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Public Health Informatics and the Health Information Infrastructure

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After reading this chapter you should know the answers to these questions:

- What are the three core functions of public health, and how do they help shape the different foci of public health and medicine?
- What are the current and potential effects of a) the genomics revolution; and b) 9/11 on public health informatics?
- What were the political, organizational, epidemiological, and technical issues that influenced the development of immunization registries? How do registries promote public health, and how can this model be expanded to other domains (be specific about those domains)? How might it fail in others? Why?
- What is the vision and purpose of the National Health Information Infrastructure? What kinds of impacts will it have, and in what time periods? Why don't we have one already? What are the political and technical barriers to its implementation? What are the characteristics of any evaluation process that would be used to judge demonstration projects?

15.1 Introduction

Biomedical informatics includes a wide range of disciplines that span information from the molecular to the population level. This chapter is primarily focused on the population level, which includes informatics applied to public health and to the entire health care system (**health information infrastructure**). Population-level informatics has its own special problems, issues, and considerations. Creating information systems at the population level has always been very difficult because of the large number of data elements and individuals that must be included, as well as the need to address data and information issues that affect health in the aggregate (e.g., environmental determinants of health). With faster and cheaper hardware and radically improved software tools, it has become financially and technically feasible to create information systems that will provide the information about individuals and populations necessary for optimized decision-making in medical care and public health. However, much work remains to fully achieve this goal.

This chapter deals with public health informatics primarily as it relates to the medical care of populations. However, it should be emphasized that the domain of public health

informatics is not limited to the medical care environment. For example, information technology is being applied to automatically detect threats to health from the food supply, water systems, and even driving conditions (such as obstacles on the roadway beyond the reach of visible headlight beams), and to assist in man-made or natural disaster management. Monitoring the environment for health risks due to biological, chemical, and radiation exposures (natural and made-made) is of increasing concern to protecting the public's health. For example, systems are now being developed and deployed to rapidly detect airborne bioterror agents. Although they do not directly relate to medical care, these applications designed to protect human health should properly be considered within the domain of public health informatics.

15.2 Public Health Informatics

Public health informatics has been defined as the systematic application of information and computer science and technology to public health practice, research, and learning (Friede et al., 1995; Yasnoff et al., 2000). Public health informatics is distinguished by its focus on populations (versus the individual), its orientation to prevention (rather than diagnosis and treatment), and its governmental context, because public health nearly always involves government agencies. It is a large and complex area that is the focus of another entire textbook in this series (O'Carroll et al., 2003).

The differences between public health informatics and other informatics specialty areas relate to the contrast between public health and medical care itself (Friede & O'Carroll, 1998; Yasnoff et al., 2000). Public health focuses on the health of the community, as opposed to that of the individual patient. In the medical care system, individuals with specific diseases or conditions are the primary concern. In public health, issues related to the community as the patient may require "treatment" such as disclosure of the disease status of an individual to prevent further spread of illness or even quarantining some individuals to protect others. Environmental factors, especially ones that affect the health of populations over the long term (e.g. air quality), are also a special focus of the public health domain. Public health places a large emphasis on the prevention of disease and injury versus intervention after the problem has already occurred. To the extent that traditional medical care involves prevention, its focus is primarily on delivery of preventive services to individual patients.

Public health actions are not limited to the clinical encounter. In public health, the nature of a given intervention is not predetermined by professional discipline, but rather by the cost, expediency, and social acceptability of intervening at any potentially effective point in the series of events leading to disease, injury, or disability. Public health interventions have included (for example) wastewater treatment and solid waste disposal systems, housing and building codes, fluoridation of municipal water supplies, removal of lead from gasoline, and smoke alarms. Contrast this with the modern healthcare system, which generally accomplishes its mission through medical and surgical encounters.

Public health also generally operates directly or indirectly through government agencies that must be responsive to legislative, regulatory, and policy directives, carefully balance competing priorities, and openly disclose their activities. In addition, certain public

health actions involve authority for specific (sometimes coercive) measures to protect the community in an emergency. Examples include closing a contaminated pond or a restaurant that fails inspection.

15.2.1 What Is Public Health?

Public health itself is a complex and varied discipline, encompassing a wide variety of specialty areas. The broad scope and diversity of activities makes it difficult to readily and concisely define and explain public health. One useful conceptualization defines public health in terms of its three core functions of assessment, policy development, and assurance (Institute of Medicine (IOM), 1988). Assessment involves monitoring and tracking the health status of populations including identifying and controlling disease outbreaks and epidemics. By relating health status to a variety of demographic, geographic, environmental, and other factors, it is possible to develop and test hypotheses about the etiology, transmission, and risk factors that contribute to health problems.

Policy development is the second core function of public health. It utilizes the results of assessment activities and etiologic research in concert with local values and culture (as reflected via citizen input) to recommend interventions and public policies that improve health status. For example, the relationship between fatalities in automobile accidents and ejection of passengers from vehicles led to recommendations, and eventually laws, mandating seat belt use. Although, at present, there is intense interest in the promise of enhanced public health surveillance using information technology to provide near-real-time access to clinical data stores, it is in the area of policy development that information technology may have its greatest impact.

Because public health is primarily a governmental activity, it depends upon and is informed by the consent of those governed. Policy development in public health is (or should be) based on science, but it is also derived from the values, beliefs, and opinions of the society it serves. Today, e-mail, Web sites, on-line discussion groups, and instant messaging are the most heavily used Internet applications. In comparison, only a minuscule fraction of the populace ever concerns itself with surveillance data. Public health officials who wish to promote certain health behaviors, or to promulgate regulations concerning, say, fluoridated water or bicycle helmets, would do well to tap into the on-line marketplace of ideas—both to understand the opinions and beliefs of their citizenry, and to (hopefully) influence them.

The third core function of public health is assurance, which refers to the duty of public health agencies to assure their constituents that services necessary to achieve agreed upon goals are provided. Note that the services in question (including medical care) might be provided directly by the public health agency or by encouraging or requiring (through regulation) other public or private entities to provide the services. For example, in some communities, local public health agencies provide a great deal of direct clinical care. In Multnomah County, Oregon, for example, the local public health agency currently provides health care services in seven primary care clinics, three county jails, thirteen schools, four community sites and in people's homes. In other communities (e.g., Pierce County, Washington), local public health agencies have sought to minimize or eliminate direct clinical care services, instead working with and relying on

community partners to provide such care. Though there is great variation across jurisdictions, the fundamental assurance function is unchanged: to assure that all members of the community have adequate access to needed services. The assurance function is not limited to access to clinical care. Rather, it refers to assurance of the conditions that allow people to be healthy and free from avoidable threats to health—which includes access to clean water, a safe food supply, well-lighted streets, responsive and effective public safety entities, and so forth.

This “core functions” framework has proven to be highly useful in clarifying the fundamental, over-arching responsibilities of public health. But if the core functions describe what public health is *for*, a more detailed and grounded delineation was needed to describe what public health agencies *do*. To meet this need, a set of ten essential public health services (Table 15.1) was developed through national and state level deliberations of public health providers and consumers (Department of Health and Human Services (DHHS), 1994). It is through these ten services that public health carries out its mission to assure the conditions in which people can be healthy.

