
Public Health Information Systems: *A National Perspective*

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This paper was developed to highlight the challenges facing the public health industry regarding the deployment and utilization of information technology, and what can be done to address these challenges. Today, the focus is on the public health industry more than ever. The general population has become dependent on public health information and data, and relies on the appropriate systems to be in place to address any unforeseen medical disasters. With the continuing rapid evolution of information technology coupled with public health's history towards hesitating on deploying new technologies, public health agencies across the country find themselves at a critical crossroads.

Introduction

The information and systems managed and operated by public health agencies across the country have been catapulted into the public spotlight. The executive branches of government (those who are accountable to the American people) want ready access to critical public health information, while local legislators try to preserve security and confidentiality of its constituency. Hospital emergency rooms, urgent care centers, and other private medical providers need to share information with each other to identify if unusual symptoms are being seen in unexplainable numbers, and are looking to public health to be their conduit. All of this is occurring while the general public demands that public health systems be in place to facilitate early

warning detection, treatment, and prevention of potential public health threats.

Background

Public health information systems and data exist within five distinct, and often disparate entities. These are:

1. Federal Government (CDC)
2. State Government (State Health Department)
3. Local Government (County Health Offices)
4. Private Medical Providers (Hospitals, Clinics, Private Practices)
5. Supporting Organizations (Managed Care, Laboratories, Pharmacies, etc...)

These systems have each been developed to fulfill the needs of each respective entity without concern for sharing data with the others. Moreover, few of these systems are technologically advanced; several are in the midst of major infrastructure overhauls; while some are saddled with aging technology and no immediate plans for upgrades. Additionally, many vendors, technology platforms, operating systems, databases, and technology standards are employed throughout these various entities.

Illustration

A patient that contracts an illness may first visit a pharmacist to buy over-the-counter medications to address his/her symptoms. If the illness persists, the patient may visit the family doctor, an urgent care center, or hospital emergency room. Here, demographic and medical data is collected into this entity's information system. Certain data elements are passed onto an insurance company or other supporting organization for billing purposes. If the patient's illness cannot be treated or accurately diagnosed, their samples are sent, or they are referred to a laboratory. If a diagnosis can be made, and if this diagnosis indicates a reportable or communicable disease, this information is passed onto the local or state health authorities, which in turn passes it onto the federal health authorities. The reported agent contracted by the patient determines the actions the local/state health authorities must take, as well as determines if the illness represents a public health threat that could potentially proliferate outside the state boundaries thereby requiring intervention by federal authorities.

The Problems

The example above illustrates just a subset of the sequence of events for a single patient with a single condition. For these types of incidents, both procedural and technological inefficiencies need to be addressed. If indeed a patient had an infectious, non-treatable, contagious disease, this agent could possibly spread until the diagnosis was made and appropriate public health intervention occurs. As can be seen in the example, intervention by public health doesn't occur until well into the process. Thus, the first issue is the timeliness of information being made available to public health.

Once information of a potential public health threat reaches local or state public health authorities, systems and processes are in place to take the appropriate action. These public health systems focus on an entirely new set of objectives. Again referring to our example, while the medical process continues to focus on treatment for the infected patient, the public health process turns its attention towards prevention and containment. Who has this person been in contact with? Where did the agent originate? What events, restaurants or public facilities has this person been to? Are other similar symptoms being seen in other medical facilities nearby?

As can be seen in the above scenario, while the patient was going through the diagnosis process as a patient with a common or treatable illness, the flow of information and the process in place is fairly sequential and logical. For treatable, non-contagious illnesses, the inherent delays and inefficiencies are an inconvenience but typically do not factor into the overall outcome. In other words, the patient gets diagnosed and treated for their illness without posing any threat to others.

These inefficiencies are greatly magnified however when the illness turns out to be contagious, involves a rare biological agent, and/or is the result of an overt act. In these types of cases, not only is the challenge to speed up the process, but also to interconnect these entities' systems, assemble all pertinent data, utilize information technology advancements to analyze, simulate, and model the data, and deploy this technology to the appropriate public health and medical authorities so that quick, effective, and confident public health decisions can be made.

Today, public health authorities and experts have to make these decisions in the absence of an integrated technology infrastructure. They are rapidly trying to address the known inefficiencies, redundancies, and incompatibilities that surround the dissemination of public health data so that the threats that challenge our public health can be quickly treated, or even prevented from occurring in the first place.

