National Electronic Disease Surveillance Systems Stakeholders Meeting Report

March 30 - 31, 2000

Atlanta, Georgia

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I. Executive Summary

To assure ongoing collaboration with essential stakeholders and partners, on March 30-31, 2000, the Centers for Disease Control and Prevention (CDC) sponsored a National Electronic Disease Surveillance Systems (NEDSS) Stakeholders Meeting in Atlanta, Georgia. The purposes of this meeting were to provide an overview of the current status of NEDSS, and to obtain stakeholder input and recommendations on several areas of importance to further development and implementation of integrated surveillance systems. Invited participants included 186 representatives from state and local health departments, federal agencies, professional associations, and other organizations.

The two day meeting consisted of plenary sessions which provided background information and updates on integrated surveillance systems and related topics. Additionally, participants were assigned to breakout groups designed to foster collaboration and consensus from the local, state, and federal perspectives on topics related to:

- Policy issues and core functions of integrated systems.
- Conceptual next steps for NEDSS.
- Security issues related to transmission of information.
- Electronic reporting: the Laboratory Demonstration Project.
- NEDSS interface with non-infectious disease surveillance systems.

Following the breakout sessions, each group presented its findings and recommendations, and responded to questions from meeting participants. More detailed summaries of the breakout group results and related discussions are provided in the body of this report. The following encapsulate the meeting outcomes.

- There was wide-spread consensus at all levels on the need for integrated systems, and broad-based support for CDC leadership in the development of standards needed to further implementation of NEDSS. In fulfilling this leadership role, CDC needs to define the processes for standards development, determine the architecture for NEDSS, and develop a comprehensive plan for implementation. This information should be disseminated to stakeholders, so they in-turn can become more fully involved in implementation, documentation, and evaluation of the systems.

- Standards development is a high priority at all levels. While CDC should play a leadership role in the development of these standards, there was general agreement that partners must take ownership and responsibility of both the process and standards once developed. Additionally, public health partners at all levels need to become more actively involved with standards development organizations' (SDO) activities, as well as in promoting the benefits of integrated systems to policy makers and the public.

- To successfully support and promote systems integration, there needs to be a clear vision of what NEDSS is and will be in the future, This vision should be developed in concert with all stakeholders, and be inclusive with respect to information and data to be collected. It should not be limited to infectious diseases and/or systems driven by categorical funding. Once the vision is developed, it should be disseminated and communicated broadly at all levels and be used to garner support and resources

needed for further development, implementation, evaluation, and maintenance.

- There was universal agreement that NEDSS should be a comprehensive, inclusive system, and that on-going, broad-based stakeholder involvement in the process is critical to success. Of great importance is the inclusion of non-public health provider systems, including the ability to integrate business systems.

- To achieve needed inclusiveness, there must be a more global view with respect to public health information, data, and demographics. Data gathering should not be limited to that which can be generated or kept in individual program files, and should include data from all areas of health practice. Further, reporting of data should have utility to a range of users such as local communities, health care providers, and policy makers.

- A sense of urgency was expressed with respect to moving forward with implementation of integrated systems. Although some meeting participants felt strongly that additional needs assessments should be conducted at the state and local levels, it was clear that moving forward is imperative. Utilizing “best practices” and modular approaches to implementation may allow health departments and other organizations at differing levels the opportunity to pilot test and evaluate integrated systems based on their needs. Having local health departments use the standards and exchange data with federal agencies would help assure success at those levels. These approaches should facilitate more rapid development and implementation of NEDSS.

- The meeting participants recognized that barriers or challenges to progress exist. These include funding issues, legal, regulatory, and political considerations, variation in technological competencies, the need for workforce training, and resistance to change on the part of those who are vested in their current systems. However, significant opportunities and avenues for collaboration exist to overcome or minimize these barriers.

- To successfully achieve integration, the systems must capture a broad array of provider needs at all levels, and reduce the workload burden. It must also be affordable in terms of human and financial resources required for implementation and maintenance, as well as ensure secure data transmission.

- Models of success are needed to facilitate support for implementation and ongoing maintenance of integrated systems. Again, modular approaches to pilot testing systems integration in varied technology and capacity settings can facilitate development of successful models, and help assure local needs are met as well. Such pilot projects could include electronic laboratory reporting, data elements for emergency departments, bioterrorism response, and managed care systems integration.

- Models of success will be beneficial in encouraging funding sources and decision/policy makers to invest and ultimately provide the resources required to

maintain the systems.

Further information on the history and current status of NEDSS, as well as a more comprehensive summary of the March, 2000 Stakeholders Meeting are provided in the following sections of this report. Appendices found at the end of the report provide additional information on NEDSS, the meeting agenda, organizations represented at the meeting, and post-conference comments related to the topic of security.

II. History and Current Status of the National Electronic Disease Surveillance Systems

The mission of the Centers for Disease Control and Prevention (CDC) is to promote health and quality of life by preventing and controlling disease, injury, and disability. Dedicated to fulfilling this mission, the CDC is the nation's lead agency in prevention. As such, the CDC has primary responsibility for public health surveillance. Crucial information and data collected through the nation's surveillance systems allows the agency to monitor the public's health, identify public health problems, develop priorities and strategies to prevent further illness, and evaluate the effectiveness of the prevention initiatives developed.

