



A Framework for Care

Recent Initiatives

Client-Level Data

Performance Measures

THE HIV/AIDS BUREAU: ADDRESSING THE HIV CARE CONTINUUM

Communities nationwide are working to improve health outcomes among people living with HIV (PLWH). This includes expanding HIV testing, improving active linkage to care, bolstering retention efforts, and increasing access to antiretroviral therapy (ART). These efforts are being aided by federal policies that focus attention on the HIV Care Continuum.

The *continuum of engagement in care* (later changed to the HIV Care Continuum) was a phrase used by Dr. Laura Cheever, HRSA's Associate Administrator for the HIV/AIDS Bureau, in her seminal 2007 editorial to describe the fluid nature of HIV health care delivery and patient experience.¹ Today, that concept of engaging patients and moving them along the HIV Care Continuum has received unprecedented attention and led to a federal HIV Care Continuum Initiative,² in which the Health Resources and Services Administration (HRSA), HIV/AIDS Bureau (HAB) plays a critical part.

Since 2006, the Centers for Disease Control and Prevention (CDC) has recommended routine screening of HIV for everyone ages 13–64 as part of regular medical care.³ For those who test positive for HIV, the U.S. Department of Health and Human Services (HHS) Panel on Antiretroviral Guidelines for Adults and Adolescents recommends immediate initiation and lifelong adherence to ART for all adults and adolescents, regardless of CD4 count. Doing so facilitates viral suppression, longer life expectancy, and decreased risk of HIV transmission.^{4,5}

DID YOU KNOW?

The Affordable Care Act strengthens HIV Care Continuum efforts by:

- Increasing coverage for HIV testing.
- Prohibiting insurance companies from denying coverage or charging more based on pre-existing conditions, including HIV.
- Expanding Medicaid coverage.
- Providing more affordable private health insurance coverage.
- Lowering prescription drug costs for Medicare recipients.
- Requiring a minimum set of benefits that must be covered
- Increasing coordinated care for people with chronic health conditions

Source: AIDS.gov. The Affordable Care Act and HIV/AIDS. Available at: <http://aids.gov/federal-resources/policies/health-care-reform/>. Accessed May 20, 2014.



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➔ DIRECTOR'S NOTES

HRSA has always worked hard to arm providers with the resources and best practices they need to advance patients in their care and improve health outcomes. Today, we now have a common language we can use to further promote federal, state, and local collaborations as we advance the National HIV/AIDS Strategy, and that's the *care continuum*.

The HIV Care Continuum reminds us that patient engagement in health care can be fluid and that we can't think of our roles as siloed but all pieces of a broader whole. The care continuum gives us very real benchmarks of where we can do better for people living with HIV. As we collect and make improvements, it's also showing us where we are succeeding.

We know more now about how to stop new transmission and reach an AIDS-free generation. Our treatment efficacy and clinical knowledge is incredible, and yet there is still so much more to do. That is why we are dedicating this *HRSA CAREAction* newsletter to the care continuum. It is our hope that this information about HRSA's activities and data along the continuum will be useful and that it will help spur ideas of how we can best approach this work together. Because together we can reduce new transmission, and together we can create healthier and brighter futures for the people we are so privileged to serve.

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Photographs

Cover: Patient receives instruction in medication adherence at Mount Sinai St. Luke's Hospital. Photograph taken for and permission granted to the Health Resources and Services Administration, HIV/AIDS Bureau.

Copies are available to be downloaded at www.hab.hrsa.gov.

This publication lists non-federal resources to provide additional information to consumers. The views and content in those resources have not been formally approved by the U.S. Department of Health and Human Services (HHS). Listing of the resources is not an endorsement by HHS or its components.

Unfortunately, many PLWH are not engaged and retained in the full spectrum of HIV treatment and care services. For example, approximately 16% of the estimated 1.1 million PLWH in the United States are undiagnosed.⁶ Data suggests that this subpopulation is responsible for one-half of new HIV infections.^{7,8} This is critical to underscore as testing serves as a pathway to accessing quality medical care that includes health-preserving, life-extending antiretroviral treatment, and additionally reduces risk of onward HIV transmission. In fact, once diagnosis is known HIV-infected individuals typically curtail risk behavior. Moreover, linkage to care and ART—necessary steps to improving health outcomes—can only take place if individuals are aware of their status.

