

Driving Public Health with Appropriate Data: Data Sharing – Why, When, Who and How?

CSTE webinar series

Implementing the Integrated Data Security and Confidentiality
Guidelines for HIV, Viral Hepatitis, Sexually Transmitted Disease,
and Tuberculosis Programs

July 25, 2013

2:00 – 3:15 pm ET



COUNCIL OF STATE AND
TERRITORIAL EPIDEMIOLOGISTS

Webinar Agenda

- **Moderator: Vincent Fears, Program Consultant/Project Officer, Division of TB Elimination**
- Introduction and Welcome: Gustavo Aquino, Associate Director for Program Integration, NCHHSTP
- Mark Stenger, Surveillance and Special Studies Team, Surveillance & Data Management Branch, DSTDP, NCHHSTP
- Ann Drobnik, PCSI Analyst & Jennifer Fuld, PCSI Coordinator, New York City Department of Health & Mental Hygiene
- Debbie Wendell, Manager of Data Management/Analysis Unit, STD/HIV Program, Louisiana Department of Health and Hospitals
- Questions and Discussion: presenters and participants

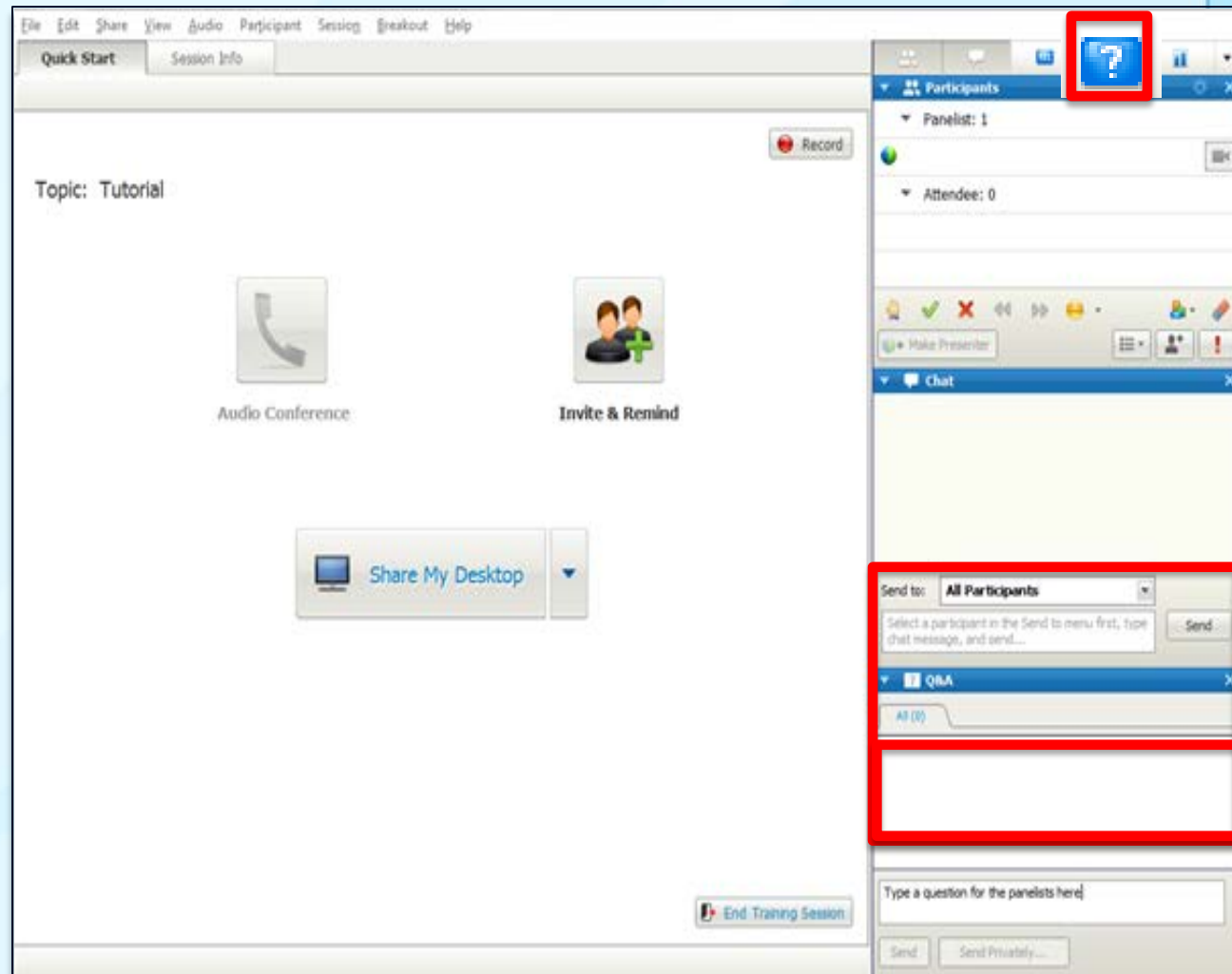


Webinar Housekeeping

- **Please note that today's webinar is being recorded**
 - The webinar recording, presentation slides, and additional tools and templates will be available in the webinar library on CSTE's website:
<http://www.cste.org/?page=WebinarLibrary>
- **All phone lines have been placed on mute**
- **There will be a question-and-answer session at the end of the webinar**
 - To ask a question, please use the Q&A box on the right side of your screen

