

Mr. Chairman, Members of the Subcommittee, I am Dr. Gianfranco Pezzino, State Epidemiologist with the Kansas Department of Health and Environment. I am very pleased to appear before the Subcommittee this morning in my capacity as president-elect of the Council of State and Territorial Epidemiologists (CSTE). CSTE is a professional organization that includes about 400 epidemiologists engaged in the practice of public health in state and local health departments. In my testimony I will address the status of public health information systems, particularly the National Electronic Disease Surveillance System, also known as NEDSS, and their role in enhancing public health practice at the state level and facilitating the recognition of and response to bioterrorism events.

Background - The problem

Let me begin by providing you with some background on the events that led to the development of current initiatives that I will briefly describe in my testimony today. Over several decades, as the need of CDC and its state and local partners for surveillance for many diseases proliferated, independent, non-standardized information systems were developed by CDC's programs and centers and by state and local public health agencies to meet each separate surveillance need. This resulted in over 100 separate information systems dependent on data collected at the state and local level that are unable to communicate with one another, so that systems in one health department or one CDC program may not be able to exchange information with systems located in other agencies that monitor similar or related conditions. The presence of multiple, non-standardized, proprietary information systems in the public and in the private sectors also impaired the ability of these two sectors to exchange information.

This situation presents multiple problems. Public health surveillance is the intelligence system that we must rely on to detect any unusual health-related event, including the consequences of a bioterrorist attack. Without an integrated, comprehensive public health surveillance system, the identification of these public health emergencies or disease outbreaks with potential national impact is very problematic. In addition, the presence of multiple, non-integrated systems leads to an undesirable error rate in record-keeping, inefficient use of time and labor, potential for under or over-reporting, and duplication of effort. As a consequence, public health agencies have been unable to build a true national public health surveillance system that can provide a comprehensive, accurate, and timely picture of the health status of our communities.

The response

Many people involved in surveillance at the state and local level, as well as private sector health reporters (such as doctors and hospitals), have suffered from these inefficiencies and have called for a different approach. CSTE has recognized that CDC has a unique role and position of leadership to play in the establishment of integrated surveillance tools. For more than a decade, CSTE has urged CDC to move away from a mentality of separated, self-contained surveillance systems and to work toward adoption of a flexible, integrated solution. The enactment of the Health Insurance Portability and

Accountability Act (HIPPA) in 1996, with its provisions for electronic data standardization, provided further impetus to the process of building an integrated, timely, national surveillance system, while also offering unprecedented opportunities for public-private electronic interface.

Three important initiatives have been launched in the last couple of years that address the limitations that hampered public health information systems. These three initiatives have been developed by the CDC with substantial input, support, and participation from local and state public health partners. These initiatives are NEDSS, the Health Alert Network, and the Epidemic Information Exchange (or Epi-X).

The National Electronic Disease Surveillance System (NEDSS) is an important effort launched by CDC in FY 2000, through funding provided by Congress. One of the most important functions of NEDSS is the establishment of a standard architecture (based on current industry standards) for public health electronic information systems. This architecture, among other features, includes specifications and standards for the secure collection, transmission, and exchange of public health records for different agencies or programs. The use of these standards will allow local, state, and federal agencies to achieve a more effective use of information technology, so that we can study and understand health-related data across different programs and jurisdictions and detect potentially related cases around the country. Some of the expected advantages of implementing NEDSS are:

- Integration of information systems currently separated by differences in data formats and codes, and unable to communicate with each other. This integration will provide the ability to pull, edit, and analyze records from different databases in a combined fashion.
- Improvement of the disease reporting mechanisms, with more timely and accurate information available for decision-making and action.
- Establishment of a national electronic disease surveillance system able to identify more promptly public health threats with national implications, both natural and **intentional** (i.e., bioterrorism attacks).
- Interface with clinical databases (e.g., laboratories, clinics) to make medical information that is valuable for surveillance purposes available in electronic format. This will allow, for example, surveillance programs to receive electronic reports from laboratories or health care providers in a more complete and timely fashion with less burden on the health care sector.

The second initiative is the Health Alert Network. This is a nationwide program that has as one of its main goals the improvement of the information technology infrastructure in local and state health departments. This network is helping public health agencies to obtain fast and secure Internet access and will facilitate linkage between local health departments and health care providers. The Health Alert Network is primarily an infrastructure project that helps health agencies assess their technology needs, acquire the

appropriate equipment to meet those needs, establish Internet connection and E-mail capability, and develop appropriate training of public health workers (particularly through the use of distant learning initiatives).

The third project, Epi-X, is an Internet browser-based software application developed by the CDC. Through its secure Web site, Epi-X allows public health officials at the CDC and in state and local health departments to exchange communication about outbreaks and other acute or emerging health events. In addition, Epi-X contains a forum area for state epidemiologists to post information on surveillance and response activities for approximately 500 public health officials around the country. This forum area has been extensively used during the anthrax-related emergency by state and local epidemiologists to share information, experience, and intervention protocols, so that lessons learned in one part of the country can be used in other parts. Another unique feature of Epi-X is emergency notification by telephone and pager to defined groups of public health officials.

How do these projects interact with each other?