Diagnosis is but one challenge. It is estimated that only 37% of PLWH are receiving regular HIV care and, despite the availability of effective, well-tolerated, and less-complicated fixed-dose ART regimens, only 25% of PLWH are virally suppressed.⁹ (See Figure 1.)

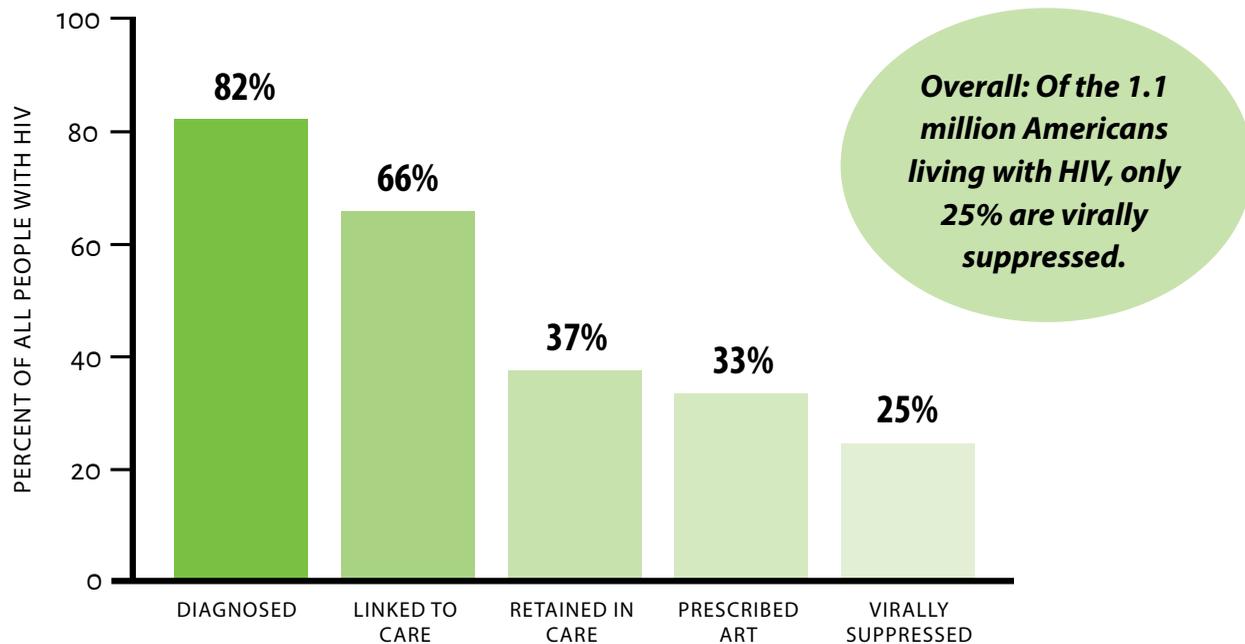
The HIV Care Continuum provides a framework to better understand HIV care and treatment in the United States. Furthermore, knowing where changes in the HIV Care Continuum are most pronounced, and for what populations, facilitates targeted interventions—and investments—that are most likely to have the greatest impact.

Data suggest that without substantial improvements at each phase of the HIV Care Continuum, more than 1.23 million new HIV infections could occur in the United States over the next 20 years.¹⁰ Although the HIV Care Continuum points to the need for progress across all phases of HIV health care delivery, the marked decrease between linkage to care and retention in care indicates that these are critical intervention points for scaling up ART coverage and maximizing public health and clinical benefits.¹¹

DISPARITIES ACROSS THE HIV CARE CONTINUUM

A deeper analysis of the HIV Care Continuum shows that there are significant health disparities related to sexual orientation, race, age, gender, class, HIV transmission category, and migrant status. These

➔ **FIGURE 1. HIV CARE CONTINUUM**



Source: Centers for Disease Control and Prevention (CDC). 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.

disparities underscore that more work must be done to reach populations that already bear a disproportionate burden of the nation's HIV epidemic.

