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Statement of

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House Committee on Government Reform

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Good afternoon, Mr. Chairman and Members of the Subcommittee. I am Seth Foldy, MD, Health Commissioner of the City of Milwaukee, Wisconsin. I am pleased to speak with you today on behalf of the National Association of County and City Health Officials (NACCHO). NACCHO is the national organization representing the nation's nearly 3000 local public health agencies. I chair NACCHO's Committee on Information Technology and am glad to share with you from the local viewpoint what we are learning about disease surveillance and how the nation can do it more effectively.

When a disease outbreak or other public health emergency occurs, local public health agencies provide the eyes, ears, hands and feet to find the cause and prevent further harm. We are usually the ones who first detect and investigate unusual occurrences of disease and execute a response. It is important for state and federal governments to alert us to potential problems, but such alerts are useless unless we have the ability to do disease investigation and response on the ground.

Today, the number of threats we face is increasing, as are the number of tools potentially available to help us address them. It will take many years of sustained investment to modernize our local public health workforce and our systems to enable us to do justice to these challenges. It will also require active, sustained involvement by the local public health community in the development of statewide and nationwide disease surveillance systems. Such systems cannot and will not function effectively unless they are designed to account fully for the processes and realities of local public health work.

The need for improved surveillance systems is critical not just to detect a bioterrorism event, but also to detect emerging communicable diseases, such as Severe Acute Respiratory Syndrome (SARS). We can never assume that the diseases we will be trying to track next month will be the same diseases that have concerned us over the past several years.

The Objectives of Disease Surveillance

The purpose of disease surveillance is the same, whether the disease is SARS or smallpox. Our objective in all cases is to detect the occurrence of an infectious disease as early as possible so that we can act to prevent its spread and minimize the number of persons affected. The sooner

we know that a disease outbreak may be occurring, the sooner we can act to confirm and contain it.

There are many ways we might learn that a communicable disease outbreak is threatened or in progress. In the 2001 anthrax event, the public health system was alerted by the diagnosis and prompt reporting of a single case of an unusual disease in Palm Beach, Florida. In the 1993 Milwaukee outbreak of *Cryptosporidium parvum,* a water-borne parasitic disease that ultimately killed more than 50 in my city, it was several days before public health authorities realized that a generalized outbreak was underway. Traditional surveillance did not awaken public health. Rather, it was calls from pharmacists running out of anti-diarrheal medications and laboratories besieged by requests for stool cultures.

These two examples illustrate the two differing types of disease surveillance: 1) direct observation, diagnosis and reporting by astute clinicians or from laboratory results; and 2) observation of community-wide patterns that indicate a possible disease outbreak. An effective disease surveillance system uses both strategies, which then function synergistically and optimize our ability to contain outbreaks. Both strategies require establishing systems that enable flows of information and health data within communities to permit timely recognition of local events. They must also adapt to the increasingly regional and national nature of laboratories and health care databases, since a sample obtained in Massachusetts may be analyzed in Atlanta. Ideally, surveillance occurs actively, with continuous scanning of patterns of disease and near-real-time notification of aberrations, rather than waiting for outbreaks to become obvious.

<u>Disease Surveillance: The Past and the Future</u>

The nation's traditional approach to disease surveillance has been slow and cumbersome. States establish lists of reportable diseases. Physicians and laboratories confirm the diagnosis of a reportable disease and record the information manually on paper. The paper is sent to the local or state health department, which processes it and determines whether it needs to be sent elsewhere and whether action needs to be taken. Often the paper forms are missing crucial pieces of information, such as the address or phone number of the patient. If it is necessary to contact

the patient to gather further information about how the disease might have been acquired or spread, someone must chase down that information before contact can be made. It can take a long time before these pieces of paper add up to the identification of a disease outbreak. Valuable time for preventing the spread of the disease is lost.

