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MEMORANDUM

To: Members of the Subcommittee on National Security,
Emerging Threats, and International Relations

From: Kristine K. McElroy

Subject: Briefing Memorandum for the hearing, *Homeland Security:
Improving Public Health Surveillance*, scheduled for Monday,
May 5, 2003, at 2 p.m. in Room 2154, Rayburn House Office
Building.

PURPOSE OF THE HEARING

The purpose of the hearing is to examine the status of public health surveillance programs and the challenges to improving local, state, federal and international health data collection and reporting.

HEARING ISSUES

- 1. How effective are public health surveillance systems?**
- 2. What are the challenges to improving local, state, federal and international health data collection and reporting?**

BACKGROUND

According to the Centers for Disease Control and Prevention:

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. (Attachment 1, p. 1)

Concerns about bioterrorism and improvements in technology, have led to an increased emphasis on the development of early warning systems to detect the presence of disease. The sooner public health authorities are made aware of a contagious disease, the quicker protective measures can be put in place to contain and control its spread. An effective public health response will depend on the timeliness and quality of communication among local, state and federal levels.

There are several types of surveillance systems:

- Passive surveillance systems rely on laboratory and hospital staff, and providers to take the initiative to provide data on illnesses to health departments. The health department will analyze and interpret the information.
- An active surveillance system is one in which public health officials contact laboratories, hospitals and providers to acquire information on conditions or diseases in order to identify cases. **(Web Resource 1)**
- A syndromic surveillance system monitors symptoms in a population.
- A diagnosis based surveillance system monitors physician or laboratory confirmation of a disease. **(Attachment 2, p. 3)**

Traditional surveillance methods were paper based and relied on astute clinicians. In the past, accuracy was valued over speed when it came to disease surveillance. Traditional surveillance systems required a disease to be diagnosed before it was reported. Physicians and public health officers would gather data and send paper copies by mail. Federal, state and private

laboratories would determine the cause of disease and confirm diagnoses. However, this process could take several days to weeks. **(Attachment 3, p. 3)**

Recent advances in technology have led to the development of automated systems that can track symptoms along with demographic information in order to provide earlier notification of potential outbreaks. Syndromic surveillance involves monitoring the population for clusters of symptoms that may provide an early warning of the presence of diseases. It is the, "collection and analysis of pre-diagnosis information that lead to an estimation of the health status of the community." **(Attachment 2, p. 7)**

Syndromic surveillance uses health care indicators such as emergency room primary complaint, international classification of disease billing codes, requests for specific laboratory tests, and over-the-counter medication sales. These indicators are then grouped into specific syndromic categories such as respiratory, gastrointestinal, neurological, dermatological, febrile, etc. **(Attachment 2, p. 7)** Other data sources for disease indicators include school absenteeism, pharmaceutical sales, nursing home information and animal and agriculture health. Syndromic surveillance looks for the change in the distribution or frequency of health indicators or syndromic groupings of indicators compared to anticipated occurrences. **(Attachment 2, pp. 7-8)** This leads to a more timely notification process since the information is based on symptom reporting and not diagnosis.

Centers for Disease Control and Prevention (CDC)

The Centers for Disease Control and Prevention have taken steps toward strengthening U.S. disease surveillance and testing a National Surveillance System to provide early warning of public health threats.

The National Electronic Disease Surveillance System (NEDSS) is a CDC initiative that, "promotes the use of data and information system standards to advance the development of efficient, integrated, and interoperable surveillance systems at federal, state and local levels." **(Attachment 4, p. 1)** The initiative is designed to, "1) facilitate the electronic transfer of appropriate information from clinical information systems in the health care industry to public health departments, 2) reduce provider burden in the provision of information, 3) enhance both the timeliness and quality of information provided." **(Attachment 4, p. 1)**

The vision of NEDSS is, "to have integrated surveillance systems that can transfer appropriate public health, laboratory, and clinical data efficiently and securely over the Internet. This will help improve the nation's ability to identify and track emerging infectious diseases and potential bioterrorism attacks as well as to investigate outbreaks and monitor disease trends." (**Attachment 4, p. 1**)