Because of the wide range of data sources, diverse information requirements, and the numbers of distinct users, no single surveillance system captures all the information necessary to carry out the comprehensive surveillance functions required to monitor the health of the public. As a result, the CDC in collaboration with its public health partners, currently maintains more than 100 surveillance and health information systems. As shown in Figure 1, many of these systems have been in place for a number of years, were originally designed to detect a single organism or condition, are not standardized, and are largely independent of one another. As a result, inefficiencies and duplication of effort are inherent in the systems.

Recognizing that the current system was inefficient and that categorical software poses significant barriers to information sharing and integration, CDC's partners insisted that changes be made to the existing systems that will enhance their surveillance capabilities, and allow more flexibility in working across jurisdictions and with non-public health providers. In 1995, the CDC/ATSDT Steering Committee on Public Health Information and Surveillance System Development was formed. Prompted by the findings and reports of this committee, the Health Information and Surveillance Systems Board (HISSB) was established in 1996.

Figure 1: Current Situation

CDC

Program Specific Reports and Summaries

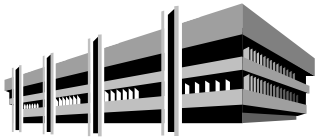
MMWR Weekly Tables

MMWR Annual Summaries

HARS TIMS NNDSS EIP Systems PHLIS

Statistical Surveys for Chronic Diseases, Injuries and Other Public Health Problems

Varied communications methods and security - specific to each system - including diskettes, e-mail, direct modem lines, etc.



State Health Department

HARS STD*MIS TIMS NETSS EIP Systems PHLIS

Reporting by Paper Form, Telephone and Fax

Data Sources

Physicians

Varied communications methods and security - specific to each system- including paper forms, diskettes, e-mail, direct modem lines, etc.

Chart Review

Lab Reports

City/County Health Department

HARS STD*MIS TIMS NETSS EIP Systems* PHLIS

*EIP Systems (ABC, UD, Foodnet)

STD*MIS (Optional at the Clinic)

TIMS (Optional at the Clinic)

Members of this Board include representatives from ASTHO, CSTE, NACCHO, APHL, and NAPHSIS.

In 1998, CDC increased funding to support activities related to the development of integrated systems. Since that time focus groups with various stakeholders have been conducted to identify and define the needs to be addressed by integrated systems, and to obtain input on the characteristics and other factors that should be incorporated. Additionally, there have been numerous working groups on the subject as well as consultations, meetings, and document reviews with state and local health departments, national organizations, CDC categorical programs, and the HISSB.

In 1999, CDC funded the Health Alert Network (HAN), and in fiscal year 2000 increased funding for HAN and NEDSS. HAN will use the Internet as a backbone for communicating surveillance and other data between the CDC and health departments. Additionally, the Director of CDC has mandated the use of integration standards in new CDC systems development.

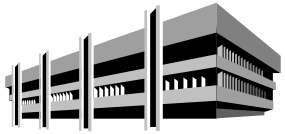
To better manage and enhance the large number of current surveillance systems and allow the public health community to respond more quickly to public health threats (e.g., outbreaks of emerging infectious diseases, bioterrorism, etc.), CDC is implementing the National Electronic Disease Surveillance System (NEDSS). As shown in Figure 2, when complete, NEDSS will electronically integrate and link together a wide variety of surveillance activities and will facilitate more accurate and timely reporting of disease information to CDC and state and local health departments. Consistent with recommendations proffered in the 1995 report, *Integrating Public Health Information and Surveillance Systems* and recommendations of various working groups, NEDSS will include data standards, an Internet based communications infrastructure built on industry standards, and policy-level agreements on data access, sharing, burden reduction, and protection of confidentiality. For additional information on the current status of NEDSS see Appendix 1, *Supporting Public Health Surveillance through the National Electronic Disease Surveillance Systems* or refer to http://www.cdc.gov/od/hissb/docs/NEDSS%20Intro.pfd.

III. Purposes of the Meeting

To assure ongoing collaboration with essential stakeholders and partners, the CDC sponsored a National Electronic Disease Surveillance Systems (NEDSS) Stakeholders Meeting in Atlanta, Georgia, March 30-31, 2000. The purposes of this meeting were to provide an overview of the current status of the integration project, and to obtain stakeholder input and recommendations in several areas of importance to the further development and implementation of NEDSS.

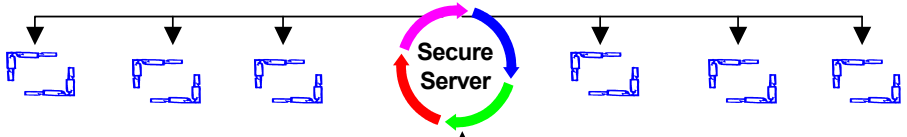
Figure 2: Proposed Integrated Surveillance Systems Solution

CDC



State Health Department

City/County Health Department



Electronic data interchange (EDI) using HL7 or other standardized format

Secure Internet

Shared Facilities and Services, e.g. common interface, software components, terminologies and data files

HIV/AIDS

Paper Forms, Telephone and FAX

Electronic data interchange (EDI) using HL7 or other standardized format

Secure Internet

Secure electronic reporting

Shared Facilities and Services, e.g. common interface, software components, terminologies, and data files

HIV/AIDS

STD Clinics

TB Clinics

Data Sources

- Physicians
- Chart Review
- Lab Reports
- Vital Statistics
- Emergency Departments
- Medicaid, Medicare Encounters
- Hospital Discharge Data

As shown in the meeting agenda (Appendix 2), the conference was designed to facilitate discussion and foster collaboration and consensus from the local, state, and federal perspectives with respect to:

- Identifying policy issues and defining the core functions of integrated systems needed at the local, state, and national levels.

