Title: *Strengthening Health Information Systems to Support Post-Disaster Healthcare in Haiti*

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Report Type and #: *4th and Final Report*

Date: November 4, 2013

IDRC Project Number-Component Number: *#106147-001*

Country/Region: Haiti

Period covered by the report: *30 March 2010 – 30 June 2013*

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Abstract: In a disaster setting, access to health information can mean the difference between life and death. In the wake of the January 2010 earthquake in Haiti, Partners In Health (PIH) and I-TECH sought to develop an integrated health information system that would enable the Haitian Ministry of Health (MSPP) to improve its response should another major disaster occur. With funding from the International Development Research Centre (IDRC), PIH and I-TECH set out to answer four questions:

1) How can health information systems (HIS) best capture patient data in a post-disaster setting?
2) What HIS design can most effectively minimize duplication and errors from multiple systems?
3) How can HIS aid disease surveillance in a post-disaster setting?
4) How can HIS improve quality and access to care as health systems are rebuilt?

The enhanced patient information systems can be found here:

- Open MRS: www.openmrs.org
- Open Boxes: https://github.com/pih/openboxes
- iSanté: https://sites.google.com/site/isantehaiti/

Keywords: Haiti, Disaster, Health Information Systems, Informatics

Glossary of Terms

Abbreviation	Full Name/Description
CCD	Continuity of Care Document, an HL7 standard
CDA	Clinical Document Architecture, an HL7 standard
CDC	US Centers for Disease Control and Prevention
eHealth architecture	Information standards and system functional specifications to support the electronic use and exchange of both individual and population information, from the facility to the national level.
EMR	Electronic Medical Record
HIS	Health Information Systems
HIV	Human Immunodeficiency Virus
iSanté	The Haitian national EMR, developed and implemented by I-TECH, CDC and MSPP
IDSR	Integrated Disease Surveillance and Response
I-TECH	International Training and Education Center for Health
MDR-TB	Multi Drug Resistant Tuberculosis
MOH	Ministry of Health
MSPP	Ministère de la Santé Publique, the Haitian Ministry of Health (http://www.mspphaiti.org)
OpenBoxes	An open source stock management tool being developed by PIH
OpenELIS	An Open source laboratory information system developed by the Association of Public Health Laboratories and implemented in Haiti by I-TECH (http://haitilis.wordpress.com/)
OpenMRS	Open Medical Record System, an Open Source EMR
PIH	Partners In Health
WHO	World Health Organization
ZL	Zanmi Lasante, the sister organization of Partners In Health in Haiti

I. Executive Summary/Research Questions

In a disaster setting, access to health information can mean the difference between life and death. In the wake of the January 2010 earthquake in Haiti, Partners In Health (PIH) and I-TECH sought to develop an integrated health information system that would enable the Haitian Ministry of Health (MSPP) to improve its response should another major disaster occur. With funding from the International Development Research Centre (IDRC), PIH and I-TECH set out to answer four questions:

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2) What HIS design can most effectively minimize duplication and errors from multiple systems?
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The overall goal of the grant was to mitigate the impact of the January 2010 earthquake and strengthen the healthcare system in Haiti, through the application of broad informatics methods to improve, integrate, and build interoperability among information systems through action research, collaboration, and learning. This goal would be accomplished by implementing and evaluating practices that would support and improve delivery of healthcare in Haiti in both short-term, emergency relief work and in long-term rebuilding efforts.

PIH and I-TECH both achieved significant accomplishments that were directly supported or facilitated by this grant award:

- Development of a new patient registration and primary care EMR based on OpenMRS which has laid the foundation for OpenMRS 2.0, piloted at University Hospital of Mirebalais
- Use of OpenMRS patient registration system developed at Lacolline Hospital to capture patient demographic information by commune, allowing creation of maps showing the geographic distribution of disease burden, such as cholera
- Expansion of the iSanté EMR to include primary care and maternal health modules, as well as a data warehouse and interface supporting malaria surveillance
- Improvements to iSanté EMR system to allow interoperability with laboratory systems such as OpenELIS
- Support for the deployment of the OpenBoxes, an open-source medical supply chain and inventory management software
- Development of interoperable patient summaries for HIV care based on the CCD standard
- Deployment and fine tuning of an improved version of OpenMRS for MDR-TB
- Support for the initial development of the Maternal Concept Laboratory
- Evaluation and fine tuning of the user experience with OpenMRS

The enhanced patient information systems can be found here:

- Open MRS: www.openmrs.org
- Open Boxes: https://github.com/pih/openboxes
- iSanté: https://sites.google.com/site/isantehaiti/

II. Project Objectives

To fulfill the grant goal, PIH, I-TECH and IDRC agreed on the following objectives:

1. To both enhance existing and develop new Haitian eHealth system functionality, and introduce principles of a standards-based national architecture, by i) drawing upon data architectures and standards being implemented in other resource-poor settings, ii) focusing on the development and evaluation of those standards to support web and mobile device applications, and iii) using standardized domains and applications;
2. To collect and analyze data about the implementation, coordination and clinical use of the different eHealth systems involved in this project and the success of different strategies for connectivity and hosting of systems; and

3. To share and broadly disseminate lessons from this experience to inform other Electronic Medical Record (EMR) efforts in post-disaster environments through meetings and workshops focused on Haitian initiatives and through scholarly publication.

While these remain the key objectives, there have inevitably been shifts in priorities and timing as the health system and the eHealth projects linked to it have evolved since the earthquake to make the funded activities more responsive to emerging needs. Delays in establishing some of the projects, such as the expansion in the use of OpenMRS, impacted the timeline of evaluation work, and shifts in government priorities affected work on surveillance, mHealth, and educational meetings. Overall progress was hampered by the cholera outbreak in October 2010 that continues to this day.

III. Technical Activities and Outcomes

Six technical activities were carried out as part of this award:

- Expand the functionality and use of OpenMRS and iSanté at PIH and I-TECH-supported sites in Haiti
- Extend stock management tools
- Extend patient-level care summaries for patients using medical information standards
- Implement automated disease surveillance from EMRs using WHO IDSR guidelines
- Extend interoperability between OpenELIS and the iSanté and OpenMRS EMRs
- Abstract the Master Patient Index (MPI) from iSanté and OpenMRS to function independently and serve multiple information systems

Technical Activity #1: Expand the functionality and use of OpenMRS and iSanté at I-TECH and PIH-supported sites in Haiti

Context: Unlike the US where most medical providers have transitioned to electronic record keeping, most facilities in Haiti still use paper-based patient charts. The disadvantages of paper-based systems, such as incomplete or lost medical records, inefficient management of patient flow, and limited record keeping organizational tools and procedures, are quality issues that HIS strive to ameliorate. With an electronic-based system, patient data can be protected and backed-up, patient registration and wait times are reduced, and coded diagnoses ensure higher data quality, all of which ultimately improve clinical care outcomes. The main challenges of implementing HIS solutions in low-resource settings include lack of IT infrastructure and resources, as well as limited training capacity for clinicians and data clerks to become effective HIS users. Both I-TECH and PIH have a long-standing presence in Haiti and both work in close partnership with the MSPP. However, each organization had health information systems with limited functionality that needed to be developed, modified and expanded before they could be integrated together and into the MSPP system.

Activities: In early 2012, the PIH/ZL Medical Informatics team deployed a point-of-care EMR and patient registration system at Lacolline Hospital in Lascahobas. Adapted from a version used at PIH sites in Rwanda, the system captures demographic information, assigns unique identifiers, and prints out ID cards. It also allows for retrospective diagnosis capture. In addition to a registration system, PIH enhanced and deployed an MDR-TB system. The team has created and integrated a list of coded diagnoses, using the WHO's ICD-10 coding guidelines, and patient records for each patient are linked to clinicians login IDs. The site's Clinical Director reviews the frequency and accuracy of these diagnoses with his team on a weekly basis. PIH also developed specialized vocabularies, forms, and subsystems to improve diagnoses and tracking of patients receiving women's health care, MDR-TB treatment, or surgical care. The experience at Lacolline Hospital significantly contributed to the design and functionality of the newest EMR system implemented in March 2013 at the University Hospital of Mirebalais. Please see the following article on the impact of the EMR at University Hospital: http://www.pih.org/blog/university-hospitals-open-source-emr-a-model-for-evidence-based-health-care.

Figures 1 and 2 demonstrate how data extracted from the EMR at University Hospital can be used to inform decisions about how to allocate staff and resources to ensure access to high-quality care for patients.

