

Instituting a Regional Syndromic Surveillance System: Barriers and Opportunities

by

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Abstract

Syndromic surveillance is a relatively new tool being explored for early detection of disease outbreaks in communities. To signal an early outbreak, syndromic surveillance utilizes non-traditional indicators such as over-the-counter drug sales, physician and emergency room visits, laboratory tests ordered, absenteeism and calls to nurse hotlines or poison control centers. Methodological issues, costs, legal issues, technological issues and lack of rigorous evaluation may all be barriers to instituting syndromic surveillance within a local region. However, exploring the feasibility of developing this system within a region can bring opportunities for increased communication and understanding between public health, medical providers and the emergency response community. Nurses can be instrumental in facilitating this process.

Constant health threats from emerging infections and bioterrorism possibilities have led to the development of syndromic surveillance systems as a tool for early recognition of disease patterns within a community. Public health began exploring syndromic surveillance in 1993 as a supplemental epidemiologic investigation process (Foldy, 2004). The Centers for Disease Control (CDC) defines 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” (Centers for Disease Control & Prevention, 2004).

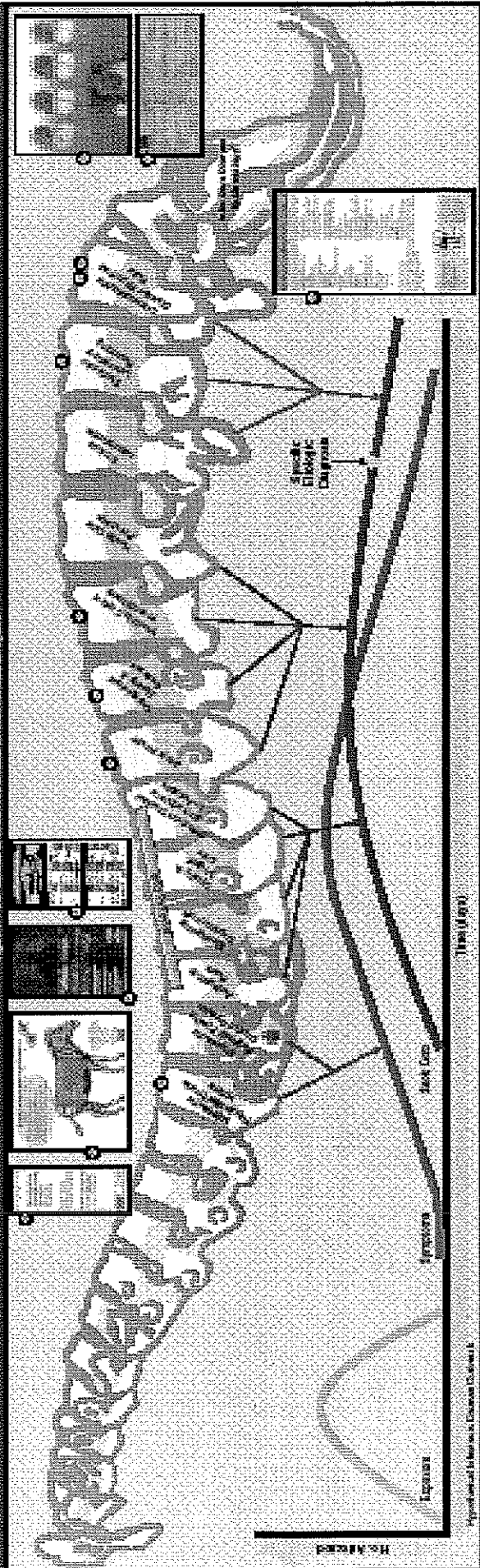
In the United States mandates exist that require healthcare providers to report specified communicable diseases. Traditionally these reports prompt an epidemiologic investigation to identify source and spread of the disease, and to control the outbreak. However, because the report is often initiated after a laboratory confirmed diagnosis, many days may be lost that could be crucial in the containment of the outbreak. The goal of syndromic surveillance is to reduce morbidity and mortality by identifying an outbreak at an earlier point in time to shorten the gap between illness onset and Public Health identification of, and response to, disease outbreaks. Syndromic surveillance utilizes non-traditional sources of information indicating illness, before an individual is diagnosed. Figure 1 on the following page from Minnesota Department of Health (Integration of Non, n. d.) illustrates the time gap reduction, which may be possible utilizing syndromic surveillance systems. This timesaving could be crucial in containing an outbreak. The time “saved” could be used to begin epidemiological investigation, mobilize resources and bolster the capacity of the community to meet increased demand on medical resources during a large outbreak.



