

CDC's Vision for Public Health Surveillance in the 21st Century



U.S. Department of Health and Human Services
Centers for Disease Control and Prevention

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Introduction

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This *MMWR* supplement summarizes the deliberations of CDC/ATSDR scientists and managers who met in September 2009 in Atlanta as part of the 2009 Consultation on CDC/ATSDR's Vision for Public Health Surveillance in the 21st Century. The meeting was convened to reflect on domestic and global public health surveillance practice and to recommend a strategic framework to advance public health surveillance to meet continuing and new challenges. The first report is an adaptation of the keynote address for the meeting, which summarized the history of public health surveillance, the need to reassess its usefulness, the rationale for topics selected for discussion, and the charge to participants. Subsequent reports summarize the discussions of workgroups that addressed specific topics in surveillance science and practices.

Public health surveillance in the United States has evolved from monitoring infectious diseases to tracking the occurrence of many noninfectious conditions, such as injuries, birth defects, chronic conditions, mental illness, illicit drug use, environmental, and occupational exposures to health risks. In 2001, the intentional dissemination of *Bacillus anthracis* spores and subsequent cases of anthrax in the United States provided an impetus for automating surveillance to enable early detection, rapid characterization, and timely continuous monitoring of urgent public health threats.

As the topics of surveillance have evolved, so have the methods of surveillance, spurred by rapid advances in information technology. With the impending mass adoption of electronic health records, procedures for conducting surveillance are taking another turn, and new opportunities for strengthening surveillance capacities are emerging. Electronic health records offer an opportunity to improve links between health-care providers and public health departments, making surveillance more effective and timely, although fulfilling that promise poses substantial challenges.

Despite these changes in scope and methods, the fundamental premise of public health surveillance remains constant. It should provide information to the public health community regarding the health of the populations served. Stewards of public health surveillance have a responsibility to ensure that the information is used to advance public health and to safeguard the confidentiality of persons who are represented in the data.

To begin the process of assessing the state of public health surveillance, CDC/ATSDR leadership conducted a survey of the opinions of CDC/ATSDR scientists and managers. The survey responses identified six major concerns that must be addressed by the public health community to advance public health surveillance in the 21st century:

- Lexicon, definitions, and conceptual framework for public health surveillance;
- Global health surveillance;
- Roles of information sciences and technological advances in public health surveillance;
- Public health surveillance work force of the future;
- Accessing and using data for public health surveillance: legal, policy, ethical, regulatory, and practical concerns related to data sharing; and
- Analytical challenges for emerging public health surveillance.

Each CDC Center/Institute/Office (CIO) identified five public health surveillance scientists or senior scientists to participate in the meeting. Other participants included the planning committee members and invited workgroup leads, including representatives from the CDC's Surveillance Science Advisory Group (SurvSAG) — a CDC/ATSDR employee organization dedicated to advancing surveillance practice. Although representatives from organizations representing state and local health departments were invited as observers and reviewed drafts of the papers in this *MMWR* supplement, the meeting was intended to generate ideas from within CDC/ATSDR and to stimulate further discussion with partners. Participation in the meeting was constrained in part because it occurred during the midst of the fall 2009 upswing in cases of H1N1 pandemic influenza, and several persons from both CDC/ATSDR and health departments were unable to attend because of their involvement in the response to the pandemic. Altogether, approximately 100 surveillance specialists from across CDC/ATSDR participated in the one and a half day meeting. Participants were divided into six workgroups that were charged to describe challenges and opportunities for each of the topic areas identified above and to propose a vision for addressing those challenges and opportunities.

The 2009 meeting was planned and convened before the 2010 CDC/ATSDR reorganization created an office devoted to surveillance science and practice, the Public Health Surveillance Program Office, located within a new umbrella organization called the Office of Surveillance, Epidemiology, and Laboratory Services (OSELS). This program office has since been merged functionally with another program in OSELS focused on public health informatics to create the Public Health Surveillance and Informatics Program Office (proposed), reflecting the interdependence between surveillance and informatics. This new office provides the CDC/ATSDR nexus for addressing common concerns in surveillance and informatics. It manages three cross-cutting surveillance systems: BioSense, the Behavioral Risk Factor Surveillance System, and the National Notifiable Diseases Surveillance System. Beyond these systems, the majority of

CDC/ATSDR surveillance systems are managed by programs across multiple CDC/ATSDR centers and offices and one institute.

In addition, the program office provides the focal point at CDC/ATSDR for addressing shared concerns in informatics, including those shaping surveillance practice, most notably opportunities arising for public health from Federal investments aimed at supporting the “meaningful use” of electronic health records to improve health care and population health.

The reports in this supplement arose from the 2009 meeting deliberations. While the reports do not reflect the insight and experience gained from surveillance practice since the 2009 meeting, the issues identified by the workshop remain relevant to surveillance practice. With the publication of this supplement, CDC/ATSDR will add to conversations about the future of public health surveillance.

Public Health Surveillance in the United States: Evolution and Challenges*

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*"In public health, we can't do anything without surveillance.
That's where public health begins."*

— David Satcher, MD, PhD, U.S. Surgeon General, 1998–2002

In its landmark 1988 report, a committee of the Institute of Medicine highlighted assessment as one of the three core functions of public health along with policy development and assurance (1). The committee recommended that every public health agency regularly and systematically collect, assemble, analyze, and make available information on the health of the community, including statistics on health status, community health needs, and epidemiologic and other studies of health problems. Public health surveillance, often called the cornerstone of public health practice, is an essential element of the assessment function.

Public health surveillance is the systematic, ongoing collection, management, analysis, and interpretation of data followed by the dissemination of these data to public health programs to stimulate public health action (2). The best recognized use of public health surveillance data is the detection of epidemics and other health problems in a community, but there are many other uses that are critical to public health practice. These data are used to estimate the scope and magnitude of a problem, including the geographic and demographic distribution of health events that will facilitate public health planning. Surveillance data also can be used to detect changes in health practices, monitor changes in infectious and environmental agents, evaluate control measures, and describe the natural history of a health event in a community that will generate hypotheses and stimulate applied research (3). In short, public health surveillance is the foundation for decision making in public health and empowers decision makers to lead and manage more effectively by providing timely, useful evidence (4).

In the United States, public health surveillance has focused historically on infectious diseases. Basic elements of surveillance were found in Rhode Island in 1741, when

the colony passed an act requiring tavern keepers to report contagious diseases among their patrons. Two years later, the colony passed a broader law requiring the reporting of smallpox, yellow fever, and cholera (5). Lemuel Shattuck's 1850 report of the Massachusetts Sanitary Commission was a landmark publication that related death, infant and maternal mortality, and communicable diseases to living conditions. Shattuck recommended a decennial census; standardization of nomenclature of causes of disease and death; and a collection of health data by age, sex, occupation, socioeconomic level, and locality. He applied these concepts to program activities in the areas of vaccination, school health, smoking, and alcohol abuse and is credited with introducing related concepts into the teaching of preventive medicine (5).

Activities associated with disease at the national level began in the United States in 1850 when mortality statistics based on death registration and the decennial census were first published by the federal government for the entire country. Systematic reporting of disease in the United States began in 1874, when the Massachusetts State Board of Health instituted a voluntary plan for physicians to provide weekly reports on prevalent diseases, using a standard postcard-reporting format. In 1878, Congress authorized the forerunner of the U.S. Public Health Service (PHS) to collect morbidity data for use in quarantine measures against such pestilential diseases as cholera, smallpox, plague, and yellow fever (5).

In 1893, Michigan became the first jurisdiction to require the reporting of specific infectious diseases. Also in 1893, a law was enacted to provide for collecting information each week from state and municipal authorities throughout the United States. By 1901, all state and municipal laws required notification (i.e., reporting) to local authorities of selected communicable diseases that included smallpox, tuberculosis, and cholera. In 1914, PHS personnel were appointed as collaborating epidemiologists to serve in state health departments and to telegraph weekly disease reports to PHS (5).

* Adapted from the Keynote Address presented by Dr. Stephen B. Thacker at the 2009 Consultation on CDC's Vision for Public Health Surveillance in the 21st Century in Atlanta, Georgia in September 2009.

In 1925, following markedly increased reporting associated with the severe poliomyelitis epidemic in 1916 and the influenza pandemic in 1918–1919, all states began participating in national morbidity reporting. Mortality data related to pneumonia and influenza were reported from 50 cities beginning in 1918 in the throes of a devastating pandemic, and that system has expanded and continues to the present to include 122 cities in 2012. A national health survey of U.S. citizens was conducted first in 1935. After a 1948 PHS study led to the revision of morbidity reporting procedures, the National Office of Vital Statistics assumed the responsibility for this activity. In 1949, weekly statistics that had appeared for several years in Public Health Reports began being published by the National Office of Vital Statistics. In 1952, mortality data were added to the publication that was the forerunner of *MMWR* (5).

Alexander Langmuir, the first chief epidemiologist at CDC, is recognized as the founder of public health surveillance, as it is known today, and his seminal 1963 publication describes the application of surveillance principles to populations rather than individual patients with a communicable disease (6). Langmuir worked with like-minded colleagues at the World Health Organization (WHO) to organize the 1968 World Health Assembly session on National and Global Surveillance of Communicable Diseases, and epidemiologic surveillance became a global practice (7).

In 1951, Langmuir established the Epidemic Intelligence Service (EIS), which provided a unique approach to training men and women in applied epidemiology (8). The program not only provided the epidemiologists for the 1955 polio investigation but has trained approximately 3,000 epidemiologists during the past six decades in the principles and practice of public health surveillance. It is now emulated as Field Epidemiology Training Programs in approximately 30 countries around the world (9,10). Langmuir also encouraged the organization of the state and territorial epidemiologists in 1952, and the Council of State and Territorial Epidemiologists now speaks effectively for the practice of applied epidemiology in the states. Other legacies of the Langmuir influence include surveillance programs in abortion, birth defects, and other crucial areas of reproductive health.

However, a single event in 1955 first put Langmuir, CDC, and public health surveillance on the map (11). The inactivated polio vaccine had become available in the spring of that year. However, soon after that national vaccine program began, cases of polio were linked to the vaccine, and the U.S. Surgeon General shut down the program. In a matter of days, Langmuir and his team of EIS officers set up a national surveillance system with daily reports from all the states and territories that were sent to the Surgeon General. Officers were sent to

the field and within weeks, the source of the problem was detected and identified at a single manufacturer. As a result, the Surgeon General was able to reassure the public and restart the vaccination program within months.

In the early 1980s, a concerted effort at CDC focused on the practice of surveillance, and in 1986, an internal report included the following revised definition of epidemiologic surveillance: The ongoing, systematic collection, analysis, and interpretation of health data essential to the planning, implementation, and evaluation of public health practice, closely integrated with the timely dissemination of these data to those who need to know (12). The final link in the surveillance chain is the application of the data to prevention and control and includes a functional capacity for data collection, analysis, and dissemination linked to public health programs (12).

The 1986 internal report was directed at CDC but also included information and recommendations (e.g., a systematic approach for evaluating surveillance systems). A subsequent paper described the confusion engendered by use of the qualifying word “epidemiologic” to describe surveillance and argued for the use of the broader term “public health” instead (13). That paper also carefully defined the boundaries of public health surveillance, especially in terms of research and practice.

Current and Future Challenges

Given the proliferation of data systems, developments in preparedness and emergency response, rapid maturation and dissemination of the information sciences, and new tools and technologies, the time has come to reassess what is meant by public health surveillance. To begin this process, the planning committee for this consultation solicited the opinions of CDC/ATSDR scientists and managers on the state of surveillance at the agency. Division directors, members of the Surveillance Science Advisory Group (SurvSAG), and scientists on the science distribution list were invited to share their opinions. A web-based surveillance survey was established in the spring of 2009. A total of 434 persons responded to the survey. Approximately 60% of respondents agreed that the general state of surveillance at CDC is strong; only 16% disagreed. The question is where does the agency go from this point?

Only one third of CDC survey respondents agreed that the agency analyzes and disseminates surveillance data in a timely fashion, and only one in five reported that CDC surveillance systems are flexible and readily able to adopt new methods in a rapidly changing environment. In short, the agency and its scientists and managers must adapt and transform its surveillance systems to meet the public health practice needs of today and tomorrow.

“For surveillance systems to be useful, they must adapt to the changing environment in which they operate and accommodate emerging public health requirements that were not conceived previously.”

— Joseph S. Lombardo, MS,

Johns Hopkins University Applied Physics Laboratory, and
David L. Buckeridge, MD, PhD, McGill University (14)

To advance public health surveillance in the 21st century, at least six major concerns must be addressed by the public health community: a common lexicon; global surveillance needs; informatics, including information technology; a skilled workforce; data access and use; and data management, storage and analysis.

Lexicon

The first concern is basic and deals with the lexicon that practitioners use, definitions, and the conceptual framework that is understood by those in public health and elsewhere who need to know. Terms used to modify surveillance are numerous, starting decades ago with “disease,” “epidemiologic,” “active,” “passive,” and “sentinel” and evolving to “integrated” and “syndromic” in recent years. Data-source terms (e.g., office-based, laboratory-based, and hospital-based) are used to clarify but sometimes only obfuscate. To complicate the lexicon further, every program adds a surveillance system modifier (e.g., chronic disease, environmental health, unintentional injury, and occupational) and surveillance systems also exist for behaviors or events (e.g., disasters or political conventions). Each new system will be designed with a different meaning and specialized framework. Most recently, the term “biosurveillance” was mandated by a Presidential Directive (Homeland Security Presidential Directive 21 [<http://www.hsdl.org/?view&did=580002>]), which was defined specifically to relate to such acute events as a terrorist threat or an influenza epidemic. These differences neither lead to clarity of purpose nor facilitate understanding.

A conceptual framework for health knowledge is a step toward increased understanding (Figure 1). Knowledge of the health of and health risks in a community or population depends on certain inputs in addition to public health surveillance, including research studies that produce generalizable knowledge, health surveys, registries of vital events (e.g., births and deaths), medical and laboratory information systems, environmental monitoring systems, censuses, and other data resources. However, a conceptual framework for public health surveillance examines many of the same data systems (Figure 2).

