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Leveraging Health Information Technology to Improve Access to and Quality of HIV/AIDS Care

People living with HIV/AIDS (PLWHA) tend to be more mobile than the general population and may seek care from multiple providers. As a result, assessing the complete HIV disease and care history of PLWHA can be next to impossible, particularly because few clinics nationwide have the capacity to exchange patient records securely online.

The consequences of incomplete records can be significant. Doctors may find themselves treating clients who have long histories of HIV treatment as being new to care and thus request redundant lab tests and medications. PLWHA—particularly those dealing with common HIV coinfections and comorbidities, such as sexually transmitted diseases, hepatitis, tuberculosis, substance use disorders, and mental health issues¹⁻⁵—may be wary of telling their doctor that they have been in care at another clinic or have previously fallen out of care. Others may believe that their new doctor has access to their records.

Electronic Medical Records, Health Information Exchanges, and SPNS

To enable clinicians to better serve PLWHA who frequent different providers, the Ryan White HIV/AIDS Program, administered by the Health Resources and Services Administration (HRSA), HIV/AIDS Bureau (HAB), has supported the development and implementation of health information technology (HIT) innovations, most notably through HAB's Special Projects of National Significance (SPNS) Program.

From 2007 to 2011, the SPNS Information Technology Networks of Care Initiative (Networks of Care Initiative) promoted the enhancement and evaluation of existing health information electronic network systems to serve PLWHA in underserved communities. Six demonstration sites (see box, p. 2) were funded for 4 years to demonstrate the benefits of updating electronic medical record (EMR) databases to securely share patient information online with other providers and ancillary points of service, such as mental health clinics and pharmacies. Known as health information exchange (HIE), this technology enables secure transmission of information across disparate database systems, enabling users to update patient records in real time. As Wayne Steward, who served as co-principal investigator with Janet Myers of the Networks of Care Initiative's Evaluation and Support Center, explains, each site used different customizations to achieve the same result: "The Initiative helped bolster the operations of existing systems so that providers could communicate electronically across locations, hence the idea of health information exchanges."

With this innovative approach to information exchange, each SPNS site sought to improve one or more of the following components of HIV/AIDS care:

- Early detection of HIV infection and reduced time to entry into care
- Management of patient health information, including referrals, appointments, maintenance, and retention of clients in the care system
- Health outcomes and quality of life.

Road Map to Success

The power of HIE to improve patient care cannot be overstated. Despite their slow adoption nationwide, EMRs and HIEs are considered part of an inevitable future of U.S. health care. The Health Information Technology for Economic and Clinical Health Act (HITECH) of 2009⁶ supports the "meaningful use" of EMRs to achieve "significant improvements in care" by means of HIEs and the development of a nationwide HIT

1

infrastructure.⁷⁻⁹ In addition, this work, along with the Networks of Care Initiative's research, aligns with goals of the National HIV/ AIDS Strategy and the forthcoming implementation of the Patient Protection and Affordable Care Act in 2014.^{10,11}

Ultimately, the availability of patients' medical records online will help providers make more informed decisions regarding prescriptions and tests and deliver more targeted care and expedient service. Upgrading an existing system to facilitate these activities, however, demanded that each Networks of Care Initiative site foster buy-in among all potential users, address any obstacles to implementation, and ensure the enhancements' sustainability.

Ensuring Buy-In for Innovation

The creation of the enhancements did not—and could not occur without full staff support, because staff would be the ones using the enhancements on a daily basis. For all the Networks of Care Initiative sites, achieving staff buy-in involved an extensive planning process that leveraged insight from as many site stakeholders as possible—doctors and front desk staff, patients and Ryan White Planning Council representatives, and community and HIE partners—through focus groups, surveys, and individual interviews. Even the incorporation of small improvements, such as the City of Paterson's staff members' idea to use emoticons (faces created with keyboard punctuation symbols) to symbolize rates of customer satisfaction, helped each site come one step closer to engaging in successful HIE.

