

Curbing the HIV Epidemic by Supporting Effective Engagement in HIV Care



Recommendations
for Health Plans
and Health Care
Purchasers

TABLE OF CONTENTS

INTRODUCTION	1
SUMMARY OF RECOMMENDATIONS	1
I. BETTER MONITORING OF ENGAGEMENT IN HIV CARE	3
Action Steps to Better Monitor Engagement in HIV Medical Care.....	5
II. INTERVENING TO SUPPORT CONTINUOUS ENGAGEMENT IN CARE	6
Action Steps to Support Continuous Engagement in HIV Care	7
III. CHANGING POLICY (through collaboration with federal, state, and local policy makers)	9
Action Steps to Promote Policy Change to Support Improved Engagement in HIV Care	9
CONCLUSION	10
ENDNOTES	11

INTRODUCTION

The United States is poised to dramatically reduce the scope of its HIV epidemic, but this demands increased leadership and attention from health plans and health care purchasers (including Medicaid, Medicare, marketplaces, and other private purchasers). While health plans and purchasers may perceive that HIV-specific prevention and care programs are better situated to lead the response to the epidemic, there are a relatively small number of actionable and meaningful steps that these entities can take that will improve health outcomes, reduce preventable HIV-related health spending, and contribute to the development of more tightly integrated systems of care. Most importantly, however, from a health plan or purchasing perspective, HIV is a chronic condition that can be effectively

managed. While some individuals with HIV may have extensive and complex needs, many are virally suppressed and require limited monitoring and laboratory services in addition to their antiretroviral therapy (ART) regimens. Effective management can help to make them a more predictable-cost population and allow plans and purchasers to appropriately tailor services to only those persons who need them.

This report identifies changes in policy and practice in clinics, communities, and health care programs to reduce unnecessary health spending, increase the effectiveness of services, and increase the integration of services. Done right, the same steps that lead to appropriate management of care by health plans and purchasers also will help to achieve national public health goals.

SUMMARY OF RECOMMENDATIONS

I. MONITORING

- Actively monitor national HIV quality metrics within health plans and health care systems.
- Adopt new metrics to identify and intervene with patients at risk for disengaging from care.
- Build quality improvement systems that include persons “not in care.”

II. INTERVENING

- Adopt systems improvements to normalize and routinize HIV screening.
- Maximize the capacity of electronic medical records to adopt provider- and system-level interventions to streamline and routinize HIV screening in accordance with CDC recommendations.
- Utilize EMR algorithms to identify patients in need of HIV testing or who have fallen out of care.
- Enhance capacity to identify cases of acute infection through best available testing technologies and timely clinical interventions.
- Expand active referral programs for linkage to care.

- Expand low cost evidence-informed approaches to promote retention in care.
- Establish programs to actively re-engage people in care who have experienced treatment interruptions.
- Address financial barriers to HIV care and treatment.

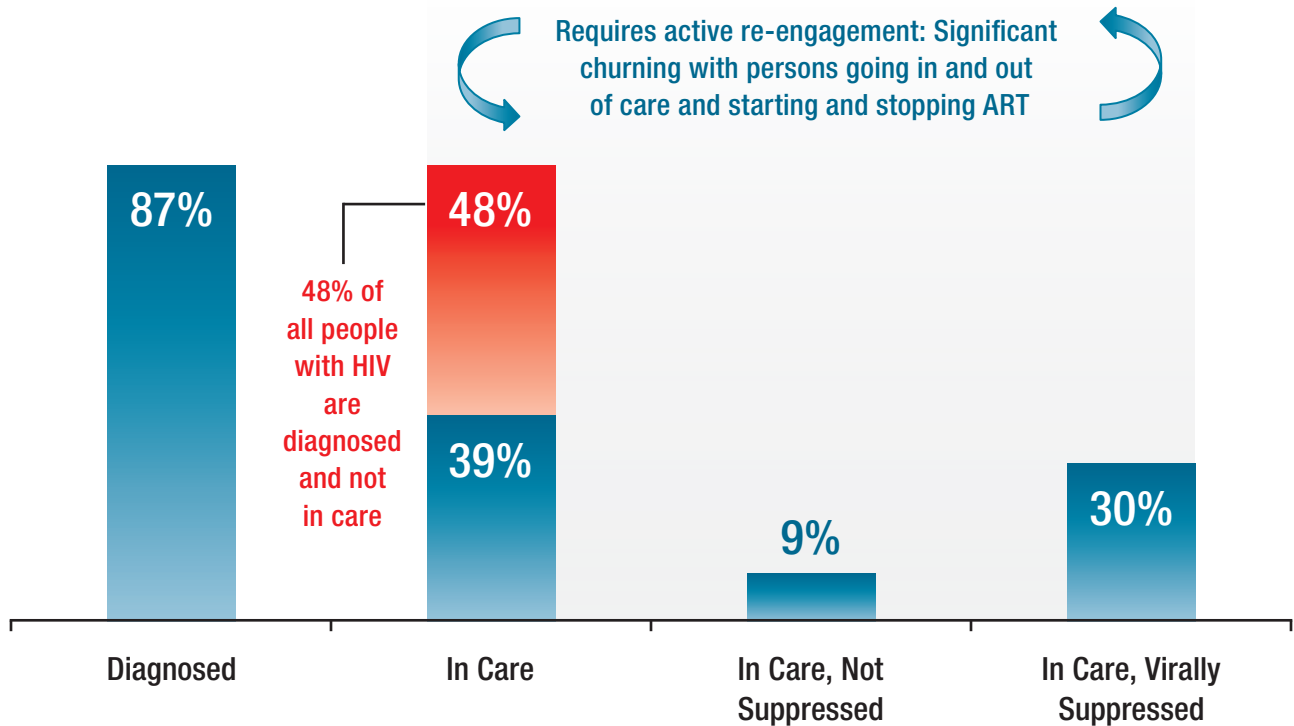
III. CHANGING POLICY (through collaboration with federal, state, and local policy makers)

- Establish “Data to Care” programs in all state health departments.
- Clarify responsibilities and strengthen coordination among federal, state, and local agencies.
- Further integrate grantee funding and oversight between CDC and HRSA.
- Establish standards for Medicare, Medicaid, and marketplaces to monitor core HIV indicators, build systems to support engagement in HIV care, and require fidelity to HHS ART guidelines.
- Establish state and local data and continuous quality improvement collaboratives.