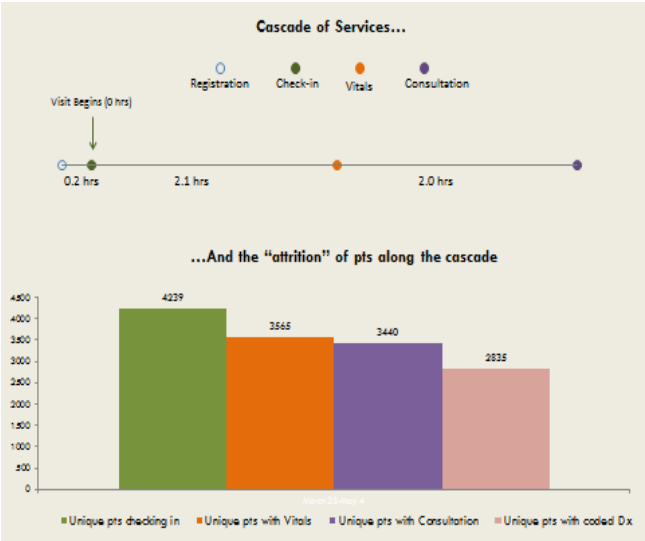

Figure 1: University Hospital Cascade of Services

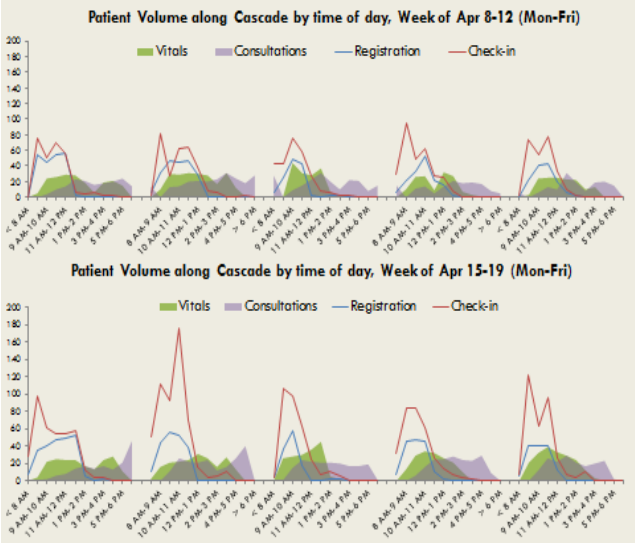

Figure 2: University Hospital Patient Volume

I-TECH worked with the MSPP to deploy new forms for primary care and women's health at PEPFAR-supported hospitals and clinics in Haiti. I-TECH clinical staff collaborated with a national stakeholder committee for strategic information systems (CONASIS) to define the content of these forms and the content of routine quality of care and aggregate facility reports to be produced from these forms. I-TECH then programmed the forms and reports into version 9.0 of iSanté, released in December 2010. Under support from I-TECH's HRSA grant, I-TECH Haiti staff collaborated with MSPP and CDC staff to deploy iSanté version 9.0 in 2011. In addition to the completion of version 9.0, I-TECH had the following accomplishments:

- A new user interface framework was developed to remove dependency on the format of the physical form, make it easier to navigate for the end user, and to provide data element validation prior to form submissions.
- Improvement and standardization of iSanté installation and setup by converting to a virtual machine deployment. Distance training was conducted on virtual server and virtual machine installation, setup, and administration to I-TECH Haiti IT staff and CDC staff.
- A national consolidated server was implemented within Haiti MOH. I-TECH transferred ownership of administration, data loading process, hosting, and responsibility of the de-identified national consolidated server to Haiti UGP. As part of the transfer of ownership, the University of Washington began transitioning the University of Washington hosted server. This transfer of ownership and centralization of data will be useful for national-level reporting, and the development of a process and technical approach for a national master patient index (MPI).

I-TECH also began exploration of the MVP concept dictionary to map concepts to iSanté. This is a key step for standardizing data collection, the syntax and semantics of those data elements, reporting from the data set, and exchange of data between health information systems, including establishing interoperability between iSanté and OpenMRS. The iSanté database structure was modified to accommodate the new standard concept dictionary and future mapping of concepts between multiple concept dictionaries. I-TECH began developing an interface tool to be able to search for, identify, and map both existing concepts and new concepts from the primary care and women's health forms into iSanté. Plans to complete the full integration of the MVP concept dictionary are beyond the funded scope of this project; however, I-TECH will seek to complete the work through other resources in the future.

While IDRC-supported work in this area ended in 2012, the momentum for deployment of the new iSanté modules continued beyond the period of IDRC support. As of June 2013, 88 facilities were using iSanté for capturing data on HIV patient care, 53 sites were using it for women's health and 43 sites were using it for primary care.

Key Outcomes

- Patient data from the Lacolline EMR have been actively used for clinical program evaluation and strengthening.
- The MDR-TB system enabled clinicians to better track treatment regimens and clinical outcomes. This is described in Annex C*: E-Health Systems for Management of MDR-TB in Resource-Poor Environments: A Decade of Experience and Recommendations for Future Work. Fraser HS et al 2013*
- The affiliated patient card system has helped decrease the amount of time patients need to wait in line—since most patients can have their ID cards quickly scanned—and has helped relieve congestion of paper records. An ID card that can be scanned at different check-in points throughout the hospital can easily show the volume of patients throughout the day and the average wait time between services, which informs decisions on how to better allocate staff and resources to ensure patients get access to quality care.
- The coded diagnostics have improved the quality of diagnoses captured and facilitated reporting. *Data to support this claim is not yet released for publication.*
- Improved data quality has illuminated the disease burden at the hospital. *Data to support this claim is not yet released for publication.*
- Notifiable diagnoses (i.e., diagnoses that must be reported to the MSPP) are flagged automatically, dramatically reducing the amount of time needed to report on them. *Data to support this claim is not yet released for publication.*
- Maps produced using data from the system have helped illustrate the geographic distribution of patients and diseases seen at the hospital. *Figure 3 shows a map of the distribution of patients registering at Lacolline hospital, providing us with information on where patients are located and where there may be unmet healthcare need.* A poster on the capture and analysis of diagnosis data from the Lacolline EMR was presented at the American Medical Informatics Association Annual Meeting in November 2012 (Ball et al, Annex D).

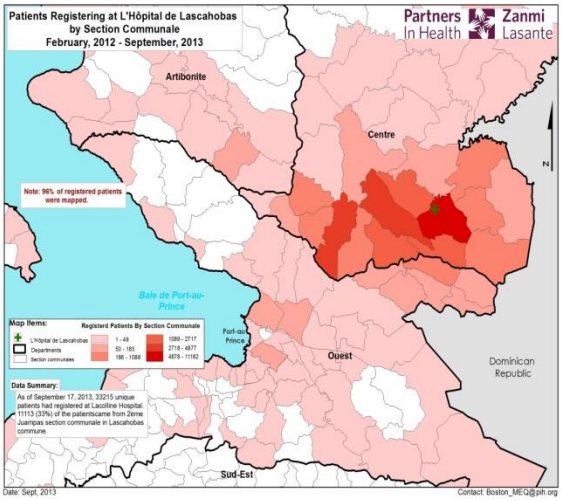

Figure 3. Geographic distribution of patients registering at Lacolline Hospital in Lascahobas.

One of the key intentions of this grant was to share lessons learned from this project to a wide audience. The OpenMRS-TB system developed for Haiti has been demonstrated at three WHO meetings (in the Philippines in 2010, at WHO headquarters in Geneva in 2011, and in Cairo in 2011), at an international conference on Information Technology for Development in London in December 2010, and at the International Union of Tuberculosis and Lung Disease Annual Meeting in Paris in October 2011. It is now forming a key component of a new collaborative project on eHealth and mHealth systems for MDR-TB management working with WHO, IRD in Pakistan, KNCV in Holland, MSH, ABT Associates and the Lilly Foundation in the US.[1] Since the conclusion of this grant, PIH/ZL has been approached to support other MSPP HIS projects, the details of which are still being negotiated.

[1] A paper describing the system was presented at the International Conference of Medical Informatics - Medinfo2013 in Copenhagen in August 2013. The paper is accessible at: http://ebooks.iospress.nl/publication/34074.

Technical Activity #2: Extend stock management tools

Context: In the aftermath of the Haiti earthquake in January 2010, PIH identified the management of purchased and donated medications and medical supplies as a crucial need for its daily operations. A review of existing third party systems failed to produce a viable option.

Activities: PIH/ZL developed and deployed OpenBoxes, its open source inventory and supply chain management system, at University Hospital and PIH/ZL's warehouses in Miami and Port-au-Prince. OpenBoxes is designed to manage the flow of supplies between warehouses, and the issue of stock from these warehouses to wards and dispensaries. The system's functionalities include: creating and classifying products, recording initial inventory levels, performing inventory counts, adjusting inventory levels, recording purchase orders, creating and sending shipments via air, sea or land, and receiving shipments within a depot. The history of each item in the system can also be individually tracked throughout the supply chain process.