Vision

There are many public health initiatives taking place today to address the challenges discussed above. Efforts at the national level include the National Electronic Disease Surveillance Systems (NEDSS) architecture, which is designed and funded by the CDC. Most state health departments have planned for or are implementing information technology initiatives including establishing statewide data registries, installing communication networks that connect key health providers (both public and private) together, and replacing traditional legacy, batch-oriented systems, with newer, more "open" systems that allows the sharing of information between distinct systems. Local health offices, meanwhile have reached out to the private providers, and established processes and systems for streamlining the sharing of information and resources. Each of these initiatives contributes to helping public health authorities address the inherent issues and challenges facing them today.

Despite these initiatives, an integrated public health vision whereby public agencies and private medical organizations have ready and real time access to information pertaining to an occurrence or set of occurrences is needed. This requires collaboration between and among the five entities. To realize this vision requires four information technology initiatives. They are:

1. Development of a conceptual design for the collection and dissemination of related public health information.
2. Development of an information technology plan that involves each of the five entities, and adheres to the conceptual design.
3. Creation of application prototypes and proofs of concept that target high-priority public health needs.
4. Implementation of the information technology plan's tasks, which are validated by the prototypes, and provide the desired outcomes.

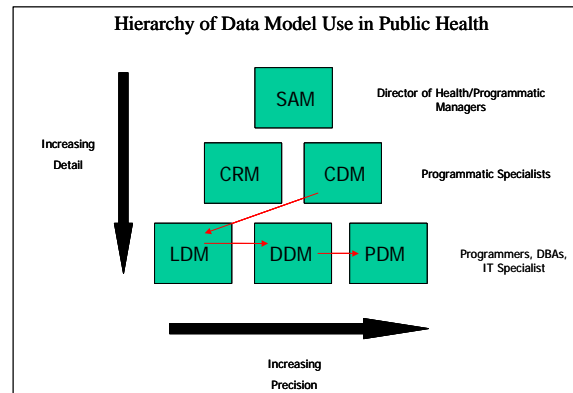
The subsequent sections of this paper looks at each of these initiatives in more detail.

Public Health Conceptual Design

Data Models document the data of a particular domain for a specific purpose using a formal specification. A data model can be represented graphically with supporting textual description and a data dictionary. Each representation of a data model uses predefined symbols, semantics and rules of construction. A data model reflects a party's knowledge of the data and allows that knowledge to be assessed by others. Data models allow reconciliation of multiple data sources, taking into account constraints, semantics, and underlying assumptions.

There are varying types of data models. The choice of which data model to use is based upon the complexity desired. The least detailed and complex of these models is the Subject Area Model (SAM). This model contains only subject area and their connections. It is used for high level planning and establishing a project scope. The Class Relationship Model (CRM) contains slightly more detail (subject areas, classes and relationships) and is used for high-level analysis and estimation of project size. The more detailed and precise Conceptual Data Model contains subject areas, classes, attributes, data types and relationships. It generally models a project-specific domain. A CDM results from a relatively

detailed level of analysis and is primarily project deliverable. The following diagram was modified from the Centers for Disease Control and Prevention's (CDC) Public Health Conceptual Data Model document. It depicts six different data model types within the hierarchy of public health.



According to CDC documentation, the Conceptual Data Model (CDM) results from a relatively detailed level of analysis and is often a primary project deliverable. It is technology independent and may be applicable to multiple organizations. The CDM is detailed enough to be used as a definition of information requirements in public health. The intended audiences for this model are programmatic managers and subject matter experts. IT specialists are responsible for ensuring the necessary infrastructure is in place for analysis and use of the public health data.

From the developed CDM, multiple logical data models (LDM) database design models (DDM) and multiple physical data models (PDM) can be developed. A PDM is the most detailed and precise of the data models discussed. It is derived sequentially by first developing a logical model, and then a database model.

The CDC has recently developed a public health conceptual data model (PHCDM) as a roadmap for state and local health offices to implement information technology solutions.

The primary objective of the PHCDM is to facilitate data standards in public health data collection, management, transmission, analysis, and dissemination. To accomplish this, the PHCDM will:

- a. Provide a framework for organizing data standards and guidelines*

Early in the NEDSS program, the Common Information for Public Health Electronic Reporting (CIPHER) was developed as a set of standards and guidelines for data representation and code values. CIPHER includes specifications and code lists for data elements such as name, date, address, race, ethnicity, and gender. The PHCDM provides a context for CIPHER as the CIPHER standards can be directly linked to attributes in the data model, and eventually become fields in computerized public health information systems.

