



What's Going on @ SPNS



AN UPDATE FROM THE U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES, HEALTH RESOURCES AND SERVICES ADMINISTRATION,
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Using Technology to Improve Health Outcomes

*"We're not just measuring outcomes, we're actively improving lives. After all, it's not data it's people."*¹

Health information technology (HIT) is about more than new ways to measure, report, or share data. Ultimately, it's about enabling providers to improve the quality of care and empowering patients to be active participants in that care.

The Health Resources and Services Administration's (HRSA's) Special Projects of National Significance (SPNS) program is a true pioneer in the advancement of HIT systems that improve HIV health outcomes through access to reliable and secure data streams. "SPNS opportunities have been the catalyst, foundation, and framework for so much success," says Dr. Peter Gordon, medical director at New York-Presbyterian (NYP) hospital, which has received multiple SPNS HIT-related grants. "It's really a remarkable legacy of vision and innovation."

SPNS' HIT Initiatives

A Decade of Success

Over the past decade, SPNS has funded many innovative and cost-effective projects that have demonstrated tangible and replicable results — both in building the capacity of Ryan White HIV/AIDS Program grantees to measure and report data and in sharing that information within regional health information exchanges. For example, the 2008 *Capacity Building to Develop Standard Electronic Client Information Data Systems Initiative* helped grantees from Parts A through D purchase or enhance electronic health information systems that facilitate reporting of client-level data. More recently, SPNS launched a similar HIT Capacity Building Initiative for Part B grantees to facilitate client-level data reporting for their AIDS Drug Assistance Programs (ADAPs).

This kind of data reporting can make a real difference to health outcomes. By helping providers identify patients in need of follow-up care and updating their information, electronic health records (EHRs) can play an important role in keeping patients actively engaged in care.² On a broader scale, health information systems also assist public health officials in recognizing important trends across patient populations.³

Increasing secure access to that data has a tremendous impact as well. Patients feel empowered, for example, when they have access to their personal health information. "I'm my own health advocate [now]," says Danny, an HIV patient at NYP.⁴ Danny gained online access to his core medical information through a patient portal application that NYP created under a grant from the 2007 SPNS *Electronic Networks of Care Initiative*. "I have the confidence now to ask important questions and make changes to better my health," he explains.

What's more, shared data enable providers to improve the management of care for people living with HIV (PLWH). Because of more effective treatment regimens, PLWH are living longer and face many years of living with both their HIV disease and any long-term diseases associated with aging.⁵⁻⁷ As a result, these patients receive care from a growing number of providers and may have increasingly complex medication regimens.

A fully integrated health information exchange (HIE) can help these multiple providers communicate better with one another. That can reduce duplication of services and make it much easier to track patients' prescribed medications, thus avoiding drug-drug interactions. "Most doctors think they're the sole provider, but a functioning HIE enables them to see that the patient has many different doctors and case managers. It can be a catalyst for stimulating all participants involved in a patient's care," says Eli Camhi, formerly at NYP.⁸

Thus, over the years SPNS HIT initiatives have had a profound impact on health outcomes. SPNS has been at the forefront of the shift to client-level data, funded the development of secure electronic records, and facilitated working regional data exchanges for relatively minimal investments. The evaluation component adds another layer of value to SPNS projects, providing evidence-based proof of results.

Supporting the National HIV/AIDS Strategic Vision

The SPNS program's efforts to develop HIT capacity also aligns with the objectives of the 2010 National HIV/AIDS Strategy (NHAS), which include improving health outcomes for PLWH along the HIV Care Continuum and reducing HIV-related health disparities.⁹ The HIV Care Continuum segments care into five distinct stages: diagnosis, linkage to care, retention in care, prescription of antiretroviral therapy, and viral suppression. Segmenting care in this way makes it easier to measure the number of people who engage in or fall out of care at each stage.