Age. HIV-positive young people (ages 13–24), for example, are far less likely than any other age group to have had their infection diagnosed.¹² Individuals in this age group are also least likely to be linked to medical care.¹³ This may be because young people have been infected more recently and had less time to be tested or linked to care compared with older adults.¹⁴ However, to achieve the National HIV/AIDS Strategy (NHAS) goals will mean increasing knowledge of HIV status among this age group and helping them move through all levels of the HIV Care Continuum.

Race/ethnicity. Blacks/African-Americans are the least likely of any race or ethnicity to be retained in care or to be virally suppressed.¹⁵ For example:

- 34% of blacks/African-Americans were retained in care compared with 37% of Hispanics/Latinos and 38% of whites; and,
- 21% of blacks/African-Americans were virally suppressed compared with 26% of Latinos and 30% of whites.¹⁶

Gender. Men are less likely to be diagnosed, linked, or retained in care compared with women.¹⁷

Sexual orientation. The most statistically significant increase of new HIV infections between 2008 and 2010 was among men who have sex with men (MSM), particularly young black MSM¹⁸ —a subpopulation among the least likely to be diagnosed or linked to HIV medical care.¹⁹

Geography. HIV Care Continuum disparities vary by geography. Nearly one-half (49%) of all HIV diagnoses in the United States in 2011 occurred in the South.²⁰ Challenges, particularly in rural southern areas, include limited access to HIV prevention and care, workforce capacity, health insurance coverage, utilization behaviors, and

➔ A CALL TO ACTION

In July 2010, President Barack Obama released the first comprehensive National HIV/AIDS Strategy (NHAS), a road map of nine measurable targets to reduce new HIV infections, improve health outcomes for PLWH, and reduce HIV-related health disparities:

- **Target 1:** By 2015, lower the annual number of new infections by 25%.
- **Target 2:** By 2015, increase from 79% to 90% PLWH who know their serostatus.
- **Target 3:** By 2015, reduce the HIV transmission rate, which is a measure of annual transmissions in relation to the number of PLWH, by 30%.
- **Target 4:** By 2015, increase the proportion of newly diagnosed patients linked to clinical care within three months of their HIV diagnosis from 65% to 85%.
- **Target 5:** By 2015, increase the proportion of Ryan White HIV/AIDS Program clients who are in continuous care (at least two visits for routine HIV medical care in 12 months at least three months apart) from 73% to 80%.
- **Target 6:** By 2015, increase the percentage of Ryan White HIV/AIDS Program clients with permanent housing to 86%.
- **Targets 7-9:** By 2015, increase viral suppression among HIV-diagnosed men who have sex with men (MSM), blacks, and Latinos by at least 20%.

Although steady progress has been made toward each of the NHAS goals, failure to engage PLWH along the HIV Care Continuum threatens the ability to meet critical NHAS targets. As such, on the third anniversary of the release of the NHAS, President Obama announced a national effort—the federal HIV Care Continuum Initiative—to increase the proportion of individuals engaged in each step along the continuum. In an executive order, President Obama called for a coordinated, multidisciplinary approach, led by the White House Office of National AIDS Policy, to prioritize and intensify efforts to improve rates of HIV testing, linkage to and retention in care, access to ART, and viral suppression, as they continue to implement the NHAS.

Sources: The White House Office of National AIDS Policy (ONAP). National HIV/AIDS strategy for the United States. 2010. Available at: <http://aids.gov/federal-resources/national-hiv-aids-strategy/nhas.pdf>. Accessed May 17, 2014.

ONAP. Executive order—HIV care continuum initiative. July 15, 2013. Available at: www.whitehouse.gov/the-press-office/2013/07/15/executive-order-hiv-care-continuum-initiative. Accessed May 17, 2014.

access to transportation to medical appointments—all critical elements towards moving patients along the HIV Care Continuum and toward better health outcomes. The Affordable Care Act is helping address this in part by allowing Ryan White HIV/AIDS Program funding to be used for critical needs like premium coverage and care completion in states electing to expand Medicaid (e.g. Massachusetts), and to very good effect. The White House Office of National AIDS Policy (ONAP) held a meeting on June 18, 2014, to draw attention to these issues and explore HIV responses in the southern states.²¹

To address disparities along the HIV Care Continuum and advance the NHAS, scalable, cost-effective, population- and geographic-specific initiatives will be vital.

