

Modernizing Our Nation's Public Health Information System: Toward an Integrated Approach

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Context

Public health is an information business. This maxim is most recently and dramatically evident in how all levels of the public health system require information to understand and respond to the COVID-19 pandemic. Furthermore, information is central to the fight against other public health threats and emergencies and to improving health equity.

Unfortunately, public health suffers from the lack of a sufficiently funded, well-coordinated, and methodically organized approach to guiding, building, and maintaining the information systems it needs to accomplish multijurisdictional health challenges. As the COVID-19 pandemic painfully demonstrated, lack of timely and accurate information compounded the challenges and increased the difficulty of an effective public health system response. Furthermore, progress on health equity will require more complete, granular, multidomain (ie, justice, child welfare, transportation, etc), and timely data, thereby allowing for useful insights into both health and social determinants of health.

In this column, we summarize the key findings and recommendations of a recent report from the Public Health Informatics Institute (PHII) supported by the Robert Wood Johnson Foundation designed to capture the present opportunity to strengthen the public health system in preparation for whatever the future may hold.¹ In addition, we add our own insights based on decades of experience in public health informatics and capacity building.

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Background and Challenge

Although we may speak of a “public health system,” we must acknowledge that the design of information systems used by local, state, and federal public health agencies is often far from systematic. Rather, given the organizational reality of local and state government autonomy, decisions about the design, development, and management of public health information systems are typically relegated to state or local decision making, although the resources needed may come from the federal government. In contrast, federal requirements may at times be at odds with local needs. As a result, systems are created that might not be interoperable nationally or locally, use outdated technologies, and be managed by public health professionals without updated information technology tools and skills. As a result, timely and accurate information needed to guide a well-coordinated response to public health crises is often lacking. Furthermore, although some data systems designed to serve individual public health programs were developed systematically, these systems are often not interoperable across the entire organization.

A key part of the challenge is related to scoping, to *clearly define what must be modernized* (ie, that this is about a discrete subset of public health information-intensive work)—and why. It is centrally important to focus on those informational challenges that require national or regional or other cross-jurisdictional and cross-agency information exchange. Those are the needs that drive the acceptance of standards, development of new policies and Memorandums of Understanding (MOUs), special training for parts of the public health workforce, and even new legislation, if necessary, to get the job done. People must truly comprehend and embrace the compelling case to meet these cross-jurisdictional information exchange needs, or they will just want to keep doing business the same way but with faster/fancier information technology.

The Opportunity

As many now recognize, the COVID-19 pandemic offers a challenge to the public health system to “build

back better.” In the views of national experts and thought leaders in public health informatics who provided input into the development of the PHII report, now is the time to develop an integrated approach to collecting, sharing, and using data to support the mission of public health.¹ Already, new financial resources are being made available to help rebuild the public health system that is acknowledged to suffer from chronic underinvestment and inattention to core infrastructure needs. Just as the roads and bridges of our nation are in desperate need of attention and repair, so too is our nation's public health information infrastructure. We advocate for an urgent call to action guided by a number of guiding principles and supporting a range of best practices. The time for action is now.

The Key Elements of Success

Leadership

Real change in public health is a group effort. Charismatic, energetic leadership can help. Grassroots efforts can help. But to really effect change, these forces must merge. It is not a bottom-up process alone, nor is it a top-down process alone. Those at all levels of the public health system must play a leadership role for major system change to occur.² Governance of the change process and courageous decision making are essential to enhance alignment and a sense of shared purpose across a wide range of public health partners. Executive leadership of public health agencies, in particular, must commit to sustained sponsorship for transformation of public health data systems and approaches. Without this executive sponsorship and support, good “projects” will not scale and good “efforts” are likely to die on the vine without truly transforming the data ecosystem.

Openness to change

Public health leaders must be willing to examine and, if necessary, change certain practices that public health has embraced for a long time, if we really want to have operational capacity to exchange data effectively during the next epidemic, flood, hurricane, or other large-scale public health crisis. As with our National (disaster) Response Framework,³ we can maintain state control of public health and yet have the capacity for a coordinated national response with rapid, secure data sharing across boundaries when it is urgently needed or when the need is sufficiently great. The National Response Framework offers a model in that, with federal leadership, disaster response systems have been adapted to maintain state control

through federal funding, standards, training, MOUs, and exercises. Emergency management leaders have continued to change and improve the framework over time through self-criticism, policy changes, and retraining of the workforce.