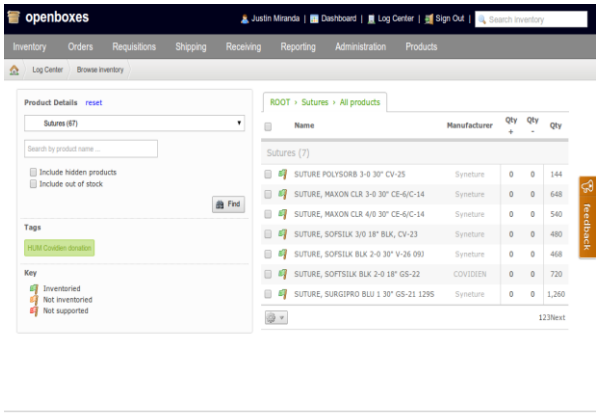

Figure 4. Example of tracking inventory for surgical sutures in OpenBoxes

Outcomes:

- OpenBoxes has greatly reduced the amount of time and effort that PIH staff need to spend to track the contents of a shipment. It has also helped PIH staff quickly find the location of supplies when these are needed in an emergency.
- Going forward, the system will yield important data that will help management at the hospital improve purchasing decisions and run the facility more efficiently.

Technical Activity #3: Extend patient-level care summaries for patients using medical information standards

Context: The existing HIS systems in Haiti did not allow for patient information to be transferred between facilities. When a patient is transitioned from a primary care facility to a hospital or when a patient changes geographic location, they must carry their paper record with them. This often results in patients being registered at multiple sites within a health system, or important patient information getting lost in the transfer process.

Activities: I-TECH created patient summaries for patient transfer within iSanté, following clinical document architecture (CDA) standards for the syntax and format of data summaries. I-TECH researched and tested the IBM OpenHealth framework, which is used in implementation of the Health Information Exchange (HIE) profiles within the United States.

Outcome:

- These simplified tools can be applied quickly to both iSanté and OpenMRS.

Technical Activity #4: Implement automated disease surveillance from EMRs using WHO IDSR guidelines

Problem/Context: In Haiti, no tool existed that would enable the MSPP to predict or quickly respond to disease outbreaks.

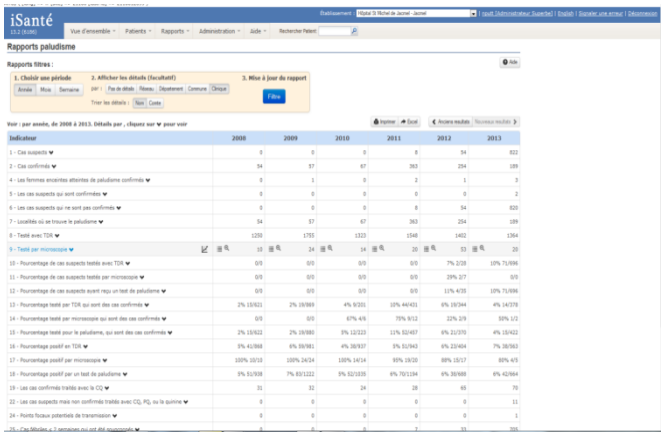

Figure 5. iSanté malaria surveillance interface

Activities: I-TECH developed a malaria surveillance interface that has been rolled out nationally with additional support from other partners.

Outcomes: The outcomes of this specific aspect of work will depend on how the system is used by the MSPP. It was released to the MSPP in March 2013.

Technical Activity #5: Extend interoperability between OpenELIS and the iSanté and OpenMRS EMRs

Problem/Context: Interoperability is the ability of a system to securely communicate and exchange data in an accurate, reliable, and meaningful way with another information system so that the clinical or operational purpose of the data are preserved and unaltered. Interoperability does not translate to assimilation of systems; rather, it is the ability to exchange and report on data without requiring all systems to be identical. Benefits of interoperability in the case of this project extend beyond the patient medical record. It includes additional tools that will be developed to link medical record systems data and pharmacy systems, as well as for disease surveillance, such as for cholera. At grant start, there was no interoperability for systems to effectively interact with the OpenMRS and iSanté systems.

Activities: I-TECH completed the iSanté/OpenELIS interface for lab results and patient demographics in early 2012. In August 2013, I-TECH released new versions of iSanté (version 13.2) and OpenELIS (version 3.3) with improved features for interoperability. PIH and I-TECH initiated design work focused on iSanté and OpenMRS EMR interoperability.

Outcomes: The latest interoperable versions of iSanté and OpenELIS, including transfer of both lab results and lab orders, were released in October 2013. The interoperable systems are being piloted intensively at two MSPP departmental hospitals and will be deployed more widely in coming months.

Technical Activity #6: Abstract the Master Patient Index (MPI) from iSanté and OpenMRS to function independently and serve multiple information systems

Problem/Context: A Master Patient Index (MPI) provides a set of functions useful to manage identity information at the facility, network, department, and national levels. The MPI is a separate server acting as a central repository containing essential patient information across multiple sites. This set-up allows health information systems to contact the server and access information about patients, thereby more efficiently sharing patient information within those systems.

Activities: PIH/ZL completed preliminary work toward this goal by developing the ability for the University Hospital to import data from the Lacolline EMR system. This work occurred beyond the grant funding period but built on earlier IDRC-funded work.

Future Outcome: Once complete the MPI will allow OpenMRS and iSanté to contact the server and access information about patients, thereby more efficiently sharing patient information. Emerging MSPP and donor priorities may delay completion of this product.

IV. Research and Learning Activities and Outcomes

Our research and learning goals were to:

- Examine EMR implementations as part of a model of healthcare and broader social and development initiatives.
- Identify barriers and enabling principals to the development of policies which enable the sharing and transfer of HIV care and treatment information in the setting of significant population displacement.
- Identify key flows of data and resources on which to observe and collect data
- Examine past experiences of EMRs in responding to disasters and contributing new reflections and insights on empirical evidence from this collaborative effort in Haiti

- Evaluate different ways of deploying EMR systems in such environments including remote servers, local servers, handheld devices and cell phone-based tools
- Evaluate the use and effectiveness of the tools that have been developed from the point of view of clinical and management staff
- Evaluate the field effectiveness of these tools in pilot sites measured by data quality, timeliness and completeness

PIH and I-TECH's work demonstrated multiple ways in which EMR implementation can play an important role in improving the quality, availability and use of data to drive both clinical decisions at point-of-care and programmatic decisions to strengthen healthcare development initiatives. This work included increasing the number and reliability of quality of care indicators available and use of data to drive program evaluation and strengthening.

In order to identify and improve key workflows and evaluate the use and effectiveness of the HIS tools developed from the point of view of staff using them, PIH/ZL completed workflow analysis through usability testing at Lacolline. PIH/ZL also developed a clinician diagnosis reference sheet categorizing diagnoses into functional groupings for doctors to use as a reference. The PIH/ZL Medical Informatics team held regular meetings with the Medical Director to discuss EMR, data quality, and ongoing challenges concerning the EMR system at Lacolline. PIH/ZL staff developed reports to identify different levels of data quality issues that focused on completeness, concordance, and correctness.
The PIH Medical Informatics team maintained its focus on measuring the performance and impact of EMR systems in resource-poor settings through this project in Haiti. The introduction of EMR systems in Lacolline Hospital and University Hospital at Mirebalais have enabled PIH/ZL to more clearly quantify and demonstrate the essential role EMR systems can play in improving health care systems in such settings. This grant demonstrated three key ways that technology can play an important role in the rapid changes in health systems in developing countries like Haiti: (1) the ability to collect core clinical and process data for use by clinicians and managers (2) the ability to capture basic quality of care indicators in real time and (3) the ability to track orders, shipments, and inventories of supplies.

Through the work in the past years, PIH and I-TECH also identified multiple barriers to policy development that would have enabled the sharing and transfer of HIV care and treatment information. Not surprisingly, there was little formal policy development in the wake of the earthquake, and little use of the transfer functionality for several reasons: a) lack of a plan for training providers in its availability and use; b) lack of procedures for assuring providers understood their professional obligations for patient privacy protection in the context of use of this new functionality; c) challenges in policy development and d) lack of clarity on whether this functionality should be enduring in its use or only used during a time-limited period in emergency conditions. Decisions about emergency use of patient data would best be debated and decided during non-emergency periods. However, once the immediacy of need for assuring continuity of HIV care for displaced Haitians receded, it was not necessarily a priority to return to these discussions and decisions. In order to enable the sharing and transfer of HIV care and treatment information (or equivalent data on other diseases), there is a need to create a core data set, implement a patient summary based on that data set using a selected standard, and test the performance of systems for capture, exporting and analyzing that data. Policies on patient confidentiality and ownership of records will need to be clarified with the Haitian government before this can be completed.

PIH/ZL completed workflow analyses to identify key flows of patients and resources used to observe and collect data. Workflow analyses enable PIH/ZL to ensure systems are designed to meet real needs and have positive (or less negative) impacts on productivity while delivering important benefits. The initial usability analysis in Lacolline Hospital is an example of this approach and has been followed by extensive usability testing at University Hospital at Mirebalais.