Integration of Non-traditional Infectious Disease Surveillance Mechanisms into the "Backbone" of Traditional Infectious Diseases Surveillance

Health Surveillance, Epidemiology, and Prevention Branch, Division of Field Epidemiology, Centers for Disease Control and Prevention, Atlanta, Georgia

Figure 1. The Backbone of Infectious Diseases Surveillance Systems



Surveillance involves the systematic and ongoing collection, analysis, and interpretation of health data essential to the development, implementation, and evaluation of public health practice. [1]

Surveillance systems are the mechanisms and processes used to collect, analyze, and interpret health data. [2]

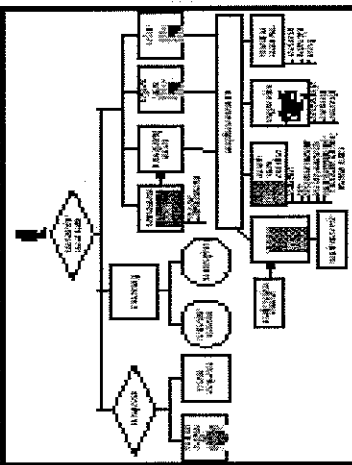
Surveillance systems can be categorized into several types: [3]

- **Active surveillance:** involves the systematic and ongoing collection of data on a specific disease or condition.
- **Passive surveillance:** involves the collection of data from existing sources, such as hospital records or death certificates.
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Surveillance systems are essential for the early detection and control of infectious diseases. [4]

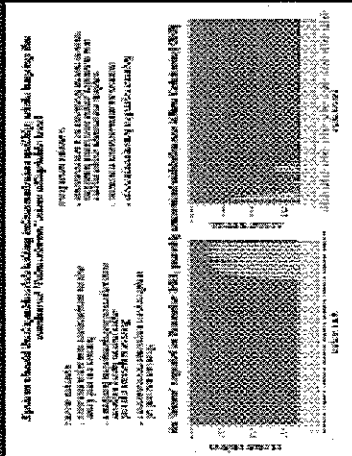
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A variety of non-traditional disease indicators and data sources are being explored for early detection of disease in a community. Commonly used data sources include physician and emergency room visits, hospital or ICU admissions, 911 and emergency medical service calls, over the counter pharmacy sales, calls to nurse hotlines or poison control centers, laboratory tests ordered, school and work absenteeism, and insurance billing (Henning, 2003). Less frequently used sources, due to increased time lag between illness onset and the report, include coroner's reports and case volume (Henning, 2003). Utilizing these sources, public health officials analyze data for deviation from the "expected" and significant variation triggers an investigational response.

Syndromic surveillance systems can be either manual or automatic. Manual systems are time intensive, requiring personnel to input specific data into the system for analysis. Because they are labor intensive and the data is not used for other operational purposes, these systems are hard to sustain. "Drop-in" systems are manual active surveillance systems that do not require extensive technological infrastructure, and are put in place for a short period of time, usually during high profile events. These systems analyze manually input data from emergency rooms and large clinics to rapidly evaluate an "unusual occurrence" during or immediately following the event. "Drop-in" systems are beneficial for short-term rapid disease detection and for reassurance that an outbreak has not occurred. They have been utilized at events such as the 1999 World Trade Organization Meeting in Seattle, for the 2001 presidential inauguration, during both the Republican and Democratic National conventions, the Winter Olympics and in New York City following September 11th, 2001 (Institute of Medicine, 2003).

Automated syndromic surveillance systems are more frequently utilized. Although much harder to establish due to the technological aspects, these systems automatically transfer

electronic data normally collected by a variety of entities. Because this information is already being collected for routine business purposes, sustainability is high. The table below shows the advantages and disadvantages of the different types of syndromic surveillance systems.

