The National Electronic Disease Surveillance System (NEDSS):
A standards based approach to connect public health and clinical medicine
Presentation for Childhood Lead Surveillance Meeting
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Limitations of current surveillance systems
- Multiplicity of categorical systems
- Data incomplete, often not timely
- Burden on respondents in health care sector increasingly unacceptable
- Systems do not utilize state of the art information technology
- NEDSS transforms state surveillance by:
  - Current data collection integrated and over the web
  - Automatic input from existing electronic databases

Current Opportunities
- Progress in technology, informatics concepts
- National standards for health electronic data interchange with HIPAA ‘96
- Funding for National Electronic Disease Surveillance System (NEDSS)
  - FY2000 $20 million, FY2001 $27 million,
  - FY2002 $27 million
NEDSS Vision

- To have integrated surveillance systems that can transfer appropriate public health, laboratory, and clinical data efficiently and securely over the internet
- Allow the gathering and analysis of information quickly and accurately
- Improve ability to identify outbreaks, monitor disease trends, identify and track emerging infections, recognize/respond to potential bioterrorism attacks

NEDSS Principles

- Utilization of industry standards
- Reliance on off-the-shelf software
- Internet-based secure transmission of data
- A common “look and feel” of systems
- No requirement to use specific software

NEDSS Systems Architecture

- Brings structure, standards and interoperability to the information systems elements of surveillance – not another system - a way for many to build interoperable systems
- Provides a structure around which CDC systems can be integrated
- Allows the latitude for states and local health departments to do specific implementations and fulfill public health needs
- Is respectful of local / state / federal data flow issues
- Facilitates the ready exchange of comparable data and reports between public health organizations without reprogramming
NEDSS “at-a-glance”

- NEDSS is a broad initiative using national data and information system standards for development of efficient, integrated, and interoperable surveillance systems at the state and local levels
- Includes tools for electronic data transfer to health department from health care system
  - e.g. from multi-jurisdictional clinical labs
- Security standards (HIPAA compliant) to maintain public health track record in protecting sensitive data
- Starts with focus— infectious disease—but keeps big picture in mind

Implement an integrated data repository
- able to be patient centered, non-categorical

Implement a security system and appropriate security policies (Internet-based, with a firewall and certificates or tokens)
Conduct and support web browser-based data entry and data management.

Accept, route and process electronic HL7 messages containing laboratory and clinical content (LOINC, SNOMED).

Develop active data translation and exchange (integration broker) functionality (XML, DTD), HTTPS.)
Develop data reporting and visualization capability.

Implement a shareable directory of public health personnel (LDAP).

Develop transportable business logic capability.
CDC Forms and Applications → Integrated State/Local Data Repository

XML Data Exchange

Will support and run CDC developed applications and web-based “case reports” that interoperate with this environment.

State “Base System” Option
A NEDSS compatible system for state use developed by an experienced web software developer (Computer Sciences Corporation)

- “Base system” includes Core Demographics and Nationally Notifiable Disease Module; person based Integrated Data repository; HL-7 messaging
- First Production Release of NEDSS Base System scheduled for completion September 30 – will include electronic lab reporting capability
- Base system is platform for other modules (PAMs)
- States have option to use (or not) CDC developed modules

NEDSS Base System and Program Area Modules
- Core Investigation Functionality (approximately 65 diseases)
- Extended Investigation Functionality (PAM’s – Program Area Modules)
  - Hepatitis
  - Bacterial Meningitis and Invasive Respiratory Diseases
  - Vaccine Preventable Diseases

NEDSS Base System
- Core Demographics
- Investigative Disease
- Case Notifications
- Messaging
- PAM’s

PAM’s
- Hepatitis PAM
- Bacterial Meningitis
- Invasive Respiratory Diseases
- Vaccine Preventable Diseases

Message Services
- CDC Form Services
- Public Health Lab Reporting Services
- Messaging Services
- Additional PAMs

Additional PAMs
- STD PAM
- HIV PAM
- Lyme Disease PAM
- Measles, Rubella, Pertussis, Congenital Rubella
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- Lyme Disease PAM
- Measles, Rubella, Pertussis, Congenital Rubella
- STD PAM
- Additional PAMs
Program Area Module Development
Phased Process

• Initial Design Specification
• Requirements Development
• Design Prototype
• Beta Testing
• Production Implementation
• New NEDSS PAM Task Order imminent – award October 2002

Additional Collaboration in NEDSS

• Partner organization “point of contact” & coordination, IT Committees (ASTHO, NACCHO, CSTE, APHL, NAPHSIS, NAHDO)
• State and local health department participation in developing NEDSS Base System
  – Joint Application Development (JAD) sessions
  – Ongoing review of requirements drafts, prototypes
• Collaboration with e Health Initiative, LabCorp, Quest
• Web Board conferences, postings

NEDSS Extra-mural Activities

Assessment and Planning – Assess current information systems personnel and technical infrastructure, evaluate that infrastructure against the NEDSS systems architecture and develop plans to migrate to the NEDSS architecture as needed.

Element Development – Implement between one and four of the NEDSS system architecture elements and use in the setting of identified public health activities.

Charter Sites – Conduct activities to implement and demonstrate the fully described systems architecture.
Current Status of NEDSS

- 50 states, 6 cities, and 1 territory funded for NEDSS: 43 started with Assessment & Planning phase in 2000.
- September 2001: 35 states and 1 city receiving funds for development of NEDSS compatible systems
  - 16 implementing NEDSS compatible state developed system
  - 20 deploying NEDSS Base System (NBS)
- January 2002: Public Health and Social Services Emergency Fund (Emergency and Bioterrorism Preparedness) provides major funding for state and local public health capacity, including guidance from HHS on surveillance and IT capacity.

NEDSS and the Environmental Health Tracking Network (EHTN)

- NEDSS can provide in coordinated fashion with investments made for IT capacity for emergency preparedness, the necessary infrastructure upon which the EHTN can be built.
- NEDSS has defined data types useful for public health as well as standard codes, vocabularies and messages to describe and electronically transmit those data; additional resources/work needed to define data standards for environmental exposures.

Third National NEDSS Stakeholders’ Meeting

- May 10 & 11, 2002: ~ 600 participants
- Broad representation from states, local health departments, public health laboratories, and private clinical care, partner organizations, CDC, HRSA, CMS
- Active exchange of information on NEDSS implementation, including demonstration of Base System
- Strong interest in how NEDSS standards based approach and infra-structure could be used to support broader health department information needs, for example web based Vital Statistics systems, HIPAA
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