

Louisiana's Special Projects of National Significance Systems

Linkages and Access to Care for Populations at High Risk of HIV

Infection Initiative

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Section 1 – Summary

The Louisiana Public Health Information Exchange (LaPHIE) is a secure, bi-directional electronic exchange of public health information between the Louisiana Department of Health and Hospital's Office of Public Health – STD/HIV Program (OPH-SHP), and originally, the Louisiana State University (LSU)'s public hospitals. LaPHIE was developed to identify persons who are HIV-positive and who have fallen out of care based on OPH-SHP's surveillance data and laboratory reporting. Persons who do not have recent laboratory results for viral load or CD4 count are considered to be out of care. If an out of care person is admitted (for inpatient or outpatient services) to a LaPHIE-participating medical center, a match is made with the OPH-SHP's out of care data set, and an alert appears in the patient's electronic medical record (EMR), alerting the clinician that the patient is out of care for HIV. The alert prompts the clinician with a series of check boxes to guide a discussion on the importance of HIV care and becoming re-established in care. LaPHIE also has the functionality to alert a clinician if a patient is out of care for syphilis and tuberculosis.

Target Audience

This manual provides guidance for clinical settings in Louisiana who are interested in implementing (or re-instating) LaPHIE, and for entities outside of Louisiana who are interested in implementing a public health information exchange (PHIE) like LaPHIE, which could include state or county health departments, private or public clinical settings, including inpatient and outpatient care, urgent care clinics, and federally qualified healthcare settings.

Rationale & Description of Need

In 2013, of the 18,199 persons living with HIV in Louisiana, 46% were not retained in care¹. Though Louisiana has outperformed the national average, where, in 2011 (latest data available), 60% of persons living with HIV/AIDS were not retained in care², it remains challenging to find HIV-positive persons who have fallen out of care and re-engage them with the health care system. Though a person may be out of care for their HIV infection, it is likely that they, on occasion, will engage with the healthcare system in other ways, for

¹ Radtke Friedrich, Kira. "Continuum of Care and HIV Testing Slide Deck." E-mail. 6 Feb. 2015.

² "Vital Signs: HIV Diagnosis, Care, and Treatment Among Persons Living with HIV - United States, 2011." *Morbidity and Mortality Weekly Report* 63.47 (2014): 1113-117. *Morbidity and Mortality Weekly Report (MMWR)*. Centers for Disease Control and Prevention. Web. 8 Apr. 2015. http://www.cdc.gov/mmwr/preview/mmwrhtml/mm6347a5.htm.

other ailments. LaPHIE is a process for locating persons out of care for HIV in a health care encounter that is conducive to acknowledging and sparking dialogue on the impact of HIV on overall health.

Section 2 – Historical Background of LaPHIE

The Idea for LaPHIE

In 2005, OPH-SHP and LSU providers met to discuss the issue of persons in need of follow-up for select infectious conditions, namely HIV, syphilis and tuberculosis. With the guidance of the Louisiana Public Health Institute, a collaborative process was agreed upon to determine the issues preventing routine follow-up for these populations and solutions for addressing these issues.

Developing LaPHIE

Guiding principles for the collaborative were outlined and subcommittees of representatives from OPH-SHP and LSU were organized. The groups met to discuss the processes for screening, reporting, referral, and treatment for three targeted conditions, HIV, syphilis, tuberculosis. From these work flow discussions emerged many missed opportunities to deliver seamless care. The committees identified the inability to share information across systems as a major contributor to these missed opportunities. A person deemed out of care, may be interfacing with the health care delivery system for other reasons and not disclosing the need for follow-up for HIV, syphilis or TB, or may not be aware of his/her infection. OPH-SHP would be looking for a person interacting with LSU, but LSU would not know that the person was deemed out of care. The subcommittees (later deemed work groups) began designing solutions to the information sharing barrier. Much work ensued on the potential solutions and what it would take to operationalize these approaches. The subcommittees further organized around content areas and expertise, and created workgroups to address executive leadership decision making, technical, clinical, and compliance and ethics issues.

Legislation Analysis

In the early stages of developing LaPHIE, it was evident that sharing public health information over a bi-directional electronic exchange had ethical and legal implications. To address these legal aspects, the Louisiana Department of Health and Hospital's Deputy General Counsel and staff conducted a legal analysis to understand both the federal and state regulations that may impact the electronic health information exchange proposed under LaPHIE. State, Federal and case law were reviewed, including the HIPAA Privacy

Rule, to better understand the Office of Public Health's mission, authority, and ability to disclose patient health information. This analysis determined that information exchange that constitutes LaPHIE was permissible. A copy of the LaPHIE legal position paper prepared by the Louisiana Department of Health and Hospitals is included in Appendix A.

Focus Groups

Input from affected populations was highly valued and considered an essential component of the development phase. A consumer study was conducted in advance of developing LaPHIE. The focus groups were conducted by the Louisiana Department of Health and Hospitals, the Louisiana Public Health Institute, and The National Alliance for Health Information Technology, and were funded by the Robert Wood Johnson Foundation. The primary objectives of the study were to:

- 1) outline consumer perceptions of current health record sharing practices,
- 2) describe the consumer opinion about the concept of electronic health records (EHR),
- 3) outline the consumer's perceived advantages and disadvantages of sharing sensitive health records.
- 4) assess the level of concern consumers had about sharing EHR, determine the consumer opinion on the level of involvement the Louisiana Office of Public has or should have,
- 5) describe the opinion consumers have about privacy protection, and identify consumer solutions.³

A total of sixteen focus groups were conducted, with eight held in New Orleans, and eight held in Shreveport (Northwest area of the state). The focus groups were stratified according to the following variables: insured/uninsured, diagnosis/matched but no diagnosis (control group), diagnostic category (chronic illness, STD/HIV, behavioral/substance abuse, developmental disabilities), ethnicity, and income. Appendix B further explains the study design. Respondents were asked their age, gender, ethnicity, annual household income, employment status, and whether they owned a computer and cell phone, or both.

The focus groups yielded important findings about health record privacy and confidentiality, and transitioning from a paper-based record system to an electronic system. Not surprisingly, control of content in the EHR and controlling access to the record was the most critical aspect for consumers. Somewhat of a surprise was that consumers assumed that such exchanges of information were already happening. A full copy of the

 $^{^{3}\,}$ Consumer Perspectives: Privacy and Sharing Data Louisiana Focus Groups: Report

report may be requested from the OPH-SHP, but some additional key findings are included below:

- Consumers believed having an electronic health records would directly result in better quality care.
- Although consumers expected Federal laws to protect the privacy of their information in an EHR, they did not want government, particularly [state] government, to be in charge of implementing and maintaining the records.
- Consumers believed the health benefits of EHRs far outweighed the potential privacy issues.
- Those who are insured assumed that they were entitled to an EHR; the uninsured did not.
- Those who have a sensitive diagnosis and have experienced negative consequences and/or stigma were particularly desirous of control over EHR content and access.
- The Louisiana Office of Public Health has consumer permission to act to protect individual and public health in the case of a Level I diagnosis (aggressive intervention and treatment) and, to some extent, in the case of a Level II diagnosis (inform and suggest only).
- It is highly unlikely that most consumers would easily understand the technology specifications of an HER.
- Consumers almost unanimously wanted the right to opt out of having an HER.

LaPHIE at LSU

In 2009, LaPHIE was implemented at the LSU hospital system by the Medical Informatics division. LaPHIE was designed for LSU's "homegrown" electronic medical record (EMR) called CLinical InQuiry (CLIQ). Ultimately, LaPHIE was implemented in eight of the ten LSU hospitals, seven of which fell under the administration of LSU-Health Care Services Division, and one under the administration of LSU-Shreveport. At these facilities, LaPHIE was active in the emergency room, inpatient and outpatient clinical encounters, meaning that if a patient was admitted into any of these settings, and a match was made with the out of care dataset at OPH-SHP, a LaPHIE alert would display in the patient's CLIQ EMR. On average, across the eight hospitals, 341 distinct (unduplicated) LaPHIE alerts were generated per year (for time period 2010-2013⁴), with the majority of alerts originating at the Interim LSU Hospital in New Orleans. The most common clinical settings for LaPHIE alerts were the emergency room and HIV clinics.

In the spring of 2013, the LSU hospital in Baton Rouge, Earl K. Long Hospital, was shuttered (and eventually demolished in 2015) and clinical management and administration was transferred to a private health care entity, the Franciscan Missionaries of Our Lady Health System's Our Lady of the Lake Regional Medical Center, also in Baton Rouge. It was further decided by Louisiana's state government that most, if not all of the LSU hospitals would enter into public-private partnerships, where either clinical management would transfer to

⁴ Luis Smith. Email. 31 Aug. 2015.

the private partner and services would remain at the former LSU site, or the LSU building would be closed and all clinical services would transfer to the partner's facility. However, in commencing with this transition and the resulting changes in EMR systems, some former LSU facilities have lost their LaPHIE functionality.

Special Projects of National Significance

In 2011, the OPH-SHP was awarded a Special Projects of National Significance (SPNS) Systems Linkages and Access to Care for Populations at High Risk of HIV Infection Initiative grant from the U.S. Department of Health and Human Services, Human Resources and Services Administration (HRSA), HIV/AIDS Bureau⁵. One of the proposed projects under the grant was to expand LaPHIE to the first private hospital in the state. Up to that time, only the state's public funded (LSU) hospitals had implemented LaPHIE. It was decided that Our Lady of the Lake (OLOL) Regional Medical Center's Emergency Department in Baton Rouge would be the location for this initial expansion into the private sector, with the original intent of providing another point of access into the HIV care system in the Baton Rouge community. The Baton Rouge community is an area of the state greatly affected by HIV, with over 4,770 people living with HIV/AIDS⁶. Additionally, after OLOL was selected as an expansion site for LaPHIE, it was learned that the LSU hospital in the Baton Rouge area, and where LaPHIE was in operation, would be closing, thereby leaving the Baton Rouge area without LaPHIE. Fortunately, OLOL assumed the administration of Earl K. Long's outpatient clinics, including the infectious disease clinic, after the main hospital was closed.

In August 2015, LaPHIE was successfully launched at OLOL's Emergency Room.

⁵ http://hab.hrsa.gov/abouthab/special/systemslinkages.html

⁶ 20th Annual National HIV Testing Day Louisiana and Baton Rouge Region. (2014, June 27). Retrieved August 28, 2015, from http://www.hiv411.org/files/File/2014 National HIV Testing Day Region 4.pdf

Section 3 - General Overview of LaPHIE

As depicted in Figure 1, LaPHIE facilitates the exchange of information from the hospital (or clinical setting) to the OPH-SHP and back. The exchange of information occurs through HL7 messaging⁷. Once a patient is registered into a participating hospital setting, the patient's identifiers (such as date of birth, social security) are transmitted to the OHP-SHP using an HL7 **ADT**, or an **Admit Discharge Transfer**, message. If the patient matches a record in the out of care dataset, and thus should receive a LaPHIE alert, an HL7 **PPR**, or **Patient Problem**, message is sent from the OPH-SHP back to the hospital. Once a LaPHIE user takes action on the LaPHIE alert (by responding to the checkboxes and saving/submitting their responses) and the patient is electronically discharged in the system, another HL7 message, a **PRR**, or Patient Problem Response, is sent back to the OPH-SHP to record the LaPHIE user's responses and to trigger removing the patient from the out of care dataset. Alternately, instead of PRR, the response can be passed to a webbased entry tool. The original ADT message is discarded if no match is made to a person in the out of care dataset, or when the response (either by way of a PRR or the web entry tool) is cataloged.

A screen shot of the LaPHIE alert is provided in Figure 2.

⁷ Health Level 7(HL7) is an international standard development organization that enables interoperability of healthcare information. HL7 creates standards for the exchange, management, and integration of electronic healthcare information.

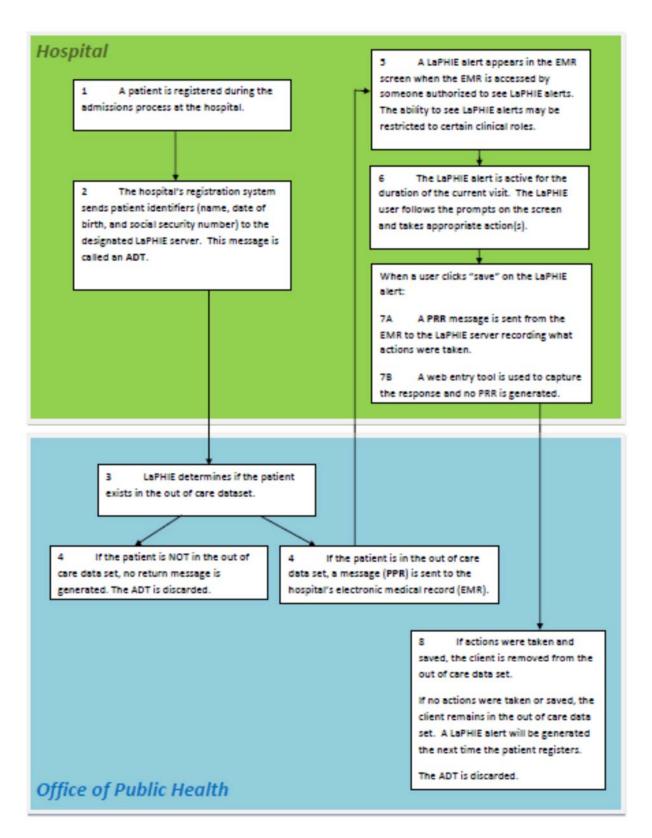


Figure 1 – LaPHIE process map

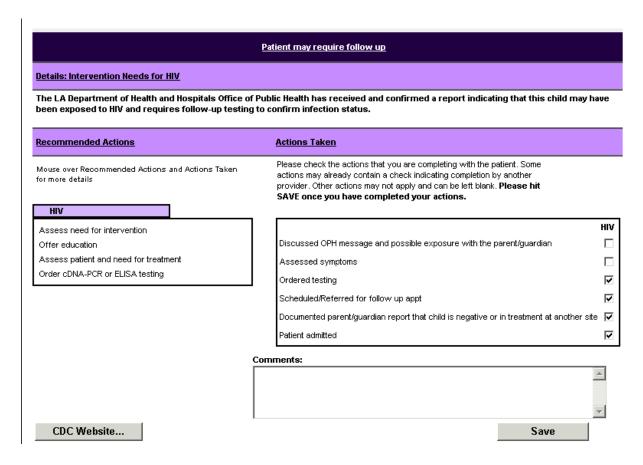


Figure 2 – Screen shot of LaPHIE alert

Section 4 - Expansion of LaPHIE within Louisiana

The expansion of LaPHIE to new settings within Louisiana is relatively straightforward, as much of the preparatory "leg work" has been completed as part of the efforts to launch LaPHIE, first in the LSU system and then under the SPNS Initiative. A site considering LaPHIE, however, should still anticipate that there will be a needed investment of time and resources to scale up the data exchange system. It is important that any new sites contemplating adopting LaPHIE be aware of the historical work the OPH-SHP and LSU undertook to develop LaPHIE, but also take the time to synthesize how LaPHIE will impact their site(s).

