

**Testimony to the National Committee for Vital and Health Statistics
hearing on public health standards**

**Public Health Informatics Institute
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Thank you for asking us for our comments on this important subject. Since the Committee will be hearing from many areas of public health today, we at the Public Health Informatics Institute wanted to share our observations and recommendations from both a historical and a future perspective across the public health enterprise.

To begin with some general comments, experience tells us that standards emerge and evolve driven by needs for health information, at times by economic needs, and at times driven by technological innovations that compel their use. Standards, like IT itself, are a means to an end.

The legal federation of public health jurisdictions, coupled with a diverse range in public opinion about the desirable scope of public health activities within a given jurisdiction, complicates and challenges formation and adoption of standards. Whether we're talking the development of a standard as a "normalized" process of work, or a standard information system tool, or a standard means of transporting data, or even a standard data element, all have been made problematic historically because adoption of a standard in public health is influenced by politics, funding, idiosyncratic jurisdictional decision making, and the absence of an overall strategy and funding to guide and support modernization of public health information systems. We will respond to the questions you asked us to address within the context of what is possible in such a federated public health system.

You ask us to comment on the **current state**. In our view, functional, technical and semantic standards have emerged and been widely adopted in several key program areas of public health. For example, the immunization registry community has over the past 20+ years collaboratively developed a suite of standards that have been adopted nationally. Similarly, cancer registries and vital records have developed standards and have succeeded in moving those standards from concept into widespread adoption, and in reducing jurisdictional variability in how the standards are implemented. Electronic lab reporting and syndromic surveillance are more recent examples.

In terms of **lessons and drivers**, the lesson we learn from these experiences is that standards will emerge *and be adopted* when there is a clear need and business case driving their creation and adoption, *and* when the community of stakeholders most empowered by the adoption of a standard drive the process. These examples show that no single standards or other organization was needed to create or force adoption. Rather, each of these enterprise systems developed standards because of the sheer willpower of the community of users and developers, with the help of knowledgeable informatics experts working in cooperation with relevant SDOs. They needed consistency to realize the solution to

their health information problem. Their stakeholders needed consistency. And, they had a compelling information problem to solve that links directly to an understanding of the health problem at issue.

The **incentives and drivers** for these examples are found in the compelling programmatic need and in the understanding that all parties either are or should be doing the same work in the same way. The recognition that we have more in common than different undergirds effective diffusion of standards in our federated public health system. Absent a firm belief that we do the same work, there is no reason to adopt a standard. In the case of immunizations, it was the recognition that all states and localities were funded via 317 funds to maintain an IIS and that it was possible to define the essential or core functions of an IIS. Once the immunization community published and advocated for the acceptance of the core functions standard, it was further empowered to recognize that it needed to collect a uniform minimum data set, which lent itself to standard definition. The standard dataset was driven by essential immunization program information needs, like being able to use the IIS to inform overall population coverage rates and to inform providers of care the status of a given child's immunization history. These programmatic information needs drove the need for a standard. The point is that the standard did not evolve in the abstract; each of the standards was created and has evolved to meet specific programmatic and exchange needs.

The **implementation challenges** we see mostly relate to how long it takes for new ideas to diffuse, how public health funds information systems, and how jurisdictions choose to support adoption of new systems. Because each jurisdiction dictates its legal and financial future, we depend on standards adoption to be driven by compelling business case rather than on edict from funders. Short of a federal law mandating a specific data reporting form, as is the case with Medicare billing, adopting new standards within hundreds of autonomous jurisdictions depends upon their ability and willingness to fund a transition to new or enhanced system, have the technical capacity to adopt the new system, and/or understand the business purpose driving their use of a standard. In the case of immunization registry, it has taken two decades to reach national adoption by most jurisdictions. The ARRA HITECH Meaningful Use provisions that included IIS reporting added the final touch on the momentum that had been gathering over time.

Clearly the greatest implementation challenge comes down to the capacity of public health practitioners and their respective associations to engage in standards development work, starting with building the value proposition and going through widespread adoption and effective use. Too many current standards-related activities suffer from minimal practitioner involvement. Any solution to this problem must entail several components: sufficient numbers of people available for the length of time required; sufficient knowledge within those individuals in both the program need and the overall standards development process; availability of standards development expertise when needed to navigate projects through the rather arcane process of standards approval; and, very importantly and largely missing today, a clear strategy shared by CDC and the local and state practice community on ensuring widespread adoption and effective use.

As we look forward to the e-health and e-public health era, you ask **what interoperability standards** are needed to assure public health being able to work in tandem with health care. We believe the answer

to this question does not lie in specifying specific standards but rather in public health specifying value propositions that have meaning to data exchange partners. Our point is simple but very important: Creating a standard means nothing if it is not used. In fact, we believe the standards community at large needs to assess its impact based on *actual adoption and use*, not on existence of a standard, no matter how elegant. To achieve use one needs to reach the hearts and minds of the people who must use it and pay for its implementation. To reach them, you need to have a clear and compelling reason that adoption of a standard brings tangible benefit to all. If, for instance, only public health will benefit, then healthcare will not bother, and vice versa. It is upon a foundation of rational joint economic interest that we will see the right standards being developed and broadly adopted.

For example, CDC's Chronic Disease Center has been working with states, HL7 and others for nearly two years to develop and receive balloted approval for a body mass index reporting standard for EHRs. Convincing healthcare providers to adopt this standard for reporting BMI to public health will hinge on how much value those providers see in the information gained in terms of benefit to their patients, and/or benefit to their financial bottom lines by using the standard. The burden of building the business case falls to public health. Short of incorporating public health reporting of BMI into requirements for Meaningful Use and EHR national certification, adoption of such a standard will require that providers pay their vendors to implement new interfaces, something that would have to be replicated across potentially dozens of EHR systems.

In conclusion, we suggest that it will be the programmatic needs that drive the *creation* of standards. It will be a joint business case that drives *adoption* of new standards. Standards will be meaningless absent a commitment by public health agencies to their health care partners—and to each other—that they can hold up their technology side of the exchange.

We urge the Committee to make an urgent and emphatic recommendation to the Secretary that an omni-directional data partnership among public health and its health care and other community partners is a business relationship that will require new financial commitment, one needed to support and modernize the information infrastructure of public health. We ask the Committee to recommend the creation of a *public health information trust fund* to support several major activities:

1. Support the public health informatics and public health services and systems research communities in assessing adoption levels of current standards.
2. Conduct analyzes of public health program areas within which a clear value proposition for a standard exists but has not yet been acted upon by the community, including what informatics support they need.
3. Engage standards experts, such as through CDC, and make them available to a public health program community, not to drive development of the standard but to support the community in the process of establishing its standards based on defined business needs.
4. Support the collaborative development of a "roadmap" document that lays out a path for how public health can transition away from today's monolithic and inflexible information systems toward a more modular, reusable and sharable services-based design of information systems.

Public health is an information enterprise. Standards clearly play a part in public health being effective as an information enterprise. But absent a broader engagement strategy, clearly articulated and compelling business needs, and adequate funding and expertise, little of real and actionable value can be achieved in our federated public health system.

Thank you for the opportunity to testify. We hope the Committee will use its credible voice to advocate for real change in how public health invests in its information infrastructure in an e-health era.