Global Surveillance Needs

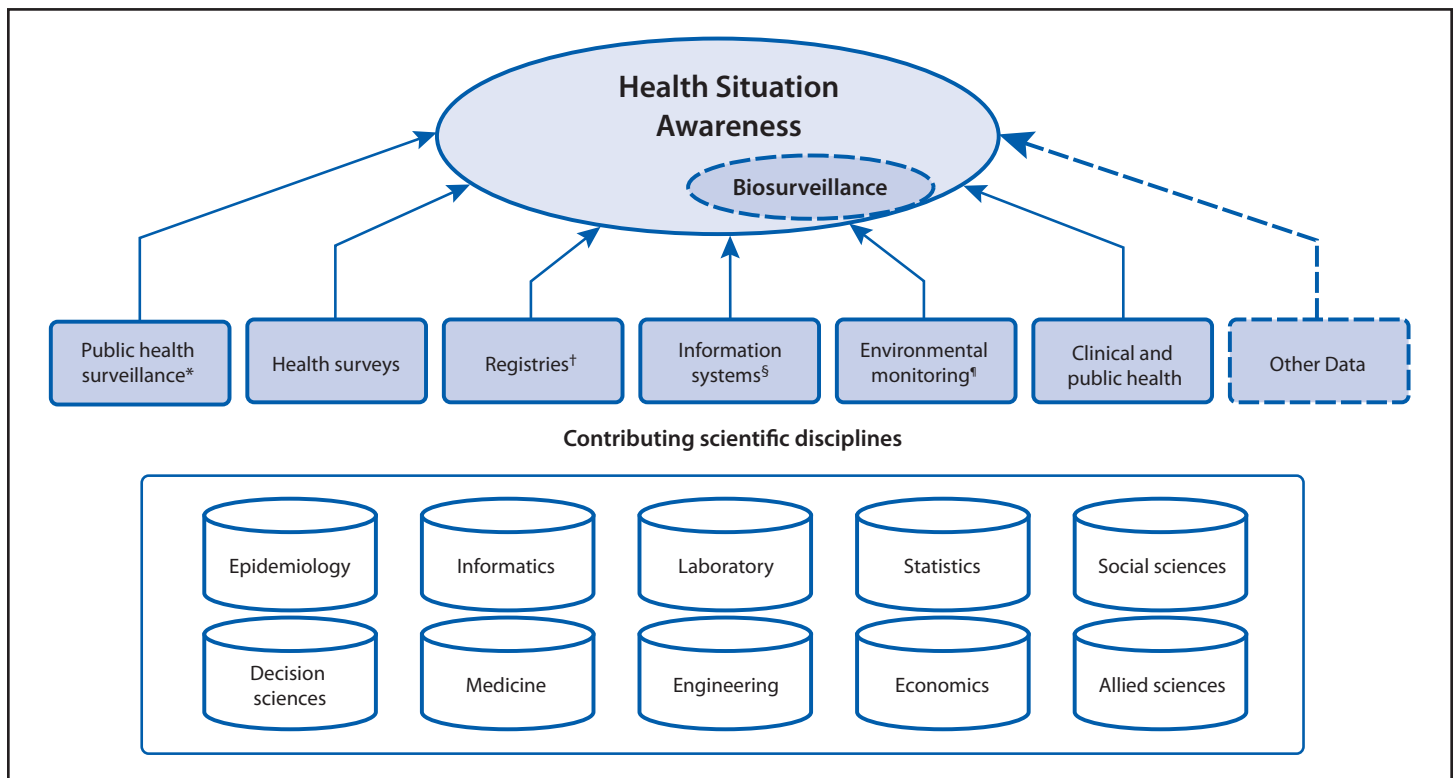
CDC is an agency with global reach, and the agency and the world must collaborate for global public health surveillance. WHO has developed a global framework for infectious disease surveillance, which includes formal collaborators (e.g., national public health authorities and WHO collaborating centers and laboratories) and informal collaborators (e.g., nongovernmental organizations, including foundations) (Figure 3) (14). According to the planning committee survey, CDC scientists and managers agree to a limited degree (40%) that the agency maintains international partnerships to address global surveillance needs; however, one in four respondents did not know or had no opinion on this question. Clearly, through expanding global efforts in such vertical programs as global immunization, the acquired immunodeficiency syndrome programs, and the Field Epidemiology Training Programs, a strong effort should be directed towards public health surveillance.

Information Science and Technology

The roles of surveillance in information sciences and emerging technologies is possibly the most pressing issue that confronts the agency and its partners. At the same time, virtually everyone in public health acknowledges that the progress in informatics, including information technology, has paved the way for exciting opportunities to practice public health surveillance more efficiently and effectively. However, only 22% of respondents to the CDC survey agreed that CDC surveillance systems work well in today's world of information technology, and 60% of respondents agreed that the agency should provide and support a common standard for the informatics framework applicable to all surveillance systems across the agency. Data quality can be improved and information made accessible in a more timely manner, especially through use of integrated electronic health records.

Through improved tools and better strategies, the opportunity exists to link to important data not available traditionally in public health. For CDC and its partners to take advantage of these opportunities, development and use of standards should be improved to facilitate data exchange. This will depend on more effective policies to enable partnering with state and local health departments as well as other federal agencies engaging in public health surveillance (e.g., the U.S. Departments of Homeland Security and Defense and the Environmental Protection Agency [<http://www.hsdl.org/?view&did=580002>]) and our global partners both governmental and private. This will require substantial time, resources, effort, and commitment. Approximately 70% of CDC scientists and managers agreed that CDC leadership

FIGURE 1. Various data feeds to support health situation awareness



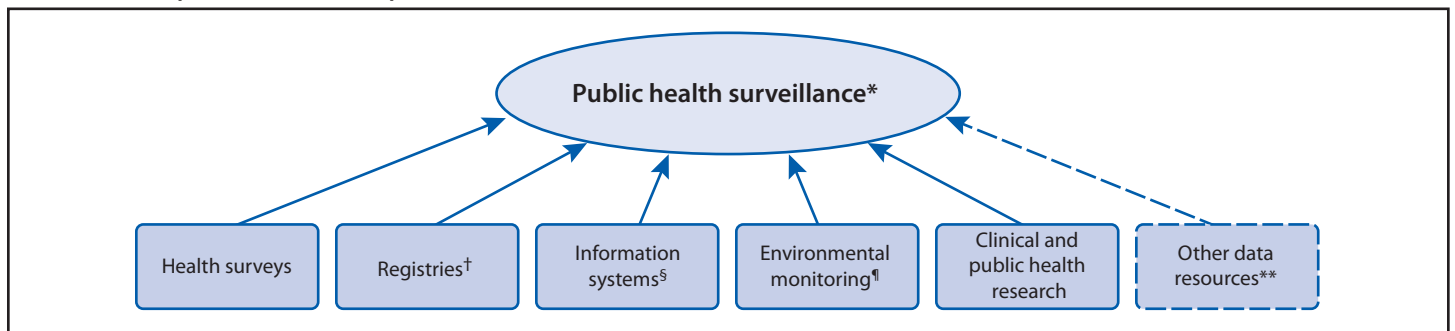
* Systematic and continuous collection, analysis, and interpretation of data, closely integrated with the timely and coherent dissemination of the results and assessment to those who have the right to know so that action can be taken (Porta MA, Dictionary of Epidemiology, 5th Ed., Oxford University Press, 2008).

† Vital registration, cancer registries, and exposure registries.

§ Medical and laboratory records, criminal justice information, and Lexis-Nexis.

¶ Weather, climate change, and pollution.

FIGURE 2. Conceptual framework for public health surveillance



* Systematic and continuous collection, analysis, and interpretation of data, closely integrated with the timely and coherent dissemination of the results and assessment to those who have the right to know so that action can be taken (Porta MA, Dictionary of Epidemiology, 5th Ed., Oxford University Press, 2008).

† Vital registration, cancer registries, and exposure registries.

§ Medical and laboratory records, pharmacy records.

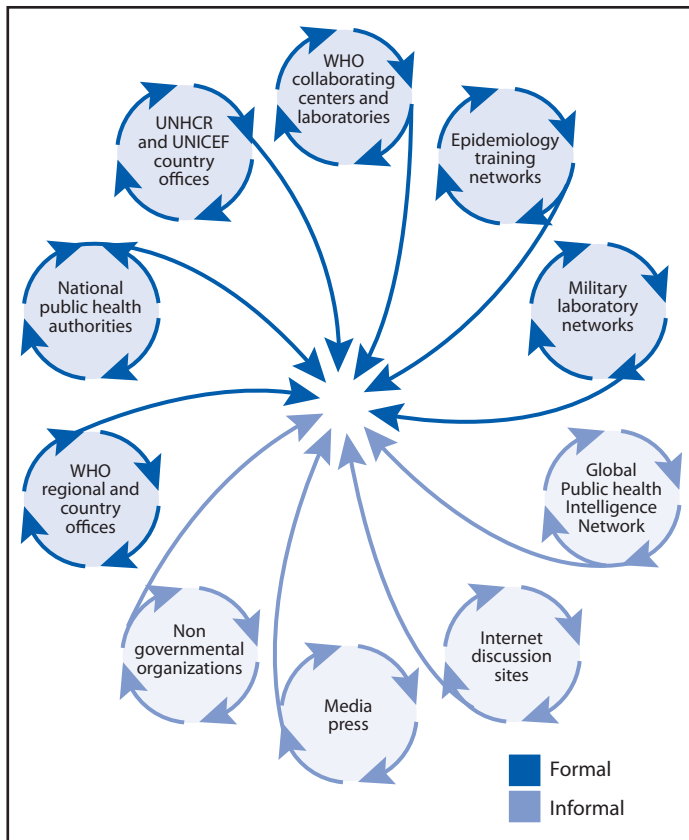
¶ Weather, climate change, and pollution.

** Criminal justice information, Lexis-Nexis, and census.

values the work and scientific contribution of surveillance activities, and in 2009, the CDC Director made surveillance a visible priority for this agency. Meanwhile, only 18% of respondents agreed that the agency adequately funds surveillance activities and that increased resources to rebuild

partnerships to address local, state, and global surveillance were needed both centrally (51%) and in individual programs (69%). However, to be useful, technology must have a purpose; user requirements must have a higher priority than solutions that are technologically exciting (15).

FIGURE 3. Global infectious disease surveillance frameworks



Abbreviations: UNHCR = United Nations High Commission for Refugees; UNICEF = United Nations Children's Fund; WHO = World Health Organization.

Source: Nsubuga P, White E, Thacker SB, et al. Public health surveillance: a tool for targeting and monitoring interventions [Chapter 53]. In: World Bank Group. Disease control priorities for developing countries. 2nd ed. Jamison DT, Breman JG, Measham AR, et al., eds. Washington, DC: World Bank Publishers; 2006: 1012.

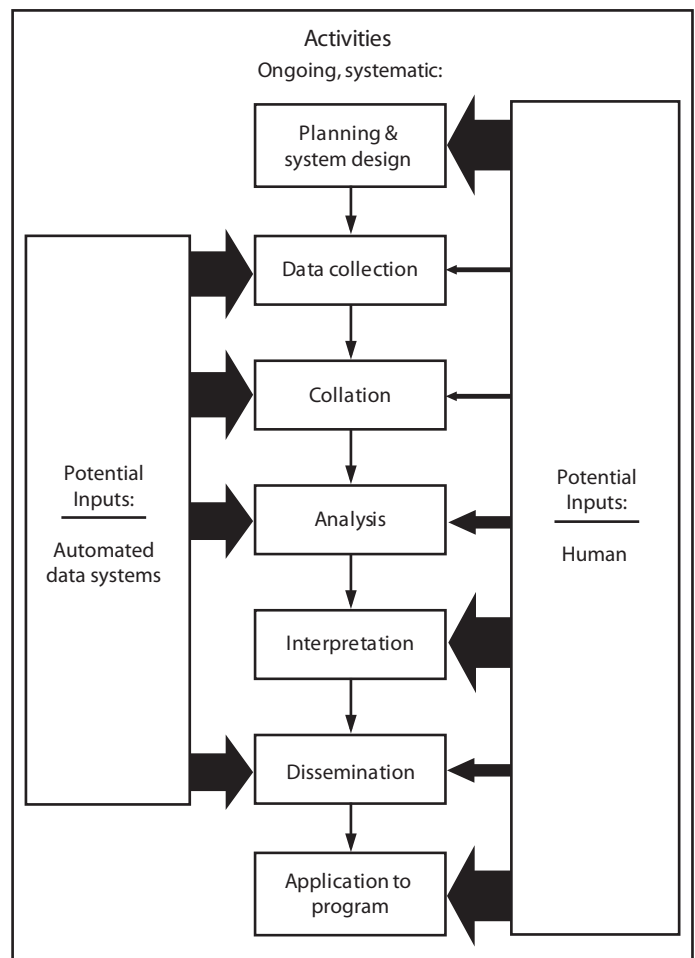
Skilled Workforce

Two thirds of the CDC survey respondents agreed that CDC has surveillance expertise across subject matters throughout the agency; however, only 38% agreed that the agency offers training that promotes high-quality surveillance methods. Approximately 70% of respondents agreed that CDC should implement a broad initiative to train all agency staff about skills needed for effective public health surveillance in the 21st century. An even greater existing and future need exists for workforce development in state and local health departments and internationally (16,17). Despite the increasing efficiencies that automation might bring to surveillance, even in the most sophisticated systems, human input will remain large and consequential (Figure 4).

Data Access and Use

A fifth major issue in advancing public health surveillance relates to accessing and using data. A limited number of

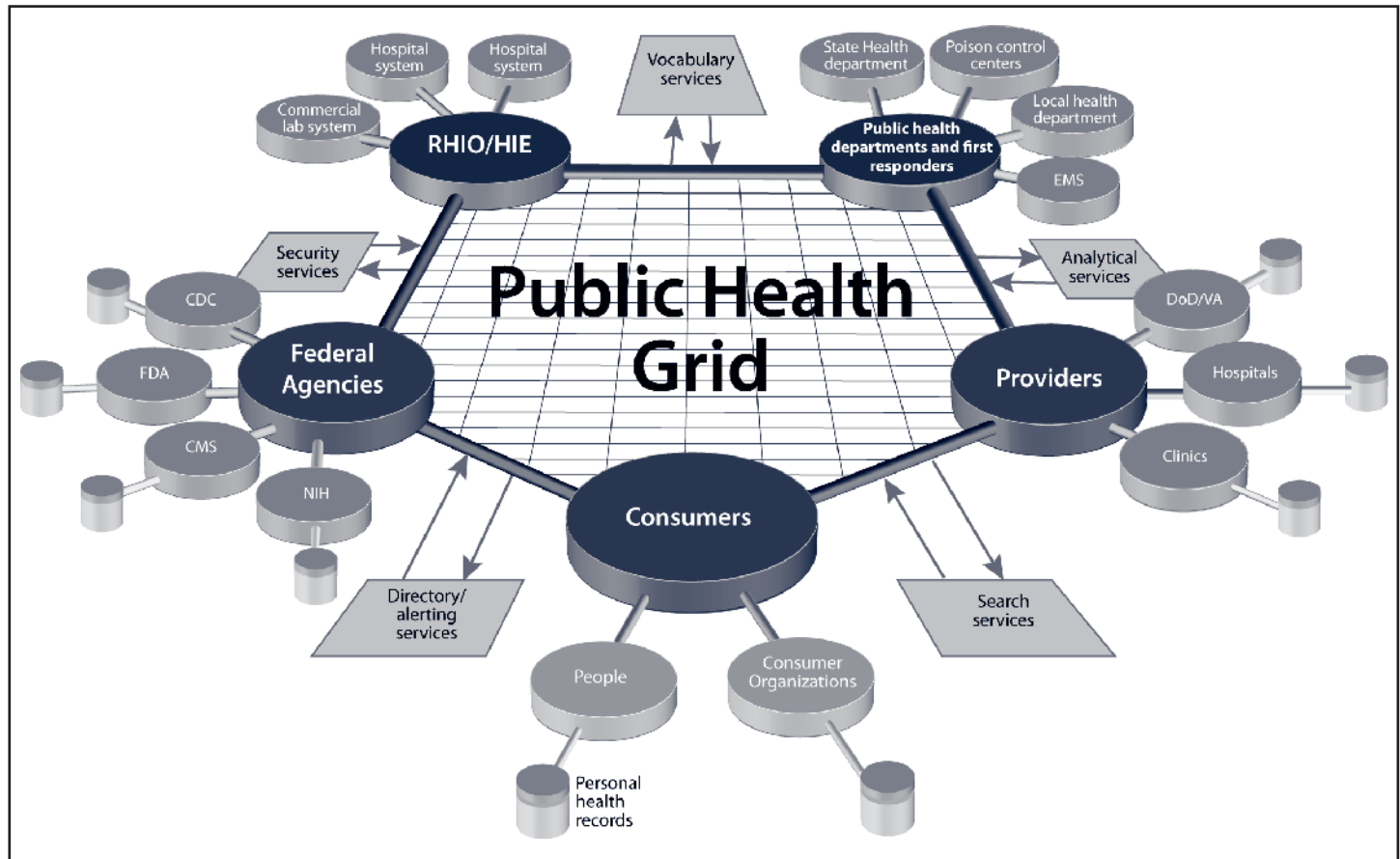
FIGURE 4. Optimal balance of human and automated inputs into ongoing, systematic public health surveillance system activities*



