

## What is Syndromic Surveillance?

Kelly J. Henning

*New York City Department of Health and Mental Hygiene, New York, New York*

**Corresponding author:** Kelly J. Henning, New York City Department of Health and Mental Hygiene, 125 Worth Street, CN-6, New York, NY 10013. Telephone: 212-788-0234; Fax: 212-788-4473; E-mail: khenning@health.nyc.gov.

### Abstract

*Innovative electronic surveillance systems are being developed to improve early detection of outbreaks attributable to biologic terrorism or other causes. A review of the rationale, goals, definitions, and realistic expectations for these surveillance systems is a crucial first step toward establishing a framework for further research and development in this area. This commentary provides such a review for current syndromic surveillance systems.*

*Syndromic surveillance has been used for early detection of outbreaks, to follow the size, spread, and tempo of outbreaks, to monitor disease trends, and to provide reassurance that an outbreak has not occurred. Syndromic surveillance systems seek to use existing health data in real time to provide immediate analysis and feedback to those charged with investigation and follow-up of potential outbreaks. Optimal syndrome definitions for continuous monitoring and specific data sources best suited to outbreak surveillance for specific diseases have not been determined. Broadly applicable signal-detection methodologies and response protocols that would maximize detection while preserving scant resources are being sought.*

*Stakeholders need to understand the advantages and limitations of syndromic surveillance systems. Syndromic surveillance systems might enhance collaboration among public health agencies, health-care providers, information-system professionals, academic investigators, and industry. However, syndromic surveillance does not replace traditional public health surveillance, nor does it substitute for direct physician reporting of unusual or suspect cases of public health importance.*

### Introduction

The desire to expand and improve upon traditional methods of public health surveillance is not new. Even before the 2001 terrorist attacks on the United States and the subsequent anthrax outbreak, public health officials had begun to enhance detection of emerging infections and illnesses caused by biologic agents. A primary objective of a 1998 CDC plan was to develop programs for early detection and investigation of outbreaks (1). CDC's 2000 strategic plan for biologic and chemical preparedness called for early detection by integrating terrorism preparedness into existing systems and developing "new mechanisms for detecting, evaluating, and reporting suspicious events" (2). Although the need for innovative surveillance techniques had already been identified, the anthrax outbreak after *Bacillus anthracis* spores were released through the mail in 2001 (3) accelerated the implementation of syndromic surveillance systems across the United States. An overview of the location and scope of the earliest systems implemented before and after fall 2001 has been published (4).

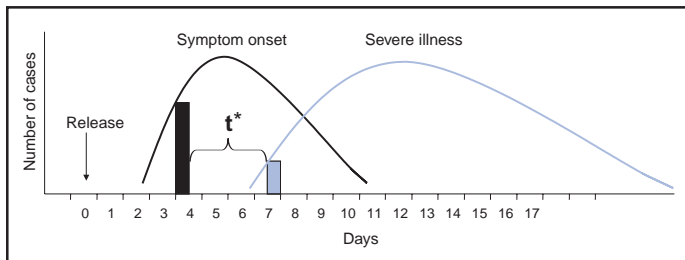
### Goals and Rationale

Although syndromic surveillance was developed for early detection of a large-scale release of a biologic agent, current

surveillance goals reach beyond terrorism preparedness. Medical-provider reporting remains critical for identifying unusual disease clusters or sentinel cases. Nevertheless, syndromic surveillance might help determine the size, spread, and tempo of an outbreak after it is detected (5), or provide reassurance that a large-scale outbreak is not occurring, particularly in times of enhanced surveillance (e.g., during a high-profile event). Finally, syndromic surveillance is beginning to be used to monitor disease trends, which is increasingly possible as longitudinal data are obtained and syndrome definitions refined.