RECNT HAB HIV CARE CONTINUUM INITIATIVES

The Ryan White HIV/AIDS Program, administered by HAB, is the largest federal program devoted exclusively to HIV disease. The Program provides HIV care, treatment, and support services to more than 536,000 PLWH across the country with a focus on improving engagement and health outcomes along the HIV Care Continuum.

INCREASING CAPACITY AND DEVELOPING TARGETED INTERVENTIONS

HAB has been including language about and emphasizing the HIV Care Continuum in recent funding opportunity announcements. A project funded by the Secretary's Minority Health Initiative is the Health Information Technology Capacity Building for Monitoring and Improving Health Outcomes along the HIV Care Continuum Initiative under the Special Projects of National Significance (SPNS) Program. This new three-year 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. This work aligns with the Affordable Care Act and the NHAS and is critical given that "HIT has the potential to increase utilization of services, improve health outcomes for people with HIV, and reduce community viral load and subsequent transmission of HIV."²²

Another recently announced project is the System-Level Workforce Capacity Building for Integrating HIV Primary Care in Community Healthcare Settings Initiative. This SPNS project is funding 15 grantees and an evaluation and technical assistance center to promote the design, implementation, and evaluation of system-level change in staffing structures that improve health outcomes along the HIV Care Continuum.

SPNS grantees research innovative models of care and develop evidence of best practice to be shared with the broader HIV community. Particular emphasis has been on addressing the needs of vulnerable populations who bear a disproportionate burden of HIV and are least likely to be engaged along the HIV Care Continuum. For example, SPNS is currently funding initiatives focused on transgender women, Latinos, and homeless populations who are multiply diagnosed. Previous initiatives have examined barriers to care and engagement of women of color and of young men who have sex with men (YMSM). (See "Spotlight: Assisting YMSM Along the HIV Care Continuum" to learn more.)

SPNS work has demonstrated that with outreach workers, patient navigators, medication counselors, and others, populations most at-risk for falling out of care can be readily engaged into care. For example, the Enhancing

SPOTLIGHT: ASSISTING YMSM ALONG THE HIV CARE CONTINUUM

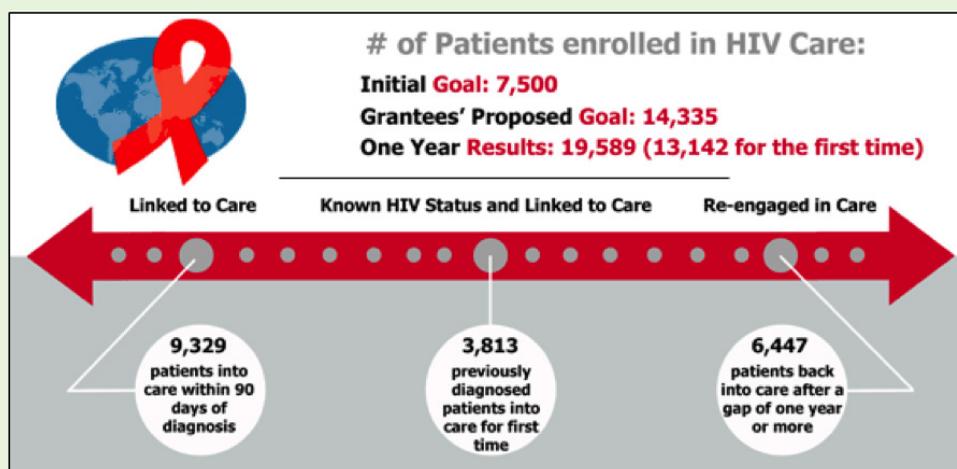
Young men who have sex with men (YMSM) are being infected with HIV at alarming rates, and young people are faring worse along the HIV Care Continuum. To address these trends, HAB is funding projects to proactively link, engage, and retain HIV-positive YMSM as well as inform grantees and providers on best practices for treating this population.