FIGURE 1

Engagement in Care Along the HIV Care Continuum (United States and Puerto Rico, 2012)

Share of all people with HIV at this stage



Source: Frieden TR, Foti KE, Mermin J. Applying public health principles to the HIV epidemic — How are we doing? *N Engl J Med.* 2015;373(23):2281–2287; Skarbinski J, Rosenberg E, Paz-Bailey G, et al. Human immunodeficiency virus transmission at each step of the care continuum in the United States. *JAMA Intern Med.* 2015;175(4):588–596.
Note: “In care” means receiving at least two HIV specialty care visits per year at least 90 days apart.

The HIV care continuum (Figure 1) is used to estimate how many people with HIV are engaged in the various stages of care, from diagnosis to viral suppression.¹ These estimates have received considerable attention as a way to measure national, state, and local success in supporting all people with HIV to learn their status and benefit from effective treatment. The U.S. health system does a fairly good job of serving many people living with HIV once they establish an ongoing relationship with a qualified HIV care provider.¹ The problem is that too many are not continually engaged in HIV care, which drives the continued cycle of HIV transmission that results in roughly 50,000 new infections annually.²

The Centers for Disease Control and Prevention (CDC) estimates that only 8% of HIV transmissions in the U.S. result from persons receiving ongoing HIV care (Figure 2). Most surprising, perhaps, CDC data

indicate that almost half of all people diagnosed with HIV in the U.S. are not receiving regular HIV care, and they account for roughly seven in ten HIV transmissions.

Now is a unique moment when much progress is possible. While some diagnosed individuals not in care are uninsured, others have insurance, yet are not receiving regular HIV care either because they are not engaged in care or because the care they receive is not addressing their HIV infection. Therefore, if health plans are able to ensure that all of their members with HIV are receiving appropriate HIV medical care, then we can dramatically reduce HIV morbidity and mortality, as well as onward HIV transmission. New scientific knowledge has created greater urgency for finding people soon after diagnosis and starting ART right away. In 2015, the START Study, a randomized controlled trial (RCT), conclusively demonstrated the clinical benefits for people with HIV

to begin ART as soon as possible after diagnosis.^{3,4} In addition, the HPTN-052 study, published in 2011, provides strong evidence of the effectiveness of early ART in reducing onward HIV transmission.⁵ This RCT found that early treatment reduced the risk of transmission by up to 96%. A third RCT, the SMART Study, published in 2006, tested a strategy of interrupted ART and found a 160% increased risk of death in persons not receiving continuous ART.^{6,7} The challenge for the health system is not only to get persons diagnosed and to start ART, but also to achieve and maintain high levels of adherence to care and treatment. For a variety of reasons, a sizable share of people with HIV have started care, even may have started ART, but subsequently disengage from care. New approaches are needed to systematically identify and engage these individuals.

Expanded health insurance coverage resulting from the Affordable Care Act (ACA) and changes in how health care is delivered create new opportunities for progress. Some ACA marketplace plans have adopted formulary policies that place all ART medications on the highest cost tiers. Such practices are inconsistent with federal ART treatment guidelines and appear discriminatory against people with HIV. These policies and practices must be ended. On the whole, however, Medicaid, Medicare, private group health plans, and most ACA marketplace plans provide reasonable prescription drug coverage for people with HIV. Therefore, insurance already covers what is overwhelmingly the most costly component of HIV care, suggesting that it is not necessary to dramatically expand the scope of services provided. Rather, understanding the barriers to care and the unique challenges facing some people living with HIV may call for expanded approaches to care management and service coordination and greater funding for ancillary services for some individuals that address adherence to treatment, mental health, substance use, and other co-morbid conditions. Notably, the National HIV/AIDS Strategy for the United States, updated by the Obama Administration in 2015 to guide the nation's efforts through 2020, has prioritized efforts to increase knowledge of HIV status, increase engagement in care and viral suppression, and expand access to pre-exposure prophylaxis (PrEP). Clearly, health plans and purchasers are critical to the Strategy's success.

There are three primary domains within which health plans and health care purchasers can consider taking action:

1. Better monitoring of engagement in HIV care;
2. Intervening to support continuous and sustained engagement in care and HIV viral suppression; and,
3. Supporting policy changes at all levels of government to strengthen engagement in HIV care.

I. BETTER MONITORING OF ENGAGEMENT IN HIV CARE

To improve outcomes and reduce costly medical interventions, it is necessary to strengthen the systematic monitoring of engagement in care and viral suppression. This demands new partnerships and data sharing arrangements between health plans, health departments, clinical and non-clinical providers, pharmacies, and commercial laboratories. The establishment of these arrangements at the local level requires new alignment, flexibility, and coordination between various federal and state agencies that fund programs and services with overlapping goals, working alongside health plans and purchasers.

Significant work has taken place on this front in recent years. The Ryan White HIV/AIDS Program, which is the largest domestic program focused solely on the care and treatment of people with HIV, is the linchpin of the HIV care system in the U.S. It funds HIV services for uninsured and underinsured people with HIV and invests in health care capacity and infrastructure to support a nationwide system of HIV care.

Because public health surveillance centralizes HIV-positive test results from all testing service providers, and viral load and CD4 counts from all laboratories and medical providers, these surveillance systems expand information beyond what individual health plans could previously use.