The fundamental objective of syndromic surveillance is to identify illness clusters early, before diagnoses are confirmed and reported to public health agencies, and to mobilize a rapid response, thereby reducing morbidity and mortality. Epidemic curves for persons with earliest symptom onset and those with severe illness can be depicted graphically (Figure). The time between symptom onset for an increasing number of cases caused by deliberate release of a biologic agent and subsequent patient visits to a health-care facility resulting in a definitive diagnosis is represented by  $t$ . Syndromic surveillance aims to identify a threshold number of early symptomatic cases, allowing detection of an outbreak  $t$  days earlier than would conventional reporting of confirmed cases. The ability of syndromic surveillance to detect outbreaks earlier than con-

**FIGURE. Syndromic surveillance — rationale for early detection**



\*  $t$  = time between detection by syndromic (prediagnostic) surveillance and detection by traditional (diagnosis-based) surveillance.

ventional surveillance methods depends on such factors as the size of the outbreak, the population dispersion of those affected, the data sources and syndrome definitions used, the criteria for investigating threshold alerts, and the health-care provider's ability to detect and report unusual cases (6). CDC's framework for evaluating public health surveillance systems for early detection of outbreaks should be useful for comparing syndromic surveillance across jurisdictions and for evaluating system performance (7).

Specific definitions for syndromic surveillance are lacking, and the name itself is imprecise. Certain programs monitor surrogate data sources (e.g., over-the-counter prescription sales or school absenteeism), not specific disease syndromes. Meanwhile, certain well-defined disease or clinical syndromes (e.g., hemolytic uremic syndrome or Kawasaki's syndrome) are not included in syndrome definitions, often leading to confusion about what "syndromic" surveillance actually monitors. Diverse names used to describe public health surveillance systems for early outbreak detection include

- early warning systems (8,9);
- prodrome surveillance (10);
- outbreak detection systems (11);
- information system-based sentinel surveillance (12);
- biosurveillance systems (13–15);
- health indicator surveillance (16); and
- symptom-based surveillance (17).

However, *syndromic surveillance* is the term that has persisted.

In defining syndromic surveillance, certain authors have emphasized the importance of monitoring the frequency of illnesses with a specific set of clinical features (18), a definition that does not account for nonclinical data sources. Others have emphasized the importance of prediagnostic data to estimate a community's health status, particularly by relying on outpatient visits (19). Inherent in the use of existing electronic data to describe prediagnostic health indicators is the central role of timeliness in the analysis, detection, and investigation of alerts. Perhaps the most comprehensive definition

to date, and likely the one to be broadly adopted, is provided by CDC's evaluation framework, which describes syndromic surveillance as "an investigational approach where health department staff, assisted by automated data acquisition and generation of statistical alerts, monitor disease indicators in real-time or near real-time to detect outbreaks of disease earlier than would otherwise be possible with traditional public health methods" (7).

Syndromic surveillance systems vary by their planned duration and their manner of acquiring data (Table). Short-duration, event-based systems are usually used to provide enhanced surveillance around a discrete event (e.g., the Olympic Games or a national political convention) (20,23). Historically, these short-term syndromic surveillance projects, sometimes termed *drop-in surveillance*, have required medical providers or others to collect nonroutine information (20). More recent event-based surveillance systems have relied on rapid implementation of electronically transferred data (23). Manual data entry, which occurred after September 11, 2001, in 15 New York City emergency departments (EDs), is difficult to sustain (21). Using pre-existing health data for syndromic surveillance offers immediate accessibility and poses limited burden to providers and health-care institutions.

Categorizing symptoms and diagnoses into syndromes is a fundamental component of syndromic surveillance systems that use clinical data sets. Although the majority of investigators have devised broad categories aimed at early detection of biologic terrorism, validation of syndrome definitions is only beginning. Respiratory, gastrointestinal, rash, neurologic and sepsis syndromes have been monitored consistently (19,22). Because numerous ED and outpatient settings have *International Classification of Diseases, Ninth Revision, Clinical Modification* (ICD-9-CM) data available electronically, ICD-9-CM codes have been used to categorize syndromes. To facilitate comparability between surveillance systems, a CDC working group published lists of candidate syndrome groups based on ICD-9-CM codes (27). The usefulness of ICD-9-CM codes compared with other data streams, particularly with regard to the data's timeliness, requires evaluation by each surveillance program.