Table 1

Types of syndromic surveillance—selected characteristics, advantages, and disadvantages

Surveillance Type	Selected Characteristics	Advantages	Disadvantages
Event Based surveillance “Drop –in” systems	Active Defined duration Emergency departments Large clinics	Develop relationships with ED staff and infection-control professionals Transportable to various sites	Labor intensive Not sustainable Not scalable
Sustained surveillance Manual	Active and passive Faxed 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 a week Not sustainable
Electronic	Passive Automated transfer of hospital 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	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	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

Note. From “What is syndromic surveillance?”, by K.J. Henning, 2003. *Morbidity and Mortality Weekly Report*, 53, p. 9.

A multitude of syndromic surveillance systems has been developed globally with differing types of data, and variable methods of data collection and analysis. A brief overview of a variety of systems utilized in the U.S. follows.

Syndromic Surveillance Tally Sheet

Santa Clara County, California is utilizing this manual collection system. It utilizes eight syndromes. Hospital emergency room triage nurses indicate on a paper tally sheet whether at presentation the patient has none, one, or greater than one of the syndromes of interest. The information is collected multiple times per day and faxed to the health department. The public health department then inputs the data into a database and graphic displays are then generated (Bravata et al., 2004) (IOM, 2003).

Electronic Surveillance System for the Early Notification of Community-Based Epidemics (ESSENCE)

ESSENCE is a Department of Defense surveillance system developed in conjunction with the Centers for Disease Control, Walter Reed Army Institute of Research, Emergency Medical Associates of New Jersey Research Foundation, New York City Department of Health and Mental Hygiene, and Harvard Medical School and Harvard Pilgrim Health Care (Foster, 2004). ESSENCE collects data from all military treatment facilities worldwide to include 104 U.S. Department of Defense primary care and emergency clinic, 121 U.S. Army, 110 U.S. Navy, 80 U.S. Air Force, and 2 U.S. Coast Guard installations. This automated, near real time system collects information from non-traditional sources such as International Classification of Diseases, 9th Revision Modification (ICD-9-CM) codes, pharmacy sales, and emergency room chief complaints.

The data are analyzed to recognize patterns of disease and can detect concurrent infections throughout the world. This system has mapping ability and utilizes 179 geographic clusters. It is HIPAA compliant and utilizes a secure website, which is password protected (Lombardo et al., 2003) (Foster, 2004).

Early Aberration Reporting System (EARS)

EARS is a CDC developed syndromic surveillance software system which has been widely utilized by U.S. city, county, and state public health departments and internationally. Data is collected from emergency departments, 911 calls, physician office visits, school and business absenteeism reports, and over the counter drug sales. The data is analyzed using a SAS platform, and the resulting tables and graphs are obtained from an HTML Website linked through a homepage. This tool is available at no cost from CDC (Hutwagner, Browne, Seeman, & Fleischauer, 2005).

Rapid Syndrome Validation Project (RSVP)

The RSVP system was developed in collaboration with the U.S. Department of Energy and Sandia National Laboratories (Zelicoff, Gimpson, & Robertson, 2002) and tracks 6 different syndromes: flu like illness, fever with skin findings, fever with altered mental status, acute bloody diarrhea, hepatitis, and adult respiratory distress syndrome (Institute of Medicine, 2003). The data is collected by clinicians in a variety of medical settings. Medical personnel input data using touch screens. This system has been utilized both as a permanent system and as a “drop-in” system. The data is transmitted to public health officials and an automated warning signal can alert authorities to new trends in disease.

The officials can also post alerts to emergency departments through this system. This system has been utilized by New York City, California, Texas, and is being piloted in New Mexico currently (Zelicoff, Gimpson, & Robertson, 2002) (Herring, 2004).

Real-time Outbreak and Disease Surveillance (RODS)

The RODS Open Source Project has been in development at the University of Pittsburgh since 1999. RODS initially focused on developing surveillance from de-identified text entries of chief complaints at ER presentation and clinics, and collection of over the counter pharmaceutical data. In addition, it now contains modules which also collect electronic laboratory reports, laboratory orders, dictated radiology and hospital reports, and poison control center calls (Espino, 2004). In late 2002, the RODS system was made available to public health departments free of charge. It has a Web based interface with GIS capability. Multiple requests for technical support resulted in releasing the software under an open-source license and the creation of the RODS Open Source Project for the sharing of “knowledge and skills related to the software, including its design, installation, configuration, and customization” (Espino, 2004).

