Testimony Before the
House Government Reform Subcommittee on Technology, Information Policy, Intergovernmental Relations and the Census

On
"Health Informatics: What is the prescription for success in intergovernmental information sharing and emergency response?"

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Statement of
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Testimony –
"Health Informatics: What is the prescription for success in intergovernmental information sharing and emergency response?"

Mr. Chairman, members of the committee, thank you for this opportunity to discuss the state of information technology and intergovernmental information sharing as it relates to public health preparedness and emergency response. The Centers for Disease Control and Prevention (CDC) is working closely with federal, state, and local partners to enhance and integrate information systems that connect all levels of public health. My testimony will focus on the public health functions that are essential in supporting current and emerging public health preparedness and response needs, and our progress in developing systems to support these functions.

The CDC is mandated to advance national preparedness and response capabilities for naturally occurring diseases and conditions and the deliberate use of all threats, including biological, chemical, and radiological agents. Information technology is now a critical part of this preparedness.

In the event of a major health event, the goal is to minimize morbidity and mortality. Achieving this goal for any particular event involves relying on systems that can provide early event detection, outbreak management, electronic laboratory result reporting, case reporting, countermeasure and response administration, and communications among key personnel and with the public.

The CDC is supporting the need for national public health preparedness, through the Public Health Information Network (PHIN). PHIN is advancing preparedness by identifying the critical need for interoperability and communication between national preparedness information systems. This interoperability is being achieved within the federal government through the development, adoption, and implementation of federal health data standards, as a result of work being done as part of the Presidential E-government Consolidated Health Informatics initiative. CHI and PHIN are working with the National Committee on Vital and Health Statistics and other State and local entities to ensure interoperability nationwide. Adherence to data standards adopted by CHI is required in order for CDC and HRSA PHIN investments to receive supplemental preparedness funding. Through adherence to these data standards, PHIN is now building the components of a real-time national network. This includes the development of critical interoperability tools, and certification that systems built with preparedness funding actually meet the needed functions in a way that supports the broad goal of an interoperable public health network. In order to move PHIN forward to achieve this goal, we are closely coordinating with the newly created Office of the National Coordinator for Health Information Technology (ONCHIT), the Federal Health Architecture (FHA) program management office, the Consolidated Health Informatics initiative working groups, and the Biosurveillance initiative being led by the Homeland Security Council. Each of these entities play an important role in informing public health preparedness needs.

In order to protect the public from major health threat events a variety of organizations need to communicate and inform each other, making public health preparedness a complicated activity. To provide the full spectrum of public health activities, the information and technology at local and state health departments, clinical care facilities, federal agencies , public health labs, and law enforcement need to become more interoperable so that data analysis and information exchange can take place.

All of these organizations are in stages of developing information systems to support their own internal needs. Clinical care is progressing toward electronic medical records, public health and clinical testing labs use laboratory information systems to access specimens and record and manage test results, health departments need systems to identify and manage disease events and trends. Public health preparedness involves ensuring that these organizations have electronic information system capacity and the ability to appropriately share data and information. Public health entities, for example, need to have the capability to receive data from clinical care entities in order to identify unusual disease trends. Clinical care providers need health information from public health related to disease events and suspicious trends to facilitate appropriate prevention and response activities. Health departments need specialized test results from public health labs to confirm or rule out specific diseases and agents. In all circumstances, the information systems and the data and information exchanges between organizations need to be developed, tested and regularly used in order for them to be reliably available during the time of an emergency.

Although the involvement of multiple organizations and organizational functions make public health information technology preparedness a challenging endeavor, substantial progress is being made through PHIN and its component initiatives. The PHIN infrastructure integrates and leverages previously funded initiatives, which have been established to support the overall goal of system interoperability. PHIN received its first funding of $10 million in fiscal year 2004.

The major components of PHIN are outlined below:

Early event detection improves public health preparedness because the earlier an event is identified and understood, the sooner it can be contained and further cases prevented. Recently, the varying international experiences with SARS demonstrated how large a problem can develop when a communicable disease is not responded to quickly and disease spread occurs. Information technology offers great promise for early event detection, by allowing health related data to be analyzed for disease trends without requiring the submission of a traditional case report.

BioSense is a new approach to early detection to improve the Nation's event detection capabilities. It establishes the capacity for rapid, real-time electronic data transmissions to public health agencies from health data sources such as hospitals, laboratories, doctor's offices, and pharmacies to identify early signs of a possible event is one of the objectives of the proposed FY 2005 investments in BioSense and the National Biosurveillance Initiative. The BioSense initiative will support early event detection by complementing astute clinicians in identifying initial events and also supporting public health's needs to

immediately understand the scope of an event and where it is occurring. This information will assist in the further investigation of the event.

BioSense is part of a multi-departmental Biosurveillance initiative included in the President's FY 2005 budget request. Phase I of the BioSense system is now operational and includes data from an initial set of data providers such as DoD and VA. The system has over 220 users in over 30 cities and 32 states nationally.