To Ask a Question

- Click on the blue question mark tab on the top right panel of your screen
- This will open the Q&A box on the bottom right panel on your screen
- Type a question
- Send questions to All Panelists
- Questions will be answered during the Q&A period



Webinar Agenda

- Moderator: Vincent Fears, Program Consultant/Project Officer, Division of TB Elimination
- **Introduction and Welcome: Gustavo Aquino, Associate Director for Program Integration, NCHHSTP**
- Mark Stenger, Surveillance and Special Studies Team, Surveillance & Data Management Branch, DSTDP, NCHHSTP
- Ann Drobnik, PCSI Analyst & Jennifer Fuld, PCSI Coordinator, New York City Department of Health & Mental Hygiene
- Debbie Wendell, Manager of Data Management/Analysis Unit, STD/HIV Program, Louisiana Department of Health and Hospitals
- Questions and Discussion: presenters and participants

Data Security and Confidentiality Guidelines for HIV, Viral Hepatitis, STD, and TB

Driving Public Health with Appropriate Data: Data
Sharing – Why, When, Who and How?

Introduction and Welcome

Gustavo Aquino

Associate Director for Program Integration

CDC/OID/NCHHSTP

July 25, 2013

Webinars will now be available...

Webinars recorded and available online in the Webinar library at www.cste.org

- ✓ The First Step: Conducting an Initial Assessment
- ✓ Developing Policies & Procedures and Periodic Assessments
- ✓ Creating a Confidential and Secure Physical & Electronic Environment and the Process of Certification and Validation

Today's session

- ✓ Driving Public Health with Appropriate Data: Data Sharing – Why, When, Who and How?

Coming Soon

- ✓ Active Responsible Stewardship – From Training to Responding: Monday, August 26, 2013, 1:00 - 2:15 pm ET

More Templates, Examples and Tools Coming

- ❑ **Templates and examples for implementing the 2011 NCHHSTP S&C Guidelines are being posted with the webinar recordings and slides at www.cste.org**
- ❑ **Look for these as they are posted at the time of each webinar and throughout the coming months**
- ❑ **Examples include**
 - Initial and Periodic Assessments Templates and Examples
 - Sample policies, procedures and forms

Webinar Agenda

- Moderator: Vincent Fears, Program Consultant/Project Officer, Division of TB Elimination
- Introduction and Welcome: Gustavo Aquino, Associate Director for Program Integration, NCHHSTP
- **Mark Stenger, Surveillance and Special Studies Team, Surveillance & Data Management Branch, DSTDP, NCHHSTP**
- Ann Drobnik, PCSI Analyst & Jennifer Fuld, PCSI Coordinator, New York City Department of Health & Mental Hygiene
- Debbie Wendell, Manager of Data Management/Analysis Unit, STD/HIV Program, Louisiana Department of Health and Hospitals
- Questions and Discussion: presenters and participants

Driving Public Health with Appropriate Data: Data Sharing – Why, When, Who and How?

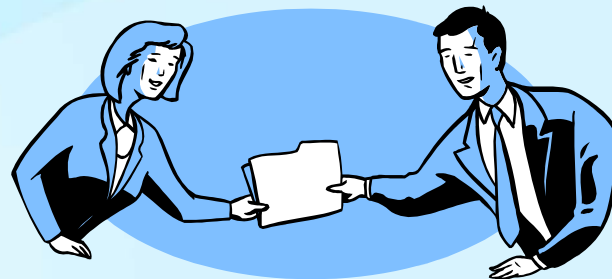
Mark Stenger

Surveillance & Special Studies Team, Surveillance & Data
Management Branch, Division of STD Prevention

Webinar Context

- Implementation of NCHHSTP's

“Data Security And Confidentiality Guidelines for HIV, Viral Hepatitis, Sexually Transmitted Disease and Tuberculosis Programs: *Standards to Facilitate Sharing and Use of Surveillance Data for Public Health Action*”



Purpose of Today's Webinar

- Why share surveillance data?
- When should these data be shared?
- Who should we be sharing with?
- How should data sharing be governed?

What do we mean by data sharing?

Allowing minimum access to personally identifiable information to public health staff or agencies outside of the surveillance unit for specific public health purposes.