The core function of assessment, and several of the essential public health services rely heavily on public health **surveillance**, one of the oldest systematic activities of the public health sector. Surveillance in the public health context refers to the ongoing collection, analysis, interpretation, and dissemination of data on health conditions (e.g., breast cancer) and threats to health (e.g., smoking prevalence). Surveillance data represent one of the fundamental means by which priorities for public health action are set. Surveillance data are useful not only in the short term (e.g., in surveillance for acute infectious diseases such as influenza, measles, and HIV/AIDS), but also in the longer term, e.g., in determining leading causes of premature death, injury, or disability. In either case, what distinguishes surveillance is that the data are collected for the purposes of action—either to guide a public health response (e.g., an outbreak investigation, or mitigation of a threat to a food or water source) or to help direct public health policy. A recent example of the latter is the surveillance data showing the dramatic rise in obesity in the United States. A tremendous amount of energy and public focus has been brought to bear on this problem—including a major DHHS program, the *HealthierUS* initiative—driven largely by compelling surveillance data.

Table 15.1. Ten essential services of public health (DHHS, 1994).

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1. Monitor the health status of individuals in the community to identify community health problems
 2. Diagnose and investigate community health problems and community health hazards
 3. Inform, educate, and empower the community with respect to health issues
 4. Mobilize community partnerships in identifying and solving community health problems
 5. Develop policies and plans that support individual and community efforts to improve health
 6. Enforce laws and rules that protect the public health and ensure safety in accordance with those laws and rules
 7. Link individuals who have a need for community and personal health services to appropriate community and private providers
 8. Ensure a competent workforce for the provision of essential public health services
 9. Research new insights and innovate solutions to community health problems
 10. Evaluate the effectiveness, accessibility, and quality of personal and population-based health services in a community
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15.2.2 *Information Systems in Public Health*

The fundamental science of public health is **epidemiology**, which is the study of the prevalence and determinants of disability and disease in *populations*. Hence, most public health information systems have focused on information about aggregate populations. Almost all medical information systems focus almost exclusively on identifying information about *individuals*. For example, almost any clinical laboratory system can quickly find Jane Smith's culture results. What public health practitioners want to know is the time trend of antibiotic resistance for the *population* that the clinic serves, or the trend for the population that the clinic actually covers.

Most health care professionals are surprised to learn that there is no uniform national routine reporting – never mind information system – for most diseases, disabilities, risk factors, or prevention activities in the United States. In contrast, France, Great Britain, Denmark, Norway and Sweden have comprehensive systems in selected areas, such as occupational injuries, infectious diseases, and cancer; no country, however, has complete reporting for every problem. In fact, it is only births, deaths, and – to a lesser extent – fetal deaths that are uniformly and relatively completely reported in the United States by the National Vital Statistics System, operated by the states and the Centers for Disease Control and Prevention (CDC). If you have an angioplasty and survive, nobody at the state or federal level necessarily knows.

Public health information systems have been designed with special features. For example, they are optimized for retrieval from very large (multi-million) record databases, and to be able to quickly cross-tabulate, study secular trends, and look for patterns. The use of personal identifiers in these systems is very limited, and their use is generally restricted to linking data from different sources (e.g., data from a state laboratory and a disease surveillance form). A few examples of these kinds of population-focused systems include CDC systems such as the HIV/AIDS reporting system, which collects millions of observations concerning people infected with the Human Immunodeficiency Virus (HIV) and those diagnosed with Acquired Immunodeficiency Syndrome (AIDS) and is used to conduct dozens of studies (and which does not collect personal identifiers; individuals are tracked by pseudo-identifiers); the National Notifiable Disease Surveillance System, which state epidemiologists use to report some 60 diseases (the exact number varies as conditions wax and wane) every week to the CDC (and which makes up the center tables in the Morbidity and Mortality Weekly Report [MMWR]). The CDC WONDER system (Friede et al., 1996), which contains tens of millions of observations drawn from some 30 databases, explicitly blanks cells with fewer than three to five observations (depending on the dataset), specifically to prevent individuals with unusual characteristics from being identified.

If there is no national individual reporting, how are estimates obtained for, say, the trends in teenage smoking or in the incidence of breast cancer? How are epidemics found? Data from periodic surveys and special studies, surveillance systems, and disease registries are handled by numerous stand-alone information systems. These systems – usually managed by state health departments and federal health agencies (largely the CDC) or their agents – provide periodic estimates of the incidence and prevalence of diseases and of certain risk factors (for example, smoking and obesity); however,

because the data are from population samples, it is usually impossible to obtain estimates at a level of geographic detail finer than a region or state. Moreover, many of the behavioral indices are patient self-reported (although extensive validation studies have shown that they are good for trends and sometimes are more reliable than are data obtained from clinical systems). In the case of special surveys, such as CDC's National Health and Nutrition Examination Survey (NHANES), there is primary data entry into a CDC system. The data are complete, but the survey costs many millions of dollars, is done only every few years, and it takes years for the data to be made available.

There are also disease registries that track – often completely – the incidence of certain conditions, especially cancers, birth defects, and conditions associated with environmental contamination. They tend to focus on one topic or to cover certain diseases for specific time periods. The CDC maintains dozens of surveillance systems that attempt to track completely the incidence of many conditions, including lead poisoning, injuries and deaths in the workplace, and birth defects. (Some of these systems use samples or cover only certain states or cities). As discussed above, there is also a list of about 60 notifiable diseases (revised every year) that the state epidemiologists and the CDC have determined are of national significance and warrant routine, complete reporting; however, it is up to providers to report the data, and reporting is still often done by telephone or mail, so the data are incomplete. Finally, some states do collect hospital discharge summaries, but now that more care is being delivered in the ambulatory setting, these data capture only a small fraction of medical care. They are also notoriously difficult to access.

What all these systems have in common is that they rely on special data collection. It is rare that they are seamlessly linked to ongoing clinical information systems. Even clinical data such as hospital infections is reentered. Why? All these systems grew up at the same time that information systems were being put in hospitals and clinics. Hence, there is duplicate data entry, which can result in the data being shallow, delayed, and subject to input error and recall bias. Furthermore, the systems themselves are often unpopular with state agencies and health care providers precisely because they require duplicate data entry (a child with lead poisoning and salmonella needs to be entered in two different CDC systems). The National Electronic Disease Surveillance System (NEDSS) is a major CDC initiative that addresses this issue by promoting the use of data and information system standards to advance the development of efficient, integrated, and interoperable surveillance systems at federal, state and local levels (see www.cdc.gov/nedss). This activity is designed to facilitate the electronic transfer of appropriate information from clinical information systems in the health care industry to public health departments, reduce provider burden in the provision of information, and enhance both the timeliness and quality of information provided.

Now that historical and epidemiological forces are making the world smaller and causing lines between medicine and public health to blur, systems will need to be multi-functional, and clinical and public health systems will, of necessity, coalesce. What is needed are systems that can tell us about individuals *and* the world in which those individuals live. To fill that need, public health and clinical informaticians will need to work closely together to build the tools to study and control new and emerging threats such as bioterror, HIV/AIDS, SARS and its congeners, and the environmental effects of the

shrinking ozone layer and greenhouse gases. It can be done. For example, in the late 1990's, Columbia Presbyterian Medical Center and the New York City Department of Health collaborated on the development of a tuberculosis registry for northern Manhattan, and the Emory University System of Health Care and the Georgia Department of Public Health built a similar system for tuberculosis monitoring and treatment in Atlanta. It is not by chance that these two cities each developed tuberculosis systems; rather, tuberculosis is a perfect example of what was once a public health problem (that affected primarily the poor and underserved) coming into the mainstream population as a result of an emerging infectious disease (AIDS), immigration, increased international travel, multidrug resistance, and our growing prison population. Hence, the changing ecology of disease, coupled with revolutionary changes in how health care is managed and paid for, will necessitate information systems that serve both individual medical and public health needs.