As will be discussed later, the challenge facing state and local health departments is the ability to modify or update their information systems to comply with CIPHER guidelines and other nationally established technology standards. Since many of the legacy systems in use by public health agencies which house these key data elements identified by CIPHER are outdated, static, and not conducive to change, major system overhauls are required for them to get into compliance. Furthermore, these data elements typically reside in multiple, disparate systems that have no logical or physical connection thus compounding the problem of getting state and local health systems in place for the purpose of adhering to these and other standards.

The CDC has done their part in setting forth the standards and guidelines. It is now incumbent on the state and local health agencies across the country to implement these standards by first bringing their legacy systems up to par technologically so that standards and interfaces with other systems can be facilitated.

b. Reduce development effort for computerized information systems used in public health

One of the most pressing challenges facing public health is the proliferation of redundant and duplicate data, which reside in the various systems of the five entities described earlier. It is impractical to assume that all entities will abandon their information systems infrastructure for the purpose of adhering to new standards or to prevent themselves or other public health entities from having to duplicate data elements in their systems. The CDC has therefore focused on creating and promoting the use of reusable tools as opposed to developing detailed applications, which conform to a strict technological platform.

One of the key concepts behind the PHCDM and NEDSS architecture for example, is the Integrated Data Repository (IDR). The PHCDM should provide

reusable database design and data analysis capabilities. This will help build a common starting platform to be used by public health offices and modified as new national requirements become available.

c. Enhance data sharing through consistency

One of the advantages in reusing the PHCDM in database design is the increased level of consistency in data representation amongst independently developed solutions. This will help increase the sharing of data across multiple systems, which could potentially enable more timely and accurate analysis of emerging public health problems, and provide useful information when setting a community's public health policy.

d. Represent public health data needs to national setting bodies

The PHCDM is to help CDC and its public health partners collaborate with national standards-setting bodies in defining information exchange needs, standards, and guidelines among public health stakeholders and healthcare providers. For example, by incorporating recognized standards, organizational framework and models such as Health Level Seven's Reference Information Model (HL7 RIM), the needs of the public health community will be more readily recognized by information system vendors and provider organizations, which also participate in HL7. This will help in having these systems and organizations serve as original data sources for public health.

e. Facilitate collaboration between CDC and its state and local public health partners

Collecting, analyzing, and reporting data related to public health are done at local, state, and national levels. The data standards defined by the PHCDM and CIPHER can be used by all parties involved in public health, helping reconcile the information needs at the federal, state, and local level for disease surveillance, intervention efforts, and programmatic planning. Through collaboration with state and local entities, the PHCDM is to lay a foundation for a unified view across the full spectrum of public health activities.

Despite the absence of a PHCDM in the past, the CDC, with the cooperation of the state and territorial epidemiologists, has implemented and managed over 100 separate disease surveillance and health information systems to help monitor and analyze the

nation's public health status. Each of these systems has been developed and administered independently by specific programs, relying upon data collection and reporting from the state and local public health stakeholders using non-standardized data formats. The result of this non-standardized approach is the inability of most of these systems to share data or to communicate with one another. The consequences at both the state and federal level include duplicate efforts, incorrect estimates of disease rates, undesirable errors, inefficient use of scarce public health resources, and the inability to link or overlay data from different systems to enhance knowledge and improve public health decisions. This fragmented approach prohibits the construction of a truly national disease surveillance system. Another consequence of this is that the early detection of a bioterrorism event and/or disease outbreak of national importance will likely be delayed.

An additional consideration of great importance at present is the Health Insurance Portability and Accountability Act (HIPAA). This is bringing enormous attention to the exchange and storage of health-related data and is requiring public and private health practitioners to use electronic data exchange and storage standards. These facts not only demand reevaluation of data handling and storage/security systems but also provide an unparalleled opportunity for reevaluation of surveillance and reporting methodology as well as the use of direct electronic importation of data and information from a variety of potential reporting sources.

The CDC is attempting to address this through the development of the National Electronic Disease Surveillance (NEDSS) Program. The NEDSS goal is to standardize the methods and tools, upon which public health information systems are constructed, managed, maintained, and integrated. It is the goal of these national efforts to have public health information systems proliferated throughout the country that specifically address the NEDSS initiatives, are compliant with nationally developed and recognized standards (i.e. HIPAA, CIPHER, HL7, etc...), and fit within the framework of the PHCDM.