The CDC is also collaborating with the American Association of Health Plans, Harvard Medical School, five health plans or physician groups (Harvard Pilgrim Health Care/Harvard Vanguard Medical Associates (Massachusetts), Health Partners (Minnesota), Kaiser Permanente (Colorado), Scott and White Healthcare System (Texas), the Austin Regional Clinic (Texas)), and Optum, a nationwide consumer health information company to implement a syndromic surveillance system covering more than 20 million individuals with pre-paid healthcare in all 50 states. This system will use data from routine and urgent office visits and from nurse telephone triage and health information systems. Information will be received daily, and syndromes will be grouped into specified geographic regions. (**Attachment 5, p. 1**)

The system will be based on an earlier project between CDC and Harvard Pilgrim Health Care entitled the "National Bioterrorism Syndromic Surveillance Demonstration Program" which gathered symptom data from nurse call-in lines, and physician visits using patient zip codes to look for patterns of symptoms. Conducting surveillance through health plans is thought to be quicker than tracking emergency room visits since patients may call nurse help lines when symptoms first appear, before seeking emergency care. (**Attachment 6, p. 1**)

BioWatch is a multi-agency program with the Department of Energy (DOE), the Environmental Protection Agency (EPA), and the Department of Health and Human Services. The program includes air filter sampling to look for bio-agents in certain cities. The filters are tested for six agents. The program is an extension of EPA air quality testing. Testing in two cities is up and running. There are thirty cities now included in the program, and may go as high as 120 cities. CDC is putting people in state laboratories. The plan is to have 19 cities up and running by March. The Lawrence-Livermore laboratory is doing the testing until the state labs can take over. Data from

another CDC program called BioSense can be used to match data from BioWatch to compare indicators.¹ **(Web Resource 2)**

The Enhanced Surveillance Project (ESP) is another CDC program that can be used during special events to monitor sentinel hospital emergency department visit data to establish syndrome baseline and threshold data. ESP has been used at the World Trade Organization Ministerial in Seattle and the Republican and Democratic National Conventions. **(Attachment 4, p. 2)**

The Health Alert Network (HAN) is a nationwide program to establish communication, information and distance learning. The HAN will link local health departments to one another and to laboratories, CDC, and community first responders. Early warning systems such as broadcast faxes can be used to alert local, state, and federal authorities. **(Web Resource 3)**

The National Electronic Telecommunications System for Surveillance (NETSS) is a computerized public health surveillance information system that provides the CDC with weekly data regarding cases of nationally notifiable disease. The list of notifiable diseases varies over time and by state. The Council of State and Territorial Epidemiologists (CSTE) determines the list of infectious diseases, conditions, and toxic exposure under nationwide surveillance in consultation with CDC. **(Attachment 4, p. 3)**

The CDC has also provided funding for bioterrorism surveillance and epidemiology coordination to all state health departments, and some major metropolitan cities and territories. **(Attachment 4, p. 8)** Several cities and states have implemented their own syndromic surveillance systems including California, New Mexico, Texas, Boston, New York City, and Pittsburgh. **(Attachment 3, p. 3)**

Department of Defense Global Emerging Infections Surveillance and Response System (DOD-GEIS)

The Department of Defense Global Emerging Infections Surveillance and Response System (GEIS) was established in response to Presidential Decision Directive NSTC-7, June 1996. According to President Bill

¹ BioSense is a CDC project that is designed to tap clinical data, military medical affairs, and nurse call lines.

