Module Objectives

- Describe at least two considerations that support a real-time reporting system
- Discuss the four guiding concepts of data management.
- List at least three best practices of data management
- List and briefly describe basic elements of STD data systems

Module Objectives

- Identify essential elements for STD forms usability
- Summarize the advantages and disadvantages of web-based systems
- Explain the relationship between evaluation, quality improvement, and maintenance of STD data management systems
- Summarize the staff capacity and critical skills need to maintain reporting and data management systems
Outline

- Reporting
- Reporting versus Case Management
- Data Management Concepts & Best Practices
- Data systems for STD programs
- Forms, usability, methods
- QA and evaluation
- Staff capacity for STD programs

Public Health ‘Reporters’

- Public health planning and disease control activities depend on a network of informed and collaborating clinicians, facilities and laboratories
- STD programs usually have a higher volume of reportable conditions than other health department programs
- Reporting requirements carry legal weight in most jurisdictions, yet the goodwill of providers will more fully insure timely and complete compliance

Collaborating Relationships

- Reporting relationships should be viewed like any other business collaboration
- STD programs should have a plan to maintain contact with reporters
- Annual letters of appreciation, including STD fact sheets and reminders of reporting requirements are a useful method of maintaining relationships

“Regardless of the changes in technology, well-crafted messages will always have an audience.”
Steve Burnett
**Rationale for Reporting**

- Clear statement of the importance of reporting STDs should be communicated to providers
  - Enables public health tracking of disease trends
  - Reporting can help assure timely treatment and facilitate partner services
- Providers should be reassured about the privacy of their patient’s health information
  - Surveillance activities are exempt from HIPPA requirements
  - Freedom of Information Act requests do not apply to personally identifiable records

**Rationale for Reporting**

- Specific information about the legal basis and requirements for disease reporting should be conveyed
  - State statutes govern specific conditions reportable by providers, laboratories and health care facilities in each jurisdiction
  - The Council of State and Territorial Epidemiologists (CSTE) recommends specific conditions for national reporting to CDC

**NETSS Reporting**

- The National Electronic Telecommunications System for Surveillance (NETSS) is the system that provides CDC with weekly morbidity reporting from states and territories
- Nationally notifiable STDs include:
  - Syphilis (all stages)
  - Congenital syphilis
  - Gonorrhea
  - Chlamydia
  - Chancroid
- Gender, age, county of residence, race and Hispanic ethnicity are core NETSS variables
- States may require reporting of additional diseases (HSV, GI, LGV, PID, etc.)
Reporting and Case Management
- STD Programs have responsibility for assuring case reporting at the state and national level and also may have some responsibilities for case management in the field.
- Management needs of these two program functions can vary greatly in complexity and system requirements.
  - Case management information needs to be dynamic and easily available for frequent reference and update by field staff.
  - Reporting data need to be clean, complete, valid and static.

Guiding Concepts in Data Management
- Ownership of the data
  - Data are the property of the program and responsibility for quality, security and use reside with the program manager.
- Minimization of data
  - Collect & archive only those data elements that meet a specific surveillance purpose.
- Accountability
  - Who, when, where and why of each record or data element should be documented.
- Evaluation/Quality Improvement
  - Reporting completeness and timeliness should be periodically evaluated.
  - Data quality improvement should be an ongoing activity.

Data Management Best Practices
- Maintain a data dictionary - list of all data elements collected and how they are coded for STD surveillance and case management.
- Sources of all data collected should be documented.
- Data uses, including data requests from stakeholders and data sharing agreements should be documented.
- Compliance with applicable data confidentiality and security laws, regulations and policies should be documented.
- Data collected should be harmonized with other systems where desirable (HIV) to assure interoperability and encourage integration.
Business Rules

- Understanding the various program needs for data and data management help define the systems best suited to your program.
- Business rules are explicit statements describing steps and processes for managing, validating, accessing and archiving STD information for each specific purpose, for example:
  - Case reports will be recorded in the case registry within 10 days of receipt.
  - Laboratory reports will be matched against previously reported cases prior to creating a new case record.
  - Interviews and field records will be reviewed by the program manager.
  - Syphilis serologies will be run against a reactor grid prior to field investigation.

STD Data Management

- STD data management processes should be formalized in program policies and procedures.
- Data management methods should be periodically reviewed.
- Data validation and quality assurance should be integrated into data management processes.
- Data must be secure and patient confidentiality protected.
  - Stakeholders should be aware of data security considerations.
  - Access to data must be appropriately controlled.
  - Policies should be in place for suppressing small cell sizes in release of data.

Basic Elements of STD Data Systems

- STD programs need to manage data associated with diverse program activities for quality assurance and performance measurement:
  - Case reporting/surveillance
  - Prevalence monitoring
  - Case/partner management
  - Reporting and NETSS transmission.
Data systems can be either case-based or person-based.

The simplest STD data management systems are databases installed on a single computer or local area network in the state or local program office.

- Advantages include security control, ease of maintenance, control over data entry practices and minimum network requirements.
- Disadvantages include centralized data entry requirements, delay in case reporting and lack of access for case management by field staff.

Many programs are constrained in their choice of data management systems by local agency policies and network standards.

Data managers/data stewards should be familiar with their home agency requirements.