Information Technology Plan

As nationally agreed upon standards continue to be established along with the continued refinement of a model by which to implement public health information systems, the information technology planning process can commence.

The CDC has allocated Phase 1 funding to most state health offices across the country. The intent of these funds was for states to develop a comprehensive NEDSS strategic plan. This included measuring eight identified NEDSS elements against each of the state's capabilities to determine the readiness of the IT infrastructure in place. These eight elements are:

1. Conduct and support web browser-based data entry and data management.
2. Accept, route and process electronic HL7 messages containing laboratory and clinical content.
3. Implement an Integrated Data Repository (IDR).
4. Develop data analysis, visualization, and reporting capabilities.
5. Implement a directory of public health personnel.
6. Implement a security system and appropriate security policies.
7. Develop active data translation and exchange (integration broker functionality)
8. Develop transportable business logic capability.

These eight elements illustrate a state health department's ability to effectively implement a national electronic disease surveillance system. In order to objectively evaluate a state's capabilities of addressing these eight elements, a thorough information technology plan is needed. By going through the planning process, each of these elements can be evaluated against the current information systems infrastructure in place.

The planning process involves five key steps or phases. These are:

1. Data collection/Discovery
2. Assessment (procedurally, legislatively, and technologically)
3. Alternative analysis
4. Recommendations
5. Implementation Plan

Discovery Phase

During the discovery phase, information is gathered on the existing systems and processes related to the current method of collecting, processing, and reporting public health information. This includes gathering detailed information on the technological infrastructure of the state health department's systems as well as those systems that interact with the

state including associated public health agencies and private sector providers.

Assessment Phase

Once the data is collected and the process of disease reporting is understood, an assessment of the existing infrastructure is conducted against each of the eight elements. Strengths and weaknesses are illustrated within each of the elements. Each element can be ranked or graded against the capabilities required to fulfill the requirements of that element. This assessment not only highlights what needs to be done within each element in order to be in compliance, but also provides an immediate illustration as to which elements need the most attention. Here, priorities can be established, specific projects can begin forming, and organizational changes may be able to be identified. Some of the weaknesses associated with an element may not involve technological changes but instead may need organizational, procedural or legislative changes. Each of these characteristics and the barriers they pose towards complying with each of the elements are described in this phase of the planning process.

Alternative Analysis Phase

Addressing the issues that stem from the discovery and assessment phases within a state health department often can be done with taking more than one approach. For the plan to maintain credibility, it is vital that each alternative is given a fair assessment. There should not be any hidden agendas or misleading information for the purposes of securing a pre-determined outcome desired by any stakeholder.

Each alternative is assessed as to how they address the weaknesses associated with each of the eight elements, how they fit into the overall infrastructure of the state health department, how long they take to implement, costs associated to implement, and the resources required to support the implementation for the long term.

Each alternative's advantages/disadvantages are illustrated. This exercise typically involves applying a normalized rating system to illustrate each alternative's ability to cost-effectively address the issues associated with the eight NEDSS elements. The rating system is designed to weight the characteristics of an alternative based on pre-determined criteria. For example, "required hardware platform" may be a category that receives a high weighting number. If it is determined that all

alternatives need to be able to operate on a particular hardware platform, those that do would score high in this category and those that don't would receive a low score. Scores are compiled, totaled and the results are summarized.

The key to this type of alternative analysis is that it not only factors in an alternative's ability to adhere to the eight NEDSS elements, but also analyzes an alternative's ability to fit within the structure of the organization.

Recommendations Phase

Recommendations are made based on the alternative assessments completed in the previous phase of the process. They are then categorized and sorted consistent with their corresponding requirements to address the eight elements. Each mandatory requirement or set of requirements is assigned a corresponding recommendation(s). This provides a logical sequence to the subsequent implementation, and facilitates the prioritization of those recommendations that provide the most benefit in the shortest amount of time.

The implementation plan is the primary deliverable of the information technology planning process. All the previous steps provide the supporting material to validate the recommended tasks, schedule, and associated costs of the plan.

Prototypes/Proofs of Concept

Depending on the readiness of a state's technology infrastructure and its availability of data, certain recommendations made in the planning process could be quickly illustrated by creating prototypes or proofs of concept.