National Retail Data Monitor (NRDM)

This system was also developed by the University of Pittsburgh and has been operational since 2002. During system development it was hypothesized that because individuals frequently purchase remedies early in their illness, if these purchases were monitored and analyzed, disease could be detected earlier than monitoring physician visits. Using Universal Product Codes (UPCs), NRDM collects and analyzes daily sales of over the

counter medications. Data that includes zipcodes and medications purchased is analyzed and results can be accessed via secure Internet connections. Currently 40% of the nation's over the counter drug sales are captured by this system. NRDM is a free public health surveillance tool now being utilized by over 400 health departments in 44 states and Puerto Rico (Wagner et al., 2004).

BioSense

BioSense is the third component of a national Bioterrorism initiative which was developed for early detection of disease outbreaks. It uses Public Health Information Network Standards (PHIN) for integration and data exchange with an outbreak management system. It collects real-time, diagnostic and pre-diagnostic data from clinical care data systems (Loonsk, Walker, & Rolka, 2004). The data includes Department of Defense and Veterans Administration ambulatory care and emergency room diagnoses, procedures, clinical laboratory tests and over-the-counter drug sales (Loonsk et al, 2004).

Barriers to Syndromic Surveillance These systems represent only a small fraction of syndromic surveillance systems available through public health collaborations or via the private sector. The multitude of systems available, each with different characteristics, is in itself a barrier to instituting a regional syndromic surveillance system. There are no standardized reports for comparison of system attributes to guide officials in selection of the most appropriate system for a region.

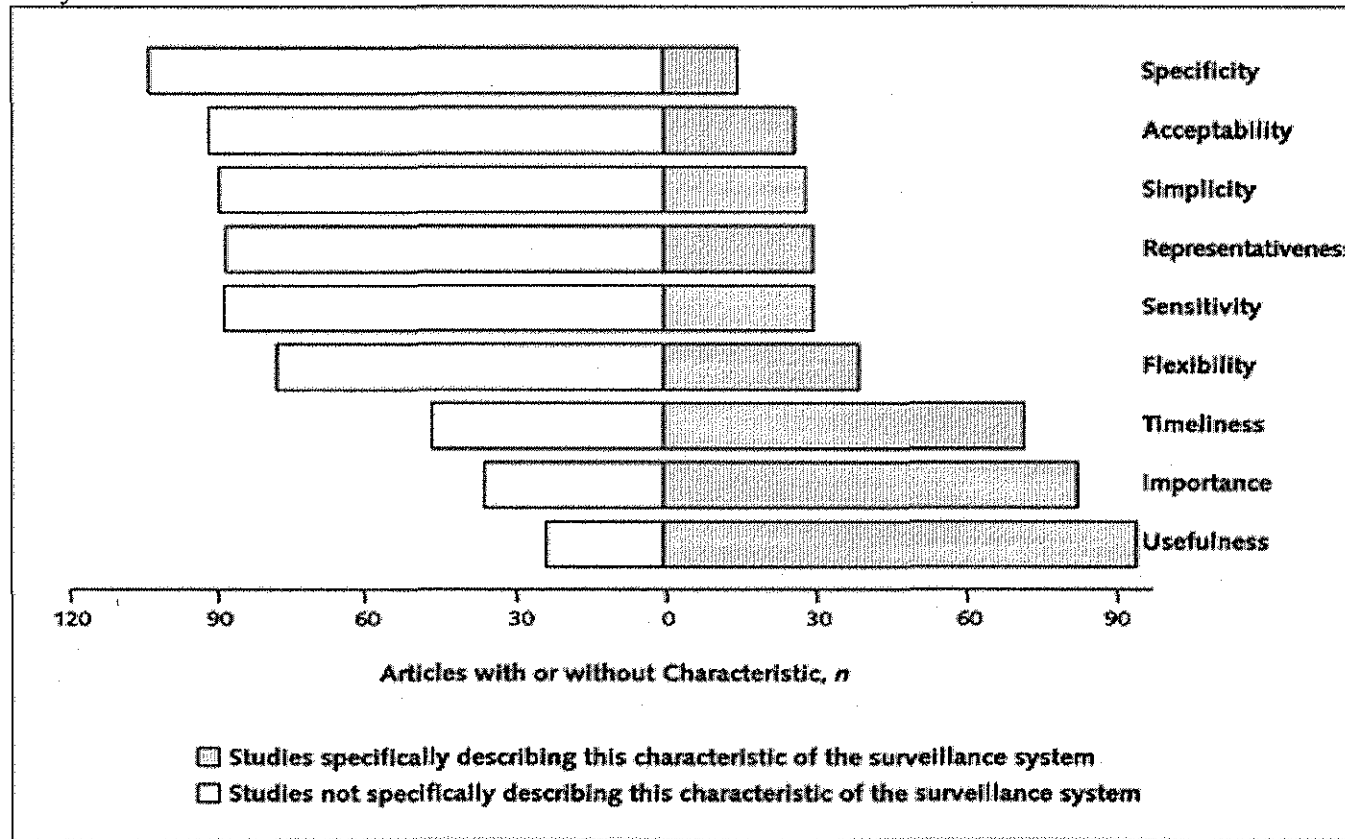
Furthermore, syndromic surveillance systems have not undergone rigorous evaluation. In guidelines for evaluating public health surveillance systems (CDC, 2001), the CDC recommends that all surveillance systems be evaluated using these major indicators:

