perception that many public health training programs, especially those at the masters’ level, do not provide adequate training in informatics. As a result, there is an insufficient number of new graduates entering public health with the skills to effectively manage and use significant public health data. Public health agencies will need the resources to train new graduates, hire informatics specialists from other fields and retain them over the long run. It is also important to acknowledge that the COVID-19 pandemic has increased workload, fatigue and burnout among the current public health workforce. In this way, the COVID-19 pandemic will exacerbate many of the staffing, hiring and retention challenges that public health agencies at all levels have been facing for many years.

### Initiatives and innovations

During the environmental scan and discussions with thought leaders, numerous initiatives and innovations—sometimes in the form of events, regulations, policies or technologies—were identified as laying the groundwork for transformation of public health data and infrastructure. Although the following list is not exhaustive, it is intended to highlight some of the innovations that have occurred in the public and private sectors over the past decade or more. Collectively, these initiatives and innovations should provide encouragement and evidence that the exchange and use of public health data can be more functional, efficient and effective. In short, transforming the way public health functions is not only critical but also *possible and timely*.

#### A lesson from Indiana

As part of Indiana’s COVID-19 response, the Indiana Health Information Exchange (IHIE) deployed visual data dashboards for the state and local public health departments to track important measures on how COVID-19 is impacting Indiana. The Indiana State Department of Health gets real-time updates of COVID-19 tests made possible through the correct testing, coding and data processing of critical information at the time of care and through connecting labs with electronic health information exchange.

The initiatives and innovations included in Table 2 are in chronological order, with the earliest initiatives and innovations shown first and the most recent shown last. For additional information about each of the initiatives and innovations listed below, please refer to [Appendix A](#) of this report.

Table 2. Initiatives and innovations

<b>Health Insurance Portability and Accountability Act (HIPAA)</b>	The privacy standards issued as part of the Health Insurance Portability and Accountability Act of 1996 (HIPAA) provide protection for the privacy of certain individually identifiable health data, known as protected health information. To balance public health’s need to protect communities, the privacy rule allows it to collect identifiable data without individual authorization for the purposes of preventing or controlling disease, injury or disability. This balancing act allows for electronic case reporting and permits public health officials to collect and use important public health data to create policy interventions to keep the population safe from existing and emerging threats.
<b>BioSense</b>	BioSense, now referred to as the National Syndromic Surveillance Program (NSSP), is a CDC initiative to collect syndromic surveillance data to support situational awareness and may provide early detection of disease outbreaks through timely acquisition of emergency department data. The BioSense platform accepts near real-time data from electronic health record systems (EHRs) and promotes electronic data exchange between healthcare facilities and public health agencies. It is an example of a shared service that enables local and state participation and configuration in a single cloud-based system.
<b>Public Health Information Network (PHIN)</b>	The Public Health Information Network (PHIN), developed by CDC, is an initiative to advance the development of fully capable and interoperable information systems in public health organizations. PHIN supports core public health functions, including outbreak detection, data analysis, and public health response management. PHIN includes technical and data standards. CDC developed tools to help increase public health agencies’ capacity to electronically exchange health information.
<b>APHL Informatics Messaging Service (AIMS)</b>	The APHL Informatics Messaging Service (AIMS) is a secure, cloud-based platform that accelerates health messaging by providing shared services to aid in the hosting, transport, validation, translation and routing of electronic data. AIMS is a national resource for interoperability with connections to over 50 state and local public health agencies, CDC, private laboratories and healthcare facilities.
<b>Health Information Technology for Economic and Clinical Health (HITECH) – also see Meaningful Use</b>	The Health Information Technology for Economic and Clinical Health (HITECH) Act, enacted as part of the American Recovery and Reinvestment Act of 2009, promotes the adoption and meaningful use of health information technology. The HITECH Act provides financial incentives to reimburse healthcare providers for their Meaningful Use of EHRs.
<b>Meaningful Use – also see HITECH</b>	Meaningful Use is a concept proposed as part of the HITECH Act which encourages the "meaningful use" of interoperable electronic health records throughout the United States' healthcare delivery system. Since 2018, Meaningful Use has focused on interoperability and improving patient access to health information. Meaningful