UCare4Life: The goal of UCare4Life is a mobile texting program that helps patients with HIV infection to better adhere to strict medication regimens and to remain in care for the disease. This two-year project will focus on southern states, where the epidemic is rising quickly among youth. It consists of developing a message library for delivering timely phone text reminders in English and Spanish to HIV-positive individuals for medical appointments and for taking medications as prescribed.

SPNS: The Outreach, Care, and Prevention to Engage HIV Seropositive Young MSM of Color Initiative funded eight demonstration projects to develop and evaluate innovative outreach efforts to assist HIV-infected young (ages 13–24) MSM of color in learning their HIV status, linking them with primary care services, and preventing transmission of HIV infection.

Black MSM: The Resource and Technical Assistance Center for HIV Prevention and Care for Black Men who have Sex with Men (BMSM) Cooperative Agreement is a new project funded by HAB to inventory existing evidence-based interventions and strategies and to identify and disseminate best practices and effective models of care for BMSM, including young BMSM (ages 13–24).

➔ FIGURE 2. FIRST YEAR RESULTS FOR IAHCT



Source: Health Resources and Services Administration. Increasing access to HIV care and treatment (IAHCT). [Infographic.] Available at: <http://blog.aids.gov/2014/01/encouraging-first-year-results-for-the-increasing-access-to-hiv-care-and-treatment-initiative.htm>. Accessed September 22, 2014.

Linkages to HIV Primary Care & Services in Jail Settings Initiative (EnhanceLink) successfully connected PLWH recently released from jail to HIV primary care and medical case management. Without discharge plans and a linkage intervention, barriers to care that existed prior to jail admission were likely to remain when previously incarcerated persons reentered the community.

DEVELOPING PARTNERSHIPS TO IMPROVE CARE

HAB has made it a priority over the years to connect with other federal partners, share lessons learned, and collaborate on initiatives. In FY 2012, HRSA's Bureau of Primary Health Care (BPHC) and HAB worked in collaboration to award over \$10 million to 275 Ryan White HIV/AIDS Program Part C Early Intervention Services grantees, of which nearly half are dually-funded by BPHC.

In addition, as part of the \$15 million IAHCT funding, 14 new healthcare entities were competitively awarded \$4.6 million to provide HIV primary care and early intervention services."

The additional supplemental funding for IAHCT allowed clinics to expand outreach and testing for high-risk populations; expand service hours for medical care; enhance systems to identify, connect with, and keep PLWH

in care; expand support services; and hire additional service providers experienced in HIV primary care.²³

Although IAHCT initially aimed to enroll 7,500 patients across the country in its first year, it far surpassed that goal.²⁴ From June 2012 through May 2013, the initiative linked 19,589 patients to HIV medical care, including 13,142 people who were linked to care for the first time.²⁵ The sites also met the needs of HIV-infected individuals at different stages along the HIV Care Continuum. For example:

- A total of 9,329 patients were newly diagnosed and were linked to medical care within 90 days of diagnosis.²⁶
- An additional 3,813 previously diagnosed patients entered medical care and treatment for the first time.²⁷
- A total of 6,447 HIV-infected people who had not received care in more than a year were brought back into care.²⁸

In addition to federal partnerships such as IAHCT, HAB is encouraging—and facilitating—partnerships across Ryan White HIV/AIDS Program Parts. Consider the HIV Care Continuum Cross-Part Collaborative (H4C) for example. HAB invited five states—Arkansas, Mississippi, Missouri, New Jersey, and Ohio—to participate in H4C as part of a collaborative effort to build regional capacity

to increase viral suppression. Each state team will implement joint quality improvement activities to advance the quality of care for PLWH within a region; coordinate HIV services seamlessly across Parts; and, ultimately, move patients along the HIV Care Continuum.

CREATING A NATIONAL RETENTION CAMPAIGN

The in+care Campaign, a retention initiative through the National Quality Center and funded by HAB, examined best practices and developed service models that promote retention in HIV primary care. The in+care Campaign encouraged Ryan White HIV/AIDS Program grantees and providers to measure retention and viral suppression, develop quality improvement projects, and share successes and challenges with others.

