

# Blueprint for a National Public Health Surveillance System for the 21<sup>st</sup> Century

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*This article lays out a blueprint for public health surveillance and assessment for the year 2000 and beyond. The blueprint defines the roles of local, state, and national public health agencies and partners in the medical care system in conducting surveillance and assessment activities. It proposes a new overarching National Public Health Surveillance System to be the conceptual framework for all public health surveillance and assessment activities into the 21<sup>st</sup> century.*

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Since the U.S. Public Health Service assigned responsibility for national collection and coordination of surveillance activities to what is now the Centers for Disease Control and Prevention (CDC) in 1961, CDC has provided leadership, resources and training for state and local public health surveillance activities. The 1988 Institute of Medicine report on *The Future of Public Health* emphasized the importance of these activities, broadened their scope to include monitoring of health status and health needs, and placed them in an overall public health context. This report identified assessment as one of the three core functions of public health and defined it as the regular and systematic collection, assembly, analysis, and dissemination of health information coupled with epidemiologic and other health studies.<sup>1</sup>

The definition corresponds well to a number of definitions of public health surveillance emanating over a period of four decades from CDC.<sup>2-4</sup> CDC's current formal definition states:

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 timely dissemination of these data to those who need to know. The final link in the surveillance chain is the application of these data to prevention and control. A surveillance system includes a functional capacity for data collection, analysis, and dissemination linked to public health programs.<sup>3</sup>

Thus, assessment as defined by the Institute of Medicine includes both surveillance and analytic studies of public health problems and needs. It includes traditional public health problems and programs and also medical, social, and environmental risks and hazards, resources, and services. Public health surveillance and assessment will be increasingly important tools to monitor health status of the entire population and health care and prevention program outcomes as the health system undergoes reform.<sup>5</sup>

During the 1980s and 1990s, CDC and the states have expanded their traditional roles in surveillance and assessment of communicable and infectious diseases to the areas of environmental hazards and illness, injuries, chronic diseases, health behaviors, and maternal and child health.<sup>6-13</sup> It has become increasingly common for epidemiologists practicing at the state level to have formal and specific professional training in epidemiology.

As the focus on surveillance and assessment as a core public health function has sharpened and technical capacity at the state level has increased, there has been a growing concern at the state level about the quality of surveillance and assessment data, the limitations of traditional surveillance methods,

and the paucity and maldistribution of resources for collection, analysis, and interpretation of the data.

<sup>11-24</sup> This led the Council of State and Territorial Epidemiologist (CSTE), the affiliate designated in 1951 by the Association of State and Territorial Health Officers, to determine the nationally notifiable diseases, to embark on a reevaluation of communicable disease surveillance systems in collaboration with CDC. This effort has evolved over time and expanded in scope as a result of input from epidemiologists working in chronic disease, environmental, occupational, injury, maternal and child health, and reproductive epidemiology.

**The blueprint defines the roles of local, state, and national public health agencies and partners in the medical care system in conducting surveillance and assessment activities.**

This article lays out a blueprint for public health surveillance and assessment for the year 2000 and beyond. The blueprint defines the roles of local, state, and national public health agencies and partners in the medical care system in conducting surveillance and assessment activities. It proposes a new overarching National Public Health Surveillance System (NPHSS) to be the conceptual framework for all public health surveillance and assessment activities into the 21<sup>st</sup> century. The blueprint identifies the principles on which public health surveillance systems and the information systems that support them should be established and operated. It proposes a collaborative process by which public health professionals at the state, national, and local levels can reach a consensus about which diseases, conditions, risk factors, services, and outcomes should be under surveillance or subject to assessment throughout the nation and recommend the epidemiologic methods that should be utilized. Finally, the article identifies areas needing further discussion and research.

This article is a product of an active and ongoing professional discussion among practicing public health epidemiologists at state and federal public health agencies. It represents work in progress that will continue and evolve over time. In the future, this discussion should be broader and should include practicing public health epidemiologists from all areas of interest and at the local as well as state and national levels. CSTE has invited other professional organizations and agencies to participate in a collaborative process to develop coordinated surveillance, assessment, and information systems and to strengthen and prioritize surveillance and assessment activities at the state and national levels.