Clinton, "the mission of the DOD would be expanded to include support of global surveillance, training, research, and response to emerging infectious disease threats." DOD-GEIS is designed to, "strengthen the prevention of, surveillance of and response to infectious diseases that are a threat to military personnel and families, reduce medical readiness or present a risk to U.S. national security." **(Attachment 7, p. 1)**

DOD-GEIS is managed by a Central Hub office located at the Walter Reed Army Institute of Research. DOD-GEIS operates within five Army and Navy overseas medical research laboratories, and within the infrastructure of the military health system (MHS). DOD-GEIS works to strengthen laboratory-based surveillance, and monitors for global emerging infections. **(Attachment 7, p. 1)**

In response to concerns about bioterrorism, and the need for creating an early warning system, DOD-GEIS created the Electronic Surveillance System for the Early Notification of Community based Epidemics called ESSENCE. ESSENCE started receiving Ambulatory Data System (ADS) information from military treatment facilities (MTF) in December 1999 for the National Capital Area (NCA). Seven syndrome groups were created based on the International Classification of Diseases, Ninth Revision, Clinical Modification (ICD-9-CM) codes.² **(Web Resource 4)** These groups include respiratory, gastrointestinal, neurologic, dermatologic-hemorrhagic, dermatologic-vesicular (smallpox-like), fever/malaise/sepsis, and coma/sudden death. **(Attachment 2, pp. 10-11)** In September 2001, ESSENCE began receiving information from all MTFs that submit data to the ADA. ESSENCE collects information that is available via secure DOD website. **(Attachment 7, p. 5)**

Every eight hours data is downloaded and graphs of syndrome counts are automatically created. Based on historical data, a baseline of normal ranges is created. If syndrome counts exceed baseline ranges, further investigation will be needed to determine the cause. Syndromic cases can be sorted by patient home zip code. There are plans to sort active duty personnel records by work zip code since geographic identification is useful in determining the source of an outbreak. **(Attachment 7, p. 4)** ESSENCE has already detected outbreaks domestic and worldwide. Most of the

² ICD-9-CM is the official system of assigning codes to diagnoses and procedures associated with hospital utilization in the United States.

detected outbreaks were in the gastrointestinal or respiratory category. **(Attachment 2, p. 19)**

In FY01, Walter Reed Army Institute of Research (WRAIR)/DOD-GEIS entered into a Cooperative Research and Development Agreement with the John Hopkins University Applied Physics Laboratory for development of nontraditional sources of data for disease outbreak detection and management. This agreement led to ESSENCE II, a project that was awarded a Defense Advanced Research Projects Agency (DARPA) grant for \$12,000,000 over a four year period. **(Attachment 7, p. 5)**

Essence II is a syndromic surveillance system that collects non-traditional data sources from military and civilian outpatient visits, over the counter drug sales, school absenteeism, and animal health data in Washington DC, Maryland and Virginia. ESSENCE II also collects data on emergency room activity, requests for lab tests, confirmed lab results, 911 calls, and ems services. The ESSENCE II system is only accessible by secure web site to health departments participating in the program. Maryland and the District of Columbia Health Department are members of ESSENCE, but the Virginia Health Department has not yet formally joined. **(Attachment 7, p. 5)**

World Health Organization (WHO)

The World Health Organization is an international health agency with over 50 years of experience. WHO staff, consultants, and advisers have special access to countries, since the organization tries to remain neutral. WHO has six regional offices and 141 country offices, located within or close to ministries of health, and in areas where epidemics frequently occur. WHO is also supported by a network of 250 laboratories and institutions formally designated as WHO Collaborating Centers. **(Attachment 8, p. 6)**

WHO coordinates several electronic "detective" systems and databases to keep experts alert to changes in infectious disease situations. These networks monitor disease-related events from new strain of viruses and outbreaks. **(Attachment 8, p. 7)** The surveillance networks work within the International Health Regulations, which provide the only international legally binding instrument governing the reporting of epidemic-prone disease and prevention measures. **(Web Resource 5)**

WHO also uses a semi-automatic electronic system by Health CANADA that scans Web sites, news wires, public health email services, electronic discussion groups, and local online newspapers for rumors of outbreaks. This enables WHO to monitor the world for informal news that may suggest unusual disease occurrences. A WHO team responsible for outbreak investigation examines scans each morning to determine if the reports pose a health threat. **(Attachment 8, p. 9)**