Innovation

Innovation should proceed through a range of steps moving from initial concept to proof of concept and, ultimately, diffusion of innovation broadly. The process of leading innovation and taking programs to scale should follow accepted paths⁴ and championed at the top of organizations impacted by innovative change.

Technical expertise

Technical expertise in informatics does not solve data problems alone. It actually may be the easiest part. Central to the process of system redesign is a fundamental shift in mindsets and attitudes. We need public health practitioners to have the skills to appreciate and characterize an information problem, envision a preferred better state, and comprehend how to support changing their agency's information capabilities to realize the better information state.

Workforce

We often talk about needing a bigger public health informatics workforce. But having more horse-drawn ice trucks at the dawn of refrigerators was a workforce solution that was wrong for the times. We need to think clearly and critically about how emerging informatics tools will reshape the public health workforce needs and where we may need new kinds of public health professionals and skills, particularly in public health informatics.

Money

Money is important but will not solve the informatics and data problems alone if it is ineffectively spent. Buying technology is tricky and avoiding bias toward specific commercial products and services is critical. Being very clear on the use case and data needs by practitioners and customers is the essential first step and one that should not be colored by a particular commercial approach. Furthermore, investment must be sustained at a high level over many years to address the need for a dedicated, long-term investment that addresses broad enterprise-wide needs in contrast to more narrow purposes that contribute to reinforcing “data silos.” Furthermore, jurisdictions should be

given adequate time to spend new federal funding wisely and well; if agencies are pushed to spend too quickly, errors that are costly in the long term will emerge.

Data and systems standards

As money becomes available now, the missing link in ensuring that funds will be well spent is clear guidance from the funding agency. Guidance should include clear data and system standards, based on core guiding principles and best practices as noted later and in more detail in our recent report.¹

Where to Begin

While acknowledging that important building blocks have been created that can play a role in addressing certain existing needs, we affirm that a comprehensive effort is needed now rather than piecemeal, incremental change. To be clear, we are advocating for an unprecedented national commitment to transform our nation's public health information infrastructure at a scope and scale that exceeds what has come before.

In essence, we are really talking about launching the virtual highway equivalent of Eisenhower's national highway trust fund that built and maintains to this day our national interstate highway system. A massive public health information infrastructure transformation should be conceptualized and supported in the same way.

In order for this project to succeed, top-level leadership at all levels of the public health system will be required to sponsor and advocate for this mission. Without a resolute commitment from top-level leaders, any effort to modernize the fragmented system will fall short. As a result, although a few positive steps may be taken, a successful journey to a comprehensive system overhaul will not occur and an unprecedented opportunity for major system change will be missed.

To create a blueprint for change, a "guiding coalition" should be empowered to lead the effort to articulate the benefits and costs of comprehensive system change. As noted in the recent PHII report,¹ the coalition should be charged with developing a clear and compelling case for system change that can be embraced and shared with decision makers. Among other tasks, the coalition should advocate for a set of guiding principles and best practices to guide the work of information and data system redesign and development. This group should lead the creation of a strategic road map that can guide implementation efforts conforming to certain national standards. The

strategic road map should be linked to a sustainable funding stream such as a public health information infrastructure trust fund. The road map should guide the actual build-out of the road map recommendations and could even establish the governance body that oversees it. The road map should focus on those key parts of public health work (eg, immunization, most infectious diseases, and some environmentally caused conditions) that cut across local and state jurisdictions while leaving the purely local systems to local discretion.

This group should include thought leaders and informatics experts outside the "public health family" in order to question old assumptions, challenge outdated approaches, and point the way to emerging industry standard methods and techniques that are now evolving at "light speed." As a result of the rapid change in information technology, public health risks falling further behind if the field does not embrace outside expertise and forge strategic partnerships with the private sector and academic experts.

Guiding Principles and Best Practices

If this massive effort is to succeed, we advocate for a range of guiding principles leading to a set of best practices that should underlie the creation of a unified public health information system using a set of uniform approaches to equip public health to protect the health of the public in the future and to establish the information foundation to improve health equity.