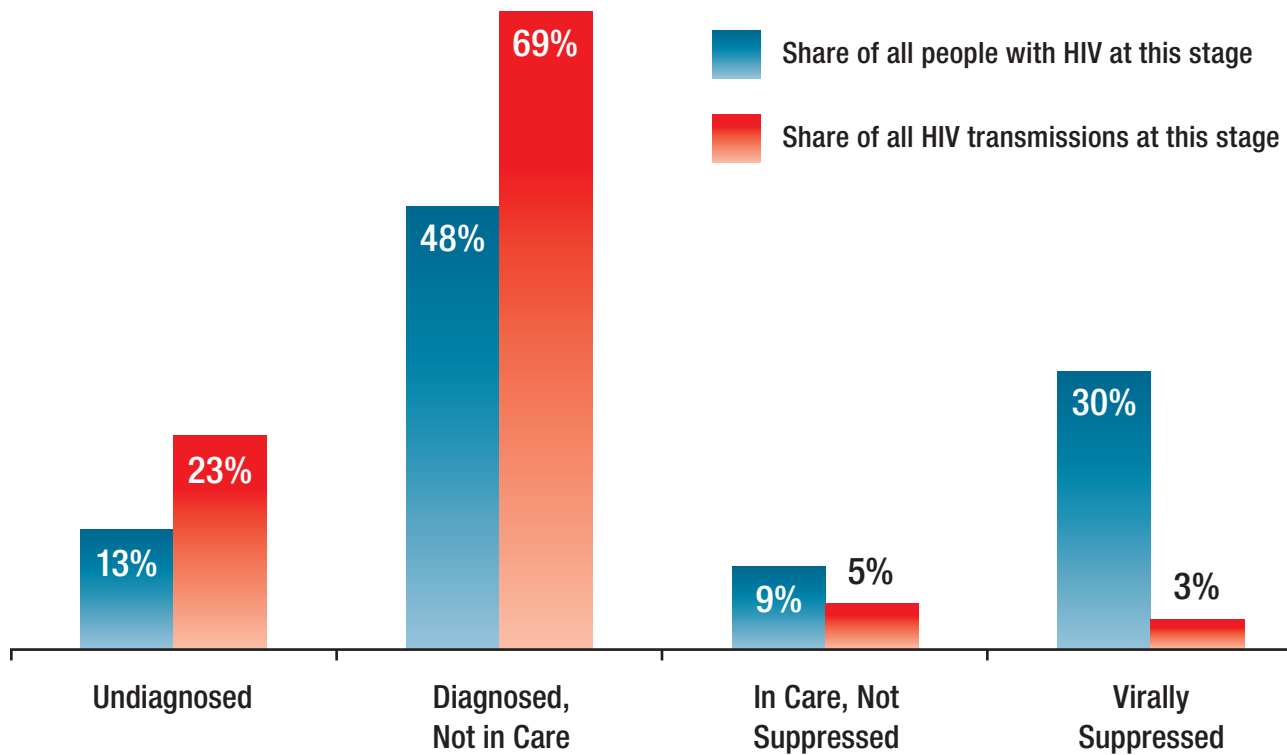
The Health Resources and Services Administration (HRSA) that administers the program estimates that in 2014, three-fourths of Ryan White clients had some form of insurance coverage.⁸ In such cases, the program covers needed services not covered by insurance and assists with cost sharing to prevent cost from being a barrier to care. The program has spent several years implementing a client-level data system that is now operational and is yielding new information to help policy makers, clinics, and other service

providers take strategic actions to improve the allocation of resources and strengthen the quality of care.⁹ In 2010, the White House commissioned the Institute of Medicine (IOM) to examine questions related to the monitoring of HIV care in the U.S. The IOM produced two reports that identified a core set of HIV clinical care indicators¹⁰ and provided recommendations for using existing HIV and other data sets to strengthen the monitoring of HIV care.¹¹ Concurrently, the Office of

FIGURE 2

Estimated HIV Transmissions Along the HIV Care Continuum
(United States and Puerto Rico, 2012)

The majority of HIV transmissions could be prevented by getting all diagnosed persons into HIV care; many of these individuals already have health insurance coverage



Source: Frieden TR, Foti KE, Mermin J. Applying public health principles to the HIV epidemic — How are we doing? *N Engl J Med.* 2015;373(23):2281–2287; Skarbinski J, Rosenberg E, Paz-Bailey G, et al. Human immunodeficiency virus transmission at each step of the care continuum in the United States. *JAMA Intern Med.* 2015;175(4):588–596.
Note: “In care” means receiving at least two HIV specialty care visits per year at least 90 days apart.

HIV/AIDS and Infectious Diseases Policy (OHAIDP) at the Department of Health and Human Services (HHS) convened relevant HHS agencies along with the Housing Opportunities for People with AIDS (HOPWA) program at the Department of Housing and Urban Development (HUD) to align definitions for and streamline the reporting of key indicators in order to reduce the reporting burden on federal grantees (Figure 3).

Additionally, the 2015 Updated National HIV/AIDS Strategy revised national targets for the next five years.¹² While these indicators provide a critical barometer of our overall performance as a nation, other readily available and evidence-informed measures, indicators, and interventions must be pursued in clinical settings to increase rates of

HIV viral suppression and other clinical outcomes. Attention is also needed to address the differential performance of and outcomes in specific populations, which may call for more tailored approaches to better support certain groups such as adolescents, women, and young gay and bisexual men of color.

One of the more exciting developments in recent years has been the expansion of public health surveillance data systems in most states to include mandatory reporting of all HIV viral load (measure of HIV virus circulating in the body) and CD4 counts (measure of a specific immune system component).¹³ Using evidence of a recent HIV viral load and/or CD4 count laboratory test as a proxy for HIV medical care visits,

FIGURE 3

Common Federal Indicators for HIV Programs and Services

Measure	Numerator	Denominator
HIV positivity	Number of HIV positive tests in the 12-month measurement period	Number of HIV tests conducted in the 12-month measurement period
Late HIV diagnosis	Number of persons with a diagnosis of Stage 3 HIV infection (AIDS) within 3 months of diagnosis of HIV infection in the 12-month measurement period	Number of persons with an HIV diagnosis in the 12-month measurement period
Linkage to HIV Medical Care	Number of persons who attended a routine HIV medical care visit within 3 months of HIV diagnosis	Number of persons with an HIV diagnosis in 12-month measurement period
Retention in HIV Medical Care	Number of persons with an HIV diagnosis who had at least one HIV medical care visit in each 6-month period of the 24-month measurement period, with a minimum of 60 days between the first medical visit in the prior 6-month period and the last medical visit in the subsequent 6-month period	Number of persons with an HIV diagnosis with at least one HIV medical care visit in the first 6 months of the 24-month measurement period
Antiretroviral Therapy (ART) Among Persons in HIV Medical Care	Number of persons with an HIV diagnosis who are prescribed ART in the 12-month measurement period	Number of persons with an HIV diagnosis and who had at least one HIV medical care visit in the 12-month measurement period
Viral Load Suppression Among Persons in HIV Medical Care	Number of persons with an HIV diagnosis with a viral load <200 copies/mL at last test in the 12-month measurement period	Number of persons with an HIV diagnosis and who had at least one HIV medical care visit in the 12-month measurement period
Housing Status	Number of persons with an HIV diagnosis who were homeless or unstably housed in the 12-month measurement period	Number of persons with an HIV diagnosis receiving HIV services in the last 12 months