- Simplicity (of both operation and structure)
- Flexibility (can be easily adapted to changing needs or case definitions)
- Data quality (completeness and validity of data collected)
- Acceptability (of the system to end users; participation of users)
- Sensitivity (the proportion of cases detected or ability to detect outbreaks)
- Predictive value positive (proportion of cases that have the health related event)
- Representativeness (accurately describes the event in terms of person, place and time)
- Timeliness (speed between surveillance steps)
- Stability (the reliability and availability when needed)
- Usefulness (contributes to prevention and control of disease)

Bravata and colleagues reviewed over 17,500 article citations and 8,088 Web sites to ascertain the level of evaluation done on 115 surveillance systems developed for early detection of disease (Bravata et al., 2004). The figure on the following page shows the results of their review. They concluded, “Because current evaluations of surveillance systems for detecting bioterrorism and emerging infections are insufficient to characterize the timeliness or sensitivity and specificity, clinical and public health decision making based on these systems may be compromised.” (Bravata et al, 2004). Although this lack of evaluation of current systems has been cited as a reason for caution in instituting syndromic surveillance systems, it does not mean

Figure 2

Application of the Centers for Disease Control and Prevention evaluation guideline to peer-reviewed reports of surveillance systems



From "Systematic review: surveillance systems for early detection of bioterrorism-related diseases", by Bravata, D.M., et al, 2004, Annals of Internal Medicine, 140, p.916

that they are not potentially beneficial for early detection of disease in a community (Bioterrorism, 2002)

Another barrier to instituting regional syndromic surveillance is the lack of consistency in definition of the syndromes themselves, and the postulated diagnosis from these syndromes (IOM, 2003). Currently there is no national standard (IOM, 2003). Many syndromic systems rely on data derived from ICD-9-CM codes, physician discharge diagnosis, or chief complaint of the patient. A study by Fleischauer and colleagues comparing these different methods has shown inconsistency in these reporting sources (Fleischauer et al., 2004). In manual systems, because there is not standardization, physicians or other medical personnel may not know when to include a presentation, thus skewing the data. Furthermore, there may be problems transferring the data electronically, as there is no medical industry standard for data collection and utilization (Mandl et al, 2004).

