Transforming U.S. Public Health Data and Infrastructure to Protect Health and Achieve Health Equity

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1. Explain the challenges posed by the way public health currently functions.

1.1 Persistent health inequities
- Traditionally, public health data are collected and interpreted without significant input from communities in most need of public health and other resources (e.g., housing, education, social services).
- Although public health data are often collected at the local level, practitioners have variable capacity to analyze and use data for response or intervention activities.
- Surveillance data are often missing or too incomplete to enable health departments to identify communities or populations with disparate burdens or more severe outcomes.
- 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.

1.2 Lack of interoperability
- The categorical and siloed nature of public health programs, funding streams and information systems rarely support agency-wide solutions or information system enhancements, let alone interagency or cross-jurisdictional solutions or enhancements.
- Instead, it is common for public health agencies to use different systems that each support a specific program or disease (e.g., vital records, immunizations, newborn screening, syndromic surveillance).
- Rarely are these various information systems designed to be interoperable with other information systems within the agency or across jurisdictions (e.g., between states).
- Non-interoperable information systems lack the ability to communicate with one another, exchange data accurately, effectively and consistently, and easily incorporate and use the exchanged information.

1.3 Governance, policy and regulatory constraints
- Public health agencies 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.
- Legal and regulatory restrictions, such as the Health Insurance Portability and Accountability Act (HIPAA) are often cited as a reason for public health agencies 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.

1.4 Emphasis on data collection versus use
- National public health agencies rely on state, tribal, local and territorial (STLT) agencies to collect data necessary for core public health functions, such as disease surveillance. Methods through which STLT share data are often redundant and inefficient and place additional burden on already stretched staff.
- Simultaneously, STLT agencies are often focused on gathering data needed to conduct their own state- or local-level public health activities, spending a large amount of resources on being data gatherers (i.e., 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 to inform daily decisions that effectively serve their target populations.

1.5 Insufficient investment in the public health 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.
- Additionally, many public health jurisdictions face barriers (e.g., uncompetitive salaries, hiring restrictions) in hiring and retaining staff with informatics expertise.
- The combination of centralized IT functions and increased reliance on contractors strips agencies of in-house informatics expertise and can lead to an over-reliance on technology vendors and repeated need to train and familiarize vendors with the existing infrastructure and systems.
2. Describe the opportunities to transform U.S. public health data and infrastructure to protect health and achieve health equity.

2.1 COVID-19 pandemic as horrific event and enormous opportunity
- 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.
- The pandemic 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 affected disproportionately.

2.2 Focus on equity
- Equitable policies, programs and systems reduce poor health outcomes and health disparities, benefiting all communities.
- During the COVID-19 pandemic, lack of consistently reported, collected and standardized data on variables such as race, ethnicity and occupation contributed to a delay in identifying that some racial and ethnic minority groups are disproportionately affected.
- Any new nationwide strategy and common public health 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.

2.3 Need for a nationwide strategy
- There is a need for a nationwide strategy to modernize public health information infrastructure. Without this strategy, STLT agencies are left to create their own data sharing strategies and approaches.
- There is a need to convene the public and private sectors to develop a vision and road map for developing and implementing a nationwide architecture for collecting, managing, exchanging and using public health data.

2.4 Importance of a common data architecture
- There is a need for a common functional architecture and technology platform, standardizing like public health functions.
- This common framework could serve as a blueprint for how public health agencies can use information technology, treat data as a shared asset, facilitate improved system interoperability, reduce duplicate system development and help ensure healthy and equitable outcomes.
- A legal framework is also needed to simplify decision support and handle data in a manner that protects privacy.

2.5 Enhance the informatics capacity of the public health workforce
- There is a growing need for public health practitioners trained as data scientists or informaticians: individuals who are able to provide requirements, select systems, participate in system design and management, automate processes, ensure data quality, and analyze and manage complex data. In addition, they must be able to develop understandable and actionable visualizations for decision-makers and the public.
- While trained data scientists and informaticians are in short supply, it might be beneficial to provide public health agencies access to these skill sets through a regionalized or cohort approach: those with experience serve a public health region rather than only one public health agency. On-the-job training could also be beneficial and used to supplement formal education in data science.
3. Describe the recommendations\(^1\) made to the Robert Wood Johnson Foundation (RWJF) National Commission to Transform Public Health Data Systems.

3.1 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

- Develop a nationwide strategy and common functional architecture to transform current processes to gather and use significant public health data.

3.2 Promote efforts to make equity the cornerstone of all public health activities

- Incentivize 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.

3.3 Sponsor the development of a nationwide requirements project

- 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.

3.4 Invest in the public health workforce

- It is imperative to support the ability of STLT 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.

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\(^1\) These recommendations were prepared and submitted by the Public Health Informatics Institute to the RWJF National Commission to Transform Public Health Data Systems in June 2021. The full report is available at: [https://www.phii.org/resources/view/9808/building-back-better](https://www.phii.org/resources/view/9808/building-back-better)
4. Explain what STLT health departments can do now to transform U.S. public health data and infrastructure while waiting for a nationwide strategy and common functional architecture.

4.1 Support the concept of a nationwide strategy and common functional architecture
- There is a need for a nationwide strategy to modernize public health information infrastructure. It will provide necessary guidance to public health agencies that are already – and will continue to be – actively engaged in activities related to the transformation of their respective data systems and infrastructure.
- Importantly, a nationwide strategy does not mean that there should be a single, unified approach that is imposed on all STLT health departments and jurisdictions. In fact, a single approach would be detrimental to progress in transforming public health data systems because it would eliminate and replace data systems that are already working well in some jurisdictions.
- It is critical to develop a common functional data architecture with standards supporting interoperability that is specifically designed to meet the needs of STLT health departments. To this end, STLT professionals must be actively engaged in all aspects of public health data systems transformation (e.g., system design, standards development).

4.2 Collaborate with other public health professionals within and across jurisdictions to identify potential solutions to data challenges
- There are public health departments across the country that have implemented innovative and effective approaches to mitigate or solve their respective data challenges.
- Now is the time to collaborate within and across jurisdictions to learn from one another in an effort to identify potential solutions to common data challenges. While collaboration can benefit all public health departments, those that are smaller and/or poorly resourced may benefit the most from the capacity building that can result from collaboration.
- Health departments should explore opportunities to convene informatics staff across the entire enterprise to develop and implement strategies to address their challenges. This is critical to build enterprise-wide, disease-agnostic systems and layer data to promote interoperability, use common standards and leverage common technologies.

4.3 Think strategically and pace appropriately
- The current environment, which may well include funding and a sense of urgency, makes it tempting to move extremely fast. While timeliness is important, it is also possible to move too fast and thereby miss opportunities to think strategically about what needs to be done and how best to do it.
- Health departments need to evaluate their current capabilities, more ideal capabilities and the steps they should take toward that ideal.

4.4 Build awareness among leadership about the importance of transforming the way that public health does its work and the critical role of informatics
- There is variability in the extent to which public health leaders and elected officials or decision-makers within jurisdictions are aware and supportive of the need to transform the way that public health does its work and the role informatics plays.
- There is also variability in the extent to which public health leaders are knowledgeable about issues that are central to transforming public health data (e.g., data standards, interoperability, data architecture). Seek opportunities to build the knowledge of leaders and decision-makers so that they can become effective champions for the transformation of public health data and infrastructure.

4.5 Include public health data systems work as a budget line item
- Effective and efficient public health data systems are foundational to public health work.
- Given the importance of public health data systems and the need for sustainability, the resources needed to support these systems must be included as a line-item in health department budgets, as opposed to a project or initiative cost.