Source: Common Indicators for HHS-funded HIV Programs and Services. July 2012. <http://hab.hrsa.gov/data/servicesdelivered/2014RWHAPDataReport.pdf>. Accessed April 4, 2016.

a new public health surveillance tool is available to comprehensively monitor engagement along each step on the continuum.¹⁴ Expanded “active” surveillance has the potential to become a game changer for health plans to improve the management of their members with HIV. By matching public health surveillance data with health plan data, plans are able to narrow the roster of people with HIV not engaged in care by excluding those persons seen elsewhere, who have moved, or who may have died, thereby facilitating more targeted interventions for those persons needing re-engagement services. The CDC’s Data to Care Initiative provides resources for health departments, health plans, and providers to build systems to adopt “active” surveillance programs to improve patient care.¹⁵

ACTION STEPS TO BETTER MONITOR ENGAGEMENT IN HIV MEDICAL CARE

- **Actively monitor HIV quality metrics within health plans and health care systems.**

The ability of the health system to expand its capacity to measure population-level outcomes depends on the quality of client-level data. National indicators, however, are also critically important for improving clinical outcomes at the individual level. Therefore, health plans and clinics must ensure that they are monitoring priority HIV indicators

such as those approved by the National Quality Forum¹⁶ and, when appropriate for clinical settings, those used by the National HIV/AIDS Strategy. Clinical management systems can use indicators such as time from diagnosis to start of ART and CD4 levels at diagnosis (suggesting potential delays in early HIV diagnosis and/or treatment) to monitor successes and gaps in quality care.^{17,18} Given the estimated cost savings of averting a single HIV infection (\$229,800),¹⁹ total cost savings from reduced odds of onward infection through quality HIV care is compelling. Further, these estimates do not account for the potential cost savings attributable to proper management, which prevents the development of co-morbid conditions and reduces the need for clinical care and services. Purchasers should include new monitoring requirements in purchasing specifications and increase payments to health plans to account for the added costs associated with more extensive monitoring of members with HIV.

- **Adopt new metrics to identify and intervene with patients disengaging from care.**

While national indicators focus on important outcomes along the continuum of care, other data can be helpful in identifying early signs of disengagement from HIV care. For example, missed medical visits have been consistently linked to adverse HIV biomarkers and clinical outcomes and are measurable and actionable in real time at the clinic level.²⁰ Health plans and clinics are in a unique position to access outcomes data, as well as visit no-shows, elapsed days out of care, and change in clinical outcomes at the individual level. Such data can be used proactively to avert extended disengagement from care. Monitoring beyond existing national quality indicators should include missed clinic visits, as they are a harbinger of patients about to become lost to care. Monitoring also may be expanded to include other factors identified in local data sets as predictive of outcomes. Models for clinical care sites to use their internal data to monitor and intervene in a timely fashion with at-risk patients on their panels are emerging,²¹ but lack systematic nationwide adoption. Health plans, purchasers, and clinics all can contribute to the development of scalable approaches to tracking missed clinic visits that lead to wide-scale adoption.

- **Build quality improvement systems that include persons “not in care.”**

Health plans, Medicaid programs, and other payers should build more comprehensive quality improvement programs that include monitoring not only of persons “in care,” but all health plan members or beneficiaries with HIV. For instance, health plans could develop actionable strategies for managing their members with HIV that support continued engagement and, when needed, provide for specific steps for re-engaging persons in care. This could be operationalized by establishing Utilization Management (UM) or Care Coordination (CC)

teams that focus on connecting newly diagnosed members to sites within their provider network that are able to deliver HIV-informed primary care and connect with other community resources to support adherence and impact viral suppression. Depending on the specific health plan model, in many circumstances, the most effective approach would not be to build new capacity within plans to perform all of these functions, but to formalize relationships with existing community services providers. Among the specific supports that these UM/CC teams can assist with are personal appointment reminders, facilitating escorts (if necessary) and increasing consumers’ ability to navigate healthcare and related social services. At a minimum, health plans must be able to connect members with HIV to primary care within their provider networks that is equipped to provide quality HIV care.

II. INTERVENING TO SUPPORT CONTINUOUS ENGAGEMENT IN CARE

Living with HIV, accessing care in a complex health care system, and adhering to ART over one’s life are challenging even for the most motivated individuals. Major life challenges, transitions, and stressors such as unemployment, relationship distress, family responsibilities, and financial distress create immediate, high-priority needs that can compete with engaging in HIV care.²² Individuals can cycle and churn in and out of care at a single clinic; some estimates suggest that about 25% of patients churn in 12-month cycles,²³ and as many as 60% of patients who experience gaps in HIV care will return to care within a five- to seven-year timeframe.²⁴ Churning between clinics and regions also has been identified through the Market Scan Medicaid Multisite Database and other “Big Data” systems, but these aggregated data sets may inappropriately classify over a quarter of patients who appear to have gaps in care in single source or single state registries, but are actually receiving care elsewhere.²⁵ Considerable attention to reducing churn due to changes in coverage eligibility (coverage churn) is emerging in the era of substantial changes in national plans and marketplaces.^{26,27}

The federal government, working with state and local governments, is taking important steps to improve engagement in care along the HIV care continuum. In 2013, President Obama issued an Executive Order that established an HIV Care Continuum Initiative to focus cross-agency attention on high priority areas of collaboration.²⁸ As the ACA has increased insurance coverage for people living with HIV, there is a new opportunity for the Centers for Medicare and Medicaid Services (CMS), Medicare, Medicaid programs, health plans, and

marketplaces, working in conjunction with the Ryan White HIV/AIDS Program and health departments, to play a more proactive role in developing new models of care that support continual engagement and retention in HIV care, informed by integrated data systems to allow for more accurate individual-level monitoring and delineation of “in care” or “out of care” status.