WHO also formed the "Global Outbreak Alert and Response Network" in April 2000. The Network brings together 72 other networks operating under WHO, as well as national or regional nongovernmental organizations. The Network reports and verifies information on a daily basis from a wide range of sources including ministries of health, government and military health facilities and laboratories and nongovernmental organizations. Once an affected country is judged as being in need of WHO assistance, as agreed upon in confidential consultation with the affected country and experts from the Network, WHO will coordinate a quick and appropriate response. **(Attachment 8, p. 10)**

WHO has also set up an Early Warning and Response Network (EWARN) in partnership with nongovernmental organizations present in the field to cover seven diseases and a large geographical area to ensure epidemics are rapidly detected and investigated. **(Attachment 8, p. 10)**

DISCUSSION OF HEARING ISSUES

1. How effective are public health surveillance systems?

While several cities and states are implementing syndromic based surveillance systems, others remain skeptical about the systems' usefulness and overall effectiveness to support public health activities or detect bioterrorism. Some believe syndromic surveillance may not be sensitive enough to provide sufficient information for finding events or to find them in a timely manner. **(Attachment 5, p. 4)**

Syndromic surveillance systems rely on statistics and calculating the probability of an event based on changes to historic data. However, a new disease, or bioterrorist event may not look anomalous against historic data on known diseases in a population. **(Attachment 9, p. 1)** Others believe it

is important to collect data now, in order to establish baseline reference points over time that will later be useful for tracking anomalous events.

Syndromic based systems such as ESSENCE have several limitations. There is a lag time in data acquisition. Currently, data is received within 1 to 3 days of a patient visit. However some believe this is not timely enough should an outbreak occur. **(Attachment 7, p. 4)** An astute clinician may call attention to an illness of concern faster than a syndromic surveillance system. In the case of the anthrax incidents in 2001, it was a Florida clinician who determined it to be anthrax. **(Attachment 9, p. 1)** However, others argue while a syndromic surveillance system may not be useful to catch a small number cases, it will be helpful in recognizing larger incidents of bioterrorism.

There is also concerns regarding protecting individual privacy. While syndromic surveillance systems do not typically contain names, zipcodes are identified, and should public health authorities need further information, identities may be given. Current regulations allow public health authorities to examine medical records for public health purposes. **(Web Resource 6)**

2. What are the challenges to improving local, state, federal and international health data collection and reporting?

There are various challenges to improving health data collection and reporting. The threat of bioterrorism has placed additional burden on public health departments to develop surveillance capacity and to have staff available to provide timely analyzation and response.

A recent GAO report entitled *Bioterrorism: Preparedness Varied across State and Local Jurisdictions* found shortages in personnel in state and local public health departments, laboratories and hospitals. Some states and cities were concerned they did not have enough epidemiologists to do the appropriate investigations in an emergency. **(Web Resource 1)**

GAO found local officials felt their surveillance systems were inadequate to detect a bioterrorist event. Some of the cities used a passive surveillance system. A passive surveillance system is not timely, and is therefore inadequate for identifying diseases early. There is also chronic underreporting and a time lag between diagnosing a condition and the health

department's receipt of the report. Many local health departments were lacking the resources needed to sustain an active surveillance system. **(Web Resource 1)**

Challenges posed to a national public health surveillance system include the ability of epidemiologists and public health officials to interpret and sort through data. While computer systems can function in real time staff at hospitals and physician offices have to enter the data into the system, and may face time constraints in trying to keep data current.

Challenges to receiving timely health data and reporting from the local level depends on public health infrastructure, and the government's willingness to report disease. The WHO has had difficulties in the past with countries reluctant to report outbreaks due to concerns about the impact on trade, and tourism. **(Attachment 8, p. 12)**

Some are concerned WHO member states determine for themselves, without existent standards, whether an outbreak is a public health emergency of international concern. For instance, China did not feel it had to notify the WHO until the SARS outbreak got out of control. **(Attachment 10, p. 2)** However, some believe increased access to the Internet and electronic media press have helped facilitate alternative information sources for finding out about infectious diseases which have not yet been officially reported by the affected jurisdiction. **(Attachment 8, p. 12)**