PIH's IDRC-funded work to develop OpenMRS resulted in new insights into the use of EMRs in emergency situations, such as with the cholera epidemic. The creation of the address hierarchy and its integration into OpenMRS enabled PIH/ZL to map the geographic distribution of cholera patients to better track the burden of disease. Figure 6 illustrates the geographic distribution of cholera incidences of patients visiting the cholera treatment center in Mirebalais, indicating which commune may have a higher burden of cholera or where more treatment outreach may be needed. The lack of such data from the key hospitals in the affected areas in November 2010 was identified as a critical gap in cholera control by MSPP and CDC staff (Hamish Fraser, personal communication).

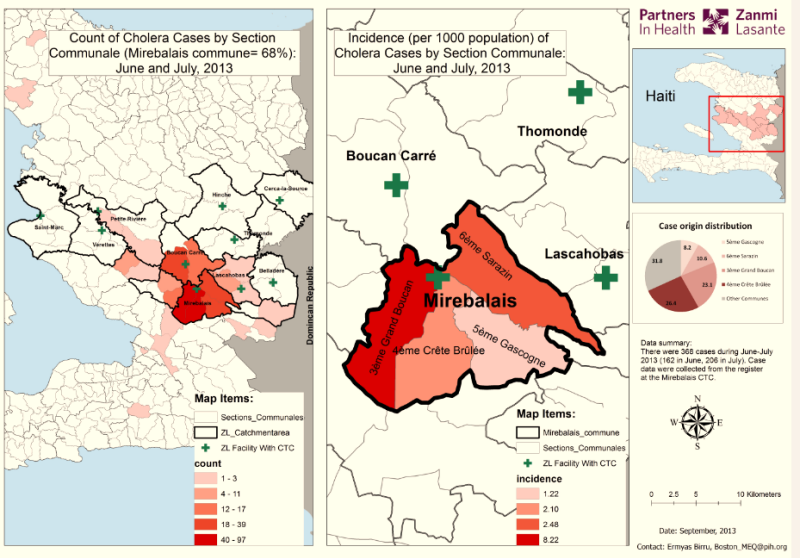

Figure 6. Cholera Cases by Commune at Mirebalais Cholera Treatment Center

In an effort to increase the effectiveness of tools that have been developed from the view point of clinical and management staff, PIH/ZL developed a clinician diagnosis reference sheet categorizing diagnoses into functional groupings for doctors to use as a reference. This tool helped clinicians to more precisely document clinical impressions and made it easier for archive staff to enter the diagnoses. The PIH/ZL Medical Informatics team also held regular meetings with the Medical Director to discuss EMR, data quality, and ongoing challenges concerning the EMR system at Lacolline.

PIH/ZL worked to better understand the effectiveness of tools in terms of data quality, timeliness and completeness by developing reports that identified different levels of data quality issues that focused on completeness, concordance, and correctness. On a weekly basis, staff ran a report to track which patients had paid for a consultation but not received a diagnosis, in order to monitor the completeness of data entry. To track concordance, staff completed monthly lot quality assurance (LQAS) reports. These reports randomly selected 25 patients from visits from a one month period of time, and staff compared what was entered into the system with what was documented on the paper-based chart. To assess correctness, the team created a report that displayed diagnoses that are implausible for a patient's age and sex to identify potential entry errors. In general, the introduction of automated reports through the EMR system (i.e. monthly MSPP reports on certain diagnoses broken down by age and gender) enabled the staff to switch focus from the production of the report itself to the quality of the data being reported.

Writer's Workshop

To further build capacity for medical informatics research and related skills in Haiti, a writing workshop was organized. The workshop occurred in Port-au-Prince on June 3-5, 2013, with members of PIH/ZL, I-TECH, and MSPP present. The first goal was to develop capacity for systematic scientific writing through outcome-focused exercises designed to achieve the second goal of the workshop: to develop, offer ownership of, and fill a "pipeline" of academic writing, from ideas through finished manuscripts. The third day of the workshop was used to facilitate a stakeholder meeting. A workshop summary is included in Annex A.

This workshop was very valuable for discussing issues of interoperability and standards. While we had some difficulty convening workshops during the grant period, in part due to concerns of the participants over the scope of the discussions and the decisions that would be made, convening around dissemination was much less controversial and provided a good platform to discuss many of the same issues.

Abstracts or papers that were initiated at or influenced by the Writer's Workshop include:

- Paper: *iSanté - OpenELIS Interoperability (I-TECH)* – Development of the paper is deferred until I-TECH has additional time to accumulate experience with new technical approaches to iSanté and OpenELIS data exchange, as it will be most useful to describe challenges and lessons learned from improved interoperability features of new versions of iSanté and OpenELIS.
- Paper: *Description of Diagnoses in iSanté Primary Care Sites (I-TECH)* – Development of the paper is deferred until I-TECH can do further investigation of key problems with data quality within the iSanté primary care module.
- Paper and Abstract accepted for presentation at American Public Health Association 2013 Conference: *Addressing data quality gaps to ensure quality of care in a large HIV program in rural Haiti (Dr. Jean-Gregory Jerome of PIH/ZL)* – The abstract discusses a data quality audit designed to increase EMR utility for surveillance and improvement in ZL's HIV program, which began using an EMR system in 2002. Concordance between paper and electronic records was evaluated on selected key data elements for over 22,424 patient records (87% of registered patients). Based on improved data quality, targeted outreach driven by EMR data was initiated for patients at risk for default and those in need monitoring. This research demonstrates how an up-to-date EMR with quality data is crucial for a large-scale HIV program to have real-time access to accurate patient data for care and program surveillance. These challenges with data quality and completeness were in part due to the disruption of systems and staffing after the earthquake.
- Abstract accepted for presentation at the 2013 Global Health and Innovation Conference: *The impact of opening a new tertiary care hospital on geographic care-seeking patterns in rural Haiti (Eddy, et al. of PIH/ZL)* – The abstract discusses an analysis of changes in healthcare utilization patterns in Haiti's Central Plateau after a new tertiary hospital was opened. The assessment measured care-seeking patterns at the tertiary-level hospital and nearby lower-level facilities and found that care-seeking patterns had not been disrupted.
- Abstract accepted at the 2013 ESRI conference: *Using a point-of-care EMR for primary care surveillance at University Hospital in Mirebalais, Haiti (Eddy, et al. of PIH/ZL)* – The abstract discusses an analysis of diagnoses and service utilization using information collected with a new OpenMRS at the University Hospital at Mirebalais.

V. Conclusion and Recommendations

Over the course of the IDRC grant, both I-TECH and PIH learned many lessons regarding implementation of HIS in Haiti. Better training of IT staff is essential, as well as providing simpler, more robust IT infrastructure with effective power backups and easily supported software. Clinicians, managers and ministry of health staff require training on the potential that information systems have to improve access to care, quality of care, supply chain management, and clinical research. Their training needs to emphasize the importance of high quality data and its use with information technology as an enabler, and not an end in itself.

Work on patient identification is of crucial importance in determining which patients come to clinics and ensuring that their clinical data is linked to previous visits, and that data sources such as laboratory forms and prescription forms are correctly labeled. Effective and reliable IDs also form the foundation for effective interoperability between systems.

We have learned a number of lessons about the difficulty of hiring staff to work on informatics projects in Haiti. Hiring PIH-trained Rwandan staff to help with this process also proved challenging. Going forward a key requirement in Haiti will be to set up a medical informatics training program with components for data managers, developers, IT staff, and users.

Open-source systems, such as OpenMRS and more recently OpenELIS, that are developed collaboratively have the potential to allow dissemination of best practices and ideas to many countries. Haiti has benefited from the work performed in other countries in developing and testing the systems, which has also helped to engage the support of other funders and collaborators. As of September 2013, the work funded by the project has informed work in other countries, such as India where the JSS hospital is adopting and co-developing the same OpenMRS system as University Hospital.

Work with OpenMRS and iSanté in Haiti is helping to guide the shift from paper-based data entry to direct entry in an EMR by clinicians and other staff. Interoperability of eHealth systems like ISanté or OpenMRS with OpenELIS can improve speed and reliability of data entry into EMR systems. However, systems have to be carefully designed and tested to ensure reliability. Effective interoperability requires good collaboration between groups leading projects. To ensure sustainability and on-going local capacity building, Ministries of Health must help define, establish and support standards for medical data coding and interoperability.

Evaluation of eHealth systems is essential at all stages in development and deployment. Particular priority needs to be placed on monitoring systems in the field, clinical impact and costs.

As it is not always a priority or feasible for a Ministry of Health in a low resource setting to embrace interoperability and establish a favorable policy environment for interoperable HIS, there is an impulse to focus resources on a single system to reduce the burden of customized software development, training, and system deployment. The downsides of this strategy in terms of suppressing innovation or failing to optimize system implementation in specific local contexts may not be obvious. In Haiti, MSPP is presently actively debating whether it should endorse a single EMR system or sanction multiple systems which meet basic standards. This question was a focus of the discussion at the stakeholder meeting at the Writer's Workshop.

A final lesson from this project is the need to try a wide range of approaches to developing and implementing information systems in environments like Haiti so as to overcome the many challenges faced. The initial plan and timeline had to be revised multiple times and success or continuation of projects was not assured, but the use of established systems like OpenMRS and iSanté provided momentum and allowed sharing of resources and ideas making the process more robust, scalable and replicable.