In July 2013, the White House Office of National AIDS Policy (ONAP) announced a call to action for a multidisciplinary approach to reduce drop-offs across the continuum of care.¹⁰ This federal HIV Care Continuum Initiative focuses on collaborative efforts at each point of patient care, and an HIV Care Continuum Working Group was created to coordinate those efforts. In its December 2013 report, the Working Group specifically identified the need for health IT initiatives that strengthen the collection, coordination, and use of data to improve health outcomes along the continuum.¹¹

Building on Prior HIT Successes

SPNS has led the way in developing effective HIT systems that help providers improve the quality of HIV care. As mentioned previously, SPNS has funded several initiatives to help grantees improve their ability to report client-level data.

Facilitating Client-Level Data Reporting

Some early grants allowed many grantees to purchase a software program called Electronic Comprehensive Outcomes Measurement Program for Accountability and Success, known generally as eCOMPAS, and customize it for HIV data reporting. "Providers often have to report data to multiple funders," explains Jesse Thomas, a developer with RDE Systems, the firm that created the software. "If you are using different data sets for multiple systems, there's no way to have one integrated view of all your patients. With eCOMPAS, providers can see data in the aggregate, but they also can drill down to the patient level, so they can track individual health outcomes," says Thomas. "This capability is where data can make a real difference."

Example: The Hyacinth AIDS Foundation in New Jersey received a HIT capacity building grant to build a data export capability that was compatible with CAREWare, HRSA's free software for managing and monitoring HIV clinical care. "As New Jersey's oldest and largest provider of services to PLWH, Hyacinth faces many challenges with duplication and fragmentation of data, especially since Hyacinth must report client-level data to four different regions, plus the state and other sources," says Grants Manager Jodi Riccardi. "The state also requires CAREWare data submissions, and that's where SPNS has really saved the day," she adds. "We are now able to have one single repository for integrated data views, population health management, and unified Ryan White HIV/AIDS Program Services Report (RSR) reporting. We have

What is HIT?

Health information technology (HIT) is a broad term comprising various clinical applications. Key applications, as defined by the National Alliance for Health Information Technology, include:

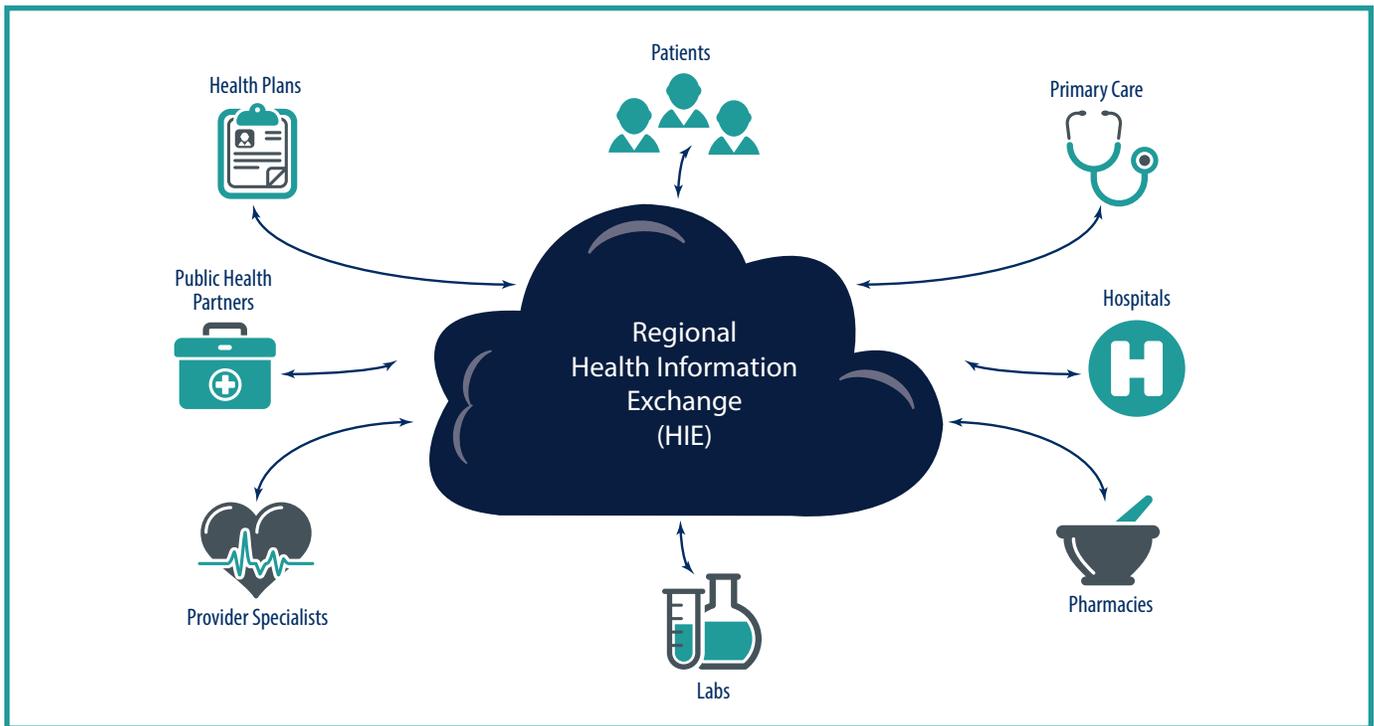
- **Electronic Health Records (EHRs)** are electronic records of patients' health-related information that can be created, gathered, managed, and consulted by authorized clinicians and staff.
- **Personal Health Records (PHRs)** are electronic records of patients' health-related information that can be drawn from multiple sources (including the patient) while being managed, shared, and controlled by the individual.
- **Health Information Exchange (HIE)** is the electronic movement of health-related information among health organizations according to nationally recognized standards