### **Goals and Methods of Public Health Surveillance**

The goals of surveillance (see box entitled "Goals of Surveillance") often differ at different levels of the public health system. <sup>1,12</sup> Surveillance data are used to allocate resources and evaluate the impact of control and prevention strategies and programs at all levels. However, at the local level the use of surveillance to trigger investigation and control activities predominates for infectious diseases and environmental hazards. In contrast, monitoring for trends, measuring the effectiveness of specific interventions, and conducting research to elucidate risk factors predominate at the national level. State public health agencies typically share both perspectives. Local public health agencies utilize chronic disease and maternal and child health data much like state and national agencies but have the added challenge of small area analysis with limited epidemiologic capacity. States also often have a responsibility for quality assurance and tend to prioritize prevention and control activities and monitoring of trends above research. Research that is done at the state and local level tends to focus on pragmatic issues related to local service delivery and prevention effectiveness and may not be generalizable.

### **Goals of Surveillance**

1. To recognize cases or clusters of cases to trigger interventions to prevent transmission or to reduce morbidity and mortality (includes the special case in which surveillance at the national level is to recognize multi-state clusters);
2. To assess the public health impact of health event or determinant and measure trends;
3. To demonstrate the need for public health intervention programs and resources, and allocate resources;
4. To monitor effectiveness of prevention and control measures and intervention strategies;
5. To identify high-risk population groups or geographic areas to target interventions and guide analytic studies; and
6. To develop hypotheses leading to analytic studies about risk factors for disease causation, propagation or progression.

Different goals require different approaches to data collection. Trade-offs are necessary between timeliness and detail, between achieving representiveness and getting case reports for control of transmission or exposure or other individualized interventions. For example, at the local level a case of measles in a day-care center requires an immediate public health response to prevent spread based on clinical findings prior to laboratory confirmation. In contrast, only laboratory-confirmed cases and those epidemiologically linked to confirmed cases are used at the state and national levels to monitor progress toward measles elimination. In similar fashion, local public health authorities use elevated blood lead levels to assure that the individual receives appropriate medical care and that the environmental or workplace hazard is rectified. At the state level, cases of lead intoxication may be mapped using sophisticated geographic information systems not available locally to identify neighborhoods or counties where screening and remediation should be targeted. At the national level, rates of elevated lead levels from screening data are used to judge the effectiveness of nationwide control strategies such as removing lead from gasoline and to modify recommendations for screening as lead control efforts evolve.

The traditional system of individual cases reporting by practicing physicians to local public health authorities was designed to identify individual cases primarily of communicable diseases for investigation and control and to provide gross estimates of both disease burden and efficacy of control strategies. While this century-old system continues to meet some needs, it cannot meet all the demands of our present day public health system for assessment information. The evolution of the medical care system toward managed care organizations serving defined populations with a hoped-for preventive emphasis poses new opportunities and challenges for collecting high quality, comprehensive public health assessment data.

### **The National Public Health Surveillance System**

To remedy fragmentation of the surveillance system, to make the best use of limited resources for surveillance to meet the challenges of an evolving medical care system and new information systems technology, and to improve the reliability and usefulness of assessment data a new, flexible approach is needed for public health surveillance. This new, systematic approach should match data collection techniques and funding levels to the goals of assessment at each level of the public health system for each outcome under surveillance. The new system should be based on a consensus among practicing public health epidemiologist at the local, state, and national levels about surveillance priorities and methods in light of available resources.<sup>24</sup> This approach should be applied by all disciplines in public health surveillance and assessment. There is a need to move from traditional and fragmented approaches to surveillance to a coordinated and flexible NPHSS for the 21<sup>st</sup> century.<sup>6,25</sup> NPHSS should be a conceptual framework and virtual surveillance system that incorporates both existing and new

surveillance systems for health events (diseases, conditions, and injuries) and determinants (risk factors, hazards, health care and societal costs, and outcome of both individual medical care and community-based public health programs).<sup>26</sup> NPHSS and its constituent surveillance systems should be constructed in a rational manner and be based on sound epidemiologic and public health principles. It should serve as a basis for local and state public health agencies to prioritize surveillance and assessment activities and for public health agencies at all levels to advocate for necessary resources for assessment.