15.3 Immunization Registries: A Public Health Informatics Example

Immunization registries are confidential, population based, computerized information systems that contain data about children and vaccinations (National Vaccine Advisory Committee, 1999). They represent a good example for illustrating the principles of public health informatics. In addition to their orientation to prevention, they can only function properly through continuing interaction with the health care system. They also must exist in a governmental context because there is little incentive (and significant organizational barriers) for the private sector to maintain such registries. Although immunization registries are among the largest and most complex public health information systems, the successful implementations show conclusively that it is possible to overcome the challenging informatics problems they present.

15.3.1 History and Background of Immunization Registries

Childhood immunizations have been among the most successful public health interventions, resulting in the near elimination of nine vaccine preventable diseases that historically extracted a major toll in terms of both morbidity and mortality (IOM, 2000a). The need for immunization registries stems from the challenge of assuring complete immunization protection for the approximately 11,000 children born each day in the United States in the context of three complicating factors: the scattering of immunization records among multiple providers; an immunization schedule that has become increasingly complex as the number of vaccines has grown; and the conundrum that the very success of mass immunization has reduced the incidence of disease, lulling parents and providers into a sense of complacency.

The 1989-91 U.S. measles outbreak, which resulted in 55,000 cases and 123 preventable deaths (Atkinson et al., 1992), helped stimulate the public health community to expand the limited earlier efforts to develop immunization registries. Because CDC was proscribed by Congress from creating a single national immunization registry (due to

privacy concerns), the Robert Wood Johnson Foundation, in cooperation with several other private foundations, established the All Kids Count (AKC) program that awarded funds to 24 states and communities in 1992 to assist in the development of immunization registries. AKC funded the best projects through a competitive process, recruited a talented staff to provide technical assistance, and made deliberate efforts to ensure sharing of the lessons learned, such as regular, highly interactive meetings of the grantees. Subsequent funding of 13 states by CDC and the Woodruff Foundation via the Information Network for Public Health Officials (INPHO) project (Baker et al., 1995) was greatly augmented by a presidential commitment to immunization registries announced in 1997 (White House, 1997). This resulted in every state's involvement in registry development.

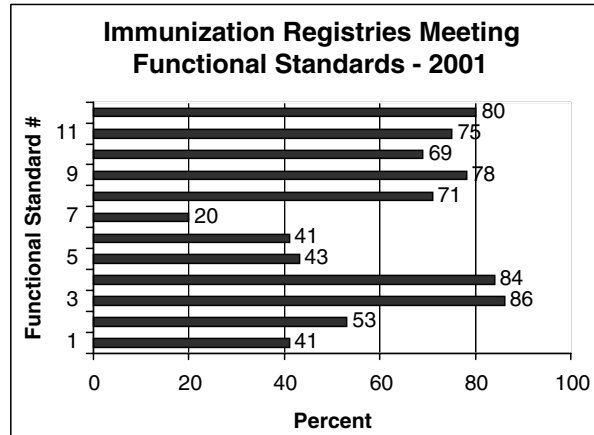
Immunization registries must be able to exchange information to ensure that children who relocate receive needed immunizations. To accomplish this, standards were needed to prevent the development of multiple, incompatible immunization transmission formats. Beginning in 1995, CDC worked closely with the Health Level 7 standards development organization (see Chapter 7) to define HL7 messages and an implementation guide for immunization record transactions. The initial data standard was approved by HL7 in 1997 and an updated implementation guide was developed in 1999. CDC continues its efforts to encourage the standards-based exchange of immunization records among registries.

As more experience accumulated, AKC and CDC collaborated to develop an immunization registry development guide (CDC, 1997) that captured the hard-won lessons developed by dozens of projects over many years. By 2000, a consensus on the 12 needed functions of immunization registries had emerged (Table 15.2), codifying years of experience in refining system requirements. CDC also established a measurement system for tracking progress that periodically assesses the percentage of immunization registries that have operationalized each of the 12 functions (Figure 15.1). Further formalizing the public policy commitment to the development of immunization

Table 15.2. Twelve functional standards for immunization registries (CDC, 2002).

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1. Electronically store data regarding all National Vaccine Advisory Committee-approved core data elements
 2. Establish a registry record within 6 weeks of birth for each child born in the catchment area
 3. Enable access to vaccine information from the registry at the time of the encounter
 4. Receive and process vaccine information within 1 month of vaccine administration
 5. Protect the confidentiality of medical information
 6. Protect the security of medical information
 7. Exchange vaccination records by using Health Level 7 standards
 8. Automatically determine the immunization(s) needed when a person is seen by the health care provider for a scheduled vaccination
 9. Automatically identify persons due or late for vaccinations to enable the production of reminder and recall notices
 10. Automatically produce vaccine coverage reports by providers, age groups, and geographic areas
 11. Produce authorized immunization records
 12. Promote accuracy and completeness of registry data
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Figure 15.1. Measurement system for tracking progress of immunization registries.



registries, the national Healthy People 2010 objectives include the goal of having 95% of all U.S. children covered by fully functioning immunization registries (DHHS, 2000).

15.3.2 Key Informatics Issues in Immunization Registries

The development and implementation of immunization registries presents challenging informatics issues in at least four areas: 1) interdisciplinary communication; 2) organizational and collaborative issues; 3) funding and sustainability; and 4) system design. While the specific manifestations of these issues are unique to immunization registries, these four areas represent the typical domains that must be addressed and overcome in public health informatics projects.

15.3.2.1 Interdisciplinary Communications

Interdisciplinary communications is a key challenge in any biomedical informatics project—it is certainly not specific to public health informatics. To be useful, a public health information system must accurately represent and enable the complex concepts and processes that underlie the specific business functions required. Information systems represent a highly abstract and complex set of data, processes, and interactions. This complexity needs to be discussed, specified, and understood in detail by a variety of personnel with little or no expertise in the terminology and concepts of information technology. Therefore, successful immunization registry implementation requires clear communication among public health specialists, immunization specialists, providers, IT specialists, and related disciplines, an effort complicated by the lack of a shared vocabulary and differences in the usage of common terms from the various domains.

Added to these potential communication problems are the anxieties and concerns inherent in the development of any new information system. Change is an inevitable part of such a project—and change is uncomfortable for everyone involved. Furthermore, information is power—and power shifts are unavoidable with the

implementation of information systems. In this context, tensions and anxieties can further degrade communications.

To deal with the communications challenges, particularly between IT and public health specialists, it is essential to identify an interlocutor who has familiarity with both information technology and public health. The interlocutor should spend sufficient time in the user environment to develop a deep understanding of the information processing context of both the current and proposed systems. It is also important for individuals from all the disciplines related to the project to have representation in the decision-making processes.

15.3.2.2 Organizational and Collaborative Issues

The organizational and collaborative issues involved in developing immunization registries are daunting because of the large number and wide variety of partners. Both public and private sector providers and other organizations are likely participants. For the providers, particularly in the private sector, immunization is just one of many concerns. However, it is essential to mobilize private providers to submit immunization information to the registry. In addition to communicating regularly to this group about the goals, plans, and progress of the registry, an invaluable tool to enlist their participation is a technical solution that minimizes their time and expense for registry data entry, while maximizing the benefit in terms of improved information about their patients. It is critical to recognize the constraints of the private provider environment, where income is generated mostly from “piecework” and time is the most precious resource.

Governance issues are also critical to success. All the key stakeholders need to be represented in the decision-making processes, guided by a mutually acceptable governance mechanism. Large information system projects involving multiple partners — such as immunization registries — often require multiple committees to ensure that all parties have a voice in the development process. In particular, all decisions that materially affect a stakeholder should be made in a setting that includes their representation.