- Partner/contact management
- Integrated assessment of parallel epidemics or syndemics
- Engagement with care and treatment assurance
- Quality of care assurance
- Limited public health research purposes

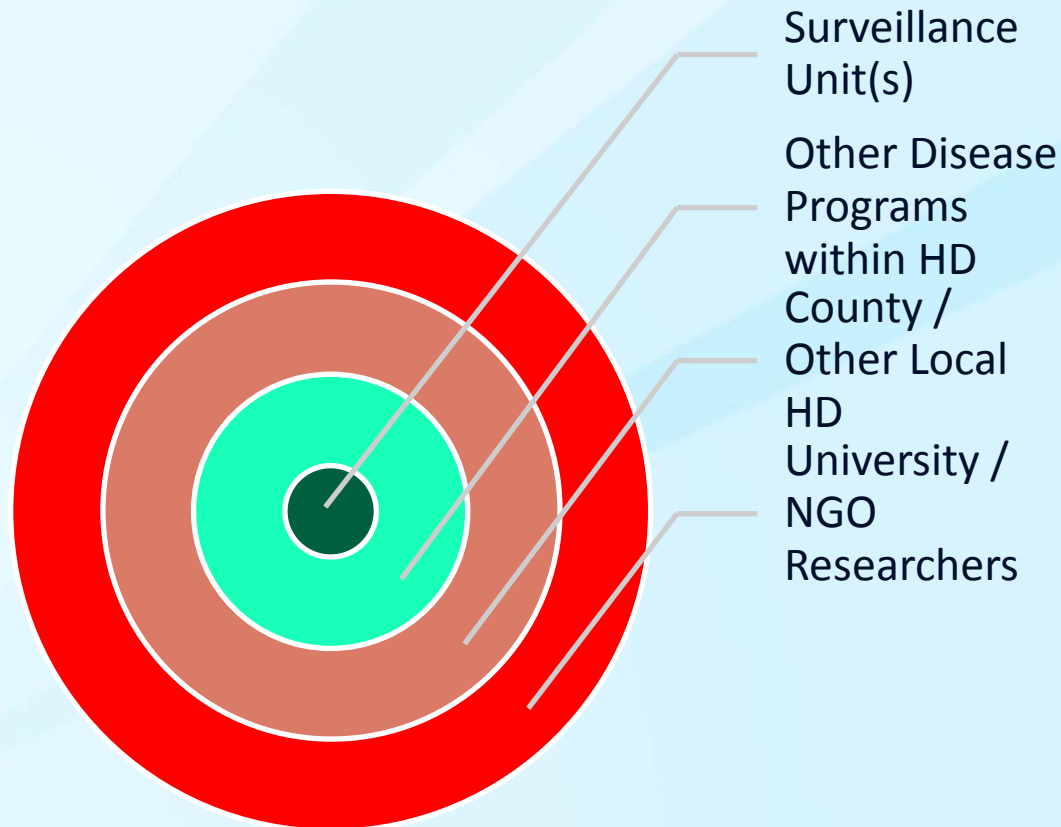
Data sharing: Granting certain individuals or organizations access to data that contain personally identifiable information with the understanding that personally identifiable or potentially identifiable data cannot be re-released further unless a special data-sharing agreement governs the use and re-release of the data and is agreed upon by the receiving program and the data provider(s).

When? Now!

- Data sharing to inform partner/contact management and other urgent public health follow-up must be sufficiently timely to achieve desired outcomes
 - Patient-level co-infection status
 - Engagement with care/treatment
- Assessment of parallel epidemics and syndemics might be periodic, or ad hoc as needed by state and local public health partners
- Public health research for quality assurance and program evaluation as needed.

Who Shares, Who Receives?

- Data sharing agreements (DSA) might need to be developed depending on who data are to be shared with:



Essential Elements of Data Sharing Agreements (DSA)

- Once determination is made that a DSA is needed, the following elements should be included:
 - Specific identification of the parties providing data
 - Names of the parties receiving data and all of those who will have access
 - Roles and responsibilities of all persons with access to data
 - Description of data to be shared (specific data elements, data formats)
 - Method data will be shared (how often, how transmitted)
 - Date range data sharing agreement in force and renewal date/procedures
 - Specific purpose(s) for which data will be shared
 - Data re-release prohibition or restriction
 - Specific physical/electronic data security procedures
 - Description of staff training and confidentiality certifications
 - Procedures to destroy or remove access to data at termination of DSA
 - Process for amendment
 - Notification of breach or misuse of data
 - Penalties for non-compliance or violation of agreement terms
 - Signatures of certifying officials

How may data be shared?

- Data may be shared via integrated surveillance systems
- Periodic matches across surveillance registries
- Through direct contact with surveillance units
- By electronic access or other means

As long as...

