NATIONAL ASSOCIATION OF HEALTH DATA ORGANIZATIONS

Improving Health Care Data Collection and Use Since 1986

National Committee on Vital and Health Statistics Subcommittee on Standards
Hearing on Public Health data Standards

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It is an honor to present this testimony on behalf of the members of the National Association of Health Data Organizations (NAHDO) to the state of health data standards to the National Committee on Vital and Health Statistics (NCVHS) Subcommittee on Standards. Standards are an essential underpinning for population and public health programs, reducing the costs of system-wide data aggregation and facilitating the transformation of data into actionable information. As important as standards are, there are challenges to their development and maintenance, especially within the public health enterprise. NAHDO welcomes this dialogue today, as no individual state or organization is able to solve these complex challenges.

About NAHDO

NAHDO is a national non-profit membership organization established in 1986 dedicated to the public availability and uniformity of health care data. Our major mission is to advance the collection and use of statewide health care data and transform the data into useful information for cost, quality, access, and policy applications. NAHDO has worked for decades to assist states in developing and expanding hospital discharge data reporting systems. The demand and need for timely information on treatment costs, disease incidence, and health outcomes is greater than ever and states are rapidly expanding reporting to include All-Payer Claims Databases (APCDs). APCDs consolidate claims and eligibility data across payers. Because these are new data systems, without federal funding, states are implementing non-uniform approaches to data collection, raising the reporting costs to the payers and limiting the comparability and utility of the information generated from the data.

Current state of public health related standards:

Because of NAHDO's mission of improving the uniformity and comparability of health care data, NAHDO has concentrated on adapting industry standards to state and public health reporting needs. Through collaboration with and support from the National Center for Health Statistics (NCHS) and the Public Health Data Standards Consortium (PHDSC), the APCD Council (NAHDO and the University of New Hampshire). Taking a "ground-up" approach to standards development, harmonizing state formats and aligning national standards, NAHDO and its partners have accomplished the following:

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- Developed a pharmacy claim reporting standard for states in collaboration with X12N and the National Council for Prescription Drug Programs (NCPDP);
- Health Care Data Services Reporting Guide for inpatient discharge data reporting
- Developed medical (professional and institutional) claim reporting standard for states with the ASC X12 Post-Adjudicated Claims Data Reporting Workgroup
- Engaged with the HIX Transactions Special Appointed Committee that is addressing the requirements for payer enrollment transactions and state reporting needs.
- Continued state representation on the content standards developed by the National Uniform Billing Committee and National Uniform Claims Committee.

What these efforts have in common is the advocacy for and adaption of transaction-based content standards for public health reporting. The health care providers and the industry are the source of most public health reporting. Tapping into the workflow processes of these data sources is proven to be cost-effective for the aggregation of system-wide core data.

What are the incentives and drivers for adopting and using public health data standards; what are the barriers and challenges?

Based on NAHDO's experience in statewide reporting programs, standards reduce the provider reporting burden and improve data comparability, resulting in better information. National standards for industry transactions are too often not aligned with state reporting needs. Historically, states would tweak the standard or create state-specific fields to fill these gaps---but provider push-back and the lack of comparability limited the analytic potential (including benchmarks) of the data. States have learned that working collectively, national standards can be shaped to meet state needs. Collective action is imperative, as state data agencies or public health agencies do not have the organizational budgets or workforce bench to fully participate in (or stay abreast of) standards development.

Public health's standards engagement has been remarkable, given the lack of resources, but more is needed. Volunteer standards representation has gotten public health to the table and we are greatly indebted to this voluntary workforce. We have influenced industry transaction standards to reflect population and quality reporting needs. But, reliance on NAHDO and PHDSC in-kind contributions to standards development is not sufficient. No individual association or state or agency can address standards needs alone. Government agency workforce reductions limit the pool of volunteers and budget constraints render this volunteer workforce model not sustainable or effective. We need a new standards engagement model for public health that, much like the industry and specialty societies, employs full-time standards experts with field experience in data systems development and familiarity with industry and public health cultures.

What is the state of information exchanges of public health data from EHR systems; what are the standards being used; the drivers/incentives; challenges/issues?

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In theory, health information exchanges (HIE) have the potential to create the needed infrastructure for health care data exchange. While many HIEs are laboratories of innovation for clinical data exchange, their role in aggregation of system-wide population health data is today mostly aspirational. As a growing number of HIEs struggle with sustainability, it is apparent that a business model that supports the common good, public good of cross-system data aggregation and exchange is a challenge. While most everyone agrees that the functions of an HIE are valuable, how these enterprises are funded and sustained is unresolved.