	<p>Use is now known as the Promoting Interoperability Program for hospitals. Although it did not provide funding to public health agencies, it did enable interoperability between healthcare and public health by rapidly accelerating healthcare and EHR adoption of standards.</p>
<p><b>HL7 PH Working Group</b></p>	<p>The Public Health Working Group is a voluntary, open committee that leads the Health Level Seven (HL7) consensus process for public health-related standards activities. The group works on standards including immunizations, vital records reporting (birth, death), provider reporting (cancer, birth defects, electronic case reports), lab results (reportable results and blood spots), occupational data for health and healthcare-associated infections.</p>
<p><b>Reportable Conditions Knowledge Management System (RCKMS)</b></p>	<p>The Reportable Conditions Knowledge Management System (RCKMS) is an authoritative, real-time portal that aims to enhance disease surveillance by providing comprehensive information to reporters and public health about the “who, what, where, when, why, and how” of case reporting. RCKMS is designed to handle the variation in reporting criteria that exists between jurisdictions. It is an example of a centrally and collaboratively developed shared service that enables consistent decision support and interoperability.</p>
<p><b>Public Health Community Platform (PHCP)</b></p>	<p>The Public Health Community Platform (PHCP) was a CDC-funded, ASTHO-led initiative to develop a space to find solutions for common public health informatics problems that state, local, territorial, tribal health agencies and their partners experience. The platform was designed as a resource to increase jurisdictional efficiencies by leveraging shared infrastructure, data and services to fundamentally change public health workflows and foster innovative solutions to public health problems. (Inactive)</p>
<p><b>Making EHR Data More Available for Research and Public Health (MedMorph)</b></p>	<p>The goal of MedMorph is to create a reliable, scalable and interoperable method to get electronic health record data for multiple public health and research scenarios (use cases). The development of a reference architecture and demonstrated implementation is intended to reduce the burden on healthcare providers and help provide the standards and methods to receive and send data from EHRs for a variety of public health and research purposes.</p>
<p><b>Digital Bridge</b></p>	<p>Digital Bridge is a forum which facilitates communication between healthcare experts, public health professionals and healthcare industry partners. A unique characteristic of Digital Bridge is its commitment to promoting bidirectional, or two-way, information exchange between healthcare and public health, ensuring that the needs of each stakeholder group are met and fostering a better connection between the two—a relationship that is integral to efficient public health surveillance. The first use case of Digital Bridge was electronic case reporting.</p>
<p><b>U.S. Core Data for Interoperability (USCDI)</b></p>	<p>The U.S. Core Data for Interoperability (USCDI) initiative from the Office of the National Coordinator for Health Information (ONC) aims to develop a minimum set of data classes that will be required to be interoperable on a national scale. The overall goal of USCDI is to establish the information that all electronic health record</p>

	<p>systems should be able to share, regardless of location within the United States, and regardless of the information systems in use within any given healthcare facility.</p>
<p><b>CDC Data Modernization Initiative (DMI)</b></p>	<p>CDC’s Data Modernization Initiative (DMI) is a comprehensive strategy to modernize data, technology and workforce capabilities to achieve increased surveillance and research to aid in public health decision-making. The purpose of the Data Modernization Initiative is to improve data quality while also improving the speed and coordination of the people and systems involved with public health data collection and the way in which data is stored and analyzed.</p>
<p><b>eCR Now</b></p>	<p>eCR Now is a strategic initiative that allows for rapid adoption and implementation of electronic case reporting (eCR) for COVID-19. eCR Now makes disease reporting from healthcare to public health faster and easier by moving data securely and seamlessly—from the EHR at the point of care, to data systems at state, territorial and local agencies. Built on the RCKMS, eCR Now can also manage all nationally notifiable conditions by turning on the full set of RCKMS trigger codes developed by CSTE.</p>
<p><b>District Health Information Software 2 (DHIS2)</b></p>	<p>An open source, web-based platform for collecting, analyzing, visualizing and sharing data. DHIS2 is the world’s leading health management information system (HMIS), currently being used in more than 100 low- and middle-income countries.</p>
<p><b>Childhood Obesity Data Initiative (CODI)</b></p>	<p>To improve data capacity for childhood obesity research, the CDC is leading the Childhood Obesity Data Initiative (CODI) to leverage existing information technology tools in innovative ways to facilitate access to childhood obesity data across health systems and sectors. The goal of the CODI initiative is to develop a proven solution for using and linking clinical and community data.</p>
<p><b>Multi-State EHR-based Disease Surveillance Network (MENDS)</b></p>	<p>MENDS is a CDC-funded initiative to conduct a demonstration of an electronic health record (EHR)-based chronic disease surveillance system. MENDS represents a collaboration among state health departments, healthcare organizations and data aggregators (e.g., health information exchanges). If successful, this demonstration project will lead to a real-time, chronic disease surveillance system in participating states using EHR data.</p>
<p><b>Immunization Gateway</b></p>	<p>The Immunization Gateway (IZ Gateway) is a data exchange hub that enables efficient data exchange between critical immunization information systems across the nation. It includes a portfolio of components that share a common IT infrastructure. These components support the exchange of immunization data between immunization information systems (IIS), provider organizations and consumer applications.</p>
<p><b>Apple and Google’s Exposure Notification System</b></p>	<p>Apple and Google’s exposure notification system is a framework and protocol specification to facilitate digital contact tracing during the COVID-19 pandemic. When used by health authorities, it augments more traditional contact tracing techniques by automatically logging encounters with other notification system users using their Android or iOS smartphone.</p>