As the Affordable Care Act (ACA) has expanded access to insurance coverage and as the concept of treatment as prevention is integrated into our thinking about how we reduce HIV transmission, it is important to note that the early stages of the continuum traditionally have been the purview of health departments and the public health system, while the health insurance system and Medicaid programs have not seen it as their primary role to improve diagnosis, linkage, and retention in care. This must change.

ACTION STEPS TO SUPPORT CONTINUOUS ENGAGEMENT IN HIV CARE

- **Adopt systems improvements to increase the percentage of people screened for HIV.**

Routine HIV screening programs in clinical settings can ensure that all people are offered screening for HIV when they come in for care, even without an identified risk factor for HIV infection. Research has found that even when risk factors are present, providers do not always initiate testing, but routinization is intended to reach persons that would not otherwise be identified for testing.²⁹ Routinizing HIV screening removes the burden from the individual to self-identify as at risk for HIV and thereby reduces potential stigma. In addition, both providers and patients sometimes fail to accurately assess risk. Purchasers need to establish indicators and link reimbursement to increasing the percentage of health plan members or clinic patients who accessed health care services within the past year who were screened for HIV. Purchasers also should consider “bill above” policies that reimburse for screening in settings where capitated or bundled reimbursements could otherwise discourage screening.

- **Maximize the capacity of electronic medical records to adopt provider- and system-level interventions to streamline and routinize HIV screening in accordance with CDC recommendations.**

Clinical leaders should conduct baseline assessments to identify the number and percentage of individuals age 15–65 that have “ever” tested for HIV, as well as those that receive an annual HIV test, and under what conditions they are tested (e.g., in concert with STD screening or diagnosis, as part of preventative care visits, or on patient request). They should use this information to determine continuous quality improvement activities to steadily increase the number of health plan members being tested. Health plans could establish a health maintenance goal and provide incentives for certain groups to complete an annual HIV test. With certain subpopulations such as gay and bisexual men, routine HIV testing, at least annually and perhaps more frequently, should become part of the standard of care.

- **Utilize EMR algorithms to identify patients in need of HIV testing or who have fallen out of care.**

Purchasers, electronic medical record (EMR) vendors, health plans, and clinics should examine systems-level improvements, including the development of EMR algorithms to make the offering of an HIV test something that happens by default at every patient encounter. In busy clinic settings where the sheer number of guidelines and requirements quickly reach unmanageable levels, strategies to implement and monitor HIV guidelines are needed. This can include providing a check box or using automated systems within electronic health records so that an HIV test is ordered by default, with the option of the patient opting out. Other options include batch test ordering; batch reminder cards to patients; “best practice alerts/prompts” with one-click ordering for patients at risk and with no evidence of recent HIV testing in the electronic health record; linking HIV testing to many panels, including STI or Hepatitis C testing, PAP smears, and cholesterol level testing; or including HIV testing as part of a health maintenance annual checklist in the electronic health record.

- **Enhance the capacity to identify cases of acute infection through best available testing technologies and timely clinical interventions.**

Until recently, readily available testing technology in the U.S. was unable to diagnose infection while persons were in the acute phase, when they are most infectious. CDC guidance issued in 2014 recommends the adoption of fourth-generation HIV testing technologies within hospitals and health systems, making it the standard of care for HIV testing and screening programs.³⁰ Health plans, hospitals, and clinics all have a role to play in increasing access to fourth-generation testing, which allows for identification of acute and early infections

that would have been missed with older tests. In addition to purchasing this technology, these entities should work collaboratively with health departments and community partners to invest in outreach programs that link acutely infected individuals to care as soon as possible to interrupt transmission within their sexual and social networks.

- **Expand active referral programs for ‘immediate’ linkage to care.**

Ensuring seamless and immediate linkage (i.e., within hours or one to two days) to medical care at the point of diagnosis is a weak spot on the care continuum. Whether conducted by a masters level case manager, as was done for the CDC ARTAS study,^{31,32} or by linkage coordinators,³³ having a designated person assigned to assist someone newly diagnosed with HIV enter medical care has proven to be an effective strategy. Efforts should be made to expand such programs, tailored to local contexts and resources, to ensure dedicated programs and appropriate personnel are in place in every jurisdiction. Health plans, clinics, and purchasers should build systems and develop formalized agreements or contractual requirements with all testing providers to ensure a rapid, welcoming handoff from a testing provider to the appropriate clinical staff.

- **Expand low cost evidence-informed approaches to promote retention in care.**

Although there is a paucity of proven approaches to improve retention in care, those that exist should be rapidly implemented and scaled up. A study jointly funded by CDC and HRSA demonstrated that a low cost, clinic-wide intervention including posters, brochures, and brief messages about coming to visits produced a modest increase in retention in care.³⁴ Similarly, a second approach evaluated in the study showed that a brief educational session about the importance of continuous HIV care followed by personal reminder calls seven and two days before scheduled appointments, and within 48 hours of missed appointments, led to improved retention in care, at modest cost.^{35,36} Notably, the same person who developed a relationship with the study participant made the calls. With modest resources, these intervention approaches have the potential for considerable impact if there is widespread uptake at high volume HIV clinics.

- **Establish programs to actively re-engage people in care who have experienced treatment interruptions.**

Because perfect retention over one’s lifetime is a virtually impossible, perhaps the most urgent action that health plans and purchasers can undertake is to build programs and systems to identify persons at risk for extended or terminal gaps in care, and then work to promote re-engagement before negative consequences are realized.³⁷ One of the major advantages of coordinating integrated data monitoring

with provider- and clinic-level feedback loops is to forewarn service providers when clinical indicators of potential problems arise. Missed visits, failure to refill medications, a lapse of more than 90 days after a missed visit, or other locally identified indicators can alert providers of the need for immediate action. For persons who have stopped engaging in care, standard practice must be to take staged and increasingly intensive steps to re-engage them and offer tailored options for overcoming barriers to continued engagement, similar to differentiated care strategies recommended by the World Health Organization.³⁸

Strategies for re-engaging or averting disengagement are best when tailored to one’s specific community, as regions differ in patterns of HIV care retention,³⁹ which may reflect important diversities in challenges and resources. Community-based participatory practices are critical to determining synergies between health plans, health departments, and community and institutional providers. Working collaboratively, health plans and clinics should establish partnerships with community-based organizations to improve the effectiveness of their efforts to retain their members in care. These organizations often have unparalleled levels of community trust and can offer a range of services, including peer support, educational programs, social case management, and other services that support adherence to care and ART therapy that may be more difficult for health plans to deliver in a typical clinical environment.