- Conceptualizing the next steps for NEDSS with respect to standards and development issues, as well as identifying related priorities.

- Assuring that high level security is in place for the transmission of surveillance information.
- Using the Electronic Reporting Laboratory Demonstration Project as a model for interfacing between the private health sector and local, state, and federal health entities, including state public health laboratories.

- Extending the NEDSS umbrella to include an infectious disease approach for interfacing with non-infectious disease surveillance systems, as well as identifying which surveillance programs should participate, opportunities for data exchange, and priority areas for standards development.

IV. Meeting Design and Methods

Building on the concepts and issues detailed above, the CDC in collaboration with representatives from stakeholder organizations (APHL, ASTHO, CSTE, NACCHO, NAPHSIS), planned and developed the March 30-31, 2000 meeting agenda. Meeting participants included invited representatives from state and local health departments, federal agencies, professional associations, research institutes and foundations, public health laboratories, and other health related organizations. In total, 186 representatives from state, local, federal, and other agencies attended (Appendix 3).

The meeting began with a one-half day plenary session designed to set the stage for discussions to follow in breakout groups. Topics presented and discussed during this session included: the commonalities between public health and clinical data and the need for information standards; the impact of information technology on public health; the importance of expanded partnerships in the development of new health information systems needed in the 21st century; and, an update on the current status of NEDSS and the Secure Data Network (SDN).

Following the plenary session, meeting attendees participated in assigned breakout groups. There were five breakout groups with 30 to 40 participants in each group. Discussions in each breakout group were facilitated by three co-chairs who were assisted by several resource individuals with expertise in the topic being addressed. Individuals serving as co-chairs represented state, local, and federal agencies and/or national professional associations. Additionally, note takers were assigned to each group to record the outcomes of the discussions, and each group meeting was audio-taped to assure accuracy in reporting. The five breakout groups were:

Group 1: Policy Issues and Core Functions Needed

Group 2: Conceptual Next Steps for NEDSS

Group 3: Security Issues

Group 4: Electronic Reporting: Laboratory Demonstration Project

Group 5: NEDSS Interface Beyond Infectious Disease

The group co-chairs were asked to facilitate discussions on each of the above topics by focusing on the following issues from the local, state, and federal perspectives:

1. Assess where we are now with respect to the specific topic being discussed.

2. Identify the important next steps for moving forward with NEDSS.

3. Identify the challenges or barriers to progress that exist, and propose possible solutions for addressing or overcoming those challenges.

4. Prioritize the next steps required to move forward and discuss the roles and responsibilities for each step.

5. Propose approaches and recommendations for addressing the top five priorities identified.

Following the breakout group discussions at the end of the first day, the co-chairs met with their individual note takers and summarized their meeting outcomes and conclusions. To assure concurrence with all group participants, the summaries were discussed and revised where appropriate the morning of March 31st when the breakout groups reconvened.

The remainder of the meeting focused primarily on the group presentations followed by questions and answers related to each report. Following the group reports there were closing comments related to the progress achieved during the meeting, as well as CDC's strong commitment to working with NEDSS stakeholders in moving forward with systems integration.

The following section summarizes the breakout group reports and recommendations. While the original intent of this report was to assure that local, state, and federal perspectives were presented separately on each of the issues discussed, the outcomes from each group indicated there was widespread congruency across all levels with respect to needs, challenges, and priorities. Therefore, each group elected to consolidate its findings with respect to the various perspectives. Discussions stimulated by the questions and answers following each report in the March 31st plenary session are also included where appropriate.

V. Summary of Breakout Group Reports

As noted previously, each breakout group was given general guidelines to assist in facilitation of discussions related to the issues outlined in Section IV above. As might be expected, some groups felt additional or alternative issues needed to be addressed as well. Therefore, the following individual group reports vary in their approaches to addressing the issues outlined.

Further, it is important to note that at the beginning of each presentation, the groups reported wide-spread consensus on the need for integrated surveillance and health information systems, as well as broad-based support for CDC leadership in the development and implementation of NEDSS. Each group report also stressed the need for ongoing collaboration with stakeholders, and appreciation for the opportunity to participate in this important initiative.

A. Group 1: Policy Issues and Core Functions Needed

The discussion guidelines provided to this group requested that the participants begin by focusing on what has been learned to date from the local, state, and federal perspectives, and then to identify the core functions of integrated systems needed at each of these levels. The desired outcome from these discussions was a description of what success would look like (e.g.,ability to receive and exchange HL7 messages, etc.).

1. Vision of Success

This group felt there was very wide buy-in to a broad vision of integrated surveillance and information systems, and began by developing a tentative vision statement: "Integrated surveillance". In the context of the information revolution, the mission is to design and implement seamless surveillance and information systems that take advantage of the best in information and surveillance technology, and serve the following needs at the local, state, and national levels:

- Monitor and assess trends.
- Identify needs for resources and allocate resources.
- Guide prevention and intervention programs.
- Inform public health policy and policy makers.
- Identify issues needing public health research.
- Provide information for community and program planning.
- Protect confidentiality while providing information to those who need to know.

Several components and functions were felt to be critical to the success of integrated systems. These include rapid reporting, secure data transmission, inclusion of a broad array of user/provider needs in reporting, accessing and utilizing data at all levels, data standards and definitions across jurisdictional lines, affordability with respect to the financial and human resources required for implementation and maintenance of the systems, comprehensive training for system users, and the eventual inclusion of all types of surveillance data, not just those restricted to infectious diseases and/or categorical funding driven systems. The following summarize these ideal characteristics.

a). Rapid Reporting and Security of Information Transmission

- Speed in reporting is felt to be an important characteristic of integrated systems, as well as assuring that transmission of all data is secure.