The recommended methods and data elements to be collected for surveillance purposes for each type of surveillance, case definitions, and priority for resources should be specified for each outcome at each level of the public health system: local, state, and national. Surveillance information regarding human health events and determinants (e.g., behavioral risk factors) and those in animals that affect human health should be collected primarily by state health departments and be forwarded to CDC. Other types of surveillance information (e.g., air quality data) may be collected by either public health or non-public health agencies at the state and national level but should be made available for public health uses through an integrated information system for public health surveillance.

### **Information System for Public Health Surveillance**

During the 1980s, the revolution in personal computing technology led to computerization of surveillance data.<sup>26-28</sup> This new technology held out the promise that public health epidemiologists would be able to use surveillance data more efficiently and more rapidly.<sup>4,27</sup> This promise has not been fulfilled in spite of substantial efforts at both the national and state levels to develop software and telecommunications systems to support assessment. This is because of the relatively poor quality of the data, limited fiscal and personnel resources for data analysis and interpretation, and a lack of coordination at both state and national levels. Recently, Lumkin et al. reviewed this subject and made excellent recommendations for capturing the promise of the information revolution for public health surveillance and assessment.<sup>29</sup>

Based on these and CDC recommendations, NPHSS should be supported by an integrated information system that links relevant surveillance data and information system in states and multiple federal agencies in a virtual system that appears as one to users.<sup>26</sup> Surveillance and assessment data and information for health events and determinants included in NPHSS or its location should be maintained by CDC. The information system for NPHSS should cross-reference the location of these data so that persons seeking public health information will have a single location from which they can identify the outcomes that are under surveillance and where they may obtain the data. The information system for NPHSS should also make surveillance datasets available electronically with appropriate confidentiality protections to public health professionals and researchers within six months of collection by CDC or other federal agencies.

### **Principles on Which NPHSS Development and Operation Should Be Based**

#### **A. Definition of public health surveillance**

Public health surveillance for any health event (disease, condition, injury, or other outcome) or determinant (behavioral and biological risk factors, exposures, and medical care) means the ongoing collection, analysis, interpretation, and dissemination of data for a stated public health purpose. Surveillance for some outcomes may be temporary and/or intermittent but must be regular. Surveillance data can be used to monitor health events and determinants and to form, but not generally to test, hypotheses. (While ecologic studies can often be done using surveillance data, these studies are hypothesis-generating not hypothesis-testing exercises). Therefore, surveillance should lead to, but not confused with, research. When an outcome is placed under surveillance and when surveillance information is disseminated, the surveillance case definition should be stated.

#### **B. Definition of public health assessment**

Public health assessment includes ongoing surveillance activities, analytic studies to evaluate hypotheses arising from surveillance data and other sources, and program or service evaluation.

#### **C. Surveillance and assessment efforts need to be prioritized because of limited resources**

This issue is addressed in an accompanying article. (See Osterholm's article "Impediments to Public Health Surveillance in the 1990s" in this issue.)

**D. Adequate resources are needed for public health surveillance and Assessment**

This issue is addressed in an accompanying article in this issue (see Osterholm's article. Journal of Public Health Management and Practice/Fall 1996)

**E. Collaboration is needed in the design of NPHSS**

The institute of Medicine's *The Future of Public Health* calls for states to be recognized as "the central force in public health" because they "bear primary public sector responsibility for health."<sup>1p7</sup> In addition, statutory authority to collect public health surveillance data rests primarily at the state level, but surveillance and assessment data are also needed at the local and national levels. There must be collaboration in the design of surveillance systems involving all levels of the public health system and taking into account the professional capabilities and fiscal resources available throughout the system. However, individual states retain the authority to make decisions about the outcomes for which surveillance will be done, the methods of data collection and sharing, and the analytic and evaluative efforts undertaken within their jurisdiction. This means that states should play a key role in setting surveillance priorities and designing surveillance and allied information systems.