* The size of the arrow indicates the relative human and automated inputs into each activity

respondents to CDC's survey (20%) agreed that CDC provides timely access to surveillance data internal to the agency through centralized data bases, and a slightly higher percentage (25%) agreed that the agency provides timely access to public use datasets from surveillance activities. In contrast, a substantial percentage (77%) agreed that CDC should apply consistent standards across the agency for timely dissemination of surveillance data. The opportunities are great. The future system is likely to consolidate information in health information exchanges that allow providers and institutions to share patient data among themselves and with public health agencies without having to turn over the data to the participating institutions. Nationally, an electronic health grid could include consumers, providers, and public health agencies at all levels participating in such data sharing for public health surveillance (Figure 5). In this grid, data can be shared without violating confidentiality and the "owner"

FIGURE 5. National public health grid



Abbreviations: CMS = Centers for Medicare and Medicaid Services; DOD/VA = U.S. Department of defense/Department of Veterans Affairs; EMS = Emergency Medical Services; FDA = Food and Drug Administration; NIH = National Institutes of Health; RHIO/HIE = Regional Health Information Organization/Health Information Exchange. **Source:** Savel TG, Hall KE, Lee B, et al. A public health grid (PH Grid): architecture and value proposition for 21st century public health. *J Med Informat* 2010;79:523–9.

remains the responsible steward for ensuring this and other factors (e.g., quality and discoverability). This “shared” model facilitates improved public health by providing access and a relation among complex data sets/systems.

Data Management, Storage and Analysis

The last concern relates to analytical challenges, and the most urgent of these challenges relates to data base management. With the increasing availability of clinical, insurer, social, and environmental data sets, the immediate challenge is to organize the data into a format that is accessible and useful for epidemiologists, statisticians, and others who might be able to use these data for public health surveillance. Until these data are available in a useable format, interpretation by subject matter experts is impossible and the data will not be useful. Only 28% of survey respondents agreed that the agency maintains rigorous standards for the collection, maintenance,

and analysis of data for CDC/ATSDR and its partners. Clearly, there remains much to do.

Conclusion

In summary, the challenge remains to take this opportunity to build on the existing organizational resources and common interests to strengthen public health surveillance. This consultation offers a tremendous opportunity to inform and shape the direction of the new organizational unit to be developed under the new Deputy Director for Surveillance, Epidemiology, and Laboratory Services. This is also an opportunity to build relationships with other surveillance professionals at CDC/ATSDR through shared knowledge and experience and has the potential to build collaborations that can leverage resources and expertise to enhance the practice of public health surveillance at the agency and among our partners, domestic and international.

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Lexicon, Definitions, and Conceptual Framework for Public Health Surveillance

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Public health surveillance is essential to the practice of public health and to guide prevention and control activities and evaluate outcomes of such activities. With advances in information sciences and technology, changes in methodology, data availability and data synthesis, and expanded health information needs, the question arises whether redefining public health surveillance is needed for the 21st century. The current definition is “Public health surveillance is the ongoing, systematic collection, analysis, and interpretation of health data, essential to the planning, implementation and evaluation of public health practice, closely integrated with the dissemination of these data to those who need to know and linked to prevention and control (1).”

This report describes a review of this definition and considers proposed needs for health information (Box). This topic was identified by CDC leadership as one of six major concerns that must be addressed by the public health community to advance public health surveillance in the 21st century. The six topics were discussed by CDC workgroups that were convened as part of the 2009 Surveillance Consultation to advance public health surveillance to meet continuing and new challenges (2). This report is based on workgroup discussions and is intended to continue the conversations with the public health community for a shared vision for public health surveillance in the 21st century.

Changing Landscape and Health Information Needs

Health information needs reflect innovations or qualitative changes in health metrics and methodologies and changes in knowledge needs. They also have been accompanied by the development and use of new terms, an inclusion of more complex health events under the scope of surveillance activities, and new questions regarding the overlap of surveillance with

other types of activities in information sciences and public health practice. The workgroup consultants proposed the data needs and reviewed related terminology to define what public health surveillance is and what it is not. The review included the purpose or intent of public health surveillance: why, in what areas, and how public health surveillance is conducted. Furthermore, the workgroup consultants reviewed relations among data collection, analysis, reporting activities, and a conceptual framework for population health assessment.

Gaps and Opportunities

The value of surveillance lies in the effective and efficient delivery of useful information. Therefore, a surveillance system must be flexible enough to adjust to expanding health information needs and to use the best technology to deliver the data when and where they are needed. Failure of public health surveillance to deliver needed information can occur when single-disease systems cannot be used to determine relations between health conditions or comorbidities (e.g., through data linkage), or when appropriate health information is not collected when a potential exists for a substantial threat but what needs to be measured is not known. Gaps in health knowledge can occur when surveillance systems are not timely, complete, easily adapted, or efficient. For example, information that is not timely can result in a missed opportunity to intervene, especially for acute events. Information that is not complete can result in failure to recognize a public health threat. Surveillance systems that are not easily adapted to changing information needs might not be able to evaluate the impact of new prevention interventions in different population subgroups. Surveillance systems that are not efficient (e.g., the delivery of needed information demands more resources than are available) will not be useful.

BOX. Health information needs for the 21st century

- Preparedness
- New information systems/technologies
- Availability of more and new data/new data sources/databases
- Health-care reform
- Electronic health/medical records
- Performance accountability
- Comparative effectiveness of medical interventions
- Measuring positive indicators
- Infrastructure and capacity
- Globalization
- Interoperability
- Changes in the economy
- Expanding scope of public health practice
- Data privacy issues
- Data security
- Public participation in public health activities

To address these gaps, public health surveillance can benefit from advances in information sciences and technology and the increasing availability of databases and data sources. New information technologies provide opportunities for better data compilation, analysis, and dissemination. Electronic reporting, electronic health records, standardized data exchange, and automated data processing are examples of how the practice of surveillance has changed or is likely to change in the future, as are the uses of such methods in laboratory information systems and electronic health records. New data or information sources, such as unstructured clinical data, internet data sources, media content, and environmental and climate change data provide expanded opportunities to enhance health knowledge by facilitating more detailed characterization of events of interest with respect to time, place, and person. A clear definition of public health surveillance is needed to determine whether systems that use these types of data constitute public health surveillance.

Principles of Public Health Surveillance

For the purpose of discussing the lexicon, definitions, and the conceptual framework of public health surveillance, articulating the basic principles underlying public health surveillance is useful and important. The workgroup consultants derived two basic principles from the definition of public health surveillance.

One of these basic principles relates to the purpose of public health surveillance, which is twofold: 1) to address a defined public health problem or question, and 2) to use the data to guide efforts that will protect and promote population health. A second basic principle relates to the nature of public health surveillance as an ongoing and systematic implementation of a set of processes consisting of 1) planning and system design, 2) data collection, 3) data analysis, 4) interpretation of results of analysis (i.e., generation of information), 5) dissemination and communication of information, and 6) application of information to public health programs and practice.

These principles were considered useful for framing deliberations on key public health surveillance concepts and terms and relations among data collection and use activities and placing public health surveillance activities within the larger context of population health assessment and actionable public health knowledge (i.e., knowledge for public health decision making and/or disease control and prevention).

Concepts of Public Health Surveillance

The traditional definition of public health surveillance includes a series of concepts that can be interpreted in various ways. A traditional interpretation of key concepts leads to a narrow definition of the scope of public health surveillance systems to include morbidity and mortality of diseases or specific health events. Conversely, a more expansive interpretation opens the field of public health surveillance to new areas of public health inquiry using innovative data sources, methods of data collection and analysis, and application to several public health concerns. This latter interpretation of key concepts was adopted because it was considered essential to adapt to the health information needs and the advancement of public health surveillance in the 21st century.

In this regard, selected key concepts were considered in detail. Primary among them is the ongoing systematic collection of health data. The temporal aspects of surveillance are divided into two concepts: the temporal occurrence of events and the reporting frequency of those events. The concept of “ongoing” can be interpreted to imply that all events are equally likely to be captured in the surveillance system regardless of the time in which the events occurred. This approach is often applied to disease “case” surveillance systems (e.g., the National Notifiable Diseases Surveillance System). Although these systems rarely capture all cases of disease, they do attempt to consistently capture a proportion of events over time. This is in contrast to an approach that captures snapshots of events in a defined period, which is repeated periodically and on an ongoing basis. Certain

events occurring with some periodicity, but not in synchrony with the data collection process, would not be captured because their occurrence in a time period was not included in the data collection. This latter approach was considered to be analogous to sentinel surveillance based on location, in which certain cases would not be captured because of the geographic variation of their occurrence. The periodic data collection, regardless of whether the periodicity is regular or irregular, conforms to the concept of ongoing systematic collection.

Reporting frequency is related to the usefulness of the data to inform public health programs. Delayed reporting, whether for primary capture in the system or for interpretation of data for programs, might limit the usefulness of the data and weaken the link to prevention and control activities. Under such circumstances, the link between data collection and public health program activities might be lost; consequently, the data collection activity might not meet the purpose of public health surveillance. Nonetheless, whether the reporting frequency is determined to be adequate depends on the topic or event addressed by the surveillance system. Although rapid reporting is essential for detection and prevention of high-hazard events (e.g., lethal communicable diseases), rapid reporting might not be essential for chronic disease surveillance where time frames for interventions are longer. For different types of health events, the time scales of public health program intervention differ dramatically, and thus the effective frequency of reporting for different events differ. For this reason, the frequency of reporting was not considered a determining factor in the definition of public health surveillance.

Another important concept is health information. Many traditional public health surveillance systems address morbidity and mortality in human populations, whereby health information is directly related to human health. However, many types of information inform public health programs. These types of information include, but are not limited to, environmental exposures, occupational exposures, disease vectors and vehicles, risk behaviors, population characteristics, and health policies. For example, health policy information might be applicable to health-care reform, a topic of interest to decision makers and public health programs. Several types of health information, whether directly or indirectly related to human health, might be applicable to public health surveillance. The type of health information used does not define public health surveillance. Rather, the crux of public health surveillance is related to the key principles of applying information to a defined public health problem and its use to guide strategies that protect and promote population health.

The sources of health information in public health surveillance are similarly varied. Sources include direct ascertainment from persons in a population, from clinical or laboratory sources, or

from other systems designed for a purpose other than public health surveillance. For example, the census is conducted for many purposes and is not considered a public health surveillance system. However, the census is a source of population data used in public health surveillance systems.

The final key concept is the link to prevention and control. This concept can be broadly defined in the context of public health surveillance. The link of information to interventions in prevention and control of disease or injury is essential for a surveillance program to consider. Public health surveillance might be conducted for conditions for which no public health interventions exist (e.g., for the occurrence and outcomes related to certain congenital diseases or disorders). Nonetheless, public health surveillance for these conditions might be important to prioritize and guide research, which guide development of public health interventions for use in the future or for planning services. In addition, this type of surveillance might be important to guide interventions for other important sequelae such as co-morbidities or behavioral modifications to allow family members, health systems, and communities to better accommodate persons with certain conditions.

For these concepts and others related to the definition of public health surveillance, broad, flexible interpretations were applied. This approach was considered critical for meeting the demands on and opportunities for public health programs in the 21st century. Future needs and concerns might be ongoing issues or variations of them or new challenges. Public health surveillance will need to be innovative to meet the needs of decision makers and drive prevention and control programs of the future.

Relations Between Public Health Surveillance and Other Data Collection Activities

Public health surveillance is not defined by the system used to collect data but by the purpose of the data collection — the specific public health question that the data will be used to answer and the link to disease prevention and control. Tracking the health of the population is an essential component of effective public health practice. Data are needed for monitoring trends and patterns, identifying outbreaks, developing and evaluating interventions, setting research priorities, monitoring quality of care and patient outcomes, recognizing drug resistance to infectious disease agents, identifying underserved populations, and planning services. In some instances, data to address health concerns can be collected in a single system, particularly if a mandate for reporting is included. One example is the CDC National Electronic Disease Surveillance System,

which was established to facilitate accurate, complete, and timely reporting of infectious diseases from state and local health departments. However, for many noninfectious diseases and conditions, surveillance must be broad in scope and must rely on numerous other data collection activities. Public health surveillance for noninfectious disease is often built on a framework of indicators from different data sources.

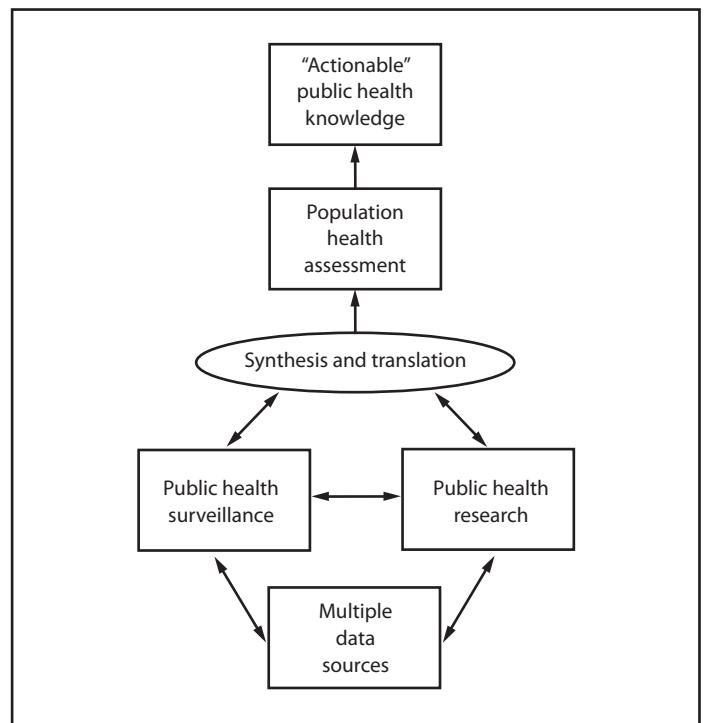
Even when surveillance is not the primary aim of the activity, data collection can still yield valuable information for surveillance purposes when the data collection adheres to some of the basic principles for surveillance. For example, health data collected for administrative purposes (e.g., Medicare and hospital discharges) cover a majority of the population and are particularly useful for monitoring trends and assessing burden of disease. Surveys can be a rich source of surveillance data when they are periodic, population based, and maintain assessment standards over time. Surveys such as the National Health and Nutrition Examination Survey, Behavioral Risk Factor Surveillance System, National Health Interview Survey, and the National Ambulatory Medical Care Survey have provided valuable surveillance data on behaviors, biomarkers, preventive services, and risk factor and condition prevalence. Disease registries are often established for research purposes or to track adverse events, yet they can provide valuable data for surveillance purposes. For example, cancer registries can provide cancer-specific incidence data, mortality rates by geographic area, and age-adjusted rates for comparisons over time and across communities/regions. Even hospital-based registries can provide surveillance data when the population covered can be defined and estimated.

