What's Going on @SPNS

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Advancing the HIV Care Continuum Initiative through Demonstration Projects

"We've got to keep pushing. We've got to make access to health care more available and affordable for folks living with HIV."[1]

—President Barack Obama, June 13, 2013

People living with HIV (PLWH) have increasing reasons to feel hopeful about the future. In many cases, treatment and care advances have transformed HIV into a long-term manageable disease. Treatment also has been shown to lower the risk of HIV transmission to uninfected partners.[2]

At the same time, the National HIV/AIDS Strategy (NHAS) demonstrates a renewed national commitment to turn the tide against the disease. It focuses public health efforts on three key objectives: reducing new infections, increasing access to care and optimizing health outcomes, and reducing health disparities.[3] Furthermore, the Affordable Care Act (ACA) is enabling more people to gain needed health insurance coverage. The new law even requires insurance companies to cover many preventive services, including HIV testing, with no out-of-pocket costs.

Despite these reasons for optimism, however, there's still much work to be done. Research shows that more than 1.1 million people are living with HIV in the United States, and of those, only about 25% have the virus under control.[4]

What does that really mean for PLWH and the community at large? It means that three out of four HIV-positive people are *still not getting the care they need* to live healthier lives and to reduce the chances of transmitting the disease to others.

Often, they are part of the most vulnerable or disadvantaged groups in our society. Transgender, bisexual, and men who have sex with men (MSM), particularly young MSM of color, are the groups most seriously affected by HIV; African Americans in general, Hispanics/Latinos, and injection drug users also are disproportionately affected.[5] What's more, PLWH who struggle with poverty or mental health and substance use disorders, or who are unstably housed, face many barriers to care and a greater tendency to fall out of care.[6,7] This makes it harder to keep one's viral load suppressed.

The HIV Care Continuum: Identifying Who Falls Out of Care and When

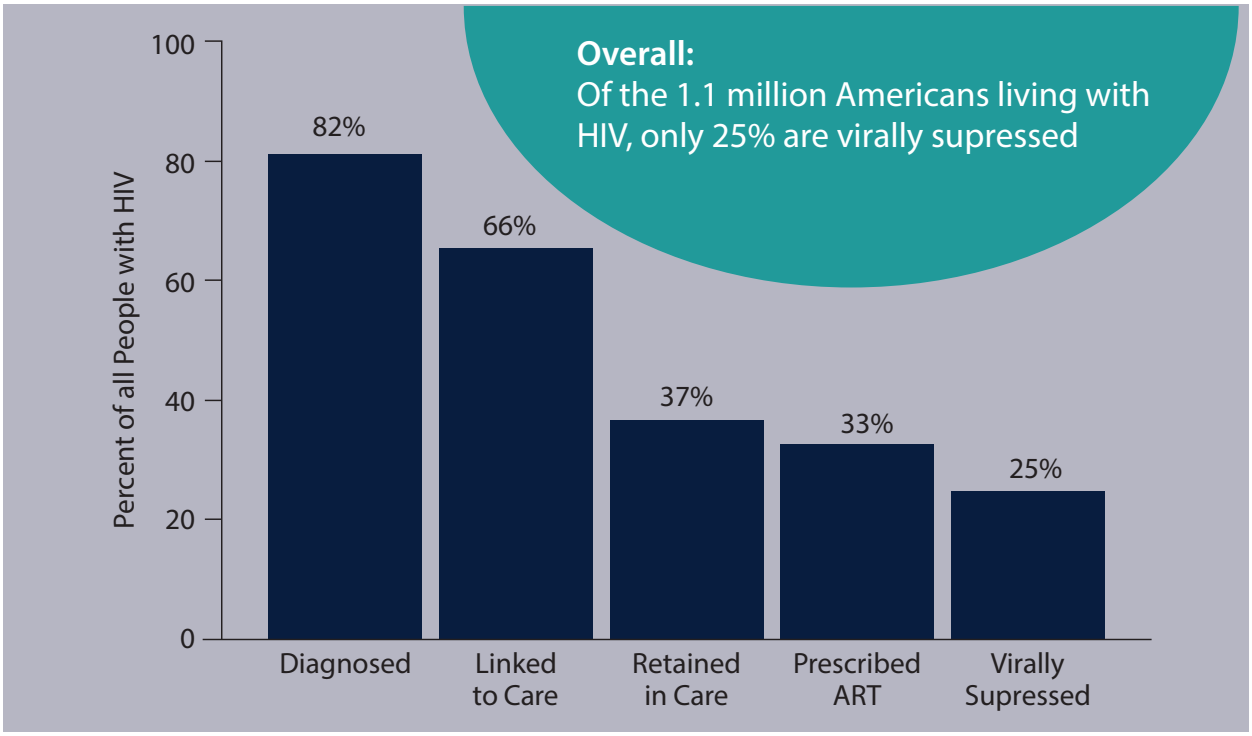
In July 2013, the White House Office of National AIDS Policy (ONAP) announced a call to action to reduce these drop-offs across the "continuum of care." This HIV Care Continuum Initiative refers to five stages of care—diagnosis, linkage to care, retention in care, adherence to medication therapy, and viral suppression—and incorporates research by the Centers for Disease Control and Prevention (CDC) estimating the percentage of PLWH who fall out of care during each stage (see chart, "HIV Care Continuum Drop-Offs").