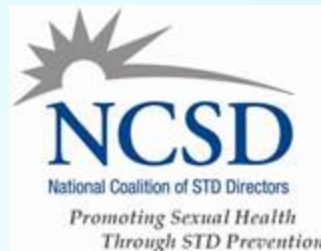
- Public health purpose of data sharing is explicit and appropriate
- Uses are consistent with initial purpose of data collection
- Data security is assured
- Recipient systems and staff are in full compliance with S & C Guidance
- ORP(s) aware and fully approve the data and data sharing methods
- Data sharing agreements or informal/formal plans are in place where needed

Implementation and Compliance with S & C Guidance

- Facilitating sharing for legitimate public health purposes is a key element of the NCHHSTP guidance
 - Due diligence in initial assessment and assuring compliance across programs removes barriers to sharing
 - Common understanding and training for all staff accessing surveillance data facilitates use of data for public health action
 - Overall responsible party mediates disagreements and facilitates compliance and sharing where legitimate public health purposes are identified
 - Data sharing should be considered as two-way communications, with information flowing back to originating surveillance program to enhance overall quality of information (more complete risk information is an example)

Examples and Best Practices

- NASTAD/NCSD recently surveyed membership on data sharing – results are encouraging yet also identifies areas of missed opportunities



- Appendix C in the Guidelines
- Useful tools accompanying this webinar

Webinar Agenda

- Moderator: Vincent Fears, Program Consultant/Project Officer, Division of TB Elimination
- Introduction and Welcome: Gustavo Aquino, Associate Director for Program Integration, NCHHSTP
- Mark Stenger, Surveillance and Special Studies Team, Surveillance & Data Management Branch, DSTDP, NCHHSTP
- **Ann Drobnik, PCSI Analyst & Jennifer Fuld, PCSI Coordinator, New York City Department of Health & Mental Hygiene**
- Debbie Wendell, Manager of Data Management/Analysis Unit, STD/HIV Program, Louisiana Department of Health and Hospitals
- Questions and Discussion: presenters and participants

Increasing data sharing and integration across disease areas in New York City through Program Collaboration and Service Integration (PCSI)

Ann Drobnik, MPH, PCSI Analyst
Jennifer Fuld, MA, PCSI Coordinator
Division of Disease Control

New York City Department of Health and Mental Hygiene



Program Collaboration & Service Integration
HIV, Viral Hepatitis, STD & TB • Division of Disease Control
NYC Department of Health



Overview

- ❑ PCSI at NYC DOHMH
- ❑ What do we mean by data sharing?
- ❑ New York State and City laws
- ❑ Delineating ‘legally permissible’ from health department policies
- ❑ Specifying data sharing requirements
- ❑ Challenges , lessons learned and next steps

NYC Commissioner of Health

General
Counsel

Confidentiality
Officer/Chief
Privacy Officer

Division of
Disease
Control

Division of
Informatics
and
Information
Technology

PCSI

Bureau of
Communicable
Disease

- **Viral hepatitis surveillance**
- Surveillance of other infectious diseases

Bureau of
HIV

- **HIV surveillance**
- HIV Testing
- Care and tx
- Field services
- Prevention
- HIV training center
- PPG, Planning council

Bureau of
TB
Control

- **TB surveillance**
- TB testing
- TB care and case management
- Field services
- HIV testing
- Hep testing for active cases

Public
Health
Lab

Bureau of
STD

- **STD surveillance**
- Public STD clinics – STD and HIV testing
- Care and tx
- Field services
- STD HIV Prevention Training Center

Bureau of
Immunization

- Vaccine preventable surveillance
- Perinatal Hepatitis B Program
- Citywide Immunization registry

PCSI

NYC
Health

*Partial NYC DOHMH org chart highlighting current PCSI

Data Sharing in the Context of PCSI

❑ PCSI goals:

- Understand co-infection: populations impacted, risk factors
- Reduce inefficiencies and maximize resources
- Facilitate data sharing

❑ PCSI Data Advisory Committee

- HIV, TB, STD and Viral Hepatitis surveillance programs, HIV Care, Treatment & Housing, General Counsel's Office, and IT
- Routine collaboration through meetings
- Shared decision making

What do we mean by data sharing?

❑ Sharing with whom?

- Internal: inside of the Health Department
- External: with providers, patients, researchers

❑ To link or match disease surveillance databases to conduct retrospective epidemiologic analyses

❑ To gain information about an individual case for case investigation, case management, partner services, etc.

- Locating information
- Demographic information
- Co-infection information
- Risk factors, labs

PCSI Needs Assessment

- ❑ **Identification of barriers to data sharing**
 - Lack of information among staff about laws around data sharing
 - State HIV law – amended in 2010
 - State STD law – amended in 2013
- ❑ **Assessment of legal challenges of data sharing in NYC:**
http://www.cdc.gov/nchhstp/ProgramIntegration/docs/PCSI_Legal_White_Paper_April_2012.pdf
- ❑ **CDC & NNPHI developing national inventory of public health laws & policies for 50 states**

New York State and City Confidentiality Laws

Disease	First NY Surveillance	State Law	Date of Passage	Amended	NYC Law	Date of Passage	Amended
TB	1897	Pub. Health Law § 2221	1953	1956	Health Code § 11.21	1991	1993, 2008, 2010
Viral Hepatitis	1952	Pub. Health Law § 18 (General provision)	1986	1987, 1990, 1991, 1992, 1998, 1999, 2004, 2010	Health Code § 11.11	1991	1993, 2008
STDs	1912	Pub. Health Law § 2306	1980	1992, 2010, 2013	Health Code § 11.11	1991	1993, 2008
HIV/AIDS	1989	Pub. Health Law § 2135	1998	2010	N/A		

What's permissible vs. what is good practice?