Often, data are not available on the whole population. In such situations, sentinel surveillance systems can provide sufficient information for making public health decisions or detecting trends. The main purpose of sentinel surveillance is to obtain timely information on a preventable disease, injury, or untimely death, the occurrence of which serves as an indicator that the quality of preventive or therapeutic care might need improvement. Sentinel surveillance is of value when national surveillance systems are not available, large surveys would be too costly, or condition prevalence is high and collecting data on every case would be impractical. Types of sentinel surveillance include 1) monitoring specific health events in clinical settings; 2) reporting by hospitals or networks of providers of data on specific conditions or events; and 3) localized, longitudinal cohorts, registries, and screening programs. Although data from these sources are not nationally representative, they can provide a detailed picture of disease and risk-factor trends in a geographically defined area or in a population subgroup defined by age, sex, race/ethnicity or other demographic characteristics.

Information from varied data sources can be incorporated into public health surveillance activities. Some are not strictly health data but might include climate, occupational exposures, environmental hazards, risk factors, laws and regulations, or social determinants of health. Tracking these data over time is important for understanding the context in which disease occurs and, when linked with health outcomes at the individual or population level, can provide federal, state, and local agencies important information for disease prevention, detection, and control. Another emerging source of health data for surveillance is the electronic health record (EHR). Although the technology has yet to be widely adopted and concerns about access and privacy need to be resolved, EHRs have the potential to generate entirely new data for monitoring the health of the population. What is traditionally regarded as clinical data (e.g., records from out-patient clinics, laboratories, or pharmacies) could be transformed into surveillance data at the population level. The data also could be used to establish new disease registries yielding previously unavailable population-based morbidity and disease incidence data and to track how persons move through and beyond the health-care system across the lifespan.

Numerous sources of data that are used for public health surveillance also are the basis for public health research (Figure 1). Surveillance and research are distinguished by

FIGURE 1. Public health surveillance in the larger context of health knowledge



the purpose of the data collection. Surveillance is used to gather data and knowledge that can be used to identify and control a health problem or improve a public health program or service, whereas the purpose of research is to generate generalizable knowledge. In some instances, public health surveillance activities can serve as a source of case finding for further research or can suggest hypotheses or areas of interest for more in-depth research. Data collection activities originally designed for research can serve as vital sources of surveillance data. Although different in purpose, public health research and public health surveillance are closely linked in public health practice and rely on many of the same data sources and methods.

This review considered the purpose of public health surveillance; relations among data collection, analysis, reporting activities; and a conceptual framework for population health assessment. The workgroup conclusion is that the existing definition of public health surveillance remains relevant, applicable, and flexible and does not need to be changed.

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Global Health Surveillance

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Awareness of the importance of global health surveillance increased in the latter part of the 20th century with the global emergence of human immunodeficiency virus and novel strains of influenza. In the first decade of the 21st century, several events further highlighted global shared interests in and vulnerability to infectious diseases. Bioterrorist use of anthrax spores in 2001 raised awareness of the value of public health surveillance for national security. The epidemic of severe acute respiratory syndrome (SARS) in 2003, re-emergence of a panzootic of avian influenza A H5N1 in 2005, and the sudden emergence of pandemic H1N1 in North America in 2009 all highlighted the importance of shared global responsibility for surveillance and disease control (1,2). In particular, in 2003, SARS precipitated changes in awareness of the world's collective economic vulnerability to epidemic shocks.

Global public health surveillance is critical for the identification and prevention of emerging and reemerging diseases, both for infectious and noncommunicable diseases that account for the greatest burden of diseases, even in very poor countries. It should provide health information in a timely manner so that countries have the information that they need to fight epidemics now or to plan for the future. Several public health problems have been addressed effectively by the development and maintenance of surveillance systems. One example is smallpox, which was eradicated through a switch in strategy from mass vaccination to surveillance with rapid response (3). In the poliomyelitis eradication campaign, the world is covered effectively by an integrated surveillance system that channels specimens rapidly to genotyping within days to weeks (4).

Individual countries are responsible for disease surveillance and response. The most important and only binding international agreement on disease control is the International Health Regulations (IHR), which was revised in 2005 to include additional infectious diseases and to extend regulation to other public health events of international concern (5,6). IHR 2005 further shifts the focus from control at borders to detection and control at the sources and requires countries to document capacity for detection, verification, and response

within borders (7). The regulations require countries that identify public health events of international concern to report to the World Health Organization (WHO), which disseminates the information, as needed, to other countries.

Global health surveillance and routine surveillance in low-resource countries differ from surveillance in industrialized countries in several ways: 1) more must be done with less, 2) strengthening surveillance is more complicated, and 3) sustainability is more challenging. This report proposes a vision for global health surveillance, identifies challenges and opportunities, and suggests approaches to attain the vision. The topic was identified by CDC leadership as one of six major domains that must be addressed by the public health community to advance public health surveillance in the 21st century. The six topics were discussed by CDC workgroups that were convened as part of the 2009 Surveillance Consultation to advance public health surveillance to meet continuing and new challenges (8). This report is based on workgroup discussions and is intended to continue the conversations with the public health community for a shared vision for public health surveillance in the 21st century.

A single statement could not adequately encompass the needed vision for global health surveillance. Instead, two vision statements are needed: one that reflects the net global effect of quality surveillance and a second that conveys to the national level the responsibility for managing public health surveillance that meets the health goals of each country.

Vision

For the world: A globally connected network of public health surveillance systems that optimizes disease prevention and health promotion.

For each nation: A fully functioning, efficient set of national public health surveillance systems that protect the nation's public health and provides timely information to guide public health action.

Challenges

Realizing these visions for effective surveillance for global health threats will require meeting several challenging. These include a need for greater commitment and leadership (9,10); inadequate surveillance of priority conditions; inadequate standardization and interoperability of surveillance systems; insufficient mechanisms for or commitment to effective partnerships; and insufficient research, innovation, and effective acceptance of technology into global health surveillance.

Leadership

Leadership is the first and most essential requirement for reaching the two interdependent visions. Strong leadership is required to support movement toward more fully coordinated, interoperable, sustainable global public health surveillance systems. In low-resource settings, the challenges and service leadership requirements are more challenging because of the range of national and international partners that need to work in a mutually reinforcing fashion. Donor-driven priorities or international concerns in a country often result in multiple, vertical, disease-specific surveillance programs that use separate information systems, personnel, vehicles, and office space at every administrative level of the country (11). Integration of similar surveillance functions across multiple diseases can lead to greater efficiencies, but only if resources are maintained and if engaged leadership for surveillance and health situation awareness is recognized as a major governmental responsibility (12). Public health surveillance and health information systems usually require important financial commitments. Commitment and leadership is essential to create an enabling environment for surveillance.

Surveillance of Priority Conditions

A critical challenge in moving toward the proposed vision for global health surveillance is to address the imbalance in coverage of surveillance systems for critical health problems. In many low-resource settings, resources for surveillance are made available on the basis of targeted global initiatives and global priorities (e.g., through the Global Fund for AIDS, TB, and Malaria), whereas other health priorities often go unaddressed (13). Even among the poorest countries with the highest infectious disease burden, the leading causes of death have become chronic, noncommunicable diseases; as a result, surveillance for tobacco use, obesity, and other noninfectious conditions also become pressing priorities for public health surveillance. Emerging epidemics of cardiovascular disease, cancer, and motor vehicle injury are not monitored

systematically in many countries, so even the most essential information for public health action — the rates and causes of death in the population — are estimated loosely based on estimates from other countries. Ensuring that surveillance systems result not only in enhanced health security for industrialized nations but also improved health of persons in the poorest countries is essential (1,14).

Standardization and Interoperability

Surveillance systems often are set up without due diligence for the information system and surveillance architecture in which they need to operate. The idiosyncratic experience of one international consultant might result in a recommendation of a surveillance approach, data definitions and formats, laboratory methods recommended, or software used that is mismatched to what would be optimal for the country. In addition, accepting assistance from international partners might obligate the country to purchase or use certain equipment or to adopt approaches to surveillance that complicate or contribute to fragmenting the surveillance and health protection enterprise in the country (15). The establishment of detailed informatics standards for surveillance at the global level would provide countries with the opportunity to adapt those standards to each country's epidemiology, disease control, and health promotion priorities (12). Furthermore, consensus standards that are needed go beyond basic surveillance science and informatics and extend to ethical concerns, data sharing, privacy and confidentiality, and human subjects protection (16,17).

Technology

The expansion of information and communication technology in recent decades has barely penetrated the domain of public health surveillance in many countries. The potential for harnessing new technology for surveillance is evident. However, development and implementation of these technologies lacks the coordination and trusted curation needed to ensure efficient identification of best global practices, harmonization, and standardization. Without a coordinated effort to identify best practices and share them with all nations, countries would be left to independently assess and experiment with methods to incorporate the new technologies into their national surveillance programs.

Partnerships and Resources

These challenges can only be addressed by energized, highly effective, and 'joined up' partnerships among low-resource countries and the diverse international organizations that provide support for surveillance. The multiple demands of

partners and networks that provide assistance for a specific type of surveillance can strain understaffed and underequipped ministries of health and surveillance units in poor countries (18). The complexity of managing the national enterprise of surveillance in many low-resource countries is increased by fragmented assistance and multiple international partners with different programs, schedules, funding streams, and monitoring requirements (19).

To address such challenges, the 2005 Paris Declaration for Aid Effectiveness promotes country ownership of programs, use of country systems, and development of and adherence to consensus global standards to make improved performance more feasible for poor countries (12). Organizational innovation and commitment are needed to allow various stakeholders in the public health surveillance environment to begin operating in a more harmonized and aligned fashion.

The human resources necessary to perform surveillance activities are at a premium in developing countries. Health officials in developing countries might find it difficult to fill key technical positions (e.g., laboratory technicians and health information systems staff) because few applicants have the necessary skills. Equipment shortages also constrain surveillance. The ability of developing country health officials to provide accurate disease information is compromised further by their frequent lack of clear and accurate diagnostic tests that they can perform themselves or ready access to functioning laboratories (20). As a result, they have difficulty making appropriate decisions about disease-control measures and might waste valuable resources (e.g., antibiotics and vaccines). Few developing countries have independent public health laboratories. Therefore, testing to confirm outbreaks must compete with testing to support patient-care decisions.

Opportunities

Increased attention and resources, advances in technology, and international policies promoting disease control and surveillance can help improve global public health surveillance.

Leadership

WHO overhauled IHR in 2005 (5,6). For the first time, IHR explicitly required each signatory to ensure the development of capacity at the national level to detect aberrations in the health status of all segments of the population within its jurisdiction. In addition, they required the ability to investigate, assess the threat, and respond accordingly, including rapid disclosure of known and suspected threats. This revolutionary global health pact elevates public health surveillance, response, and

transparent reporting to a new level of international diplomacy and standards for normative behavior in health information of a national population. IHR 2005 sets a new bar for surveillance system performance that will encourage surveillance authorities in low-resource countries and their national and international partners to strengthen surveillance programs in every country substantially by the end of 2012, when the new IHR requires achievement of new global surveillance capacity standards (7). The United States can support and highlight surveillance requirements articulated in IHR 2005 in international forums, (e.g., meetings of the World Health Assembly and the United Nations General Assembly) and can dedicate resources to countries willing to commit their own resources (including the time and attention of leaders) to truly establishing the surveillance and response capacities required by the IHR 2005. Technical agencies like CDC can provide crosscutting technical support to partner countries eager to progress in this area.

Partnerships and Resources

An increasing number of organizations are providing technical and/or financial support for improved public health surveillance. WHO provides overall global leadership on public health surveillance (21,22). Other United Nations agencies, the World Bank, and other international development banks also provide support to disease prevention programs in low-resource countries and increasingly underwrite surveillance activities (20). Beginning around 2000, several private or quasi-private global health organizations have become major supporters of global health, including surveillance activities (23). Approximately 100 Global Health Partnerships founded in the past include surveillance components for diseases of special interest (23).

Global initiatives that support surveillance for one particular global health priority can be encouraged or required to do so in a fashion that reinforces and contributes to international norms and standards. These initiatives enable low-resource countries to launch or extend their national strategies and systems to conduct surveillance for their own health priorities. In particular, international disease elimination or eradication programs can help develop or reinforce the infrastructure needed for other national surveillance systems and requirements. These programs often have considerable resources, and integrating surveillance and control efforts where these are a natural fit can improve overall surveillance (24,25). Surveillance systems for eradication of polio, guinea worm, malaria, and onchocerciasis have helped contribute to strengthening of other basic surveillance systems and to health-situation awareness in the most remote and challenging areas.

Technical Standards Development and Interoperability

Adoption of the same norms, rules, and processes (e.g., data standards, standardized data dictionaries, data interfaces, and software development methods) promotes the ability to link data across surveillance programs and is easier for health-care workers and public health surveillance workers to use. WHO has produced standardized case definitions for surveillance, and the Health Metrics Network has developed a conceptual Technical Framework for Health Information Systems at a national level that locates surveillance within a larger enterprise architecture (26,27). WHO promotes an approach to improve overall national public health surveillance by streamlining resources and coordinating surveillance functions at all levels of the health system. It attempts to provide countries with a framework to produce systems that are effective, efficient, and sustainable and to organize all public health surveillance activities into a common public service (28). In general, it is probably most feasible to move stepwise toward standards-based interoperable systems rather than attempting comprehensive surveillance integration initiative all at once (18).

Organizations and an increasing number of networks operate to support, coordinate, and harmonize surveillance. These networks can be important and useful sources of information, technical assistance, mentoring, and tools to surveillance programs in low-resource settings. As new resources and partners become available, developing plans for coordinating work is important for keeping surveillance as simple and sustainable as possible.

Technology in Global Health Settings

New communication and information technologies have the potential to enhance surveillance and health promotion in global health settings. Mobile phone handsets and networks have penetrated the poorest and most peripheral populations (29). The Internet continues to increase in scope and capacity globally. Health surveys can be conducted on handheld computing devices with global positioning system capacity, which has resulted in improved accuracy, sampling, supervision, and timeliness of analysis and reporting (30,31). Laboratory testing technology has evolved so that new assays can be implemented in simpler formats that are usable in environments with weak infrastructures (32,33). Initiatives, such as the Grand Challenges in Global Health (34), promise to continue to spin off new laboratory tools to support surveillance in areas that have lacked laboratory capacity. As new technologies become available, it will be important

to systematically and transparently identify and curate best global practices and harmonize and standardize the practices recommended for low-resource settings.