Prototypes

Prototypes are samples of actual applications. They apply the recommended technology to an identified task or set of tasks to solidify the characteristics of the application; to involve the users of the application early in the design process; and to determine if the recommended approach is capable of providing the desired outcome.

One example of a prototype within the aforementioned CDC NEDSS initiative is the development of a web-based Communicable Disease Reporting (CDR) application. Since certain diseases have mandated reporting requirements, and since this

reporting process is currently done manually to public health authorities, a web-based prototype for capturing and reporting diseases can be developed using the recommended CDR tools from the planning process. A second example is a collaborative effort between Sandia and Los Alamos National Laboratories, the University of New Mexico Department of Emergency Medicine and the New Mexico Department of Health Office of Epidemiology, to implement a syndrome surveillance system called the Rapid Syndrome Validation Project (RSVP).¹ This prototype was developed to determine the value of capturing pre-determined symptoms being seen in an Emergency Room for the early detection of diseases. Since reporting currently doesn't happen until after a diagnosis is made, and since diagnosis is often a result of coincidental events (i.e. one doctor sees multiple cases of unusual or extreme symptoms), RSVP was developed to address these issues.

Each of these prototypes are designed to serve a specific need, however, both support surveillance. The RSVP project is assessing the value of capturing potential disease information through symptoms, while the CDR process captures disease information through mandated reporting. Since all mandated diseases are not reported and symptoms alone are not validation of a disease, it becomes clear that for health professionals, there is value in integrating and using data from both systems. Similarly, there is value in using other resources to supplement this information. The prototype process therefore, not only provides a validation of each independent application, but also provides a mechanism for highlighting the relationships between them and how they need to interface with each other.

Proofs of Concept

Proofs of concept, much like prototypes, provide a more visual insight into potential public health solutions. The differences between the two are subtle. Prototypes tend to be focused on applying technology to an existing process while proofs of concept are focused on creating new applications or processes. These are often used to secure money from outside sources, such as foundations or grants, based on a new concept that has yet to be proven.

Possible proofs of concept for early detection and intervention for example, may be a Public Health Event Tracking System. In this proof of concept, state epidemiologists could see if a population with recently reported ominous symptoms or diagnosis fits a public event tailored to that same population.

Another example may be to create a proof of concept by obtaining access to pharmaceutical data to see if medicines are being bought and/or prescribed for symptoms related to a potential outbreak recently reported.

The value of prototypes and proofs of concept lies in their ability to allow public health officials to actually see and interact with the technology and provide suggestions for improvements prior to investing in putting them into production. Furthermore, these provide an immediate bridge between the planning process and the subsequent implementation process.

Implementation

With a conceptual public health data model in place, information technology planning processes in various stages of completion across the country, and the availability of technology tools that facilitate the rapid development of prototypes and proofs of concept, the attention now turns towards implementation.

Implementation involves putting into production the recommendations identified in the plan that adhere to the national standards set forth in the data model, and possibly validated with prototypes or proofs of concept. The primary concerns associated with implementation typically involve securing adequate funding, finding the right expertise (both in-house and vendor related), and developing collaboration from the five entities.

All the technological components have been identified through the previous initiatives described above, and thus, at the time implementation commences, there should be little discussion about the approach to be taken or the timeframe for implementation. Indeed, the final deliverable of the planning process should have broken down the implementation into logical phases that have realistic timeframes. The phases of the plan should be broken up so that each can be completed in a 6-15 month timeframe.

As was discussed earlier in this report, certain states are in better positions than others to begin immediate implementation of tools and applications to address technological barriers that exist described in this document. Those states however, that are still maintaining outdated technology and thus are unprepared to deploy nationwide or even statewide public health solutions can still benefit from engaging in the previous initiatives. The only difference is the outcome of the plan will involve an additional,

introductory step of addressing their internal deficiencies prior to launching into the implementation of the national model.

Summary

This paper highlights the plethora of technological challenges facing public health today, as well as a framework for effectively addressing these challenges. Although efforts are underway which involve applying technology to solving public health issues, many of these continue to be done without consideration for the larger good. Exciting technology projects can be found within every one of the five key entities described in this paper, each attempting to address independent needs and requirements. But to achieve the results of a system designed to protect the health of the country's entire population, a broader focus needs to be woven into the fabric of each entities' information system initiatives.

References

¹ Zelicoff AI, MD, Brillman J, MD et al., "The Rapid Syndrome Validation Project (RSVP)," Internal Paper 2001.

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