- ❑ Reportable to the Health Department ≠ anyone can access it
- ❑ Even if no specific legal restriction on use, there are standards
 - Need to know
 - Minimum necessary
- ❑ Electronic systems afford more control
 - Audits
 - Access based on job description
- ❑ Internal policies are fluid and can be reassessed

Identifying Data Sharing Requirements

- ❑ **Who wants it? (Access)**
- ❑ **What do they want? (Access)**
- ❑ **For what purpose? (Use)**
 - What does the law say?
 - Is the use otherwise justified for public health purposes?
- ❑ **What does IT need to do to make it happen?**

Challenges

❑ Limited uses of data

- If use is limited, how much access makes sense?

❑ Automated matching

- Data are incomplete and dirty
- Conservative matching algorithms

❑ Need for staff training

- Having access brings responsibility to maintain confidentiality

❑ IT resources

- Many solutions are electronic, but need to be supported

Lessons Learned

- ❑ Start with understanding state and local laws
- ❑ Examine current internal data sharing practices
- ❑ Identify and document use and access
- ❑ Collaboration works

Next Steps

- ❑ Identifying the need for a uniform data sharing policy or standing data sharing agreement
- ❑ Identifying requirements to facilitate the process of greater sharing
- ❑ End goal: automated sharing that reduces the burden on staff and can be used to improve public health

Acknowledgements

- ❑ Rose Gasner, former Chief Privacy Officer, NYC DOHMH
- ❑ Jay K. Varma, Deputy Commissioner, Disease Control NYC DOHMH
- ❑ Elizabeth Terranova, PCSI Project Specialist

Acknowledgements

❑ PCSI Data Advisory Committee

- Katie Bornschlegel, Bureau of Communicable Diseases
- Jennifer Baumgartner, Bureau of Communicable Diseases
- Julie Schillinger, Bureau of STD Control
- Robin Hennessy, Bureau of STD Control
- Preeti Pathela, Bureau of STD Control
- Shama Ahuja, Bureau of TB Control
- Lisa Trieu, Bureau of TB Control
- Colin Shepard, Bureau of HIV/AIDS Prevention and Control
- Sarah Braunstein, Bureau of HIV/AIDS Prevention and Control
- Laura Stadelmann, Bureau of HIV/AIDS Prevention and Control
- Christopher Williams, Bureau of HIV/AIDS Prevention and Control
- Jacinthe Thomas, Bureau of HIV/AIDS Prevention and Control
- Jim Hadler, Office of the Commissioner
- Suzette Gordon, General Counsel's Office
- Maushumi Mavinkurve, Division of Informatics and Information Technology

All under one roof...



Webinar Agenda

- Moderator: Vincent Fears, Program Consultant/Project Officer, Division of TB Elimination
- Introduction and Welcome: Gustavo Aquino, Associate Director for Program Integration, NCHHSTP
- Mark Stenger, Surveillance and Special Studies Team, Surveillance & Data Management Branch, DSTDP, NCHHSTP
- Ann Drobnik, PCSI Analyst & Jennifer Fuld, PCSI Coordinator, New York City Department of Health & Mental Hygiene
- **Debbie Wendell, Manager of Data Management/Analysis Unit, STD/HIV Program, Louisiana Department of Health and Hospitals**
- Questions and Discussion: presenters and participants