Syndromic surveillance focuses on the early symptom (prodrome) period before clinical or laboratory confirmation of a particular disease and uses both clinical and alternative data sources (Box). Strictly defined, syndromic surveillance gathers information about patients' symptoms (e.g., cough, fever, or shortness of breath) during the early phases of illness. However, in practice, certain syndromic surveillance systems collect surrogate data indicating early illness (e.g., school or work

**TABLE. Types of syndromic surveillance — selected characteristics, advantages, and disadvantages**

Surveillance type	Selected characteristics	Advantages	Disadvantages
<b>Event-based surveillance</b> Drop-in (20,21)	Active Defined duration Emergency departments (EDs) Large clinics	Develop relationships with ED staff and infection-control professionals Transportable to various sites	Labor-intensive Not sustainable Not scalable
<b>Sustained surveillance</b> Manual (22)	Active and passive Fax-based reporting ED triage staff typically log and tally sheets	Develop relationships with hospital staff Easy to initiate Detailed information obtainable	Labor-intensive Difficult to maintain 24 hours, 7 days/week Not sustainable
Electronic (8,19,23,24)	Passive Automated transfer of hospital (usually ED triage or diagnosis) or outpatient data Use of data collected for other purposes Data mining of large collections or from multiple sources	Can be scalable Requires minimal or no provider input Data available continuously Data are standardized	Need programming and informatics expertise Confidentiality issues
Novel modes of collection (25)	Passive Hand-held or touch-screen devices	Easy to use; rapid provider feedback; can post alerts and information	Requires provider input Not sustainable
Novel data sources (26)	Active and passive Medical examiner data Unexplained death or severe illness data	Clearly defined syndrome Can be supplemented with laboratory data	Not an early warning Unclear whether it can be rapidly and broadly expanded

absenteeism data or veterinary data such as unexpected avian deaths or other potential precursors of human illness). Alternative data sources have potential problems, including a presumed low specificity for syndromes of interest, high probability of influence by factors unrelated to personal health (e.g., weather or holidays), and difficulty in retracing data aberrations to individual patients. Despite these qualifiers, the optimal system might be one that integrates data from multiple sources, potentially increasing investigators' confidence in the relevance of an alert from any single data source.

## Analytic Methods for Signal Detection

The analytic challenge in using syndromic surveillance for outbreak detection is to identify a signal corresponding to an outbreak or cluster amid substantial “background noise” in the data. Syndromic surveillance systems use an array of aberration-detection methods to identify increases in syndromes above predetermined thresholds. However, signal-detection methods have not yet been standardized. Temporal and spatio-temporal methods have been used to assess day-to-day and day and place variability of data from an expected baseline (27,28).

## BOX. Potential data sources for syndromic surveillance

### Clinical data sources

- Emergency department (ED) or clinic total patient volume
- Total hospital or intensive-care-unit admissions from ED
- ED triage log of chief complaints
- ED visit outcome (diagnosis)
- Ambulatory-care clinic/HMO outcome (diagnosis)
- Emergency medical system (911) call type
- Provider hotline volume, chief complaint
- Poison control center calls
- Unexplained deaths
- Medical examiner case volume, syndromes
- Insurance claims or billing data
- Clinical laboratory or radiology ordering volume

### Alternative data sources

- School absenteeism
- Work absenteeism
- Over-the-counter medication sales
- Health-care provider database searches
- Volume of Internet-based health inquiries by the public
- Internet-based illness reporting
- Animal illnesses or deaths

## Response Protocols

Response protocols for investigating syndromic surveillance alerts are under development by multiple programs. Obstacles to effective, efficient follow-up include the difficulty of predicting how well the syndromes themselves correlate with target diseases under surveillance; the extremely low positive predictive value of any given signal based on the high level of system sensitivity; and investigators' relative lack of experience with syndromic surveillance under real-world conditions (30).

Programmatic requirements for effective signal response (e.g., documented procedures; staff with appropriate expertise; 24-hour/day, 7-day/week analysis and response; and plans for information dissemination) are complex. Certain circumstances surrounding an alert might prompt rapid investigation, including clustering of cases by location; severe symptoms; unexplained deaths; sudden, substantial case numbers; simultaneous alerts from multiple data sources; or restriction of an alert to a particular population (e.g., age group or sex) (31). Diagnostic confirmation is a paramount step in investigating alerts, particularly given the nonspecific nature of certain syndrome categories. Developing protocols to address alerts from data sources in which individual cases are unidentifiable (e.g., over-the-counter medication sales) is particularly challenging.

