

# Using HIV Surveillance Data to Prompt Clinical Action

## A Novel Electronic Information Exchange Linking “Lost” Patients with Clinical Care

Jessica Cole, MPH, on behalf of the  
Louisiana Public Health Information Exchange Partners

# Disclosures

- No financial arrangement or affiliation with a commercial interest to disclose
- No unlabeled/unapproved uses of drugs or products to be referenced

# Learning Objectives

1. By the end of this session participants will be able to describe a practical, working example of the use of public health data to improve linkage to care for persons with HIV.
2. By the end of the session participants will be able to discuss the operational considerations when utilizing surveillance data for clinical purposes.
3. By the end of the session participants will be able to outline the primary legal and ethical questions involved with sharing public health data.

# Introduction



A collaborative project of:



LSU HCSD



Funded in part by HRSA  
Grant #H97HA08476

# Outline

- Using HIV surveillance to support public health programs
- Overview of HIV, TB, STDs in Louisiana
- Development of LaPHIE
- Considerations in using surveillance data for public health action

# HRSA Model of Care

Not in Care



In Care

Unaware of HIV Status (not tested or never received results)	Know HIV Status (not referred to care or didn't keep referral)	May Be Receiving Other Medical Care But Not HIV Care	Entered HIV Primary Medical Care But Dropped Out (lost to follow-up)	In and Out of HIV Care or Infrequent User	Fully Engaged in HIV Primary Medical Care
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# Surveillance: What is it?

- *Public health surveillance is*

*“...the ongoing systematic collection, analysis, and interpretation of health data...*

*...essential to the planning, implementation, and evaluation of public health practice...*

*...closely integrated with the timely dissemination of these data to those responsible for prevention and control.”*