PIH and I-TECH's recommendations based on experience gained through this project are included below:

- Set up training programs for medical informatics and related skills in Haiti modeled on those in Rwanda, Kenya and the Harvard-MIT eHealth course.
- Develop robust, standard packages of software and hardware and good documentation to implement emergency patient tracking, triage and surveillance. These should be deployable in a range of disaster situations and run on several platforms including PCs and mHealth hardware.
- Promote effective searches for existing designs and tools before embarking on new eHealth and mHealth projects. Such sharing can range from common form or report designs, through curated common data dictionaries like MCL, to sharing of the actual code as with OpenMRS, OpenELIS and OpenBoxes.
- Include resources for robust evaluation of eHealth systems in projects and grants.
- Publicize the challenges seen in informatics projects in Haiti and how they can inform policy and practice in other countries.

PIH and I-TECH are grateful for IDRC's support of their work to strengthen the healthcare system in Haiti through the improved application of information systems. IDRC has funded significant innovations in the use of OpenMRS and iSanté, and this funding has catalyzed the growth of related initiatives that will strengthen the provision of care in Haiti for years to come.

VI. Notes on Supporting Data

Some of the results in this report include or are supported by data that has not yet been released for public dissemination either because it is being included a manuscript in preparation for submission to a peer-reviewed journal or because the data quality, while good enough for internal program evaluation, does not meet our internal standards for public sharing. The PIH and I-TECH teams would be delighted to share full abstracts and papers related to our medical informatics work as they are published.

Annex A: Summary of Writer's Workshop Activities

Day 1:

Summary of IDRC grant activities

Didactic content:

- Getting Started—The Evaluation Question & Writing a Scientific Manuscript for a Peer-Reviewed Journal
- The Methods Section, Working with Tables and Figures for Qualitative Research Articles
- Results & Discussion Sections
- Morning Session Wrap-up, Looking Ahead to Afternoon Session

Initial work on paper concepts

- Discussion of ideas for paper topics

Day 2:

Evaluation of Health Information Systems

Group work on paper concepts and presentations for Wednesday's partners meeting

Day 3:

Partners' Meeting

At the Writer's Workshop, discussion concerning I-TECH's presentation focused on the current use of iSanté and potential research papers regarding iSanté. The iSanté system is widely implemented in 80+ sites, and the iSanté system provides useful data at the individual facility level, but also permits secondary uses of these data for other purposes. For example, iSanté data are currently shared with the MSPP's HASS system for ongoing HIV case reporting and surveillance. I-TECH is encouraging the development of MSPP protocols for appropriate, ethical use of the data for applied research and evaluation.

The group discussed interest in research concerning whether health-worker training and use of standardized data collection tools for clinical encounters together result in greater diversity of diagnoses over time within primary care, based on a comparison of diagnoses recorded within iSanté versus diagnoses recorded in prior paper-based tools. The group also discussed a paper on iSanté – OpenELIS interoperability. In addition to analyzing data on the number, timing, and type of laboratory results transferred from OpenELIS to iSanté at each site, the I-TECH group identified that a manuscript would be strengthened by gathering more data from the sites using the functionality, related to the following questions:

1. What was evidence on technical assistance provided to the sites to assist in use of the interoperability features?
2. What were the technical problems experienced, and how would these be classified?
3. What was the total number of laboratory tests done, by type, which should ideally have had results transferred to iSanté during each monthly period when the interoperability feature was in place?

PIH/ZL presented on a recent effort to review and clean patient data that was undertaken to ensure records were up-to-date with respect to current health status of HIV patients. PIH/ZL's data quality review work was supported by the development of a "data audit summary" tool which helped to highlight invalid data. Discussion centered on the benefits and drawbacks of cleaning data within the EMR versus migrating the data to a summary warehouse prior to cleaning. PIH/ZL also engaged the group in a discussion about a possible evaluation of a planned transition from a paper-based medical record archive at St. Nicholas Hospital in St. Marc to an EMR system.

Broad discussion at the workshop covered the need for an improved understanding of reporting indicators, since different EMRs may compute the same indicators in slightly different ways. The group also highlighted building buy-in of site personnel in improvements in information systems as a critical step in moving HIS work forward. As it can be difficult to build more transparent information systems when transparency is seen as threatening by some entities within the health system, it is important to build

consensus around the importance of evidence-based judgments. Another difficulty for groups engaged in HIS work is encouraging health workers to embrace standardized coding, such as for diagnosis lists. Both PIH/ZL and I-TECH shared examples of when health workers accepted standardized coding with time (at Lacolline and some iSanté sites). PIH/ZL also shared how a simple color-coded tool helped healthcare workers follow standardized coding.

The group's discussion of interoperability focused on the MSPP's information needs and the need to have a unified national system with the possibility of diverse sub-systems which contribute to the common information needs of the MSPP. Stakeholders agreed that it will be important for the MSPP to provide overall directives for strengthening of HIS. Ultimately, interoperability will depend on effective collaboration and engagement of multiple partners. Participants discussed MSPP's interest in CONASIS playing a vital role in convening and informing its decisions.

The group recognized the need to build a culture that supports using data, both at the level of individual patient care but also for programmatic changes, such as using data for resource allocation and procurement decisions. Participants agreed that an important area for further research and evaluation is factors that prevent or encourage the use of data for decision-making, as local use of data at the point of collection is very important for data quality. An additional topic of discussion involved the lack of funding in research initiatives to use existing data; there is a lot of investment in systems for routine data collection, but less investment in data analysis designed to ensure high quality. There can be a strong link between M&E and operational research through the use of existing, accessible data. The group concluded its discussion by highlighting the need for more scientific forums in Haiti, similar to the Writer's Workshop.

Annex B: Partner Information

Partners

PIH is a Boston-based non-profit founded in 1987 to support the work of its sister organization in Haiti, Zanmi Lasante (ZL). PIH/ZL works to promote health care as a human right and demonstrate that high quality healthcare services can and should be provided to the worlds' most vulnerable populations. Today, PIH/ ZL supports healthcare services at twelve sites in Haiti in a partnership with Haiti's Ministère de la Santé Publique et de la Population (MSPP). These facilities include University Hospital at Mirebalais, a state-of-the-art teaching hospital that was built in response to the earthquake in Haiti's Central Plateau, which began operating in March 2013. PIH was an early pioneer in the development and implementation of web-based Electronic Medical Records (EMRs) to support health care in the developing world, introducing an EMR to manage its HIV patients in Haiti in 2003, and working with other international organizations in 2005 to create OpenMRS, an open source, web-based EMR.

I-TECH is a Center created by the University of Washington's Department of Global Health in partnership with the University of California, San Francisco. I-TECH has offices in Africa, India and Haiti. Since 2004, I-TECH has collaborated with the MSPP and the United States Centers for Disease Control and Prevention (CDC) to strengthen Haiti's health system and improve HIV/AIDS treatment and care through expansion of medical services and improved training for health care workers. As part of this work, I-TECH developed a national EMR system known as iSanté. Originally designed to promote quality HIV care and case surveillance, iSanté has been expanded to support maternal health and primary care as well. Prior to the start of the grant, iSanté had been deployed at 67 clinics and hospitals in Haiti, including government facilities, private hospitals, faith-based organizations, non-governmental organizations (NGOs) and other networks.

Partners' Relationship with the MSPP

PIH/ZL and I-TECH are both committed to strengthening the public sector's ability to deliver health care, and as a result, have a close relationship with the MSPP. Staff at PIH-supported hospitals include both MSPP and ZL colleagues, and PIH/ZL leadership works closely with the MSPP in the design of programs and the delivery of services. I-TECH supports health services and trainings in a number of MSPP facilities and works closely with the MSPP's Comité National des Systèmes d'Information de la Santé (CONASIS) as well as other partners on the design and implementation of iSanté.