Jesse Thomas, who served as technical director for the City of Paterson site and is a developer with RDE Systems, says the exchange of ideas proved to be as important as the upgrades themselves, and created a sense of camaraderie among the group and a sense of ownership of the changes in their agency's approach to tracking care. Thomas, whose firm produces the software program Electronic Comprehensive Outcomes Measurement Program for Accountability and Success, known generally as eCompas or e2, notes that "people tend to focus on the product, but it's the process—where staff talk about daily work habits and how [services] are delivered to PLWHA—that makes the biggest difference in improving care outcomes."

The process also speaks to why HIEs are essential to ensuring that vulnerable PLWHA are engaged in care. Data exchange systems that meet the needs of both clinical and nonclinical entities foster system linkages and improve health outcomes for PLWHA. The HIE development process gave Networks of Care Initiative staff and stakeholders a voice in its design and implementation.

Each site enhanced its systems in a manner that "made sense" within the context of the agency's operations, working with the agency's current database system. Moreover, site staff had to have the motivation to implement the changes once they were determined; otherwise, the updates would be abandoned for past,

SPNS Grantees

- Bronx-Lebanon Hospital, Bronx, New York
- New York-Presbyterian Hospital, New York, New York
- Duke University, Durham, North Carolina
- St. Mary Medical Center Foundation–Long Beach, Long Beach, California
- Louisiana Public Health Information Exchange, Louisiana State University, Baton Rouge, Louisiana
- City of Paterson, New Jersey

proven ways of tracking and conducting appointments and maintaining patient data.

As Steward explains, "Doctors are often running from appointment to appointment. Systems that are out of sync with the clinics' daily workflow would be an extra administrative burden." Such a situation would have limited a clinic's ability to complete EMRs and participate in HIEs, both of which were essential to meeting the goals of the Networks of Care Initiative and improving health outcomes of PLWHA.

To maintain engagement with and commitment to the project, the sites regularly updated stakeholders on the project's progress, engaging them in the often extensive and intensive testing and review processes. This approach ensured that stakeholders understood—as well as had a voice and an investment in—the complexity of the process and the ultimate benefits of the final product. Working with the existing system also helped staff identify areas that needed to be addressed and upgraded. Steward says that "not reinventing the wheel" saved the agencies time and money and gave providers a head start "on how to make full use of the new components as they were turned on."

Thomas says the process also imbued a sense of ownership among the stakeholders working on the project: "They were excited to see their ideas realized. Creating buy-in from the ground up makes implementing a system much easier rather than selling it after the fact."

Challenges and Lessons From HIEs

Each site reported several key lessons learned during the enhancement process. For example, some sites found working with local partners a challenge, particularly when it came to agreeing on the logistics and security measures around the HIEs. Although the benefits of EMR and HIE technologies in ramping up the function, efficiency, and efficacy of health clinics have been well documented,¹²⁻¹⁴ they have yet to be adopted by many medical providers, particularly in the smaller community clinics and practices where many PLWHA access their care.⁷

Network of Care Initiative Project Officers

The SPNS project officers for the Networks of Care Initiative are

- Adan Cajina, Chief (301.443.3180; acajina@hrsa.gov),
- Faye Malitz (301.443.3259; fmalitz@hrsa.gov),
- Robert Mills (301.443.3899; rmills@hrsa.gov), and
- Melinda Tinsley (301.443.3496; mtinsley1@hrsa.gov).

Much of this reluctance relates to the perceived costs associated with the implementation of newer technologies, although HITECH offers some support for certain providers implementing HIT. Several HIV/AIDS service providers partnering with SPNS sites expressed concerned about the labor and security risks involved in replacing paper files and closed electronic database systems with EMRs and HIEs. Other SPNS sites worked with partners that operated under overly restrictive interpretations of the Health Insurance Portability and Accountability Act (HIPAA), thereby placing considerable constraints on the types of information that could be shared and initially limiting HIE implementation and facilitation.¹¹

Some sites also encountered obstacles when negotiating memoranda of understanding about HIEs between themselves and other agencies. Questions arose concerning who would be storing and maintaining the data and where one institution's responsibilities ended and another's began. In those instances, Steward says, "there was a lot of educating that needed to be done. We assured the institution officials involved that information exchange was [allowed] under HIPAA."