History of LaPHIE and Frequently Asked Questions

The history of the development of LaPHIE is addressed in Section 2 of this document. However, the most common questions/concerns about the development of LaPHIE are answered below.

- **Is LaPHIE legal?** Yes. The Louisiana Department of Health & Hospitals underwent a legislative analysis and determined that it is within the role and scope of the Office of Public Health to share client-specific surveillance data with a third party (hospital or clinic) for the purpose of communicable disease and public health safety.
- With which EMR is LaPHIE compatible? To date, OPH-SHP has been able to implement LaPHIE using LSU's CLIQ and the Cerner electronic health record systems. However, OPH-SHP is confident that LaPHIE can be programmed for any EMR that is meaningful use certified⁸.
- **Is a separate consent form needed?** Generally no. LaPHIE-related clinical interactions and discussions will be covered if a clinical setting's existing consent form authorizes its providers to treat a patient for medical needs identified in the course of delivering care but that are not necessarily related to the patient's original presenting symptoms. If a medical setting's current consent form does not encompass the aforementioned scenario, then a different consent form may need to be developed.

⁸ http://www.healthit.gov/providers-professionals/how-attain-meaningful-use

- How accurate are the LaPHIE hits? The out of care database is updated nightly and adds new people from the OPH surveillance records to the list based on a series of logic statements. The OPH is fortunate to have a very sophisticated up-to-date surveillance system, with most surveillance records being reported electronically directly from providers. There is almost no lag time for the point at which diagnoses and critical lab test are made available to providers and their entry into Louisiana's surveillance records. Therefore, LaPHIE matches are almost always accurate, although an occasional erroneous match can occur.
- How many LaPHIE hits can a hospital/clinical setting expect? Implementing LaPHIE will not cause your clinicians to be inundated with LaPHIE alerts. Because the HIV/AIDS epidemic is more concentrated in the New Orleans and Baton Rouge area, clinical sites in those regions could expect to receive more alerts than other areas of the state. However, historical data indicates that an average of 30-35 LaPHIE hits occurred per month among all active facilities.

Considerations for a Hospital or Clinic Site

The following are considerations for the hospital or clinic site when contemplating implementing LaPHIE. This is by no means a list of pre-requisites or "must haves" that must be met or achieved in order to implement LaPHIE. The OPH-SHP is very willing to consult with the hospital/clinical leadership to address any concerns or barriers.

1) Basic considerations

- **a.** Is LaPHIE in alignment with the institution's goals, mission, vision, and priorities?
- **b.** What type of service encounter or where in the institution would be appropriate for LaPHIE alerts? In patient only? Outpatient only? Only specific clinics?
- c. Is consent to treat a patient for their presenting condition (complaint) also a consent that would permit treatment of other conditions (such as HIV) on the basis of improving individual care?
- **d.** Does the hospital or clinic have multiple sites, and would LaPHIE be live at all, some, or only one site(s)?
- **e.** What is the composition of hospital or clinic leadership and how are decisions made?
- **f.** How are institution-wide trainings conducted? Would current-hires and new-hires be handled differently? Would annual refresher trainings be made available?
- **g.** Are there other large-scale projects, transitions, or changes anticipated in the near future?

2) Electronic Medical Record (EMR)

- **a.** Do you use a certified electronic medical record (EMR)? Which EMR brand do you use?
- **b.** Is the EMR the same for inpatient, outpatient, and any private physician practices on site?
- c. Are you planning any EMR upgrades or brand changes in the near future?

3) HIV Knowledge and Care

- **a.** What services are offered by your site with respect to HIV?
- **b.** Where do you refer patients to for HIV care? Is this place on-site, off-site (but still in your hospital network), or external?
 - i. If external, do you have a formal affiliation with this site?
 - ii. How is release of information handled for external institutions?
 - iii. How are out-of-network referrals handled?
 - iv. Would a particular house staff physician be responsible for out-of-network referrals?
- c. Is social work staff available for counseling HIV-positive patients, if necessary?

4) Clinician's Role

- **a.** Are clinicians familiar with responding to alerts in the EMR? How many other alerts are acted upon in the EMR?
- **b.** Who, of the clinical staff, would be most appropriate to see and act upon alerts? Only physicians? Only nurses?
- c. How comfortable are non-infectious disease clinicians discussing HIV and HIV care?

5) Considerations for Hospital or Clinical Setting IT Staff

- **a.** Do you use a certified electronic medical record (EMR)? Which EMR brand do you use?
- **a.** How easy or difficult is it to write new codes for the EMR?
- **b.** Can the EMR be programmed to show alerts?
- **c.** Can changes to EMR be made by in-house information technology (IT) and information system (IS) staff or must the EMR's parent company make changes?
- **d.** What rights and privileges do in-house IT/IS staff have with respect to EMR, patient registries, and test environments? Are these privileges limited, such that certain tasks can only be performed by a certain person?
- e. What other large-scale IT projects have already been scheduled?
- **f.** Are any EMR-related projects planned? Conversion to EMR? Switching to a different EMR? Consolidate EMRs into one?

g. How much time and effort would IT/IS staff have to devote to LaPHIE? Would that impact other projects?

Documentation and Reference Materials

- Non-Technical Guide (Appendix C)
- LaPHIE Data Entry Schema Documentation Version 2015.08.21, available at:
- LaPHIE Troubleshooting Guide (Appendix D)

Section 5 – Replicating a PHIE

There is no denying that locating HIV-positive clients who are lost to care and subsequently re-engaging them through an information exchange like LaPHIE advantageous. However, there are many things to consider before taking the plunge into creating a public health information exchange (PHIE) like LaPHIE. Outlined below are considerations that should be made by the health department, the hospital (or clinical setting) where alerts would be generated, and the IT/IS staff of the hospital/clinic setting.

NB: The following was written to reflect a PHIE with persons of interest being HIV-positive and out of care. It is possible for a system also to identify individuals out of care for other diseases or conditions. Many of the same considerations, albeit with minor modifications, will be relevant to PHIEs that focus on diseases other than HIV.

Considerations for a Health Department

1) Basic considerations

- **a.** Is this a role the health department is prepared to take on and in synch with the philosophy of the health department?
- **b.** What are the political or other dynamics between the health department and local hospitals or clinics? Will this help or hinder the process?
- **c.** Would leadership in the health department support a project like this? If not, what would the barriers be?
- **d.** Is this an issue the health department wants to focus resources on?
- **e.** Is the HIV unit of the health department a "heavy hitter" or a "wall flower"? Is the HIV unit a strong leader in affecting change, proposing policies, etc.?
- **f.** Who would "champion" this project and keep up the momentum of the project?

2) State or local laws

- **a.** Does the public health sanitary code (or similar) in your state/county require mandatory HIV reporting?
- **b.** Are there other state or local laws or statutes that would prohibit the health department from sharing HIV diagnoses with another, external agency or system (such as a hospital)?
- c. Does state statute (or similar other policies or regulations) permit the health department, and under what circumstances, to disclose individual patient information to a hospital or clinical setting without being required to obtain the patient's written authorization?

d. Does the role or mission of the state/county health department address endeavors such as a PHIE, or similar, for protecting the public's health?

3) Surveillance system and laboratory reporting: An essential component to a PHIE is the generation of an out of care data set based on surveillance records and laboratory data.

- **a.** Is your surveillance system centrally housed or do counties or regions of the state maintain their own?
- **b.** How up-to-date are your HIV testing records? Can you determine who was notified of their HIV status?
- **c.** Do you receive laboratory reports related to HIV (CD4, viral load)?
- **d.** Do you receive laboratory reports electronically, paper-based, or a combination of the two?
- **e.** How timely is your laboratory reporting? If there is a lag in reporting, is the delay consistent or does it fluctuate?
- f. Can you determine who is in care for HIV, and who is not?
- **g.** Can you determine who has tested positive for HIV and has not received their results?

4) Bi-directional exchange of data with an external party

- **a.** What steps are necessary for establishing affiliation agreements and/or data sharing agreements? How long does that process usually take?
- **b.** Would security protocols and/or confidentiality policies permit a PHIE?
- **c.** Does the state (or county) have experience with other kinds of real-time data sharing or exchange?
- **d.** Has something like a PHIE ever been attempted before in your state? What was the outcome and why?

5) IT

- **a.** Have resources, internal or external, been identified to provide any programming or technical support that will be required to accomplish an exchange such as this?
 - i. Does the health department have its own IT staff, specifically software developers/programmers? If not, could the appropriate staff be hired or contracted for? How long would that take to accomplish?
 - ii. Does the IT staff have available time for developing and coding a PHIE?
- iii. Does the health department have the financial resources for staff (potentially additional staff) and needed equipment?

Considerations for a Hospital or Clinic Setting

6) Basic considerations

- **a.** Is an information exchange in alignment with the institution's goals, mission, vision, and priorities?
- **b.** What type of service encounter or where in the institution would be appropriate for alerts? In patient only? Outpatient only? Only specific clinics?
- **c.** Is consent to treat a patient for their presenting condition (complaint) also a consent that would permit treatment of other conditions (such as HIV) on the basis of improving individual care?
- **d.** Is the hospital or clinic multiple sites, and would an information exchange be live at all, some, or only one site(s)?
- **e.** What is the composition of hospital or clinic leadership and how are decisions made?
- **f.** How are institution-wide trainings conducted? Would current-hires and new-hires be handled differently? Would annual refresher trainings be made available?
- g. Are there other large-scale projects, transitions, changes scheduled?
- **h.** Who would "champion" this project and keep up the momentum of the project?

7) Electronic Medical Record (EMR)

- a. Do you use a certified electronic medical record (EMR)?
- **b.** Is the EMR the same for emergency room, inpatient, outpatient, and any private physician offices on site?
- **c.** Are you planning any EMR upgrades or brand changes in the near future?

8) HIV Knowledge and Care

- a. What services are offered by your site with respect to HIV?
- **b.** Where do you refer patients to for HIV care? Is this place on-site, off-site (but still in your hospital network), or external?
 - i. If external, do you have a formal affiliation with this site?
 - ii. How is release of information handled for external institutions?
 - iii. How are out-of-network referrals handled?
 - iv. Would a particular house staff physician be responsible for out-of-network referrals?
- **c.** How comfortable are non-infectious disease clinicians discussing HIV and HIV care?
- d. Is social work staff available for counseling HIV-positive patients, if necessary?

9) Clinician's Role

- **a.** Are clinicians familiar with responding to alerts in the EMR? How many other alerts are acted upon in the EMR?
- b. What considerations are there for workflow and clinical decision making?
- **c.** Who, of the clinical staff, would be most appropriate to see and act upon alerts? Only physicians? Only nurses? Both? Others?

10) Considerations for Hospital or Clinical Setting IT Staff

- **a.** Do you use a certified electronic medical record (EMR)? How easy or difficult is it to write new codes for the EMR?
- **b.** Can the EMR be programmed to show alerts?
- **c.** Can changes to EMR be made by in-house IT/IS staff or must the EMR's parent company make changes?
- **d.** What rights and privileges do in-house IT/IS staff have with respect to EMR, patient registries, test environments? Are these privileges limited, such that certain tasks can only be performed by a certain person?
- **e.** What other large-scale IT projects are coming down the pike?
- **f.** Are any EMR-related projects planned? Conversion to EMR? Switching to a different EMR? Consolidate EMRs into one?
- **g.** How much time and effort would IT/IS staff have to devote to a PHIE? Would that impact other projects?

Identifying Work Teams

Building a PHIE requires a team approach. Input, decision making, and dedication is required from a variety of personnel, and though not every person has a role or function throughout the entire process, and certain people's level of participation may wax and wane throughout the project, commitment to the process is needed regardless. Figure 3 proposes key members for the three work groups or teams, the leadership team, the technical team, and the clinical team.

Leadership Team

Executive-level decision makers
Champions

Technical Team

Programmers
IT support staff from health
department, hospital
registration, EMR
Network administrator

Clinical Team

Frontline clinicians
Public health representation
"Champion"
Compliance & Ethics
Legal
Consumers

Figure 3 – Schematic of work group teams

Samples of Specific Roles & Functions Needed

Sometimes, it's not evident at the outset of project who you need to be part of the work team(s). To help facilitate team member selection and reduce potential delays, Table 1 identifies a subset of individuals likely to be essential to a PHIE implementation team.

Staff Roles at the Health Department

IT Security Expert - responsible for making adjustments to health department's security settings to allow HL7 messaging between health department and hospital, provides server and network support.

