Louisiana Public Health Information Exchange (LaPHIE)

The following program description was written by representatives from the Louisiana Department of Health and Hospital's Office of Public Health STD/HIV Program and from the Louisiana State University's Health Care Services Division. The description is provided as an example of how this jurisdiction is conducting data to care work. CDC has not been involved in the development, implementation or evaluation of this program.

Project Overview

LaPHIE is a secure, bi-directional exchange of public health information between the Louisiana Department of Health and Hospital's Office of Public Health (OPH) and eight medical centers across Louisiana. The exchange uses OPH's surveillance data to alert clinicians of the LaPHIE participating facilities that a patient with HIV may be unaware of their HIV status or out of care.
How it works:

1) When any patient registers at a participating medical center, his or her identifying information is added to the medical center's electronic registration system.
2) The facility electronically notifies OPH (via LaPHIE) that the patient has arrived. It sends the patient's demographic information to a secure, designated LaPHIE server housed at OPH.
3) When OPH receives an alert from the facility, the LaPHIE logic checks the out of care patient database to determine if the patient has not been receiving care.
4) If OPH finds a match in it's out of care database, it automatically sends a standard, disease-specific electronic alert to the facility's electronic medical record (EMR) system.
5) The EMR system receives and stores the alert from OPH. Then it displays the alert as a pop up alert for authorized clinicians who open the patient's EMR. When clinicians click on the alert, they see a list of suggested actions which can be checked off on the screen.
6) After a patient meets with a clinician, the EMR system automatically returns a message to OPH, reporting how doctors and nurses responded to the alert.
7) OPH adds this information to its databases, which are automatically updated nightly to determine which individuals should be included in the out of care dataset.

Health Department Program Integration

The Louisiana Department of Health and Hospital's Office of Public Health STD/HIV Program is a combined program under a single Administrative Director that includes surveillance, prevention, and care programs for both HIV and STD. The STD/HIV Program has a Data Management/Analysis Unit which conducts data entry, management, and analysis of data from surveillance, prevention and services data systems facilitating data linkage and timely analysis.

The STD/HIV Program has five core programmatic sections: Surveillance/Data Management, Prevention, Care and Services, Regional/Field Operations, and Program Evaluation, and has 85 full-time employees. In Louisiana, a medium morbidity jurisdiction, approximately 1,200 people are diagnosed with HIV each year, and as of December 2012, 18,700 persons were known to be living with HIV infection in the state.

LaPHIE Program Description

The LaPHIE program, one of Louisiana's data to care initiatives, uses a healthcare provider model to directly contact patients and facilitate linkage to or re-engagement in care. Providers (physicians, registered nurses, physician assistants, and nurse practitioners) who practice within the participating medical centers are the facilitators of this data to care work.

When a patient registers at any of the participating medical centers, demographics collected at registration are sent to the LaPHIE server at OPH and matched against the OPH out of care dataset in real time to determine if the registered patient is an individual for whom an alert should be issued. When records match exactly, a LaPHIE alert, issued as a standard HL7 Patient Problem (PPR) message, is sent back to the EMR where the LaPHIE alert is presented to providers on the opening screen of the patient's record. Alerts are only visible to clinicians who have a "nurse and physician" security role to limit visibility to those clinicians who are in a position to take action. When clinicians see the alert, they have an option to *Take Action Now* or *Take Action Later*. When they select *Take Action Now*, they are directed to a screen that includes the clinical support recommendations and a structured documentation tool to record the clinical actions taken. Clinicians are expected to make sure there is adequate time to discuss and answer a patient's questions; discuss the message with the patient in a confidential, sensitive and supportive manner; inform the patient of the importance of treatment; encourage the patient to seek follow up care; and arrange for follow-up care and treatment.

After the medical provider speaks to the patient they record one or more of the actions taken: 1) discuss OPH message and need for treatment with the patient; 2) re-order a confirmatory test; 3) assess stage of illness; 4) schedule/refer for a follow-up appointment; 5) counsel pregnant patient; 6) document patient report of receiving treatment at another site; and 7) confirm patient is not interested in treatment at this time. The medical provider checks off the services that are provided on the LaPHIE screen in the EMR, and this information is automatically sent back to OPH. If an alert is missed, a department supervisor either notifies the clinician or follows up directly with HIV clinic staff who can attempt to contact the patient to assist with linkage to care.