Legal representatives helped work out details on other issues and facilitated final agreements. Vendors working on the enhancements faced their own unique challenges as well. Staff and the programmers found the enhancement implementation process time consuming, although its iterative nature was seen as a good thing.

William Cunningham of the University of California, Los Angeles, who served as an evaluator for St. Mary Medical Center Foundation, Comprehensive AIDS Resource Education (CARE) in Long Beach, California, says, "For a programmer, the immense amount of programming involved to get the enhancements to function properly was not surprising. Clinicians, however, did not readily understand why these changes were not simply 'plug and play,' and [they] needed more explanation and support."

Several contractors eschewed traditional technology vendor protocol, which recommends charging for services by the hour. Indeed, vendors on the project, such as e2, which worked with the City of Paterson, were more interested in mitigating HIV/AIDS than in profits. Cunningham says that the work often demanded more work than either the site or the vendor planned: "It took a ton of programming, patching errors, and a great deal of testing [but we] made the applications work seamlessly."

Some of the greatest obstacles to facilitating HIEs at each site occurred among the staff themselves. Several doctors, for instance, were initially averse to any change in the way they worked. Data entry managers feared that the EMR and HIE enhancements threatened their job security. "That was a surprising barrier," says Cunningham. "We hadn't anticipated that. Fortunately, they were trained to take over other duties and, over the years, have been on board with the enhancements, too."

Success Is in the Sharing

Although challenging to implement, HIEs enable providers to deliver care more effectively and, ultimately, improve engagement and retention of PLWHA in care. In the SPNS Networks of Care Initiative, the process also reduced the cost of data maintenance. Logging updates to the database online meant that information did not have to be recorded first on paper records and then entered into the system later. As a result, the risks of double entry and transcription errors were eliminated.

Implementation of time-saving techniques has been particularly important for agencies in recent years. The economic downturn has meant that agencies have had to work with smaller budgets and staffs. In addition, the aging of the HIV workforce has meant that many experienced personnel are now retiring or going into different fields of health care.¹⁵⁻¹⁷

Several of the Networks of Care Initiative sites also gathered data demonstrating the effectiveness of safe, secure HIEs in improving PLWHA health outcomes. For instance, the CARE site established an electronic bridge between itself and local agencies using different clinical management software applications. Using this bidirectional interface, the CARE site is now able to capture and disseminate laboratory results and medication orders from its patients' EMRs.

Cunningham says that from the start, the CARE site's HIE improved communication between patients and doctors. "Doctors were able to access patients' laboratory results in real time," says Cunningham. As a result, they were able to "discuss critical labs more easily with patients. . . . [They] ultimately created significant improvement in patients' CD4 counts and viral load, and facilitated treatment planning."

The enhanced CARE EMR system also improved tracking of clients' treatment adherence. "Rather than hand patients a prescription and trust that it would be filled, doctors now could send prescriptions electronically to the pharmacy," Cunningham says. Pharmacies, in turn, logged the date and time patients picked up their prescriptions and noted any pending refills. Clinic staff could then readily identify patients not engaging in prescribed antiretroviral therapy and provide them with the additional support service linkages and education necessary to achieve and sustain treatment adherence.

The City of Paterson achieved similar success with its HIE. Thomas, a representative of e2, which had worked on several SPNS projects prior to the Networks of Care Initiative and understood the power of HIT, was initially unsure whether an IT enhancement could improve health outcomes for PLWHA. The firm programmed the City of Paterson's system to comb client records and automatically alert physicians about patients who needed labs, medical exams, and other tests.

To the City of Paterson's surprise, its HIE appeared to improve not only patients' health but also the health of their communities. Thomas says, "Patients received better care. More got their screenings and saw their doctors on time, which led to a greater reduction in viral load for them personally—and for the population."

Information sharing also revealed treatment trends among patients. Cunningham says the CARE site is conducting additional analysis on preliminary data suggesting that its HIE has helped reduce the gap in treatment adherence between Black and White patients. The Networks of Care Initiative "changed how clinicians at the City of Paterson site looked at data—and how to use it as an intervention of care," says Thomas.