Conclusion

Public health surveillance plays a critical role in mobilizing and targeting sufficient resources toward health impact goals, and this is especially true in low-resource settings. However, the quality of surveillance in these countries is limited by several factors that should be addressed. More training is needed for clinical, laboratory, informatics, and public health surveillance officers to implement the most promising practices and uses of technology. The design of surveillance systems needs to be appropriate for each country while conforming to standards for global health surveillance. Surveillance systems should span the full spectrum of public health problems (i.e., infectious, chronic, injury, and environmental) corresponding to burden of disease in each country.

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The Role of Public Health Informatics in Enhancing Public Health Surveillance

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Public health surveillance has benefitted from, and has often pioneered, informatics analyses and solutions. However, the field of informatics also serves other facets of public health including emergency response, environmental health, nursing, and administration. Public health informatics has been defined as the systematic application of information and computer science and technology to public health practice, research, and learning (1). It is an interdisciplinary profession that applies mathematics, engineering, information science, and related social sciences (e.g., decision analysis) to important public health problems and processes. Public health informatics is a subdomain of the larger field known as biomedical or health informatics. Health informatics is not synonymous with the term health information technology (IT). Although the concept of health IT encompasses the use of technology in the field of health care, one can think of health informatics as defining the science, the how and why, behind health IT. For example, health IT professionals should be able to resolve infrastructure problems with a network connection, whereas trained public health informaticians should be able to support public health decisions by facilitating the availability of timely, relevant, and high-quality information. In other words, they should always be able to provide advice on methods for achieving a public health goal faster, better, or at a lower cost by leveraging computer science, information science, or technology.

This report proposes a vision for informatics in enhancing public health surveillance, identifies challenges and opportunities, and suggests approaches to attain the vision. This topic was identified by CDC leadership as one of six major concerns that must be addressed by the public health community to advance public health surveillance in the 21st century. The six topics were discussed by CDC workgroups that were convened as part of the 2009 Surveillance Consultation to advance public health surveillance to meet continuing and new challenges (2). Although this report is not based on workgroup discussions, it is intended to continue the conversations with the public health community for a shared vision for public health surveillance in the 21st century.

The work of public health informatics can be divided into three categories. First is the study and description of complex

systems (e.g., models of disease transmission or public health nursing work flow). Second is the identification of opportunities to improve the efficiency and effectiveness of public health systems through innovative data collection or use of information. Third is the implementation and maintenance of processes and systems to achieve such improvements.

The informatics perspective can provide insights and opportunities to improve each of the seven ongoing elements of any public health surveillance system (3). Examples include the following:

- *Planning and system design* – Identifying information and sources that best address a surveillance goal; identifying who will access information, by what methods and under what conditions; and improving analysis or action by improving the surveillance system interaction with other information systems.
- *Data collection* – Identifying potential bias associated with different collection methods (e.g., telephone use or cultural attitudes toward technology); identifying appropriate use of structured data compared with free text, most useful vocabulary, and data standards; and recommending technologies (e.g., global positioning systems and radio-frequency identification) to support easier, faster, and higher-quality data entry in the field.
- *Data management and collation* – Identifying ways to share data across different computing/technology platforms; linking new data with data from legacy systems; and identifying and remedying data-quality problems while ensuring data privacy and security.
- *Analysis* – Identifying appropriate statistical and visualization applications; generating algorithms to alert users to aberrations in health events; and leveraging high-performance computational resources for large data sets or complex analyses.
- *Interpretation* – Determining usefulness of comparing information from one surveillance program with other data sets (related by time, place, person, or condition) for new perspectives and combining data of other sources and quality to provide a context for interpretation.

- *Dissemination* – Recommending appropriate displays of information for users and the best methods to reach the intended audience; facilitating information finding; and identifying benefits for data providers.
- *Application to public health programs* – Assessing the utility of having surveillance data directly flow into information systems that support public health interventions and information elements or standards that facilitate this linkage of surveillance to action and improving access to and use of information produced by a surveillance system for workers in the field and health-care providers.

The evolving field of surveillance informatics presents both challenges and opportunities. The challenges include finding efficient and effective ways of combining multiple sources of complex data and information into meaningful and actionable knowledge (e.g., for situational awareness). As these challenges are met, opportunities will arise for faster, better, and lower cost surveillance and interpretation of health events and trends. The domain of public health informatics designs and evaluates methods appropriate for this complex environment.

Vision

High-value data, information, and knowledge are exchanged in a secure and timely manner for use in public health surveillance tools that are powerful and sophisticated but user friendly to accomplish the work of surveillance and response.

Challenges

Realizing this vision for 21st century public health surveillance requires attention to technology and process and to the specific needs (i.e., requirements) of the public health community. The technology challenges for public health surveillance are daunting. Public health surveillance systems manage data that are high volume, heterogeneous, and distributed widely. In addition, data-quality concerns also might exist, occurring in both new and older legacy systems. Data from many information systems might not be shared easily or exchanged, as that might not have been a requirement of the system at the time of its development. Changing these systems in an environment of limited funding and time presents barriers that are at least as substantial as those for technologic and scientific concerns. Impediments include laws and regulations that preserve different data collection and sharing rules, privacy and security concerns, and academic and economic disincentives to sharing and collaboration.

Technology

Technology that seems the most innovative often relies on adopting and leveraging technology standards. Systems must have the ability not only to talk and listen, but also to understand each other. Unfortunately, adopting only certain standards is insufficient. Both semantic (vocabulary) and syntactic (sentence structure) standards must be implemented and tested to ensure a system's validity. Certain types of errors are associated with data manipulation. Even highly structured data-collection techniques do not completely eliminate data errors. For example, providing data elements that can be selected from a drop-down list cannot prevent the entry of a male who is documented as receiving a Papanicolaou test. However, structured data collection techniques can simplify minimizing or identifying many such data-quality problems.

The standardization process that facilitates computer-readable forms of data, by its very nature, risks losing the richness of information found within unstructured documents (i.e., clinicians' notes or field observations). Accessing and integrating both structured and unstructured data is a major focus in health informatics. As public health surveillance systems collect more and more structured data directly from clinical information systems, this capacity for structured and unstructured data access is increasingly important.

Economic pressures on health care and public health are diminishing the practicality of conducting active surveillance techniques (e.g., using detailed patient interviews, manual chart reviews, or manual data entry). In addition, the need for speed in the face of rapid global pandemics and bioterrorism makes the often incomplete ascertainment from passive reporting processes a substantial challenge. The application of informatics science can help ensure that 21st century systems are as valid as current methods while providing improved efficiency.

Transitioning Systems

The process of change is difficult, and transforming information systems and work flows is no exception. Initial investments of time, human resources, and capital are difficult to assemble. Transitioning to interconnected (i.e., interoperable) public health surveillance information systems from multiple, stand-alone siloed systems involves unique challenges. For example, setting up automated data-collection streams from electronic health record (EHR) data sources is different from manual data abstraction from health-care records. Concerns related to data quality, data standardization, process automation, work flow design, and system validation all need to be addressed. The need to use new and legacy systems

in parallel for a period must be considered and planned for, including the challenging process of transitioning users off legacy systems. Challenges and resistance to change must be balanced by clearly defined desirable goals and objectives associated with the new surveillance system and informed by strong, systematic informatics analyses.

Leadership and Workforce

Because 21st century surveillance crosses the lines of complex social and political systems, it can no longer rely solely on creative innovation among field personnel, but requires senior leaders who can see the opportunities and have the resources to address the challenges. Optimistic and strong leadership for public health informatics is critical to augment public health surveillance sufficiently in the 21st century. Public health leaders have the responsibility of examining their workforce and making the conscious decisions to augment it with public health informatics expertise. Leadership also requires the ability to assemble the appropriate set of stakeholders when addressing 21st century public health surveillance challenges. New challenges will, for example, require input and guidance from legal and privacy subject-matter specialists. Leadership is needed to devote adequate funding to implement short-term improvements and long-term visions of informatics-augmented public health surveillance. The leadership challenge is complex considering the need to integrate siloed systems, which are often governed and funded independently (i.e., HIV, TB, lead poisoning). All members of the team, from senior management to the end user, need to be invested in creating the most usable, goal-oriented system possible, identifying the ways electronic information can be managed and used for the maximum benefit.

Opportunities

Numerous opportunities are available to facilitate public health informatics' impact on public health surveillance. An important opportunity is the increasing adoption of EHRs and health information exchange (HIE) systems. The demonstration of meaningful use of EHRs, as articulated in the Centers for Medicare and Medicaid Services (CMS) final rule, and described in detail in the next section, includes three public health requirements: electronic submission to public health agencies of immunization registry data, reportable lab results data, and syndromic surveillance data.

Electronic Health Records

EHR and HIE systems collate information about individual patients from different information systems (e.g., registration, clinical record, laboratory, and imaging) and through information exchange or aggregation from across different provider entities. Adoption of the systems is being incentivized and facilitated by the Health Information Technology for Economic and Clinical Health (HITECH) Act in the United States. Enacted as part of the American Recovery and Reinvestment Act (ARRA) of 2009 (4), the HITECH act authorized Medicaid and Medicare financial incentives for providers to adopt and use EHRs and authorized funding for the Office of the National Coordinator for Health Information Technology (ONC) to encourage health IT adoption, aid in standard-setting, build work force, and support state- and regional-level development of HIE.

The goal of this funding has been to modernize the health system by promoting and expanding the adoption of health information technology by 2014. Consequently, opportunities are available to facilitate public health informatics' impact on public health surveillance. For example, hospitals now have an economic incentive to electronically transmit reportable laboratory results to public health agencies (electronic laboratory reporting). This can improve the speed and ascertainment completeness of reporting and also can affect the surveillance work flow and work load. As the semantics and the syntax of such electronic reports become more widely adopted (a process also accelerated by the HITECH Act), such information can flow more easily between computer applications and systems (i.e., interoperability). This interoperability creates the potential to eliminate data-reentry into case management applications, which can improve efficiency while reducing resource requirements and data-entry errors. As clinicians and public health workers increasingly work in electronic environments using the same types of interoperable data, the opportunity for bidirectional communication around cases or clusters of conditions also can increase.

Meaningful Use of EHRs

In the summer of 2010, the CMS issued a final rule on the Electronic Health Record Incentive Program (42 CFR Parts 412, 413, 422, and 495). To be eligible to receive CMS incentive payments for the use of electronic health record technology, participants must implement certified technology and also must demonstrate meaningful use of that technology. To receive incentive payments in 2011 and 2012, eligible providers must perform one of three forms of

reporting to public health agencies: submitting electronic data to immunization registries, submitting reportable lab results to public health agencies, and submitting electronic syndromic surveillance data to public health agencies. EHRs also must record demographic and other data of interest for surveillance systems (e.g., racial, ethnic, and language). The requirements for meaningful use incentives will change and evolve over the next few years. In fact, though incentives are currently in place, financial penalties are scheduled to take effect by 2015 (5).

Other Funding

Several other programs provide additional funds to support the development of health IT solutions. One is the Strategic Health IT Advanced Research Projects (SHARP) program, which is funded by ARRA through the ONC. SHARP awards have funded research to identify technology solutions to address well-documented problems impeding adoption of health information technology (health IT). CDC is on the federal steering committee overseeing the SHARP program and is providing input to ensure that the public health perspective is considered. Another series of grants support HIE systems in states and advanced demonstrations for the use of exchange systems to improve care quality and public health outcomes in local areas (BEACON grants). Another program, the Program of Assistance for University-Based Training, is prepared to produce trained public health informaticians in universities during the next few years (6).

Technologic Advances

Electronic real-time data regarding the environment (e.g., water-quality data from supervisory control and data-acquisition systems) and remote sensing systems (continuous and/or automated collection and transmission) combined with the global positioning system and geographic information system revolutions also facilitate the overlay of environmental and person-centric information by time and place. As public participation in submitting information into the World Wide Web increases (often labeled Web 2.0 and accelerated by the widespread adoption of smart phones and other wireless devices), the possibility exists to tap into information directly supplied by large numbers of persons (crowdsourcing) (7) or derived from near-real time information-seeking behaviors (8). Several of these types of data have been used to derive signals of important health trends faster and more broadly than more traditional case reporting systems (e.g., outbreak detection or monitoring by syndromic surveillance systems).

Public Health Informaticians

One of the most valuable resources to be tapped is the diverse population of public health professionals (formally trained or not) who have already made informatics a priority in their work. These include staff at CDC and other federal agencies; state and local health departments, members of the Public Health Data Standards Consortium and informatics leaders in several public health associations, workers from all walks of public health life who attend Public Health Information Network meetings, university scholars of public health informatics, and staffs of nonprofit organizations like the Public Health Informatics Institute. Representatives of these groups come together to harmonize an ongoing agenda for public health informatics at the Joint Public Health Informatics Taskforce, a coordinating body of several associations (9). By educating leaders and peers, testing innovations, and disseminating lessons learned, these persons and agencies are improving public health surveillance (and ultimately health outcomes) by reducing costs, bridging silos, and improving access to timely, quality information.

Conclusion

These opportunities also represent a crisis: the move from manual reporting from traditional data sources to automated data collection from novel data sources has suddenly begun in earnest, and public health agencies will need to keep pace or risk gradually losing old systems of health event ascertainment and failing to achieve the benefits of new electronic reporting. Several steps can help public health agencies. ONC-specified standards to accept surveillance information from health-care providers should be adopted but will require changes to established surveillance and other information management systems. Public health agencies with limited informatics support might find it valuable to work with academic centers or other agencies to facilitate their transition to the use of more standardized electronic data. Using this form of data should, in time, enable them to reduce labor while increasing the sophistication of their analyses in both surveillance systems and response systems. Active collaboration on new information system and data collection initiatives can reap substantial benefits.

To achieve the vision, certain key points must be addressed. Stand-alone systems should be considered only when no other options are available. Existing systems (including commercial off-the-shelf solutions) should be used or modified wherever possible and existing data streams should be leveraged for multiple purposes. In the search for change, the Pareto principle is instructive — that there exists a 20% change that has the ability to solve 80% of the problem (10). Rather than

delaying work by striving to develop an ideal system, small, incremental steps should be considered rather than immediate wholesale changes. Although time consuming, planning for evaluations of surveillance systems can affect both time and resource savings. Combining disparate sources and forms of information can provide a richer picture of disease burden than individual data streams. Whenever possible, support staff should be enabled to sharpen their skills in fundamentals of public health informatics using local resources, online training, or national conferences. Even with the best planning, problems will occur; detecting them as early as possible and addressing them immediately is essential. Active participation in EHR/HIE initiatives will help ensure that public health is represented in planning as the overall health-care system continues to change and evolve.

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Public Health Surveillance Workforce of the Future

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Although electronic data systems that monitor for health threats are becoming increasingly automated, human expertise is, and always will be, critical to recognizing potential cases of disease, diagnosing disease, reporting diseases or conditions, analyzing and interpreting data, and communicating results to all stakeholders. For this reason, the nation's health professionals from all disciplines and at all levels are fundamental to sustaining and enhancing public health surveillance capacity.