The Campaign had 655 Ryan White HIV/AIDS Program grantees, providers, and sub-providers across all Program Parts sign up to participate, representing 473,235 PLWH (not unduplicated). Through the guidance of a Technical Working Committee, composed of national experts from across the country including Dr. Laura Cheever, the in+care Campaign developed a set of four measures: retention in care for newly diagnosed individuals, retention over 24 months, gaps in care longer than 6 months, and viral suppression for grantees to use to measure—and improve upon—their HIV Care Continuum work.

USING DATA AND PERFORMANCE MEASURES TO IMPROVE THE HIV CARE CONTINUUM

Client-level Data

In 2009, all Ryan White HIV/AIDS Program grantees began reporting client-level demographic and clinical data annually in the Ryan White HIV/AIDS Program Services Report (RSR). The RSR is used to determine the total number and demographic information of patients served and clinical data for those receiving HIV medical care funded by the Ryan White HIV/AIDS Program. From the RSR data, HAB is able to understand client engagement along the HIV Care Continuum.

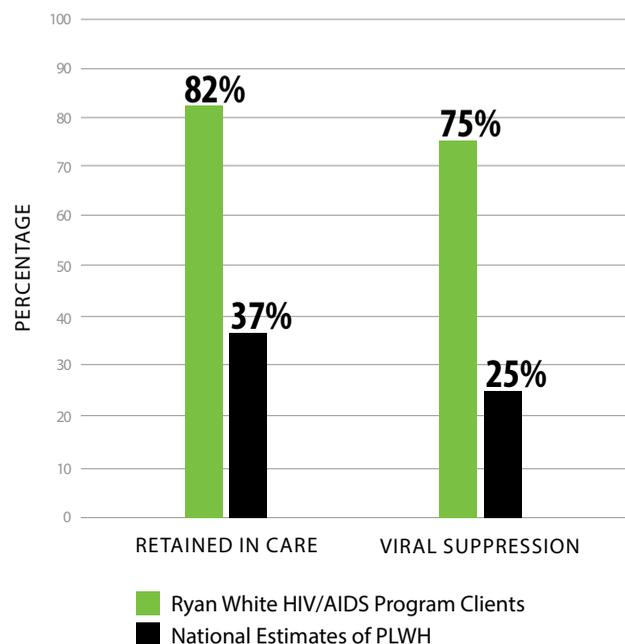
Analyses of RSR data revealed that PLWH who receive care in HAB-funded clinics are better engaged, retained, and virally suppressed than national HIV Care Continuum estimates.²⁹ A forthcoming HAB data report and a recent article in *Clinical Infectious Diseases* outline RSR data along the HIV Care Continuum.³⁰ Figure 3 depicts

comparisons of RSR data in 2012, the most recent year for which data is available, against national estimates for viral suppression and retention in care.*

The Ryan White HIV/AIDS Program is unique in that it provides medical care and comprehensive services including substance abuse treatment, mental health support, transportation, emergency food assistance, and other services that vulnerable populations need to be retained in care. Grantees take a public health approach to care and are encouraged to look at population-specific needs and address them, always with an emphasis on cultural competency. Additionally, through the SPNS program, HAB funds initiatives to develop evidence of best practices and to disseminate these best practices to the broader

* HAB defines *viral suppression* as having had at least one outpatient/ambulatory medical care visit, at least one viral load count, and a last viral load test <200. *Retained in care* is defined as having had at least one outpatient/ambulatory medical care visit before September 1, 2012, and having had at least two visits 90 or more days apart.

FIGURE 3. RYAN WHITE HIV/AIDS PROGRAM CLIENTS VS. NATIONAL ESTIMATES OF PLWH, 2012



Source: Health Resources and Services Administration (HRSA), HIV/AIDS Bureau (HAB). Ryan White HIV/AIDS Program 2012 Services Report (RSR). [Unpublished.]

Ryan White HIV/AIDS Program community. Concurrently, the AIDS Education and Training Centers (AETCs) focus on training health care staff on patient needs and health care guidance. Altogether, these efforts are helping engage—and retain—PLWH in Ryan White HIV/AIDS Program-funded facilities.³¹

Although rates of retention and viral load suppression among Ryan White HIV/AIDS Program clients are high compared with national estimates, these data demonstrate room for improvement. Given that patients retained in care are more likely to be medication-adherent and have undetectable viral loads, fewer opportunistic infections, and fewer HIV transmissions, efforts to keep patients in care or bring them back to care are critical and HAB will continue to prioritize and support such efforts.