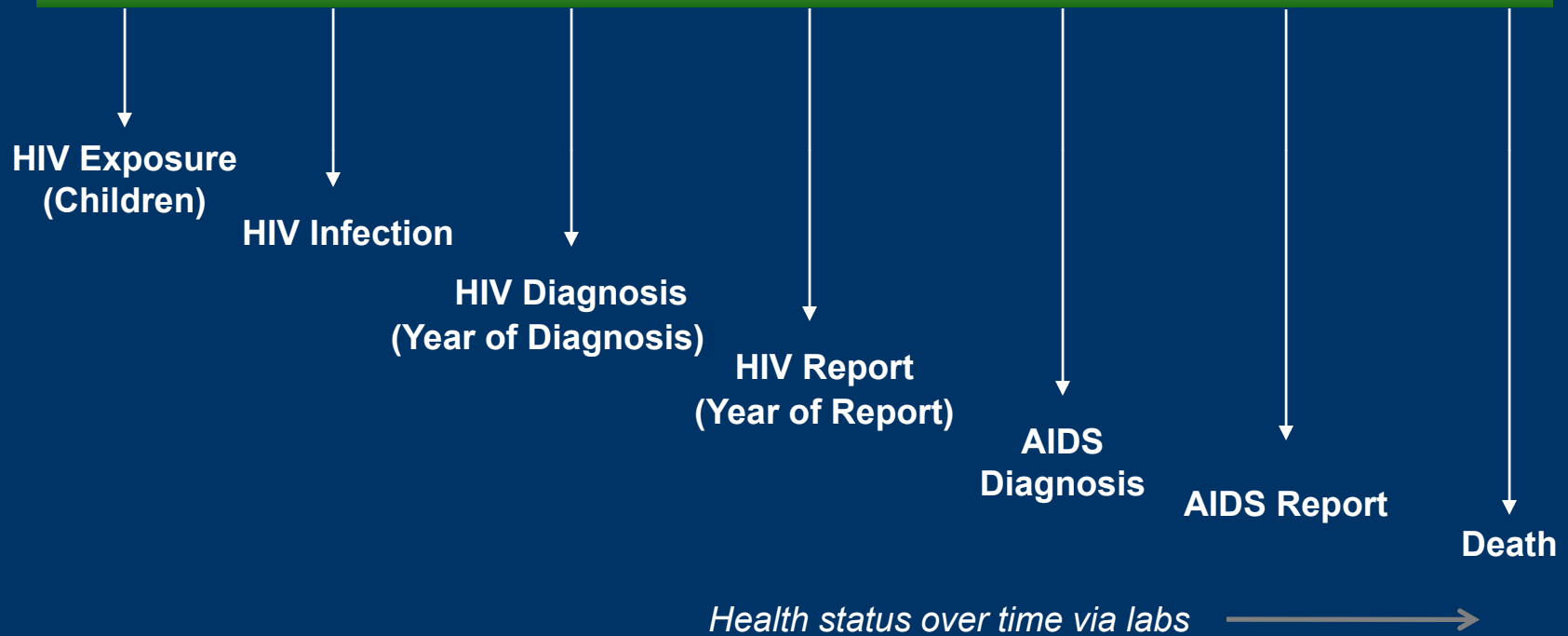
# The Roles of HIV Surveillance

- Tracking the progression of the epidemic
- Detecting changes in transmission patterns
- Targeting and planning prevention and care activities
- Informing allocation of resources
- Estimating unmet need



# The Roles of HIV Surveillance

## Sentinel Events



# Evolution of HIV Surveillance

- Historically, only aggregate data shared...
  - Due to lack of effective treatments (earlier in epidemic)
  - Stigma/discrimination
    - *other major public health conditions (e.g. TB, syphilis) have historically used individual-level data for intervention*

# Evolution of HIV Surveillance

- Now greater support for using surveillance data for individual-level interventions, but very strict confidentiality and security standards required by CDC remain for surveillance programs

→ *CDC moving towards a center-wide confidentiality and security standards in order to facilitate information exchange between programs*

*Local-level RW programs may be able to strengthen partnerships w/surveillance by adopting similar policies*

# HIV Surveillance and Individual-level Interventions

- Surveillance can identify cases that may benefit from direct follow-up and linkage to care
  - HIV Partner Services for newly diagnosed cases
  - Pregnant HIV+ women, exposed babies
  - Cases of high public health priority

