National Committee on Vital and Health Statistics (NCVHS), Subcommittee on Standards
National Center for Health Statistics, 3311 Toledo Road, Hyattsville, MD 20782
Tuesday, November 12, 2013
http://www.ncvhs.hhs.gov/

Written Testimony from Joe Gibson, Director of Epidemiology, Marion County Public Health Department, Indianapolis, Indiana

Contents

Introduction 1
Current state of public health-related standards 2
Data coding standards – we need standard coding for our common datasets 2
Standard measures – we should all use a core set of validated measures 2
Privacy and confidentiality protection standards – It's a jungle out there. We need to migrate our policies toward a consistent standard. 2
Data exchange standards 3
Data exchange agreements 3
Coding systems (semantics) & Message format (syntax) 3
Interface specifications (interoperability specifications) 3
Data exchange standards must include quality standards 3
Participation by public health practitioners in standards development – adequate participation requires funded, not voluntary, time 4
We (barely) have enough knowledgeable people for sufficient participation 4
We have a hard time participating 4
For some very important issues, we have had very effective coordination of input 4
Readiness 5
Most local health departments depend on state health departments for electronic population health systems 5
Most of the US population is served by large local health departments that have electronic population health systems, and could implement standards, given time 5
What is most important 5

Introduction

My name is Joe Gibson. I am the director of epidemiology at the Marion County Public Health Department, serving Indianapolis, Indiana. I am chair of the National Association of City and County Health Officials (NACCHO)'s informatics workgroup. I am also chair of the BioSense Governance Group, which advises the CDC in the development of a shared, cloud-based syndromic surveillance platform. In Indianapolis, I work closely with the Regenstrief Institute, a worldwide leader in clinical informatics research, and IHIE, one of the oldest and largest health information exchanges in the country. I have been fairly active in public health informatics for

the past decade. My testimony will be primarily from the perspective of an epidemiologist at a local health department.

Current state of public health-related standards

Data coding standards – we need standard coding for our common datasets

Birth certificates, death certificate, and other data sets are common across public health agencies, but there are no national standards regarding the coding of this data, or if there are, they are not well advertised. At my health department, we create our own analytic data sets from the common data sources. If I could find a standard for field names, field types, field lengths, and coding systems for these data sources, I would be happy to conform to it. That would open much more opportunity for collaboration and shared tools among public health agencies. But I have looked for such data set standards, and not found any. I looked for them on websites of appropriate public health associations, NIEM, or the AHRQ's United States Health Information Knowledgebase (USHIK).

Standard measures – we should all use a core set of validated measures

We have a huge variety of measures we can choose from to describe population health, and more get invented each year. Having a core set of well validated, set of fairly comprehensive population health measures could improve the quality and comparability of the public health statistics generated by jurisdictions across the country. This is essentially recommendation number two of the IOM 2010 "For the Public's Health: The Role of Measurement in Action and Accountability" (http://www.iom.edu/Reports/2010/For-the-Publics-Health-The-Role-of-Measurement-in-Action-and-Accountability.aspx). Not having that core set, I spent a lot of time deciding what measures to present and reports, and trying to find comparable statistics from comparable jurisdictions. So do many health department epidemiologists around the country. There is likely to be a lot of debate about what should be in a core set of measures. Any core set will be imperfect and will reflect subjective decisions. But having an imperfect core set will be much more valuable than having no core set. If some broad panel were convened to develop a core set, and an organization with the reputation and scientific muscle like NCHS were to endorse it, I think that many jurisdictions would adopt it.

A core set of measures would be especially valuable now the public health jurisdictions are working to become accredited. It could help in bringing focus to community health assessments, which are required for accreditation, and which can easily mushroom into resource draining efforts.

Privacy and confidentiality protection standards – It's a jungle out there. We need to migrate our policies toward a consistent standard.

Confidentiality laws vary from disease to disease, and from jurisdiction to jurisdiction. This creates a complex network of rules, and the easiest way to deal with it is to be either abide by the most protective rules, to assure that no rules are violated, or to not share data at all. I have spent years trying to get access to cancer registry and WIC data for my jurisdiction, as a record level data set rather than an aggregate report. Recently, we finally got access to the cancer registry data, but not yet to WIC data, despite our health department being the WIC provider for the county. At the national level, I sometimes hear statements from program leadership (WIC, HIV, etc.) encouraging the sharing of this information within public health, but local interpretations of national privacy guidelines around this data (and other data sets) are often made to minimize risk, rather than to maximize value. Actions sometimes focus on using the data to generate national statistics, rather using it locally to address the problems. As a result, data does not get shared with

those responsible for monitoring the health of populations, and for intervening at the local population level.
This might be addressed through model confidentiality policy toward which jurisdictions and national programs could migrate their rules. The policy should balance protection of confidentiality with assuring that decision-makers (such as clinicians, policymakers, or program managers) have timely access to the information they need to make informed decisions about maintaining and improving health. We have an obligation to protect the identity of persons in confidential data that is entrusted to us, and we also have an obligation to share information, if sharing that information will protect the health of someone.

Data exchange standards

Data exchange agreements

The greatest barriers to data exchange involve willingness and policy, rather than technical issues. Even when both parties are interested in exchanging data, developing the formal data exchange agreements can be challenging and time consuming. Nationally, a disproportionate amount of effort is put toward technical issues, relative to policy issues. We need model data exchange agreements that we can mimic – model agreements endorsed by appropriate organizations. And we need to give decision-makers and policymakers a better understanding of how data can shared to generate great benefit at minimal risk.
This issue is likely to come to the fore again soon, as state health departments receive the public health Meaningful Use data streams, and local health departments seek access to that data. If the past is an indicator, many states will be very slow to share that data with local health departments, especially in the absence of rules specifically authorizing that sharing. A lot of consternation might be avoided if some model policies were put out now around the sharing of this data between state and local health departments, before each state develops its own policy.