- **Address financial barriers to HIV care and treatment.**

The maintenance of health for people with HIV demands lifelong engagement in care, although advances in pharmacology have dramatically decreased the daily burden of HIV-treatment regimens. Nonetheless, like other chronic conditions, consistent presentation in care for monitoring, daily medication taking, and frequent pharmacy refills are needed. Unlike many other chronic conditions, however, the consequences of days without dosing (i.e., over two days with no dosing) can be severe for the individual in terms of viral rebound,⁴⁰ thus also creating opportunities for onward transmission. Continuity of coverage for medications and for attending regular HIV-care visits is critical, and, as noted previously, failures result in coverage churn. For those with a choice of health plans, even the optimal health plan may impose financial burdens that create substantial barriers to care and treatment. This can be the case even in programs such as Medicaid, which have reduced cost sharing for low-income individuals. With an estimated 40% of people living with HIV residing in states that have not yet expanded Medicaid,⁴¹ strategies are needed to support enrollment in marketplace health plans and to educate consumers about how to access services and how deductibles and other components of enrollee cost-sharing work. Furthermore, it is essential to ensure that systems are in place to support individuals in order to prevent disengagement in care.⁴²

Health plans need to become more active in helping individuals with HIV to navigate their insurance benefits, access care appropriately, and minimize personal out-of-pocket costs. When appropriate, health plans also should help members to avail themselves of public and private programs that provide supplemental financial assistance (such as pharmacy assistance programs, Ryan White AIDS Drug Assistance Programs [ADAPs], and other community resources).

III. CHANGING POLICY (through collaboration with federal, state, and local policy makers)

Health plans should seek opportunities to engage with health departments, purchasers, and providers to advance an agenda for change that creates systems to ensure that standard practices lead to optimal care. Whereas the National HIV/AIDS Strategy and other policy documents provide a clear vision of what the nation needs to do to end the HIV epidemic, translating this vision into actionable steps within health plans, provider offices, clinics, and communities is often neglected. Many health plans, health care purchasers, and providers may perceive their role as caring for individuals and not worrying about population-level impact. Nonetheless, there are rich opportunities to enact policies that both work toward common national goals and facilitate the delivery of high quality care, while also reducing costs.

ACTION STEPS TO PROMOTE POLICY CHANGE TO SUPPORT IMPROVED ENGAGEMENT IN HIV CARE

- **Establish “Data to Care” programs in all state health departments.**

The CDC has launched a “Data to Care” campaign, providing technical assistance for the implementation of health department, clinical, or combination models that use surveillance data to facilitate linkage, retention, and re-engagement in HIV medical care. New efforts are needed to expand on this effort so that all health departments have the staffing, capacity, and funding to implement such programs. The CDC should be applauded for this initiative, and now is the time to re-allocate significant resources to expanding it. Health plans benefit greatly when health departments are able to integrate community-wide monitoring with client-level data from individual clinics or health plans. Therefore, health plans should advocate for access to surveillance data on their

members in order to activate UM/CC teams and/or work with contracted network providers to facilitate care engagement and retention.

- **Clarify responsibilities and strengthen coordination among federal agencies.**

No single agency is responsible for HIV testing, public health functions such as partner notification and contact tracing, supportive services, and medical care. The CDC, HRSA, SAMHSA, and other federal agencies are strongly encouraged to commit to promulgating coordinated cross-agency guidance on issues related to the HIV care continuum and providing clear direction to grantees for resolving questions in order to avoid duplication and ensure consistency across federal programs. These agencies already have taken important steps in this direction, including working with states and local jurisdictions to streamline resource planning for federal prevention and care services. The status quo, however, in which each federal program issues its own guidance, continues to produce confusion in the field and is in need of further coordination. Health plans and health care purchasers should urge federal agencies to review current guidance related to testing, linkage, retention, and adherence to care in order to identify conflicts and propose remedies to align guidance across programs or, where necessary, to explicitly note divergence in policies across programs. For future regulation and policy guidance, there should be a commitment that all policy guidance would be reviewed by all relevant agencies, with a designated entity within HHS (such as OHAIDP) responsible for mediating policy disagreements.

- **Further integrate grantee funding and oversight between CDC and HRSA.**

HRSA's Ryan White Services Report that provides client-level data is an important tool for informing program planning and is an important complement to the CDC's Data to Care program and the Medical Monitoring Project (MMP).⁴³ While both agencies have greatly expanded their collaboration in recent years, substantial new efforts are needed to ensure that HIV care and HIV prevention activities are not housed in entirely separate silos. This should include detailing key staff from one agency to the other, aligning funding announcements, and, when possible, issuing blended funding program announcements. Furthermore, the expansion of Data to Care and the integration with client-level data requires building data management capacity in health departments that does not currently exist in most jurisdictions. Therefore, joint funding between various parts of the Ryan White HIV/AIDS Program with an expanded Data to Care program that clearly permits health departments to add data management staff could be an important way to spur critical progress and reduce local barriers to sharing program data between public health authorities focused on prevention and those focused on care. Health plans and health care

purchasers should engage with policy makers around these issues and urge their adoption in a manner that facilitates engagement by health plans in new data collaborations.

- **Establish standards for Medicare, Medicaid, and marketplaces to monitor core HIV indicators, build systems to support engagement in HIV care, and require fidelity to HHS ART guidelines.**

Medicare and Medicaid are the dominant purchasers of HIV care in the U.S., representing more than half of the federal investment in domestic HIV spending. To date, while federal policy has encouraged these programs to provide quality HIV care, it has failed to use its market power to demand that these programs adhere to federal evidence-based standards. Federally administered marketplaces also have an opportunity to ensure that HIV clinical practices adhere to the latest standards. CMS, which oversees Medicaid, Medicare, and health care marketplaces, should issue enforceable guidance to require all three to collect the same data and actively monitor HIV viral suppression and other HHS core HIV indicators. Moreover, given that federal ART guidelines are the gold standard for evidence-based clinical HIV practice guidelines, CMS should establish legally enforceable policies across Medicare, Medicaid, and federally facilitated marketplaces to ensure that formulary policies are non-discriminatory and provide appropriate access to ART consistent with the latest federal guidelines. Health plans and purchasers should support standardization across these programs to ensure that individual health plans are not at a competitive disadvantage when they meet the current standard of HIV care.