E-Health systems for management of MDR-TB in resource-poor environments: A decade of experience and recommendations for future work

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Abstract

Introduction: *Multi-drug resistant TB (MDR-TB) is a complex infectious disease that is a growing threat to global health. It requires lengthy treatment with multiple drugs and specialized laboratory testing. To effectively scale up treatment to thousands of patients requires good information systems to support clinical care, reporting, drug forecasting, supply chain management and monitoring.*

Methods: *Over the last decade we have developed the PIH-EMR electronic medical record system, and subsequently OpenMRS-TB, to support the treatment of MDR-TB in Peru, Haiti, Pakistan, and other resource-poor environments.* ***Results:*** *We describe here the experience with implementing these systems and evaluating many aspects of their performance, and review other systems for MDR-TB management.*

Conclusions: *We recommend a new approach to information systems to address the barriers to scale up of MDR-TB treatment, particularly access to the appropriate drugs and lab data. We propose moving away from fragmented, vertical systems to focus on common platforms, addressing all stages of TB care, support for open data standards and interoperability, care for a wide range of diseases including HIV, integration with mHealth applications, and ability to function in resource-poor environments.*

Keywords

OpenMRS, EMR, Multidrug-Resistant Tuberculosis, mHealth, Low-resource Countries

Introduction

Tuberculosis (TB) is a leading cause of death and disability in developing countries and continues to be a public health threat worldwide. Multi-drug resistant TB (MDR-TB) occurs when the *Mycobacterium tuberculosis* strain is resistant to at least the two main drugs used to treat TB (isoniazid and rifampicin), with extensively drug resistant TB (XDR-TB) defined as MDR-TB resistant to an additional two classes of anti-TB drugs. MDR-TB is recognized as a major and growing threat to health worldwide, with large burdens reported in Southern Africa, Eastern Europe, South Asia, China and South America. Eighty-four countries have to date reported at least one XDR-TB case. The World Health Organization (WHO) estimates that about 630,000 TB patients have MDR at any one time and require treatment. MDR-TB is a complex disease which predisposes to chronicity. It generally requires two years or more of treatment with complex and often toxic drug regimens. TB isolates have to be screened for resistance to anti-tuberculous drugs with Drug Sensitivity Testing (DST), and patients' response to treatment has to be monitored by sputum microscopy (smear) and culture [1]. While many countries with high TB burdens have successfully scaled up the treatment of drug sensitive TB with a strategy called Directly Observed Therapy Short Course (DOTS), MDR-TB remains a major challenge with only approximately 19% of the global disease burden currently being reported to be placed on treatment, often of unknown efficacy [1]. Moreover, in many countries, results of DST performed on TB patients are often not reported to the TB programme as a result of inefficient data transfer. Since the effective treatment of MDR-TB has been included in global guidelines [2] it has been recognized that good documentation and information management is needed for effective scale up [3]. Early projects in South Africa, Peru and Latvia demonstrated the benefits of electronic data collection and management for clinical care, reporting and surveillance.

DOTS treatment requires collection of a small dataset on patient enrollment, follow-up, and smear results, but MDR-TB requires much more detailed data on drug regimens, laboratory results, and treatment side effects and complications. A major challenge to effective scale up of MDR-TB is effective forecasting of requirements for specialized second-line anti-tuberculosis drugs, and the management of the supply chain. In this paper we describe more than a decade of development and use of information systems by Partners In Health (PIH) and collaborators to support the scale up of treatment for MDR-TB in Peru, the Philippines, Haiti, Pakistan and other countries, emphasizing pharmacy and laboratory data. We also describe other key information systems in use, and make recommendations for future work to improve interoperability and scale up of such systems and their integration into broader health systems.

Materials and Methods

We describe the development and implementation of two information systems, the PIH-EMR and OpenMRS-TB, including the evaluation of a number of key functions in use in resource-poor environments.

The PIH-EMR

The PIH-EMR is a web based Electronic Medical Record (EMR) System developed by PIH starting in 2000. It was designed to support the scale up of MDR-TB treatment in Peru in a project supported by the Bill & Melinda Gates Foundation and subsequently the Global Fund for AIDS, TB and Malaria. The system was set up and managed by Socios En Salud (the PIH sister organization in Peru) and expanded to support the management of patients in the National TB program (NTP), ultimately being handed over to the Peruvian NTP in 2007. The goals of the PIH-EMR were to:

- support direct clinical care, tele-consultation and quality improvement
- allow reporting to funders, the NTP and WHO
- support clinical research
- improve medication management, including prescribing, dispensing and forecasting of requirements.

The system was developed as a secure web-based EMR with data entry and use in Lima. Custom tools were developed for data quality control, clinical data access, and data analysis [4].

OpenMRS-TB

Several challenges were identified in broadening the use of the PIH-EMR to other countries. Firstly it was designed as a vertical system for MDR-TB, and in particular it had limited tools for supporting the simultaneous care of HIV, a critical issue in sub-Saharan Africa. We also needed a system that was easy for other projects and governments to adapt, translate into other languages and deploy particularly in resource-poor environments. These requirements led us to co-develop a new open source EMR system platform called OpenMRS with partners from the Regenstrief Institute in Indiana, USA, and the South African Medical Research Council [5]. OpenMRS uses a concept dictionary to code data items that can be entered and has a modular software architecture. It was first deployed in 2006 and is now used in over 50 developing countries mainly to support HIV treatment and primary care [6,7].

OpenMRS has a number of key advantages as a tool for managing the scale up of MDR-TB internationally. It has a modular architecture simplifying customization for specific purposes either by the original developers or local implementing organizations. It uses a concept dictionary to describe data items that can be stored allowing the creation and sharing of a definitions of individual concepts or whole, validated libraries. It also supports open standards for data coding such as ICD10, SNOMED and LOINC, and data exchange standards including HL7, promoting interoperability with other systems. OpenMRS supports interoperability with mobile phone software used for field data collection or viewing. Finally, the open source code has helped foster a large international community that develops, deploys and supports the system [6,7].

Results

The PIH-EMR

We have performed a variety of studies that examined the functioning and impact of the PIH-EMR in use in Peru [8]. These included:

1. A study of a component developed to support order entry of drug regimens for MDR-TB. This included warnings about drugs to which a patient was known to be allergic, or where there was evidence from DST of an organism resistant to that drug. Error rates for two clinics in Lima were compared for prescriptions entered in (1) a paper and spreadsheet based system and (2) the order entry system. This showed that there was no significant difference in the control group's error rate before or after the study (8.6% vs. 6.9%, P=0.66) but the intervention group showed a significant drop in errors (17.4% vs. 3.1%, P=0.0074), and the system was better liked by nurses and other staff [9]. To evaluate the longer term impact, three years of field data were analyzed, (focusing on drugs to which a patient's isolate was resistant) in order to assess how decision support rules and their alerts affected prescriptions entered into the system. We found that 78% of warnings were overridden by staff and 7% of warnings were definitely responded to. This is consistent with other studies of alerts for computerized order entry, and suggests that the system has an ongoing impact on quality of care [10].

2. A study was performed of analysis tools designed to calculate the drug requirements for groups of patients based on drug regimens entered in the EMR. These tools use data on the current drug regimens of all patients in treatment along with expected remaining time in treatment and recruitment rate of new patients. The prediction of drug usage in 2003 and 2004 was compared with the record for drugs actually dispensed from the pharmacy for over 1000 patients. This showed a discrepancy between predicted and actual drug use of 1% - 3% [8,11]. In another study of the actual drug use of 58 patients treated between 2003 and 2005, the standard prediction based on previous consumption was compared to the prediction of the PIH-EMR for 5 main drug classes. The standard method gave a prediction of 145% of actual consumption whereas the EMR estimate was 99% [12]. Medication costs for the PIH Peru program in 2003 were $2.7 million (63% of total treatment costs) [8] making tools of this sort potentially valuable in achieving cost savings as well as improving access to medications.

3. We also completed a study of a mobile health (mHealth) solution using Palm Pilots to assist staff in collecting TB laboratory data from 98 clinics in four districts in the Lima area. In a randomized controlled trial (RCT) of the PDA-based system in the four districts, the median time to enter results in the EMR for cultures fell from 23 to 8 days ($p < 0.001$) and for smears from 25 to 12 days ($p < 0.001$). The proportion of cultures with delays greater than 90 days was reduced from 9.2% to 0.1%, and errors decreased by 57.1% ($p = 0.005$). The mobile health solution reduced work load by 70% [13].

4. Another study evaluated a second web-based laboratory component called eChasqui. This was added to the PIH-EMR to track samples to the laboratory, monitor their processing, and provide quality control tools for lab staff. eChasqui also provided web-based access to lab results on clinicians' desktop computers along with email alerts. In a large RCT of 1671 patients in 44 clinics, 12 clinics were randomized to receive initial access to the system. Rates of errors (mostly missing results) fell for cultures by 87% (15.1% vs. 2.0%, $P < 0.001$) and for DSTs by 82% (11.9% vs. 2.1%, $P < 0.001$) [14]. Delays for cultures fell from a medium of 8 to 5 days (Hazard Ratio 0.68 [0.65-0.72]), and for DSTs from a median of 17 to 11 days (Hazard Ratio 0.67 [0.62-0.72]). Importantly, the time until patients in intervention health centers were deemed no longer infectious was reduced by 20% (time to culture conversion) (p=0.047) [J Blaya, unpublished study]. In 2004, the PIH-EMR was adapted and implemented in the

Philippines to support an MDR-TB treatment program. A second version was created for HIV care and is used in Haiti.

OpenMRS

Starting in 2008, we created a custom distribution of the EMR called OpenMRS-TB. It was adapted to the specific needs of MDR-TB management, incorporating key functions and lessons learned from the PIH-EMR. It supports three main functions: clinical care, reporting and drug forecasting. Several innovations were added to the core OpenMRS system:

- The concept dictionary structure was extended to allow multi-level hierarchies of concepts. This allowed the representation of the complex TB lab data such as DSTs.
- Tools to enter, display and track lab reports, modeled on aspects of eChasqui.
- A custom timeline display created to allow visualization of the full treatment experience of the patient (figure 1).
- New reporting tools were added to allow patient records to be searched by a range of clinical criteria, as well as custom export of data. These complement the existing built in reporting tools: the cohort builder used to search for sets of patients by a wide range of criteria and concepts; and the reporting framework designed to create reports for data quality, clinical care or outcomes.
- Custom analysis tools were created for drug requirements forecasting.