PERFORMANCE MEASURES

HAB establishes and monitors key HIV performance measures to ensure high-quality care, advancement along the HIV Care Continuum, alignment with the NHAS, and adherence to HHS standards. HAB funds quality improvement programs and provides leadership in development and implementation of quality measures.³²

For example, HAB, in partnership with the CDC, recently sought and received endorsement of four additional

performance measures (e.g., HIV viral load suppression, prescription of ART, medical visit frequency, and gap in HIV medical visits) from the National Quality Forum, a nonpartisan organization that works to catalyze improvements in health care, for broad national use. HAB is working to make these four endorsed measures available for use in electronic health records (EHRs).

At the same time, HAB is seeking inclusion of the four measures in the Centers for Medicare & Medicaid Services (CMS) Medicare and Medicaid EHR Incentive Programs (meaningful use stage 3), and Physician Quality Reporting System (PQRS). The EHR Incentive Program provides financial incentives for certified EHR technology to improve patient care while PQRS is a reporting program combining incentive payments and payment adjustments.³³⁻³⁵

Through these activities, HAB is:

- meeting its legislative mandate of establishing clinical quality management programs to assess the extent to which HIV health services are consistent with Public Health Service guidelines
- arming providers with necessary measures to gauge and inform their work; and
- improving the overall health outcomes of PLWH across the country.

 **TABLE 1. ALIGNMENT OF HAB PERFORMANCE MEASURES**

HAB Measure	in+care Campaign Measure	National Quality Forum (NQF) Endorsed	Core Measure	Point on HIV Care Continuum	HHS Measure	Centers for Medicare & Medicaid Services (CMS) Program
HIV viral suppression	Yes	Yes — NQF 2082	Yes	Yes	Yes	Pending acceptance to MU stage 3
Prescription of ART	Yes	Yes — NQF 2083	Yes	Yes	Yes	
24-month HIV medical visit frequency	Yes	Yes — NQF 2079	Yes	Yes	Yes	
Gap in HIV medical visits	Yes	Yes — NQF 2080	Yes		No	

ONLINE RESOURCES

AETC Engagement in Care Toolkit

<http://aidsetc.org/resource/aetc-engagement-care-toolkit>

AETC National Resource Center

<http://aidsetc.org/topic/hiv-continuum-care>

AIDS.gov: HIV Care Continuum

<http://aids.gov/federal-resources/policies/care-continuum/>

HIV Care Continuum Webinars

<http://blog.aids.gov/2013/09/white-house-office-of-national-aids-policy-hiv-care-continuum-webinars.html>

HRSA: HIV Care Continuum

<http://hab.hrsa.gov/data/reports/continuumofcare/continuumabstract.html>

HRSA's HIV/AIDS Bureau's Revised Performance Measures

<http://hab.hrsa.gov/deliverhivaids/habperformmeasures.html>

Integrating HIV Innovative Practices (IHIP) SPNS Project

<https://careacttarget.org/ihip>

TARGET Center Engagement in Care Resources

<https://careacttarget.org/category/topics/engagement-care>

White House: Executive Order—HIV Care Continuum Initiative

www.whitehouse.gov/the-press-office/2013/07/15/executive-order-hiv-care-continuum-initiative

White House: Improving Outcomes, Accelerating Progress Along the HIV Care Continuum

www.whitehouse.gov/sites/default/files/onap_nhas_improving_outcomes_dec_2013.pdf

CONCLUSION

Progress along the HIV Care Continuum has been made. However, as long as new infections are occurring and PLWH are falling out of care there is more work to be done. The HIV Care Continuum has been called a “report card,”³⁶ demonstrating both progress in the fight against HIV as well as underscoring areas in need of increased attention and investment.

Thanks to client-level data, HAB and its grantees have more information about the HIV Care Continuum at their disposal than ever before. Applying HIV best practices as well as targeting initiatives and interventions along the HIV Care Continuum will remain critical to meeting the goals of the NHAS and to creating a brighter future for PLWH across the country.



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