Database Developer – *Creates tables* and appropriate logic coding to compile and edit out of care dataset

Surveillance Manager – responsible for overseeing the completeness of surveillance records, such that the out of care dataset is accurate

HL7 Programmer – responsible for writing code and building applications to allow HL7 messaging between the health department and hospital

Quality Monitor – ensures that the correct patients receive alerts, that alerts are fired in a timely manner, and that the HL7 messages flow appropriately

Program Coordinator – responsible for ensuring that implementation and execution of PHIE project remains on track, facilitates efforts between the health department and the clinical site.

Staff Roles at the Hospital

HL7 Programmer - responsible for writing code and building applications to allow HL7 messaging between the health department and hospital

Visual Basic or Java Programmer – responsible for creating the alert screens that are embedded into the EMR.

EMR Programmer – responsible for programming EMR to allow an alert screen to appear and function in harmony with the EMR and other screens.

Executive Leadership – interfaces with the PHIE project leadership, may need to execute service contracts, may need to enter into data sharing agreements

Clinical staff – provides input on workflow and decision support

Legal support - may be needed to perform legislative analysis, execute data sharing agreements, ethics review.

Executive "champion" - advocates for the PHIE implementation at the executive level and supports the efforts made to launch the project.

Continued on next page →

Staff Roles at the Health Department

Business Coordinator – responsible for executing contracts for services, purchasing equipment, handling related administrative duties.

Legal Support – may be needed to perform legislative analysis, execute data sharing agreements, ethics review.

"Champion" - advocates for the PHIE implementation and supports the efforts made to launch the project.

Optional staff:

Network manager

Interface manager

SQL database manager

Staff Roles at the Hospital

Clinical "champion" –advocates for the PHIE implementation at the clinician's level and supports the efforts made to launch the project.

Quality Monitor – ensures that the PHIE is being responded to by clinicians in the manner prescribed and recommends (or provides) technical assistance to rectify gaps in alert responses.

Linkage to care coordinator/ referral coordinator – may be utilized to link PHIE patients back to care or initiate entry to care after an alert.

Optional staff:

Web-based Report Programmer

HTML Programmer

Section 6 – Step By Step Creation of a PHIE

Step 1: Defining Persons of Interest – The population of people who *might* be eligible for receiving a PHIE alert can be defined many ways and may include: gender, age, ethnicity, health condition(s), treatment history, care seeking behaviors.



In Louisiana, persons of interest are Louisiana residents who are HIV-positive and who have fallen out of care for their HIV disease management, irrespective of gender, age, or ethnicity.

Step 2: Establishing Criteria for Out of Care Dataset — Criteria will need to be set for defining who among the persons of interest will be eligible for a PHIE alert. The criteria you choose should be based on the accuracy of your surveillance data, nationally-recognized standards for care and treatment, and standards and prevailing conventions for engagement in medical services related to the disease.



In Louisiana, someone is considered out of care if they are newly diagnosed HIV-positive (diagnosed at least six months ago) and have not had a viral load or CD4 drawn in at least 6 months, or if they were previously in care and have not had a viral load or CD4 in at least 9 months. In Appendix E, the out of care criteria definitions are explained more thoroughly.

Step 3: Building an Out of Care Dataset - . A database will need to be created to periodically introduce new persons to the list of people who meet the out of care criteria and to remove persons who have had a PHIE alert generated and subsequently addressed.



In Louisiana, a host of surveillance systems (e.g., eHARS, PRISM) are searched nightly for persons of interest to add to the LaPHIE Out of Care dataset. The search is an automated activity.

Step 4: Design an HL7 Interface Between the Hospital and the Health Department

The interface has three primary functions:

- 1) To receive ADTs from the hospital and subsequently query the out of care database to see if the patient is a person of interest,
- 2) To generate a PPR message back to the hospital if there is a hit on the patient,
- 3) To receive PRR or web response from the hospital and update the OOC database.

Section 7 – Preparing to Launch a PHIE

Testing the PHIE

Developing the PHIE should incorporate significant time to address any issues that may arise in the test domain as well as in the production domain. **Do not leave this until the last minute**. You may encounter issues that need time-intensive resolutions. In general, the test process flows as follows:

- The health department will load test (fake) patients into the Out of Care Dataset (OOCD). Test patients have unlikely names and social security numbers that are outside the range or legitimate social security prefixes, so as to not match any real patient record which may be in the system.
- The hospital will register ("admit") test patients to a clinical encounter at wherever the PHIE is designed to function (such as the ER). An ADT message is sent to the health department.
- If a match is made in the out OOCD, a PPR is sent to the hospital.
- In the test patient's electronic medical record, the PHIE alert should display.
- Once action(s) is taken on the alert and saved, a PRR will be sent back to the health
 department and the patient is removed from the out of care data set. Alternately, if
 using web entry tool, the actions taken on the alert are saved into database on health
 department's server.

It is important to test the whole process from beginning to end (called point-to-point testing, or A to Z testing) for multiple patients to ensure that the PHIE works consistently correctly. Further, during testing it's important to mimic a clinical encounter-like transaction in the alert—clicking different boxes, typing different notes, opening and closing the alert so as to reference other parts of a patient's chart, having a second user access the alert and edit the response, etc. Also, any hyperlinks or text that appears as a hover over should be checked.

A guide for testing considerations for a PHIE is included in Appendix F.

Determine Referral to Care Process or Other Actions to Be Taken

Depending on the nature of the PHIE alert, a different form referral to care, treatment, etc. may be warranted. Regardless, every institution has a different process for referring and linking clients to care. One of the first items is to determine if services are provided inhouse/in-network, or if the services are out-of-network elsewhere in the community. If the service is in-house/in-network, the referral process should follow the already established process used for any patient. If the clinic is out-of-network, an affiliation agreement may need to be drawn up, which usually involves the legal departments of both institutions (or parent entities), and has the potential to be a lengthy process.

It is also important to consider how patient health information will be shared with an out-of-network provider without compromising HIPAA. Depending on the arrangement, a lead physician at the PHIE-using institution may need to be appointed to handle PHIE-related referrals to out-of-network clinics.

Identifying PHIE Users

It is necessary to determine who in the clinical setting will be able to see PHIE alerts and act upon them, who may need to be aware of PHIE hits, and who will respond to the alerts. It is recommended that two types of users be identified: super users and regular users.

Super users may serve as champions for the PHIE project, serve as trainers, and liaise with the health department about issues related to the PHIE matches or the system's users. Super users are your "go to" people in the clinical setting who can field questions about the PHIE and address basic questions. Depending on the IT or IS arrangement, super users may also receive an email alert when a PHIE hit is made (this can be in real time), as well as indicate in which clinical setting the hit occurred. The super users may also need to address problems related to responding to PHIE alerts with specific staff or departments.

Regular users are those who will see the PHIE alert pop up in the patient's EMR and who are responsible for taking action on the alert. It is the institution's decision on who will be a user. Some institutions restrict who is a user based on their clinical role (e.g., a physician might see the alert, but a physician assistant might not), or based on service/clinic location (e.g, the main hospital might see the alert, but the satellite clinic across town might not, or inpatient and outpatient clinics will see the alert, but the pharmacy won't). For institutions that use multiple EMR across different clinical settings, but might have clinical staff who see patients across different clinical settings, the alert will only pop for the user when they're using the EMR that the PHIE was built for.

Lists for super users and regular users will need to be assembled with enough time allotted for programmers to code the user permissions.

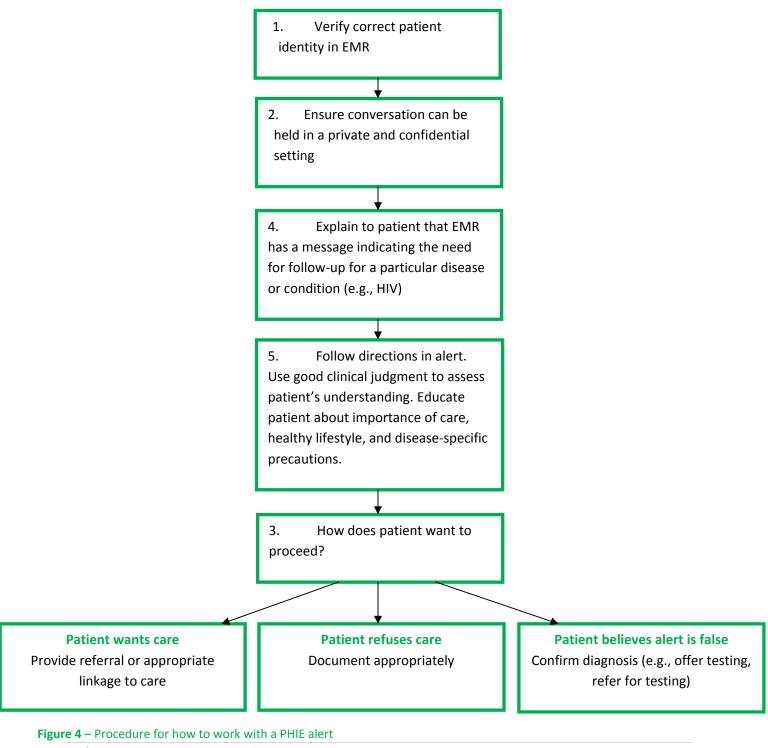
Educating PHIE Users

Providing education to those who will become PHIE users can be handled in a variety of different formats depending on normal practices in the health care setting and on how many staff will be trained. The bulk of the training concerns familiarity with the PHIE alert screens, how to respond to the alerts, how to find the alert screens in the EMR (should the user need to click to a different screen or look at something else in the chart and then return to the alert), and how to best refer or link the patient to care. Training is generally provided close to the date that the PHIE will go live. An annual refresher training is encouraged, but may not be necessary. The individual institution may opt for new providers and staff to receive training on the PHIE as part of their new-hire orientation. Presentation of the training materials can be as simple as a fact sheet or bulletin (Appendix G^9) or more didactic in nature, such as PowerPoint-based lecture training (Appendix H^{10}).

⁹ "Louisiana Office of Public Health HIV Alert." Franciscan Missionaries of Our Lady Health System, 2015. Print.

¹⁰ Herwehe, Jane. "LaPHIE Training Presentation and Self Test." LSU Health Care Services Division. 2009. Training.

Section 8 – Procedure for Working with a PHIE Alert



Section 9 – Monitoring PHIE Utilization

It is important to monitor both the IT and clinical aspects of the PHIE to ensure that the system is working as designed. Both the health department and the hospital site should designate a quality monitor.

Quality Monitoring for the Health Department

The health department's quality monitor should be concerned with the following:

- Validity of alerts determine whether patients who receive alerts from the PHIE are truly out of care, meaning the hit was valid, based upon confirmation from surveillance records and the out of care criteria defined by the health department.
- Timeliness of alerts determine whether the alerts are posting in real time or close to real time.
- Maintenance of the out of care dataset ensure that new patients are being identified as
 out of care based on the criteria and being populated into the out of care dataset. Also,
 determine whether patients who have receive a PHIE hit that has been responded to,
 are subsequently removed from the out of care dataset, and promptly, so as to not
 generate a repeat hit.
- Connectivity ensure that the interfaces are operational, and that the messaging to and from the health department is happening without errors or problems.

Quality Monitoring for the Hospital

The hospital site's quality monitor should be concerned with the following:

- Feedback from clinicians and patients about handling alerts and the clinician-patient interaction.
- Responsiveness determine whether alerts are being responded to or ignored, and whether certain PHIE users are repeatedly ignoring alerts.
- Whether additional training is needed to improve or clarify how to best respond to PHIE alerts and discuss re-engagement in HIV care with patients.

Reporting

Feedback from the health department to the hospital is especially important in the first few months of the PHIE being live. Naturally, both entities will be interested in knowing how the PHIE is working during that time period. The health department should be able to provide the hospital with aggregate reports on the number of unduplicated out of care patients receiving hits, where the alerts were being generated (if the PHIE is live in more than one clinical location), and what the response rate is on the alerts. Depending on hit volume, reporting to the hospital site can be more or less frequent after the initial start-up. Reports should be shared with the PHIE users, as they will be most interested to know the outcome of their clinical interaction addressing the alert.

Appendix A – DHH-OPH Position Paper on the Electronic Exchange of Public Health Information

DHH-OPH Position Paper on the Electronic Exchange of Public Health Information

I. Background

The Louisiana Public Health Information Exchange (LaPHIE) is a network of health care practitioners which includes the Louisiana State University Health Care Services Division (LSU HCSD), and the State of Louisiana, Department of Health and Hospitals (DHH) Office of Public Health (OPH) HIV/AIDS Program (HAP), the Sexually Transmitted Disease (STD) Program, and TB Program and the Louisiana Public Health Institute (LPHI). Through collaborative efforts, the partners have worked together to develop an electronic health information exchange to support the timely diagnosis and treatment for persons with HIV/AIDS, Tuberculosis (TB) and syphilis. (For detailed information regarding the background of LaPHIE, please see Appendix A) The system supports electronic condition reporting and a clinical messaging system to electronically reach persons unaware and/or untreated for these targeted conditions. Essentially, by exchanging messages related to lost or out of care patients among network providers, the system promotes the "no wrong door" concept so that any clinical "door" (LSU HCSD Emergency Department, Inpatient Unit or clinic) a patient enters should be the "right door" for follow up.

Using secure data exchange protocols, persons known to be lost to follow-up or out of care can be matched to LSU HCSD patient registration systems to identify patients in need of intervention. The clinical alert and message provides decision support to clinicians on a person's condition. For example, a patient may be accessing an emergency room for one reason (i.e. asthma), but may be in need of counseling or HIV-related testing or care from a previous diagnosis of which both provider and patient are unaware. By identifying the patient's condition with the assistance of OPH messages, a provider would be able to inform the patient of his/her illness, and educate and offer clinical treatment and access to ancillary services while the person is in the health care environment. In addition, the provider can make sure the treatment opportunity is correctly applied as they may have further information that will impact the patient's treatment. As a result, knowledge would be leveraged to reduce disparities in access and improve a patient's opportunities for treatment.