Source: Health Resources and Services Administration (HRSA). What should every provider know about IT? Available at: www.hrsa.gov/healthit/toolbox/hivaidscarettoolbox/introduction/whatshldeveryprovknw.html. Accessed February 28, 2014.

RSR and ADR: What These Data Reports Measure and Why They Are Important

As mandated by Congress, Ryan White HIV/AIDS Program grantees began collecting client-level data for the new Ryan White Services Report (RSR) in 2009.¹² More recently, state AIDS Drug Assistance Programs (ADAPs) began submitting client-level data as well, through the ADAP Data Report (ADR).¹³

For years, annual grantee reports included only aggregate data from providers, which led to duplicated counts when clients visited multiple providers. Unduplicated, client-level data, in contrast, allow both grantees and the Health Resources and Services Administration (HRSA) to track the true number of clients in care, as well as the services received by each client, the quality of those services, and health outcomes. With this data, grantees can better track progress on meeting performance measure guidelines, and HRSA can ensure that it continues to reach the communities most in need of support.¹⁴



eliminated double data entry into CareWARE by simply pressing a button in eCOMPAS,” she says. “We believe this saves us more than 100 hours per year, which is better spent on client services.”

Enabling Working Data Exchanges

SPNS funding has also facilitated working data exchanges. For example, the [Electronic Networks of Care Initiative](#) funded six demonstration sites for four years (from 2007 to 2011) to promote and evaluate the enhancement of existing HIE network systems for PLWH in underserved communities. One of the most successful demonstration projects in this initiative was the Louisiana Public Health Information Exchange (LaPHIE). LaPHIE provided real-time alerts to HIV primary care providers when a person living with HIV who had not had CD4 or HIV viral load monitoring in over a year was seen for any reason within a network of seven hospitals. LaPHIE was extraordinarily successful: Of the 344 out-of-care patients identified during the first 18 months of implementation, 82% were successfully linked to HIV care.¹⁵ The project’s success clearly shows that linking statewide public health HIV surveillance data with patient-level data can increase opportunities for re-engagement in care.¹⁶ In fact, in its [December 2013 report](#) the federal HIV Care Continuum Working Group specifically cited LaPHIE as an example of a HIT initiative that successfully supports the goals of the HIV Care Continuum Initiative.

Replicating LaPHIE in Georgia

In October 2012, the Georgia Department of Public Health received a Secretary’s Minority AIDS Initiative (MAI) grant titled “Replication of a Public Health Information Exchange to support engagement in HIV care,” managed through the SPNS program.