## Perspectives and Challenges

Distinguishing those points on which multiple investigators agree from those that are less well-delineated might be helpful in defining realistic expectations for syndromic surveillance. Investigators usually agree on the following:

- Syndromic surveillance is being used in numerous states and localities to detect a potential large-scale biologic attack.
- Pre-existing electronic health data will likely become increasingly available, thereby enhancing system development.
- Syndromic surveillance does not replace traditional public health surveillance.
- Syndromic surveillance is unlikely to detect an individual case of a particular illness.
- Syndromic surveillance cannot replace the critical contribution of physicians in early detection and reporting of unusual diseases and events.

Although syndromic surveillance's ability to detect a terrorism-related outbreak earlier than traditional surveillance remains unknown, it will likely be useful for defining the scope of an outbreak, providing reassurance that a large-

scale outbreak has not occurred, and conducting surveillance of noninfectious health problems (e.g., monitoring nicotine replacement therapy sales following tobacco-tax increases). However, integral components of syndromic surveillance require additional research and evaluation, including the following:

- defining optimal data sources;
- evaluating appropriate syndromic definitions;
- standardizing signal-detection methods;
- developing minimally acceptable response protocols;
- clarifying the use of simulation data sets to test systems; and
- advancing the debate regarding resource commitment for syndromic versus traditional surveillance.

On a broader policy level, defining the role of academic partners in bridging any potential analytic gaps, defining the role and scope of a national syndromic data repository, and developing policy for integrating laboratory testing and laboratory information systems with syndromic surveillance are on the horizon.

### Acknowledgments

Farzad Mostashari, Don Weiss, Rick Heffernan, and other members of the New York City Department of Health and Mental Hygiene syndromic surveillance team provided data and program information.

### References

1. CDC. Preventing emerging infectious diseases: a strategy for the 21<sup>st</sup> century. Atlanta, GA: US Department of Health and Human Services, 1998. Available at <http://www.cdc.gov/ncidod/emergplan/index.htm>.
2. CDC. Biological and chemical terrorism: strategic plan for preparedness and response: recommendations of the CDC strategic planning workgroup. *MMWR* 2000;49(No. RR-4):1-14.
3. CDC. Update: investigation of anthrax associated with intentional exposure and interim public health guidelines, October 2001. *MMWR* 2001;50:889-93.
4. Henning KJ. Syndromic surveillance. In: Smolinski MS, Hamburg MA, Lederberg J (eds.). *Microbial threats to health: emergence, detection, and response*. Washington, DC: National Academies Press, 2003;309-50.
5. Mostashari F, Hartman J. Syndromic surveillance: a local perspective. *J Urban Health* 2003;80(2 Suppl 1):i1-7.
6. Buehler JW, Berkelman RL, Hartley DM, Peters CJ. Syndromic surveillance and bioterrorism-related epidemics. *Emerg Infect Dis* 2002;9:1197-1204.
7. CDC. Framework for evaluating public health surveillance systems for early detection of outbreaks: recommendations from the CDC working group. *MMWR* 2004;53(No. RR-5).
8. Wagner MM, Tsui F-C, Espino JU, et al. The emerging science of very early detection of disease outbreaks. *J Public Health Manag Pract* 2001;7:50-8.
9. Brinsfield KH, Gunn JE, Barry MA, McKenna V, Syer KS, Sulis C. Using volume-based surveillance for an outbreak early warning system [Abstract]. *Acad Emerg Med* 2001;8:492.