Traditional legally-mandated disease reporting that is based on the definitive diagnosis of illness and relies on clinicians making the effort to notify public health authorities may be too slow and unreliable for some of today's challenges. It has been estimated that each hour delay in the recognition of an airborne anthrax attack might cost hundreds of millions of dollars due to missed opportunities to limit exposures and offer prophylactic treatment. Moreover, the traditional model will not detect emerging communicable diseases that too new for mandated reporting regulations.

Imagine how different it would be with real-time, electronic systems instead of paper and fax or mail. Physicians, hospitals and laboratories record information one time in their electronic record, but uniform data standards permit that data to flow through interoperable information systems to serve the needs of pharmacies, labs, billing departments and public health authorities. Information of interest to public health is automatically identified, filed, stored, counted, analyzed, and displayed. Computers programmed with algorithms recognize an unusual pattern of symptoms, laboratory tests, or diagnoses, sounding a virtual alarm at the text pager of a health department physician or epidemiologist who logs in via the nearest computer, examines the data promptly and determines whether further investigation is needed. Patterns of time, location and population affected are rapidly assessed by working backward through electronically linked information

Disease Surveillance: Today

Our present approach to disease surveillance is beginning to move beyond the limitations of paper-and-pencil reporting of specified diagnoses. However, several steps separate us from the vision described above. Much health care information remains in paper records. Existing electronic health data systems do not produce information in standardized ways in order to

permit another system to receive or comprehend it. Information systems at local, state and federal public health agencies are often rudimental and outdated.

The Health Insurance Portability and Accountability Act (HIPAA) is setting the stage for such interoperability. Despite some provider anxiety about HIPAA regulations, they lay the foundation for interoperable health information systems by requiring common data standards and defining appropriate security and confidentiality. Creation, refinement and adoption of information standards useful for public health are being facilitated by CDC's Public Health Information System functions and requirements. The recent adoption of a first set of uniform health information standards across federal agencies is another exciting development.

Most successful models are being developed and tested at the local level. For instance, the Kansas City Health Department receives electronic notification of reportable lab results from multiple medical laboratories who share the same Laboratory Information System vendor. This is called electronic laboratory reporting and it is probably the technology most likely to produce immediate improvement in traditional disease surveillance. Kansas City's health officer reports that this reduced lag time in disease reporting and increased the receipt of complete information, enabling faster response with fewer wasted resources. Like most improvements in surveillance, however, this system generates more reports of disease that require public health follow-up. This is a desirable result, but it demonstrates that surveillance is the tip of an iceberg that leads to many other types of local public health responsibilities.

In Milwaukee, many hospital emergency rooms have voluntarily reported daily counts of defined symptom syndromes electronically to my health department using a Regional Emergency Medicine Internet application. We are using that system now to perform surveillance for symptoms associated with SARS. This is one form of what is known as syndromic surveillance. We do not receive personally identifiable information, but each hospital has a way to help us locate the persons with symptoms if necessary. While it is simple to use, it does require extra data collection and data entry by Emergency Department personnel. Because the system operates on the World Wide Web it was fairly easily adopted by other communities for

the SARS epidemic. More information on this project is available at www.frontlinesmed.org/sars-sp.

Syndromic surveillance cannot definitively establish that a particular disease is causing an outbreak. It alerts local public health to the need for more investigation. But we can alert clinicians and laboratorians to be on the look-out to help us pin down a diagnosis. Similarly, such surveillance may be helpful in tracking an ongoing situation, and we have used it during heat waves for this function.

Syndromic surveillance relies on our ability to compare current trends to what is "normal". Longitudinal experience and statistical algorithms are needed to exploit the potential of such systems. When algorithms are too sensitive, false alarms strain public health resources. If they are too insensitive, important events are missed. Development of good algorithms for syndromic surveillance is a science in its infancy. There are many syndromic surveillance systems being touted, but most still require rigorous evaluation and fine-tuning over time.