- Fundamental to security is the necessity to protect individual identifiers.

b). Inclusive of all User/Provider Needs

- Integrated systems should capture a broad array of provider needs at all levels, and reduce the burden on the provider rather than increase complexity of use and workload.

- The ability to integrate with business systems would be an important enhancement.

- Reporting and analysis capabilities should be such that it is possible to merge with denominators in various databases. Data display and information in user friendly formats are needed for communication with and among local health departments and providers. These capabilities are necessary because of the need to meet differing legal and political

requirements at all levels.

- The system should be easy to access and give the user the ability to produce general health reports rather than being restricted to categorical data reports. Thus, the reporting of data should have utility to a range of users such as local communities, health care providers, and policy makers.

- The system format should be a virtual/pluralistic one based on standards. There should be inherent capability within the system for each state/locality to create its own software when desired.

- The vision of the system should be comprehensive. While the initial system should focus on infectious diseases, capacity for expansion to broader applications needs to be built in so that other types of surveillance data and support information can eventually be included to incorporate the full scope of public health practice.

c). Uniform Data Standard Definitions

- A critical necessity for integrated systems is having standard definitions within data across public health and other jurisdictions. This would enhance user capacity to exchange data with the CDC, as well as augment the capability of close jurisdictions to deal with cross-boundary outbreaks in an efficient manner.

- An outbreak definition algorithm should be part of the system, both to screen large amounts of data efficiently and to detect problems across jurisdictional boundaries.

d). User Friendly, Cost-Effective, and Efficient

- The system should be practical, easy to use with logical steps, and affordable.

- Training for staff should be an integral component of the system.

- Workplace issues should be minimized in terms of the number of people needed to operate the system. It should be possible to operate the system without having to hire many, if any, new personnel.

- There should be on-going evaluation of the system to monitor how well it works, its effectiveness, and its efficiency.

- The systems' utility and benefits should be clear to all constituents so that financial support is attractive to funding sources at all levels.

2. Challenges and Barriers

A number of challenges and barriers which are potential impediments to the success and vision of the system were noted. These include resistance to change, lack of sustained and non-categorical funding for ongoing support and maintenance, issues related to privacy, confidentiality, and security of data, varying levels of technical competency, and differing legal requirements at the local, state, and national levels.

a). Resistance to Change

- There is a commitment to current functionality in existing categorical programs and in certain advocacy groups. Additionally, some states have integrated functional systems that are operational, but may not be compatible with other systems. Translation from legacy systems may be difficult.

- Many different organizations perform data collection and analysis in a variety of ways, which may contribute to a sense of ownership by each organization. This sense of ownership has the potential to result in "turf" issues. Finding commonalities on which to integrate systems among these organizations is imperative in order to overcome this challenge.

- Staff are trained on the present systems and there may be reluctance to change systems along with ways of reporting and maintaining data.

- Because state and local health departments currently have large databases, assurance must be given that existing data will not be lost and will be accessible through the new systems.

b). Funding Issues

- Sustained funding for the maintenance and development of the system may be difficult. It is important to have 'buy-in' from different funding sources, including categorically funded systems.

- Policymakers at all levels need to be informed of the importance and uses of the system so they understand how the system can better meet their needs with respect to decision making. This would make sustained funding more attractive and less of an issue.

c). Privacy, Confidentiality, and Security

- Perceptions of what constitutes privacy vary across the nation, and collecting information on healthy people may create concerns on the part of the public.

- Similarly, there is no uniform definition of confidentiality. A standard definition needs to be developed and applied at all levels. The public and legislators need to be

  informed and understand the definition of confidentiality as well as what the term encompasses.

- There also needs to be a clear understanding at all levels of how and what information about an individual's health is protected.

d). Technical Competency

- Technical competency varies by organization, and regional differences exist in technical capacity. Care should be taken that organizations with lower technical competency are not left behind. Solutions to avoid this challenge must be sought.

e). Legal Requirements

- Potential legal difficulties exist with respect to sharing data across jurisdictional boundaries. There are myriad laws, regulations, and rules that govern what diseases have to be reported,

who has to report them, to whom they are reported, the information to be collected, and with whom the data can be shared. Thus, to operationalize integrated systems at all levels it will be necessary to work with legislatures, boards of health, and other agencies that are responsible for assuring regulatory requirements are met. However, as demonstrated by experience in Washington State, creative mutually acceptable solutions are possible.

3. Solutions to Overcoming Barriers

Subsequent to the identification of the potential barriers outlined above, the following solutions to overcome these barriers were offered.

- To address issues related to resistance to change as well as privacy and confidentiality, the surveillance integration project should develop standards and definitions for key components of the system and disseminate them widely to federal, state, and local health departments. This would foster collaboration and the ability to share data more effectively. Additionally, a continuation of the on-going, inclusive process for stakeholder involvement is imperative. The ability to communicate with other levels, including the CDC, during this process is very important to continued progress.

- With respect to funding issues, incentives should be put in place to ensure funding support is available at the local, state, and federal levels. In addition, this support should be a mixture of categorical and non-categorical funding, which could be accomplished by having integrated systems that meet categorical needs supported by categorical funding. Finally, having some successes in using the integrated systems would be beneficial in encouraging funding sources and decision/policymakers to invest and ultimately to provide sustained funding. When the system produces results, it is more likely there will be involvement by a variety of funding partners. Marketing these success stories to policy makers, the public, and

  to decision makers in state and local health departments is another important step in this process.