STD Data Systems & Tools

Programs may be using databases specifically designed for STDs or may have developed local tools using a variety of database platforms.

A variety of data management systems are now available at low cost for STD program use:

- STD-MIS, PRISM

Additional software tools are also useful for analysis, data visualization and data manipulation:

- SAS, R, SPSS, PowerPoint, Epi Info, etc.
STD*MIS

- STD*MIS is a STD-specific data application developed by CDC for local/state program use
  - STD-MIS provides functionality for most aspects of STD surveillance, case management and reporting
  - NETSS file production is built in, assuring reliable national reporting
  - Program-level performance measure reporting is incorporated in later versions
  - Many additional process reports are pre-programmed to facilitate local and state quality assurance activities

Data Management & Analysis Tools

- Data analysis
  - SAS (CDC License available to grantees)
  - SPSS
  - ArcGIS (ESRI) Geographic Information Systems tools
  - R statistical computing and graphics
- Record matching
  - LinkPlus (CDC)
  - Febrl (Freely Extensible Biomedical Record Linkage)
- Graphics Packages
  - Excel
  - PowerPoint
  - Origin

Forms

- Paper-based and electronic forms are the backbone of all public health reporting
- Even in an electronic reporting environment, there is still a need for paper-based forms
  - Emergency situations, power outages
  - Providers without reliable access to electronic media
- Case, laboratory, interview and field record reports are the basic units of STD surveillance
Usability/Acceptability

- Forms used to report cases of disease should clearly explain their purpose, be user-friendly and where space permits:
  - Have a descriptive title
  - Provide a brief rationale for the information being collected
  - Clearly explain confidentiality protections for the information the user is reporting
- Forms should be piloted and modified based on user feedback

STD Program-Specific Forms

- **Case Reports**
  - For use by providers and local health jurisdictions
  - Patient identifiers
  - Demographics and limited behavioral information
  - Provider information
  - Diagnosis, treatment and laboratory information

- **Case Management Interview Forms**
  - For use by DIS and other field staff
  - Captures behavioral data during exposure period
  - Records partner contact information

- **Field Records**
  - Records contact, notification and partner disposition information

Specialized & local use forms

- Congenital syphilis
- Neonatal HSV
- Infertility prevention project forms
- Special conditions surveillance tools (DGI, etc.)
- Enhanced surveillance activities (SSuN)
On-line Forms and Reporting

- Many STD programs are reducing manual data entry burden at the state program
  - Distributing data entry to field/local staff reduces central data entry burden
  - Reporting may be facilitated by secure web-based systems
  - Electronic reporting may provide opportunities for more timely and complete information
- Electronic forms that are identical, or very similar to, paper forms can help speed adoption of electronic reporting and data entry
- Providers of STD diagnostic services are moving toward electronic medical records, which will be mined for case reporting in the future

Web-based Systems

- A number of states have developed web-based surveillance systems with a variety of core and extended functionality
  - PA-NEDSS (PA)
  - PRISM (ftp://ftp.pub.doh.state.fl.us/pub/bstd/)
  - MDSS (Michigan)
  - PHIMS-STD (WA)
- Primary advantages include distributed data entry burden, easy access by field staff for case management and potential for more timely reporting of cases
- Disadvantages may include development and maintenance costs, increased need for ongoing data validation/data cleaning and managing training needs of multiple users

Electronic Reporting

- Many states are implementing electronic laboratory reporting systems which can facilitate reporting of laboratory information, including those associated with reportable STDs
- Electronic reporting requires that data systems be at least minimally “interoperable”
  - Compatible data elements
  - Standard data formats
  - Ability to translate, import and export files
- Skill-set needed to build and maintain electronic reporting infrastructure can be highly specialized and expensive
- Electronic reporting of lab and case data can significantly enhance program activities
Data Transmission & Security
- NETSS data are transmitted to CDC via a secure data network maintained by CDC (SDN).
- Other STD case data are often needed in locations remote from the program office.
- Insuring the security and integrity of case data requires secure transmission methods:
  - Encryption (PGP, Seal, etc.)
  - Secure file transport systems (encrypted in transmission)
  - Certificate-mediated HTTPS protocols for web systems
  - Secure fax locations
- Policies should be reviewed to assure they consider recent changes in technology.

Evaluation and Quality Assurance
- Like any other program component, data management systems and methods should be regularly evaluated:
  - Completeness of reporting (cases, IX, FR, lab, etc.)
  - Completeness of data elements (case audit reports)
  - Validity of data (periodic case reviews)
  - Timeliness of reporting (performance measurement)

Evaluation and Quality Assurance
- In addition to system and data quality assurance, data management processes should be evaluated for efficiency:
  - Data entry methods
  - Data retrieval and reporting
  - Data extracts for analyses
- Changes in technology offer opportunities for continuous quality improvement; data management methods should be expected to mature and evolve as other program elements.
Program Staff Capacity

- Desirable STD Program staff capacities related to data management should include:
  - Previous experience with database management
    - Dbase, Oracle, SQL, Access, etc.
  - Programming skills
    - Basic data manipulation using SQL, VBasic, SAS, SPSS, R, Stata, ArcGIS or other packages
    - Basic understanding of relational databases
    - Understanding of network architecture
    - Familiarity with application development processes