The City of Paterson soon became the best performing Ryan White HIV/AIDS Program grantee within the State of New Jersey, and it quickly set new standards for HIV care during its participation in the HRSA/HAB Cross-Part Collaborative, established in October 2008. With its Collaborative partners—Connecticut, Pennsylvania, Texas, and Virginia—the City of Paterson and other New Jersey grantees set quality management measures and submitted data reports in an effort to track and improve PLWHA health.¹⁸

In addition to the successes of the HIEs themselves, the Networks of Care Initiative created a peer-to-peer network offering technical assistance and information based on participants' own experiences. This network created long-lasting, productive partnerships that benefited the clinics and the populations they serve.

Sustainability and the Future of HIEs

The SPNS Networks of Care Initiative has answered the call to create more innovative methods for sharing PLWHA information securely and efficiently by developing proven and replicable models that leverage HIT and, ultimately, improve the engagement and health outcomes of vulnerable PLWHA. "The SPNS program gave us a shot in the arm to take it to another level," Thomas says. The changes were created with complete buy-in at each Networks of Care Initiative site. Rather than a top-down decision forced on

Announcement: Lessons Learned From SPNS Grantees

The Special Projects of National Significance (SPNS) Program is pleased to announce the launch of IHIP—Integrating HIV Innovative Practices. IHIP projects help grantees and providers learn about SPNS-tested HIV care delivery strategies with demonstrated success and replicability across health care settings. IHIP helps Ryan White grantees take tested innovations and turn them into practice. The results are more informed providers, better care delivery, and healthier patients and communities.

The first training manual, curriculum, and monograph cover the integration of buprenorphine into HIV primary care settings. A Webinar on this topic has been posted online, and additional training Webinars are forthcoming. To find out more and help spread the word, visit the IHIP website (www.careacttarget.org/library/integrating-hiv-innovative-practices-ihip) and download the IHIP Web badge.

employees, the enhancements were the product of what Thomas calls "grassroots, bottom-up change."

All the Networks of Care Initiative sites successfully engaged in HIEs, and the infrastructures that facilitated the HIEs have been incorporated permanently. Cunningham says that unlike many of his past projects, "the enhancements are now part of the clinical practice for each SPNS site, and there are no plans to go back to the old way."

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SPNS Staff

- Adan Cajina, Chief (301.443.3180; acajina@hrsa.gov)
- Pamela Belton (301.443.4461; pbelton@hrsa.gov)
- Katherine Godesky (301.443.7874; vgodesky@hrsa.gov)
- Melinda Tinsley (301.443.3496; mtinsley1@hrsa.gov)
- Jessica Xavier (301.443.0833; jxavier@hrsa.gov).
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Additional Resources

Consult the following resources for more information about the Networks of Care Initiative.

Websites

• HRSA/HAB Web page for the Networks of Care Initiative: http://hab.hrsa.gov/abouthab/special/underservedcommunities.html

Publications

- July 2007 edition of *What's Going On @ SPNS* bulletin, "Information Technology: Improving HIV/AIDS Care": www.careact-target.org/library/SPNSBulletin/spnsbulletin.jul07.pdf
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Presentations

- HIE and HIV: Leverage of Information for Increasing Opportunities for Care and Support, by Jane Herwehe of the Louisiana Public Health Information Exchange and Frank Lombard of the Regional Health Information Integration Project, North Carolina: www. careacttarget.org/; search on "HIE."
- *Health Information Technology in Health Centers: A Beginner's Overview and Where We Are Now,* by Christie Brown and Mark Yanick, HRSA Office of Health Information Technology: www.careacttarget.org/; search on "HIE."
- *Begin with the End in Mind . . . Key Principles in EHR Adoption and Use* (Experiences with Open Health Architecture): www. hrsa.gov/healthit/toolbox/webinars/webinarvideos.html#tips/.

Webinars

• *Tips for Using EHRs to Improve Quality of Care and Health Outcomes Webinar*, October 10, 2010: www.hrsa.gov/healthit/ toolbox/webinars/webinar

(5)