When a provider selects to take action later, the alert continues to post with each return to the Patient Summary Screen, alerting the provider that action is still needed. Alerts are turned off at patient discharge. When an alert triggers, an email notification simultaneously posts to medical center personnel assigned to monitor LaPHIE to avoid missed opportunities when a provider chooses to *Take Action Later* or fails to respond to an alert. Should an alert lack response, a unit supervisor can communicate to staff the need to follow-up with the patient.

Use of Surveillance Data and Quality Assurance

For persons living with HIV (PLWH), the definition for "out of care" is no record of a CD4/VL in the OPH surveillance database in the past 9 months. For persons newly-diagnosed with HIV, the definition for "out of care" is no CD4/VL in the OPH surveillance database in the 6 months since the HIV diagnosis date. In order to be included in the LaPHIE out of care dataset, a person must be alive, have a current address in Louisiana, and have had at least one confirmatory lab result since 2000. Persons with a physician diagnosis only are excluded.

LaPHIE uses both new HIV diagnoses and prevalent cases (i.e., persons living with HIV in Louisiana) to determine which individuals are out of care. All persons identified as out of care who meet the LaPHIE inclusion criteria are included in the LaPHIE out of care dataset. There is no prioritization of cases with LaPHIE.

Because LaPHIE is an automated system that alerts providers that they are seeing a patient who is HIV-infected and out of care, it is critical that laboratory data be timely, complete and accurate. OPH monitors laboratory data quality on an ongoing basis through a variety of mechanisms. The majority of laboratory data are reported electronically on a daily basis through "Alexander." (Alexander is an automated, custom-built computer program for parsing and storing electronic lab reports that is written in the Visual Basic language and runs on the Microsoft .NET 4 platform.) Electronic labs arrive at OPH through a secure, encrypted connection. If a file cannot be automatically imported (because of missing data or invalid format), an email alert is sent to data management staff informing them that the file did not import. In addition, OPH uses a database auditing routine that scans available data to automatically determine both when a sending lab last reported to OPH and how frequently a sending lab reports to OPH. If the program finds that a lab is behind schedule, it sends an email alert to data management staff. OPH also uses the "Benjamin" program to monitor labs. The program provides an easy-to-use, point-and-click screen that makes it simple for data managers to monitor how many records each sending lab has reported to OPH during a given time period. Lab completeness is monitored through queries that analyze the monthly volume of lab reports for each test type (CD4, viral load, etc.) by the laboratory submitter (e.g., LabCorp, ARUP, participating facilities' labs) and by medical provider. Each week surveillance supervisors review lab QA reports, and the Laboratory Surveillance Coordinator immediately follows up on any issues.

As described above, HIV surveillance data trigger linkage to care follow-up activity. Participating medical facilities share the following variables with OPH on all persons who register for a clinical encounter: medical record number, name, DOB, and SSN. For all persons who match OPH's out of care dataset, OPH sends back the MRN and an alert in HL7 format. The alert for persons out of care for 9 months is "The LA Department of Health and Hospitals Office of Public Health records indicate that this patient has HIV, but does not appear to have accessed HIV-related medical care in at least the last 9 months. No CD4 or viral load test results have been received by OPH from public or private laboratories." The alert for persons who may not be aware of their HIV status is "The LA Department of Health and Hospitals Office of Public Health has received and confirmed test results that indicate that the patient has HIV infection and possibly has not been informed of the results."

LaPHIE has ongoing monitoring of each alert for validity. Each LaPHIE alert, whether acted upon or missed, is recorded and reviewed. Any data issues on either the OPH or medical center side are immediately investigated by Data Management staff. LaPHIE staff follow up with providers who miss alerts to ensure they understand their role in responding to alerts and assisting patients with linkage to care. There are also mechanisms in place for ongoing feedback from providers and patients. Any time the LaPHIE eligibility criteria or any other aspects of the protocol are being changed, the LaPHIE legal/ethical workgroup and project leadership meets beforehand to ensure that the changes are in line with the mission and scope of LaPHIE and to ensure that there are no risks to patients. LaPHIE has had both external and internal evaluators and program monitors to evaluate the effectiveness of the system. Data on the number of alerts issued, the actions taken for each alert, the percentage of persons linked or re-engaged in care and retained in care, viral load/CD4 values upon entrance to care and other indicators are monitored to determine program success.