- **Establish state and local data and continuous quality improvement collaboratives.**

Given that state and local capacity to manage and use data varies dramatically, and health plans and providers may be unclear as to how they can contribute to population health initiatives, health departments should establish data collaboratives that bring together the health department, Medicaid, the marketplace, health plans, providers, and community stakeholders to develop a strategic plan for sharing data to improve engagement in HIV care. Such collaboratives could lead to the development of a clear state or local agenda and goals for data sharing, building community support for such efforts, examining barriers to sharing and using data, and identifying stepwise priorities for action, which can then be monitored via continuous quality improvement initiatives. Health care purchasers should fund these types of collaboratives at the local and state levels, and health plans should proactively engage in the establishment of these efforts.

CONCLUSION

The U.S. can move forward and better support people with HIV to be diagnosed and engaged in continuous medical care. There are reasonable and strategic steps that health plans and various health care purchasers can take today that will help improve clinical outcomes, reduce wasteful spending, and reduce the scope and impact of the HIV epidemic in the U.S.

This report was prepared for amfAR by Jeffrey S. Crowley, O'Neill Institute for National and Global Health Law at Georgetown University; K. Rivet Amico, University of Michigan; and Michael Mugavero, University of Alabama, Birmingham.

The authors thank Greg Millett, Kali Lindsey, Brian Honermann, and Jack MacAllister, amfAR Public Policy Office, for their guidance throughout the project. Numerous others provided guidance, participated in background interviews, reviewed drafts, and provided other assistance. We are grateful to (listed alphabetically): Sean Bland, Sonia Canzater, Lindsey Dawson, Patty Dietz (and other CDC colleagues), Andrew Forsyth, Thomas Giordano, Robert Greenwald, Michael Horberg, Jen Kates, Amy Killelea, Eugene McCray, Patrick McGovern, Terrance Moore, Jane Simoni, Patrick Sullivan, Ronald Valdiserri, Rochelle Walensky, Andrea Weddle, and Doug Wirth.

ENDNOTES

- 1 The Health Resources and Services Administration (HRSA) defines “retained in care” as receiving at least two outpatient/ambulatory medical care visits in a year, at least 90 days apart.
- 2 Centers for Disease Control and Prevention. *HIV Surveillance Report, 2014*; vol. 26. November 2015. <http://www.cdc.gov/hiv/library/reports/surveillance/>. Accessed April 4, 2016.
- 3 The INSIGHT START Study Group. Initiation of antiretroviral therapy in early asymptomatic HIV infection. *N Engl J Med*. 2015;373(9):795–807.
- 4 Fauci AS, Marston HD. Ending the HIV-AIDS pandemic — Follow the science. *N Engl J Med*. 2015;373(23):2197–2199.
- 5 Cohen MS, Chen YQ, McCauley M, et al. Prevention of HIV-1 infection with early antiretroviral therapy. *N Engl J Med*. 2011;365(6):493–505.
- 6 The Strategies for Management of Antiretroviral Therapy (SMART). Study Group. CD4+ count-guided interruption of antiretroviral treatment. *N Engl J Med*. 2006;355(22):2283–2296.
- 7 Fauci AS, Marston HD, *supra*, note 4.
- 8 Health Resources and Services Administration. *Ryan White HIV/AIDS Program Annual Client-Level Data Report, 2014*. December 2015. <http://hab.hrsa.gov/data/servicesdelivered/2014RWHAPDataReport.pdf>. Accessed April 4, 2016.
- 9 *Ibid*.
- 10 Institute of Medicine. *Monitoring HIV Care in United States: Indicators and Data Systems*. March 15, 2012. <http://www.iom.edu/Reports/2012/Monitoring-HIV-Care-in-the-United-States.aspx>. Accessed April 4, 2016.
- 11 Institute of Medicine. *Monitoring HIV Care in the United States: A Strategy for Generating National Estimates of HIV Care and Coverage*. October 5, 2012. <http://www.iom.edu/Reports/2012/Monitoring-HIV-Care-in-the-United-States-A-Strategy-for-Generating-National-Estimates-of-HIV-Care-and-Coverage.aspx>. Accessed April 4, 2016.
- 12 *The National HIV/AIDS Strategy for the United States: Update to 2020*. July 2015. <https://www.aids.gov/federal-resources/national-hiv-aids-strategy/nhas-update.pdf>. Accessed April 4, 2016.
- 13 Sweeney P, Gardner LI, Buchacz K, et al. Shifting the paradigm: Using HIV surveillance data as a foundation for improving HIV care and preventing HIV infection. *Milbank Q*. 2013;91(3):558–603.
- 14 Dombrowski JC, Kent JB, Buskin SE, Stekler JD, Golden MR. Population-based metrics for the timing of HIV diagnosis, engagement in HIV care, and virologic suppression. *AIDS*. 2012; 26(1):77–86.
- 15 Centers for Disease Control and Prevention. *High Impact Prevention. Data to Care: Using HIV Surveillance Data to Support the HIV Care Continuum*. 2015. <https://effectiveinterventions.cdc.gov/en/highimpactprevention/publichealthstrategies/DatatoCare.aspx>. Accessed April 4, 2016.
- 16 National Quality Forum. *NQF Endorses Infectious Disease Measures*. January 8, 2013. https://www.qualityforum.org/News_And_Resources/Press_Releases/2013/NQF_Endorses_Infectious_Disease_Measures.aspx. Accessed April 4, 2016.
- 17 Horberg M, Hurley L, Towner W, et al. HIV quality performance measures in a large Integrated healthcare system. *AIDS Patient Care STDs*. 2011;25(1):21–28.
- 18 Horberg M, Hurley L, Towner W, et al. The HIV care cascade measured over time and by age, sex, and race in a large national integrated care system. *AIDS Patient Care STDs*. 2015;90(11):582–590.
- 19 Schackman BR, Fleishman JA, Su AE, et al. The lifetime medical cost savings from preventing HIV in the United States. *Med Care*. 2015; 53(4): 293–301. http://www.natap.org/2015/CROI/The_Lifetime_Medical_Cost_Savings_From_Preventing.99070.pdf
- 20 Mugavero MJ, Westfall AO, Cole SR, et al. Beyond core indicators of retention in HIV care: Missed clinic visits are independently associated with all-cause mortality. *Clin Infect Dis*. 2014;59(10):1471–1479.
- 21 E.g., New York State Department of Health AIDS Institute. *Drilling Down Data to Understand Barriers to Care: Looking Behind Numbers to Improve Care in Your Clinic*. February 2015. <http://www.hivguidelines.org/wp-content/uploads/2015/04/drilling-down-data-to-understand-barriers-to-care-03-31-2015.pdf>. Accessed April 4, 2016.
- 22 Mugavero MJ, Raper JL, Reif S, et al. Overload: The impact of incident stressful events on antiretroviral medication adherence and virologic failure in a longitudinal, multi-site HIV cohort study. *Psychosom Med*. 2009;71(9):920–926.
- 23 Rebeiro P, Althoff KN, Buchacz K, et al. Retention among North American HIV-infected persons in clinical care, 2000–2008. *J Acquir Immune Defic Syndr*. 2013;62(3):352–362.