Legislative and regulatory issues must be considered in an informatics context because they impact the likelihood of success of projects. With respect to immunization registries, the specific issues of confidentiality, data submission, and liability are critical. The specific policies with respect to confidentiality must be defined to allow access to those who need it while denying access to others. Regulatory or legislative efforts in this domain must also operate within the context of the federal Health Insurance Portability and Accountability Act (HIPAA) that sets national minimum privacy requirements for personal health information. Some jurisdictions have enacted regulations requiring providers to submit immunization data to the registry. The effectiveness of such actions on the cooperation of providers must be carefully evaluated. Liability of the participating providers and of the registry operation itself may also require legislative and/or regulatory clarification.

15.3.2.3 Funding and Sustainability

Funding and sustainability are continuing challenges for all immunization registries. In particular, without assurances of ongoing operational funding, it will be difficult to

secure the commitments needed for the development work. Naturally, an important tool for securing funding is development of a business case that shows the anticipated costs and benefits of the registry. While a substantial amount of information now exists about costs and benefits of immunization registries (Horne et al., 2000), many of the registries that are currently operational had to develop their business cases prior to the availability of good quantitative data. Specific benefits associated with registries include preventing duplicative immunizations, eliminating the necessity to review the vaccination records for school and day care entry, and efficiencies in provider offices from the immediate availability of complete immunization history information and patient-specific vaccine schedule recommendations. The careful assessment of costs and benefits of specific immunization registry functions may also be helpful in prioritizing system requirements. As with all information systems, it is important to distinguish “needs” (those things people will pay for) from “wants” (those things people would like to have but are not willing to spend money on) (Rubin, 2003). Information system “needs” are typically supported by a strong business case, whereas “wants” often are not.

15.3.2.4 System Design

System design is also an important factor in the success of immunization registries. Difficult design issues include data acquisition, database organization, identification and matching of children, generating immunization recommendations, and access to data, particularly for providers. Acquiring immunization data is perhaps the most challenging system design issue. Within the context of busy pediatric practices (where the majority of childhood immunizations are given), the data acquisition strategy must of necessity be extremely efficient. Ideally, information about immunizations would be extracted from existing electronic medical records or from streams of electronic billing data; either strategy should result in no additional work for participating providers. Unfortunately neither of these options is typically available. Electronic medical records are currently implemented only in roughly 10-15% of physician practices. While the use of billing records is appealing, it is often difficult to get such records on a timely basis without impinging on their primary function—namely, to generate revenue for the practice. Also, data quality, particularly with respect to duplicate records, is often a problem with billing information. A variety of approaches have been used to address this issue, including various forms of direct data entry as well as the use of bar codes (Yasnoff, 2003).

Database design also must be carefully considered. Once the desired functions of an immunization registry are known, the database design must allow efficient implementation of these capabilities. The operational needs for data access and data entry, as well as producing individual assessments of immunization status, often require different approaches to design compared to requirements for population-based immunization assessment, management of vaccine inventory, and generating recall and reminder notices. One particularly important database design decision for immunization registries is whether to represent immunization information by vaccine or by antigen. Vaccine-based representations map each available preparation, including those with multiple antigens, into its own specific data element. Antigen-based representations translate multi-component vaccines into their individual antigens prior to storage. In some cases,

it may be desirable to represent the immunization information both ways. Specific consideration of required response times for specific queries must also be factored into key design decisions.

Identification and matching of individuals within immunization registries is another critical issue. Because it is relatively common for a child to receive immunizations from multiple providers, any system must be able to match information from multiple sources to complete an immunization record. In the absence of a national unique patient identifier, most immunization registries will assign an arbitrary number to each child. Of course, provisions must be made for the situation where this identification number is lost or unavailable. This requires a matching algorithm, which utilizes multiple items of demographic information to assess the probability that two records are really data from the same person. Development of such algorithms and optimization of their parameters has been the subject of active investigation in the context of immunization registries, particularly with respect to deduplication (Miller et al., 2001).

Another critical design issue is generating vaccine recommendations from a child's prior immunization history, based on guidance from the CDC's Advisory Committee on Immunization Practices (ACIP). As more childhood vaccines have become available, both individually and in various combinations, the immunization schedule has become increasingly complex, especially if any delays occur in receiving doses, a child has a contraindication, or local issues require special consideration. The language used in the written guidelines is sometimes incomplete, not covering every potential situation. In addition, there is often some ambiguity with respect to definitions, e.g., for ages and intervals, making implementation of decision support systems problematic. Considering that the recommendations are updated relatively frequently, sometimes several times each year, maintaining software that produces accurate immunization recommendations is a continuing challenge. Accordingly, the implementation, testing, and maintenance of decision support systems to produce vaccine recommendations has been the subject of extensive study (Yasnoff & Miller, 2003).

Finally, easy access to the information in an immunization registry is essential. While this may initially seem to be a relatively simple problem, it is complicated by private providers' lack of high-speed connectivity. Even if a provider office has the capability for Internet access, for example, it may not be immediately available at all times, particularly in the examination room. Immunization registries have developed alternative data access methods such as fax-back and telephone query to address this problem. Since the primary benefit of the registry to providers is manifest in rapid access to the data, this issue must be addressed. Ready access to immunization registry information is a powerful incentive to providers for entering the data from their practice.

15.4 Health Information Infrastructure

In the United States, the first major report calling for a Health Information Infrastructure was issued by the Institute of Medicine of the National Academy of Sciences in 1991 (IOM, 1991). This report, "The Computer-Based Patient Record," was the first in a series of national expert panel reports recommending transformation of

the health care system from reliance on paper to electronic information management. In response to the IOM report, the Computer-based Patient Record Institute (CPRI), a private not-for-profit corporation, was formed for the purpose of facilitating the transition to computer-based records. A number of community health information networks (CHINs) were established around the country in an effort to coalesce the multiple community stakeholders in common efforts towards electronic information exchange. The Institute of Medicine updated its original report in 1997 (IOM, 1997), again emphasizing the urgency to apply information technology to the information intensive field of health care.

However, most of the community health information networks were not successful. Perhaps the primary reason for this was that the standards and technology were not yet ready for cost-effective community-based electronic health information exchange. Another problem was the focus on availability of aggregated health information for secondary users (e.g., policy development), rather than individual information for the direct provision of patient care. Also, there was neither a sense of extreme urgency nor were there substantial funds available to pursue these endeavors. However, at least one community, Indianapolis, continued to move forward throughout this period and has now emerged as an a national example of the application of information technology to health care both in individual health care settings and throughout the community.

The year 2000 brought widespread attention to this issue with the IOM report "To Err is Human" (IOM, 2000b). In this landmark study, the IOM documented the accumulating evidence of the high error rate in the medical care system, including an estimated 44,000 to 98,000 preventable deaths each year in hospitals alone. This report has proven to be a milestone in terms of public awareness of the consequences of paper-based information management in health care. Along with the follow-up report, "Crossing the Quality Chasm" (IOM, 2001), the systematic inability of the health care system to operate at high degree of reliability has been thoroughly elucidated. The report clearly placed the blame on the system, not the dedicated health care professionals who work in an environment without effective tools to promote quality and minimize errors.

Several additional national expert panel reports have emphasized the IOM findings. In 2001, the President's Information Technology Advisory Committee (PITAC) issued a report entitled "Transforming Health Care Through Information Technology" (PITAC, 2001). That same year, the Computer Science and Telecommunications Board of the National Research Council (NRC) released "Networking Health: Prescriptions for the Internet" (NRC, 2001) which emphasized the potential for using the Internet to improve electronic exchange of health care information. Finally, the National Committee on Vital and Health Statistics (NCVHS) outlined the vision and strategy for building a National Health Information Infrastructure (NHII) in its report, "Information for Health" (NCVHS, 2001). NCVHS, a statutory advisory body to DHHS, indicated that federal government leadership was needed to facilitate further development of an NHII.