# Towards Surveillance Supporting (Thoughtful) Action

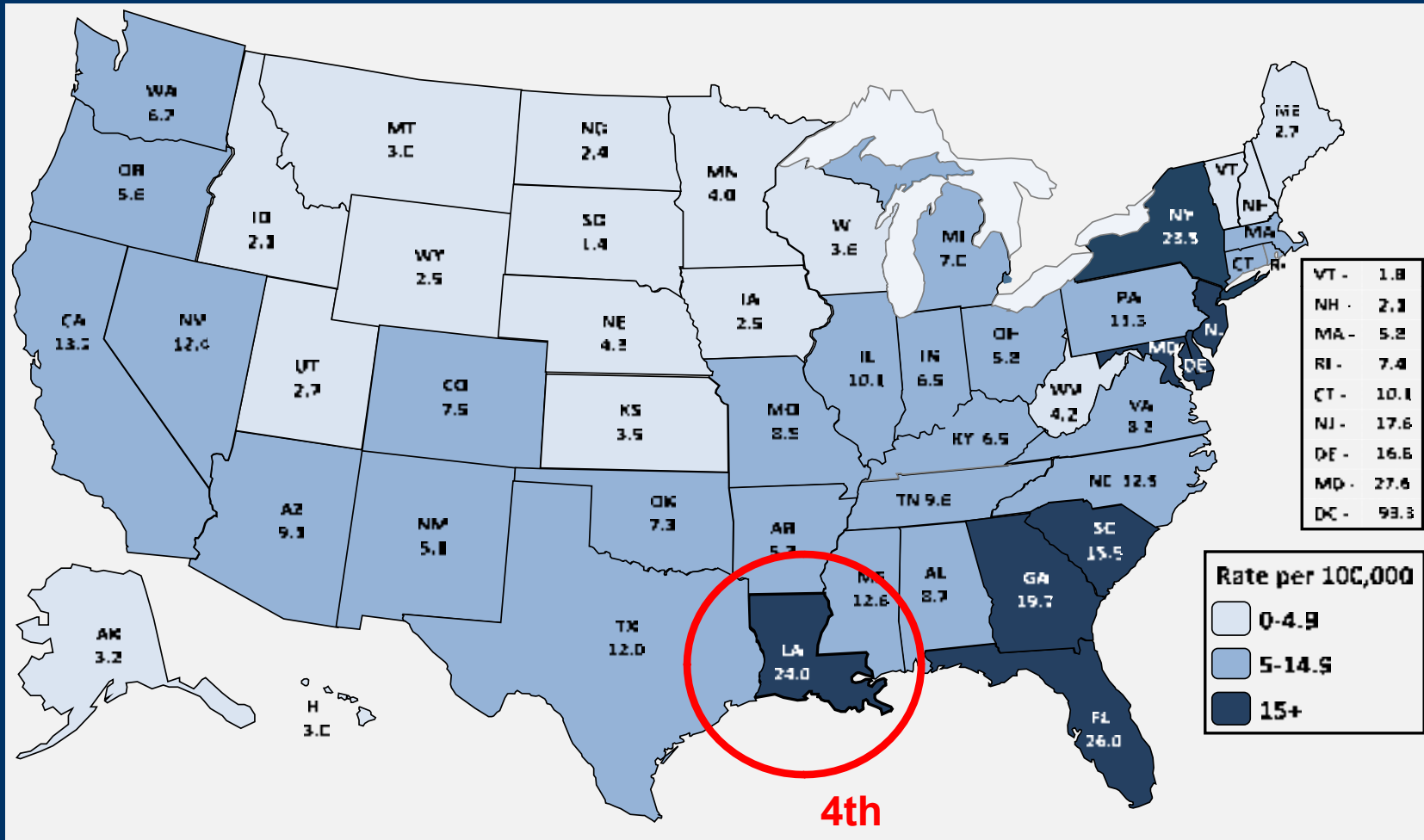
- Confidential name-based HIV reporting system (2009 all jurisdictions)
- Increasing emphasis on “linkage to care”
  - Failure over time to curb epidemic
  - Recognition that diagnosis and treatment contribute to prevention
  - HRSA priority
  - CDC priority

A problem...