Surveillance data come from different sources. Clinicians recognize diseases and other conditions, intentional or unintentional injuries, poisonings, or other health threats and report findings to state and local health departments (1). After collecting the surveillance data, public health workers synthesize, analyze, interpret, and act on the findings. Professionals from diverse disciplines — working in the nation's health system and at all levels of government and geographic jurisdictions — provide the skills necessary for the components of a surveillance system to work effectively.

Traditional disciplines performing surveillance include epidemiologists, environmental health specialists, laboratorians, physicians, nurses, infection-control professionals, and public health managers (1). Other disciplines have become increasingly important, including informaticians, pharmacists, law enforcement, coroners, medical examiners, and analytic specialists (e.g., statisticians and mathematics modelers), information and decision scientists (i.e., scientists who use highly advanced modeling, statistical tools, and behavioral predictive models to inform decision makers on public health policy), natural language processing specialists, analytic data management programmers, and knowledge managers (i.e., professionals representing varied fields who apply concepts of information systems, computer science, and business administration to improve knowledge sharing, reuse, learning, collaboration, and innovation within a public health organization).

Although the astute clinician remains a crucial link in surveillance, persons from other disciplines (e.g., laboratorians, pharmacists, and law enforcement) are often the first to recognize events that require prompt interventions of public health workers. In light of the importance of each professional to the effectiveness of the nation's surveillance system, workforce initiatives are needed to ensure that the right talent is in the right job at the right time. Such efforts would focus on enhancing the skills and availability of public health workers and also the diverse disciplines that contribute information and expertise to the surveillance process. Strengthening the nation's public health surveillance capacity requires commitment of resources and creative solutions to extend the skills and reach of the workforce. These solutions can create job opportunities, training, and viable career paths for health professionals at federal, state, and local levels.

This report proposes a vision for the public health workforce of the future, identifies challenges and opportunities, and suggests approaches to attain the vision. This topic was identified by CDC leadership as one of six major concerns that must be addressed by the public health community to advance public health surveillance in the 21st century. The six topics were discussed by CDC workgroups that were convened as part of the 2009 Surveillance Consultation to advance public health surveillance to meet continuing and new challenges (2). This report is based on workgroup discussions and is intended to continue the conversations with the public health community for a shared vision for public health surveillance in the 21st century.

Vision

A knowledgeable, skilled, and effective workforce to meet the diverse needs of public health surveillance.

Challenges

Workforce Shortages and Need for Analysis

Serious public health workforce shortages exist in disciplines that perform surveillance functions, and these shortages limit the nation's capacity and plans for enhancement. Throughout the country, states and communities report a need for more public health nurses, epidemiologists, laboratory workers, informaticians, and environmental health professionals. The Association of Schools of Public Health (ASPH) estimates that 250,000 more public health workers will be needed by 2020 to maintain capacity (3,4). Data are lacking for the numbers of workers in the diverse disciplines that perform surveillance functions.

Although reports indicate that the number of public health workers is insufficient, enumeration studies of the public health workforce are dated, incomplete, and lack specificity (5–7). For example, the Council of State and Territorial Epidemiologists (CSTE) reports biannually on epidemiologic capacity as determined by each state epidemiologist, but this type of information for other disciplines is lacking or incomplete (8). Knowledge also is limited regarding the disciplines that are new to performing or supporting surveillance. Their roles, contributions, and extent of their surveillance activities have not been described and warrant articulation. This is doubly important in the context of health reform, as public health practice is changing and the effect on the public health workforce is not yet known.

An ongoing systematic approach for monitoring the workforce is needed, including strategies that characterize the workforce for surveillance — who they are, where they work, and their roles by discipline, program areas, and geography. More information is needed regarding existing surveillance workforce gaps and the diversity and balance or mix of disciplines to determine which are underrepresented, what new disciplines are needed, and where they are needed.

Need for Continuous Learning and Core Competencies

Numerous reports document the status of academic education for health professionals (e.g., public health professionals, physicians, and nurses) and the need for continuous learning (9–18). Addressing the education of both health care and public health professionals, a Global Independent Commission on Education of Health Professionals for the 21st Century stated, “Professional education has not kept pace with 21st century challenges, largely because of fragmented, outdated, and static curricula that produce ill-equipped graduates. The

problems include a mismatch of competencies to patient and population needs ... and efforts to address the deficiencies have mostly floundered, in part because of the tendency of various professions to act in isolation or even in competition with each other” (10). This commission called for “a new round of more agile and rapid core competencies based on transnational, multiprofessional, and long-term perspectives to serve the needs of individuals and populations.”

Recommendations have been made for improving U.S. public health education over several decades (12–14). The majority of public health workers lack formal training in public health (i.e., only 20%–25% of the public health workforce graduates from an accredited school or program of public health) (11,13). In 1988, The Institute of Medicine (IOM) recommended that schools of public health should focus on the training of leaders and that professional education be grounded in real world public health, adding practicum experiences to the curriculum and formal linkages between schools of public health and public health agencies so that students could learn from instructors with hands-on experience (11,13). The 2003 IOM report “Who Will Keep the Public Healthy” examined the education of public health professionals in the 21st century and provided a framework and recommendations for strengthening public health education (14). Among the recommendations were curricula and teaching approaches to incorporate enhanced participation in the educational process by those in senior practice positions; expansion of supervised practice opportunities and sites, such as community-based public health programs, delivery systems, and health agencies; and establishment of relations with other health-science schools, community organizations, and health organizations.

In a 2005 symposium, public health scholar/practitioners reassessed the status of practice-oriented scholarship (15). They acknowledged that changes had occurred and the early vision for practice-oriented scholarship had been realized. However, comments from some of these leaders indicated ongoing challenges, including “the public health faculty member with practice experience is a rare commodity” and “high proportions of public health faculty are classic academics with PhDs whose scope of experience is research, publishing, and academic conferencing” (15). In 2009, ASPH stated that schools of public health had essentially met the challenges raised by the 1988 and 2003 IOM reports on enhancing academic-practice linkages, but acknowledged that practice-based service for public health remains challenging (11,14,16).

Further complicating workforce capacity for surveillance, many physicians, nurses, and other health professionals graduate with little to no grounding in the concept of prevention or population health (1,16,18). Although multiple IOM reports addressed the importance of a population health

perspective in preparing physicians, multiple publications indicate the implementation has been neither consistent nor effective (9-12,14,18,19). Health promotion and disease-prevention education that includes a surveillance component added to the curriculum for health professionals would raise clinician awareness of their roles in public health surveillance (9,19,20).

To guide workforce development activities for improving education and to support recruitment and career paths for health professionals and others who contribute to public health surveillance, competencies are needed. General competencies have not been developed for the workforce that contributes to surveillance, and discipline-specific competencies with levels and tiers are incomplete. Epidemiology and informatics have general and discipline-specific surveillance competencies with levels and tiers, whereas other disciplines do not (21,22).

Because many public health workers, clinicians, and those new to roles in surveillance have not had academic preparation in public health or surveillance, life-long learning is critical (11,12,23). Vital to improving the nation's surveillance capacity is the establishment of a framework for continuous learning and training to ensure that current and future workers are prepared to meet the challenges ahead. The workforce work group of the 2009 Consultation on CDC's Vision for Public Health Surveillance concluded that such a framework would

- articulate professional roles and competencies for what various disciplines need to know, and establish levels of proficiency;
- base training and education on competency requirements and instructionally sound programs throughout the educational continuum, from academic curricula for students to continuing education programs for current workers;
- include new, evolving curricula and use various learning methods to combine face-to-face instruction and distance learning with the aim of providing realistic and practical opportunities for learners;
- include evaluation for a continuous improvement loop for program accountability; and
- offer training and career-development paths to increase the proficiency of those who serve in a surveillance role.

Despite the documented recommendations for improvements in education and training, funding for these programs has been unstable. Enhancements are challenging in an era of shrinking budgets even for CDC's established, highly regarded, applied epidemiology and informatics fellowship training programs. These fellowship programs, other CDC training programs (e.g., the National Laboratory Training Network), training at all levels of the public health system, and development of surveillance training for health-care practitioners are critical to

effect workforce improvements of public health surveillance. Investments in education and training must be a priority for sustainable changes to occur.

Organizational Obstacles

Organizational, operational, and human resource challenges influence workers' ability to do their jobs. Public health agencies often have rigid classification systems that hamper the creation of new positions and lack the organizational support structure (e.g., supervision, technical assistance, and technology) for integrating new positions. Lack of job classifications affects both hiring and career paths in public health agencies. In certain cases, position descriptions are not available for newer disciplines to facilitate hiring for certain skill sets (e.g., informatics). Also, without a job classification, no clear path exists for promotion or career advancement. Assessments are needed to identify administrative gaps and inefficiencies (e.g., the effects of inadequate support staff on surveillance functions) and to ensure the workforce has access to technology and other tools with which to do their jobs.

Budget and Staffing Context

Budget shortfalls and staff shortages at local, state, and federal levels affect the public health surveillance workforce. Examples of challenges related to solving public health workforce shortages include the volume of retiring workers, an insufficient supply of trained workers to replace retirees, need for training funding, and uncompetitive salaries and benefits (5). Inequities in pay and benefits (between federal and state or local government and between government and private sectors) and the frequent use of cost-cutting measures that restrict staffing (e.g., hiring caps or freezes, travel freezes, and furloughs) compromise the ability to attract and retain qualified public health workers. As federal, state, and local funds have diminished, positions are being eliminated when workers leave, creating long-term losses. Consequently, positions are unavailable for new disciplines to support surveillance activities. In addition, at a time when critical infrastructure needs have been identified (e.g., training for new skills and information technology support for surveillance), resources to meet those needs are lacking.

The U.S. economic recession further complicates the situation. Although certain public health workers might be delaying retirement, others are being forced to leave jobs because of layoffs. The Association of State and Territorial Health Officials (ASTHO) conducts semiannual surveys of budget cut effects on public health. Before the September 2009 Surveillance Consultation, ASTHO reported accelerating job and program cuts and that 44% of states had a vacancy rate of

≥10% (24). The March 2011 ASTHO survey reported that approximately 15,250 jobs have been lost and that, since 2008, 87% of all state and territorial health agencies have experienced job losses (7). The National Association of County and City Health Officials (NACCHO) reported in March 2011 that 29,000 cumulative jobs were lost in local health departments across the country from 2008 to 2010 (6). If resources to secure necessary workers continue to be scarce, state and local public health workforce shortages are likely to worsen and impact public health surveillance.

Opportunities

Health reform provides an opportunity to clarify or redefine surveillance workforce needs, roles, and disciplines. The emphasis on prevention drives closer alignment of health care and public health professionals to practice in an era of accountability. It also provides impetus to strengthen links among federal agencies and partnerships with other public health and professional organizations to support workforce recruitment, training, and retention. Collaboration among traditional public health partners (e.g., CDC, ASTHO, NACCHO, CSTE, ASPH, and the Association of Public Health Laboratories) and other stakeholder organizations (e.g., Health Resources and Services Administration, American Medical Association, National Environmental Health Association, and American Medical Informatics Association) can be strengthened to better articulate roles, determine training needs, and guide standards and policy development. In addition, existing partnerships might be underdeveloped and new partnerships are needed (e.g., those aimed at improving links between the nation's public health and health-care systems). If these potentials are actualized, the workforce will be stronger, more competent, and better prepared to enhance surveillance capacity and to improve individual health and that of communities. The American Recovery and Reinvestment Act (ARRA) of 2009 and the 2010 Patient Protection and Affordable Care Act (ACA) present opportunities for strengthening the workforce for public health surveillance (25,26).

ARRA provided a one-time investment in public health to help offset deep budget reductions of state and local public health departments. An investment of \$50 million was authorized to support surveillance in states and prevention of health-care-associated infections (HAIs), encourage collaboration, train the workforce in HAI prevention, and measure outcomes (27,28). ACA has selected provisions designed to eliminate shortages of public health workers and

to strengthen workforce capacity (29). ACA provisions focus on improving public health workforce analysis and capacity and expanding Epidemiology and Laboratory Capacity grants to public health agencies for advancing surveillance and workforce roles related to surveillance functions. ACA also expands CDC's fellowship programs in applied public health epidemiology, public health laboratory science, and public health informatics to address documented workforce shortages in state and local health departments. With ACA's provisions related to public health infrastructure, training, surveillance, and epidemiology and information technology, potential exists for establishing a comprehensive framework for public health workforce improvement. Appropriation decisions will determine the degree to which the provisions can be implemented (29,30).

Conclusions

Developing the workforce to support public health surveillance requires multiple actions. A workforce analysis is necessary to provide information about the composition and numbers of workers. This activity would include enumeration of the workforce and existing gaps, forecasting and identifying future needs, and monitoring how a workforce analysis is applied to addressing programmatic needs. Immediate training needs could be addressed by conducting a surveillance training needs assessment and job task analysis; developing surveillance competencies that complement other competency sets; designing, developing, providing, and supporting training for the existing workforce; establishing systems for continuous learning and making resources available; and evaluating the effectiveness of existing and future training.

Adequate support structures and access to essential tools are necessary for the surveillance workforce to perform their jobs. Additional actions might include the following:

- conducting job task analysis with representatives of different disciplines;
- identifying administrative inefficiencies (e.g., conduct cost analyses) and needed technologic tools;
- acquiring resources to ensure access to those tools;
- providing opportunities for career advancement; and
- monitoring workforce retention.

Finally, partnerships among stakeholders can be strengthened to increase visibility of workforce needs and influence supportive policies within organizations and at federal, state, and local levels. Partner collaborations can include identifying and sharing successful interventions, developing an overarching workforce strategy, identifying existing laws and

policies relevant to the public health workforce and leveraging these among the stakeholders and their constituencies, and monitoring and evaluating the effect of policy changes on the workforce (e.g., accreditation standards and ACA).

Because of the changing epidemiology of diseases and related reporting requirements, combined with the opportunities offered by the advances in information technology and enhanced public health surveillance, education and training are critical to strengthening public health workforce capacity. An adequate, educated, knowledgeable, and skilled health workforce that is equipped with necessary tools is vital for an effective public health surveillance system. To achieve these goals, collaboration with partners is essential for enhancing the public health surveillance workforce of the future.

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Public Health Surveillance Data: Legal, Policy, Ethical, Regulatory, and Practical Issues

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In the United States, data systems are created by the ongoing, systematic collection of health, demographic, and other information through federally funded national surveys, vital statistics, public and private administrative and claims data, regulatory data, and medical records data. Certain data systems are designed to support public health surveillance and have used well-defined protocols and standard analytic methods for assessing specific health outcomes, exposures, or other endpoints. However, other data systems have been designed for a different purpose but can be used by public health programs for surveillance. Several public health surveillance programs rely substantially on others' data systems. An example of data used for surveillance purposes but collected for another reason is vital statistics data. CDC's National Center for Health Statistics (NCHS) purchases, aggregates, and disseminates vital statistics (birth and death rates) that are collected at the state level. These data are used to understand disease burden, monitor trends, and guide public health action. Administrative data also can be used for surveillance purposes (e.g., Medicare and Social Security Disability data that have been linked to survey data to monitor changes in health and health-care use over time).

