

## Roundtable Discussion

# Assessing Syndromic Surveillance: Costs, Benefits, Future

Syndromic surveillance, long embraced by the military to detect potential outbreaks that might imperil U.S. troops and other DoD healthcare beneficiaries, has taken on great interest and great expectations within the civilian public health community, fueled mainly by concern over the threats of bioterrorism and pandemic influenza.

At the same time, questions have arisen as to the actual value of mining volumes of data for signs of a potential disease outbreak: Is the benefit worth the cost at a time when public health resources are growing increasingly scarce? Just how useful are the data collected, especially if there are no resources or plans for taking action based on those data?

Or, as the question has been posed in the medical literature — and was explored at a roundtable discussion held by the nonprofit U.S. Medicine Institute for Health Studies to assess syndromic surveillance: If syndromic surveillance is the answer, what is the question?

The roundtable was attended by representatives from federal agencies, Capitol Hill, academia, state and local health departments and other members of the public health community. There was consensus that solid research is needed to determine the value of syndromic surveillance, assessment of which now is based largely on anecdotal reports. There need to be a clear definition of syn-

dromic surveillance, development of “clear and compelling” criteria for its implementation and for judging its usefulness, comparisons of systems, and validation of systems to assess quality.

While there has been an infusion of federal and state funding into syndromic surveillance since September 11, 2001, development of those systems has been “chaotic.” A means is needed provide a peer-review type process, “so those that meet the purpose get the funding.”

The goal of syndromic surveillance, participants agreed, should be to complement public health efforts, not substitute for them — to bolster the “astute physician” but not make surveillance an end in itself. Similarly, the tool of a syndromic surveillance *system* should not be an endpoint; rather, focus should be on how this tool is used and evaluated.

Additional recommendations made during the roundtable include:

- *There should be a national strategy for syndromic surveillance.* This would allow more disciplined investments in such systems and could help identify the types of scenarios that should be monitored. At the same time, it’s important to recognize the need for local discretion.

Different variables likely merit different weight, and testing is needed to determine how best to identify, define and evaluate the important variables. The value of syndromic

## Discussion Highlights

- The goal for syndromic surveillance has evolved from one of detecting a bioterrorism attack at the earliest possible moment to serving as a public health tool for monitoring outbreaks. “Hopefully, it will become a useful tool in the near future, but we’re not there yet.”
- Integration is needed between small and large systems. While surveillance at the local level can provide earlier detection, the import of local findings can be lost — as isolated local outbreaks — if they are not aggregated at a national level.
- It’s important to avoid confusing the convenience of data with its utility. Further, the emphasis on syndromic surveillance that emerged in the wake of the 2001 anthrax attacks has produced some systems that are flashy and marketable but of only “incidental” benefit.
- Data on the effectiveness of syndromic surveillance can be problematic. For example, some systems list individuals by where they live, not where they work. Consequently, an incident in a large building such as the Pentagon would improperly categorize the site of exposure as across more than 100 zip codes, skewing the results. Such data anomalies can, and should, be rectified.
- The value of data depends on the resources available to look for things and to take followup action.

surveillance may depend most on local conditions and requirements.

As resources become increasingly tight, “Should we limit ourselves to data that give the most benefit?”

- *There should be greater sharing between public health and information technology.* Automatic data capture is valuable, but it needs to be properly interpreted. Public health professionals should be involved in electronic health record development.

- *Current regulations governing patient privacy — HIPAA (Health Insurance Portability and Accountability Act) in particular — should be modified to allow collecting relevant personal data.*

It is currently difficult to integrate data and develop partnerships for taking action.

- *General practitioners need education in surveillance.* “Medical schools provide almost no training in epidemiology and disease reporting.”

Participants noted that the International Society for Disease Surveillance is developing a course in surveillance that will offer CME credit, and the World Medical Association has a similar undertaking.

- *There would be value in integrating animal data into syndromic surveillance systems.* Roundtable participants agreed inclusion of animal data could provide early warning of potential outbreaks, but noted there currently is no means of collecting such data.

### Early Warning

The whole point of syndromic surveillance is to have early warning of potential disease outbreaks, roundtable participants noted, so that action can be taken to limit their spread and reduce illness, and, often, to rule

out false alerts.

Numerous participants said they find value in the surveillance systems they are using — in early detection of influenza, for example. A small study within the Veterans Affairs Department has validated the role of syndromic surveillance in detecting influenza before it would be recognized through regular reporting channels.

One widely used system is ESSENCE, developed by the Defense Department’s Global Emerging Infections Surveillance and Response System (GEIS) and used — and found valuable — by numerous local health districts as well as military hospitals and agencies. Within the military system, data are automatically downloaded and grouped by ICD-9 codes; a pilot program linking data to temporal and geospatial analysis tools is being implemented throughout the military system.

Suggestions for other types of early warning systems made during the roundtable include monitoring intensive care units and using leftover blood from samples drawn every day for regular medical care to watch for early signs of potential outbreaks.

### Situational Awareness

The latest role envisioned for syndromic surveillance is in situational awareness — a term derived from aviation that means having total awareness of everything in the immediate environment and being able to predict what might happen, and then plan for it. But, participants said, there is no agreement on just what this means in regard to syndromic surveillance. “We need to be concrete as to how it is helpful and what it is not able to do.”

While situational awareness works well in such fields as aviation and weather forecasting, surveillance does not have the sophisticated modeling tools used in these fields, one participant pointed out.

Participants called for research to determine just what syndromic surveillance is expected to accomplish — what should be detected, and why.

Participants in this roundtable: Robert Aarhus of the Defense Department; Cynthia Bascetta of the Government Accountability Office; Tanis Batsel of the U.S. Navy; Howard Burkom of Johns Hopkins University; Jean-Paul Chrétien of DoD GEIS; Kenneth Cox of the Defense Department; Joh Davies-Cole of the District of Columbia Department of Health; Tracy DuVernoy of DoD GEIS; Robert DeFraites of the U.S. Army; Jerome Donlan of HHS; Ralph Loren Erickson of DoD GEIS; Dennis Faix of the Naval Health Research Center; Charlotte Gaydos of Johns Hopkins University; Joel Gaydos of DoD GEIS; Penny Hitchcock of the University of Pittsburgh; G.D. Kelen of Johns Hopkins University; Sheri Lewis of Johns Hopkins University; Victor MacIntosh of DoD GEIS; Joseph Malone of the Department of State; Larissa May of George Washington University; James Neville of the U.S. Air Force; Arnauld Nicogossian of George Mason University; Donald Noah of the Department of Homeland Security; Cara Olsen of the Uniformed Services University of the Health Sciences; Jean Otto of DoD GEIS; Gregg Pane of the District of Columbia Department of Health; Robert Pinner of the Centers for Disease Control and Prevention; Beverly Pritchett of the District of Columbia Department of Health; Gary Roselle of the Veterans Health Administration; Richard Rothman of Johns Hopkins University; Ashley Shelton of the Senate Health, Education, Labor and Pensions Committee; Michael Stoto of Georgetown University; Donald Thomson of the Defense Department; and David Trump of the Virginia Department of Health.

The roundtable was moderated by Patrick W. Kelley of the Boards on Global Health and African Science Academy Development at the Institute of Medicine. USMI Managing Director is Nancy Tomich ([www.usminstitute.org](http://www.usminstitute.org)). The roundtable was sponsored by DoD GEIS.