These functions can be explored in an online demo (www.openmrs.org/demo). OpenMRS-TB is currently deployed in Haiti, Pakistan, Nepal, Tajikistan, Indonesia, Kenya and Botswana. IRD in Pakistan is responsible for many of the deployments and has added several key features to the system. These include integration with mHealth applications to track and record supervised therapy. Managers can view the geographical location of patients in Karachi, Pakistan, color coded by drug adherence (DOT) status, and click on individual patient icons to check clinical status. More recent deployments of the system use the OpenXdata system [15] to allow community health workers to record data on a patient's clinical condition and side effects.

OpenMRS has also been used to support clinical research studies. It formed the core of the data management system for a large NIH-funded cohort study of MDR-TB transmission, which enrolled and followed over 4,000 patient households. That study uses custom tools for double data entry reconciliation, and to link GPS devices directly to the EMR. This experience has provided valuable insights into how best to collect, report, export and analyze research data from OpenMRS [16].

Discussion

Current needs, challenges and recommendations

A meeting at the Institute of Medicine in Washington DC in July 2012 [17] identified important gaps and deficiencies in the information systems and processes to scale up MDR-TB treatment with a particular emphasis on supply of second line drugs. This built on several recent international meetings examining barriers to treatment scale up. Based on those findings and the experience described here, we propose the following next steps:

Drug forecasting

Supply chain deficiencies for SLDs are seen as a critical barrier to scaling up care for MDR-TB [17]. While a range of problems were identified in the supply chain, one of the main points of failure was the lack of accurate and accessible data on the number of patients with possible or proven MDR-TB, how many of these were on treatment, and their current drug regimens. In principle such data should be available from a basic patient register, but experience has shown that data from paper registers are not easily accessible. Given that a typical two-year drug regimen for MDR-TB can cost USD3000 or more, the costs of basic record keeping and information systems appear reasonable. Effective forecasting also requires software algorithms to combine the number of patients registered, their length of time in treatment, the rate of recruitment of new patients and their drug regimens. As shown in Peru, this can result in highly accurate forecasts [11].

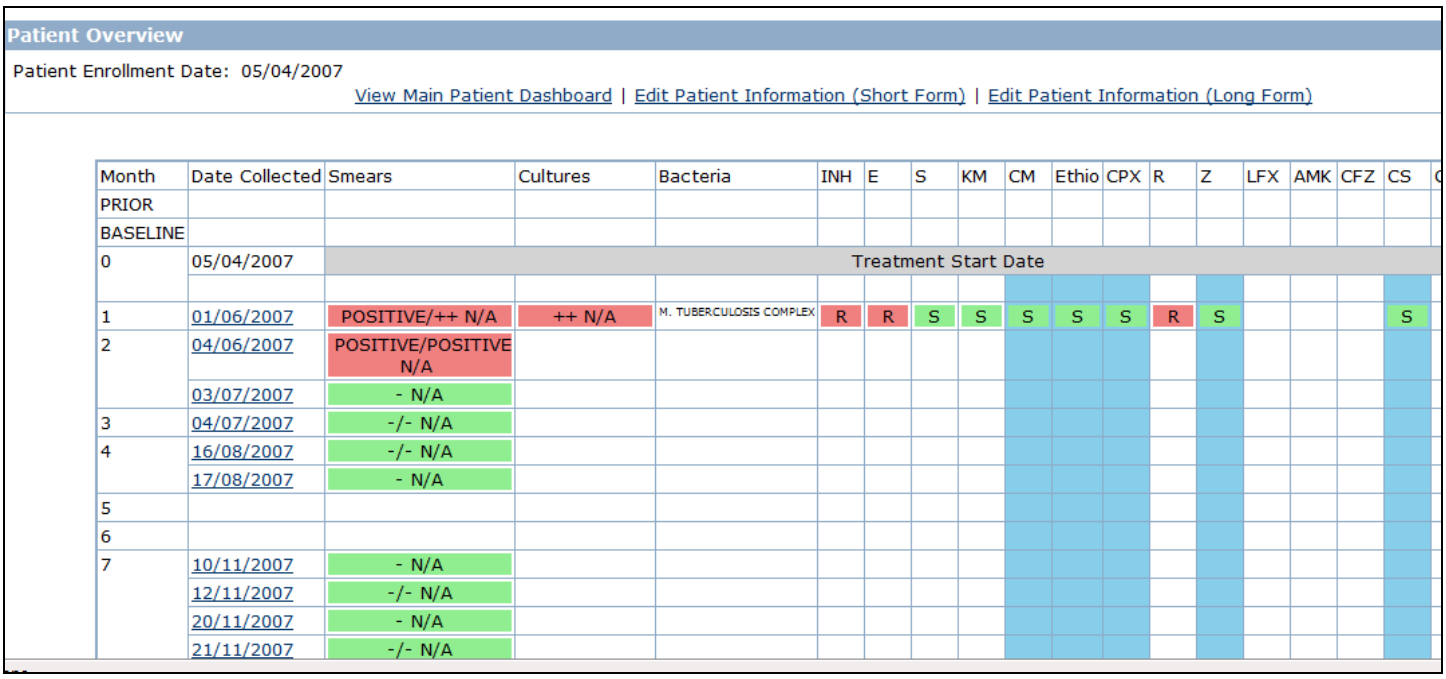

Figure 1- timeline of lab data and drug regimens (blue) for an MDR-TB patient in OpenMRS-TB. Month one includes DST results.

Drug supply, inventory and shipping

Better systems are required to track shipments worldwide and to manage inventory at national, district and local level. A particular gap is the lack of a widely used convention for bar coding of drugs including name, batch numbers, expiry dates, and quality control data. Without such barcodes all this data has to be manually entered and updated with each transaction, which in our experience rarely happens consistently without information management support.

Other systems for TB and MDR-TB management

A number of other electronic tools have been created by different programmes and technical partners to facilitate data management in connection with MDR-TB. For instance, eTB manager, developed by Management Sciences for Health, is a web-based medical information system that is deployed widely in Brazil and in several other countries [J Keravec, personal communication]. It includes tools for patient registration and collection of some clinical data about MDR-TB, as well as comprehensive TB lab data. Drug regimen data are used to forecast drug requirements and in addition the system has detailed data on drug inventory in every clinic. This allows detailed and up to date monitoring of predicted drug requirements and actual stock currently available across all sites [18]. The system has a good workflow and user interface. ETR.Net is a TB reporting system developed in South Africa with funding from the US CDC. It has been adapted to support MDR-TB reporting (www.etrnet.info). Imogene is an open-source system developed by the French Institute of Space Medicine and Physiology (MEDES; www.medes.fr) to enable data management on different operating systems, via web or mobile phone environments. It has been deployed to support TB projects in resource-poor environments (see code.google.com/p/Imogene). MOTECH is a project supported by the Bill & Melinda Gates Foundation combining mobile phone based data collection with a clinical EMR (OpenMRS) and district and national reporting tools (District Health Information System). It is being deployed in a state wide project in Bihar, India, to support health initiatives including monitoring the adherence and outcomes of TB treatment.

Support for general purpose health information systems

While some success has been seen with vertical information systems focused on MDR-TB, many countries are moving to more comprehensive health systems covering a wide range of diseases. Some EMR systems like OpenMRS and mHealth tools like OpenXdata have the flexibility to support the care of other diseases. OpenMRS is being deployed as part of national eHealth Architecture plans in Rwanda and Kenya. The challenge with other vertical systems like eTB manager is to either broaden their design to cover other diseases, particularly HIV and primary care, or to extend them to interoperate with other health information systems, leveraging strengths in supply chain, reporting and surveillance. Another aspect of broadening systems is to integrate the EMRs or registries for managing TB screening, DOTS and MDR-TB treatment to provide comprehensive tracking of all stages of case finding, treatment, quality improvement and disease surveillance.

Information systems need to be well designed and evaluated to ensure they are quick and easy to use by often overloaded clinical staff caring for these complex patients. This will also assist with the critical goal of ensuring the collection of complete and accurate core data. Sites with limited infrastructure like Haiti can be challenging for any information system and will typically need investment in power, connectivity and IT support. mHealth tools and applications including phones and tablets can be more robust to poor infrastructure of this sort.