II. Analysis of Legislation

Early on, the LaPHIE partners recognized using public health information in a bidirectional exchange has ethical and legal implications as well as implications for future directions of the role of public health for leveraging electronic information resources to expand its reach to effectively intervene to protect individual and population health. To address these legal aspects, the partners engaged Louisiana Department of Health and Hospital's Deputy General Counsel and staff to understand both the federal and state regulations that may impact the electronic health information exchange proposed under LaPHIE.

State, Federal and case law were reviewed based on a series of specific legal questions posed by the partners and stakeholders in LaPHIE. The general results and conclusions of that

analysis are set forth in parts III and IV of this Position Paper below. Attachment A consists of the questions that were posed and the Deputy General Counsel's answers to those questions, with citations to supporting statutes and rules that apply particularly to one or more of the diseases of concern to LaPHIE (HIV/AIDS, TB and syphilis).

III. Results of Analysis

As a result of the legal analysis, LaPHIE network partners came to a clearer understanding of the Louisiana Department of Health and Hospitals Office of Public Health (OPH) authority as well as the relationship to its mission.

At the outset, it is important to understand that OPH has two distinct roles in Louisiana's health care system:

- As the state's public health authority, it performs what might be called
 "classic" public health functions which are distinctive to such an agency.
 Those functions are focused on the maintenance of the health of the state's
 population as a whole and the surveillance, prevention and control of disease
 in the population.¹
- Through its parish health units and other treatment facilities and programs, it
 provides medical services directly to individuals, with a focus on the
 prevention and treatment of disease in those individuals.

Significantly, these two roles -- public health authority and provider of medical treatment to individuals -- are not mutually exclusive. Instead, they frequently merge and overlap with each other and may become virtually indistinguishable, particularly in the operation of a system such as LaPHIE.

Even when the focus is on OPH's efforts as a public health agency to prevent
the spread of infectious disease, those efforts may entail, as a collateral
consequence, the provision of medical treatment to individuals who have
contracted the disease or are at risk of contracting it; in turn, that treatment
often will necessitate the disclosure of information on such individuals to

"The office of public health shall perform the functions of the state which relate to the general health of the people of the state, including but not limited to responsibility for the preparation and supervision of the Sanitary Code, local health units, . . . physical fitness, supplemental food programs for women, infants, and children, emergency medical services, and related functions affecting the public health. It shall also perform those functions of the state provided by law relating to environmental quality and pollution control which are related to the public health and which are specifically assigned to the department . . . " (Emphasis added)

State law sets forth OPH's mission as follows in R.S. 36:258(B):

other treatment providers, including LSU HCSD. OPH may have obtained that information either through its own treatment activities or through the mandatory reporting of information to it by other providers pursuant to the state's public health laws.

Conversely, even when the focus is on OPH's efforts as a direct treatment
provider to prevent or treat infectious disease in an individual, those efforts
may promote the "classic" public health goal of prevention and control of the
disease in the population at large.

Clearly, when OPH discloses information about individual patients to LSU HCSD, it is acting in furtherance of at least one or the other of these roles; indeed, a strong case probably could be made that it is acting in furtherance of both of them simultaneously.

The key legal question to be answered here is whether, and under what circumstances, OPH may disclose individual patient information to LSU HCSD without being required to obtain the patient's written authorization. The general answer to this question is found in the two major laws which govern the privacy and confidentiality of individual patient/client information possessed by OPH: (1) R.S. 46:56, Louisiana's statute governing the privacy of individual client information possessed by OPH (as well as other agencies of DHH); and (2) the federal HIPAA Privacy Rule (45 C.F.R. Parts 160, 164).

A. R.S. 46:56

R.S. 46:56 provides for the confidentiality of individual client records of DHH (which includes OPH), as well as those of certain other state agencies which do not concern us here. Subsection (A) generally prohibits the disclosure or use of such records or of the information contained therein "for any purpose not directly connected with the administration of the programs of the department." Subsection (D) prohibits the disclosure of such information "to an outside source not directly connected with the administration of the programs of the department" without a written authorization by the client.

A disclosure of individual patient/client information made by OPH to LSU HCSD in the course of the operations of LaPHIE would be "directly connected with the administration of the programs of" OPH and thus would be permissible under this statute, regardless of whether OPH makes the disclosure in furtherance of its "classic" public health role, its direct treatment provider role, or both.

B. HIPAA Privacy Rule

DHH, which includes OPH, is a "covered entity" which is subject to the restrictions of the HIPAA Privacy Rule. Generally, the Rule prohibits the disclosure of "protected health information" by a covered entity without the patient's written authorization, unless one of the Rule's numerous exceptions is applicable. Three of those exceptions appear to be applicable here:

- 1. To the extent that OPH discloses information to LSU HCSD in furtherance of its "classic" public health role, it generally will be acting pursuant to the mandates of the state's public health laws (many of which are referenced in Attachment A). Such actions would fall within the HIPAA Privacy Rule's "required by law" exception, whereby "[a] covered entity may use or disclose protected health information to the extent that such use or disclosure is required by law and the use or disclosure complies with and is limited to the relevant requirements of such law."²
- 2. To the extent that OPH discloses information to LSU HCSD in furtherance of the treatment of the patient by either of them, the disclosure falls under the HIPAA Privacy Rule's "TPO" ("treatment, payment and operations") provisions, whereby a covered entity (OPH) may disclose information to another covered entity or provider (LSU HCSD) for the treatment activities of either entity. For example, if OPH has cause to believe that a person who enters the LSU hospital system is unaware and not receiving treatment for a communicable condition such as HIV/AIDS, TB or syphilis, OPH is within its authority to share that information with the medical provider with the intention of facilitating treatment.
- 3. In the operation of LaPHIE, LSU HCSD acts to some extent as an agent or extension of OPH in its public health role, and it could be considered to be acting as something of a public health authority itself. Unlike private hospitals, LSU HCSD is given certain duties regarding the general health of Louisiana citizens under state law. Those duties include:
 - To represent the public interest in providing hospital and medical care in the region served.
 - To perform comprehensive health planning in cooperation with other public or private institutions and agencies engaged in providing hospital and other health services to residents of the state.
 - To provide for coordination in the delivery of services provided by LSU with those services provided by DHH, local health departments, federally qualified health centers, and other providers.⁴

State law also provides that the Secretary of DHH and the Chancellor of LSU Health Sciences Center "shall provide for coordination in the delivery of services provided by [LSU Health

^{2 45} C.F.R. §164.512(a)(1).

^{3 45} C.F.R. §164.506(c)(1), (2).

⁴ R.S. 17:1519.5(B)(1), (6), (7).

Sciences Center] with those services provided by [DHH], local health departments, and federally qualified health centers, including but not limited to . . . public health services . . . "5

The HIPAA Privacy Rule recognizes the important public health role that public hospitals can play, as is shown by the fact that the preamble to the Rule specifically refers to "a public hospital conducting infectious disease surveillance in its role as an arm of the public health department" as being an example of "a covered entity that is acting as a public health authority".

All this is relevant because it brings LaPHIE disclosures of protected health information within the "public health" exception to the HIPAA Privacy Rule, whereby "[a] covered entity may disclose protected health information for the public health activities and purposes described in this paragraph to . . . [a] public health authority that is authorized by law to collect or receive such information for the purpose of preventing or controlling disease, injury, or disability, including, but not limited to, the reporting of disease, injury, vital events such as birth or death, and the conduct of public health surveillance, public health investigations, and public health interventions . . . "

IV. Summary and Conclusion

Privacy and confidentiality are paramount in the world of medical records. They are particularly important when it comes to diagnoses like HIV/AIDS because of the increased likelihood of social stigma and/or isolation. However, privacy should not override legitimate public health objectives or the health of the individual. It is clear from the statutes that a person's infection status may be disclosed in certain circumstances. The LaPHIE data-sharing in question is undoubtedly geared toward the improvement of individual patients' health and that of the public at large. It is also significant that the data will be shared only within the medical community, where the social isolation and stigma that is feared is much less likely to occur. Results of the LaPHIE legal analyses support the mission and obligation of OPH, to protect individual and population health as well as respect individual privacy by assuring that all information shared is accurate and handled in the most confidential manner and only shared with the authorized treating entity.

As is explained in part III above, OPH's sharing of individual patient information with LSU HCSD within the LaPHIE system will always be carried out in fulfillment of one or the other, and most likely both, of OPH's legitimate roles: (1) as the state's public health authority, and (2) as a provider of individual medical treatment. To express it in a slightly different way: In any given situation, OPH will be sharing the information either for "classic" public health purposes, for individual treatment purposes, or most likely for both purposes. In either case, we believe that the applicable laws -- including the state laws and HIPAA Privacy Rule discussed above, and the state statutes and rules discussed in Attachment A -- permit OPH to do so without the necessity of obtaining the patient's written authorization.

⁵ R.S. 36:251(B) (emphasis added).

^{6 65} F.R. 82526 (Dec. 28, 2000).

^{7 45} C.F.R. §164.512(b)(1)(i).

Attachment A:

Answers to Specific Questions With Supporting Statutes and Rules

The main body of the Position Paper sets forth the general analysis leading to the conclusion that OPH may legally share individual patient information with LSU HCSD within the LaPHIE system without being required to obtain the patient's written authorization. This Attachment A presents a synopsis of the specific questions posed by LaPHIE partners and stakeholders and the answers to those questions, with citations to particular Louisiana statutes and rules supporting the answers. Each citation or paragraph is followed by a notation of the disease(s) -- HIV/AIDS, TB and/or syphilis -- to which it applies.

These answers are intended to provide useful guidance on the most important issues that have been raised by the partners and stakeholders. However, it would be impossible to anticipate and address in this document every possible question or scenario that might arise in the operation of LaPHIE.

Question 1: Disclosures of Information and Information Sharing

When an out of care person (either adult or child) with HIV/AIDS, TB or syphilis registers as a patient in the LSU HCSD system, can OPH legally share PHI on the patient with LSU HCSD in order to facilitate treatment without obtaining the patient's prior consent or authorization?

(The lengthiness of the following answer reflects the fact that this is the most central and fundamental question that has arisen regarding the permissible extent of information sharing within LaPHIE.)

Answer: Yes. This answer is not only supported by the general analysis and conclusions set forth in parts III and IV of the Position Paper, but is reinforced by Louisiana's public health statutes and the rules promulgated by OPH (including the Sanitary Code), which contain many provisions requiring or permitting OPH to implement strong (and sometimes aggressive) measures to prevent the spread of infectious diseases. Significantly, all three of the diseases of concern to LaPHIE -- HIV/AIDS, TB and syphilis - are among the diseases that are required to be reported to OPH by physicians, hospitals, laboratories and other health care providers, and even by parents, schools and day care centers. The statutory and Sanitary Code provisions requiring the reporting of these diseases are:

- R.S. 40:1065 (HIV/AIDS, syphilis)
- Sanitary Code, Part II, §105(A)(2)(a)(xviii) (syphilis)
- Sanitary Code, Part II, §105(A)(2)(a)(xx) (TB)
- Sanitary Code, Part II, §105(A)(3)(a)(i) (HIV/AIDS)

Furthermore, "[c]ustodians of medical records on patients known or suspected of being cases or carriers of a communicable disease, shall make such records available for review by the state health officer." Sanitary Code, Part II, §119. Although these mandatory reporting provisions say nothing about the flow of information from OPH to health care providers, they do show the great extent of the public health concerns surrounding these diseases, and thus they are a reminder of the importance of taking vigorous action to prevent their spread. (HIV/AIDS, TB, syphilis)

As noted in part III of the Position Paper, OPH's implementation of measures aimed at protecting the public's health often will, of necessity, entail the disclosure of information about infected (or potentially infected) individuals to LSU HCSD or another treatment provider, regardless of whether the patient knows of the infection or whether he/she has consented to the disclosure. In a sense, information sharing could itself be considered a type of public health control measure, and one that is less invasive of the patient's privacy than many of the other measures that are available to OPH. The following is a summary of the most significant of those public health statutes and rules.

Disease Control Measures in General

Although the public health statutes usually do not address information sharing as such, they grant OPH a great deal of authority and discretion with regard to individuals with communicable diseases. R.S. 40:4(A)(2) provides, in pertinent part:

In order to prevent the occurrence or spread of communicable diseases, the rules and regulations of the Sanitary Code shall . . . provide for and require the reporting, investigation, and application and implementation of appropriate control measures . . . for all communicable diseases of public health significance.

Likewise, R.S. 40:5(2) authorizes OPH and the State Health Officer to "take such action as is necessary to accomplish the subsidence and suppression of diseases of all kinds in order to prevent their spread." These general provisions are implemented by various sections of Part II of the Sanitary Code, particularly §§115(A) and 117. (HIV/AIDS, TB, syphilis)

Isolation, Quarantine and Commitment

The most invasive power granted to OPH and the State Health Officer with regard to communicable diseases is the authority to impose isolation or quarantine, which is expressly granted by R.S. 40:4(A)(1) and 40:5(1). Detailed provisions are found in the Sanitary Code, Part II, §117 ("Disease Control Measures Including Isolation/Quarantine"). (HIV/AIDS, TB, syphilis)

Pursuant to R.S. 40:4(A)(2)(c)(vii), the Sanitary Code must require isolation and/or quarantine for directly observed therapy of any person with communicable TB "who has failed to comply with a daily self-administered course of chemotherapy" prescribed by a physician, and the patient's failure to comply can lead to the imposition of more restrictive isolation or quarantine or even to criminal prosecution. These requirements are implemented by the Sanitary Code, Part II, §121 ("Special Tuberculosis Control Measures"). Detailed provisions regarding

commitment and confinement of patients with communicable TB are also found in R.S. 40:17 and 40:31.21 et seq. (TB)

R.S. 40:1064 provides that any person affected with a "venereal disease" – which is defined to include HIV/AIDS and syphilis – "is subject to isolation, quarantine, or interment, on the order of [OPH], and shall submit to any treatment for such a time and under such restrictions as seems reasonable and proper to [OPH]." (HIV/AIDS, syphilis)

Since the law not only allows, but sometimes requires, OPH to impose isolation, quarantine or other harsh measures for patients with these communicable diseases in order to control their spread, it is logical that it would also promote efficient information sharing between OPH and hospitals if it can assist in treatment (and control) of those diseases.