<p><b>Patient-Generated Healthcare Data (PGHD)</b></p>	<p>This Patient-Centered Outcomes Research Institute (PCORI)-led initiative will create a community of stakeholders to identify evidence gaps in determining the value of patient-generated health data (PGHD). Answering how PGHD informs patient care, what value stakeholders place on PGHD, what information is needed to support decision-making to recommend or adopt PGHD and what challenges stakeholders face when interpreting PGHD will shape the research agenda necessary to inform use of PGHD technologies to improve patient care.</p>
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In addition to these initiatives and innovations, a number of use cases have been developed to illustrate how electronic data exchange can and has been conducted in public health practice. The following table provides information about three use cases, initially presented by the Association of State and Territorial Health Officials (ASTHO) in a 2018 guidance document for state health officials.<sup>7</sup>

Table 3. Use case examples of electronic data exchange in public health practice

	<p><b>Immunization Information Systems</b></p>	<p>Immunization information systems (IIS), or immunization registries, are confidential, population-based, computerized databases that record all immunization doses administered by participating providers to persons residing within a given geopolitical area. IIS provide consolidated immunization history at the point of care and aggregate data for use in surveillance at the population level. IIS exist in most every state and numerous other jurisdictions. In some states, laws mandate provider participation. In most states the IIS support bidirectional data exchange with EHRs to ensure that children get only the vaccines that meet the standard vaccine schedule.</p>
	<p><b>Newborn Screening</b></p>	<p>Newborn screening for heritable and congenital disorders is a federally mandated public health program aimed promptly identify conditions for which early, timely interventions can lead to the elimination or reduction of associated mortality, morbidity, and disabilities. Gaining timely access to newborn screening results is critical to provide effective continuity of care to newborns. Providers experience barriers to gaining access to the screening results, such as infants born in a facility where the provider has no privileges, transfers to the provider’s practice, infants born in other states, and manual processes to receive results. For example, there are initiatives to create bidirectional information exchange for newborn screening at Johns Hopkins Hospital and the Maryland Department of Health and Mental Hygiene.</p>
	<p><b>Syndromic Surveillance</b></p>	<p>Chief complaint data from emergency departments are sent from EHRs to syndromic surveillance systems, which analyze and group them into syndromes. Epidemiologists are alerted to potential outbreaks based on system algorithms. The New York City Department of Health and Mental Hygiene (NYDOHMH) launched an effort to utilize syndromic data and bidirectional data exchange with public health systems to carry out a fuller array of public health and clinical care functions. Specifically, NYDOHMH targeted data exchange for syndromic surveillance of tobacco use risks. This allowed NYDOHMH to send clinical sites the results of the aggregated data analysis for communities.</p>

<sup>7</sup> Leading Public Health Practice Through Health Informatics and Technology. Developed by the Association of State and Territorial Health Officials (ASTHO); 2018. <https://www.astho.org/ASTHOReports/ASTHO-Informatics-Guidebook/12-14-18/>



## Recommendations

The resounding recommendation from thought leaders across multiple public and private organizations is that transformation of public health data and infrastructure *must occur now*. Despite the progress made by some previous initiatives and innovations, the pandemic has made it aware that fractured parts of the current system still exist and that short-term fixes will not suffice. The pandemic has provided the sense of urgency to undertake more overarching transformation now.

Informed by the environmental scan and discussions with thought leaders, the following recommendations highlight the initial steps that must be taken to transform the public health system into one that is equitable and can be effectively used to monitor, respond and improve the health and well-being of the U.S. population:

1. **Convene a multi-disciplinary group of thought leaders from the public and private sectors to develop a vision, strategy, road map, policy framework and call-to-action** for developing a nationwide strategy and common functional architecture to transform current processes to gather and use significant public health data. The fact that public health agencies are not always the ones that generate or own this data underscores the need for a multidisciplinary group comprised not only of governmental public health agencies but also sectors such as private health care, education and social services. The strategy and common architecture must be based on legitimate participation of the communities that will be affected and represent collaborative and joint decisions about the collection and use of public health data. It must also include representation from all levels of government: state, tribal, local and territorial. In addition to a nationwide strategy and common architecture, a use case should be developed based on the U.S. response to the COVID-19 pandemic to underscore the frailties of the public health system and highlight opportunities to transform the way data is exchanged and used to promote health, protect against health threats and ensure health equity. Consideration must also be given to federal legislation needed to ease the process for this type of data infrastructure development.