On top of this of bevy of national expert panel reports, there has been continuing attention in both scientific and lay publications to cost, quality, and error issues in the health care system. The anthrax attacks of late 2001 further sensitized the nation to the

need for greatly improved disease detection and emergency medical response capabilities. What has followed has been the largest-ever investment in public health information infrastructure in the history of the United States. Some local areas, such as Indianapolis and Pittsburgh, have begun to actively utilize electronic information from the health care system for early detection of bioterrorism and other disease outbreaks. In 2003, separate large national conferences were devoted to both the CDC's Public Health Information Network (PHIN) (CDC, 2003) and the DHHS NHII initiative (DHHS, 2003 Yasnoff et al., 2004).

While the discussion here has focused on the development of NHII in the United States, many other countries are involved in similar activities and in fact have progressed further along this road. Canada, Australia, and a number of European nations have devoted considerable time and resources to their own national health information infrastructures. The United Kingdom, for example, has announced its intention to allocate several billion pounds over the next few years to substantially upgrade its health information system capabilities. It should be noted, however, that all of these nations have centralized, government-controlled health care systems. This organizational difference from the multifaceted, mainly private health care system in the U.S. results in a somewhat different set of issues and problems. Hopefully, the lessons learned from health information infrastructure development activities across the globe can be effectively shared to ease the difficulties of everyone who is working toward these important goals.

15.4.1 Vision and Benefits of NHII

The vision of the National Health Information Infrastructure is anytime, anywhere health care information at the point of care. The intent is to create a distributed system, not a centralized national database. Patient information would be collected and stored at each care site. When a patient presented for care, the various existing electronic records would be located, collected, integrated, and immediately delivered to allow the provider to have complete and current information upon which to base clinical decisions. In addition, clinical decision support (see Chapter 20) would be integrated with information delivery. In this way, clinicians could receive reminders of the most recent clinical guidelines and research results during the patient care process, thereby avoiding the need for superhuman memory capabilities to assure the effective practice of medicine.

The potential benefits of NHII are both numerous and substantial. Perhaps most important are error reduction and improved quality of care. Numerous studies have shown that the complexity of present-day medical care results in very frequent errors of both omission and commission. This problem was clearly articulated at the 2001 meeting of the Institute of Medicine: "Current practice depends upon the clinical decision making capacity and reliability of autonomous individual practitioners, for classes of problems that routinely exceed the bounds of unaided human cognition" (Masys, 2001). Electronic health information systems can contribute significantly to improving this problem by reminding practitioners about recommended actions at the point of care. This can include both notifications of actions that may have been missed, as well as warnings about planned treatments or procedures that may be harmful or unnecessary. Literally dozens of research studies have shown that such reminders improve safety and

reduce costs (Kass, 2001; Bates, 2000). In one such study (Bates et al., 1998), medication errors were reduced by 55%.

A more recent study by the Rand Corporation showed that only 55 % of U.S. adults were receiving recommended care (McGlynn et al., 2003). The same techniques used to reduce medical errors with electronic health information systems also contribute substantially to ensuring that recommended care is provided. This is becoming increasingly important as the population ages and the prevalence of chronic disease increases.

Guidelines and reminders also can improve the effectiveness of dissemination of new research results. At present, widespread application of a new research in the clinical setting takes an average of 17 years (Balas & Boren, 2000). Patient-specific reminders delivered at the point of care highlighting important new research results could substantially increase the adoption rate.

Another important contribution of NHII to the research domain is improving the efficiency of clinical trials. At present, most clinical trials require creation of a unique information infrastructure to insure protocol compliance and collect essential research data. With NHII, where every practitioner would have access to a fully functional electronic health record, clinical trials could routinely be implemented through the dissemination of guidelines that specify the research protocol. Data collection would occur automatically in the course of administering the protocol, reducing time and costs. In addition, there would be substantial value in analyzing deidentified aggregate data from routine patient care to assess the outcomes of various treatments, and monitor the health of the population.

Another critical function for NHII is early detection of patterns of disease, particularly early detection of possible bioterrorism. Our current system of disease surveillance, which depends on alert clinicians diagnosing and reporting unusual conditions, is both slow and potentially unreliable. Most disease reporting still occurs using the Postal Service, and the information is relayed from local to state to national public health authorities. Even when fax or phone is employed, the system still depends on the ability of clinicians to accurately recognize rare and unusual diseases. Even assuming such capabilities, individual clinicians cannot discern patterns of disease beyond their sphere of practice. These problems are illustrated by the seven unreported cases of cutaneous anthrax in the New York City area two weeks before the so-called "index" case in Florida in the Fall of 2001 (Lipton & Johnson, 2001). Since all the patients were seen by different clinicians, the pattern could not have been evident to any of them even if the diagnosis had immediately been made in every case. Wagner et al have elucidated nine categories of requirements for surveillance systems for potential bioterrorism outbreaks—several categories must have immediate electronic reporting to insure early detection (Wagner et al., 2003).

NHII would allow immediate electronic reporting of both relevant clinical events and laboratory results to public health. Not only would this be an invaluable aid in early detection of bioterrorism, it would also serve to improve the detection of the much more frequent naturally occurring disease outbreaks. In fact, early results from a number of electronic reporting demonstration projects show that disease outbreaks can routinely be detected sooner than was ever possible using the current system (Overhage et al., 2001). While early detection has been shown to be a key factor in reducing

morbidity and mortality from bioterrorism (Kaufmann et al., 1997), it will also be extremely helpful in reducing the negative consequences from other disease outbreaks. This aspect of NHII is discussed in more detail in section 15.5.

Finally, NHII can substantially reduce health-care costs. The inefficiencies and duplication in our present paper-based health care system are enormous. Recent study showed that the anticipated nationwide savings from implementing advanced computerized provider order entry (CPOE) systems in the outpatient environment would be \$44 billion per year (Johnston et al., 2003), while a related study (Walker et al., 2004) estimated \$78 billion more in savings from health information exchange (for a total of \$112 billion per year). Substantial additional savings are possible in the inpatient setting—numerous hospitals have reported large net savings from implementation of electronic health records. Another example, electronic prescribing, would not only reduce medication errors from transcription, but also drastically decrease the administrative costs of transferring prescription information from provider offices to pharmacies. A more recent analysis concluded that the total efficiency and patient safety savings from NHII would be in range of \$142-371 billion each year (Hillestad et al., 2005). While detailed studies of the potential savings from comprehensive implementation of NHII, including both electronic health records and effective exchange of health information, are still ongoing, it is clear that the cost reductions will amount to hundreds of billions of dollars each year. It is important to note that much of the savings depends not just on the widespread implementation of electronic health records, but the effective interchange of this information to insure that the complete medical record for every patient is immediately available in every care setting.

15.4.2 Barriers and Challenges to NHII

There are a number of significant barriers and challenges to the development of NHII. Perhaps the most important of these relates to protecting the confidentiality of electronic medical records. The public correctly perceives that all efforts to make medical records more accessible for appropriate and authorized purposes simultaneously carry the risk of increased availability for unscrupulous use. While the implementation of the HIPAA privacy and security rules (see Chapter 10) has established nationwide policies for access to medical information, maintaining public confidence requires mechanisms that affirmatively prevent privacy and confidentiality breaches before they occur. Development, testing, and implementation of such procedures must be an integral part of any NHII strategy.