- Pilot programs could provide some promising solutions to many of the barriers noted above. In implementing short-term pilot programs designed to focus on implementation of the standards and specifications, a modular approach could be utilized so they can be broadly applied and transportable to different areas and levels. The pilot projects should be conducted in different areas and setting, such as state health departments with and without existing integrated systems. Additionally, having local health departments use the standards and exchange data with federal agencies would help assure success at those levels. This modular, pilot project approach would help address the variations found in technical competency and assure some organizations and regions of the country are not left behind. Providing prototypes of NEDSS that include needed functionalities for categorical programs would be helpful to aid in categorical program buy-in. However, it is important that categorical programs adhere to the standards developed.

- Continued communication and evaluation are extremely important components of the system. The CDC should take a leadership role in serving as a clearing house for quick diffusion of information about successes, as well as providing information to users about what doesn't work well. This would allow state and local agencies to build on successes in terms of securing funding and other support for integrated systems. This quick dissemination of information should be a continuous process.

4. Next Steps and Priorities

This group identified the following steps that should be taken to successfully continue the development and implementation processes.

- After pilot programs have been implemented and evaluated, funding should be provided to a large number of states to use working prototypes and specifications for systems integration activities, including planning. Collaboration with partners should be encouraged, and there should be support for personnel to champion integration activities and systems development.

- CDC should take affirmative action to ensure that categorical programs are not restricted in participating in the integrated systems.

- It is essential that the development of standards be a priority.

- On-going communication and collaboration with stakeholders should also be a fundamental priority. These activities should include determining a mechanism for governance of the system, determining ways to ensure buy-in and endorsement by all partners, and mechanisms through which learning could be shared with all partners.

- A clearly articulated vision and mission statement are needed to assure universal understanding of NEDSS. CDC should form a smaller group of internal and external constituents to develop the vision and mission statements.

B. Group 2: Conceptual Next Steps for NEDSS

The assigned goal for this group was to discuss NEDSS standards and development issues, and determine the priorities for the next steps from the local, state, and federal perspectives. The group participants began addressing this goal by developing a set of principles which should guide NEDSS development. Participants then identified potential barriers to these principles and systems integration, as well as the next steps and priorities to assure success.

1. Principles

The first step taken to address the goal assigned to this group was to decide what integration is or means. There are many ways to achieve integration, ranging from “tight integration”, to common standards, or to “loose integration”, including data warehousing.

Consensus was achieved on the point that integration of public health surveillance and information systems needs to be part of the larger information environment and encompass health care and clinical data. Additionally, there needs to be an understanding that integration will include both information systems and business processes. Since the goal of integrated systems is to improve the public’s health, it should encompass the following principles.

- The system must have multidirectional data flow, both vertical and lateral, and should include the provision of data back to the health care system for use in clinical practice.

- There was a strong sense that the system should be person-based rather than disease-

based. Although it is recognized that having this type of system may leave out some public health activities.

- Training of staff and staff capacity are key components to successful integration.
- Any information systems developed must be supportable with a combination of CDC, state, and local resources in order to maintain the systems over time.
- The system must also be adaptable for local use and have the ability to interface with other systems.
- NEDSS should be integrated closely with the Health Insurance Portability and Accountability Act (HIPPA) and standards development organizations (SDOs).

2. Barriers

Barriers to progress identified include the following.

- There is a lack of understanding of NEDSS at all levels and insufficient clarity of what CDC programs should do.
- There is also a lack of familiarity and acceptance of external data standards among public health partners.
- There are insufficient management structures that ensure accountability for system integration, and to assure that when standards are developed something actually happens with them.
- Public health participation in the standards development organizations' processes is insufficient.
- There are tools for integration in the current stovepipe systems, and defined architecture and guidance are needed for developing tools or new systems.
- There is inadequate funding for infrastructure development and maintenance coupled with issues related to categorical funding and resultant organizational structures that have grown from those funding streams.
- Data sharing is often difficult between programs because of perceived confidentiality issues.
- Lack of consistency in needs and capabilities among local and state, and small and large states, poses challenges in determining direction of integration.
- The current investment analysis process is felt to be so difficult that it discourages integration.
- There is no well defined process for implementing an integrated approach.

3. Priorities and Next Steps

The group identified several priorities and next steps it felt to be important to enhancing progress toward integration.

a). Business Process Re-engineering

- Integration of surveillance activities has to be part of the "larger system", and not just focus on information systems. We should use this opportunity and re-evaluate how the "business" of surveillance is conducted. This provides an opportunity to reorganize how surveillance is conducted in general, and not only integrate but maintain the current stovepipe systems as well.

- To accomplish this, it would be helpful to have multiple categorical programs collaborate to identify areas of commonality so that the systems developed share common functionalities.

- The results of re-engineering surveillance systems at the state and local levels should be reviewed to take advantage of what has already been learned.

- Advantage should also be taken of non- public health data systems and structures in clinical or other settings, and industry consultations should be considered to achieve successful business integration of systems.

b). Public Health Conceptual Data Model (PHCDM)

- This model is the foundation on which NEDSS is built and encompasses its architecture. The first version of the PHCDM should be finished and publicized, and care should be taken to integrate it with the work being done by the Public Health Data Standards Consortium.