Some data can be released easily to others with few or no restrictions. These include public use data sets and some regulatory or administrative data; however, these files were restricted at some point but were altered to protect respondent confidentiality and privacy. Public use data sets can be shared with everyone because they will not contain personally identifiable information (PII) and have had information removed that would allow identification of any persons. Some data cannot be released to anyone under almost any circumstances because they are highly sensitive and considered classified for security purposes. Data that allow identification of persons, either collected by surveillance programs or by other programs, can only be shared if regulation or legislation allows. PII usually is needed to identify information that allows these data to be linked to other data sets or to identify persons with a

specific health condition or disease. In all but the most unusual circumstances at the level of data collection, identifiable data are maintained where public health surveillance interventions occur, usually at the local or state level.

Collaborative efforts to meet the needs of public health surveillance programs and other initiatives, programs, or objectives (e.g., information on payment, increased use of medical records, or evaluation of effectiveness of treatment) can maximize the utility of data collected. Information from disparate sources or programs often shed light on patterns that individual program data cannot. Furthermore, appropriate use of data sets collected for multiple purposes can, in some instances, be more cost effective than the collection of new data targeted at a specific condition or health event. The ability of data stewards to share with surveillance or other programs depends on several factors: 1) the rules and regulations governing how and why the data are collected and released, 2) the availability of resources to put the data into a form that can be shared, and 3) the willingness to use those resources. One method of distributing previously restricted data is to determine how to make the data unrestricted (e.g., by perturbing the data or releasing pretabulated, aggregated estimates that preserve confidentiality).

This report proposes a vision for improving access to and sharing of data useful for public health surveillance, identifies challenges and opportunities, and suggests approaches to attain the vision. This topic was identified by CDC leadership as one of six major concerns that must be addressed by the public health community to advance public health surveillance in the 21st century. The six topics were discussed by CDC workgroups that were convened as part of the 2009 Surveillance Consultation to advance public health surveillance to meet continuing and new challenges (1). This report is based on workgroup discussions and is intended to continue the conversations with the public health community for a shared vision for public health surveillance in the 21st century.

Vision

All data potentially relevant to public health surveillance would be harmonized across data systems, interoperable, and easily accessed by the maximum number of users in as timely a manner while protecting confidentiality and privacy of respondents.

Challenges

Constraints on data sharing of nonpublic-use (i.e., restricted) data exist. Occasionally, data stewards are reluctant to release data to others because they fear misuse of the data by those who are not well acquainted with its legal and technical limitations on use. In other cases, data stewards are not willing to share data either for political or historical reasons or because they fear that if someone else has access to their data their program's importance or visibility might be reduced. However, there are methods that can help protect against the identification of persons. For example, data perturbation is a data security technique that allows users to ascertain key summary information about the data while preventing a security breach.

Legal, Regulatory, and Ethical Limitations

All governmental data collection and release activities are governed by rules, regulations, and legislative authorizations. These include authorizing legislation. For example, Section 308 (d) of the Public Health Service Act (2) limits the release of the sensitive surveillance data that are either identifiable or potentially identifiable for any purpose other than the purpose for which it was supplied. The Health Insurance Portability and Accountability Act of (HIPAA) Privacy Rule (3) regulates the use and disclosure of individually identifiable information by health plans, providers, and other covered entities. The majority of government organizations have their own internal confidentiality restrictions on data they release. These might be more (but not less) stringent than those imposed by federal legislation and regulations. In other situations, an agency or program receives funds to collect and/or analyze specific data when it would be more efficient, or effective, for another program to do so. The funding streams and mechanisms affect how data are collected. For some private enterprises, data might not be released because they are proprietary (e.g., they might require other users to purchase the data and they are not bound by any rules or impetus requiring them to release data if they do not wish to do so).

In addition, ethical constraints not specified in legislation and regulation must be considered. Uses of data beyond those

for disease-monitoring purposes should be ethically justified and meet some minimal standard for the data to be shared (4). For example, public health surveillance data are collected without patient consent and contain sensitive information. Even if law or regulation allows these data to be shared, uses other than those for which they are specifically collected should be considered carefully when sharing data with others. For data collection processes in which respondents have signed or signified that they consent to have their data collected, analyzed, and released, data can only be used for purposes that the respondents agreed to when consenting to provide data.

Administrative Barriers

Administrative and regulatory requirements of federal, state, and local governments can limit data sharing. Security concerns and regulations, multimode displays (e.g., displaying data both in hard copy and web-based formats), and required use of specific software for data dissemination can affect timeliness and the ability to release data. These requirements can secure data and computer systems and ensure patient, enrollee, or respondent privacy and confidentiality. However, substantial programmatic resources and financial and personnel support are necessary to implement these mandates.

Resources are often used heavily in the front-end planning, data collection, and analytic phases of public health surveillance with proportionately less focus on data dissemination and translation phases. This could be related to insufficient resources that often make data sharing and investment in data sharing enhancements a lower priority than program work. Scarce resources also might make competition for funding contentious, which can result in lack of attention to relationship building at the highest levels that, if remedied, could facilitate future data-sharing arrangements.

Processing data can result in delays for their release. Certain data collection programs do expend substantial resources on data cleaning and presentation and believe that data must be cleaned thoroughly and manipulated before they can be released and interpreted correctly by users. However, by the time data can be released, the value to public health surveillance programs might be limited if rapid response to a problem is necessary (e.g., to prevent spread of an infectious disease). On the other hand, programs that address chronic health conditions that develop slowly over time can benefit from use of data with longer, but specified, release delays.

However, by the time data can be released, they are of limited value to the public health surveillance programs that need data that are as current as possible. This is sometimes the case for

programs that want to use the data for outbreak surveillance or evaluation of new policies and programs. However, other programs can use data with longer, but specified, release delays.

Existing funding mechanisms for surveillance activities can impede the ability of federal agencies to negotiate data sharing and hinder their ability to influence how data collected can be shared with others. For example, the use of cooperative agreements can limit the ability of federal agencies to require data sharing because the funding agency might have less control over data products than when the funding mechanism is a contract that can directly specify the delivery and form of data release.

Data Incompatibilities

Data sharing can be impeded if coding, formatting, definitions, and methods differ substantially or if data are stored in incompatible formats. Resources are needed to manipulate, code, and transmit data to partners. Also, some analysis of data (e.g., analysis of trends) could be affected over time by changes in data collection, methods, and coding. These caveats often are not documented.

Data sharing can be limited by the lack of user-friendly data dissemination tools or adequate and detailed documentation and distribution. If data descriptions are not available, well-documented, and advertised, detailed data from federal data systems are much less likely to be used by others, including surveillance programs, to meet their specific data needs.

Data Sharing Guidance

Although policies on data sharing exist in federal and other governmental agencies, a lack of standard language and processes related to data sharing across federal programs exists, with perhaps even less standardization at state and local levels. Efforts to standardize data sharing methods have been attempted throughout the U.S. Department of Health and Human Services but have not been realized in several instances. To date, guidance by the research and policy community on matters related to data policies and procedures at the national, state, and local levels has been inconsistent.

Federal, state, and local governments have produced guidance documents on dissemination and sharing of data. For example, CDC and the Council of State and Territorial Epidemiologists developed the *CDC/ATSDR Policy on Releasing and Sharing Data* (5). These documents ensure that CDC routinely provides data to its partners for appropriate public health purposes while balancing privacy concerns, federal and state confidentiality concerns, proprietary

interests, national security interests, or law enforcement activities (6). However, certain data stewards or potential data users might not be familiar with these documents. Similarly, experts and resources on how to create agreements with other agencies and nongovernmental organizations exists but are not easily located or shared (7).

Opportunities

Even with legal and regulatory restrictions on release and use of data sets that can be used for public health surveillance, mechanisms have been created that facilitate surveillance and other programs' ability to share data or to use other programs' data. In many cases, the possibility exists to either 1) deidentify the data, 2) obtain a subset of restricted data that complies with regulations concerning release (e.g., a perturbed data set in which data are changed before the dissemination in such a way that the disclosure risk for the confidential data is decreased but the information content is retained as far as possible, or one with small cells suppressed), or 3) develop agreements whereby data are released to others who need it for public health surveillance but who agree not to identify or contact any persons. In some cases, with sufficient cooperation or collaboration between surveillance program and data steward, surveillance programs are able to obtain at least a subset of data that meets their needs. Providing feedback or other incentives to the data stewards can encourage data sharing.

Several federal projects have been conducted successfully that share restricted data with other agencies and nongovernmental organizations. For example, CDC has an ongoing relation with the Social Security Administration and the Centers for Medicare and Medicaid Services to link their data to health-survey data and vital statistics data. Lessons learned in the process of negotiating and implementing these interagency agreements could be useful to others interested in sharing data with these agencies (6). However, other federal, state, and local agencies and health departments have failed to obtain access to desired administrative or survey data. Interagency agreements specify the conditions that must be met for government entities to share data and allow data to be shared under specific conditions and constraints. As more data-sharing agreements are realized, important lessons in how to share data have emerged, such as how to write data sharing agreements, how to transmit and receive data securely, and how to release shared data without violating confidentiality and privacy of respondents. Past collaborations have been the basis for model data-sharing agreements. Personnel participating in these data-sharing arrangements also can be a valuable resource for new initiatives.

Another example is the collaborative review process developed between NCHS and the National Association for Public Health Statistics and Information Systems (representing the states and territories) for review and approval of data requests involving release of restricted vital statistics files to researchers. This review by state representatives is conducted before the NCHS review and includes both federal and nonfederal requests for restricted data files for research purposes, enabling the state data owners to share oversight with NCHS in the dissemination of the restricted data.

Researchers can gain access to some restricted data by using the NCHS Research Data Center (RDC) (available from <http://www.cdc.gov/rdc/>), which facilitates access to detailed data files in a secure environment without jeopardizing the privacy of respondents or confidentiality of the data. Resources are necessary to operate the RDCs and to prepare the data for use within the RDCs. Numerous federal agencies, including NCHS, AHRQ, and the U.S. Census Bureau, are sponsoring RDCs through which they can allow use of confidential data. Multiple data sets can be combined in these RDC settings.

Opportunities are available for collecting new information using existing data collection systems. For example, certain federally funded, annually conducted surveillance surveys invite interested parties to propose new data elements or topic-specific modules. States and partners can add new modules to the Behavioral Risk Factor Surveillance System (BRFSS) questionnaires after review and permission of state BRFSS coordinators; questions have been added to the BRFSS to monitor new or ongoing program or policy initiatives.

Collection of informed consent at the time of data collection to permit less restricted use of respondents' data can enhance data use. If respondents do not consent to have their data used for specific purposes, including data sharing, when they are first interviewed or when their data are collected, obtaining consent at a later date is difficult.

The Office of Management and Budget mandates the use of specific questions for selected variables (e.g., race, ethnicity, and sex). This is a first step in promoting standards for data that can be used in public health surveillance. The next steps are to standardize data formats and data elements, codes, and methods across programs to meet the needs of both data collectors and surveillance programs. However, some flexibility must be maintained to ensure collection of the most accurate and appropriate data to meet the goals of the surveillance systems. With increasing emphasis on electronic data-standards development, opportunities are created to develop public/private partnerships that benefit all partners and enhance data collection and use for public health surveillance.

With the evolution of new technologies, database managers are able increasingly to share information and provide ready

access (e.g., user-friendly, web-based query systems) to their program-specific data. Potential users can then familiarize themselves with the data. This allows potential data users to determine how the data can meet their specific program objectives and then pursue data-sharing arrangements for restricted data sets. This approach has been successful for sharing violent death data from the National Violent Death Reporting System. Public use data are available on the Web-based Injury Statistics Query and Reporting System (WISQARS) (available at <http://www.cdc.gov/injury/wisqars>) and a system is in place to request a restricted-access, detailed NVDRS data file. States and localities also have new and innovative data extraction tools, including Utah's IBIS system (<http://ibis.health.utah.gov/home/ContactInformation.html>), Missouri's MICA portals (<http://www.dhss.mo.gov/DataAndStatisticalReports/index.html>), and Boston's Health Indicators Project (<http://www.preventioninstitute.org/component/jlibrary/article/id-275/127.html>). One recent innovation is the HHS-wide collaboration to produce the Health Indicators Warehouse (HIW), which stores preconstructed indicator data at the national, state, hospital referral region, and county level. HIW is designed to allow users to easily download these indicators to be used for their own applications and applies suppression rules that allow previously restricted data to be accessed easily at subnational levels.

Conclusion

Improving data sharing to allow more and better data to be used to monitor the public's health is in everyone's interest. As the lead public health surveillance agency in the Federal government, the *CDC/ATSDR Policy on Releasing and Sharing Data* states: "CDC believes that public health and scientific advancement are best served when data are released to, or shared with, other public health agencies, academic researchers, and appropriate private researchers in an open, timely, and appropriate way. The interests of the public, which include timely releases of data for further analysis, transcends whatever claim scientists may believe they have to ownership of data acquired or generated using federal funds. Such data are, in fact, owned by the federal government and thus belong to the citizens of the United States" (6). To meet this policy, organizations that conduct public health surveillance and collect surveillance-related data should provide leadership, expertise, and service and devote sufficient resources to nurturing new data-sharing arrangements and to support existing ones. The goal is to have guidance on data release and sharing that balances the desire to disseminate data as broadly as possible with the need to maintain high standards and

protect individuals' privacy and the confidentiality of the data (8). Specifically, data-use agreements should be shared widely to provide models for others interested in sharing data; data sharing should be promoted by developing supportive funding mechanisms, devoting resources, fostering partnerships and centralizing support; and methods and procedures should be standardized across datasets.

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Analytical Challenges for Emerging Public Health Surveillance

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The root of effective disease control and prevention is an informed understanding of the epidemiology of a particular disease based on sound scientific interpretation of evidence. Such evidence must frequently be transformed from raw data into consumable information before it can be used for making decisions, determining policy, and conducting programs. However, the work of building such evidence in public health practice — doing the right thing at the right time — is essentially hidden from view. Surveillance involves acquiring, analyzing, and interpreting data and information from several sources across various systems. Achieving the goals and objectives of surveillance investments requires attention to analytic requirements of such systems. The process requires computer programming, statistical reasoning, subject matter expertise, often modeling, and effective communication skills.

Public health surveillance relies heavily on data collected by two different approaches that require different types of analyses and interpretations of what the data represent. First are surveys that are designed to be representative of the population from which they are sampled. These data are analyzed using validated statistical methodologies that directly correspond to the survey design for exploration and inference in public health. In contrast, data used for public health surveillance that are not collected using probability sampling (e.g., case reports, automated electronic health record data, or syndromic surveillance) require a different approach for analysis and interpretation. To avoid bias, maintain objectivity, cross-validate findings, and ensure data quality, analysts must work with the data empirically on a regular basis (i.e., every day) to have a thorough understanding of the data-generating environment, detailed particulars of the specific data source, and the purpose of the surveillance system.