Another important barrier to NHII is the misalignment of financial incentives in the health care system. Although the benefits of NHII are substantial, they do not accrue equally across all segments of the system. In particular, the benefits are typically not proportional to the required investments for a number of specific stakeholder groups. Perhaps most problematic is the situation for individual and small group health care providers, who are being asked to make substantial allocations of resources to electronic health record

systems that mostly benefit others. Mechanisms must be found to assure the equitable distribution of NHII benefits in proportion to investments made. While this issue is the subject of continuing study, early results indicate that most of the NHII financial benefit accrues to payers of care. Therefore, programs and policies must be established to transfer appropriate savings back to those parties who have expended funds to produce them.

One consequence of the misaligned financial incentives is that the return on investment for health information technology needed for NHII is relatively uncertain. While a number of health care institutions, particularly large hospitals, have reported substantial cost improvements from electronic medical record systems, the direct financial benefits are by no means a forgone conclusion, especially for smaller organizations. The existing reimbursement system in the United States does not provide ready access to the substantial capital required by many institutions. For health care organizations operating on extremely thin margins, or even in the red, investments in information technology are impractical regardless of the potential return.

In addition, certain legal and regulatory barriers prevent the transfer of funds from those who benefit from health information technology to those who need to invest but have neither the means nor the incentive of substantial returns. Laws and regulations designed to prevent fraud and abuse, payments for referrals, and private distribution of disguised “profits” from nonprofit organizations are among those needing review. It is important that mechanisms be found to enable appropriate redistribution of savings generated from health information technology without creating loopholes that would allow abusive practices.

Another key barrier to NHII is that many of the benefits relate to exchanges of information between multiple health care organizations. The lack of interoperable electronic medical record systems that provide for easy transfer of records from one place to another is a substantial obstacle to achieving the advantages of NHII. Also, there is a “first mover disadvantage” in such exchange systems. The largest value is generated when all health care organizations in a community participate electronic information exchange. Therefore, if only a few organizations begin the effort, their costs may not be offset by the benefits.

15.4.3 Approaches to Accelerating HII Progress

A number of steps are currently under way to accelerate the progress towards NHII in the United States. These include establishing standards, fostering collaboration, funding demonstration projects in communities that include careful evaluation, and establishing consensus measures of progress.

15.4.3.1 Establishing Standards

Establishing electronic health record standards that would promote interoperability is the most widely recognized need in health information technology at the present time. Within institutions that have implemented specific departmental applications, extensive time and energy is spent developing and maintaining interfaces among the various

systems. Although much progress has been made in this area by organizations such as Health Level 7, even electronic transactions of specific health care data (such as laboratory results) are often problematic due to differing interpretations of the implementation of existing standards.

Recently, the U.S. government has made substantial progress in this area. NCVHS, the official advisory body on these matters to DHHS, has been studying the issues of both message and content standards for patient medical record information for several years (NCVHS, 2000). The Consolidated Healthcare Informatics (CHI) initiative recommended five key standards (HL7 version 2.x, LOINC, DICOM, IEEE 1073, and NCPDP SCRIPT) that were adopted for government-wide use in early 2003, followed by 15 more that were added in 2004.

In July, 2003, the Federal government licensed the comprehensive medical vocabulary known as SNOMED (Systematized Nomenclature of MEDicine; [see Chapter 7](#)), making it available to all U.S. users at no charge. This represents a major step forward in the deployment of vocabulary standards for health information systems. Unlike message format standards, such as HL7, vocabulary standards are complex and expensive to develop and maintain and therefore require ongoing financial support. Deriving the needed funding from end users creates a financial obstacle to deployment of the standard. Removing this key barrier to adoption should promote much more widespread use over the next few years.

Another important project now under way is the joint effort of the Institute of Medicine and HL7 to develop a detailed functional definition of the electronic health record (EHR). These functional standards will provide a benchmark for comparison of existing and future EHR systems, and also may be utilized as criteria for possible financial incentives that could be provided to individuals and organizations that implement such systems. The elucidation of a consensus functional definition of the EHR also should help prepare the way for its widespread implementation by engaging all the stakeholders in an extended discussion of its desired capabilities.

This functional standardization of the EHR is expected to be followed by the development of a formal Interchange Format Standard (IFS) to be added to HL7 version 3. This standard would enable full interoperability of EHR systems through the implementation of an import and export capability to and from the IFS. While it is possible at the present time to exchange complete electronic health records with existing standards, is both difficult and inconvenient. The IFS will greatly simplify the process, making it easy to accomplish the commonly needed operation of transferring an entire electronic medical record from one facility to another.

Another key standard that is needed involves the representation of guideline recommendations. While the standard known as Arden Syntax (HL7, 2003; [see Chapter 7](#)) partially addresses this need, many real-world medical care guidelines are too complex to be represented easily in this format. At the present time, the considerable effort required to translate written guidelines and protocols into computer executable form must be repeated at every health care organization wishing to incorporate them in their EHR. Development of an effective guideline interchange standard would allow medical knowledge to be encoded once and then distributed widely, greatly increasing the efficiency of the process (Peleg et al., 2003).

15.4.3.2 Promoting Collaboration

Collaboration is another important strategy in promoting NHII. To enable the massive changes needed to transform the health care system from its current paper-based operation to the widespread utilization of electronic health information systems, the support of a very large number of organizations and individuals with highly varied agendas is required. Gathering and focusing this support requires extensive cooperative efforts and specific mechanisms for insuring that everyone's issues and concerns are expressed, appreciated, and incorporated into the ongoing efforts. This process is greatly aided by a widespread recognition of the serious problems that exist today in the U.S. healthcare system. A number of private collaboration efforts have been established such as the e-Health Initiative and the National Alliance for Health Information Technology (NAHIT). In the public sector, National Health Information Infrastructure (NHII) has become a focus of activity at DHHS. As part of this effort, the first ever national stakeholders meeting for NHII was convened in mid-2003 to develop a consensus national agenda for moving forward (Yasnoff et al., 2004).

These multiple efforts are having the collective effect of both catalyzing and promoting organizational commitment to NHII. For example, many of the key stakeholders are now forming high-level committees to specifically address NHII issues. For some of these organizations, this represents the first formal recognition that this transformational process is underway and will have a major impact on their activities. It is essential to include all stakeholders in this process. In addition to the traditional groups such as providers, payers, hospitals, health plans, health IT vendors, and health informatics professionals, representatives of groups such as consumers (e.g., AARP) and the pharmaceutical industry must be brought into the process.

15.4.3.3 Demonstration Projects

The most concrete and visible strategy for promoting NHII is the encouragement of demonstration projects in communities, including the provision of seed funding. By establishing clear examples of the benefits and advantages of comprehensive health information systems in communities, additional support for widespread implementation can be garnered at the same time that concerns of wary citizens and skeptical policy-makers are addressed.

There are several important reasons for selecting a community-based strategy for NHII implementation. First and foremost, the existing models of health information infrastructures (e.g., Indianapolis and Spokane, WA) are based in local communities. This provides proof that it is possible to develop comprehensive electronic health care information exchange systems in these environments. In contrast, there is little or no evidence that such systems can be directly developed on a larger scale. Furthermore, increasing the size of informatics projects disproportionately increases their complexity and risk of failure. Therefore, keeping projects as small as possible is always a good strategy. Since NHII can be created by effectively connecting communities that have developed local health information infrastructures (LHIIs), it is not necessary to invoke a direct national approach to achieve the desired end result. A good analogy is the

telephone network, which is composed of a large number of local exchanges that are then connected to each other to form community and then national and international networks.