- In order to ensure growth and appropriate evolution, the CDC systems should be mapped to the PHCDM, and a determination of the relationship of this model to state integration efforts should be made.

- The rationale for the PHCDM should be widely marketed so that those in public health understand what it is, and why it is being done. There should be continued efforts to integrate PHCDM with other clinical data models such as HL7, recognizing that NEDSS does not function in a vacuum.

c). Public Health Data Standards

- The development of data standards should be hastened, and any data collected by CDC should be standardized. Deadlines should be set for accomplishing this goal, and collection of non-standardized data should not be allowed.

- The CDC should take the lead on the advancement and adoption of data standards and obtaining approval and buy-in from all levels as standards are defined. A process for facilitating these activities needs to be developed and partner organizations should identify appropriate individuals to participate.

- A process for disseminating, using, and critiquing standards as well as arbitrating decisions within public health needs to be developed. There is support for beginning with laboratory data standards as a priority. CDC management should mandate and enforce development

and adherence to standards in CDC surveillance information systems. Mechanisms should be identified by which state and local health departments can participate more actively in SDOs.

d). Integration of Systems

- It is imperative to determine now what the architecture and approach for NEDSS will be, so that CDC systems appear to be unified. There is a need to develop stronger CDC policies regarding the development of systems and adherence to more clearly defined standards. There should not be a focus on only "tight" or "loose" integration. Rather, the system should be flexible, users should be able to define when 'tight'" or "loose" integration is indicated. If "tight" integration is indicated, there must be the ability to use a single (seamless) system with the appropriate modules and standard data exchange.

- Additionally, CDC should continue to assure availability of critical software application. This should involve evaluation of state-based systems and the transportation of knowledge, technical understanding, and architecture principles learned. This would prevent agencies from having to "reinvent the wheel". Applications should be built to industry standards and use standard industry tools.

- Local, state, and federal organizations need to leverage categorical funds to support surveillance integration in addition to cross-cutting funding as there is a need for both. CDC should include explicit requirements for collaborating around integration in categorical cooperative agreements. The investment analysis process should be redesigned to facilitate its use for building integrated systems.

- Tools for data and information management need to be developed. For example, a disease registry could be used as an example to facilitate the understanding of how data elements are used and coded. HIPAA standards must be consistently implemented at the state level in a way that does not restrict data linkage and integration.

e). Marketing

- The goals and rationale for surveillance integration need to be marketed to a variety of audiences, including CIOs within CDC. There is a need to clarify what NEDSS means in terms of actual implementation, such as defining specific components and activities for CDC programs as well as state and local agencies. Thus, one of the highest priorities should be to market the goals and rationale of integration within public health as well as to other health care providers and the public in general. The "value added" of systems integration must be demonstrated at these levels if constituents are to understand that integration will improve the health of their communities.

f). Communication/Exchange of Ideas/Education

- Exchange of ideas should be facilitated at national and regional public health meetings. The public health workforce should be educated about HIPAA and its implications, the importance of the Data Model and how to use it, and other areas of public health informatics. It may be possible to use Health Alert Network (HAN) resources, such as teleconferences, to provide programs on these issues.

g). Overall Priorities

- It is important to remember that data are the key, but are not sufficient. There is an urgent need to institutionalize systems integration with respect to organizational structure, enforcement, and a core group that ensures active integration.

- As a first priority, the process to be used for integration should be defined, then time lines should be developed for addressing each of the needs identified above. Along with time lines, roles and responsibilities of local, state, and federal organizations should also be defined. Of particular importance is determining when CDC should develop systems, versus facilitating contracts for consultants to do the work.

C. Group 3: Security Issues

This group was asked to address security issues at the local, state, and national levels, and to identify how to assure that a high level of security will be in place for the transmission of surveillance information. The group began by assessing the current situation, identified potential barriers to progress, and made a number of recommendations with respect to next steps and priorities, as well as roles and responsibilities.

1. Where We Are Now

- State and local health departments have varying degrees of technical capability and sophistication. Some states have already developed integrated surveillance systems and as such have strong partnerships with their local health departments. Other states do not have this infrastructure.

- State Departments of Health (DOHs) are supportive of using the Internet as a vehicle to report to CDC data systems. Additionally, local health departments are supportive of using Internet protocol to report to state DOHs, and to exchange information with each other. However, not all local and state health departments have dedicated Internet access, so funding and local MIS control are issues of concern.

- The current observed quality of service (QOS) for Internet availability leaves questions about the reliability of this vehicle, especially in a biologic emergency. For example, getting quick access to data in an emergency could become an issue if the Internet is clogged with heavy usage.

- Although HIPPA would set the base level of requirements for Internet interchange, there are varying levels of need at the state and local level regarding the actual mechanisms for implementing encryption, authentication, authorization, audit trails, and assuring transaction and data integrity needed to effect this. It is imperative that NEDSS meet these needs.

- Much work has already been done related to security of health information, and we should take advantage of this work. (National Research Council (1997): For the Record: Protecting Electronic Health Information *http://bob.nap.edu/html/for/* ; and,

HIPAA NPRM for Security and Electronic Signature Standards (Aug 1988): *http://aspe.hhs.gov/admnsimp/nprm/seclist.htm.)*

2. Challenges to Progress

- Public and provider perceptions regarding information transport on the Internet is a very significant issue. Collaboration is needed at the local, state, and national levels to develop common ground approaches to convincing the public of the security of information transported over the Internet.