Understanding who is dropping out of care and when is vitally important because it helps policymakers and service providers develop interventions that target gaps in service. The idea is to engage and retain more people in care so they can achieve viral load suppression, helping them live longer and healthier lives and breaking the cycle of HIV transmission. In this way, the federal HIV Care Continuum Initiative becomes an essential roadmap for achieving the goals of the NHAS and realizing the dream of an AIDS-free generation.

SPNS Initiatives Support the HIV Care Continuum Model

At the federal level, the HIV Care Continuum Initiative directs government agencies to use the HIV Care Continuum model to guide informed decisions, allocate resources, and monitor progress against the goals outlined in the NHAS. The Health Resources and Services Administration (HRSA) is fully committed to achieving that directive through the various funding parts of the Ryan White HIV/AIDS Program.

HIV Care Continuum Drop-Offs



Source: Centers for Disease Control and Prevention. HIV in the United States: Stages of Care [fact sheet]. July 2012. Available at: www.cdc.gov/hiv/pdf/research_mmp_stagesofcare.pdf. Accessed March 20, 2014.

HRSA's Special Projects of National Significance (SPNS) program, funded by Part F, has been addressing emerging trends and needs along the HIV Care Continuum since the early 1990s. The mission of the SPNS program is to provide HIV service delivery through demonstration projects and evaluation focused primarily on underserved, underinsured, and uninsured populations. Over the years, SPNS has funded demonstration projects to test innovative service delivery models in outreach and inreach, linkage to care, retention in care and medication adherence—all highly relevant to keeping people engaged in care at every stage in the continuum, from diagnosis to viral suppression.

Early Initiatives

Several early SPNS initiatives are featured in two workbooks published in 2004 and 2006 by HRSA's HIV/AIDS Bureau and the AIDS Action Foundation. *Connecting to Care: Addressing Unmet Needs in HIV* Workbook I and Workbook II both include descriptions of successful interventions that have helped HIV-positive individuals initiate and maintain connections to medical care and treatment. These workbooks are available at https://careacttarget.org/content/connecting-care-addressing-unmet-need-hiv and https://careacttarget.org/library/connecting-care-addressing-unmet-need-hiv-ii, respectively.

Many other SPNS initiatives have focused on connecting people to and retaining them in care, and assisting them with treatment adherence. Some examples include:

- Outreach for the Underserved: Targeted HIV Outreach and Intervention Model Development and Evaluation for Underserved HIV-Positive Populations Not in Care Initiative
- Outreach for Young MSM: Outreach, Care, and Prevention to Engage HIV Seropositive Young MSM of Color Initiative
- Jail Linkages: Enhancing Linkages to HIV Primary Care and Services in Jail Settings Initiative
- Adherence: Assessing Existing Efforts to Increase Adherence to Medications Initiative.

When a Patient Can't Speak for Himself

An HIV patient was in the emergency room with asthma so severe he couldn't speak. Luckily he was a patient in New York-Presbyterian Hospital System's SelectHealth program. SelectHealth had given him a MyHealthProfile card, part of a Continuity of Care Record (CCR) it had developed through a Special Projects of National Significance (SPNS) grant.

"During his stay in the hospital, [doctors] knew exactly what medications he was on so they were able to keep him on the correct antiretrovirals without interruption," said Esmerlin Valdez, the CCR project's community coach.

The CCR project was part of the *Electronic Networks of Care*, which funded six demonstration sites for four years, beginning in 2007. By linking patients' personal data to an existing regional health information network, various regional providers (as well as the patients themselves) gained access to core clinical, demographic, and care coordination data via a secure Internet connection.

The impact of the MyHealthProfile on patients has been transformational. Giving patients access to their own medical information has increased engagement in their own health care, and the training they have received in using the system has improved both their computer and health literacy.

"I have the confidence now to ask important questions and make changes to better my health," explained Danny, another patient who received access to his MyHealthProfile CCR.

Coordinating hospital information technology with regional health information exchange networks is a complex undertaking, and SPNS funding was critical to making it happen. The results are patients who feel empowered and have newly acquired skills to help them overcome many barriers to remaining in care, as well as providers who have access to needed information about where patients are accessing or falling out of care.