-
- 24 Byrd KK, Furtado M, Bush T, Gardner L. Evaluating patterns in retention, continuation, gaps, and re-engagement in HIV care in a Medicaid-insured population, 2006–2012, United States. *AIDS Care*. 2015;27(11):1387–1395.
- 25 *Ibid.*
- 26 Rosenbaum S, Lopez N, Dorley M, Teitelbaum J, Burke T, Miller J. Mitigating the efforts of churning under the Affordable Care Act: Lessons from Medicaid. *Issue Brief (Commonw Fund)*. 2014;12:1–8.
- 27 Swartz K, Short PF, Graefe DR, Uberoi N. Reducing Medicaid churning: Extending eligibility for twelve months or to end of calendar year is most effective. *Health Aff (Millwood)*. 2015;34(7):1180–1187.
- 28 The White House. Office of the Press Secretary. *Executive Order — HIV Care Continuum Initiative*. July 15, 2013. <https://www.whitehouse.gov/the-press-office/2013/07/15/executive-order-hiv-care-continuum-initiative>. Accessed April 4, 2016.
- 29 Sionean C, Le BC, Hageman K, et al. HIV risk, prevention, and testing behaviors among heterosexuals at increased risk for HIV infection — National HIV Behavioral Surveillance System, 21 U.S. cities, 2010. *MMWR Surveill Summ*. 2014;63(14):1–39.
- 30 Centers for Disease Control and Prevention, Association of Public Health Laboratories. *Laboratory Testing for the Diagnosis of HIV Infection: Updated Recommendations*. June 27, 2014. <http://stacks.cdc.gov/view/cdc/23447>. Accessed April 4, 2016.
- 31 Gardner LI, Metsch LR, Anderson-Mahoney P, et al. Efficacy of a brief case management intervention to link recently diagnosed HIV-infected persons to care. *AIDS*. 2005;19(4):423–431.
- 32 Craw JA, Gardner LI, Marks G, et al. Brief strengths-based case management promotes entry into HIV medical care: Results of the antiretroviral treatment access study-II. *J Acquir Immune Defic Syndr*. 2008;47(5):597–606.
- 33 Gilman B, Hidalgo J, Thomas C, Au M, Hargreaves M. Linkages to care for newly diagnosed individuals who test HIV positive in nonprimary care settings. *AIDS Patient Care STDs*. 2012;26(3):132–140.
- 34 Gardner LI, Marks G, Craw JA, et al. A low-effort, clinic-wide intervention improves attendance for HIV primary care. *Clin Infect Dis*. 2012;55(8):1124–1134.
- 35 Gardner LI, Giordano TP, Marks G, et al. Enhanced personal contact with HIV patients improves retention in primary care: A randomized trial in six U.S. HIV clinics. *Clin Infect Dis*. 2014;59(5):725–734.
- 36 Shrestha RK, Gardner L, Marks G, et al. Estimating the cost of increasing retention in care for HIV-infected patients: Results of the CDC/HRSA retention in care trial. *J Acquir Immune Defic Syndr*. 2015;68(3):345–350.
- 37 Edwards JK, Cole SR, Westreich D, et al. Loss to clinic and five-year mortality among HIV-infected antiretroviral therapy initiators. *PLoS One*. 2014;9(7):e102305.
- 38 World Health Organization. *HIV Treatment and Care. What's New in Service Delivery*. November 2015. http://apps.who.int/iris/bitstream/10665/204461/1/WHO_HIV_2015.46_eng.pdf?ua=1. Accessed April 22, 2016.
- 39 Rebeiro PF, Gange SJ, Horberg MA, et al. Geographic variations in retention in care among HIV-infected adults in the United States. *PLoS One*. 2016;11(1):e0146119.
- 40 Haberer JE, Musinguzi N, Boum Y, et al. Duration of antiretroviral therapy adherence interruption is associated with risk of virologic rebound as determined by real-time adherence monitoring in rural Uganda. *J Acquir Immune Defic Syndr*. 2015;70(4):386–392.
- 41 Kates J, Garfield R, Young K, Quinn K, Frazier E, Skarbinski. *Assessing the Impact of the Affordable Care Act on Health Insurance Coverage of People with HIV*. January 7, 2014. <http://kff.org/report-section/assessing-the-impact-of-the-affordable-care-act-on-health-insurance-coverage-of-people-with-hiv-issue-brief/>. Accessed April 4, 2016.
- 42 Kates J, Dawson L, Udem T, Perry K. *Health insurance coverage for people with HIV under the Affordable Care Act: Experiences in five states*. December 19, 2014. <http://kff.org/report-section/health-insurance-coverage-for-people-with-hiv-issue-brief/>. Accessed April 4, 2016.
- 43 Centers for Disease Control and Prevention. *Medical Monitoring Project*. March 19, 2015. <http://www.cdc.gov/hiv/statistics/systems/mmp/>. Accessed April 4, 2016.
-



amfAR Public Policy Office 1100 Vermont, NW • Suite 600
Washington, DC 20005 • T: +1 202.331.8600 F: +1 202.331.8606