**There must be collaboration in the design of surveillance systems involving all levels of the public health system and taking into account the professional capabilities and fiscal resources available.**

**F. Surveillance goals often differ at different levels of the public health system and over time.**

Surveillance goals often differ for different levels of the public health system and for different health events and determinants. Surveillance systems must be customized to meet the needs of each level of the public health system for each outcome under surveillance and they must be flexible and able to meet changing needs over time. The goals for surveillance (see box entitled "Goals of Surveillance") for each health event or determinant should be clearly articulated and reviewed periodically in light of evolving circumstances, including incidence, prevalence, severity, health system and societal costs, and the availability of interventions and resources.

**G Surveillance methods and sources should be matched to surveillance goals**

Data sources and surveillance methods must be carefully selected to match the specified goals of surveillance and to maximize the attributes (timeliness, sensitivity, positive predictive value, simplicity, flexibility) of greatest importance at each level of the public health system for each health event or determinant.<sup>30</sup> Data that is not needed should not be collected unless it is more efficient to collect a standard set of easily attainable data for a group of health events or determinants. Data should be collected in the least labor-intensive manner possible consistent with the quality, scope, and detail needed. An efficient surveillance system is one in which minimal provider or local or state public health resources (personnel and fiscal) are expended to collect information they will not use. For each health event or determinant under surveillance, the surveillance methods selected should be those that are the most appropriate for each level of the public health system based on the goals at that level, available resources, and the most efficient sources of data. Common methods and the criteria for each are shown in the box entitled " Surveillance Methods". Many of these methods may be used in combination to improve the efficiency and quality of data collection. Sentinel surveillance, secondary data analysis, prevalence surveys, and vital records are not sufficient for health event requiring an immediate public health response, but may be used to supplement clinician surveillance for such diseases and injuries.

**H. High-quality data are needed if surveillance and assessment information are to be relied upon in public health decision making**

Attention must be given to the quality of data in designing, implementing, and evaluating surveillance systems and analytic and evaluative studies. Analysis and interpretation of surveillance data are only as good as the quality of the data collected.

## Surveillance Methods

Reportable by clinicians or health care facilities

- Require immediate public health response; or
- Recognizable solely by clinicians.

Reportable by laboratories

- Immediate public health response NOT needed;
- Laboratory test needed for recognition or to meet case definition;
- Laboratory test adds relevant information (e.g. Salmonella serotypes, antibiotic susceptibilities for tuberculosis and pneumococcus, cell type for cancer); or
- As a back-up to clinician reporting.

Sentinel surveillance: Useful for collecting detailed information on a subset of cases.

Representative sentinel surveillance

- Designed so findings can be generalized to specified population.

Nonrepresentative sentinel surveillance:

- Convenience sampling;
- To generate hypotheses regarding risk factors;
- To evaluate the effectiveness of a public health or clinical intervention (e.g., National Nosocomial Infection Surveillance System, Hepatitis Sentinel Counties); or
- To collect limited information to recognize the onset, termination, and characteristics of a particular public health problem of limited duration (e.g., influenza) or that is new.

Secondary analysis of datasets collected for other purposes

- Places no additional burden on public health surveillance system sources;
- Places a minimal burden on public health programs if the data are already assembled;
- Costly if data must be assembled by public health ;
- Data may be of limited quality;
- Care must be taken in analysis and interpretation;
- Immediate public health response NOT needed;
- To assess the public health impact or monitor trends;
- To measure morbidity and health system costs due to chronic or recurrent health events;
- Potential data sources include hospitals discharge, managed care encounter, billing, insurance, emergency room, school/work attendance, and environmental monitoring data, immunization registries, work-site injury and death reports, and law enforcement records

Periodic or ongoing prevalence surveys

- To assess prevalence trends over time (e.g., HIV seroprevalence surveys, NHIS, BRFSS, NHANES).
- Optimal if designed to be useful to state and local public health agencies and managed care organizations.

Vital records

- For surveillance of births and deaths;
- May be used alone for some analytic studies because essentially all vital events for the entire population are recorded as well as some risk factor information;
- Under purview of the Association of Public Health Statistics and information systems.

Temporary surveillance

- Any method of surveillance;
- To assess public health impact;
- To evaluate the effectiveness of a public health or clinical intervention; or
- To develop hypotheses about risk factors.