Other Disease Control Measures

R.S. 40:1063 provides that OPH, "through an authorized medical representative appointed for that purpose, may give a physical examination to any person suspected of being infected with a venereal disease. [Again, that term is defined to include HIV/AIDS and syphilis.] The examination shall be given under conditions thought reasonable by [OPH]. No person shall fail or refuse to submit to this examination." When OPH follows this procedure, it will necessarily have to communicate the patient's infection status to the "authorized medical representative" it appoints, who could, of course, be a physician working at an LSU HCSD facility. (HIV/AIDS, syphilis)

Pursuant to R.S. 40:4(A)(2)(vi) and the Sanitary Code, Part II, §503(D), any person with AIDS or known to be infected with HIV, in the process of receiving medical treatment related to such condition, must be screened for communicable TB. Again, any physician or other health care personnel involved in performing the mandatory screening would necessarily have to be informed of the patient's HIV/AIDS status. (HIV/AIDS, TB)

Information Sharing in General

Part II of the Sanitary Code, §115(A) ("Investigations"), provides in pertinent part:

The state health officer may immediately upon receiving notification of any communicable disease . . . , investigate as the circumstances may require for the purpose of verification of the diagnosis, to ascertain the source of the causative agent, to disclose unreported cases and to reveal susceptible contacts if such information is required to prevent a serious health threat to the community.

(Emphasis added) (HIV/AIDS, TB, syphilis)

R.S. 40:1300.14 ("Confidentiality of HIV test result; disclosure") begins with the general premise that HIV test results1 are confidential. However, this statute is subject to numerous exceptions, including the exception permitting release of HIV test results to "[a] health care provider or health facility, when knowledge of the HIV test results is necessary to provide appropriate care or treatment to the patient and afford the health care provider and the personnel of the health facility an opportunity to protect themselves from transmission of the virus." R.S. 40:1300.14(B)(3). The first clause of this exception (knowledge of test results is necessary to provide appropriate care or treatment to the patient) will always be applicable to LaPHIE; it is very similar to the HIPAA Privacy Rule's "TPO" ("treatment, payment and operations") provisions which, as discussed in part III of the Position Paper, permit a covered entity (such as OPH) to disclose information to another covered entity or provider (such as LSU HCSD) for the treatment activities of either entity without the patient's written authorization. The second clause of this exception (knowledge of test results is necessary to afford health care personnel the opportunity to protect themselves from the virus) may also be applicable to some situations, particularly when the patient and/or the treating physician or hospital personnel are unaware that the patient is HIV positive. Therefore, this statute does not create an obstacle to the information sharing contemplated in LaPHIE. (HIV/AIDS)

The Centers for Disease Control and Prevention's Technical Guidance for HIV/AIDS Surveillance Programs, Volume III: Security and Confidentiality Guidelines, Attachment G, p. 1-72 (2006), states:

[H]ealth departments may determine that [an] appropriate use of surveillance data is to use individual-level data from HIV surveillance registries to prompt follow up by the health department with patients or providers to offer voluntary referrals for various patient services. Individual-level data include case specific data where individuals are identified.

Although this CDC publication lacks the force of law, it is instructive because it confirms that it is legitimate for a "health department" such as OPH to share "individual-level" HIV data with providers to promote the treatment of the individual patient, even when the agency obtained such data in the course of performing its "classic" public health activities (e.g., surveillance). (HIV/AIDS)

¹ For the purposes of this statute, "HIV test result" is defined as "the original document, or copy thereof, transmitted to the medical record from the laboratory or other testing site the result of an HIV-related test. The term shall not include any other note, notation, diagnosis, report, or other writing or document." R.S. 40:1300.12(B). In turn, "HIV-related test" is defined as "a test which is performed solely to diagnose infection with [HIV]." R.S. 40:1300.12(A).

Notification of Contacts

R.S. 40:1300.14(E) permits a physician to disclose "confidential HIV test results" to contacts, either directly or through "a public health officer", but only under somewhat restrictive conditions; for example, the physician must first counsel the patient regarding the need to notify the contact and must reasonably believe that the patient will not inform the contact, and the identity of the patient or of any other contact cannot be disclosed. Part II of the Sanitary Code, §115(D), implements these provisions with regard to the role that the State Health Officer may play in notifying "spouses and/or sexual contacts" of HIV infected persons. (The State Health Officer is required to "make a good faith effort" to provide such notification.) (HIV/AIDS)

Question 2: Sharing Information About Minor Patients in General

Are there laws that pertain to children? Can their information be shared and how?

Answer: This question, and questions no. 3 and 4 below, involve the HIPAA Privacy Rule's concept of the "personal representative" – that is, a person who, under applicable law (usually state law), has the authority to consent to medical treatment on behalf of the patient and therefore "stands in the shoes" of the patient and has a right of access to his or her medical information.

Situations involving personal representative status with regard to a patient who is a minor (a person under the age of 18 who is not legally emancipated) can be broken down into three broad categories:

- 1. Minor is accompanied by a parent or legal guardian when presenting to the provider for medical treatment or testing: There is no legal obstacle to sharing information about the treatment with the parent³ or legal guardian, who is the personal representative and thus has access to all of the child's medical information. A legal guardian (Louisiana law uses the word "tutor") is a person appointed by a court to have the care and custody of a child. (HIV/AIDS, TB, syphilis)
- Minor is alone and unaccompanied by any adult when presenting to the provider for medical treatment or testing. A minor who is or believes himself to be afflicted with an illness or disease may validly consent to the provision of medical care from a physician, hospital

² For the purposes of this statute, "contact" is defined as "a sex-sharing or needle-sharing partner, a person who has had contact with blood or body fluids to which universal precautions apply through percutaneous inoculation or contact with an open wound, non-intact skin, or mucous membrane, or a person who has otherwise been exposed to an HIV infected person in such a way that infection may have occurred as defined by the Department of Health and Hospitals regulations based upon Center for Disease Control guidelines." R.S. 40:1300.12(C).

³ Pursuant to R.S. 40:1299.55, which is part of the Louisiana Medical Consent Law, "parent" includes a stepparent.

or public clinic as if he or she were an adult, and the consent of the minor's parent or guardian is not required. In such situations, the physician or a member of the medical staff is permitted, but not required, to "inform the spouse, parent or guardian of any such minor as to the treatment given or needed, and such information may be given to, or withheld from the spouse, parent or guardian without the consent and over the express objection of the minor." R.S. 40:1095. (HIV/AIDS, TB, syphilis) Identical provisions specifically applicable to treatment for a "venereal disease" – defined to include HIV/AIDS and syphilis – are found in R.S. 40:1065.1. (HIV/AIDS, syphilis) This gives the provider the choice either to treat the parent or guardian as the child's personal representative or to treat the minor as his or her "own person" with the same control over the access to his or her medical information that an adult patient has. This choice should be determined according to the professional judgment of the medical provider, based on an evaluation of the child's age, maturity, discretion and other relevant circumstances.

 Minor is accompanied by an adult other than a parent or legal guardian when presenting to the provider for medical treatment or testing: See question no. 3 below.

Question 3: Sharing Information About Minor Patients With Adults Other Than Parents and Legal Guardians

Can information be shared with a guardian such as an aunt or grandmother if the child is exposed or infected and needs testing or care? Is there a distinction between a formal and an informal guardian?

Answer: The key to answering this question is found in R.S. 40:1299.53(A) ("Persons who may consent to surgical or medical treatment"), which is part of the Louisiana Medical Consent Law. This statute lists the hierarchy of persons who may consent to medical treatment on behalf of a patient, which also serves as the hierarchy of persons who can be treated as the patient's personal representative. If the patient is a minor, that hierarchy consists of the following, in order of priority (that is, the right to act as personal representative belongs to the first person in the list who is reasonably available, willing, and competent to act):

- The judicially appointed tutor (legal guardian), if one has been appointed.
- (2) Any parent.
- (3) Any adult sibling.⁴
- Any other ascendant (grandparent, great-grandparent).
- (5) "Any person temporarily standing in loco parentis, whether formally serving or not, for the minor under his care and any guardian for his ward".

⁴ Pursuant to R.S. 40:1299.55, which is part of the Louisiana Medical Consent Law, "sibling" includes a stepbrother or stepsister.

Category 1 in this hierarchy, a tutor or guardian who has been appointed by a court to care for the child (a relatively rare event), is the same as the "legal guardian" mentioned in question no. 2 above. This would also include a person or agency to whom a juvenile court has awarded custody of a child; see question no. 4 below. A legal guardian would outrank everyone else, including even a parent (category 2), in having the authority to act as personal representative and the right to access the child's medical information. (HIV/AIDS, TB, syphilis)

Categories 3 and 4, adult siblings and ascendants, who are outranked by legal guardians and parents, are fairly straightforward. Category 5, the lowest ranking, is more problematic. The term "in loco parentis" means "in the place of a parent", and the Louisiana courts have defined the phrase "person in loco parentis" as "one who has assumed the status and obligations of a parent without a formal adoption." Aside from that, the law does not provide much help in determining which persons fit that classification. Nor is the meaning of the phrase "any guardian for his ward" entirely clear, since the tutor or legal guardian is already included in the first category of the hierarchy. Given the law's lack of precision in defining the persons covered in category 5, caution should be exercised in evaluating whether an individual falls within that category. At a bare minimum, it would seem that only a custodian with whom the child resides should be included. (HIV/AIDS, TB, syphilis)

Louisiana law does not distinguish between "formal" and "informal" guardians as such. A judicially appointed tutor or legal guardian certainly would be a "formal" guardian, while a person falling within category 5 (see preceding paragraph) could be thought of as an "informal" guardian.

Thus, when a child is accompanied by an adult other than a parent or legal guardian when presenting to the provider for medical treatment or testing, the adult may be regarded as the child's legal representative and may, in that capacity, be given information related to the treatment or testing if:

- The adult is the child's adult sibling or ascendant; or
- The adult is a member of the child's family other than an adult sibling or ascendant (i.e., stepparent, aunt, uncle, cousin) or a family friend, and the provider possesses reliable information that the child resides with the adult and the adult acts as the custodian of the child.

Even if the adult accompanying the child does not meet these requirements and does not legally qualify as a personal representative, he or she is not necessarily prohibited from being given information relevant to the treatment or testing that is performed. Providers often are not

⁵ R.S. 9:975 authorizes a "non-legal custodian", who is not a foster parent, to give legal consent for a child in his custody to receive any medical or educational services for which parental consent is usually required, if the custodian executes an affidavit in a prescribed form. Such a non-legal custodian would appear to qualify as a "person temporarily standing in loco parentis". Significantly, this procedure can be utilized only if the child resides with the custodian.

well positioned to evaluate or determine a child's situation with regard to parents, family, custody, guardianship, etc. Since that should not be an obstacle to the continued provision of necessary and effective medical care to the child, the provider should have some discretion to deal reasonably and in good faith with the adult who brings the child in, without having to go to great lengths to verify his or her personal representative status. The Louisiana Medical Consent Law recognizes this in R.S. 40:1299.55:

Any person acting in good faith shall be justified in relying on the representations of any person purporting to give such a consent, including, but not limited to, his identity, his age, his marital status, his emancipation, and his relationship to any other person for whom the consent is purportedly given.

Accordingly, after performing the treatment or testing, the provider may share with the adult any relevant information that is necessary to ensure and promote the further treatment and follow-up testing of the child. In addition, if the provider knows the identity and whereabouts of the child's parent, guardian or other personal representative, it should make reasonable efforts to transmit that information to such person. (HIV/AIDS, TB, syphilis)

It is important to note that the foregoing discussion addresses only the issue of sharing information with adults who are not parents or guardians. The issue of whose consent is legally required for the treatment or testing of a child is a separate one, and it presents little difficulty for the operation of LaPHIE. Generally, to the extent that the provision of medical treatment to an individual who has contracted, or is at risk of contracting, an infectious disease is part of OPH's efforts to prevent the spread of the disease, consent to treatment is not a major issue, given OPH's wide-ranging authority in this area. Some statutes specifically grant the authority to treat or test a patient without the necessity of consent on his or her behalf, such as R.S. 40:1063 (for "venereal diseases" including HIV/AIDS and syphilis; mentioned in question no. 1 above) and R.S. 40:1300.13 (for HIV/AIDS; mentioned in question no. 6 below). Finally, R.S. 40:1299.54(A) ("Emergencies"), part of the Louisiana Medical Consent Law, provides that consent to treatment is implied when an emergency exists, and it includes a broad definition of "emergency" which emphasizes the provider's professional medical judgment and which would seem to apply to any situation involving a minor child who is brought to OPH or to one of its partners in LaPHIE for treatment or testing:

[A]n emergency is defined as a situation wherein: (1) in competent medical judgment, the proposed surgical or medical treatment or procedures are reasonably necessary; and (2) a person authorized to consent under Section 1299.53 is not readily available, and any delay in treatment could reasonably be expected to jeopardize the life or health of the person affected, or could reasonably result in disfigurement or impair faculties.