In May 2001, the World Health Assembly adopted a resolution on global health security that enables WHO to investigate rumored outbreaks prior to receiving an official notification from the government of the affected country. This could help strengthen public health response time. **(Attachment 8, p. 13)**

While WHO claims to be apolitical, some are concerned WHO is not monitoring events in Taiwan in deference to political consideration in China. As a result, information regarding SARS fatalities in Taiwan, and control efforts, have been ignored by WHO. Instead, only the CDC is monitoring events in Taiwan. **(Attachment 10, p. 2)**

Dr. David W. Fleming, Deputy Director for Public Health Science, Centers for Disease Control and Prevention (CDC) will present testimony

regarding steps the CDC have taken to strengthen public health surveillance in the United States and throughout the world.

Dr. David Tornberg, Deputy Assistant Secretary of Defense for Clinical and Program Policy, Department of Defense (DOD) will present testimony regarding the role the DOD plays in infectious disease surveillance, and the status of the Global Emerging Infections Surveillance and Response System (GEIS) and the Electronic Surveillance System for Early Notification of Community-Based Epidemics (ESSENCE).

Ms. Mary C. Felecky, President, The Association of State and Territorial Health Officials (ASTHO) will present testimony regarding the steps state public health departments have taken to improve public health surveillance.

Dr. Seth L. Foldy, Chair of the National Association of County and City Health Officials (NAACHO) Information Technology Committee and the Commissioner of Health for the City of Milwaukee will present testimony regarding efforts made by the City of Milwaukee to improve public health surveillance and the role local health departments play in public health surveillance.

Dr. Julie Hall, Medical Officer, World Health Organization (WHO) will present testimony regarding steps the WHO has taken to strengthen public health surveillance challenges that remain.

Ms. Karen Ignagni, President and CEO, American Association of Health Plans will present testimony on how private health plans are working with the Centers for Disease Control and Prevention to establish early warning health surveillance systems.

ATTACHMENTS

1. Meriwether, Rebecca A. "Blueprint for a National Public Health Surveillance System for the 21st Century."
2. "Bio Surveillance: Utilizing ESSENCE II in Emergency Response" Presented at the 2003 NDMS Conference by Joe Lombardo MS and LTC Julie Pavlin MD MPH (March 9, 2003).
3. *The New York Times*. "Threats and Responses: The Bioterror Threat" (January 27, 2003).
4. CDC website articles on public health surveillance.
5. *Journal of Urban Health* "Syndromic Surveillance Using Minimum Transfer of Identifiable Data: The Example of the National Bioterrorism Syndromic Surveillance Demonstration Program" (January 24, 2003).
6. *National Journal*. "Health Plans Search For Bioterror Symptoms" (April 19, 2003).
7. DOD GEIS website articles on ESSENCE.
8. Statement by Dr. David L. Heymann, "Strengthening Global Preparedness for Defense Against Infectious Disease Threats," (September 5, 2001).
9. *The Washington Post*. "Unprepared For a Plague" (April 18, 2003).
10. *The Korea Herald*. "Killer Bug Exposes WHO's Weakness" (March 21, 2003).

WEB RESOURCES

1. General Accounting Office Report, "Bioterrorism: Preparedness Varied across State and Local Jurisdictions." [GAO-03-373](#) April 7, 2003
<http://www.gao.gov/>
2. CDC Information Council Meeting Minutes (February 27, 2003)
<http://www.cdc.gov/cic/minutes/CIC%20minutes%202-27-03.pdf>
3. CDC Health Alert Network. www.cdc.gov
4. International Classification of Diseases, Ninth Revision, Clinical Modification, Sixth Edition.
<http://www.cdc.gov/nchs/about/otheract/icd9/abtcd9.htm>
5. International Health Regulations. <http://www.who.int/csr/ihr/en/>
6. HIPAA Privacy Rule and Public Health.
<http://www.cdc.gov/mmwr/preview/mmwrhtml/m2e411a1.htm>