The initial steps to implement this recommendation are below:

- 1a) **Identify a sponsor and neutral convener** for the multi-disciplinary group.
  - 1b) **Convene the group members to develop the vision, strategy, road map, policy framework and call-to-action** for an overarching nationwide strategy for public health information infrastructure that can set a unified strategic direction for public health programs and technologies.
  - 1c) **Initiate and support the process of reviewing and synthesizing past and current recommendations** related to transformation of public health data and infrastructure into a single, cohesive and actionable set of recommendations.
  - 1d) **Support the development of a legal framework** that enables and accelerates the adoption of a nationwide strategy and common functional architecture.
  - 1e) **Support the development of a use case** based on the U.S. response to the COVID-19 pandemic.
2. **Promote efforts to make equity the cornerstone of all public health activities** by incentivizing public health systems to implement approaches to gathering and using public health data that



put communities at the center of decisions about what data are collected, how they are collected and how they are used. These efforts should include developing a framework to actively engage communities that are not adequately represented and involved in current approaches to public health data collection, management and use. These communities and community members must be engaged in discussion about the benefit of including their data in the broader system. Tools, such as the Universal Community Planning Tool, should be used to help communities create local, data-informed visions and community health improvement plans that meet their unique needs and reflect the meaningful and transparent engagement of community members.<sup>8</sup> To transform public health data infrastructure and the way practitioners interact with data sources, the voices, technology and assumptions that have been missing from the current paradigm need to be identified and actively included.

The initial steps to implement this recommendation are below:

- 2a) **Support the development and use of frameworks and planning tools** that assist public health agencies to act on the notion of “putting communities at the center” of decisions about data collection, sharing and use.
  - 2b) **Support a series of “listening sessions”** across the country to gather feedback about the transformation of public health data and infrastructure from all aspects of the health ecosystem (e.g., governmental public health agencies, healthcare delivery systems, community-based entities, businesses, media).
  - 2c) **Identify and promote the use of strategies, such as incremental Privacy-Preserving Record Linkage (iPPRL), to address privacy concerns** about the level of data integration and sharing that will be needed to fully implement this recommendation.
3. **Sponsor the development of a nationwide requirements project** on a core public health information system, such as infectious disease surveillance. This activity can help translate business needs into data and systems requirements, as well as demonstrate the benefits that can arise from a shared understanding of the actions, processes and capabilities needed to ensure the system is successful. The Office of the National Coordinator for Health Information Technology (ONC)—which supports the adoption of health information technology and the promotion of nationwide, standards-based health information exchange to improve health care—serves as an example of the type of resource that could help facilitate transformation of public health data and infrastructure. However, it is important not to address numerous systems or problems immediately and simultaneously. Instead, start with one information system or problem. Equity must also be incorporated into the planning, design and implementation of the requirements project to ensure that the result reflects the needs, values and concerns of the community it is intended to serve. The project should be leveraged as an opportunity to develop and promote a framework that actively engages communities in the reimagined system.

The initial steps to implement this recommendation are below:

- 3a) **Identify one public health system** to be the focus of the requirements project.
- 3b) **Identify a sponsor and neutral convener** for the requirements development project.

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<sup>8</sup> Public Health National Center for Innovations. Universal Community Planning Tool Project. <https://phnci.org/uploads/resource-files/PHNCI-Case-Study-Garrett-County.pdf>

- 3c) **Support the development of a framework** to facilitate community engagement in activities related to public health data and infrastructure.
- 3d) **Support the development of the nationwide requirements project** to demonstrate that some public health functions can be approached in a standardized way.
4. **Invest in the public health workforce** to ensure that public health continues to benefit from appropriate technical skills and reflects diversity nationally. It is imperative to support the ability of state, tribal, local and territorial public health agencies to recruit, train and retain personnel who have the skills to transform public health data into the information needed to support public health decision-making. The American Rescue Plan of 2021 (ARP) provides support for public health workforce initiatives, including funding to state, tribal, local and territorial public health agencies to hire staff and procure technology to support public health efforts.<sup>9</sup> The task at hand is to assist public health agencies to use these newly available funds in ways that will help build and sustain a public health workforce with the types of skills that are needed to implement transformative changes. It is also essential that the makeup of individual communities is reflected in the public health workforce. For example, a focused effort should be placed on recruit young people and people of color into public health trainings programs. The initial steps to implement this recommendation are below:

- 4a) **Identify opportunities to expand and enhance informatics trainings** for public health students and practitioners.
- 4b) **Create and support resource or coordinating centers to provide training and technical assistance to STLT agencies** related to workforce strengthening and assist in the transition of public health practitioners from data collectors to astute data users.