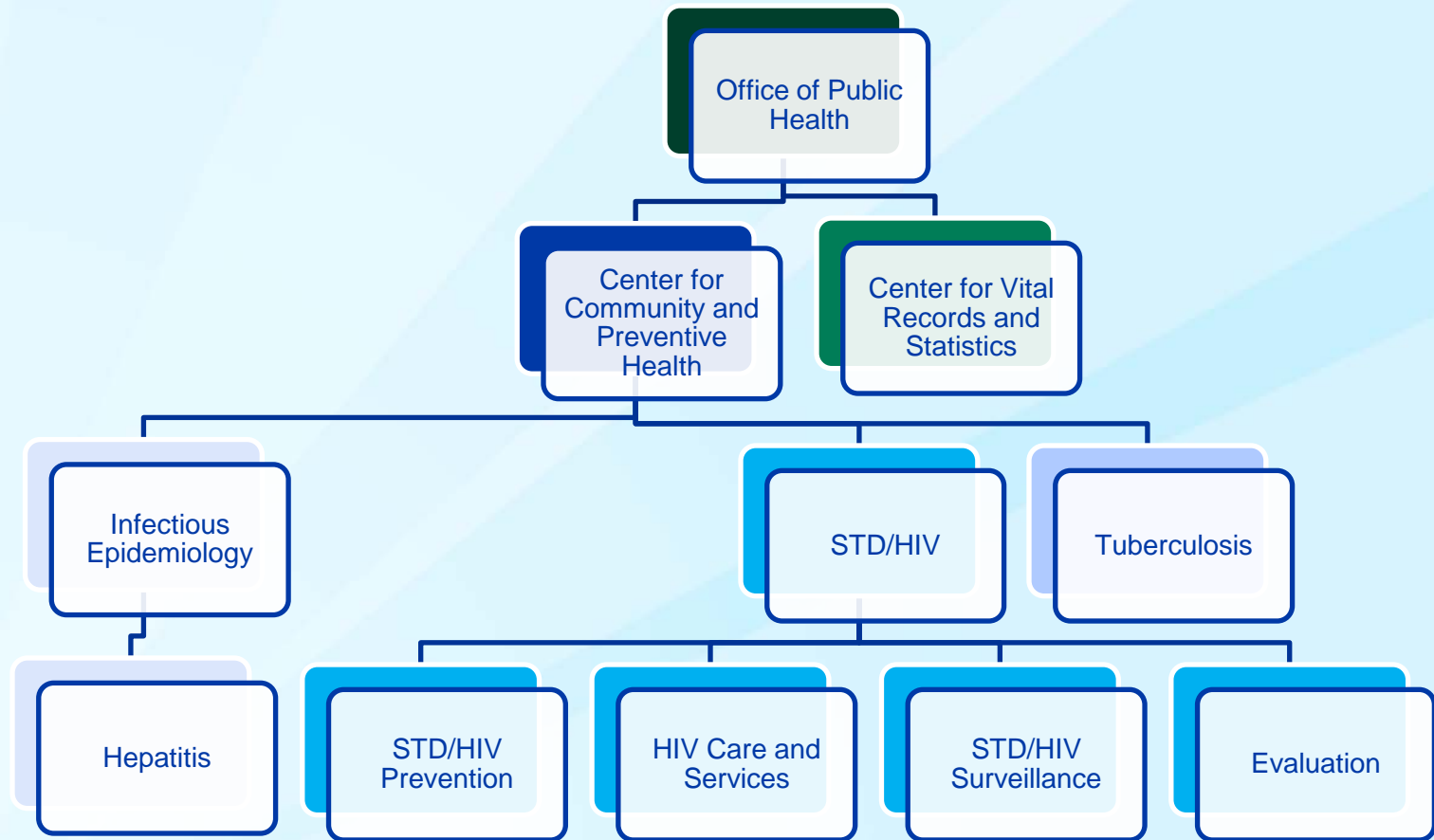
Internal and External Data Sharing for Prevention and Care in Louisiana: an Integrated Health Department's Experience

Debbie Wendell, PhD, MPH
Data Management/Analysis Unit Manager
STD/HIV Program, Office of Public Health
Louisiana Department of Health and Hospitals

Overview

- ❑ **Organization of Louisiana's health department**
- ❑ **Data sharing guiding principles**
- ❑ **Sharing HIV surveillance data internally**
 - with STD for partner services
 - with HIV prevention
 - With HIV Ryan White services
- ❑ **External sharing**
- ❑ **Successes and challenges**

Louisiana Office of Public Health



Data Sharing Guiding Principles

❑ Follow HIPAA basics:

- “A covered entity must make reasonable efforts to use, disclose, and request only the **minimum amount of protected health information** needed to accomplish the intended purpose of the use, disclosure or request.”
- “A covered entity must develop and implement policies and procedures that **restrict access and uses of protected health information** based on the specific roles of the members of their workforce.”

Before Sharing Data....

❑ Ask these questions:

- What is the purpose of sharing the data?
- Do both programs have an adequate data confidentiality and security policy?
- How will the data be securely shared?
- Who will have access to the data?
- Where and how will the data be stored and what will happen to the data after they are linked/shared?
- Do the benefits of data sharing outweigh any potential risks?
- Is a formal data sharing agreement necessary?

Before Sharing Data....

- ❑ **Refer to *CDC's Data Security and Confidentiality Guidelines for HIV, Viral Hepatitis, Sexually Transmitted Disease, and Tuberculosis Programs***
 - Data Sharing Plans (page 7) – list of elements to be included in a written data sharing plan
 - Section 3.0 Data Sharing and Release (page 20) – detailed set of 8 standards and guiding questions

Sharing HIV Surveillance Data Internally: with STD for Partner Services

- ❑ Since 1994, HIV surveillance shared new HIV diagnoses with STD for partner services**
 - STD shared updated risk, address, diagnosis, death info with surveillance
- ❑ No formal data sharing agreement**
 - had a common Medical Director who was the Overall Responsible Party (ORP)
- ❑ DIS have not had access to HIV surveillance data (eHARS); data downloaded from eHARS to the partner services database; DIS receive line lists of clients for follow-up**

Sharing HIV Surveillance Data Internally: with STD for Partner Services

- ❑ In 2010, HIV/STD programs combined and a confidentiality/security policy was created to cover both programs**

- ❑ In August 2013, PRISM will be used for both HIV and STD partner services**
 - STD and HIV cases will have a common patient profile
 - DIS will have immediate access to all new HIV diagnoses
 - Co-morbidity analyses in real time
 - Access to PRISM is limited and role-based