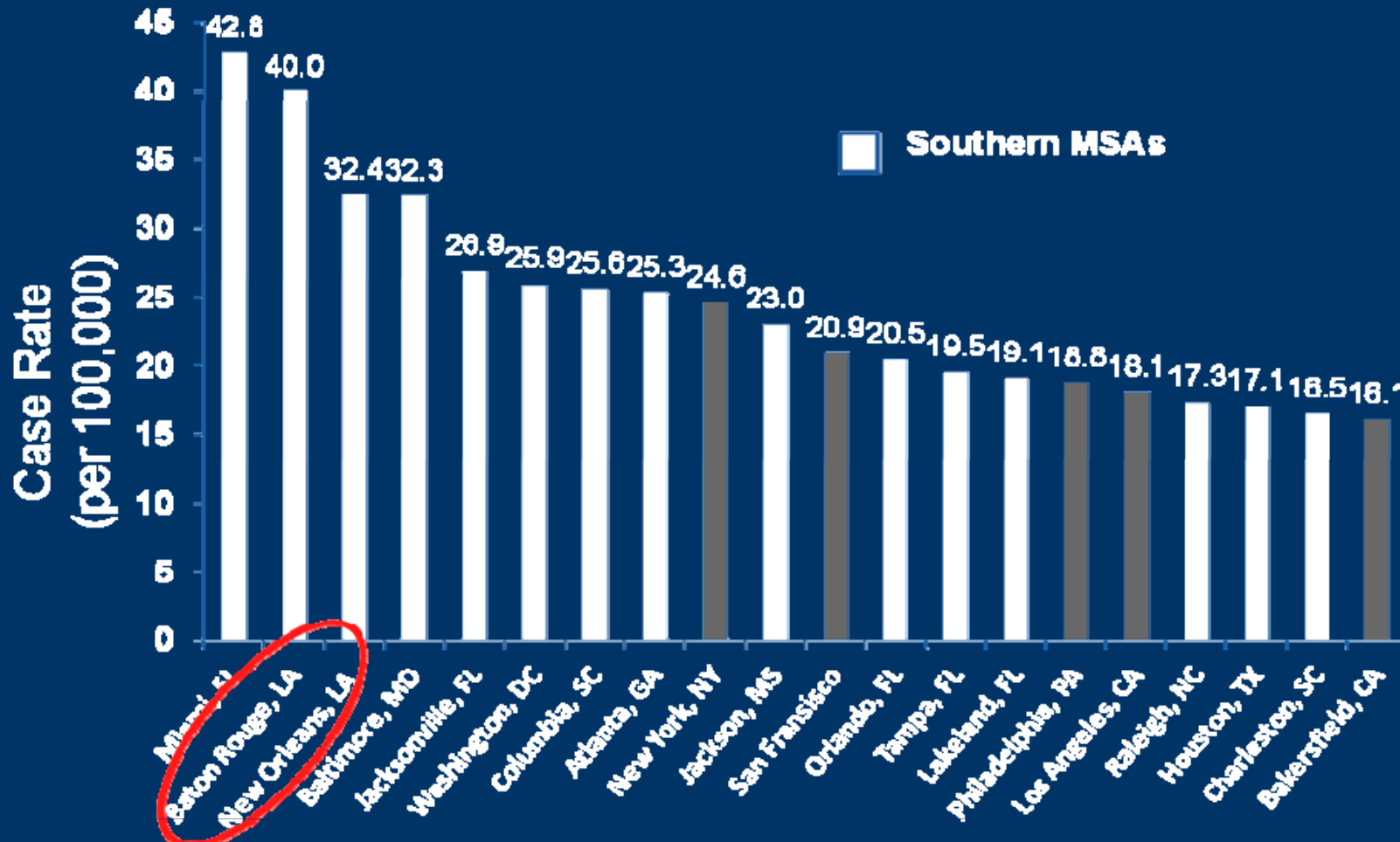
# HIV, TB, STDs in Louisiana

## 2008 AIDS Case Rates



# HIV, TB, STDs in Louisiana

## 2008 AIDS Case Rates: US Metropolitan Areas





# HIV, TB, STDs in Louisiana

- In 2008 there were over 16,000 persons living with HIV in Louisiana, with an estimated 41% “not in care”
- Nearly 30% of HIV-exposed infants born during 2005-2007 have an indeterminate HIV status
- In 2008 - 7<sup>th</sup> in number of TB cases nationwide
- In 2008— 1<sup>st</sup> in rates of primary, secondary, and congenital syphilis in the nation

An opportunity....



# Lost and Found

- Over 1000 persons whom OPH considered not in care for HIV, and 1500 persons with untreated syphilis, had attended visits for medical services in LSU HCSD facilities for other medical reasons (June 2007 match)
- The providers were unaware of their patient's infection status and need for treatment (various reasons)