Another important element in the community approach is the need for trust to overcome confidentiality concerns. Medical information is extremely sensitive and its exchange requires a high degree of confidence in everyone involved in the process. The level of trust needed seems most likely to be a product of personal relationships developed over time in a local community and motivated by a common desire to improve health care for everyone located in that area. While the technical implementation of information exchange is non-trivial, it pales in comparison to the challenges of establishing the underlying legal agreements and policy changes that must precede it. For example, when Indianapolis implemented sharing of patient information in hospital emergency rooms throughout the area, as many as 20 institutional lawyers needed to agree on the same contractual language (Overhage, 2002).

The community approach also benefits from the fact that the vast majority of health care is delivered locally. While people do travel extensively, occasionally requiring medical care while away from home, and there are few out-of-town consultations for difficult and unusual medical problems, for the most part people receive their health care in the community in which they reside. The local nature of medical care results in a natural interest of community members in maintaining and improving the quality and efficiency of their local health care system. For the same reasons, it is difficult to motivate interest in improving health care beyond the community level.

Focusing NHII efforts on one community at a time also keeps the implementation problem more reasonable in its scope. It is much more feasible to enable health information interchange among a few dozen hospitals and a few hundred or even a few thousand providers than to consider such a task for a large region or the whole country. This also allows for customized approaches sensitive to the specific needs of each local community. The problems and issues of medical care in a densely populated urban area are clearly vastly different than in a rural environment. Similarly, other demographic and organizational differences as well as the presence of specific highly specialized medical care institutions make each community's health care system unique. A local approach to HII development allows all these complex and varied factors to be considered and addressed, and respects the reality of the American political landscape, which gives high priority to local controls.

The community-based approach to HII development also benefits from the establishment of national standards. The same standards that allow effective interchange of information between communities nationwide can also greatly facilitate establishing effective communication of medical information within a community. In fact, by encouraging (and even requiring) communities to utilize national standards in building their own LHII, the later interconnection of those systems to provide nationwide access to medical care information becomes a much simpler and easier process.

Demonstration projects also are needed to develop and verify a replicable strategy for LHII development. While there are a small number of existing examples of LHII systems, no organization or group has yet demonstrated the ability to reliably and successfully establish such systems in multiple communities. From the efforts of demonstration

projects in numerous communities, it should be possible to define a set of strategies that can be applied repeatedly across the nation.

Seed funding is essential in the development of LHII systems. While health care in United States is a huge industry, spending approximately \$1.5 trillion each year and representing 14% of the GDP, shifting any of the existing funds into substantial IT investments is problematic. The beneficiaries of all the existing expenditures seem very likely to strongly oppose any such efforts. On the other hand, once initial investments begin to generate the expected substantial savings, it should be possible to develop mechanisms to channel those savings into expanding and enhancing LHII systems. Careful monitoring of the costs and benefits of local health information interchange systems will be needed to verify the practicality of this approach to funding and sustaining these projects.

Finally, it is important to assess and understand the technical challenges and solutions applied to LHII demonstration projects. While technical obstacles are usually not serious in terms of impeding progress, understanding and disseminating the most effective solutions can result in smoother implementation as experience is gained throughout the nation.

15.4.3.4 Measures to Evaluate Progress

The last element in the strategy for promoting a complex and lengthy project such as NHII is careful measurement of progress. The measures used to gauge progress define the end state and therefore must be chosen with care. Measures may also be viewed as the initial surrogate for detailed requirements. Progress measures should have certain key features. First, they should be sufficiently sensitive so that their values change at a reasonable rate (a measure that only changes value after five years will not be particularly helpful). Second, the measures must be comprehensive enough to reflect activities that impact most of the stakeholders and activities needing change. This ensures that efforts in every area will be reflected in improved measures. Third, the measures must be meaningful to policymakers. Fourth, periodic determinations of the current values of the measures should be easy so that the measurement process does not detract from the actual work. Finally, the totality of the measures must reflect the desired end state so that when the goals for all the measures are attained, the project is complete.

A number of different types or dimensions of measures for NHII progress are possible. Aggregate measures assess NHII progress over the entire nation. Examples include the percentage of the population covered by an LHII and the percentage of health care personnel whose training occurs in institutions that utilize electronic health record systems.

Another type of measure is based on the setting of care. Progress in implementation of electronic health record systems in the inpatient, outpatient, long-term care, home, and community environments could clearly be part of an NHII measurement program. Yet another dimension is health care functions performed using information systems support, including, for example, registration systems, decision support, CPOE, and community health information exchange.

It is also important to assess progress with respect to the semantic encoding of electronic health records. Clearly, there is a progression from the electronic exchange of images of documents, where the content is only readable by the end user viewing the image, to fully encoded electronic health records where all the information is indexed and accessible in machine-readable form using standards. Finally, progress can also be benchmarked based on usage of electronic health record systems by health care professionals. The transition from paper records to available electronic records to fully used electronic records is an important signal with respect to the success of NHII activities.

15.5 Example: NHII and Homeland Security

To illustrate some of the informatics challenges inherent in NHII, the example of its application to homeland security will be used. Bioterrorism preparedness in particular is now a key national priority, especially following the anthrax attacks that occurred in the Fall of 2001. Early detection of bioterrorism is critical to minimize morbidity and mortality. This is because, unlike other terrorist attacks, bioterrorism is usually silent at first. Its consequences are usually the first evidence that an attack has occurred. Traditional public health surveillance depends on alert clinicians reporting unusual diseases and conditions. However, it is difficult for clinicians to detect rare and unusual diseases since they are neither familiar with their manifestations nor suspicious of the possibility of an attack. Also, it is often difficult to differentiate potential bioterrorism from more common and benign manifestations of illness.

This is clearly illustrated by the seven cases of cutaneous anthrax that occurred in the New York City area two weeks prior to the “index “ case in Florida the Fall of 2001 (Lipton & Johnson, 2001). All these cases presented to different clinicians, none of whom recognized the diagnosis of anthrax with sufficient confidence to notify any public health authority. Furthermore, such a pattern involving similar cases presenting to multiple clinicians could not possibly be detected by any of them. It seems likely that had all seven of these patients utilized the same provider, the immediately evident pattern of unusual signs and symptoms alone would have been sufficient to result in an immediate notification of public health authorities even in the absence of any diagnosis.

Traditional public health surveillance also has significant delays. Much routine reporting is still done via postcard and fax to the local health department, and further delays occur before information is collated, analyzed, and reported to state and finally to federal authorities.

There is also an obvious need for a carefully coordinated response after a bioterrorism event is detected. Health officials, in collaboration with other emergency response agencies, must carefully assess and manage health care assets and ensure rapid deployment of backup resources. Also, the substantial increase in workload created from such an incident must be distributed effectively among available hospitals, clinics, and laboratories, often including facilities outside the affected area.

15.5.1 Vision for HII in Homeland Security

The vision for the application of NHII to homeland security involves both early detection of bioterrorism and the response to such an event. Clinical information relevant to public health would be reported electronically in near real-time. This would include clinical lab results, emergency room chief complaints, relevant syndromes (e.g., flu-like illness), and unusual signs, symptoms, or diagnoses. By generating these electronic reports automatically from electronic health record systems, the administrative reporting burden currently placed on clinicians would be eliminated. In addition, the specific diseases and conditions reported could be dynamically adjusted in response to an actual incident or even information related to specific threats. This latter capability would be extremely helpful in carefully tracking the development of an event from its early stages.

NHII could also provide much more effective medical care resource management in response to events. This could include automatic reporting of all available resources so they could be allocated rapidly and efficiently, immediate operational visibility of all health care assets, and effective balancing of the tremendous surge in demand for medical care services. This would also greatly improve decision making about deployment of backup resources.