Sharing HIV Surveillance Data Internally with HIV Prevention

- ❑ No formal data sharing agreement; under the same Administrative Director who served as the ORP**

- ❑ Data shared with Prevention to:**
 - determine if a new HIV positive person has been previously diagnosed
 - determine if persons have been linked to HIV medical care (using first CD4/VL date)
 - follow up on persons who are out of care or have high viral loads as part of the CAPUS project

Sharing HIV Surveillance Data Internally with HIV Services

- ❑ No formal data sharing agreement ; under the same Administrative Director who served as the ORP**
- ❑ Data shared with Services to:**
 - confirm that Ryan White clients are HIV positive
 - obtain data on most recent CD4/VL for the ADAP Data Report
- ❑ Updated risk, address, SSN provided to surveillance**
- ❑ Future: labs in CAREWare to assist with medical case management**

Sharing HIV Surveillance Data Externally

Louisiana Public Health Information Exchange

- ❑ LaPHIE: Bi-directional exchange of public health information between LSU and OPH**
- ❑ Uses HIV surveillance data to alert LSU clinicians that a patient with HIV may be unaware of their HIV status or out of care; uses TB and syphilis data to alert clinicians that patients have not been appropriately treated**
- ❑ Formal data sharing agreement - went through extensive legal review**
- ❑ Significant input from ethicists and medical providers prior to implementation and ongoing input from the community advisory group**

Sharing HIV Surveillance Data Externally

Louisiana Public Health Information Exchange

- ❑ Share the minimum amount of information necessary**
 - LSU sends demographic information when a patient registers
 - OPH sends a standard, disease-specific electronic message to the LSU EMR system; no PHI is sent
- ❑ Only limited LSU/OPH surveillance staff have access to LaPHIE data**
- ❑ LaPHIE database stored on a separate server behind 2 OPH firewalls**

Sharing HIV Surveillance Data Externally

LaCAN (Louisiana CAREWare Access Network)

- ❑ **Centralized data management system in CAREWare for Ryan White Parts A, B, and C**
 - State health department, city health departments, and directly-funded community-based organizations
- ❑ **Formal data sharing agreement modeled after the LaPHIE agreement**
 - HIPAA requirements
 - Permissible use of PHI
 - Ownership of patient records
 - Protection of information
 - Creation and maintenance of the shared data system
 - Training
 - Definitions

LaCAN Data Sharing Agreement

AFFILIATION AGREEMENT
BETWEEN:

LOUISIANA CAREWARE ACCESS NETWORK PARTNERS

AND

LOUISIANA DEPARTMENT OF HEALTH AND HOSPITALS
OFFICE OF PUBLIC HEALTH
STD/HIV PROGRAM

The Louisiana CAREWare Access Network (“LaCAN”) is a collaborative effort between five Ryan White grantees in Louisiana to improve the information technology capacity to collect and report client-level data to the HIV/AIDS Bureau, Health Resources and Services Administration (HRSA), HHS. This Affiliation Agreement between the “LaCAN Partners” includes

- City of New Orleans Office of Health Policy and AIDS Funding,
- City of Baton Rouge Division of Human Development and Services,
- NO/AIDS Task Force, and
- Louisiana Department of Health and Hospitals, Office of Public Health, HIV/STD Program (“DHH-OPH STD/HIV Program”)

And represents that:

WHEREAS, LaCAN Partners are subject to the provisions of Public Law 111-87 (Ryan White HIV/AIDS Treatment Extension Act of 2009), which is Federal legislation that addresses the unmet health needs of persons living with HIV disease by funding primary healthcare and support services that enhance access to and retention in care;

WHEREAS, the mission of the DHH-OPH STD/HIV Program is to educate citizens regarding disease prevention, monitor disease trends and to offer and facilitate access to care through referral and support for medical care and social services; and

Challenges

- ❑ **Unable to establish a data sharing agreement with the Medicaid program**
- ❑ **Privatization of the LSU public hospital system**
 - Need for new data sharing agreements with 8-10 private hospitals; limited understanding of the importance of data sharing for public health purposes
- ❑ **Need to avoid “creep in project scope”**
 - Written data release plan; establish Executive Committee for ongoing review of data sharing and project evaluation; ongoing staff training
- ❑ **“We heard you shared your data with LSU, can you share your data with us too?”**

Successes

- ❑ **Established data sharing agreement templates and procedures that can be easily adapted**
- ❑ **Co-morbidity analyses**
 - HIV, syphilis, gonorrhea, Chlamydia, tuberculosis, hepatitis
- ❑ **More integrated prevention and care services**
- ❑ **Enhanced data security and confidentiality standards throughout OPH**