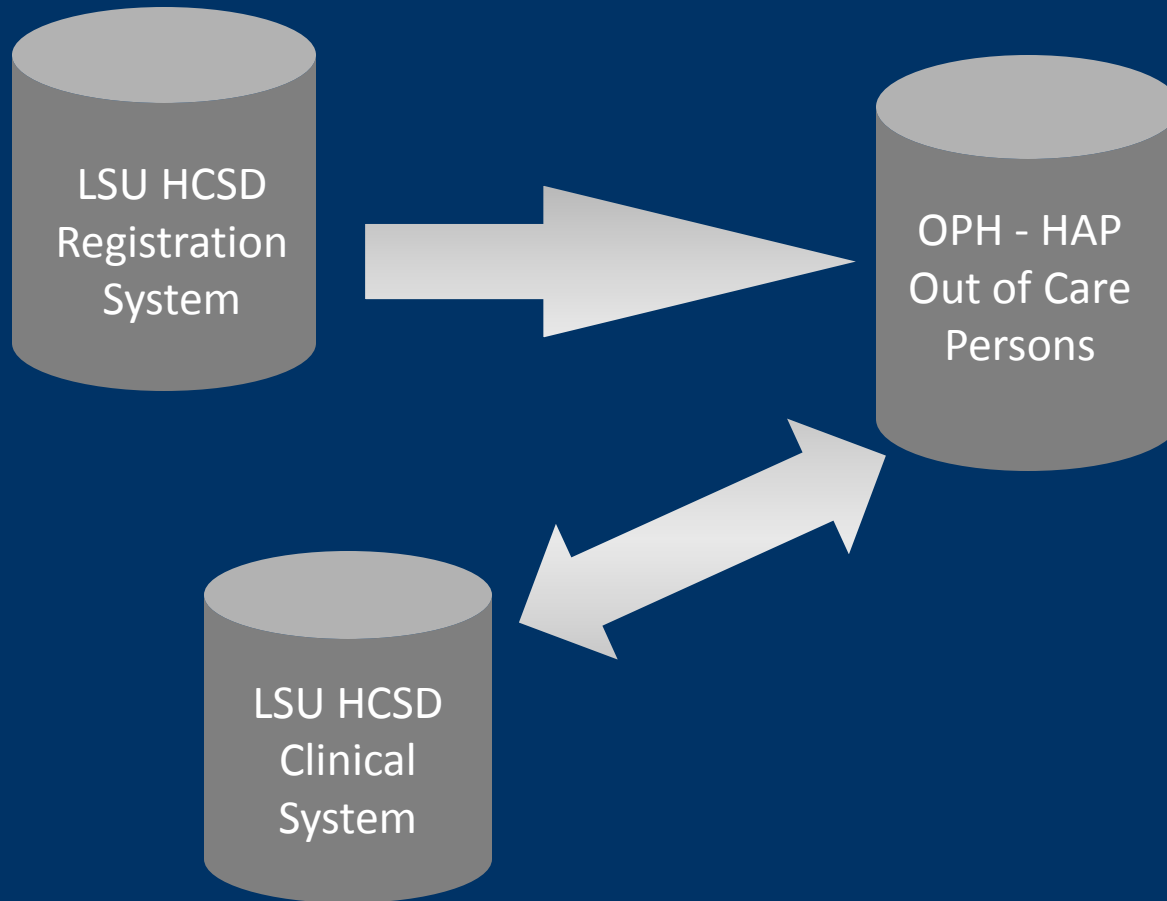
# The possibilities....

- LSU and OPH desired to leverage available information to offer intervention for infected individuals with the goal of improving health outcomes and reducing transmission
- LSU HCSD and OPH administrators embarked on a process to develop an information exchange partnership to reach people needing important public health follow-up

# Louisiana Public Health Information Exchange

- A carefully designed two-way electronic information exchange
- Uses OPH surveillance data to generate point of care messages for providers in the LSU HCSD (public hospital) system in Louisiana
- Targets patients with HIV, TB, syphilis who have fallen out of care, or never received test results, as well as perinatally HIV-exposed infants needing follow-up

# LaPHIE Data Exchange Process



Patient Name: Alvin ZzzTest

MRN: LP1100 (MCLNO)

Age: 35 Years

Gender: Male



### Patient Summary

Last Inpatient Admission: 12/19/2008

CBC	CHEM	ESR	LFT	LIPID	TSH	U/A	CXR
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QuickView - Mouse over buttons above for quick view of most recent results for these test types

Patient may require follow up for an infectious disease. [Click here to take action.](#)



### Preventive Health

#### Tobacco Use

	No record of question.	<a href="#">Add</a>
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Disease Mgt / Preventive Health Order Sheet

Health Screening	Last	Today	Units
<a href="#">Systolic BP</a>		<input type="text"/>	mmHg
<a href="#">Diastolic BP</a>		<input type="text"/>	mmHg
<a href="#">Height</a>		<input type="text"/>	<input type="radio"/> cm <input type="radio"/> in

#### Blood Pressure (mmHg)



Patient Name: Alvin ZzzTest      MRN: LP1100 (MCLNO)  
Age: 35 Years      Gender: Male