While clinical data exchange is an exciting future frontier, NAHDO believes that equally exciting innovations are within reach today through the enhancement of our existing data resources with specific clinical data. These "hybrid" data sources are proven to improve measures and measurement and modeling and are a cost-effective approach to filling critical data gaps. This hybrid approach, enhancing existing data with clinical data, will build a bridge to clinical data applications. Because the EMR and HIEs are not 'shovel ready', it is important to invest in incremental innovations and advances that bridge existing and future data sources.

An example of a low hanging fruit of enhanced administrative data: states that are linking hospital discharge data with laboratory results. Laboratory results obtained at admission provide the data for objective assessment of patients with acute clinical presentation. Laboratory data are perhaps the most scalable among all EMR domains and are not free text or expensive abstracted reports. When merged with hospital discharge data that has been classified with a clinical condition classification system (such as CCS), the risk adjustment models are more robust.[1] NAHDO believes that in the near-term, the public health information of the future will come from both clinical and administrative data sources.

Thoughts on the implementation challenges from the public health agency perspective; technical, resource, education needs to advance adoption and use of standards by public health?

The public health system is comprised of multiple data enterprises. The complexity of the individual and collective data systems is staggering. Each of these data systems, such as hospital discharge databases, have taken decades to establish, refine, and sustain. There is no "one-size-fits-all" fix to standards or reporting.

However, there are incremental improvements that can and should be made. Based on NAHDO's work with the CDC and the Cancer Registries (North American Association of Cancer Control Registries (NAACCR), there is overlap between the public health data bases, such as demographic

[1] Using electronic health record data to develop inpatient mortality predictive model: Acute Laboratory Risk of Mortality Score (ALaRMS), Tabak, Sun, Nunez, Johannes; J Am Med Inform Assoc published online October 4, 2013

and coded diagnoses/procedure fields. Aligning these across the public health enterprise and the EMR is a logical starting place for standardization.

Based on lessons learned in 30 years of statewide health care data development across states, NAHDO has observed the following lessons learned:

- Secondary data sources, like hospital discharge data, are collected for one purpose and used for another (hospital discharge data, death data. Repurposing of data reduces the burden to report, but poses other challenges. As more states and communities demand clinic and physician level information, they are establishing All-Payer Claims Databases (APCDs) to examine volume, cost, and quality patterns. There are standards challenges with these data systems. Example: the National Provider Identifier (NPI)—developed for payment/reimbursement and is now repurposed for quality measurement and payment reform---is woefully inadequate for these new applications. States are faced with building extensive provider directories that map the many NPIs to a single provider. But this is expensive. Who pays to fix it? Who is responsible? Industry? HHS? Public Health?

- Setting a standard is the first step. Application of that standard in real-life practice is another. Even when a standard is established---maintenance is important and connecting between industry, public health, and standards setting organizations to refine that standard is essential. Public health relies on volunteers and in-kind contribution from the associations and their members. It is remarkable that public health/discharge data has no full-time standards workforce representing our interests. Yet, the industry and specialty societies feel these functions are worth the investment and are well-represented in standards organizations.

How is the privacy and security covered in public health data standards? Embedded in the standard? A different workflow process?

Privacy and security is embedded in the policies and practices of public health and their data systems. Public health is in the information business, not the data business---so agencies must balance the protection of patient privacy with the public good of disclosing information. NAHDO members are pretty well-versed in such balanced policies, rely on data oversight or policy boards, data anonymization through statistical methods, and the use of data use agreements. However, the system for sharing and exchanging data between public health agencies and across jurisdictions is broken, whether it is manual or electronic. Even if both agencies or jurisdictions have their respective authorities and agree on the need for exchanging data, the level of staff time necessary to draft, approve, and execute a Memorandum of Understanding (MOU) is exceeding the capacity of the workforce to implement. Staff reductions combined with legal and political concerns hinder the basic exchange of basic information.

There are numerous barriers to advancing our nation's health information infrastructure: funding, legal, political. NAHDO proposes several approaches to enhancement and advancement of the state and national health information infrastructure.

- Incremental improvements: Enhancement of existing public health data bases with clinical information is possible now. HDDB/LAB

- National Investment: A Health Statistics Modernization Act would establish a framework and structure to enhance and advance our information assets through standards, applications, and restructuring of law that enable data sharing and information exchange, while protecting privacy and confidentiality. In the absence of such a national legal framework, some sort of public health investment/trust might help public health apply innovation solutions to improve the breadth, timeliness, and relevance of data we collect today and prepare a workforce capable of maximizing existing and future information.

- Even with technological advances, the importance of the human factor to interpret and translate information into relevant action cannot be overlooked. Hiring and retaining highly trained analytic workforce is a challenge for government agencies. A core public health curriculum for the Public Health Data Scientist is desperately needed

The Joint Public Health Informatics Task Force (JPHIT) is an established forum for deliberating health informatics and health data policy issues that span the public health enterprise. We invite the NCVHS to work with and through JPHIT to operationalize these and other recommendations from today's meeting.