- The success of NEDSS depends on meeting the needs of all stakeholders. Yet it appears that the needs of state and local health agencies and other reporters-of-data to state and local health agencies, such as hospitals, have not been fully taken into account. These needs include: technical issues, business processes, political considerations, training(informatics), legal considerations, costs to state and local health departments and health providers, reporting roles, physical ownership, and responsibility for data.

- There is a perception that CDC seems ready to pilot an integrated system, meaning that development and work on standards are complete. This should not be done until all stakeholders have participated in assessing their needs, designing the system, and developing standards. If CDC takes specific technical directions at this point, it could present a significant barrier to the success of NEDSS.

3. Possible Solutions

- It is imperative that a process of detailed needs assessment be started as soon as possible. The first step is to work with state and local health departments, including key technical and policy staff along with state information technology (IT) security officers, to establish a general technological framework. The second step is to incrementally include providers and payers to validate the framework against their needs.

- NEDSS standards specifications, design, and development must include the needs as assessed from the process outlined above. These activities should be put on hold until the assessment process is completed.

- NEDSS funding should be identified to pay for technology to facilitate the process, for example through video conferencing. Additionally, funding to assist state and local health departments should be identified to meet their security and Internet access needs.

4. Prioritization of Next Steps

- Incremental needs assessment should be completed within three months. The needs of state and local health agencies should be assessed first, followed by those of providers and payers.

- Next, an overall design document should be developed to be completed by December, 2000. NEDSS standards specifications should be revised to include the needs of partners. However, the design and development should begin only after specifications are agreed upon.

- State and local health agencies should be included in the assessment, design, development, and evaluation processes.

- The identification of appropriate funding for assisting state and local health agencies in meeting the standards should also be carried out.

5. Roles and Responsibilities

- A Separate unit in CDC should spearhead the needs assessment (e.g. CDC Governmental Affairs Unit). National organizations such as NACCHO and ASTHO, and their affiliates should assist in facilitating this process by identifying appropriate program, policy, and information technology representatives to participate.

- CDC needs to identify funding to assist state and local health agencies in meeting the NEDSS security and Internet access needs.

- State and local health agencies should work together through their own partnerships to assess needs of local health agencies and providers as well as promote the national NEDSS needs assessment process.

6. Discussion

The group's recommendation that needs assessments be carried out at the local level over a period of three months stimulated much discussion. Some participants felt such assessments were needed, while others voiced concern that such a task could not be accomplished in a short period of time and would significantly slow progress toward implementation. Alternative approaches to launching new assessment activities included recommendations to review existing state and local assessment results such as those completed in New York, and to review recently completed assessments conducted by the Department of Justice as well as those conducted during the development of HAN. The recommendation of implementing pilot projects using a modular approach would also contribute to determining the needs at the local and state levels. Security is a significant issue for all concerned. Past experience has shown that while standards can be developed at the national level, there must be ownership of those standards at the state and local levels. (For post-conference comments see Appendix 4.)

D. Group 4: Electronic Reporting: Laboratory Demonstration Project

The charge for this breakout group was to focus on the Electronic Laboratory Reporting Model as an example of interfacing between the private health sector and local, state, and federal health entities, including public health laboratories. In addressing this charge, the group identified eight issues of importance in electronic reporting. These issues are: broad public health concerns; variation in capacity and expertise within public health, including laboratories; reporting requirements; leading by example; expertise for implementation of NEDSS; the need to optimize collaboration; using incoming data effectively; and, documentation and evaluation.

1. Current Situation

- Public health concerns are broader than just disease reporting and clinical data, they also include environmental laboratory data and other sources of electronic information. As such, there should be active participation by public health in SDOs to ensure that information for public health is well standardized. Other partners need to become more involved in the

process than is currently the case. If this doesn't happen, clinical data will drive standards development.

2. Barriers

- There is wide variation in capacity and expertise within public health and laboratories. There also exists a variation in reporting requirements which may impede electronic reporting among public health jurisdictions, and from large laboratories.

- Because of differing laws and regulations, physicians and other providers, as well as commercial labs often don't understand what they must report to whom. Incomplete and delayed reporting is often a problem.

- Finally, if the system is to work well, providers of data must view it as being of benefit to them. They must have a vested interest in the data they are reporting. This is currently not always the case.

3. Solutions

- In order to deal with the variations in capacity and expertise, there must be a concerted effort to continue and enhance building of information technology infrastructure at all levels. Especially important is the necessity to build workforce capacity at the local and state levels to utilize electronic information.

- HAN, NEDSS, and electronic reporting implementation should be linked. Tiered implementation for labs (e.g., full scale messaging for some, browsers for others) would be helpful. Practical short term approaches are appropriate in some situations; however, the implementation time frame should be explicitly considered in decision making. It is important to plan strategically and implement incrementally.

- To deal with variation in reporting requirements, technical (e.g, filtering) rather than the more difficult legislative solutions may be possible and preferable. Also, information about existing requirements should be made more accessible. Finally, reportable tests and results should be standardized.

- Ways to deal with the incomplete and delayed reporting include exploring with CLIA ways to enhance reporting. It may be possible to make this a CLIA meeting agenda item. Also, a linkage between HCFA reimbursement and compliance should be explored. Providing technical assistance, as appropriate, may help to enhance reporting.

- Finally, government entities such as public health, CDC, and military labs should lead by example in a standards-based approach to reporting.

- The linking of databases should be explored in ongoing or future pilot projects. Missing information in one database which is useful for surveillance purposes may exist on other related databases. For example, forms used for reporting test results for laboratory specimens that contribute to diagnosis may not contain demographic information found in medical records or billing databases. Linking these would be beneficial to ensure completeness of data.