Welcome,  
Dr. Herwise  
Clinical Abstractor  
December 23, 2008

Back    Forward

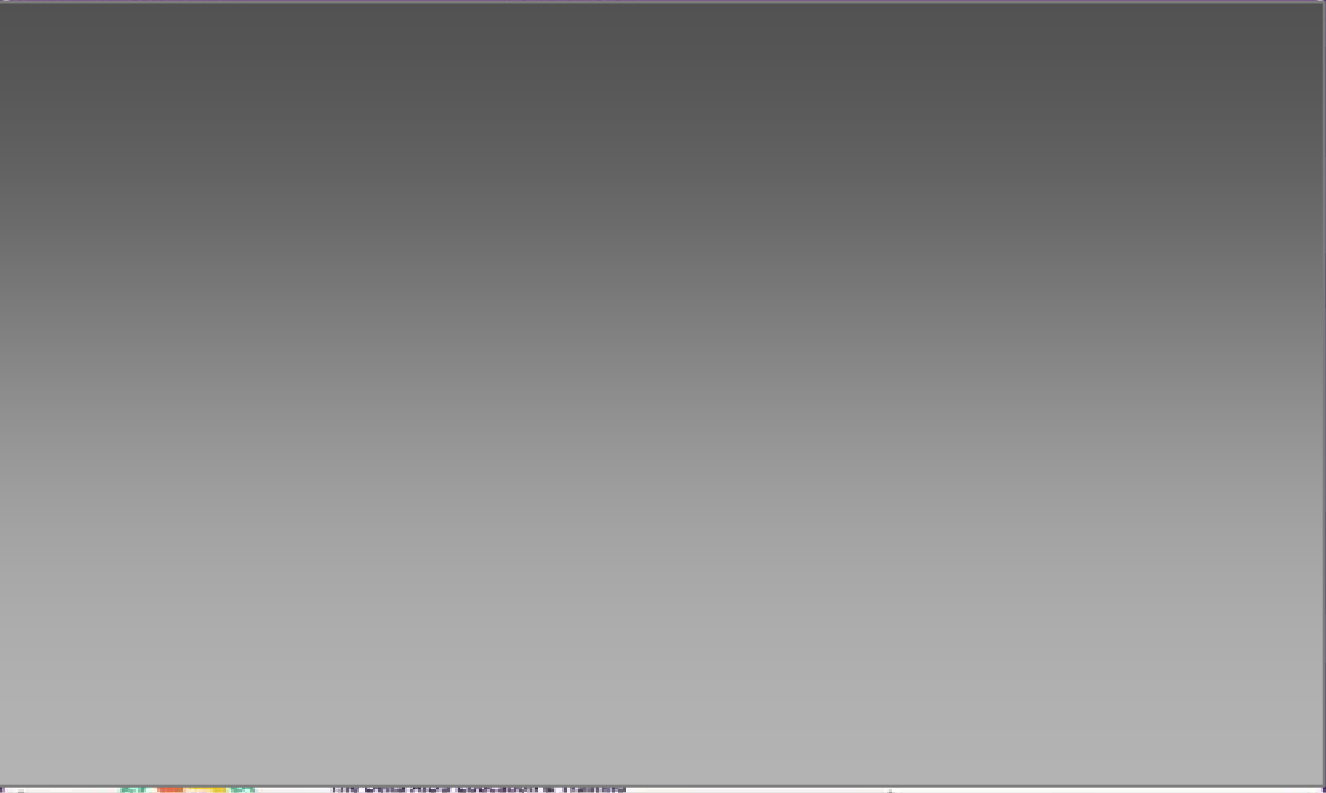
- Search
- Patient Summary
- Demographics
- Visit History
- Immunizations
- Laboratory
- Microbiology
- Pathology
- Radiology
- Pharmacy
- Print

Patient may require follow up

**Details: Intervention Needs for HIV**

The Louisiana Office of Public Health has received and confirmed test results that indicate that the patient has HIV infection and possibly has not been informed of the results.

Please proceed with the Recommended Actions for intervention.





