Shaping a Vision for 21st Century Statistics

Interim Report

Panel 3: *State and Local, Public and Private*

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Shaping a Vision for 21st Century Health Statistics

Good afternoon. My name is Michael Rodrian. I am the Director of the Center for Health Statistics in the California Department of Health Services and the State Registrar of Vital Records for California.

I also come to this hearing as a member of the National Association for Public Health Statistics and Information Systems (NAPHSIS), which represents 57 states, territories and independent registration areas in the US. Agency members of NAPHSIS include the Directors of State Centers for Health Statistics, Registrars of Vital Records and Information Systems Managers in the health statistics arena.

I want to thank the National Committee on Vital and Health Statistics as well as Dr. Lumpkin and Dr. Sondik for this opportunity to discuss how we as a nation begin *Shaping a Vision for 21st Century Health Statistics*. You truly are asking us to "think globally and act locally."

As a State Center Director and a representative of NAPHSIS, I congratulate you on drafting an excellent report, addressing the critical issues facing state and local public health agencies at this time. We are all clearly struggling to meet the diverse health information requirements of our public and private partners in this 21st Century, for the most part using the disparate array of independent legacy data systems we developed during the last century. A particular strength of the report is that it clearly outlines, in one national document, the essential principles for all to uphold as we work together to improve public health data, statistics, and information systems throughout our communities, states and the nation. I am particularly pleased with the mention of international systems and standards for organized systems.

I would like to comment generally on the document and make a few observations about how we might be able to proceed together. I also am delighted today to be able to hear directly from your other speakers, and expect to broaden greatly my understanding of the issues at hand, as well as to have my ideas about how to proceed shaped again as a result of their perspectives.

GENERAL COMMENTS

Economics drive much of our behavior. This is true in our private lives, and it is certainly true in our professional lives. Economics is often measured in dollars, however it is also about where and how we spend our time. Principally, though, it is about values, and then about how we use societal mechanisms to drive motivation to achieve what we value. As professionals in this field, we must recognize how to install and operate economic motivators to drive the system in our desired direction. My shorthand for this is an adaptation from Frank Lloyd Wright's axiom; "*form follows function*." My version is "*form follows funding*." In other words, if we want substantive change in health information systems, we must change the motivators, and we must focus on specifically *who* gets *what value* and *who pays*. Remember, value is not all about money. It can also be about a job recognized as well done.

However, in the configuration of our data structures, as in architecture, form does follow function. Funders, especially governmental funders, often perceive and define value narrowly, provide narrowly focused funding, and thus the forms of information systems follow the funding. The current "silo" development of our health data information systems demonstrates this. As we become accustomed to the 21st Century, more of us are beginning to see interrelationships that could add value to our efforts, and to our collective health. Changes in the cost and raw ability of electronic systems are also changing collective perceptions of what is possible.

What is needed now is a common vision of what value can be extracted from systems that are, or can be, better integrated. Your Vision Documents are an excellent start. At the same time, though, we need to pay particular attention to demonstrating and marketing *the value of the information to be gained by those from whom we gather our data*. A good information system should be perceived as a thing of beauty. It may be complex, but should appear simple and be easily explained. It should have a good framework, with a strong supporting architecture. Like any good structure, it should be built using rigorously tested standards for each of its basic elements. As the Society of Automotive Engineers (SAE) determined long ago, it should be built with common fasteners, so that it can easily be attached to other structures. Finally, it should have utility, and it should provide value to those who support it.

I would like to focus a bit on that last statement; *"provide value to those who support it."* Those of us who work on the design and function of information systems need to spend more time designing in value to be returned to those who labor to provide us the data we need. As this state's registrar for vital statistics, I know how valuable the data I receive is when it is packaged and provided to a host of users in the state and throughout the nation. However, I have begun to

realize I spend very little time returning value to the hospitals, doctors, nurses coroners and funeral homes critical to my data supply. A beautiful home is expected to return immediate value to its builder, but also to return long lasting value to the person who buys it, lives in it and keeps it up. I need to make sure my suppliers of data receive something of value for their efforts. If they do, they are much more likely to provide me with accurate, timely data. This approach recognizes the universal truths of economic arguments, that you get value when to give value.

In this area, I would especially like to see the NCHS and the CDC, together with HCFA begin to use their pulpit and their economic weight in the healthcare arena to start the ball rolling. Combining public health data with HCFA Medicare and Medicaid data will powerfully influence the rest of the professional health community.

CRITICAL SUCCESS FACTORS:

I would next like to comment more specifically on some of the ideas you have outlined.

Clearly, the ten principles in the *21st Century Vision* document are essential to our mutual success. Several factors are critical to the effective implementation of this vision by states and local communities.

Principle 1 on privacy and data security must be a cornerstone for implementing this 21st Century Vision. However, I believe we need a better-balanced approach. We all recognize the need to protect the data we gather about individuals from inappropriate disclosure. We provide security because of real and perceived situations where an individual or business with access receives a value at the unwarranted personal expense of the individual named by the data. Our difficulty (and cost) in keeping the data secure rises in direct proportion to its perceived value to those who wish to use it at another's expense. As a society, we can reduce the net value for these socially inappropriate uses by instituting clear and significant disincentives for any misuse of personally identifiable health data. I think Principle 1 should speak to this.

Also, I am concerned that this principle appears to equate 'public health monitoring' with 'research.' This is a problem for most state and local public health agencies, which conduct relatively little health research, but often use data to follow up with individuals likely needing assistance. Although these data may also be valuable for research, it does not follow that all data collected is for research. ***Principle 2*** should make this clear.