Integrating and analyzing data from new and multiple sources pose new challenges. A major reason is that time and experience are fundamental to learning about the data, the

system, how to prepare the data for analysis, and to analyze the data and create reports, often on a rapid cyclic schedule. In certain instances, the required work has never been done before. A contemporary example is BioSense (1), which brought together data from numerous disparate systems, relying on expert analytic data managers to quickly assess new data-source content, guide systems developers in incorporating new data into analytic data warehouses and data visualization applications, and to provide data content details to statisticians and epidemiologists preparing analytic algorithms.

One critical requirement for successful public health surveillance is the ability to analyze and present data so that it is understandable to leaders and the public. This can be viewed as the cross-cutting operational work space between data availability in data base architectures and useful information derived from data provided or generated for surveillance purposes.

This report proposes a vision for the analytic challenges for emerging public health surveillance, identifies challenges and opportunities, and suggests approaches to attain the vision. This topic was identified by CDC leadership as one of six major concerns that must be addressed by the public health community to advance public health surveillance in the 21st century. The six topics were discussed by CDC workgroups that were convened as part of the 2009 Surveillance Consultation to advance public health surveillance to meet continuing and new challenges (2). This report is based on workgroup discussions and is intended to continue the conversations with the public health community for a shared vision for public health surveillance in the 21st century.

Vision

A strong data analytic foundation is implemented widely and guides public health surveillance.

Challenges

Several ongoing and new analytic challenges for public health surveillance are apparent. Continuing challenges include managing data originating from disparate sources, protecting confidentiality, and attracting and retaining staff with appropriate skills. New challenges include demands for early detection of disease and visualization.

Data Management

Effective data management is critical to the public health surveillance mission; however, appreciation of the quality of data needed for appropriate inferences and interpretation is often lacking. Data management is the development, implementation, and maintenance of plans, policies, and programs that control, protect, and enhance the value of data. Cleaning and manipulation are not intended to alter data to reach a desired conclusion, but to ensure that data accurately reflect the true nature of what has been measured. Preparing high-quality data for public health analysis requires transformation from the data collection system for use in different formats to conduct quality checks and to prepare it for the analysts who need the analytic “flat” file (Figure 1). The analytic data management work function serves as a crosswalk across domains (Figure 2).

Early Detection of Emerging Diseases

The need for enhancing detection of emerging diseases faster and enhancing public health emergency response and recovery capabilities introduce new analytic challenges. Signal (or aberration) detection algorithms, applied to real-time processing of electronic medical records data, generate syndromic surveillance capacity to monitor for disease outbreaks and to support situation awareness and recovery monitoring. These new methodologies, developed during the smallpox vaccination activities and the anthrax attack of the early 2000s (1,3), also are useful for detecting emerging infectious diseases (e.g., severe acute respiratory syndrome), extending analytic capabilities for chronic diseases, and developing approaches to support health-care reform. Prudent application of new analytic surveillance methods and interpretation of results from novel data sources used for public health (e.g., patient health encounter records) might require interdisciplinary collaboration across public health and health-care domains, epidemiologic and statistical science domains, and public health jurisdictions.

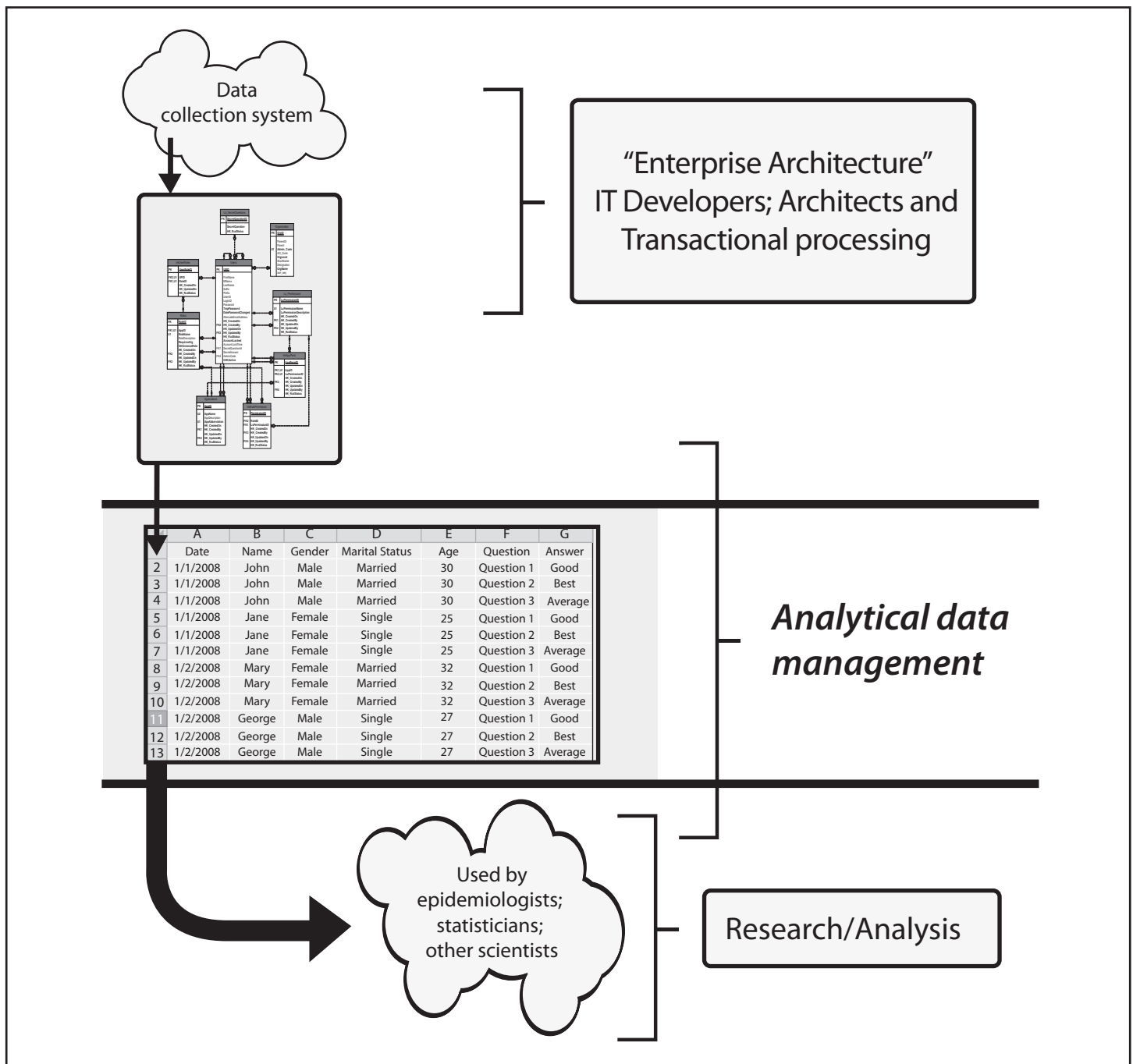
Inadequate Computing Resources

With the increase in number of sources and volume of data available for analysis, insufficient resources in the computing environment might be a limiting factor on timely processing of data and communication of results. This is particularly true for observational data such as those collected from longitudinal studies or various surveys or surveillance systems. When an emphasis is placed on real-time analysis and dissemination of the processed results from data, visual displays of data might be important. For example, displaying trends or clusters might provide information of potential bioterrorist activity, and maps of disease incidence/mortality might help target epidemiologic investigations (4). Because information needed to respond to an acute event needs a rapid response and simple, understandable display of complex data, a proactive approach would be to anticipate a need for sophisticated graphics display technology and plan for study of the cognitive aspects of such technology and how it will be used. Improved graphic displays of data is an area that requires further study.

Shortage of Skilled Staff

Human resources to accomplish analytic data management, statistical analysis, methods for performing geographic and other information displays, visualization of data and effectively communicating uncertainty in health-data evidence are needed in public health surveillance. However, persons and teams with the required skills and experience are in short supply. Furthermore, while core competencies have been developed for some public health professions (e.g., epidemiologists) to ensure staff have the skills needed to successfully perform this work (5), none have been developed for public health data managers and analysts. Leaders and managers and decision-makers who allocate staffing resources but have not worked directly in analytic data management must trust subordinates to accurately characterize resource requirements that may on the surface, appear inflated. The challenge of recruitment and retention of analytic staff is amplified in public health surveillance because of low pay grades compared with other industries. Within operational programs, analytical knowledge, procedures, and operations are frequently the most complex and detailed areas. Public health curricula have not been able to keep pace with new data management and analytic requirements. Courses that relate specifically to public health analytic data management with administrative data, a large part of where public health surveillance now resides are few.

FIGURE 1. Analytic data management functions in public health

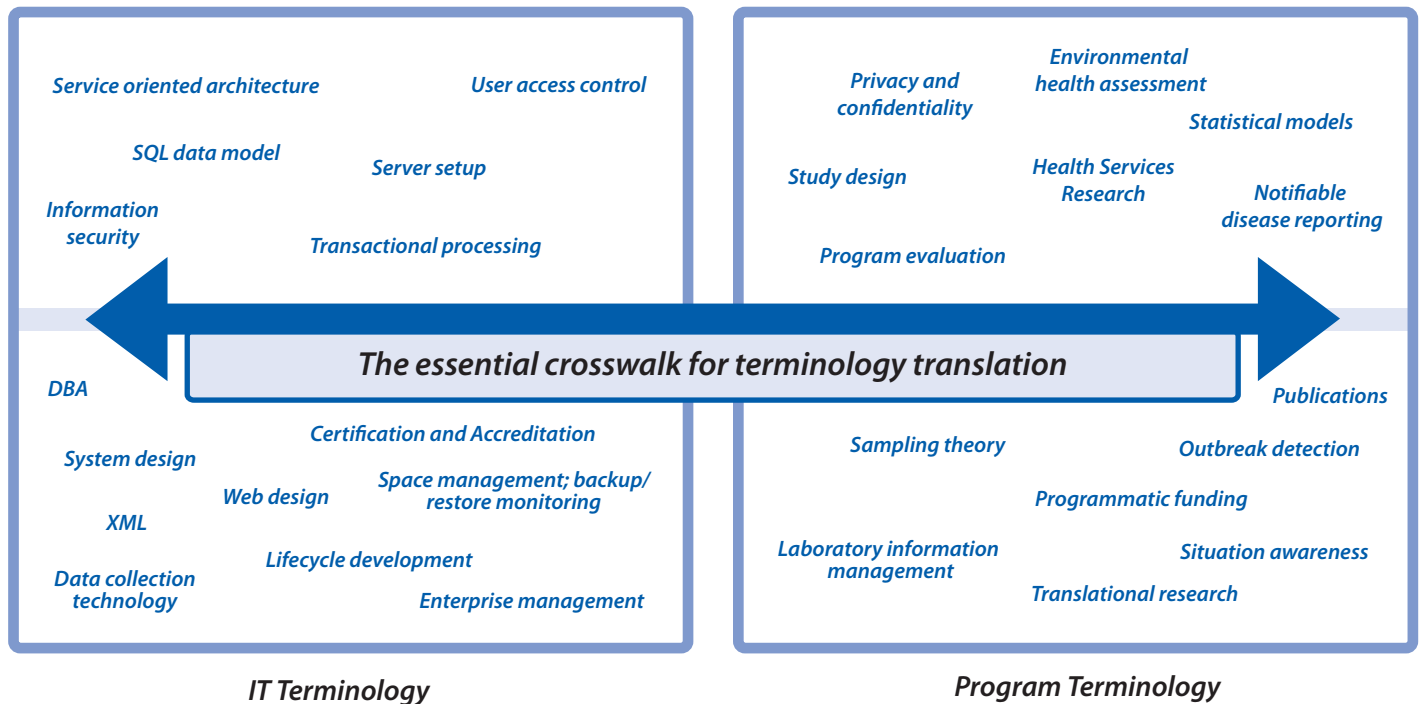


Opportunities

The beginning of the 21st century marked an era of rapid growth and change in information resources that can be useful for public health surveillance. Many new data sources with huge amounts of data can be expected from initiatives such as electronic health records and other data not developed specifically for public health surveillance purposes. Increased capacity of information technology to perform analytic

processing and increased availability of health-care-related data create opportunities to develop new surveillance and analytic methods. Data-mining tools allow analysis of data on several different types of events collected at once to determine relationships. Such tools offer potential and represent a blending of statistical methodologies with computing resources; their best application should include appropriate statistical interpretations of findings.

FIGURE 2. Analytical data managers: crosswalk between IT and science arenas



Emerging Data Useful for Surveillance

The wide-scale implementation of electronic information systems has resulted in an increased generation and availability of data. Sources available include data systems for collecting sentinel disease reports and spontaneous adverse event reports related to drugs, vaccines, and other medical products. Others include information systems designed for various other purposes (e.g., prescription pharmaceuticals, medical encounters, inventory and marketing, over-the-counter pharmaceutical sales, and emergency service dispatches) produce data that potentially can augment evidence for monitoring and assessing the health of populations. However, the data generated from such systems do not readily lend themselves to well-defined sample/population relations. No clear sampling design is available to determine how well the data represent a target population. Applications for analyzing data in such settings are empirical in nature; interpretation of these data and subsequent implications are not well informed by theory and must be acquired through experience by engaged and invested public health professionals.

Real-Time Data

Substantial real-time public health information is available that offers potential surveillance value in the form of unstructured or text data. Data or information in such form includes news or intelligence-like reports that originate from

the news media and systems like EpiX, ProMed, HealthMap, and Argus (6). Analyzing and understanding structured data requires different skills than those required for analyzing and understanding unstructured information. In addition, because unstructured data tend to be anecdotal in nature and are delivered more quickly than traditionally sourced surveillance data, the need to combine or fuse data and information of different types adds additional complexity to the analytics.

Electronic Health Records

The Centers for Medicare and Medicaid Services (CMS) is initiating a financial incentives program to help eligible providers and eligible hospitals adopt and make meaningful use of electronic health record (EHR) technology so they can provide better health care to their patients (7). Over time, the EHR incentive program under Medicare and Medicaid will accelerate and facilitate health-information technology adoption by more providers and hospitals throughout the health-care system. State health departments will need to be ready to manage and analyze the expected increase of population health data as sources of electronic medical records become available in volume, in complex data-messaging structures, and in real time as patient visits occur. In addition, the clinical care measures collected by CMS will be of interest to state and local health departments that want to monitor preventive care.

Health Information Exchanges

The State Health Information Exchange Cooperative Agreement Program (8) funds states' efforts to build capacity for exchanging health information across the health-care system both in and across states. Awardees are responsible for increasing connectivity and enabling patient-centric information flow to improve the quality and efficiency of care. This system has been built to facilitate the exchange of patient-level data among providers. It offers the potential for public health use to monitor quality of care and health status and outcomes.

Conclusion

The future of public health surveillance will depend on developing new analytical approaches to adapt to changing health data sources, increased information technology capacity, and increased concerns about the sensitivity of patient data revealed in unintentional data release. Although information technology specialists and public health programmatic or scientific staff might be comfortable within their respective domains of expertise, the new challenges will require increased attention in the analytic data management gap that exists between these two domains. To adapt the traditional public health functions of notifiable disease reporting, outbreak detection, emergency response, and program evaluation, public

health departments will need to update existing approaches to data collection and management and develop new analytical techniques to take advantage of evolving public health data sources while protecting patient confidentiality.

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