We offer, as a starting point, the following core guiding principles:

1. Interoperability of public health information systems focusing on those core sets of disease and problem areas that require interoperability.
2. Information system design and development at the local, state, and federal levels should adhere to a set of national standards and a common national data architecture, aligning with the standards and architectures used in health care to ensure public health is a credible partner in a health information ecosystem.
3. The system will use modern informatics tools and enhanced cybersecurity protections.
4. The blueprint for change should include a major commitment to strengthening the public health informatics workforce.

Promising Steps and Past Successes

To be sure, much important work has occurred in recent years that demonstrates concrete steps along

the way.² These should be recognized and celebrated. In doing so, critical success factors should be identified and successes built upon. Those informatics pioneers working in “informatics-savvy health departments” should be recognized for their courage and innovative contributions. These “public health informatics pioneers” can help form a national public health informatics service corps to provide the technical skills that will be needed to rebuild the system and to implement needed changes.⁵ Without a public health workforce skilled in informatics to guide implementation, redesign will never occur.

Recent initiatives, which should point the way, include the following:

- Digital Bridge Initiative including electronic case reporting activities;
- Electronic Laboratory Reporting;
- Electronic mortality record systems;
- Enhanced syndromic surveillance systems; and
- Immunization information systems.

In addition to more recent activities, past successful national informatics efforts such as the creation of the Information Network for Public Health Officials (INPHO)⁶ and the Health Alert Network (HAN) should be studied to identify critical success factors and enabling conditions.

Difficult Steps Along the Way and Ways to Address Them

This effort will come with major challenges that might seem insurmountably difficult. In our view, these challenges should be identified at the outset and strategies to address them quickly formulated. Most central of these challenges is the distribution and use of federal public health funding, which now proceeds along categorical programmatic lines. As a result, each area of public health practice is given funds that are then used to build information systems that are not necessarily interoperable and do not adhere to the guiding principles and best practices noted earlier. Federal funding mechanisms should be redesigned to achieve alignment with a set of national standards and best practices. Program funding should be allowed to be used toward health department-wide infrastructure that can be shared across programs.

Furthermore, legal obstacles, both real and imagined, must be addressed. For example, HIPAA standards are perceived as major obstacles to achieving system interoperability, when, in fact, this may not be as great a barrier as perceived. Other legal barriers should be identified and strategies developed to overcome these obstacles.

If the massive redesign effort is to succeed, a central national coordinating center will be needed to assist in a number of ways. A repository of best practices and innovation should be created that can assist local and state public health professionals as they engage in the redesign effort. Centralized training and technical assistance, including the creation of a peer assistance network, will be essential to guide system design and development. Unless these major challenges are addressed at the outset, any major redesign effort will not succeed.

Leading Change

In view of the magnitude of this transformational effort, leadership should paint a very clear picture of the benefits of embarking on the path of change. In doing so, leaders should be able to display in vivid fashion how the “new system” will work. To be able to socialize the changes needed, the benefits of change must be clear to address basic questions:

- How will my workflow be improved?
- How will my organization get its work done more efficiently and effectively?
- Why cannot we just keep doing what we are doing now?

To lead change of this magnitude, leaders must overcome resistance to change and engage in creative persuasion as well as direction in making the case for change. Leaders must have the vision and courage to acknowledge that some of those involved in public health data system work might not be the right people for the transformation effort we advocate. Furthermore, leaders should resist “Band-Aid solutions” where major system change is required.

Conclusion

The public health system faces an unprecedented opportunity to design and develop a forward-looking, integrated, unified, and uniform approach to managing information. In meeting the opportunity, leadership at all levels will be essential along with adoption of a range of certain guiding principles and standard practices. These standard practices should then guide the use of federal grant funding in a way that enhances interoperability and promotes the use of promising technology. National access to workforce development and technical assistance will be essential if the effort is to move from ideas into action.

The massive undertaking we outline here will require sustained leadership and strategic investment over many, many years. Therefore, committed national leadership enabled by substantial and sustained

investment along a consistent path will be essential. The time is now. We are not likely to see an opportunity of this magnitude for many years to come.

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