Development of LaPHIE

LaPHIE was initially funded through a Health Resources and Services Administration (HRSA) Special Project of National Significance (SPNS) grant award to the LSU Health Care Services Division which

deployed LaPHIE in eight public medical centers under its management. Since the implementation of LaPHIE, the LSU public hospital system has transitioned into a system of public-private partnerships with six of the eight LaPHIE medical centers now under private management, one still under LSU, and one facility closure. Despite the transition, the partnerships continue and LaPHIE operates at the seven remaining medical centers with existing staff and without any additional funding. OPH received a new HRSA SPNS grant in 2011 to expand LaPHIE to a private, not-for-profit hospital in Baton Rouge which will be implemented in early 2014.

Staffing for LaPHIE includes the following: 6 partial FTEs who manage the daily operations of LaPHIE; three are from the Louisiana State University (LSU) Health Care Services Division (Project Coordinator and two Informaticists who were part of the original grant team), and three are from OPH (Project Coordinator, Surveillance Manager, and IT Manager). Additional staff, such as clinicians, program directors, experts in compliance, the LSU Chief Medical Officer and the OPH HIV Administrative Director offer in-kind support.

Program development for LaPHIE took approximately three years. LaPHIE was implemented in one location (New Orleans) in February 2009, and then later expanded to the other 6 regions. LaPHIE is now conducted at medical centers in seven regions of the state: New Orleans, Baton Rouge, Houma, Lafayette, Lake Charles, Alexandria, and Hammond/Slidell.

Program Collaboration

Program collaboration was achieved through the establishment of a LaPHIE Executive Committee comprised of partners' leadership and several subcommittees (e.g., legal/ethical, IT/data systems) that met frequently during the development and implementation of LaPHIE. In addition, clinician acceptability was evaluated throughout the intervention. Interviews were conducted with clinician and public health end-users prior to launch to measure concerns regarding confidentiality and exchange of sensitive information. These revealed support for the project, with the perception it would improve the care of both individual patients and the community. LaPHIE EMR alerts were designed with input from clinicians and public health personnel through an iterative prototype design process as well as clinician 'cognitive walk through' of the alert.

All information is securely shared electronically using the concept of sharing the "least amount of information necessary to achieve the public health outcome."   The out of care dataset is maintained on a separate secure LaPHIE server behind the OPH firewall with very limited access to the server.

Provider Involvement

From the start, all LSU physicians, nurse practitioners and registered nurses were involved in LaPHIE and were trained on what to do when they received an alert. Providers were actively involved in the design and implementation of LaPHIE and continue to give feedback on the performance of the system.

LaPHIE Outcomes, Success Factors and Lessons Learned

As of April 2013, LaPHIE has successfully identified over 1,000 persons out of care. Of the 854 persons who had an alert as of December 31, 2012, 69% were linked to care within 90 days. Providers are responding to LaPHIE alerts at a higher rate than usually observed with EMR alerts. LaPHIE has a user-friendly interface, and the alerts are patient specific. They are only issued on patients in need of

treatment and are integrated into the work flow, characteristics which effectively overcome alert fatigue. In addition, patient feedback has been very positive, with no complaints received to date on the LaPHIE hotline. Qualitative post-intervention interviews were conducted with 20 HIV-infected persons identified via LaPHIE, and they expressed acceptance and recognized the value of the system.

Several factors contribute to the overall success of LaPHIE. These can be summarized as deliberate, inclusive and evidence-based planning and development processes.

1. The partners allowed ample time for thorough data analysis, mapping of existing public health and health care work processes, assessment of partner and community acceptability of the identified solution, legal and ethics reviews, and design and testing of a proof of concept. LaPHIE started with a conversation among a small group of public health and hospital system staff on the need for improved collaboration to address the large number of HIV-persons who were out of care. Out of those initial conversations grew a formalized partnership which established a set of guiding principles and a governance structure that exists today. The Executive Team of the partnership oversees the project and has always stressed the importance of inclusion of stakeholders and commitment to the original mission. The team includes diverse personnel from partner entities as well as community advisors that work to not only maintain the system, but to ensure it is evaluated on an ongoing basis and continues to fulfill its mission.

2. The importance of having timely, accurate surveillance data is critical.   LaPHIE does not want to incorrectly identify a person as HIV-infected who is not or tell a person they are out of care who recently had labs. Prior to LaPHIE, OPH received LSU laboratory results on a monthly basis, but more timely labs were necessary with LaPHIE, so LSU laboratory results, as well as labs from several large national reference laboratories, are now received on a real-time basis and are imported daily. There is always a balance between the desire for 100% reliable surveillance data and the desire to include as many out of care persons as possible. Eligibility criteria for LaPHIE, or any other intervention that uses Surveillance data, should be reviewed periodically to determine whether additional persons can be added to the intervention or whether there are reporting delays or incomplete data that might necessitate revising eligibility criteria.