Case reporting from clinicians and health care related personnel is the traditional way that public health officials have received notice of health events. Under this model, clinicians are required to report certain disease occurrences to their local health departments, who in turn report to the State health department and then to the CDC. Although case reporting frequently depends on clinicians taking the initiative to contact their public health department, this traditional approach remains an important component of public health surveillance because of the critical role that well trained clinicians play in helping to identify and diagnose diseases. For example, a clinician in Florida recognized and reported the first case of anthrax. Electronically enabling case reporting is also critical to national preparedness and emergency response. CDC is continuing to implement the National Electronic Disease Surveillance Systems (NEDSS) – as a component of PHIN in this area. NEDSS promotes a standards-based implementation of electronic case reporting to the state and local levels as well as to the federal level. The initiative includes the use of electronic laboratory result reporting for notifiable disease conditions to improve on the number of cases and how fast cases are reported. As an

example, in Nebraska, NEDSS has reduced the time for disease case reporting from an estimated 30 days to 1-3 days. In addition, NEDSS electronic laboratory reporting tripled the number of cases reported to public health.

Outbreak management involves a series of activities that need to occur at the local, state and federal levels once a disease event has been identified. Information technology is especially useful in managing the information about an event such as the number of possible cases, the identification of possible exposures, and common locations where a disease agent may have been spread. Recently, in both the Monkeypox and SARS events, tracing contacts that people had with other people, animals or locations was critical to managing the spread of the disease. In almost all such events, confirming which cases are "true" cases or differentiating between true threats and hoaxes involves the merging of laboratory test results data with many possible cases or events.

The Outbreak Management System (OMS) provides the functionality to achieve this component of PHIN by linking lab results with epidemiological data. It is designed to facilitate the recording of case investigations, perform contact tracing as well as support data collection, packaging, and shipment of clinical and environmental specimens. Fifteen states are evaluating or have implemented OMS for use in outbreak investigations.

Electronic laboratory reporting provides timely access to and delivery of reliable laboratory test results. Immediate case confirmation and linkage to environmental test

results is frequently necessary to assist in the identification of a threat and the extent of exposure. As there are numerous organizations with their own laboratory systems, this PHIN functional area works to provide standards and specifications to support the timely and secure exchange of electronic laboratory test results across all appropriate organizations and systems that support early event detection, outbreak management, and countermeasure and response administration.

The Laboratory Response Network (LRN) utilizes PHIN standards, specifications, and technology to ensure the reliability, integrity, confidentiality, and the secure delivery of electronic laboratory test results. Over 55,000 Health Level Seven (HL7) standard public health lab results, including those reported from BioWatch environmental air sample collectors, have been received from 18 LRN labs. The Administration's Biosurveillance initiative also includes resources to improve real-time laboratory reporting through the LRN.

Countermeasure and response administration supports the distribution and administration of prophylaxis and vaccinations and supports case isolation to contain and limit the spread of public health threats. Countermeasure administration needs to link to distribution mechanisms such as the Strategic National Stockpile to provide traceability between the distribution of pharmaceutical products and the administration of prophylaxis and vaccination. Countermeasure administration functional capabilities include the ability to track the deployment and success of countermeasure administration and the monitoring of possible adverse events, requiring integration with outbreak

management functional capabilities, inventory and distribution systems, and immunization registries.

The Countermeasure Response Administration System (CRA), formerly the Pre-Event Vaccination System (PVS), is the countermeasure and response administration portion of PHIN. CRA manages information and data through the complete lifecycle of a countermeasure action. Specifically, the system provides a systematic, standard method of data collection, to be used in performing accurate analysis of program preparedness vaccine safety and effectiveness. CRA also provides a secure and reliable means to communicate data following standard specifications.

Communications among key personnel and with the public is critical and essential for all functions that support public health preparedness and response. The public health community must have the ability to share preliminary and sensitive information in a secure environment, as well as to provide information that is ready for public dissemination. Systems supporting the communications component of PHIN include the Epidemic Information Exchange (Epi-X), the CDC website, and other health alerting tools.

The Epidemic Information Exchange (Epi-X) is a fully-deployed public health communications system with a demonstrated track record that keeps frontline public health officials informed of emerging health threats. The system's strongest feature is its ability to rapidly establish and maintain secure channels of communication between key

federal, state, and local health officials. Individual users can be alerted of a developing health threat by pager, landline phone, cell phone, and e-mail within minutes of system activation. Epi-X has a total of 3,500 users consisting of national partner organizations and public health officials at the local, state and federal levels.

The CDC website, www.cdc.gov, provides a vehicle to disseminate publications, information and linkage to public health partners, clinicians, law enforcement, policy makers, the media and the general public. The CDC website averages approximately 10.5 million visits per month.

Other communications tools include the implementation of a nationwide information and communications platform for the rapid dissemination of information on public health threats and emergencies. This communications platform disseminates a broad range of information such as health alerts, educational materials, and updates through a cascading array of communication systems – from federal to state to local to clinicians. This dissemination will be facilitated by the Health Alert Network.

Conclusion

Through several initiatives, the CDC has developed many components for a public health information network that uses national standards to support critical public health preparedness activities with information technology. PHIN is central to these efforts and ensures interoperability and full functional capabilities at all levels of public health.

Through PHIN, the CDC is developing and implementing specifications and requirements for existing and newly developed information systems and health data that are necessary to create a reliable information network capable of supporting the current and emerging needs of public health.

While we have made substantial progress toward enhancing the nation's ability to identify and respond to a public health emergency, much remains to be done. CDC is very grateful for the congressional support received to date and looks forward to working with the members of Congress, especially this committee, as we strive to protect the public's health from terrorism and other public health emergencies.

Thank you very much for your attention. I will be happy to answer any questions you may have.