This effort is an attempt to replicate the success of the LaPHIE project that linked 82% of patients to care during the study period.¹⁷ Like LaPHIE, the objective of the Georgia project is to improve health outcomes by creating a public health information exchange (PHIE) connecting the state’s HIV surveillance database to patient-level data. Also like LaPHIE, the project targets the continuum of HIV-infected people, especially people of color, who are not currently linked to, engaged in, or fully retained in care.

Georgia law protecting the confidentiality of HIV/AIDS information, however, presented an implementation challenge. Under existing law at the time, health care providers and clinical laboratories were required to report HIV cases to the state health department, but the department could not, in turn, share that information back with the patients’ care providers.

A legal/ethical workgroup was formed, as part of the PHIE project, to explore the implications of changing the confidentiality law. Based on the group’s recommendations, a new disclosure law allowing bidirectional information sharing recently passed the state legislature and was signed by the governor. Effective July 1, 2014, the law also allows near real-time clinical messaging and provider notification for HIV patients in need of care. The passage of this disclosure law will improve health outcomes along the HIV continuum in Georgia. For more information, visit www.legis.ga.gov/legislation/en-US/display/20132014/SB/342.

A New SPNS Initiative to Track Outcomes Along the HIV Care Continuum

SPNS recently announced a new three-year funding opportunity for four Ryan White HIV/AIDS Program grantees to enhance HIT

capacity—the *Health Information Technology Capacity Building for Monitoring and Improving Health Outcomes along the HIV Care Continuum Initiative*. This new initiative hopes to expand on the success of past SPNS capacity building efforts by developing or enhancing electronic networks that specifically facilitate the measuring and tracking of health outcomes along the HIV Care Continuum. The ability to measure outcomes from all relevant HIV data systems is the key to realizing the potential of the HIV Care Continuum and meeting the objectives of the NHAS.

“We will be working with Part A and Part B grantees [which include states, Eligible Metropolitan Areas, and Transitional Grant Areas] to enhance their capacity to build HIV Care Continuum models,” said Jessica Xavier, a SPNS project officer. Although some state and local health departments have begun adopting the HIV Care Continuum model,^{18–20} many have encountered challenges that limit wide-scale adoption or optimal application. “The ability to gather all of this data in one place and use it is thwarted by a number of barriers; some are technological, but others are legal or regulatory. It also depends on the size of the state and the amount of existing resources,” says Xavier. An expectation of the initiative is to develop HIV Care Continuum models for HIV-infected subpopulations that leverage existing HIT resources to overcome these specific barriers grantees are facing.

Providing better care for cultural, racial, and ethnic minorities who are disproportionately affected by HIV is another vital goal of this initiative. The NHAS also specifically calls for applying increased resources to effectively prevent and treat HIV among subpopulations who have disproportionately high rates of infection and who drop out of care at higher rates.²¹ “Improving links between HIV surveillance data and treatment services will help address those disparities by identifying the most affected groups and their most urgent unmet needs,” said Xavier.

Applicants were asked to propose various methods to improve HIT capacity infrastructure in their jurisdictions, with the provision that the improvements would enhance the ability to provide care for HIV-infected subpopulations. Examples of potential enhancements include interconnectivity improvements for existing networks and the construction of a new or improved central data repository. The flow chart on Page 3 is a visual representation of a regional data exchange system. The diagram illustrates how coordinated health information exchange enables participating service providers to both contribute to and receive core clinical information about patients. This can be especially useful in emergency situations, help prevent duplicate efforts, and contribute significantly to improved patient care.

Funding for the Care Continuum Capacity Building Initiative will be available for federal fiscal years 2014 to 2016, depending on the availability of appropriated funds and other factors.

Maximizing HIT’s Potential

While the immediate objective of any HIT development effort is to build a stronger system, the underlying goal is to inform providers and achieve positive health outcomes. Today, we also have a unified national strategic HIV vision to guide technology implementation. Focusing on measuring outcomes along the HIV Care Continuum allows us to devote our efforts and resources in the most effective way possible. SPNS will continue to lead the way in this effort, making sure that the HIT systems it builds today work to improve the lives of people for years to come.

For More Information

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