3. Health care delivery and public health systems possess diverse organizational cultures which both sides should explore and understand. Much of this stems from the fact that health care is a 24 hour/7 day/week enterprise with direct patient care, while most public health systems function with more limited hours and patient contact. These systems have different resources, types of staff, and organizational policies. Partners should not force the other to change, but rather explore ways to work together effectively.

4. When embarking on a change which may be controversial, it is best to include as many affected stakeholders as possible and to be transparent in explaining the project plans. While the LaPHIE team did a good job of including the relevant stakeholders and incorporating their feedback, a few times there were individuals who were unfamiliar with the project and shared their concerns. Staff reached out to those individuals to correct their misinformation and update them on the project status. Rather than ignoring these individuals, the partners chose to invite them to be more involved in the project. This tact has proven successful. In fact, the acknowledgement and management of the opposing opinions has further advanced national discussion on the use of surveillance data for individual linkage and retention projects. In the

future, this could be prevented by devising a communications mechanism to medical societies and national HIV advocacy groups or others which may take a position.

5. User support is also extremely important. Having a resource to field and manage questions from clinical end users is essential, especially when the technology is new. It is also advised that any new technical features not be rolled out at the end of the week or on the eve of holidays when support and maintenance personnel may not be as readily available should issues arise.

Community Engagement

During development, the LaPHIE project team conducted 16 focus groups with 149 patients with HIV or other potentially life threatening and/or stigmatizing conditions and 23 key informant interviews with patients with HIV who were infrequent users of healthcare. The purpose of the qualitative research was to measure affected individuals' opinions on the purpose and structure of this exchange of protected health information. In addition, numerous meetings with community providers and planning bodies were held prior to and during the implementation of LaPHIE. There is ongoing consumer involvement in project workgroups, particularly the legal/ethical work group.

Legal and Ethical Considerations

During the development of LaPHIE and prior to the exchange of data, there was an ethics panel discussion with national experts in biomedical ethics, public health ethics and AIDS privacy. In addition, there was a legal review of state legislation by the Louisiana Department of Health and Hospital and LSU legal staff to ensure OPH data could be shared, and they produced a written report of their findings. A data sharing agreement between OPH and the LSU system was also executed. Existing LSU and OPH data security/confidentiality policies were reviewed and were considered to adequately protect PHI.

Partnerships

LaPHIE began as a partnership between OPH and LSU, and now includes the seven participating public-private medical centers who have assumed management of the former LSU medical centers, as described earlier in the document. During the process of developing LaPHIE, an external partner, the Louisiana Public Health Institute, served as a neutral convener and assisted with project development, scheduling and facilitation of meetings, and ensured that the needs and concerns of both partners, OPH and LSU, were addressed.

Training Activities

Prior to the implementation of LaPHIE, the LSU Project Coordinator conducted in-depth training with all LaPHIE "Superusers" at each participating medical center. A Superuser is responsible for overseeing LaPHIE in their unit, and they are emailed every time there is an alert to ensure appropriate follow-up has occurred. The Superusers provide LaPHIE training to all clinicians in their unit. In addition, a LaPHIE module is included in the mandatory on-line training that all new LSU clinicians receive upon hire, and that all other clinicians complete annually. The module explains the purpose of LaPHIE, provides instructions on what to do when an alert is received, and describes what to do if a patient refuses treatment or claims the alert is an error. At the end of the module, the clinician is required to complete a ten question self-test.

Links to LaPHIE-Related Resources

Additional information is available on www.HIV411.org.

LaPHIE Publications

Herwehe J, Wilbright W, Abrams A, Bergson S, Foxhood J, Kaiser M, Smith L, Xiao K, Zapata A, Magnus M. Implementation of an innovative, integrated electronic medical record (EMR) and public health information exchange for HIV/AIDS. J Am Med Inform Assoc [Internet]. 2011 Oct 28. Available from: http://www.ncbi.nlm.nih.gov/pubmed/22037891.

Magnus M, Herwehe J, Gruber D, Wilbright W, Shepard E, Abrams A, Foxhood J, Smith L, Xiao K, DeYoung K, Kaiser M. Improved HIV-related outcomes associated with implementation of a novel public health information exchange. Int J Med Inform. 2012 Oct;81(10):e30-8. doi: 10.1016/j.ijmedinf.2012.06.005. Epub 2012 Aug 9.