### I. Confidentiality of public health surveillance data must be assured

Surveillance systems and the information systems that support them must be designed in such a manner

that personal identifying information is accessible only to the public health professionals who need to collect additional information of importance, to intervene to prevent adverse public health outcomes (e.g., transmission of communicable diseases, preventable workplace injuries, progression from mild to advanced chronic disease), or for bona fide research.

### **Establishment of NPHSS and Prioritization of Surveillance Indicators**

CSTE has traditionally determined the list of infectious diseases and conditions and some injuries and toxic exposures under nationwide surveillance in consultation with CDC. In December 1994, CSTE called for creation of a NPHSS to expand, coordinate, prioritize and standardize approaches to public health surveillance nationally and across disciplines while maintaining flexibility. To establish NPHSS, CSTE invites practicing public health epidemiologists at the state, local, and national level and their professional organizations to enter into a collaborative process to identify the health events and determinants that should be under surveillance nationwide and the most appropriate methodology and information system for each. Participating epidemiologist should include those practicing in the disciplines of infectious and communicable diseases, chronic disease, environmental exposures, occupational illnesses, injuries, maternal and child health, reproductive health, and health care system evaluation.

This interdisciplinary group of epidemiologists and their professional organizations should work towards a consensus about what should be under surveillance in each discipline and how surveillance should be done. They should review the health events and determinants currently under or proposed for widespread or nationwide surveillance, and identify those of importance for which data are missing. For each outcome, this group should identify the goals for surveillance, surveillance methods, existence of legislative mandates, and the source, approximate amount, and adequacy of resources available for data collection, analysis, interpretation, and dissemination. Part of this process should include determining the representative national professional organization that should determine the outcomes under surveillance within NPHSS for each discipline. This interdisciplinary collaboration will enrich the practice of public health epidemiologists and provide a basis for advocacy for assessment functions and ongoing collaboration.

To justify addition of a health event or determinant to NPHSS and to facilitate periodic reassessment of surveillance priorities and methods, each event or determinant should be supported by the information listed in the box entitled "Surveillance System Specifications."

### **Future Development and Research**

There should be ongoing evaluation of surveillance and assessment activities and determination of training and capacity-building needs at all levels of the public health system. An evaluation process is needed that can be applied at all levels of the public health system. CDC has developed an approach to evaluating individual surveillance systems, which should be applied based on the stated goals of surveillance for each outcome.<sup>30</sup> CSTE and CDC are collaboratively developing, through the Epidemiologic Capacity-Building Project, a process for state health departments to use to determine the strengths and weaknesses of their surveillance and assessment capacity. This process needs to be refined and modified as needed to also apply to local health departments and federal programs. In the future, standards of excellence for surveillance and assessments functions should be developed. This should enable each state to evaluate their surveillance and assessment activities and to assist them in identifying training needs and areas in which additional capacity is needed. Resources will be needed from both state and national levels to conduct evaluation and undertake capacity-building to establish programs of excellence.

### Surveillance System Specifications

- Justification:
  - Public health impact
  - Potential for prevention or control
  - Need to monitor effectiveness of public health Interventions
  - Availability of resources to conduct surveillance
  - Ability to collect meaningful data
  - Resources or plan to conduct analytic studies triggered by surveillance information
- Goals and Methods of Surveillance at Local, State, and National level
- Case Definition
- Data to be Collected
- Information System to be Utilized to Collect and Transmit Data
- Temporary/ Permanent

Research and development are needed to determine the best and most cost-effective approaches to surveillance. This is particularly true in the areas of sentinel surveillance, surveillance for morbid and chronic health events that do not require hospitalization, and health services and cost surveillance. Innovation and collaboration are needed between public health and managed care organizations to explore the usefulness of managed care data to enable public health to do better and more comprehensive job of assessing overall community health status and needs. These collaborations should also explore the usefulness of public health assessment approaches, such as the Behavioral Risk Factor Surveillance System, as cost-effective means to surveillance of health status, health indicators, and outcomes within managed care organizations. Such a collaboration is being piloted in Colorado between the state health department and Kaiser Permanente, but additional experimentation is needed.<sup>31</sup> Such collaborations between public health agencies and managed care organizations should assist with collection of important health information about the population, quality assurance, and cost-containment in both systems.

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