The cost, in terms of personnel and information technology infrastructure, may also be a barrier to instituting a syndromic surveillance system. The medical system in the U.S. falls exceptionally behind industry in utilizing information technology (Bates, 2002). Many health care providers and clinics are not computerized, and those that are, utilize electronic data mainly for billing purposes (Bates, 2002). Utilizing a manual system for data input increases cost for the provider, and should therefore be avoided. As suggested by Sosin and DeThomasis, successful implementation of a syndromic surveillance system will be dependent on identifying systems already in place and utilizing data from every day transactions to lessen the burden on the provider (Sosin & DeThomasis, 2004).

Local or regional public health agencies themselves often lack the infrastructure, both technologically and in terms of personnel with expertise in epidemiology and biostatistics.

Although bioterrorism funds have been useful in building infrastructure in local health departments, without qualified personnel reviewing aggregated or even pre-analyzed data, the system may not be effective or efficient. Signals of increased disease must be investigated. It takes a trained epidemiologist to recognize possible interfering factors contributing to a report suggesting an increase in disease. Hours of needless investigation with resulting increased costs may occur unless personnel are qualified. Conversely, a small increase in disease may need to be investigated but may not be recognized by personnel, allowing a larger outbreak to occur.

Frequently technical support is not readily available. There is limited communication and interoperability between local, state and national systems of disease reporting. Although this issue is being addressed by the Public Health Information Network (PHIN) (Broome & Loonsk, 2004), the National Electronic Disease Surveillance System (NEDSS) (IOM, 2003), and ultimately the Health Insurance Portability and Accountability Act of 1996 (HIPAA) (Bloome, Horton, Tress, Lucido, & Koo, 2003), the lag in the development of interoperability is a barrier to many local health departments when trying to institute a syndromic surveillance system.

Legal and political issues may also arise when trying to institute syndromic surveillance at the regional level. Due to the provisions of the Health Insurance Portability and Accountability Act of 1996 (HIPAA), physicians and other health care providers may be reluctant to provide surveillance data unless specifically required by law. Public health authorities in a few states have even experienced trouble with providers reporting communicable disease mandated by law (Drociuk, Gibson, & Hodge, 2004). To circumvent these problems, some localities have chosen to receive surveillance data stripped of individual identifiers by the provider. This solution imposes further resource demands on the providers, and slows the investigational response by

public health authorities. Utah has addressed this issue by expanding their communicable disease authority to include reports of specific syndromes by hospitals or public health authorities (Gesteland & Rolfs, 2004).

Opportunities Although the barriers to instituting syndromic surveillance are many, this new tool also presents opportunities for communities to build collaboration, not only among health care providers, but also with those government agencies (law enforcement, disaster management) responsible for the safety of the community (Yuan, Love, & Wilson, 2004). Opportunities exist to educate the community as to the role of Public Health in disease and disaster management. Public health nurses can be invaluable in coordinating this effort given their planning skills, their communication skills, their expertise in disease control (Friends, 2003) and their community and professional connections.

Nurses are employed by a variety of institutions: at emergency or urgent care facilities, hospitals, schools, rehabilitation centers, physician offices and clinics, home health agencies, poison control centers, educational institutions, correctional institutions and in multiple other industry and government work sites. Gaining the support of these nurses can be instrumental in building a community coalition. Educational seminars concerning disease outbreak and disaster management could be instituted at various nursing organizational meetings to motivate diverse nursing participation in disease control, and also in emergency response. Each of these nurses bring a segment of needed information to syndromic surveillance, whether through absenteeism reporting, disease recognition and follow-up, or through influencing organizations or providers to participate.

To further mobilize the region, public health nurses should convene stakeholder meetings to identify specific local barriers to regional syndromic surveillance and resources available. By

including stakeholders in the planning process, a consensual plan can be developed that assures community and regional participation. Stakeholders would include health care providers and information technology personnel, medical care institution management, nurses from multiple disciplines, military partners, government and emergency response authorities. Multiple issues would need to be addressed as shown in the following table.

Table 2

Issues in Developing Syndromic Surveillance Systems

Syndromic Surveillance Systems

The following issues must be addresses during the development of syndromic surveillance systems:

- Is there legal authority to support the system?
- What are the correct syndromes to monitor?
- How are these syndromes defined?
- What population should be under surveillance?
- Which sources of data are most sensitive, specific, and useful?
- How is timeliness ensured?
- Are security and confidentiality requirements met?
- What is the best method for detecting syndrome aberrations?
- How are aberrations (disease clusters) prioritized and investigated?
- Are there adequate personnel and laboratory resources available for investigations?
- How will surveillance results be disseminated to those who need to know?