# LaPHIE Partners

- Louisiana Office of Public Health

Provides surveillance and treatment/services functions for the State

- HIV/AIDS Program, STD Program, TB Program
- Also DHH legal staff and DHH IRB

- LSU Health Care Services Division (HCSD)

Large public hospital network (5<sup>th</sup> largest nationally), serving 6 of 9 public health regions in the state

- Medical Informatics
- Chief Medical Officer
- LSU IRB
- Clinics and Emergency Depts.



# LaPHIE Partners

- Louisiana Public Health Initiative (LPHI) as neutral convener to establish governance, facilitate the partnership, provide additional support
- George Washington University School of Public Health to assist with evaluation

# Development of LaPHIE

- Hypotheses
  - Patients who are “lost” to care or public health follow up will be linked to care and treatment through LaPHIE
  - The medical setting will be an appropriate and acceptable venue to electronically deliver public health notices to providers for their patients with important health conditions requiring follow-up

# Development of LaPHIE

- Proposed target populations
  - Persons that OPH considers “not in care” for the targeted conditions (no record of CD4/VL in 12 mo)
  - Individuals that appear to have not received tests results and to be unaware of infection status
  - Exposed infants in need of follow-up

*Does not replace other public health follow-up mechanisms (Partner Services, nurse outreach, etc.)*

# Development of LaPHIE

- Established partnership and governance
- Conducted consumer research
- Participated in an ethics review by national experts in biomedical ethics, public health ethics and AIDS privacy
- Requested a legal review of state legislation related to sharing of public health information
- Established an evaluation methodology
- Executed a data sharing agreement
- Developed and implemented the messaging system

# Essential Questions

- We have the information and the technical ability to inform clinicians about patients known to be in need of care – SHOULD WE?
- Would this be accepted by patients, providers, and the public?
- Do state laws and regulations allow the proposed information exchange?
- Is surveillance data reliable as a basis for clinical interventions?
- Can we adequately address security/privacy concerns?

# Input: “If we can, should we?”

- Ethics panel findings
  - “If you can, shouldn’t you?”
  - Keep true to your purpose (don’t extend uses of information), stay focused
  - Assure privacy and security of information
- Consumer research through focus groups supportive under certain conditions
- External community-based partner discussions

# Input: Legal

- Legal review – by DHH legal staff
  - State and federal laws
  - Produced written report of findings





# Input: Content of Message

- Created with input from clinicians and public health professionals
- Simple, intuitive design that informs users of recommended actions and allows for recording of actions taken



# Implementation!

- Technical development and roll out
- Training providers
- Now active in the seven hospitals of LSU HCSD system (started in EDs only, then expanded to clinics)

# Findings

- Preliminary Results
  - From February, 2009 to April, 2010 - 199 matches for patients out of care for HIV
  - Of these, 89 had returned to care as of May 2010

# ...And, of course, some challenges!

- Technical (capacity of hardware, sophistication of programming)
- Negotiating across systems and priorities
- Balance between desire for 100% reliable surveillance data, and desire to access as many out of care persons as possible

# Using Surveillance Data for Public Health Action—Considerations

- Helpful commentary by Lee and Gostin -  
“Ethical Collection, Storage, and Use of Public Health Data: A Proposal for a National Privacy Act.” JAMA, July 1, 2009

# Proposed Criteria as a Tool for Program Planning

- Legitimate public health purposes
  - Includes population-based or individual efforts to promote health, prevent disease
- Respect rights of individuals and communities
  - Seek input from those to be impacted
  - Minimize undue burden
- Privacy and security standards
  - Standards in place
  - Oversight and review

- Security measures
- Data use agreements
- Provide minimum information necessary
- Data quality
- Min. # of individuals and entities granted access
- Stewardship and trust
  - Question every step, adhere to agreements, avoid “creep” in scope or disclosures



# Acknowledgements

- LSU/TU clinicians
- UH Infection Control
- Delta Region AETC
- LSU SPH Medical Informatics & Telemedicine
- HCSD CEO, CMO, CIO/CMIO
- LIS Core Group
- HCSD Programming Support
- OPH HIV, STD and TB programs
- OPH nurses
- OPH epidemiologists
- OPH Disease Intervention Specialists
- OPH Medical Directors
- DHH Legal Counsel
- LPHI