Source: Health Resources and Services Administration (HRSA). Ryan White biennial progress report, 2010. Going the distance: 20 years of leadership, a legacy of care. Available at: http://hab.hrsa.gov/data/files/2010progressrpt.pdf. Accessed March 14, 2014.

Note: A highlight of the Adherence Initiative was the development of a streamlined Adherence Case Index—validating five essential questions, instead of a long battery of inquires.

SPNS Serves Populations with High Needs

In alignment with the NHAS goal to reduce health disparities, SPNS initiatives have consistently focused on populations with the highest needs. Projects funded through SPNS have included behavioral change interventions, intensive case management, patient navigation, life-skills training, literacy training, and home-based outreach, all specifically targeting the populations hardest hit by HIV/AIDS.[8] Some of the most successful projects have identified culturally competent care practices, which also have shown to lead to higher rates of engagement in care.[9]

Current Initiatives

Several current SPNS initiatives focus on advancing high-need groups along the HIV Care Continuum. Consider these examples:

- Hispanics/Latinos: Culturally Appropriate Interventions of Outreach, Access and Retention among Latino(a) Populations Initiative
- Multiply Diagnosed Homeless People: Building a Medical Home for Multiply Diagnosed HIV-positive Homeless Populations Initiative
- Women of Color: Enhancing Access to and Retention in Quality HIV Care for Women of Color Initiative
- Transgender Women of Color: Enhancing Engagement and Retention in Quality HIV Care for Transgender Women of Color Initiative

One of the most recent SPNS projects to address the HIV Care Continuum is the Systems Linkages and Access to Care for Populations at High Risk of HIV Infection Initiative. As part of this initiative, grantees in six states are integrating different components of the public health system—such as surveillance, counseling and testing, and treatment—to create new and effective systems for reaching hard-to-reach populations. The targeted groups are people who are at high risk for or infected with HIV but who are unaware of their HIV status, as well as those who are aware of their HIV infection but have never been referred to care and those who are aware but have refused referral to care.

In addition, a new initiative (starting September 2014) involves enhancing technology infrastructure to facilitate sharing health data

IHIP Tools Help Providers Replicate SPNS Findings

A national focus on decreasing drop-offs along the HIV Care Continuum means the Special Projects of National Significance (SPNS) program is more important than ever before. That's because SPNS is designed to respond to the emerging needs of HIV-positive patients by supporting and assessing the effectiveness of innovative models of care.

Helping other providers replicate findings within their programs is the key to broadening the impact of SPNS, and thus meeting the recommendations of the federal HIV Care Continuum Initiative. To help accomplish that objective, SPNS created the Integrating HIV Innovative Practices (IHIP) project.

IHIP transforms lessons learned from the most successful demonstration projects into extremely practical training resources. Depending on the subject matter, IHIP materials can include training manuals, curricula, related webinars, monographs, and pocket guides.

Current IHIP materials cover topics such as:

- Incorporating buprenorphine in primary care settings
- Engaging hard-to-reach populations
- Enhancing linkages to HIV care in jail settings
- Implementing oral health care innovations.

Future IHIP materials will include training materials on the following:

- Expanding treatment for HIV patients who are coinfected with Hepatitis C
- Increasing access to and retention in care for women of color.

For more information and to download materials, visit www.careacttarget.org/ihip.

through secure electronic record systems. The *Health Information Technology Capacity Building for Monitoring and Improving Health Outcomes along the HIV Care Continuum Initiative* will provide funding for four Ryan White Part A or Part B grantees—to use integrated clinical, surveillance, laboratory, and other program data to improve health outcomes among PLWH. This is important because the ability to measure outcomes from all relevant HIV data systems helps providers and policymakers identify where and when affected groups are falling off the HIV Care Continuum.

Focusing on the HIV Care Continuum is a fundamental part of how SPNS operates. For example, all Funding Opportunity Announcements (FOAs) now require grantees to show how their demonstration projects will advance PLWH along the HIV Care Continuum.

Working Toward a Common Vision

Given the renewed government focus on decreasing drop-offs along the HIV Care Continuum and the NHAS call for "pilot programs that utilize community models" to identify effective interventions in high-risk communities,[10] the SPNS program's mission to test and evaluate evidence-based models of care is especially relevant, as is its emphasis on enhancing care for underserved, underinsured, and uninsured populations.

As President Obama said when he introduced the federal HIV Care Continuum Initiative, we have got to "keep pushing." We have got to find new and better ways to move people along the HIV Care Continuum. SPNS is an essential part of meeting that imperative.

For More Information

Contact Adan Cajina, SPNS branch chief, at 301-443-3180 or acajina@hrsa.gov.

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