From “Syndromic surveillance”, by K. J. Henning, 2003. Microbial Threats to Health:

Emergence, Detection, and Response, p. 290 (accessed 3/3/ 2005 at:

<http://books.nap.edu/books/030908864X/html/290.html>.)

Other issues to be addressed by the coalition include assurance that all critical stakeholders are included. Automation of the system, review and response protocols, and developing a plan for expansion and evaluation (Lawson, Fitzhugh, Hall, Hutwagner, & Seeman, 2004) must be agreed upon. Costs associated with instituting and sustaining the system would also need to be discussed. Grant funding for the project might be available through CDC, Metropolitan Medical Response System (MMRS) funding or other Department of Defense grants. Ownership of each segment of the project must be explored and consensus reached.

Research and Public Health Recommendations Syndromic surveillance is a relatively new concept and extensive research, evaluation and refinement still need to be done (Bravata, et al, 2004) ("Syndromic," 2004). Sosin and DeThomasis at the CDC Epidemiology Program Office, suggest that CDC's Framework for Evaluating Public Health Surveillance Systems for Early Detection of Outbreaks "be simplified and standardized to allow comparisons across systems and across outbreak detection approaches" (Sosin & DeThomasis, 2004). They suggest the need for: testing intact system performance to verify the "early warning" premise, validating the underlying assumptions for disease outbreak modeling, and instituting standardized descriptions. Furthermore, they suggest prioritization of a "limited number of measures which would likely be of value now until experience is gained with other measures". (Sosin & DeThomasis). Their incremental approach is shown in Table 3 on the following page.

Conclusions Although syndromic surveillance systems remain under-evaluated, the theory behind utilizing data from non-traditional sources for earlier disease detection appears to be

Table 3

Priority evaluation questions for early outbreak-detection systems

1. How often does the system signal an event for further epidemiologic attention?
 - a. What was the time period (e.g., 1 month)?
 - b. What was the statistical threshold (e.g., p-value)?
 - c. If the threshold has changed, explain why.
2. How were signals responded to?
 - a. What percentage of signals were investigated through new data collection?
 - b. What percentage caused increased reporting frequency from affected sites?
 - c. What percentage conducted detailed manual analysis of any data available to the jurisdiction?
 - d. What percentage conducted manual analysis of data from the system?
 - e. What percentage were reviewed for data errors?
 - f. What percentage of signals were ignored?
 - g. What resources were directed to follow-up?
3. How many outbreaks were detected through the system?
 - a. How timely was detection relative to other systems?
 - b. How timely was detection relative to the stage of the outbreak?
 - c. What were the agent, host population, and environmental conditions of the outbreak?
4. How many outbreaks were missed by the system?
 - a. What were the agent, host, and environmental conditions?
 - b. How was the outbreak detected?
5. What was the public health response to detection (e.g., no response, urgent communication to clinicians, or vaccination campaign)?

From "Evaluation challenges for syndromic surveillance – making incremental progress", by D. M.

Sosin & J. DeThomasis, 2004, *Morbidity and Mortality Weekly Review*, 53(Suppl), p. 128

valid. Although several barriers to instituting a regional surveillance system exist for those in local health departments, many of these barriers may be overcome by collaboration with larger, on-going projects which offer data analysis and on-going technical support. Initiation of a regional syndromic surveillance will require dedicated personnel to mobilize the community to address the feasibility of instituting a syndromic surveillance system. Public health nurses can be instrumental in this effort with their knowledge of the community, their professional associations, planning and communication skills, and their knowledge of disease outbreak control. By developing a community collaborative effort, partnerships between public health, medical providers, and the emergency response community can be strengthened. The community can be further educated as to the role of public health, and all parties involved will gain a better understanding of each discipline's contribution to disease control and emergency response, and interdisciplinary communication will be facilitated. As suggested by Cochrane, "The partnerships that result from collaborative biologic surveillance projects might be more important than the projects themselves" (Cochrane, 2004).

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