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## ***The NLM-RWJF Informatics Partnership*** **Remembering our past, looking toward the future**

**Editor's note:** *The following article was adapted from a speech by Dr. David Ross, Executive Director of the Public Health Informatics Institute, to The Robert Wood Johnson Foundation/National Library of Medicine public health informatics fellows at the AMIA Annual Symposium in Washington, D.C., October 2005.*

Storytelling has a long history as an important way to convey a sense of continuity and success. As ancient nomadic tribes moved from place to place, their elders carried "sacred bundles" of objects representing important moments in their history to communicate their culture from generation to generation. I want to suggest that public health informatics, a new field, begin to place its stories in a sacred bundle as a way to show how it can make a difference to the public's health.

I would like to start loading our sacred bundle by telling a story from my recent past. A few years ago, I was working with one of the large health care IT firms, implementing three-tier client server clinical systems that integrated every component of clinical care across a multi-institutional system of care.

After several difficult years, we pulled off a remarkable big-bang conversion of 11 departmental systems including labs, pharmacy, nursing documentation, orders, results, and more than 70 major interfaces. This was an ordeal that surely shortened my life by a decade.

Over time, the health system's management began to realize that its public health reporting could be done through an electronic interface. There was only one hitch: Nobody in public health could send or receive information. In 1999, the public health agency in this particular state did not have the capability to receive an inbound HL7 feed or even a periodic batch load. They showed no interest in receiving anything but standard paper forms.

My client hospital system had to devote real dollars to creating a report and sending a printout to a clerk who then manually transferred the data to the required state forms and mailed them. What priority did these tasks take? The absolute lowest, of course.

This story speaks volumes about the kind of problems that public health informaticians will help solve. It shows us that public health is just now beginning to understand that reducing the time between recognition of a problem and an effective response to it saves lives and reduces suffering.

This story about the disconnect between public health and the private health care system also tells us that our country has yet to invest, in a meaningful way, in a public health infrastructure. And it highlights the fact that technology alone will not solve the problem. For information to make a difference, we have to acknowledge the human factor. The innovations and expertise of public health informaticians, applied to real public health problems, will help change this picture.

My hope is that stories like this will become history throughout our country.

### **The concept of public health**

Let's shift our thinking now to the concept of public health. The public's health is governed by the air we breathe, the food we eat, the environment we live in, the medical care we receive, the state of the economy, the wars we fight, the way we support growth and development of kids, and how we promote good health throughout our communities. This is a very broad concept, and the practice of public health is the governmental response to that

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broad concept. Because the state of our health affects every aspect of our lives, a rational argument could be made that government's most important function is to safeguard the public's health.

Those pursuing the study of health information systems, and thus helping define the field of public health informatics, will inevitably ask, "What is public health?"

As this question pops up, consider these concepts:

- The best public health decisions come from facts.
- Facts derive from data. Scientifically valid data is the lifeblood of public health.
- Public health applies scientifically developed facts to forge public policy.
- Gathering, assembling, analyzing, and presenting facts stands at the heart of public health informatics.

Public health is an information business that has always been dedicated to gathering facts and using those facts to point us toward progress. The facts we gather and the ways in which we distill and examine those facts to make usable information make a very profound statement about what we value and how boldly we think.

### **The rising stakes of public health**

Here's another story for our sacred bundle. In 1995 I worked at CDC. Dr. David Satcher, then director and later Surgeon General, was asked to assemble a comprehensive briefing about CDC for a leading member of Congress; my section was the role of information and its impact on public health.

Our challenge was clear: How would we explain why public health needs an information infrastructure that vastly exceeds existing capabilities? Communicating what public health does and why it needs informatics is not easy, especially when trying to engage policymakers outside the realm of public health.

To make our presentation engaging, we stole a page from game designers and created a computer program that let the Congressional member play the role of a health officer. When he logged on to a computer, it greeted him with a computer-generated voice detailing the day's schedule. The screen displayed four buttons: SURVEILLANCE, DECISION SUPPORT, COMMUNICATIONS, and VIRTUAL RESOURCE CENTER. Clicking a button opened additional tool sets on the screen.

This briefing tool acted more like a game than a series of PowerPoint slides. A few minutes after logging in and working on a community heart disease prevention initiative, the health officer was confronted by an animated "knowledgebot" (we used a barking dog) announcing that the surveillance network had detected several cases of e-coli 0157-H7. This infectious disease emergency quickly pushed aside the heart disease initiative.

The tool offered him immediate access to an online, interactive resource center that provided the latest information on treatment guidelines, case definition, outbreak management guidelines, and even video clips from past outbreaks. The scenario also forced him to interact with media, which had picked up the story. He saw how important it is to have treatment guidelines and communications materials ready to use. He saw the need for immediate, accessible, accurate information.

We used this scenario to explain in a subtle, almost invisible way, some of what public health does to protect every community and to show the high-level business case for investing in the public health information infrastructure – that is, fast detection and rapid response leads to fewer sick kids and lower costs.

What we didn't recognize at the time was that we were painting the first picture of what we now call syndromic surveillance. But one congressman connected the dots and made a profound statement, one that the public health community is still trying to comprehend. He said, simply, that public health is national security. He couldn't sell information technology or information infrastructure to Congress and the American people, he pointed out, but he could help sell national security.

My message is simple: Public health must simultaneously pursue its traditional mission and conduct its traditional activities while recognizing that it has become a part of the national security mission. We can raise public health's visibility by stressing this aspect of our work. The increasing importance of public health was highlighted when pandemic flu articles dominated the cover of Foreign Affairs (July/August 2005).