While NEDSS, the Health Alert Network, and Epi-X at first may appear like similar and perhaps overlapping or duplicative projects, a more careful examination shows that they actually address complementary needs. NEDSS fulfills the essential function of putting some order in the Tower of Babel represented by dozens of different, proprietary software applications unable to communicate with each other. The Health Alert Network helps build the technology infrastructure and networking capacity needed to link all different public health agencies **to** each other and **to** private health care providers. Epi-X allows the collection and sharing of important information on public health events, facilitating the prompt recognition of disease outbreaks and possible bioterrorism attacks and the dissemination of public health alerts. To do that, Epi-X uses the standards defined by NEDSS and exploits the network built through the Health Alert Network. All three projects provided some essential functions during the response to the anthrax threat of the past months, and facilitated the rapid and secure exchange of important information among the CDC and states and local public health agencies. In summary, each project gains strength from the presence of the others, and none of them can be successful alone. The critical factor is to assure that these projects can develop in harmony, avoiding duplication and gaps.

Future challenges

The development of these initiatives over the past few years has been a reason for satisfaction for those of us who had been frustrated by the confusion among public health information systems. While these are positive developments, much work remains to be done, and many challenges remain ahead of us. The CDC document, *Public Health's Infrastructure: Every Health Department Better Prepared; Every Community Better Protected*, laid the groundwork for a ten-year process through which our public health infrastructure can be reinforced (or, in some cases, totally rebuilt). This is an excellent document, and CSTE supports its goals. At the same time, my organization also

recognizes that the events of the past four months have changed the emphasis and importance of some of the functions outlined in that document, and our country cannot wait until the year 2010 to achieve some of the goals of the plan, especially those related to workforce development, public health surveillance, and alert and notification functions.

We have identified three priority areas that in our opinion need attention during the next months and years. First, the process of integration envisioned by NEDSS is far from being completed. Too many software applications and programs that do not comply with the NEDSS architecture still operate within CDC and in some states. As a result, the national public health surveillance system remains fragmented into pieces that cannot be combined to form a meaningful puzzle. Even within the CDC, the three projects that I have mentioned earlier, that is, NEDSS, Health Alert Network, and Epi-X, have not always built on each other's strengths, and at times have appeared to compete for the same scarce resources or to attempt to establish one project as the only one worth expansion. The consequences of these approaches are potentially severe, as they represent further barriers in an already complex process of integration, and increase confusion among state and local partners struggling to understand the strategic, unified vision underlying these projects. Efforts for better integration must continue, adequate funding for all these projects must be assured, and the CDC needs to emphasize and clarify its integration strategies both internally and externally.

Second, the link between public health departments and private health care providers such as physicians, managed care organizations, hospitals, and laboratories needs to be strengthened. Virtually all public health emergencies, including bioterrorism attacks, will be detected through some of these private providers, and they in turn must have easy access to reporting mechanisms that are fast and not burdensome. Currently, the most common communication methods between private providers and public health departments remain mail, facsimile, or telephone, and in very few cases have computerized information systems linking the two sectors been put in place. Public health surveillance must be integrated in the daily workflow of clinics and hospitals, rather than being a separate entity requiring additional efforts and resources from the providers. Mechanisms must be put into place to capture relevant surveillance data directly from medical records in a timely and secure fashion. Recent contacts between the CDC, state and local health officials, and a consortium of major private vendors of health care information systems to discuss how to achieve this integration between surveillance and clinical activities are promising, and should continue. Funding for the establishment and testing of electronic data transfer applications to link emergency room, inpatient, and laboratory data with the public health surveillance system is essential. Private health care providers also play a key role not only in the detection of, but also in the response to public health emergencies. The Health Alert Network, that in most states is currently limited to public health agencies, needs to be expanded to include as many private providers as possible, so that they can be quickly notified of the existence of public health threats and how to contain them.

Finally, it should never be forgotten that the functioning of the best surveillance

information system and computer network remains based on the presence of trained, skilled, qualified public health workers. The importance of the development and training of an adequate public health workforce cannot be overemphasized. The most timely alert will be of little or no use when it reaches a health department running three half days a week and staffed with one part time nurse, as happens in many rural areas of our country. Several CDC initiatives, such as the Epidemiology and Laboratory Capacity program (ELC), the Health alert Network, and the Emerging Infections Program (EIP), have provided **limited** support for the development of basic public health infrastructure **and workforce training** at the state and local level.

However, many state applications for support sent to these programs have been accepted but not funded for lack of resources, and are currently sitting idle. Funding for the support of a basic public health infrastructure must increase dramatically, and must represent a sustained effort that over time will yield as a dividend protection for our nation from natural or **intentional** public health threats.

Conclusion

In conclusion, the Council of State and Territorial Epidemiologists supports and appreciates the efforts made by the CDC in the past few years to improve and integrate public health information systems. Many barriers remain. Some institutional memories may be hard to change. Links between the public and the private sector remain weak. Most state and local health departments are still chronically underfunded, and many of them are functioning on bare-bone budgets and resources. Nevertheless, projects such as NEDSS, Health Alert Network, and Epi-X have contributed enormously towards achieving better integration of information, more timely detection of public health emergencies and bioterrorism events, and more prompt and effective dissemination of health alert messages. Programs such as the Epidemiology and Laboratory Capacity program (ELC) and the Emerging Infections Program (EIP) have helped states and local health departments **begin to** build the basic infrastructure **and trained workforce** without which advanced information systems cannot **function**. These initiatives are all complementary to each other, and funding and support for all of them must grow considerably so that the expected results can be achieved in as short a time as possible: we cannot afford to wait.

Finally, I want to thank you, Mr. Chairman, for the opportunity to testify this morning on this important topic. I am pleased to answer any questions sthe Subcommittee may have.