Coding systems (semantics) & Message format (syntax)

There are lots of good choices regarding coding systems and message syntax for data transfers. My impression is that the differences in the utility of these are often relatively small. If some set of informed folk recommend one coding system or another, I'm happy to use it. The sooner, the better, so I can develop systems that more readily allow collaboration.

Interface specifications (interoperability specifications)

In my health department's data exchange initiatives with our state health department, the Regenstrief Institute, or the Indiana Health Information Exchange, most of the technical work is in defining the system interactions and maintaining the connections between our systems. Conforming to a coding system or message format is relatively easy.

Data exchange standards must include quality standards

in the BioSense national syndromic surveillance system, we are beginning to amass emergency department visits from around the nation. The potential is there to detect disease patterns across the nation, patterns no longer bounded by jurisdiction borders. But, based on some initial data sharing and analyses, it is clear that BioSense will not realize that value until we can assure good data quality. I expect that we will develop data quality standards must be met before data can be shared between jurisdictions, and possibly before a new data source (e.g., a hospital or HIE) can be on-boarded into the BioSense system. In most discussions of information exchange, data quality is ignored. Interface specifications need to ensure good data quality; if not, the exchanges are likely to be abandoned, or have a lot of delay and unexpected costs before they achieve their goals.

Participation by public health practitioners in standards development – adequate participation requires funded, not voluntary, time.

We (barely) have enough knowledgeable people for sufficient participation

There are not many public health agency staff who have a firm grounding in informatics, but there are enough that we could have enough participation in national standards development to ensure that the standards fit the needs of public health agency operations. There are probably 20 or 30 public health agency staff who are very active nationally in public health informatics discussions. Each of them could probably point to at least two other staff within their agencies who would be valuable contributors to such conversations, if they could afford the time. Many other health departments have similar talent.

We have a hard time participating

- Public health practitioners are almost always asked to participate in standards development as volunteers. Participating brings good benefit public health, but no measurable benefit to the person's employer, the health department that loses work time of key staff by allowing people to participate national initiatives.
- National standards development is never a primary responsibility of someone at a state or local health department, unless there is some grant contract involved. We all have day jobs, and participate in national initiatives because we understand the importance of the effort. We can only afford to spend large amounts of time on those initiatives if, in return, we get resources offset we are not doing in our paid jobs.
- In my experience, public health practitioners are often lost in technical discussions among vendors and academics during standards development efforts. At the core, the content may be very important to public health practice, and may need to be guided by input from practitioners, but that will not happen without skillful facilitation, plain speaking, and involvement by someone who can recognize the practice implications in a discussion and assure practitioner input on those points.

We need skilled facilitators, and participants from public health agencies need funding to offset the time they spend. This could coordinated through our associations.

For some very important issues, we have had very effective coordination of input

- Working through its member associations, JPHIT has coordinated some very effective input into the rules for stage 2 of Meaningful Use. Because of that, almost everything that the public health community asked for was included in the stage 2 MU rules. The input was generated through a fairly brief, intensive effort. It is something that can be repeated, but not repeated frequently.
- The associations have been our most effective route for assuring input. For example, NACCHO's informatics workgroup has provided good quality input on issues such as meaningful use rules and CDC informatics planning. The associations can provide a unusually representative (or at least unusually broadly based) input, since associations can fairly efficiently gather it from members from a variety of health departments.

Readiness

Most local health departments depend on state health departments for electronic population health systems

Of the approximately 3000 local health departments, my guess is that 2500 have little in the way of electronic data systems for population health. They depend on state-level systems, or go without.

Most of the US population is served by large local health departments that have electronic population health systems, and could implement standards, given time

Per NACCHO's national local health department Profile survey, the 30 or so largest local health departments serve about 25% of the US population. The 150 or so largest local health departments serve about half of the US population. Most of these have passable to very good electronic population health systems. They have the tools and talent to implement standards, although they may not have the time. National standards in public health could be cultivated by targeting this relatively small number of large health departments, along with the large state health departments.

What is most important

Standards are valuable because they allow easier exchange of information and sharing of tools. In the long run, they can decrease cost and improve quality. Strategically, I think this committee should focus on creating an environment that encourages the adoption of standards, not on defining the standards themselves. Enough standards already exist. As with scientific publications, the problem is that they do not get used.

Tactically, I think the DHHS secretary could best advanced standards by requiring more coordination and uniformity of information systems supported by federal funds. Information system funding could be tied to collaborative system development. This would not require extra funding, although it would require effort to revise how proposals are scored, and coordination between siloed grantmakers within DHHS. Federal public health information systems could also be made less "siloed". There is already movement in the CDC to develop more enterprise-wide (rather than program-specific) information systems, and to combine some of the many interfaces through which the CDC received data from state public health agencies.

The use of standards also could be accelerated by coordination in funding criteria between DHHS and other influential funders such as RWJF. If RWJF and DHHS both push in the same direction, public health practice will almost certainly move that way.

Dominant standards tend to get established organically, rather than by declaration. They also evolve after being establishd. Valuable standards will be established more effectively if the federal government to creates an environment that fosters joint information system development between public health agencies, rather than if the government tries to declare what standards will be used. If doing joint development increases a jurisdiction's chance of getting funding, or the amount of funding it may get, then there will be more joint development. If some funding is specifically targeted for joint development projects, such projects will be created.

This approach could bring medium and long-term cost savings, as information tools could be shared by many public health agencies, without costly customization. It would remove many technical barriers to data exchange by decreasing the variety of systems. In the short term, the shift from home-grown or highly customized systems to more shared, standardized systems would be difficult. Change is hard, but public health needs to adapt to the information future.