- There is a need for expertise for implementation. It is important to know how to acquire and retain information technology expertise and manage implementation well. Suggested ways of achieving this goal include the use of both internal and contracted expertise. Internal expertise must include project management, and training in these skills should be part of infrastructure building.

- It is important to know how to optimize collaboration between epidemiology and laboratories in an era of electronic reporting, molecular epidemiology, and a great deal of incoming data. To do this, government labs must be recognized as reporting sources analogous to other laboratories. Leading in a standards-based approach is also important for state laboratories. Integration and linkage of state laboratory and epidemiology information systems would help to further this goal.

- In order to use incoming data effectively, the technical capacity to move incoming laboratory data into appropriate databases must exist. There should also be a provision for linkages with other sources of data (e.g., immunization records).

- Finally, to document and evaluate current electronic reporting activities, there must be a review of pilot projects to develop an implementation guide or requirements for electronic reporting (ER). The development of report card or database of projects involving implementation of HAN and electronic reporting would also prove beneficial. Disseminating what is learned from implementation efforts with ASTHO and affiliates, NACCHO (lessons learned from HAN), and the CDC would be helpful.

E. Group 5: NEDSS Interface Beyond Infectious Disease

This group explored the NEDSS approach for a non-infectious disease surveillance perspective through discussion of relevant areas that need participation, opportunities for data exchange, and priority areas for standards from local, state, and federal perspectives.

1. Background

Non-infectious disease surveillance differs from infectious disease (ID) surveillance in that there is a broader spectrum to monitor. Consideration of diseases, exposures, risks, and community-level attributes must all be taken into account. There is a wide range of conditions to assess such as maternal and child health, chronic disease, injury, and environmental exposures. There is also a greater array of partners and agencies to consider and with which to collaborate.

There are a number of challenges shared with ID such as fragmentation, effects of categorical funding, lack of coordination, and, the importance of confidentiality. Other challenges include the following.

- A need exists to articulate a vision of integrated non-infectious disease surveillance. What does “integrated surveillance” mean in the context of non-infectious disease surveillance?

- The role of surveillance along a continuum or spectrum of exposures, diseases, and health needs to be defined. At the risk of over-simplification, most ID surveillance is focused on the occurrence of acute events. In contrast, for many non-infectious diseases, surveillance must address a succession of events that occur over a comparatively much longer time period.

- The relationship to other programs needs to be explored. For a number of non-infectious conditions, health departments manage programs that serve clients and that have information management systems. Examples include diabetes and maternal and child health programs. The interface between information collection for program management and surveillance purposes needs to be defined.

2. Next Steps

- The first step is to take stock of what has already been accomplished, and ascertain the current status of state integration efforts. Current thinking and reports from other planning activities should be considered. Federal program reporting mandates and accompanying systems for supporting data collection and management systems, such as programs supported by HRSA, HCFA, EPA, etc. should be investigated. Private sector systems should also be taken into account, and electronic medical records are a further consideration.

- Next a conceptual framework for systems integration should be developed. Models of integrated surveillance for individual-level diseases, environmental exposures, risks, and, community-level attributes that affect health and prevention should be designed. The conceptual framework should include a role for different data sources. Indicator systems, such as 2010 Health Objectives, Institute of Medicine reports, community health indicators and environmental systems, should be included as well. It may be necessary to re-define and expand the NEDSS concept. Instead of looking for the next NEDSS disease category, there should be an effort to think across disease categories.

- Thirdly, a strategic plan should be developed. It is important to first determine what 'it' or the system is. In other words, we need to establish a vision for integration of non-infectious disease surveillance. To do this, surveillance needs assessments should be conducted. Goals should be developed and the uses of integrated surveillance determined. It is also important to ascertain the role and limits of surveillance; that is, how they link to research and programs. For example, needs for integration for non-infectious conditions may be much greater across programs within health departments, as opposed to improving the flow of surveillance data between states and CDC. The time to start this process is now.

- The next step would be to develop linkages. Public health needs to be "at the table" in health data and standards planning. It is also necessary to link with other agencies and organizations including those within and across public health, other federal agencies, professional organizations, and state legislatures.

- The final step would be to determine standards and develop pilot programs. Standards should link to 'hubs'. Examples of hubs include: birth certificates in the maternal and child health programs and systems; hospital discharge data in disease registries; client services in case management; emergency room records for injuries and acute events, geographic (geocode) for environment and community-level information; and, others including laboratories, medicaid managed care, poison control, and criminal justice. There should also be links across 'hubs'. Standards should be developed for format and content, and development should involve multiple stakeholders. Pilot tests should be designed to explore the use of different 'hub' systems.

VI. Conclusions

Undoubtedly, there is broad-based consensus that integrated surveillance systems are needed, and that stakeholders support a leadership role for CDC in developing the required standards and systems architecture. While barriers exist to implementation, there are solutions to overcoming them as well as opportunities for enhancing and expanding the scope of public health surveillance and information systems.

Through on-going collaboration with current stakeholders as well as expanded partnerships with private providers and other health-related organizations, integrated surveillance systems can provide tremendous opportunities and benefits for public health. These include minimizing duplication and overlap in data collection and reporting; more cost-effective systems; reduction of workload for providers, and accelerated reporting of laboratory results related to disease outbreaks and bioterrorism events, to name but a few. Ultimately, when successfully implemented and evaluated, the most significant benefits will occur through enhancing the public's health and reducing the economic burden related to disease and disability.