Accordingly, OPH and its LaPHIE partners may legally provide a minor child with any treatment or testing which they deem necessary, and may take appropriate action in response to the information in the LaPHIE system alerts, without the necessity of making an elaborate determination of the precise legal relationship between the child and the adult who brings the child in for treatment. (HIV/AIDS, TB, syphilis)

Question 4: Sharing Information About Minor Patients in Foster Care or State Custody

Are there laws that pertain to children in foster care or state custody? Can their information be shared and how?

Answer: Yes. Whenever a juvenile court awards legal custody of a child to anyone, including the state (usually the Department of Social Services, Office of Community Services), the custodian is expressly granted "the authority to consent to major medical, psychiatric, and surgical treatment" and "to provide the child with . . . ordinary medical care". La.Ch.C. Art. 116(12). The authority to consent to medical treatment carries with it the authority to have access to the child's medical information. The custodian effectively becomes the legal guardian and therefore the personal representative of the child. (HIV/AIDS, TB, syphilis)

The foregoing paragraph applies to children in foster care, who are a subset of children in the legal custody of the state. Foster parents, who care for these children under contract with DSS-OCS, have their own rights to the child's information under R.S. 46:286.13(3), which guarantees them:

[t]he right to receive all information on a child, at placement, and on an ongoing basis, that could impact the care provided the child, the health, and safety of the child and foster family members. Information shall include . . . the health [and] medical . . . history as known to the [DSS] to better meet the needs of children in their care.

Although this statute does not provide for the direct sharing of information by OPH or other health care providers with foster parents, it does indicate that DSS-OCS should forward to the foster parents any significant information that it receives from OPH or from a provider. (HIV/AIDS, TB, syphilis)

Question 5: Exposed Children as Contacts

Are exposed children (including perinatally exposed children in cases of HIV/AIDS or syphilis) considered "contacts" and communication on these children covered under investigation/contact tracing laws?

Answer: Yes, with regard to HIV/AIDS. As noted in the "Notification of Contacts" section of the answer to question no. 1 above, R.S. 40:1300.14(E) permits a physician to disclose "confidential HIV test results" to "contacts" under certain conditions, and the applicable definition of "contact" in R.S. 40:1300.12(C) includes any person who has been exposed to an HIV infected person in such a way that infection may have occurred as defined by DHH regulations based upon CDC guidelines. Perinatally exposed children certainly would qualify as "contacts" under this definition. (HIV/AIDS)

However, given the limitations of this contact notification provision, and given the fact that it applies only to HIV/AIDS, it would be more practical and useful to rely upon the HIPAA

Privacy Rule's "TPO" ("treatment, payment and operations") provisions, which permit the disclosure of information for the purpose of providing treatment to a patient without the patient's written authorization, in dealing with exposed or potentially exposed children. (HIV/AIDS, TB, syphilis). Those provisions are echoed in R.S. 40:1300.14(B)(3), which permits the disclosure of HIV test results to "[a] health care provider or health facility, when knowledge of the HIV test results is necessary to provide appropriate care or treatment to the patient". (HIV/AIDS)

Generally, whenever information is being disclosed to a treatment provider in order to further the treatment of a patient who has been or may have been exposed to an infectious disease, care should be taken to avoid disclosing the identity of the infected individual who is the source of the exposure. However, when a child's actual or potential perinatal exposure is disclosed for this purpose, it is unavoidable that such disclosure will also reveal the mother's infection status.

Question 6: OPH Intervention for Involuntary Testing or Treatment

Is OPH legally allowed to intervene if a person refuses testing or treatment for self or their child?

Answer: Yes.

Several permissible interventions have already been mentioned in the answer to question no. 1 above; they include such measures as isolation, quarantine, commitment and compulsory examinations and screenings.

R.S. 40:1300.13 generally permits individuals to refuse or "opt out" of HIV diagnostic testing, and also gives them the option to submit to the testing anonymously. However, this statute lists several situations in which testing can be performed without affording the opportunity to "opt out" or to be tested anonymously. Two of those situations are when the testing is performed:

- On any child taken into custody by DSS, where department officials have cause to believe that the child has been infected with HIV.
- On any child when the child's attending physician reasonably believes such
 test to be necessary in order to properly diagnose or treat the child's medical
 condition and documents such reason in the child's medical record, including
 all newborns whose mothers present for delivery without a diagnostic HIV
 test on record.

R.S. 40:1300.13(E)(4), (5). In these situations, the child may be tested without permission from anyone if DSS or the attending physician reasonably believes the test to be necessary. While these provisions do not address information sharing as such, they indicate that concern for the child's health may supersede autonomy and privacy considerations. (HIV/AIDS)

When a child is the subject of a juvenile court proceeding involving alleged abuse or neglect, there are several provisions of the Children's Code authorizing the court to order a medical examination or medical treatment for the child. Ch.C. Arts. 502(5), 614(A), (B), 669(A). In appropriate circumstances, these provisions might be used to compel treatment of the child deemed necessary by OPH, even over the parent's objection. (HIV/AIDS, TB, syphilis)

Question 7: Information on Patients Originating Inside or Outside the LSU System

Is there a difference in the ease with which OPH can share data back to LSU on patients that they reported originally that were their patients vs. those that originated outside of the LSU system? What about patients whose diagnosis did not originate with LSU, but they have since accessed care for that or another condition from LSU?

Answer: No, there is no legal basis to make a distinction between patients based on whether their information or diagnosis originated inside or outside the LSU system. The permissible extent of information sharing is the same for both categories of patients. (HIV/AIDS, TB, syphilis)

Question 8: Sharing Information Within OPH

Can OPH share information between programs and agencies within OPH, i.e. can the HIV/AIDS Program (HAP) share information with the WIC program or other OPH programs? For example, for a patient who is "lost for follow-up" for HAP and accessing services with the WIC program.

Answer: Generally, the various agencies and programs within OPH can share information with each other for purposes of public health or individual treatment without being required to obtain patient consent or authorization, so the general answer is yes. However, there is an important exception for WIC client information, which is subject to a fairly restrictive confidentiality regulation issued by the U. S. Department of Agriculture. That regulation, 7 C.F.R. §246.26(d), permits the use or disclosure of WIC client information for non-WIC purposes only if: (1) the State Health Officer designates in writing the permitted non-WIC uses of the information and the names of the organizations to which such information may be disclosed; (2) the client has been given prior notice that his/her WIC information may be used or disclosed for non-WIC purposes; and (3) the WIC program has a written agreement with the program receiving and using the WIC information (in this example, the HAP) which specifies the limitations on the use of the information by the receiving program. These requirements would have to be met before the WIC program could share its client information with the HAP without client consent/authorization. (HIV/AIDS, TB, syphilis)

Question 9: Sharing Information with DSS-OCS

Can the HAP or other programs in OPH share information with the Department of Social Services, Office of Community Services (DSS-OCS)?

Answer: When DSS-OCS has been awarded legal custody of a child by a court, OPH programs can freely share information on that child with DSS-OCS, which then has the same rights of access to the child's medical information that a parent ordinarily has. See the answer to question no. 3 above. When DSS-OCS has not been awarded legal custody, the answer becomes less clear-cut. For example, under some circumstances that agency might be considered a "person temporarily standing in loco parentis" or informal guardian of the child and thus might have a right of access to the child's medical information (see R.S. 40:1299.53 in the answer to question no. 4 above), even when lacking actual legal custody. (HIV/AIDS, TB, syphilis)

There are at least two state statutes that broadly encourage information sharing between DHH and DSS, but they do not actually remove any existing confidentiality barriers.

- R.S. 46:56(B)(1) provides, "It is the express intent of this Section that [DHH and DSS]... share access to each other's case records to the extent that such access is not prohibited by any contrary provision of federal law or regulation." (Emphasis added.) The HIPAA Privacy Rule is a "contrary provision" of federal regulation which generally prohibits DHH from sharing client information on a child with DSS, unless DSS has legal custody of the child or perhaps has the status of an informal guardian.
- Articles 541-545 of the Children's Code call for data sharing and integration among state and local government agencies providing services to children, including DHH and DSS, through the use of interagency agreements specifying the data to be shared and the conditions under which information is to be made available. These provisions recognize, and do not remove, any existing confidentiality barriers between the agencies. See Art. 544(A)(2): "If written consent, waiver of confidentiality, or other authorization from the person who is the subject of the information or such person's legal representative is necessary to permit the release, exchange, or sharing of information, the agency . . . requesting the information shall have the primary responsibility for obtaining such consent, waiver, or other authorization."

It is important to remember that when DSS-OCS does not have legal custody of the child, the answer to this question will be fact-sensitive and such situations must be addressed on a case-by-case basis. (HIV/AIDS, TB, syphilis)

Appendix A

Louisiana Public Health Information Exchange Legal Position Paper Background

Authors:

- Charles E. Daspit, Deputy General Counsel, Louisiana Department of Health and Hospitals, Bureau of Legal Services
- Jane Herwehe, MPH, Project Manager, Louisiana State University Health Care Services Division
- Lisa Longfellow, Program Director, Louisiana Department of Health and Hospitals,
 Office of Public Health STD Control Program
- Amy Zapata, Surveillance Program Manager, Louisiana Department of Health and Hospitals, Office of Public Health, HIV/AIDS Program
- Susan Bergson, Program Manager, Health Systems Development HIV/AIDS Programs
 Louisiana Public Health Institute
- Sarah Casey, Legal Intern, Louisiana Public Health Institute

Process:

- The Louisiana Public Health Information Exchange (LaPHIE) first came together in July 2005 when representatives of LSU HCSD, Louisiana DHH/OPH STD, HIV/AIDS and TB Programs and the Louisiana Public Health Institute formed a collaborative to consider the opportunities for electronic information exchange between public health and clinical providers. The goal of these efforts was to improve health outcomes and possibly reduce transmission of syphilis, HIV and TB. The collaborative quickly identified the need for a Compliance and Ethics group to consider the ethical and legal implications of LaPHIE. The following providers representing persons living with HIV, consumer advocates, public health practitioners and health administrators participated on the Compliance and Ethics Sub-committee:
- Diane Angelico, RN, LSU HCSD Patient Liaison Director
- Susan Bergson, Louisiana Public Health Institute
- Louise Bienvenue, AIDS Law
- Dimitre Blutcher, 'NR PEACE
- Erin Brewer, Louisiana DHH/OPH
- JoAnne Coleman, LSU HCSD, Corporate Compliance Officer
- Charles Daspit, Louisiana DHH
- Jane Herwehe, LSU HCSD
- Pam Holm, NO/AIDS Task Force
- Lisa Longfellow, OPH STD
- Dr. Joanne Marier, LSU HSC
- Erika Sugimori, New Orleans Regional AIDS Planning Council
- Carolyn Wells, American Friends Service Committee
- Amy Zapata, OPH/HAP

The LaPHIE Compliance and Ethics Sub-committee recommended that the LaPHIE partners analyze all of the federal and state laws that could impact the health information exchange (HIE) and enlist the support of a DHH legal representative to develop a LaPHIE legal position paper based on this analysis. The Sub-committee developed a list of legal questions as a starting point. Charles Daspit, Deputy General Counsel for Louisiana DHH and a 3rd year law student, Sarah Casey completed the analysis of applicable state and federal legislation and prepared the position paper.

The analysis was reviewed by the LaPHIE partners, the Compliance and Ethics Subcommittee as well as LSU Professor (Endowed Chair) of Public Health Law, Professor Edward Richards who is the LSU Harvey A. Peltier Professor of Law and Director of the LSU program in Law, Science, and Public Health.

Appendix B – Focus Group Study Design

	With Diagnosis		No Diagnosis/Matched	
	New Orleans	Shreveport	New Orleans	Shreveport
Clinical/	Group 1	Group 5	Group 9	Group 13
Chronic Illness				
	Insured	Uninsured	Uninsured	Insured
STDs/HIV	Group 2	Group 6	Group 10	Group 14
3103/1110	Group 2	Group 6	Group 10	Gloup 14
	Uninsured	Insured	Insured	Uninsured
Behavioral/	Group 3	Group 7	Group 11	Group 15
Substance				
Abuse	Insured	Uninsured	Uninsured	Insured
Developmental	Group 4	Group 8	Group 12	Group 16
Disabilities	•	•	•	•
	Insured	Insured	Insured	Uninsured

The Louisiana Public Health Information Exchange

An Overview

A collaborative initiative between the Louisiana Office of Public Health, the Louisiana State University Health Care Services Division and the Louisiana Public Health Institute.



Overview

One important job for the Louisiana Office of Public Health (OPH) is ensuring that Louisianans with infectious diseases learn about their diagnosis and receive appropriate medical care. For certain conditions (including HIV, syphilis and tuberculosis), OPH works to fulfill this duty by sending a staff person to speak with newly diagnosed patients about undergoing proper treatment. However, such methods cannot reach *every* Louisiana patient with an infectious disease. Sometimes, OPH cannot find patients after an initial diagnosis. Other times, patients may drop out of care years after learning that they have an infectious illness.

Obviously, connecting such individuals to treatment would help improve both individual and population health in Louisiana— especially in light of recent research which shows that persons taking HIV antiretroviral medications are less likely to transmit the disease.

With the above challenges in mind, OPH partnered with seven Louisiana State University (LSU) Health Care Services Division hospitals to create the Louisiana Public Health Information Exchange (LaPHIE). The exchange uses OPH's surveillance data to alert LSU clinicians that a patient might have an untreated case of HIV, tuberculosis or syphilis requiring a doctor or nurse's attention. Specifically, OPH sends a LaPHIE message to LSU clinicians when they meet with the following types of patients:

- Individuals who have tested positive for HIV but may be unaware of their status (according to OPH records),
- Individuals with confirmed HIV infection who currently do not appear to be in care (OPH has no recent viral load or CD4 laboratory tests on file),
- Children of HIV-positive mothers who may have HIV (but OPH's records are insufficient for a conclusive diagnosis),
- Individuals who have tested positive for syphilis or tuberculosis and do not appear to have completed a full course of treatment (according to OPH records).