Interoperability of information system

While eChasqui, eTB manager and other systems have shown the ability to improve the tracking of lab samples and the management of lab data, economies of scale and training requirements are pushing health systems to install comprehensive laboratory information management systems (LIMS). Such systems can provide modules for TB lab data. Clinical systems used for MDR-TB management need to be able to interoperate with LIMS, sending patient demographic data to the lab and receiving laboratory results. HL7 messaging and LOINC coding is the typical approach for transmission of lab data. An additional requirement is to allow direct data upload from new TB laboratory testing machines such as GeneXpert (Cepheid inc, Sunnyvale, CA), preferably with a LIMS. For smaller sites we are adding functionality to OpenMRS to connect to directly to GeneXpert machines.

Better integration of mobile devices

OpenMRS supports data entry using mobile devices, primarily through the xforms module, but there are still limitations in that the data flow is essentially phone-to-server, while data entry for TB often requires that users be able to view existing information about the patient while entering new data. More effective integration of mobile devices will allow OpenMRS-TB to be used in mass screening initiatives where field teams use cell phones to enter patient data. OpenXdata and some other mobile software tools can also interoperate with other suitably designed EMR systems.

Standardization of vocabularies for MDR-TB

Sharing data between information systems requires a degree of semantic interoperability, with sharing of core data definitions. EMR systems with a concept dictionary like OpenMRS simplify the development of shared vocabularies. Over many years the US CDC, WHO, PIH and other organizations developed a collaboration to create core definitions and indicators for MDR-TB case management and reporting [19],[20] which included initial work on core data items. This needs to be extended to create a core data dictionary that will allow improved interoperability and shared reporting across sites, countries and systems.

Conclusions

Scale up of MDR-TB treatment to hundreds of thousands of patients per year requires effective information systems. While some reliable systems are now available to healthcare organizations, effective scale up will require: open standards for data storage and exchange; good interoperability between EMR systems, lab systems, pharmacy systems and mobile health systems; and a move away from vertical disease specific designs. It is especially important that systems and strategies are developed collaboratively to foster local development, innovation and support worldwide. This can be facilitated by open standards and open source software.

Acknowledgements

We thank the following organizations for support: the Bill & Melinda Gates Foundation, the WHO, the Rockefeller Foundation, and the International Development Research Centre, Canada. Dennis Falzon is a staff member of WHO and is responsible for the views expressed in this paper, which do not necessarily represent decisions or policies of WHO.

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Annex D

Clinically Relevant Coded Diagnoses for Developing Countries

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Introduction

A point-of-care patient registration and primary care system was implemented by Partners In Health at the L'Hôpital de Lascahobas outpatient health center in Lascahobas, Haiti. Coded diagnoses and symptoms were selected based on frequency in a previous system and reportable diseases for the Ministry of Health.

Partners In Health (PIH) is a co-developer of OpenMRS, an open source project to support the delivery of healthcare in developing countries. Expanding on OpenMRS systems used for HIV, MDR-TB, and primary care treatment in Haiti, Rwanda, Lesotho, and Malawi, PIH developed software to register all patient visits at L'Hôpital de Lascahobas, replacing an Epi Info system, in use since 2003.

PIH is an international non-profit organization providing a preferential option for the poor in health care. Zanmi Lasante ("Partners In Health" in Haitian Kreyol) is PIH's flagship project in the Central Plateau of Haiti.

Goals

Patient registration in Lascahobas

- Produce a simple yet accurate list of clinical impressions at Lascahobas
- Collect accurate electronic data about each patient visit
- Generate reports for clinical use, monitoring quality of care, and disease surveillance

Challenges

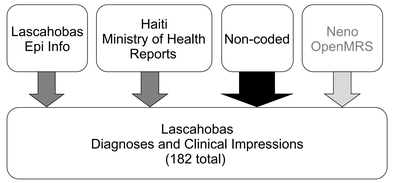
- Non-medical personnel entering clinical data retrospectively
- Staff without computer skills
- High frequency of transcription errors and missing data
- No local IT staff or programmers
- Poor infrastructure and connectivity

Registration in Lascahobas

Methods

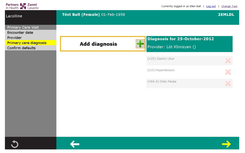
Using most-common coded and non-coded diagnoses from L'Hôpital de Lascahobas, data from Neno, Malawi[2] (Table 1), and reporting requirements for the Ministry of Health, a set of 182 diagnoses and clinical impressions with ICD10 codes was created.

Figure 1: Sources for diagnoses and clinical impressions used at the L'Hôpital de Lascahobas outpatient clinic



After a patient visit with a clinician, trained data clerks use a custom OpenMRS interface, scan the barcode from the paper chart, and enter the clinical impression from the same paper chart. The patient registration module provides a simple method for adding coded and non-coded diagnoses and symptoms (Figure 2).

Figure 2: Patient registration module provides simple method of adding clinical impressions.



Continuous Improvements

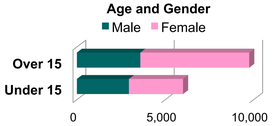
Clinical impressions are iteratively improved.

Reasons for changing the coded list	Example of improvement
The list continues to be reviewed by local clinicians	Yellow fever was removed since it is not a risk in Haiti
Multiple occurrences of a non-coded term	Urinary tract infection was added
The Ministry of Health requires a weekly report with notifiable and reportable diseases but not all were captured as coded	Diphtheria and Leprosy were added
Abbreviations were used by clinicians and added as non-coded by data entry	HTA was added as a coded diagnosis for hypertension
Clinicians used various synonyms to represent one disease, so both were added	Malaria was added as a synonym for the French term – Paludisme

Results

Well-coded diagnoses and clinical impressions improve data entry and facilitate reporting requirements. Since February 2012, almost 16,000 patients visited L'Hôpital de Lascahobas and had at least one complaint recorded. The clinic receives feedback on patient numbers, demographics and case mix (Figure 3).

Figure 3 Age and gender distribution in Lascahobas outpatients since Feb 2012.



Lascahobas Epi Info 2003 to Jan 2012	Lascahobas OpenMRS Feb to Oct 2012	Neno OpenMRS May 2008 to Feb 2011
67% coded (193K) + 33% non-coded (96K) = 289K	**87% coded (22K) + 13% non-coded (3K) = 25K**	
Gastritis 17.6%	**Gastritis 11.1%**	Malaria 31.1%
Influenza 12.8%	**Urinary tract infection 8.4%**	Upper respiratory infection 20.3%
Intestinal parasites 11.9%	**Hypertension 7.9%**	Musculoskeletal Pain 18.0%
Hypertension 11.4%	**Malaria 7.5%**	Gastroenteritis 1.9%
Malaria 9.2%	**Influenza 6.5%**	Dyspepsia 1.9%
Anemia 6.9%	**Intestinal parasites 5.5%**	Gastritis 1.9%
Scabies 4.6%	**Typhoid fever 4.5%**	Hives 1.2%
Typhoid 3.8%	**Anemia 3.9%**	Pneumonia 1.1%
Headache 2.7%	**Headache 3.7%**	Headache 1.0%
Diarrhea & Gastroenteritis 2.6%	**Abdominal pain 2.7%**	Soft tissue injury 1.0%
Other coded 16.6%	**Other coded 38.3%**	Other coded 19.9%

Table 1: Clinical impressions

A clinician reference sheet with all the coded diagnoses and symptoms (with corresponding ICD10 codes) is currently undergoing review by PIH and ZL staff. This will be a good mechanism to standardize terminology between clinicians and data entry staff, along with providing useful discussion about the currently coded concepts. The 182 diagnoses and symptoms are arranged by physical system.

Expansion is planned to Hôpital Universitaire de Mirebalais (Haiti) and in Rwanda. PIH has been collaborating with the Rwanda Ministry of Health on a set of 300 diagnoses which are mapped to ICD10 codes and ICPC-2 areas. Clinical impressions will be iteratively improved with new data from Haiti, Rwanda, Malawi, and other organizations.

Summary of Conclusions

- Data archivists have embraced and adopted the new system
- Non-coded items are reviewed regularly and the most common terms are added to the dictionary
- Reports are generated for the Ministry of Health
- Geographic Information Systems (GIS) can be used for targeted geographic intervention based on geocoded cases referenced at a facility (Figure 4)
- The major challenge is ensuring that clinical impressions are recorded clearly on patient cards by clinicians
- Direct entry by clinicians should improve data quality

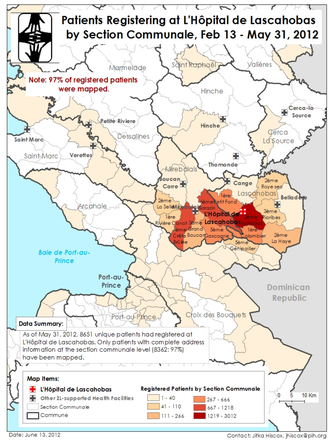


Figure 4: Zanmi Lasante Hospitals (Haiti) with catchment area for Lascahobas patients

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Acknowledgements

Our great appreciation to the International Development Research Centre, Ottawa for support of the project, along with colleagues at L'Hôpital de Lascahobas (Haiti), Neno District Hospital (Malawi), the amazing PIH Medical Informatics and MEQ teams, and the OpenMRS community.