10. Mostashari F, Karpati A. Towards a theoretical (and practical) framework for prodromic surveillance [Abstract]. International Conference on Emerging Infectious Diseases, Atlanta, GA, March 24–27, 2002.
11. Stern L, Lightfoot D. Automated outbreak detection: a quantitative retrospective analysis. *Epidemiol Infect* 1999;122:103–10.
12. Lober WB, Karras BT, Wagner MM, et al. Roundtable on bioterrorism detection: information systems-based surveillance. *J Am Med Inform Assoc* 2002;9:105–15.
13. Cochrane DH, Allegra JR, Rothman J. Comparison of physician's choice of charting template to ICD-9 codes for biosurveillance using an emergency department electronic medical records database [Abstract]. *Acad Emerg Med* 2003;10:525.
14. Olson KL, Mandl K. Geocoding patient addresses for biosurveillance [Abstract]. *Proc AMIA Symp* 2002;1119.
15. Mocny M, Cochrane DG, Allegra JR, et al. A comparison of two methods of biosurveillance of respiratory disease in the emergency department: chief complaint vs. ICD-9 diagnosis code [Abstract]. *Acad Emerg Med* 2003;10:513.
16. Pavlin JA, Mostashari F, Kortepeter MG, et al. Innovative surveillance methods for rapid detection of disease outbreaks and bioterrorism: results of an interagency workshop on health indicator surveillance. *Am J Public Health* 2003;93:1230–5.
17. Osaka K, Takahashi H, Ohyama T. Testing a symptom-based surveillance system at high-profile gatherings as a preparatory measure of bioterrorism. *Epidemiol Infect* 2002;129:429–34.
18. Reingold A. If syndromic surveillance is the answer, what is the question? *Biosecur Bioterror* 2003;1:1–5.
19. US Department of Defense. Electronic Surveillance System for the Early Notification of Community-Based Epidemics (ESSENCE). Silver Spring, MD: US Department of Defense, Global Emerging Infections Surveillance and Response System. Available at <http://www.geis.ha.osd.mil/geis/surveillanceactivities/essence/essence.asp>.
20. County of Los Angeles, Department of Health Services, Acute Communicable Disease Control. Special studies report 2000: Democratic National Convention—bioterrorism syndromic surveillance. Los Angeles: County of Los Angeles Department of Health Services, 2000. Available at <http://www.lapublichealth.org/acd/reports/spclrpts/spcrrpt00/demonatconvtn00.pdf>.
21. CDC. Syndromic surveillance for bioterrorism following the attacks on the World Trade Center—New York City, 2001. *MMWR* 2002; 51(Special Issue):13–15.
22. Begier EM, Sockwell D, Branch LM, et al. The National Capitol Region's emergency department syndromic surveillance system: do chief complaint and discharge diagnosis yield different results? *Emerg Infect Dis* 2003;9:393–6.
23. Gesteland PH, Wagner MM, Chapman WW, et al. Rapid deployment of an electronic disease surveillance system in the state of Utah for the 2002 Olympic Winter Games. *Proc AMIA Symp* 2002;285–289.
24. Lazarus R, Kleinman K, Sashevesky I, et al. Use of automated ambulatory-care encounter records for detection of acute illness clusters, including potential bioterrorism events. *Emerg Infect Dis* 2002;8:753–60.
25. Zelicoff A, Brillman J, Forslund DW, et al. The rapid syndrome validation project. *Proc AMIA Symp* 2001;771–5.
26. Kluger MD, Sofair AN, Heye CJ, Meek JI, Sodhi RK, Hadler JL. Retrospective validation of a surveillance system from unexplained illness and death: New Haven County, Connecticut. *Am J Public Health* 2001; 91:1214–9.
27. CDC. Syndrome definitions for diseases associated with critical bioterrorism-associated agents. Atlanta, GA: US Department of Health and Human Services, CDC. Available at <http://www.bt.cdc.gov/surveillance/syndromedef/index.asp>.
28. Hutwagner L, Thompson W, Seaman GM, Treadwell T. The bioterrorism preparedness and response early aberration reporting system (EARS). *J Urban Health* 2003;80(2 Suppl 1):i89–96.
29. Das D, Weiss D, Mostashari F, et al. Enhanced drop-in syndromic surveillance in New York City following September 11, 2001. *J Urban Health* 2003;80(2 Suppl 1):i76–88.
30. Duchin JS. Epidemiological response to syndromic surveillance signals. *J Urban Health* 2003;80(2 Suppl 1):i115–6.
31. Pavlin JA. Investigation of disease outbreaks detected by syndromic surveillance systems. *J Urban Health* 2003;80(2 Suppl 1):i107–4.