

TRIP REPORT: NATIONAL SYNDROMIC SURVEILLANCE CONFERENCE

New York, October 24, 2003

Jerry Gibson (presentation at this meeting by Jerry and Dan Drociuk)

This meeting was sponsored by CDC, the NY Academy of Medicine and the New York City Department of Health. Its purpose was to present research and experience on syndromic surveillance systems (SSS). There were about 200 estimated attendees just in the public health track and as many in the research track. We presented a survey of state health departments regarding legal, confidentiality and HIPAA issues in implementation of SSS.

This is a brief summary of the high points in the 12 papers in the public health track on Friday, and the two summary papers on research issues and public health issues at the end of the meeting.

1. Starting a syndromic surveillance system (SSS):

Successfully setting up the necessary flow of syndromic information from a hospital emergency department (and occasionally other sources such as lab test orders) requires attention to several key details:

- Initial careful presentation to hospital staff at which the hospital ICP, IT staff, ED chief, risk manager, attorneys and infectious disease staff are present (will take several meetings, and the “IT guy” is key),
- get details on flow of patients and of data from the ED
- try to find sources of routinely keyed data
- provide strong reassurance of your skills and commitment to protecting confidentiality and security of data,
- it's hard to get data that is potentially patient-identifiable, but worth it (e.g. offer to accept encrypted patient record number that only the hospital can decrypt, so you can give it back to them when you have to investigate a “signal” from the system),
- you need a dedicated epidemiologist in your group to analyze the data in real time, and to interpret signals, and a strong IT staff to keep the data flow coming,
- plan for secure transmission,
- do some kind of contract or agreement with the data providers, to assure them of your use and protection of data, level of detail of data needed (? HIPAA “limited data set”), their costs and quality of data expected, your need to investigate, their commitments e.g. fixing IT problems, and to create some commitment on their part,
- offer to pay some of the hospitals' costs, e.g. using HRSA hospital BT money (a few places have made getting HRSA funding contingent on providing SSS data),
- do a press conference, to show off the hospital's community concern and make other hospitals jealous.

You have to choose one of the available statistical systems to receive and analyze the data flow daily for “signals,” i.e. clusters of a specific syndrome in time (and in space beyond a single hospital if you have the software) such as the RODS system, standardized Cusums, the Schuhart statistic, Page's statistic, etc (SAS has several of these). You must feed the data back to the local health department and to your reporters

promptly (so it will be useful to them), and interpret signals and investigate them promptly. Doing that requires both an epidemiologist and an ID clinician (the “cluster doc”). There are the same data quality problems as in lab surveillance: you usually have to interpret natural language Chief Complaints with many misspellings and unexpected words and acronyms.

“Local relationships are key to making it work.” Legal force by itself is not usually enough to get the data.

2. Does it work? Does it provide value? There was no example presented of a significant outbreak identified by a SSS that had not been previously identified by regular surveillance or otherwise previously reported. There were many examples of detected outbreaks not identified by SSS, for a variety of reasons. In NYC, no spatial signal has yet been “real.” This includes the excellent New York City system (very well presented with excellent detail on how to do investigation of signals, see my notes) which is, I believe, about the best example of a SSS. The New York presenters and Dr Marci Layton (who had to miss the meeting at the last minute) say that the value of their system is not to identify unknown outbreaks or cases, but to reassure them that an identified “dangerous” case is not more widely spread in the city. Other proposed values of SSS included building stronger relationships with hospital EDs, but it’s an expensive way to do that.

Evaluating a SSS is essential, but what do you test it against? “If your system cannot identify the onset of the annual influenza epidemic locally, junk it and start over.”

“NYC has about 30 food borne outbreaks per year, and most are picked up by a citizen calling in to the health department.” (Dr Don Weiss, NY acute epi chief)

Three essential criteria to evaluate SSS against: a) sensitivity, b) positive predictive value, c) timeliness.

3. Insight on veterinary surveillance for possible BT incidents from a professor of Vet medicine at Purdue Vet School: “Very few cows or sheep live in large cities, so large animal surveillance is probably not useful. It might be worth while trying surveillance of pet deaths, but that’s hard to do.”

4. Hospitals and MCOs have many disincentives to participating in SSS, including HIPAA, costs of IT work, staff time and trouble, legal risks and lawsuits, release of business information to competitors, bad publicity, and diluting the value of their own data that they could sell to other business users such as pharmaceutical companies. You have to overcome that. Incentives to them include appearing concerned to their community, patriotism, improving the health of their community and their own employees, obeying the law, your returned analyses to help their own staffs do their jobs, and true altruism.

5. Presentation by chief of a very large ED group in New Jersey. There is real value to clinicians of having epi knowledge of “what is going around,” e.g. onset of influenza (decision to start using oral antivirals like oseltamivir?, OB of diarrhea (tell moms about oral rehydration, test for viruses and bacteria), a pertussis outbreak, ?onset of SARS etc.

He also thinks that ED “astute clinicians” cannot reliably detect a significant cluster of disease in their own ED unless it is very obvious, and need a data system to do that.

6. Legal, confidentiality and HIPAA issues: “In law, nothing is certain but the expense.” Samuel Butler. Clarification and dissemination of the real requirements of the HIPAA Rule is vital.

7. Much more emphasis needed on learning how to investigate signals efficiently and acting on them, instead of just being academic and studying which analytic method has the best sensitivity and positive predictive value. New York City protocol: a) Review the signal for errors and for common sense, b) review the recent line list, c) compile descriptive statistics, d) call the ED or ICP (s), check for coding/typing errors e) check complementary systems, f) check next day’s data unless it’s a C3 (high-level signal), g) if still looks like a signal, ICP reviews charts at hospital, g) F/U on patients, h) additional lab testing, i) send your epi-team to site.

8. University of New Mexico/NM State Health Department/Los Alamos joint SSS project: analyzed surveillance flow from a variety of different sources to see which was best: Best was the UNM Hospital Emergency Department Chief Complaints; UNM lab test orders for cultures and rapid viral tests was second best; all the rest were useless, including 911 calls, death reports, pharmacy orders, and the regional poison control center calls. None of the systems were able to detect the onset of their flu season reliably, but it was a slow flu year.

9. (Dr. Richard) Hopkins’ ten rules for any surveillance system: a) Set your objectives clearly, b) use them to design the system, c) show the reporters you’re using the data, preferably feeding it back so it is useful to them, d) nurture the personal relationships, e) remove barriers to rapid reporting, f) provide accessible consultation to reporting clinicians, g) have parallel or redundant systems, h) analyze regularly and promptly, i) all information received from different systems of the health department is analyzed and interpreted together, j) be confident!

10. Not yet clear what these are good for, except possibly in very large cities.
“Evaluate! Evaluate! Evaluate!”