Implementing these recommendations will help pave the way for true transformation of public health data, infrastructure and vital functions. When the U.S. Department of Health and Human Services launched the Public Health 3.0 initiative in 2016, it called for a new era of enhanced and broadened public health practice, increased cross-sectoral collaboration, improved community participation and new chief health strategist positions filled with leaders who have the skills and capabilities to usher public health into the new era.<sup>10</sup> In many ways, the recommendations in this report reflect and amplify several of the recommendations made in Public Health 3.0. Now, just a few years later and during a global pandemic, it is even more critical to find improved and equitable ways to carry out essential public health services. It is imperative to leverage the current public health crisis, not only to achieve the vision of Public Health 3.0, but to implement the recommendations included in this report to transform public health data, infrastructure and the system itself into one that is equitable and can be effectively used to monitor, respond and improve health and well-being.

<sup>9</sup> H.R.1319 – American Rescue Plan Act of 2021. <https://www.congress.gov/bill/117th-congress/house-bill/1319/text> (accessed April 11, 2021)

<sup>10</sup> DeSalvo KB, Wang YC, Harris A, Auerbach J, Koo D, O’Carroll P. Public Health 3.0: A Call to Action for Public Health to Meet the Challenges of the 21st Century. *Prev Chronic Dis* 2017;14:170017. [https://www.cdc.gov/pcd/issues/2017/17\\_0017.htm](https://www.cdc.gov/pcd/issues/2017/17_0017.htm) (accessed April 11, 2021)

## Appendix A.

The following information is intended to complement and expand upon the information provided in the section of this report entitled *Initiatives and Innovations*.

### Health Insurance Portability and Accountability Act (HIPAA)

The privacy standards issued as part of the Health Insurance Portability and Accountability Act of 1996 (HIPAA) provide protection for the privacy of certain individually identifiable health data, known as protected health information. To balance public health's need to protect communities, the privacy rule allows it to collect identifiable data without individual authorization for the purposes of preventing or controlling disease, injury or disability. This balancing act allows for electronic case reporting and permits public health official to collect and use important public health data to create policy interventions to keep the population safe from existing and emerging threats.

### BioSense

The BioSense program is a public health surveillance system that increases the ability of health officials at local, state and national levels to efficiently, rapidly and collaboratively monitor and respond to harmful health effects from exposure to disease or hazardous conditions. The BioSense program was launched in 2003 with the aim of establishing a nationwide integrated public health surveillance system for early detection and assessment of potential bioterrorism-related illness. BioSense provides public health officials a common electronic health information system with standardized tools and procedures for rapidly collecting, sharing and evaluating information. Implementation of BioSense promotes utilization of standardized syndromic surveillance data.

BioSense 2.0, the latest version of the BioSense program, is a CDC-led effort partnering with CSTE, ASTHO and NACCHO to create a user-driven, nationwide syndromic surveillance system. The BioSense 2.0 program pulls together information on emergency department visits and hospitalizations from multiple sources, including the Department of Veterans Affairs, the Department of Defense and civilian hospitals from around the country. The BioSense program works with state or local health departments that have agreed to share data from their own emergency department monitoring systems to collect data from civilian hospitals. Analysis of these data provides insight into the health of communities and the country. Such data are vital to guide decision-making and actions by public health agencies at local, regional and national levels.

### Public Health Information Network (PHIN)

The Public Health Information Network (PHIN), developed by CDC, is an initiative to advance the development of fully capable and interoperable information systems in public health organizations. PHIN supports core public health functions, including outbreak detection, data analysis, and managing public health response. PHIN includes technical and data standards. CDC developed tools to help increase public health agencies' capacity to electronically exchange health information. For example, the PHIN Vocabulary Access and Distribution System (PHIN VADS) provides standard vocabularies to CDC and its public health partners in one place. The PHIN Messaging System (PHINMS) is CDC software that facilitates secure electronic message transport between CDC and public health information systems. The PHIN Public Health Directory (PHIN DIR) is a repository of

information about organizations and jurisdictions important to public health programs and provides object identifiers (OIDs) for use within the public health community.