The ideal system automatically collects and transmits accurate, meaningful information without requiring busy health care providers to vary from their usual routines. That is why electronic medical records and interoperable electronic health information hold the greatest promise for enhanced disease surveillance.

The evolution of regional and national health care, insurance, pharmacy and data management companies has led to the creation of large regional and national health data systems. One possible approach to disease surveillance is to establish a regional or national center that analyzes health trends in such systems. These systems need to be tested to see if local events can be detected and meaningfully interpreted by remote analysts. Corroboration is best performed by local professionals who know and understand the community. In order to confirm an outbreak, a local professional may need to talk to physicians, emergency room staff, pharmacists or patients. No data are ever 100% accurate. Sometimes unusual patterns of disease may emerge and they represent simply an aberration or a coincidence, not an outbreak requiring intervention. A local public health authority must interpret surveillance data in a local context and prepare a local

response. As surveillance systems are established, they must integrate intimately with the work practices of the local health offices that will need to respond to them. There is no way to build an effective national surveillance system that relies on weak and overtaxed local health departments. Neither can such systems be effectively designed without taking into account the day-to-day work processes of local public health investigation and outbreak response. Indeed, the challenges of maintaining a high level of response capability for anthrax, smallpox, and SARS are sorely challenging the capabilities of many excellent local departments.

Recommendations for Improving Disease Surveillance

We are in a very exciting developmental period for disease surveillance. We are just beginning to explore the possibilities for applying sophisticated information technology in public health, a field that has lagged other sectors in technology resources and proficiency. Indeed, just a few years ago, before Congress funded the Health Alert Network program, many local public health agencies did not even have Internet access. However, public health offers a century of proven experience in disease control. Give us the proper data in usable form, and we will know how to interpret it and what to do about it. The best approach is to give public health agencies, led by the Centers for Disease Control and Prevention, the resources and ability to mine the technologic expertise of other federal agencies and the private sector. Keep disease surveillance under explicit public health leadership and direction. Remember that improving technology and information systems is not an end in itself, but a tool to assist public health science and achieve public health objectives.

There are essential roles both for federal leaders and local communities in disease surveillance. It is appropriate for federal leaders to develop a vision and specifications for an integrated, interoperable system with multiple uses, the goal of CDC's Public Health Information Network project. However, the federal government must consult early and often with the local public health agencies that will be using the system developed and must provide them the resources to participate in it. Receiving, managing, and responding to information produced at the federal level profoundly affects work processes at the local level. National initiatives (and state initiatives funded by federal programs) rarely recognize, anticipate, or prepare for this. National initiatives creating new information management demands must be accompanied by meaningful

investment in the local public health personnel and training that will make the national initiative work. Otherwise, the entire enterprise will not be effective.

Investment and incentives for creating interoperable health information systems should be supported at the federal level. Similarly, nodes of innovation in disease surveillance at the local level also should be encouraged and supported. I have mentioned Milwaukee and Kansas City; many other communities have created innovative surveillance and communications systems funded by the Health Alert Network program and other funds dedicated to local use. Local centers of innovation provide models that can be evaluated by national authorities and replicated if promising. Funding and equipping local public health departments to be partners in the development of disease surveillance will yield better outcomes than simply requesting "input". Finally, it must be noted that a strong surveillance system with a weak local public health response system is little better than no system at all. Continued investment in daily public health functions at the local level remains a critical national need.

In addition to supporting the CDC Public Health Information Network, federal policy-makers should continue to provide policy and incentives for the rapid adoption of interoperable electronic information systems in health care. This will create streams of data and produce faster and better surveillance systems of the future, as well as potentially reduce health care costs and improve health care quality. Obviously, the security and confidentiality of personal health and financial information must be scrupulously maintained in such systems or else the public will not feel confident and safe. However, I believe such security and confidentiality are technically achievable, if they are supported by an adequate policy and regulatory framework.

Thank you for your interest and for your support of the critical enterprise of disease surveillance. I will be pleased to answer any questions or provide further information for the record.