The cutting-edge program creates a secure, limited connection between a protected list of "out of care" persons housed on the OPH computers and the electronic medical record (EMR) system at LSU. The result: each time a patient checks into a LSU emergency room, clinic, or hospital, LaPHIE logic automatically examines the OPH file to determine if the patient is on OPH's out of care list. If LaPHIE's logic determines that a patient is out of care, it automatically sends a message to LSU's EMR. Then, when an authorized LSU clinician logs in to the patient's record, he or she sees a message from OPH—along with a list of suggested actions (as shown in Figure 1). The content of these messages varies depending on the patient's illness and type of care that the patient might need.

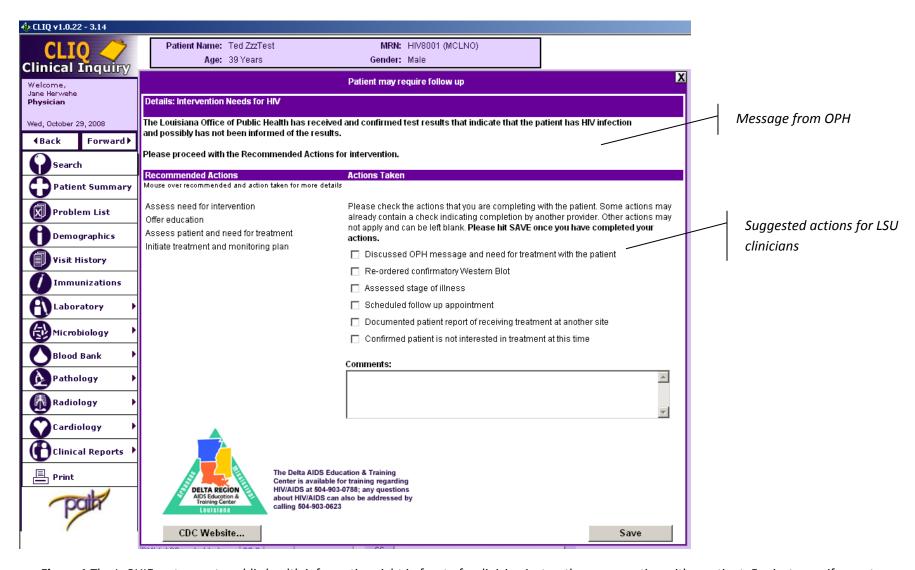


Figure 1 The LaPHIE system puts public health information right in front of a clinician just as they are meeting with a patient. For instance, if an out-of-care HIV positive patient came into an LSU emergency room with an asthma complaint, LaPHIE would show this screen on the patient's EMR.

How it Works

LaPHIE puts current public health information directly in front of a clinician by embedding a message from OPH into a patient's EMR. From a technical standpoint, this overall process is actually the culmination of many smaller tasks performed by different computer systems at OPH and LSU. The picture to the right describes the major steps, which include:

One. When any patient registers at an LSU hospital, his or her identifying information is added to the LSU computer system.

Two. LSU electronically notifies OPH (via LaPHIE) that the patient has arrived at an LSU facility. It sends the patient's demographic information to a secure, designated LaPHIE server housed at OPH.

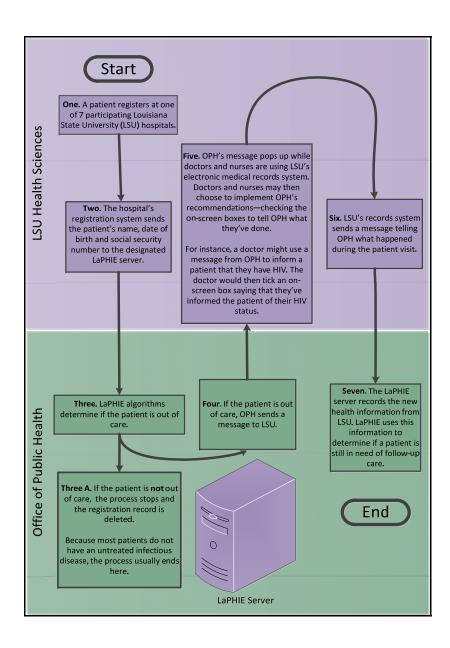
Three. When OPH receives a message from LSU, the LaPHIE logic checks the out of care patient database to determine if the patient has not been receiving treatment for his or her infectious disease.

Four. If OPH finds a match in the out of care database, it automatically sends a standard, disease-specific electronic message to the LSU EMR system.

Five. The LSU system receives and stores the message from OPH. Then it displays the message as a pop up alert for authorized clinicians who open the patient's EMR within the visit timeframe. When clinicians click on the alert, they see a list of suggested actions, which can be checked off on screen.

Six. After a patient meets with a clinician, the LSU system automatically returns a message to OPH with current contact information and the reporting of how doctors and nurses responded to the message.

Seven. OPH adds this information to its databases, which are updated nightly to determine which individuals should be included in the out of care dataset.



Legal and Ethical Concerns

Sharing protected health care and public health information is a complex (but solvable) technical problem. Yet implementing a system like LaPHIE raises many non-technical challenges and questions. Under what circumstances is it legal to share health information between health care providers and public health professionals? Is it ethical? Is building a system like LaPHIE the "right thing to do" in terms of protecting the health of individuals and the health of the population?

To answer such questions before building the exchange, LaPHIE partners formed a legal compliance and ethics workgroup consisting of public health officials, HIV-infected persons, doctors and nurses, attorneys familiar with Federal and State health laws, HIV advocates, and a medical ethicist. Over the course of a year, the workgroup developed a list of legal questions to be answered, reviewed relevant legislation, and discussed plans for the exchange with national experts in confidentiality and biomedical ethics. The group also enlisted the expertise of an independent market research firm—charged with conducting interviews and focus groups to learn how potential patients would view the project.

Following this legal and ethical analysis, the workgroup concluded that the LaPHIE project ought to be implemented because it worked to protect both individual and population health. They also found that, in Louisiana, there were no laws prohibiting information sharing for the purpose of improving individual care. In fact, the group found Louisiana legislation that facilitated communication between public health authorities and health care providers to improve treatment.

The group's conclusions were further fortified by focus group and interview results from Louisiana residents, who reported that they were in support of sharing protected information with nurses and doctors if the purpose was to give patients information and provide improved healthcare.

Frequently Asked Questions

What organizations created LaPHIE?

LaPHIE is a collaboration between the LSU Health Care Services Division, the Louisiana Office of Public Health and the Louisiana Public Health Institute.

The initiative is funded by the Health Resources and Services Administration (HRSA) as a part of its Special Project of National Significance (SPNS) initiative.

Do other states have exchanges like LaPHIE?

No. LaPHIE is the first electronic data exchange that uses public health surveillance information to provide patient-specific, EMR-integrated health information at the point of care.

Is LaPHIE a repository of all persons with HIV, syphilis or tuberculosis in Louisiana?

No. LaPHIE is designed to only identify patients who are "out of care." In some cases, this means that patients may not have received diagnostic test results and thus are unaware they have been diagnosed with a particular disease. In other cases, this means that patients may be aware of their disease but may not be undergoing treatment.

See "Protecting patient information" on page 57 to learn how LaPHIE ensures that patient information in its out of care database stays private.

Is LaPHIE the primary public health tool for stopping infectious diseases in Louisiana?

No. The LaPHIE messaging system supplements other public health interventions from OPH. For instance, OPH sends staff people to speak with Louisianans who have been newly diagnosed with HIV. LaPHIE only targets residents who have never entered care or who have dropped out of care after starting treatment for their illness.

Who can see LaPHIE disease alerts on an EMR?

Only LSU physicians, nurse practitioners and nurses have access to LaPHIE disease alerts, which constitute protected health information (PHI). In preliminary focus group discussions and interviews, respondents said that they strongly preferred that only their physicians and nurses be able to see this information. They felt that these health care professionals would be the most respectful of their privacy and best able to provide helpful information and offer treatment.

Successes

LaPHIE's early successes have been promising. In its first 24 months of operation, the system has identified over 400 Louisianans with untreated HIV—helping to link these residents back to care.

LaPHIE operates twenty-four hours a day to ensure that patients in need of treatment are connected with nurses and doctors when they are in a medical setting. System maintenance requires minimal time and expenditure—making it an efficient, added tool for improving healthcare for individuals who are otherwise hard to reach.

Creating a LaPHIE Project in Your State

Setting up a LaPHIE system does take time. It requires extensive and thoughtful planning, committed leadership, input from a variety of key players, a robust information technology infrastructure and a team of skilled computer programmers.

Planning for a LaPHIE Project

Developing a project like LaPHIE entails far more than simply directing software developers to create the system. In Louisiana, LaPHIE partners took the following steps before programmers wrote a single line of code:

- Conducted consumer research.
- Developed and refined inclusion criteria for the LaPHIE "out of care" data set
- Identified and agreed upon the strengths and limitations of surveillance data
- Participated in an ethics review by national experts in biomedical ethics, public health ethics and AIDS privacy
- Requested a legal review of Federal and State legislation related to sharing of health care and public health information
- Assessed and modified technical infrastructure at OPH and LSU
- Reviewed OPH and LSU security protocols and confidentiality policies
- Designed a series of clinical decision support prototypes for the EMR with clinicians and public professionals
- Executed a partnership Affiliation and Data Sharing Agreement
- Established an evaluation methodology

Personnel required for a LaPHIE project

Building LaPHIE required many different kinds of expertise. Specifically, LaPHIE brought together doctors, nurses, laboratory professionals, public health leaders, epidemiologists, attorneys, HIV advocates, HIV affected persons, software developers, and network administrators—who all worked together to create the project.

LaPHIE did not fill every team member's work week, but it did require continued effort, decision making and input from many different personnel.

Information technology involved in LaPHIE

When software developers sat down to actually implement the LaPHIE system, they made extensive use of information technology resources already in place at both organizations. OPH already tracked cases of infectious diseases using several surveillance databases. LSU had an existing EMR system. Each office had technology and protocols that allowed them to share secure messages using their networks.

From there, developers on each side needed to create systems that would accept, interpret and respond to communications from the other organization.

At LSU, developers used their own in-house application to receive and process incoming messages. They focused their efforts on finding relevant yet simple ways to add public health information (and corresponding clinician support) into LSU's EMR. They made sure that LaPHIE alerts would work seamlessly within hospital and clinician workflows.

At OPH, developers turned to an open source, no-cost application called Mirth to handle the task of responding to messages from the LSU system. Mirth accepts messages from a source, looks up records in a database, and returns an appropriate reply. Even though Mirth can be used for free, professional software developers were needed to install the highly-technical program and configure the rules that it uses to send and receive communications.

Protecting patient information

All patient data exchanged via LaPHIE constitutes HIPPA-protected PHI. Therefore, LaPHIE partners at OPH and LSU took steps to ensure that such only the minimally necessary information would be transmitted securely—and would be shared *only* with authorized clinicians.

Specifically, LaPHIE does all of the following to ensure that patient data is maximally protected:

- The database of "out of care" patients resides on a secure server behind a firewall at OPH. The CLIQ system resides on a secure server behind a firewall at LSU.
- All information passed between the organizations travels through a secure, private channel employing state-of-the-art encryption.
- LSU shares only minimal patient demographic data with OPH (so that OPH can determine if the patient is out of care). OPH does not store this data in order to protect patient privacy.
- When OPH finds an out of care patient, it shares only a standardized, disease-specific alert message with LSU. This ensures that OPH shares only the minimal amount of patient information needed.
- When LSU clinicians respond to an OPH alert for an out of care patient, LSU *only* sends OPH the clinician's responses (so that OPH can determine if the patient is still out of care). LSU does not send any additional information about the patient's visit.

Maintaining LaPHIE

LaPHIE is a complex computerized system so there are various ways that the normal flow of messages may be interrupted. Thus, even when LaPHIE is running smoothly, software developers and network administrators must still be on hand to diagnose and fix occasional technical glitches in the exchange.

LaPHIE also requires limited additional support from OPH Surveillance staff—who must ensure the accuracy of the out of care dataset. In addition, if clinicians miss a LaPHIE alert, an OPH staff member may follow up with the patient in person.

Next Steps

LaPHIE's novel approach and early successes have attracted the interest of many other organizations devoted to improving both healthcare delivery and overall population health.

Nearly all of the original LaPHIE partners continue to meet to discuss ways that LaPHIE and LaPHIE-like systems may help improve community health both within Louisiana and beyond.