### **APHL Informatics Messaging Service (AIMS)**

The APHL Informatics Messaging Service (AIMS) is a secure, cloud-based platform that accelerates health messaging by providing shared services to aid in the transport, validation, translation and routing of electronic data. AIMS is a national resource for interoperability with connections to over 50 state and local public health agencies, CDC, private laboratories and healthcare facilities. The AIMS platform securely transports millions of messages on a monthly basis. Examples of data currently exchanged through AIMS include aggregated Influenza test result data from public health laboratories to CDC, vaccine-preventable disease reports from testing centers of excellence to CDC, Immunization data exchange among several public health jurisdictions, and electronic case reporting (eCR) between providers and jurisdictions across the U.S.

Routing messages through the AIMS services enhance the users' ability to manage data exchange routes and trading partners; once a trading partner is on AIMS, they can send and receive with any trading partner already on the platform with minimal effort rather than maintaining multiple connections to a variety of senders and receivers. In addition, the translation and transformation services that AIMS offers make it easier for agencies and laboratories to exchange data with a variety of senders and receivers.

### **Health Information Technology for Economic and Clinical Health (HITECH)**

The Health Information Technology for Economic and Clinical Health (HITECH) Act, enacted as part of the American Recovery and Reinvestment Act of 2009, was signed into law on February 17, 2009 to promote the adoption and meaningful use of health information technology. The HITECH Act provides financial incentives to reimburse healthcare providers for their Meaningful Use of electronic health records (EHRs). These incentives provide both opportunities and challenges for public health. To receive incentives, providers must exchange specified data types with their public health partners. eCR is one option for providers. HITECH can pose challenges for public health departments because these incentives are focused on healthcare providers and do not support public health agencies to address issues such as the lack of infrastructure, trained resources and data exchange capabilities.

### **Meaningful Use**

Meaningful Use is a CDC-based initiative and is led by Centers for Medicare & Medicaid Services and the Office of the National Coordinator of Health IT (ONC). Meaningful Use is a concept proposed as part of the HITECH Act which encourages the meaningful use of interoperable electronic health records throughout the United States' healthcare delivery system. Meaningful Use specifically refers to the act of using certified EHR technology in accordance with the Secretary of Health & Human Services (HHS) information on the quality of care and other measures to provide for the electronic exchange of health information with the final goal of achieving improved quality of care. Since 2018, Meaningful Use has focused on interoperability and improving patient access to health information. In recent years, the Meaningful Use of EHR technology has been employed within Public Health Registry and Clinical Data Registry Reporting, specifically within the

reporting of immunization registry, syndromic surveillance, electronic cases, and public health registries, clinical data registries, and hospitals' electronic reportable laboratory tests.

The goals of Meaningful Use include improving care coordination as well as the quality, safety and efficiency of public health measures. Meaningful Use is also intended to reduce health disparities and ensure adequate privacy and security protection for personal health information. Beginning in 2018, all eligible healthcare professionals (EPs) or eligible clinicians (ECs) previously participating in the Medicare Promoting Interoperability program were required to report on the following Quality Payment Program (QPP) requirements: e-prescribing, health information exchange, provider-to-patient exchange, and public health and clinical data exchange. This change has resulted in an increased focus on interoperability and improving patient access to health information which will continue into the future.

### **HL7 PH Working Group**

The Public Health Working Group is a voluntary, open committee that leads the HL7 consensus process for public health-related standards activities. It has a membership that includes public health, healthcare and vendors who discuss needs, develop and review standards, and publish those standards for implementation. The HL7 Public Health Working Group, with support from CDC and other public health partners have developed implementation guides using clinical document architecture (CDA) standards for public health reporting from healthcare providers to state and local public health agencies. CDA is a messaging standard used for data exchanges between clinical systems and was recommended by the Health Information Technology Advisory Committee (HITAC). To keep in step with technology changes in healthcare, additional work to support eCR is now being advanced using Fast Healthcare Interoperability Resources (FHIR).

### **Reportable Conditions Knowledge Management System**

The Reportable Conditions Knowledge Management System (RCKMS) is an authoritative, real-time portal that aims to enhance disease surveillance by providing comprehensive information to reporters and public health about the “who, what, where, when, why, and how” of case reporting. RCKMS is designed to handle the variation in reporting criteria that exists between jurisdictions. For example, with eCR, after a trigger is met and an electronic initial report (eICR) is sent to the APHL AIMS platform, RCKMS will determine whether the potential case is reportable, and if so, to which jurisdiction. This automated process removes some of the burden of reporting and handling complexity from data reporters and gives public health agencies more capabilities to manage and communicate their reporting criteria.