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health informatics. Large investments are now being made to bring about national interoperability in data and in functional coordination. As a country, we are beginning to recognize that public health makes a difference, and that difference is largely in our information and how we use it.

To make informatics effective we must:

- generate health information backed by solid science.
- build a basis for reliable and valid data through semantic consistency, standardized vocabularies, and data structures.
- develop applications that function within the realities of public health agency boundary conditions. That means we must start with well-conceived business processes and rigorous requirements definitions, coupled with organizational and financial strategies that yield enterprise, systemic capability.

### **Information that prevents harm**

One morning in 1992 a colleague at CDC arrived at the office with an eye-opening story. Arriving home after work the previous night, she was greeted by agents from the Georgia Bureau of Investigation (GBI). By purchasing a number of grow lights for her greenhouse, she had triggered a Georgia drug law that requires retail outlets to inform the GBI of grow light sales to a single customer that exceed a reporting threshold.

This requirement sounds like the notifiable disease reporting scenario. If law enforcement can do this in a consistent, organized way, why not public health? This story – another one for public health informatics' sacred bundle—lays out one of our challenges: Make real time, on-demand, comprehensive information the norm in public health.

To reach this goal, we should view useful, usable information as the equivalent of life-saving medicine or therapy—that is, information that prevents harm.

### **The wild west of informatics**

Dr. Bill Foege, a founder of The Task Force for Child Survival and Development [parent organization of the Public Health Informatics Institute], told the world's health ministers in the late 1990's that we have witnessed a Twentieth Century marked as an age of technological triumphs and innovations. It was also an age in which societies and global health leaders dared to think of safeguarding the health of the human race as a practical objective. But, he pointed out, we ended the century with humbling gaps and discrepancies in global health.

What can we do to eliminate these gaps and discrepancies? What can we do to guarantee that every child gets a healthy start and is able and ready to learn on the first day of school? What can you, as public health informaticians, do to protect the health of every citizen?

Early efforts in informatics were adventures driven more by funding than by rational assessment of how health goals would be achieved through judicious or innovative use of information technologies. Some were basically well-conceived but not legitimized in public health strategy. Other ventures, like the development of immunization registries, were rationalized in health strategy but generally not guided by informatics science and best practices.

We let a thousand flowers bloom and hoped that some fields would eventually grow into a complete landscape. We're still hoping. Public health did eventually understand that we need architecture, and with that construct in mind, electronic disease surveillance was born. But the problems in this pursuit stem largely from a failure to understand the context in which the work gets done. These early efforts were incremental, somewhat accidental, ventures into informatics.

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Public health informaticians of the future will eliminate this haphazard approach. It is my hope that you, students guided by faculty, will bring rigor and academic discipline to the wild west of public health informatics.

As we progress, these features of public health will influence how informatics innovations penetrate public health practice:

- Public health is public. That means investment decisions are made by legislators, not organizational executives.

- Public health does not have competitors driving its organizations to excellence. We have leaders who administer budgets given to them, often with a mission that exceeds the allotted resources.
- As a monopoly, public health often finds that it's more convenient to control turf than to solve the health problem.

The incentives to change and adopt innovation come more from legislatures than from those who need to change their organizations to accommodate innovation. This disconnect explains a lot about the behavior of public health organizations. They implement informatics innovations within a narrow scope because that is the universe they can control. Implementing enterprise information systems requires those who control the departmental activities to work together, to collaborate. This is an unnatural act, usually among non-consenting adults.

### **Informatics: A catalyst for change**

Informatics is about change, and to be an active catalyst for change we must recognize and understand the conflict inherent in the mission of public health and the way it is organized and funded.

Here is my prescription for the future of public health informatics. These are the same principles that guide the Public Health Informatics Institute:

1. Enterprise solutions must build on a collaboratively constructed willingness to identify the problem to be solved with an information solution. That is, the people who need to adopt technologies must understand the health problem and see the connection between it and the informatics support offered.
2. The business processes that underlie the work must be uncovered and analyzed to help the enterprise of collaborating parties understand what information solutions must do to be useful. These collaborating parties should represent all of the stakeholders – those who will use the information, those who will benefit from it, and those who must support and sustain a complex system that knits together elements of an organization or knits one organization to other organizations. Uncovering or analyzing these business processes needs to be done in a collaborative manner that engages the stakeholders – deeply engages them – so they are taking the first steps toward organizational change. To bring about change in governmental organizations, those involved must want to change. They don't have market forces making them change, they don't have payers telling them to adopt a change or they won't get paid, and they don't have executives with the authority to order them to change.
3. Finally, we need to communicate deeply throughout this process. We must have a communications strategy that ties project development activities to the information needs of each stakeholder group through each phase of the project. In public health this builds on a collaborative approach. When we engage stakeholders correctly, we uncover their information needs. If we find ourselves wondering what a stakeholder might want to know, we have not adequately planned and implemented the communications approach the informatics project needs.

Managing the business case, requirements, and communications strategy collaboratively is challenging. We have dedicated the Institute to forging methods to support this approach. We hope we can partner with academic institutions and public health practitioners to transfer our practice-based learning as we add stories to public health informatics' sacred bundle.

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My hope is that the public health information systems experts of the future—along with public health program managers and policymakers – examine our work, take seriously the challenge of translating innovations into practice, and help make needed changes in the public's health through the application of informatics.

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