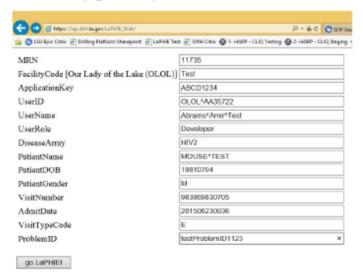
Appendix D - LaPHIE Trouble Shooting Guide

LaPHIE Troubleshooting Guide

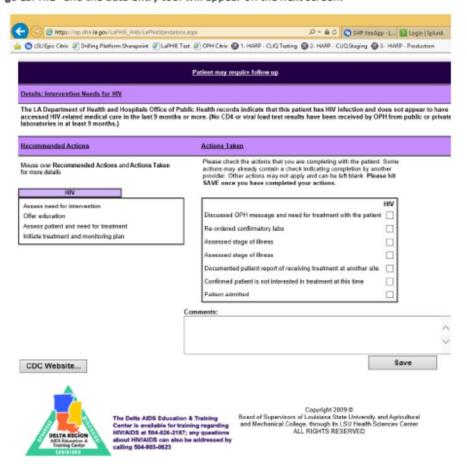
To test if the application is functional, connect to one of these URLs with IE 8 or above and login with your DHH AD account:

- Production URL: https://lap.dhh.la.gov/LaPHIE Web/
- Test URL: https://lap.dhh.la.gov/LaPHIE Web Test/

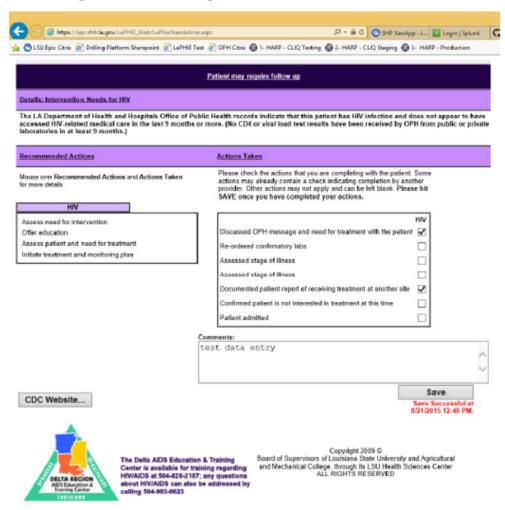
Below is the first test page used to post values to the database and redirect to the entry page:



Press "go LaPHIE" and the data entry tool will appear on the next screen:



On the data entry screen, press "Save" on the bottom right. After clicking save, you will see the "Save Successful at.." message in red on the bottom right below the Save button.



If the app is down, this pathway will not respond or return an error. The error details can be used to troubleshoot the issue.

Appendix A - LaPHIE Schema Documentation

LSU Health Care Services Division

Revised 8/21/2015

Appendix E – LaPHIE Out of Care Definitions

HIV Disease Type	Criteria	
Type 1 – "Out of Care Subset"	 All of the following must be true: Patient was diagnosed over 9 months ago with adult or pediatric HIV or AIDS Patient is out of care (no CD4 or viral loads in past 9 months) Patient is alive and current address is in Louisiana Patient does not meet the criteria for HIV Type2 (described below) AND Any one of the following must be true: Patient has a positive western blot lab result from a paper or electronic lab report since January 2004 (paper lab must include a source code from laboratory). Patient has a detectable viral load result from a paper or electronic lab report since January 2004 Patient has at least three distinct paper or electronic viral load results of any value since January 2004 Patient has at least two paper or electronic labs on record since January 2000 that show a positive WB result or a detectable viral load. 	
Type 2 – "Never in Care Subset" (6-month criteria)	All of the following must be true: • Patient was diagnosed over 6 months ago with adult or pediatric HIV or AIDS • Patient has never been in care (no CD4 or viral load on record) • Patient is alive and current address is in Louisiana AND Patient meets one of the additional lab criteria as for Type 1	

Appendix F – LaPHIE Testing Guide

Test 1: ADT sent successfully

- **a.** Select from test patients:
 - i. Spunky ZZZTest 19680628 388114321
 - ii. Mickey Mouse 19270704 388011234
 - iii. Count Chocula 19700214 540011234

At OLOL there should be at least one Male and one Female test record. Gender is not returned via PPR.

Test 2: PPR sent immediately from OPH and returned to the web portal

Test 3: Cerner displays the results of the web portal screen correctly

- **a.** Check that the message on the alert screen is appropriate. Screen should indicate HIV, not TB or syphilis.
- **b.** Check that female patients have female-related health conditions listed, particularly pregnancy. Male patients should not have pregnancy as a listed condition.
- **c.** Check that hover-overs work for i-iv respectively, and that the content in the hover-over correlates to the recommended action.
 - i. Assess need for intervention
 - ii. Offer education
 - iii. Assess patient and need for treatment
 - iv. Initiate treatment and monitoring plan
- **d.** Check that hyperlinks outside of the alert screen work
 - i. CDC
 - ii. Delta AETC (triangle with state maps)

Test 4: Taking actions (checking the boxes)

- **a.** Check that the response messages do not error out when chosen and saved.
- **b.** Select a combination of boxes, so as to mirror the clinical experience.
 - i. For some clients, save between each box checked. LSU will check that the response table is appropriately recorded
- **c.** With same client alert open, uncheck a box. Open question: what happens when a box is unchecked?

Test 5: Entering comments

a. Type into comment field content that would be similar in length to what a provider might write. Save.

Test 6: Have a 2nd user access an alert that has been acted upon

- **a.** Are the same check boxes marked that User #1 selected?
- **b.** Are the comments entered by User #1 still visible?
- **c.** Check off a new box. Save.

- i. LSU will check that the response table is appropriately recorded
- **d.** Write more comments. Save.
 - i. LSU will check that the response table is appropriately recorded
- e. Uncheck a box that User #1 had checked. Save.
 - i. LSU will check that the response table is appropriately recorded

Test 7: Is patient suspended ("removed") from out of care data set?

a. OPH will check the removal status of the patient when all transactions for a single patient are tested.

Louisiana Office of Public Health HIV Alert (LaPHIE)

Attention: Emergency Department Physicians, Mid-Levels, and Nurses

Facility Affected: Our Lady of the Lake

Change Effective: 08.19.15

Effective Wednesday, August 19, 2015, an alert will be triggered when a patient who has been identified by the Louisiana Office of Public Health as being out of care for their HIV treatment (no HIV related lab draws for 6 months if newly diagnosed as HIV positive; 9 months if a previous positive) presents to the Emergency Department.



To proceed to the patient chart, the alert must be addressed by either Taking Action Now or Taking Action Later.

If **Take Action Later** is selected, the alert will close and the patient chart will proceed to open.

When ready to address the alert, either click the "Office of Public Health Alert" tab to display the OPH form, or if reopening the chart, the alert will display again.



If the alert is not addressed, it will continue to appear each time the chart is opened until the *Actions Taken* section has been has been completed and saved.



The IS Support Center is available 24 hours a day, 7 days a week at (866) 532-4772 or online at http://issc.

Louisiana Office of Public Health HIV Alert (LaPHIE)

Attention: Emergency Department Physicians, Mid-Levels, and Nurses

Facility Affected: Our Lady of the Lake

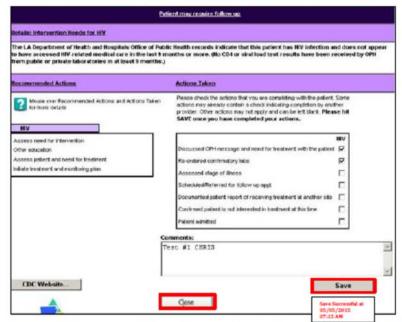
Change Effective: 08.19.15

When Take Action Now is selected, the OPH form will display.

Review **Recommended Actions**, then choose an **Actions Taken**. Comments typed into the box are not considered as Actions Taken.

Click **Save** to save your updates. If the save is successful, a message will appear below the Save button indicating the date and time the record was saved.

Click the Close button to close the window and proceed to the patient's chart.



The OPH form is viewable on the patient's chart under the new tab labeled "Office of Public Health Alert". The OPH's database will be updated each time the form is edited and saved.

Patients are removed from OPH's out of care database once an action is taken on the alert and saved. Patients may be re-entered into the database if they do not have HIV-related lab work conducted in the 6-month or 9-month timeframe.



The IS Support Center is available 24 hours a day, 7 days a week at (866) 532-4772 or online at http://issc.

Appendix H - LaPHIE Training and Self Test

Louisiana Public Health Information Exchange (LaPHIE)

A collaborative project of: LSU HCSD DHH –Office of Public Health Louisiana Public Health Institute







Funded in part by HRS.

LaPHIE

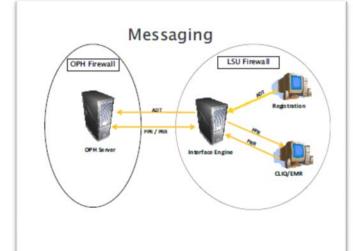
- Secure bidirectional electronic information exchange between the LSU Hospital system and the LA Office of Public Health
- Purpose: to improve timeliness of disease reporting and access to care and treatment for persons with HIV, syphilis and tuberculosis

Who will be targeted by LaPHIE?

- Only persons that OPH considers "not in care" for the targeted conditions (HIV, Syphilis, TB)
- · Definitions of "out of care"
 - Those that have not received test results and are unaware of infection status
 - Those that may have received results, but OPH has no laboratory or clinical info indicating monitoring or treatment
 - Exposed infants in need of follow up

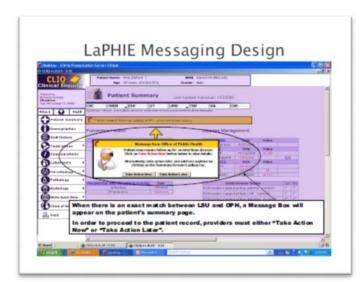
How does LaPHIE "work?"

- LSU HCSD clinical information systems are electronically connected with OPH surveillance and treatment information systems
- Upon registration, LSU HCSD patient records will be matched with OPH records of "out of care" persons based on first name, last name, DOB, and SSN.
- For records matching exactly, OPH will return a clinical message that will post in CUQ on the patient's summary page for clinician action.
- The message will notify the provider of the type of follow-up that may be required.
- Only physicians, nurse practitioners and nurses have access to the LaPHIE message.



LaPHIE Messaging Design

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

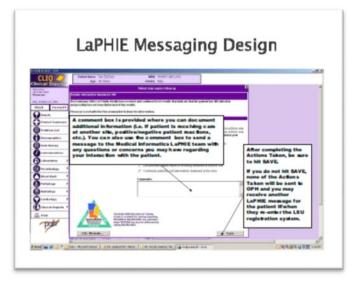












What is required of clinicians receiving a message?

Clinicians are expected to:

- Make sure there is adequate time to discuss and answer patient's questions before discussing
 Discuss the message with the patient in a confidential, sensitive, supportive manner
- · Inform patient of importance of treatment
- Encourage the patient to seek follow up care
- Arrange for follow-up care and treatment Provide treatment if indicated (i.e. syphilis only) · Indicate Actions Taken during the intervention
- The Recommended Actions have been designed collaboratively by diricians and public health professionals to guide clinicians on proposed content and flow of the discussion and intervention

Will patients know their disease status or will the clinician be breaking the news?

- Some of the patients may not have been informed of their infection status (those who didn't return for results or who OPH was unable to locate).
- · Others will know their results but may have not accessed care or completed treatment.
- Prior to discussing any LaPHIE message, it is IMPERATIVE that the clinician check the identity of the patient against the patient's CLIQ record before communicating the information.

What if the clinician does not have the clinical expertise to treat these conditions?

- Clinicians do not need to be an Infectious Disease Specialist to be able to intervene with a person out of care for HIV, TB or syphilis.
- . The intent is to be able to intervene with the person while he or she is in the clinical environment.
- The important issue is that clinicians follow the Recommended Actions indicated in the message and patients are linked into the appropriate level of care.
- · The intent is to encourage participation in care.

What if a clinician doesn't act on a message?

- · Actions Taken (Boxes checked) are forwarded to OPH and can trigger removal of the patient from the Out of Care data set. Please check the actions completed!
- If no actions are taken (no boxes checked), another out of care message will appear the next time the patient registers in the LSU
- Failures to reply to LaPHIE messages will be monitored by LaPHIE team members (by user)
- Please remember, many patients for whom messages will be issued may only enter the system on occasion. It is critical we don't miss an opportunity to offer the care and treatment they need.

What if a patient refuses treatment or claims the message is an error?

- · There is a place to document the refusal under Actions Taken.
- · HIV patients are within their rights to refuse treatment.
- TB or Syphilis patients refusing treatment should be told they are breaking the law.
- OPH will receive refusal information on patients with Tb and syphilis IF the clinician checks the refusal box.
- · If a patient claims there is an error, clinicians should document their issue and offer re-testing.
- Please note that LSU HCSD and OPH have worked diligently to make sure that only persons with confirmed cases of infection and an "out of care" status are in the dataset. However, there is a toll free number listed in the hover overs for patient to call to speak with OPH personnel if sihe desires.

Self Test **Questions 1-5**

- LaPHIE is a secure, bidirectional information exchange between the LSU hospital system and the Louisiana Office of Public Health. True or False
- Everyone in Louisiana who has been diagnosed with HIV, syphilis, and/or tuberculosis will be targeted by LaPHIE. True or False
- Only out of care persons with HIV, syphilis and/or tuberculosis that match on Last name, First name, DOB, and SSN will have messages sent back to the patient's record in CLIQ. True or False
- When a LaPHIE match occurs, a message box appears on a patient's summary page in CLIQ and must be acknowledged before a provider can work with the patient record. True or False
- 5. The yellow message bar will remain active on the patient summary page in CLIQ if providers need to address the LaPHIE message at a more convenient time during the patient visit. True or False

Self Test Questions 6-10

- Hover overs prompts will appear when you move your mouse over
 "Recommended Actions" and "Actions Taken" to help guide your interaction with
 the patient. True or False
- How do you document LaPHE interactions with patients? Select correct answer
 a. Chaoking off "Actions Taken" only
 b. Chaoking off "Actions Taken" and documenting in the paper chant
 c. Documenting in the paper chart only
 d. Typing comments in the comment box
- You must hit SAVE in order for the LaPHIE system to process your "Actions Taken" and remove a patient from the out of care dataset of the Office of Public Health.

 True or False
- If no action is taken on a LaPHIE patient, another LaPHIE notice/message may appear on the patient summary page the next time the patient registers in the LSU system. True or False
- LaPHE messages/notices in CLIQ are displayed to any staff member that logs onto CLIQ. True or False

Self Test Answers

- 1. True
- 2. False
- 3. True
- 4. True
- 5. True
- 6. True
- 7. B
- 8. True
- 9. True
- 10. False