RCKMS consists of three parts: the authoring interface, knowledge repository and decision support service. The authoring interface is a web portal for public health agencies to input, edit and manage their jurisdictional reporting criteria. The knowledge repository is a database containing default and jurisdictional reporting specifications. After being entered by users, reporting specifications are stored in the knowledge repository and deployed to the decision support service. The decision support service is invoked by an automated call from an EHR system, either directly or through an intermediary service, to determine if a potential case is reportable and to which jurisdiction(s).

### Public Health Community Platform

The Public Health Community Platform (PHCP) was a CDC-funded, ASTHO-led initiative to develop a space to find solutions for common public health informatics problems that state, local, territorial and tribal health agencies and their partners experience. The platform was designed as a resource to increase jurisdictional efficiencies by leveraging shared infrastructure, data and services to fundamentally change public health workflows and foster innovative solutions to public health problems. The PHCP provided the implementation space for national informatics pilot projects and a single source for public health decision support solutions. As one of its priority areas, the PHCP sought to define a common architecture to connect public health agencies and healthcare providers for the implementation of eCR.

### MedMorph

CDC, in partnership with an external technical expert panel, is taking steps to modernize critical information technology that allows for better sharing, receiving and use of data. Through a project entitled *Making EHR Data More Available for Research and Public Health (MedMorph)*, CDC is working to build and connect the digital public health data superhighway, which will facilitate the seamless and timely flow of EHR data.

The goal of MedMorph is to create a reliable, scalable and interoperable method to get electronic health record data for multiple public health and research scenarios (use cases). The development of a reference architecture and demonstrated implementation is intended to reduce the burden on healthcare providers and help provide the standards and methods to receive and send data from EHRs for a variety of public health and research purposes.

The MedMorph project is funded by the Patient-Centered Outcomes Research Trust Fund via the Department of Health and Human Services Assistant Secretary for Planning and Evaluation.

### Digital Bridge

Digital Bridge is a forum that facilitates communication between healthcare experts, public health professionals, and healthcare industry partners. Within this forum, information is shared in a bidirectional way between healthcare and public health to ensure efficient public health surveillance and meet the needs of both healthcare and public health. Digital Bridge aims to generate a unified approach to information exchange which will ease costs and other burdens equally for all stakeholder groups. Additionally, Digital Bridge aims to standardize bidirectional data exchange to inform clinicians on population health, environmental risks and outbreaks. These goals will aid Digital Bridge in advancing standards-based information exchange across public health and healthcare.

As its first project, Digital Bridge designed a nationally scalable, multi-jurisdictional approach to eCR, the automated generation and transmission of case reports from the EHR to public health agencies for review and action. The efficient, automated aspect of this approach not only generates more precise reports, but also eliminates guesswork and inconsistent manual reporting previously enacted by organizations and data providers, thus ensuring that higher-quality health data is collected in the future. In fall 2019, the nationwide scale-up of eCR transitioned to CDC, the Association of Public Health Laboratories (APHL), and the Council of State and Territorial Epidemiologists (CSTE).

Digital Bridge has also collaborated with health IT and privacy experts to develop the necessary legal framework to ensure that its goals can be met without encountering unexpected jurisdictional barriers. In addition, Digital Bridge has also established a series of nationwide demonstration sites which foster communication and evaluation and share feedback to better shape and inform the future of the initiative.

### [U.S. Core Data for Interoperability \(USCDI\)](#)

The U.S. Core Data for Interoperability (USCDI) initiative from the Office of the National Coordinator for Health Information (ONC) aims to develop a minimum set of data classes that will be required to be interoperable on a national scale. The overall goal of USCDI is to establish the information that all electronic health record systems should be able to share, regardless of location within the United States, and regardless of the information systems in use within any given healthcare facility.

### [CDC Data Modernization Initiative](#)

CDC's Data Modernization Initiative is a comprehensive strategy to modernize data, technology and workforce capabilities to achieve increased surveillance and research to aid in public health decision-making. The initiative upholds a series of actions, which if enacted by CDC and its partners, will protect the United States from extant public health threats and will prepare the country for developing public health threats and those which have yet to emerge. The purpose of the Data Modernization Initiative is to improve data-quality while also improving the speed and coordination of the people and systems involved with public health data collection and the way in which data is stored and analyzed. In working towards this goal, the Data Modernization Initiative aims to integrate emerging technologies. The initiative also aims to prioritize and use relationships with data partners by increasing collaboration and communication regarding data and results.

The long-term goal of the Data Modernization Initiative is to merge efficient data collection with rapid action to prioritize the implementation of more immediate, inclusive and impactful public health decisions in the post-COVID world. The initiative's increased effort to collaborate with data partners is intended to foster development of innovative tools and strengthen predictive analytics, thus benefiting the future of public health through visualization and forecasting. The initiative's equitable approach will focus on making sure every American has equal opportunity to the highest quality healthcare and equal and immediate access to healthcare-related information, thus amending the limitations of the American public health system in the pursuit of a more egalitarian approach.