Using NHII for these bioterrorism preparedness functions avoids developing a separate, very expensive infrastructure dedicated to these rare events. As previously stated, the benefits of NHII are substantial and fully justify its creation even without these bioterrorism preparedness capabilities, which would be an added bonus. Furthermore, the same infrastructure that serves as an early detection system for bioterrorism also will allow earlier and more sensitive detection of routine naturally occurring disease outbreaks (which are much more common) as well as better management of health care resources in other disaster situations.

15.5.2 Informatics Challenges of HII in Homeland Security

The application of NHII to homeland security involves a number of difficult informatics challenges. First, this activity requires participation from a very wide range of both public and private organizations. This includes all levels of government and organizations that have not had significant prior interactions with the health care system such as agriculture, police, fire, and animal health. Needless to say, these organizations have divergent objectives and cultures that do not necessarily mesh easily. Health and law enforcement in particular have a significantly different view of a bioterrorism incident. For example, an item that is considered a “specimen” in the health care system may be regarded as “evidence” by law enforcement.

Naturally, this wide variety of organizations has incompatible information systems, since for the most part they were designed and deployed without consideration for the issues raised by bioterrorism. Not only do they have discordant design objectives, but they lack standardized terminology and messages to facilitate electronic information exchange. Furthermore, there are serious policy conflicts among these various organizations, for example, with respect to access to information. In the health care system,

access to information is generally regarded as desirable, whereas in law enforcement it must be carefully protected to maintain the integrity of criminal investigations.

Complicating these organizational, cultural, and information systems issues, bioterrorism preparedness has an ambiguous governance structure. Many agencies and organizations have legitimate and overlapping authority and responsibility, so there is often no single clear path to resolve conflicting issues. Therefore, a high degree of collaboration and collegiality is required, with extensive pre-event planning so that roles and responsibilities are clarified prior to any emergency.

Within this complex environment, there is also a need for new types of systems with functions that have never before been performed. Bioterrorism preparedness results in new requirements for early disease detection and coordination of the health care system. Precisely because these requirements are new, there are few (if any) existing systems that have similar functions. Therefore careful consideration to design requirements of bioterrorism preparedness systems is essential to ensure success.

Most importantly, there is an urgent need for interdisciplinary communication among an even larger number of specialty areas than is typically the case with health information systems. All participants must recognize that each domain has its own specific terminology and operational approaches. As previously mentioned in the public health informatics example, the interlocutor function is vital. Since it is highly unlikely that any single person will be able to span all or even most of the varied disciplinary areas, everyone on the team must make a special effort to learn the vocabulary used by others.

As a result of these extensive and difficult informatics challenges, there are few operational information systems supporting bioterrorism preparedness. It is interesting to note that all the existing systems developed to date are local. This is most likely a consequence of the same issues previously delineated in the discussion of the advantages of community-based strategies for NHII development.

One such system performs automated electronic lab reporting in Indianapolis (Overhage et al., 2001). The development of this system was led by the same active informatics group that developed the LHII in the same area. Nevertheless, it took several years of persistent and difficult efforts to overcome the technical, organizational, and legal issues involved. For example, even though all laboratories submitted data in "standard" HL7 format, it turned out that many of them were interpreting the standard in such a way that the electronic transactions could not be effectively processed by the recipient system. To address this problem, extensive reworking of the software that generated these transactions was required for many of the participating laboratories.

Another example of a bioterrorism preparedness system involves emergency room chief complaint reporting in Pittsburgh (Tsui et al., 2003). This is a collaborative effort of multiple institutions with existing electronic medical record systems. It has also been led by an active informatics group that has worked long and hard to overcome technical, organizational, and legal challenges. It provides a near real-time "dashboard" for showing the incidence rates of specific types of syndromes, such as gastrointestinal and respiratory. This information is very useful for monitoring the patterns of diseases presenting to the area's emergency departments.

Note that both of these systems were built upon extensive prior work done by existing informatics groups. They also took advantage of existing local health information infrastructures that provided either available or least accessible electronic data streams. In spite of these advantages, it is clear from these and other efforts that the challenges in building bioterrorism preparedness systems are immense. However, having an existing health information infrastructure appears to be a key prerequisite. Such an infrastructure implies the existence of a capable informatics group and available electronic health data in the community.

15.6 Conclusions and Future Challenges

Public health informatics may be viewed as the application of biomedical informatics to populations. In a sense, it is the ultimate evolution of biomedical informatics, which has traditionally focused on applications related to individual patients. Public health informatics highlights the potential of the health informatics disciplines as a group to integrate information from the molecular to the population level.

Public health informatics and the development of health information infrastructures are closely related. Public health informatics deals with public health applications, whereas health information infrastructures are population-level applications primarily focused on medical care. While the information from these two areas overlaps, the orientation of both is the community rather than the individual. Public health and health care have not traditionally interacted as closely as they should. In a larger sense, both really focus on the health of communities—public health does this directly, while the medical care system does it one patient at a time. However, it is now clear that medical care must also focus on the community to integrate the effective delivery of services across all care settings for all individuals.

The informatics challenges inherent in both public health informatics and the development of health information infrastructures are immense. They include the challenge of large numbers of different types of organizations including government at all levels. This results in cultural, strategic, and personnel challenges. The legal issues involved in interinstitutional information systems, especially with regard to information sharing, can be daunting. Finally, communications challenges are particularly difficult because of the large number of areas of expertise represented, including those that go beyond the health care domain (e.g., law enforcement). To deal with these communication issues, the interlocutor function is particularly critical.

However, the effort required to address the challenges of public health informatics and health information infrastructures is worthwhile because the potential benefits are so substantial. Effective information systems in these domains can help to assure effective prevention, high-quality care, and minimization of medical errors. In addition to the resultant decreases in both morbidity and mortality, these systems also have the potential to save hundreds of billions of dollars in both direct and indirect costs.

It has been previously noted that one of the key differences between public health informatics and other informatics disciplines is that it includes interventions beyond the medical care system, and is not limited to medical and surgical treatments (Yasnoff

et al., 2000). So despite the focus of most current public health informatics activities on population-based extensions of the medical care system (leading to the orientation of this chapter), applications beyond this scope are both possible and desirable. Indeed, the phenomenal contributions to health made by the hygienic movement of the 19th and early 20th centuries suggest the power of large-scale environmental, legislative, and social changes to promote human health (Rosen, 1993). Public health informatics must explore these dimensions as energetically as those associated with prevention and clinical care at the individual level.

The effective application of informatics to populations through its use in both public health and the development of health information infrastructures is a key challenge of the 21st century. It is a challenge we must accept, understand, and overcome if we want to create an efficient and effective health care system as well as truly healthy communities for all.

Suggested Readings

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Questions for further study:

1. What are the current and potential effects of a) the genomics revolution; and b) 9/11 on public health informatics?
2. How can the successful model of immunization registries be used in other domains of public health (be specific about those domains)? How might it fail in others? Why?
3. Fourteen percent of the US GDP is spent on medical care (including public health). How could public health informatics help use those monies more efficiently? Or lower the figure absolutely?
4. Compare and contrast the database desiderata for clinical versus public health information systems. Explain it from non-technical and technical perspectives.
5. Make the case for and against investing billions in an NHII.
6. What organizational options would you consider if you were beginning the development of a local health information infrastructure? What are the pros and cons of each? How would you proceed with making a decision about which one to use?
7. If public health informatics (PHI) involves the application of information technology in any manner that improves or promotes human health, does this necessarily involve a human “user” that interacts with the PHI application? For example, could the information technology underlying anti-lock braking systems be considered a public health informatics application?