Contact Information

Debbie Wendell

Louisiana STD/HIV Program

debbie.wendell@la.gov

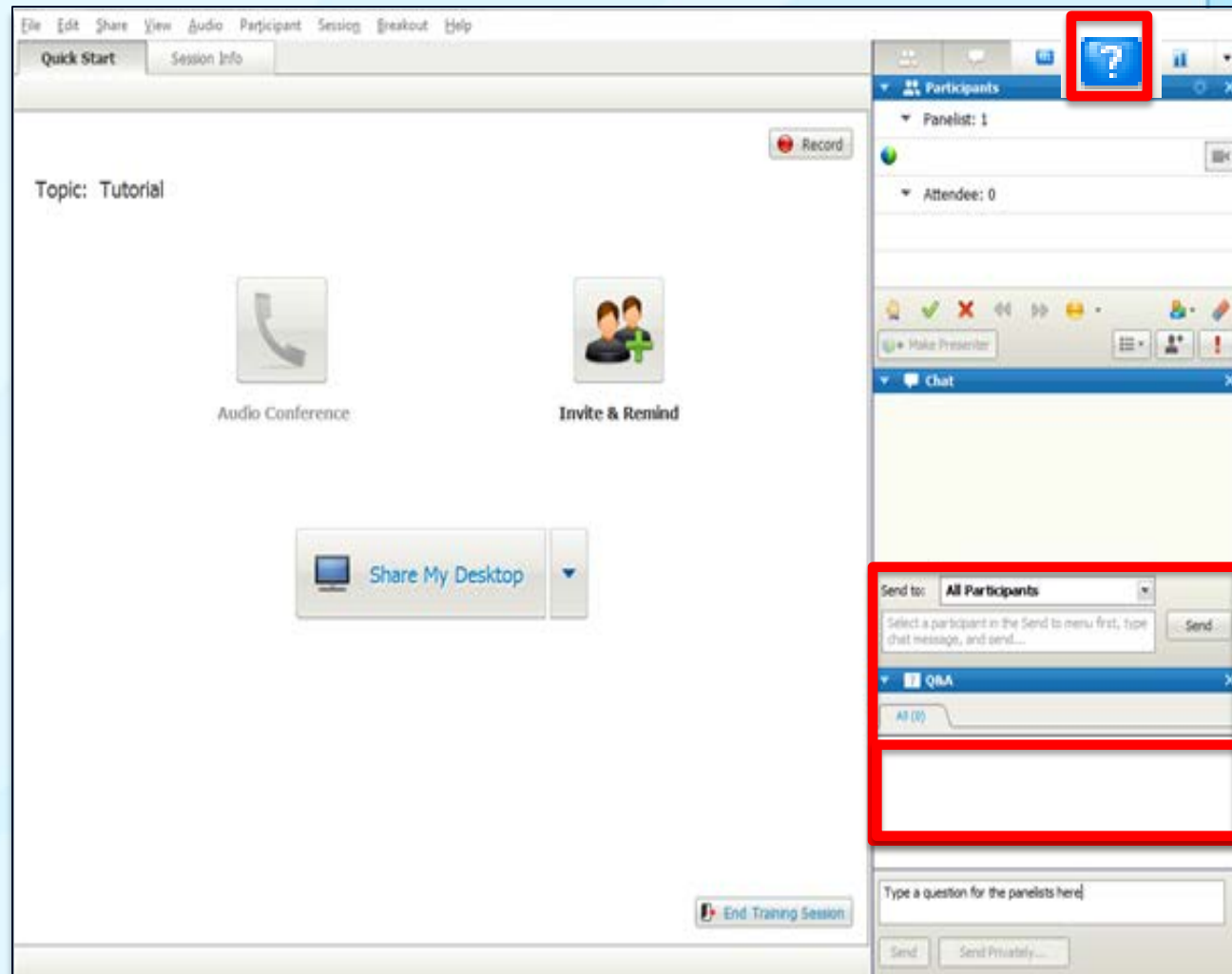
504-568-7474

Webinar Agenda

- Moderator: Vincent Fears, Program Consultant/Project Officer, Division of TB Elimination
- Introduction and Welcome: Gustavo Aquino, Associate Director for Program Integration, NCHHSTP
- Mark Stenger, Surveillance and Special Studies Team, Surveillance & Data Management Branch, DSTDP, NCHHSTP
- Ann Drobnik, PCSI Analyst & Jennifer Fuld, PCSI Coordinator, New York City Department of Health & Mental Hygiene
- Debbie Wendell, Manager of Data Management/Analysis Unit, STD/HIV Program, Louisiana Department of Health and Hospitals
- **Questions and Discussion: presenters and participants**

To Ask a Question

- Click on the blue question mark tab on the top right panel of your screen
- This will open the Q&A box on the bottom right panel on your screen
- Type a question
- Send questions to All Panelists





Thank you for your participation!

- Please complete the webinar evaluation:
<https://www.research.net/s/SCwebinar4>
- The webinar recording & slides will be available CSTE's website in the webinar library: <http://www.cste.org/?page=WebinarLibrary>
- Final webinar:
 - **Monday, August 26th, 2013, 1:00 – 2:15 pm ET: Active Responsible Stewardship – From Training to Responding** (please note date change)
 - Please pre-register by August 25:
<https://csteevents.webex.com/csteevents/onstage/g.php?t=a&d=665004287>