### [eCR Now](#)

eCR Now is a strategic initiative that allows for rapid adoption and implementation of eCR for COVID-19. It improves COVID-19 reporting immediately, allows expansion to all reportable conditions, and features three components that make it easy to implement: (a) rapid eCR implementation through small cohort groups for provider sites that use an EHR with eCR capabilities, (b) eCR Now Fast Healthcare Interoperability Resources (FHIR) app that non-eCR-enabled EHRs can rapidly implement to automate eCR for COVID-19, and (c) extension of the existing eHealth exchange policy framework through an approved Carequality eCR implementation guide.



**District Health Information Software 2 (DHIS2)**

District Health Information Software 2 (DHIS2) is an open source, web-based platform for collecting, analyzing, visualizing and sharing data. DHIS2 is the world's leading Health Management Information System (HMIS), currently being used in more than 100 low- and middle-income countries (LMICs). Most recently, DHIS2 has been used to accelerate case detection, situation reporting, active surveillance and response for COVID-19 in LMICs. It has also been used by WHO, UNICEF and Gavi, the Vaccine Alliance to improve national immunization program coverage through better data collection, analysis and use with standardized tools.

**Childhood Obesity Data Initiative (CODI)**

To improve data capacity for childhood obesity research, the CDC is leading the Childhood Obesity Data Initiative (CODI) to leverage existing information technology tools in innovative ways to facilitate access to childhood obesity data across health systems and sectors. CODI aims to facilitate access to integrated multi-sector data from clinical care and obesity- or chronic disease-related interventions based in clinical or community settings. The project seeks to build data capacity for research, surveillance and evaluation that assess strategies to prevent and treat childhood obesity and other chronic conditions. The goal of the CODI initiative is to develop a proven solution for using and linking clinical and community data.

**Multi-State EHR-based Network for Disease Surveillance (MENDS)**

In 2018, CDC's Division for Heart Disease and Stroke Prevention funded a demonstration of an electronic health record (EHR)-based chronic disease surveillance system. MENDS represents a collaboration among state health departments, healthcare organizations and data aggregators (e.g., health information exchanges). If successful, this demonstration project will lead to a real-time, chronic disease surveillance system in participating states using EHR data.

**Immunization Gateway (IZ Gateway)**

The Immunization Gateway (IZ Gateway) is a data exchange hub that enables efficient data exchange between critical immunization information systems across the nation. It includes a portfolio of components that share a common IT infrastructure. These components support the exchange of immunization data between immunization information systems (IIS), provider organizations and consumer applications.

The IZ Gateway include (a) enables large, national and non-traditional vaccinators to report to IISs; (b) ensures multiple IIS receive data from multijurisdictional provider organizations by providing a centralized data exchange connection; (c) simplifies the onboarding and data sharing process for multijurisdictional provider organizations by eliminating the need for multiple individual, point-to-point IIS connections; (d) allows exchange of immunization information across IIS jurisdictions; (e) automates sending information to an IIS for patients immunized outside of their jurisdiction; (f) consumers can access immunization records and forecasts through easy-to-use digital tools; and (g) allows providers to initiate a query for immunization information from multiple jurisdictions and receive a consolidated record.

### **Apple and Google’s Exposure Notification System**

Apple and Google’s exposure notification system is a framework and protocol specification to facilitate digital contact tracing during the COVID-19 pandemic. When used by health authorities, it augments more traditional contact tracing techniques by automatically logging encounters with other notification system users using their Android or iOS smartphone. The notification system employs random, rotating keys and identifiers to convey positive diagnoses in addition to data such as associated symptoms, proximity and duration.

### **Patient Generated Healthcare Data (PGHD)**

This PCORI-led initiative will create a community of stakeholders to identify evidence gaps in determining the value of patient-generated health data (PGHD). Answering questions about how PGHD informs patient care, what value stakeholders place on PGHD, what information is needed to support decision-making to recommend or adopt PGHD and what challenges stakeholders face when interpreting PGHD will shape the research agenda necessary to inform use of PGHD technologies to improve patient care. This project will create a sustainable foundation for PCOR inclusive of PGHD that is responsive to the needs of stakeholders. Specific aims include: 1) identifying case studies of PGHD in practice, illustrating the range of applications in healthcare; 2) creating a framework to guide research development and implementation; and 3) developing a research agenda on the most pressing and impactful areas to advance evidence on the integration of PGHD to improve patient-centered care.