The conceptual framework outlined in ***Principle 2*** is necessary to effectively integrate our legacy data islands to meet emerging information demands. I

commend the recent steps that HHS, CDC, NCVHS, ASTHO, NAPHSIS and other collaborators have taken toward defining a national standards-based, web-enabled information infrastructure. As a State Director and Registrar, I particularly value the standards put forth through CDC's NEDSS, CIPHER, etc., as well as the modular approach. In order to succeed, though, we will need to leverage the financing and human resources necessary to implement the vision.

I won't comment more on **Principle 3** except to say we are very happy with the promise of flexibility.

The importance of ***Principle 4*** must not be underestimated. As I commented earlier, priority attention should be focused on creating value for those who provide health data. In particular, we need effective means to return data quickly to each data provider along with an enhanced ability to view their own data in meaningful community, professional, and geographic context. For example, I envision a business-oriented website that will support electronic submission from those reporting health data to our department, irrespective of where in the department the data goes. The same site should add value to the reporter by reporting back information. I think principle 4 should include mention of adding value for data suppliers.

I heartily agree with the necessity for compatible standards as presented in ***Principle 5.*** CDC has demonstrated considerable success working with states and local partners to develop NEDSS/ CIPHER/ etc. However, I think <u>we need to go further</u>! The principle should mandate participation in the established national standards setting bodies that have to date established X12 for administrative and HL7 for non-administrative health data. This can be our equivalent of the SAE. I recommend both bodies devote even more attention to developing "fasteners" to provide linkages between the administrative and non-administrative data. Although labor intensive, it is hammering through the details like these that allow a strong structure to be built. *To finance this effort, I recommend that a required percentage of each federal grant for state or local health program activities (administration, service delivery, and health status assessment) be spent on establishing and implementing these standards.* This would include public/private partnerships. The Health Care Financing Administration (HCFA) has used such incentives to great success for the past 30 years, giving enhanced matching funds to systems that used electronic methods to improve Medicaid administration. Many cities require developers to invest a certain percentage of their project budget in artwork to enhance the beauty of the community. If we want beautiful information systems, we must set the standards, invest in them, and leverage them with economic principles.

Principle 6 outlines the mutual goal of unitary data collection for multiple purposes. To meet this goal, it is essential that the nation create clear fiscal incentives for data standardization and integration by state and local partners, both public and private. Particular priority must be given to incentives for those

providing health administrative and service delivery data that also can be useful for monitoring health status. Complex issues arise in the practical application of this principle, and we may need a transition plan. One approach has been to try distributed but linked systems.

As a bridging step from silos to either unitary systems or regularly linked distributed systems, I recommend we gather and carefully consider the best scientific evidence available regarding criteria and methodologies for linking data regularly from two or more databases to establish unique identifiers. This evidence base could then assist in the development of national guidelines. We should capture what criteria are most commonly available that produce reliable results. We should address what steps should be considered regarding the inevitable questionably linked data. A first step toward this could be national agreement upon a set of standard demographic data items such as California's "common core data set", earlier discussed by CDHS during previous Committee hearings in San Francisco on HIPAA standards.

As a State Center Director, I can not emphasize enough the importance of ***Principle 7.*** Local communities and statewide stakeholders need us to provide maximum user-friendly access to health data and information. This is also part of returning value to those that provide the data. I believe we should focus more time on data sets and tools that would provide graphic presentations of aggregated data (including GIS) to the public, via the web, at zip code level.

I am concerned that ***Principle 8*** is too abstract. Without adequate, stable and well-managed resources, the vision will remain just that --- a vision*. I recommend that ten percent of each federal dollar designated for state or local health program activities (administration, service delivery, and health status assessment) be allocated to establishing or adapting current systems to meet the standards embodied in the Vision Document.* Again, if beautiful systems are desired, funding must be leveraged from the existing streams.

In some ways, this has already begun to happen. Many strides were taken with Y2K system changes. HCFA has begun to look more globally at the economics of its mission, and to recognize that public health should be a meaningful added value partner. An encouraging step is the leveraged financing available for immunization registries. Many more strides can be taken as attention and substantial sums of money are invested in HIPAA compliance. Leveraging these investments to include public health data could return enhanced value to us all. This national document and national forum could further encourage this economic lever.

Creating and maintaining health data and information relevant to policy, as outlined in ***Principle 9,*** is much "easier said than done" for most states and communities. Nevertheless, it is important. Some question the value of even collecting data that cannot be immediately linked to decisions and subsequent

action. I would like to see federal assistance recommended in this document regarding how to become more policy-relevant. This principle should contain the concept that would today drive the federal government to develop and publish a matrix comparing local level data required to assess *Healthy People 2010* objectives with the data that currently exists. Documenting the gaps would support local and state agencies in data development and integration.

How can we accomplish this far-reaching 21st Century Vision for Health Statistics? As a start, ***Principle 10*** succinctly outlines the essential need for and potential opportunities to collaborate. A focus on incentives that foster collaborative national, state and local efforts would help.

To succeed we must demonstrate in economic terms the value gained by all those involved; individuals that supply their data, those who collect and report it, the analysts and epidemiologists, doctors, funders and decision-makers. The scope of this effort could bog us down. I therefore encourage you, from your national vantage, to more clearly address the economic value expected from such collaborations. I also hope that documentation of existing collaborations operating at the local and state level will find their way into a strategic plan that would follow this ***Vision,*** along with recommendations for "replication funding." I also believe a focus on bridging gaps across data islands would help move us from where we are toward our goal of a unitary data system.

IN SUMMARY

Thank you for the opportunity to address these comments to you today. I would like to repeat my opening remark, but put in a twist. In the opening, I said we should follow the political axiom, ***"think globally and act locally."*** My twist for health is that we need to ***"look locally***" (to see what works) and then ***"act globally"*** (to achieve a better national standard of health for us all).