

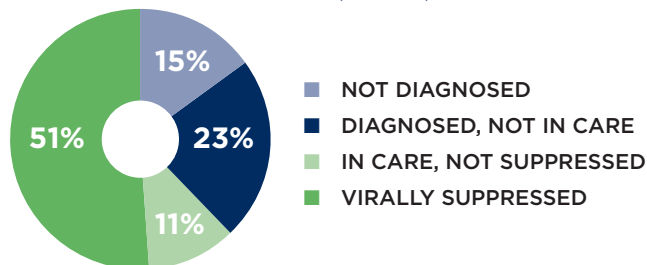
BIG IDEAS

MAXIMIZING THE IMPACT OF THE RYAN WHITE HIV/AIDS PROGRAM

BETTER MEETING THE NEEDS OF PEOPLE LIVING WITH HIV IS HOW TO END THE HIV EPIDEMIC

PEOPLE LIVING WITH HIV must remain at the center of national efforts to end the HIV epidemic. The Trump Administration is galvanizing support for its **Ending the HIV Epidemic (EHE) Initiative** with its most prominent goal being to reduce HIV transmissions in the United States by at least 90% within ten years.¹ As community stakeholders and government policymakers have promoted prevention successes and the role of pre-exposure prophylaxis (PrEP), syringe services programs (SSPs), and other

1.1 MILLION AMERICANS ARE LIVING WITH HIV (2016)



SOURCE: Vital Signs.
<https://www.cdc.gov/vitalsigns/end-hiv/index.html>

HIV CARE AND COVID-19: This brief was prepared prior to the COVID-19 pandemic. Even during this crisis, improving health care outcomes for people with HIV should not be neglected. The COVID-19 pandemic reinforces the need for strategies highlighted here that rely on public health data and that address clinical and non-clinical barriers to care.

DIFFERING STRATEGIES ARE NEEDED TO IMPROVE THE HEALTH OF ALL PEOPLE WITH HIV

Good clinical care and effective social supports work together. To increase the share of people with HIV who are in care and virally suppressed, specific strategies are needed to support:

- 1. PEOPLE WITH HIV WHO ARE UNAWARE OF THEIR INFECTION:** One in seven people with HIV have not been diagnosed and too many are diagnosed years after infection. Enhanced efforts are needed to reach specific groups to reduce disparities in diagnosis rates and to diagnose people sooner.
- 2. PEOPLE WITH HIV WHO ARE IN CARE, BUT NOT VIRALLY SUPPRESSED:** Numerous factors can impede sustained viral suppression. Critical work is needed to eliminate these barriers both within and outside of the clinic.
- 3. PEOPLE WITH HIV WHO HAVE BEEN DIAGNOSED, BUT ARE NOT IN HIV CARE:** Competing life priorities can make sustained engagement in care difficult. More attention is needed to offering linkage and retention services and adopting strategies to better identify persons who have stopped engaging in HIV care, and more intensive services models are needed for the subset of people with the greatest barriers to care.

components of comprehensive HIV prevention, many people with HIV have felt neglected and under-prioritized.

A central pillar of the EHE Initiative is “to treat HIV infection rapidly and effectively to achieve sustained viral suppression.” The apparently simple goal of achieving sustained viral suppression belies a complex set of challenges.

WHAT IS GOOD HIV CARE?

Ideally, people with HIV are diagnosed soon after acquiring the virus and are subsequently engaged in a comprehensive system of care that addresses their physical and behavioral health needs, supports healing from trauma, responds to changing and often growing needs as people age, and ensures that health care and essential support services needs are met, including housing, nutrition, and other community supports. This type of system, often made possible by the Ryan White HIV/AIDS Program, can facilitate rapid initiation of antiretroviral therapy (ART) so that individuals are quickly able to achieve and maintain durable HIV viral suppression.²

In the real world, many people with HIV have past or continuing experience with interpersonal violence, along with ongoing challenges with or vulnerability to job loss or income insecurity, unstable housing, and other unmet needs. More than 30 states have laws targeting people with HIV with criminal prosecution based on outdated understandings of HIV transmission risks and routes.³ Further, racism, homophobia, transphobia, and discrimination based on HIV status may create severe barriers to accessing high-quality and culturally relevant health care.

TAILORING RESPONSES TO DISTINCT NEEDS

It is important to calibrate strategies to address the unique circumstances of individual jurisdictions. A recent study looked at epidemiological, financing, demographic, and other characteristics of HIV epidemics in six US cities, and it found a variation from two to six times in the per person support for medical care and housing expenditures for people with HIV.⁴ The study specifically found that in cities such as Atlanta, with low testing rates and fewer testing resources, increased investments in testing, treatment initiation, and retention in care (especially among Black men who have sex with men) may be a better investment than the same type of policies in cities with different racial/ethnic distributions among people with HIV and with higher rates of testing and retention in care. Therefore, the manner and intensity with which specific services and interventions are optimally deployed may vary. In addition to

geography, it is also important to differentiate between three groups of people with HIV to tailor interventions so that they are most effective:

1. PEOPLE WITH HIV WHO ARE UNAWARE OF THEIR INFECTION

As of 2016, 85% of people with HIV in the US had been diagnosed.⁵ Still, one in seven people with HIV remain unaware of their status, and there are disparities in which groups know their status (in terms of age, risk group, gender, race/ethnicity), indicating areas where further efforts are needed. Young people aged 13-24 are the group that is least likely to know their status, with only 56% having been diagnosed in 2016.⁶ Moreover, more work is needed to diagnose people much sooner after infection. In 2017, roughly one in five diagnoses was at stage 3 (an AIDS diagnosis).⁷ In 2015, the median time from infection to diagnosis was estimated to be three years, and one in four people had been living with the virus for seven or more years at the time of their diagnosis.⁸

Federal EHE Approach: CDC is working in the EHE priority jurisdictions to make routine clinical screening a reality, and to make it possible for persons in communities or groups with the highest risk for HIV to be tested more frequently. It is seeking to support innovative strategies to expand HIV testing, including self-testing. The Health Resources and

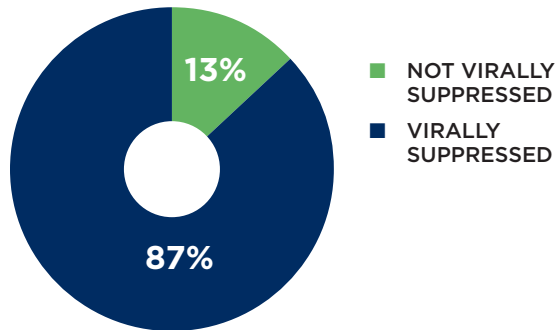
U=U CALLS FOR EHE ACTION

PEOPLE WHO ARE LIVING WITH HIV and are durably virally suppressed cannot transmit HIV sexually. This understanding, known as U=U, or undetectable equals untransmittable, has been demonstrated through research and is widely accepted by the medical establishment, but is still unknown to far too many people with HIV.

U=U must be included in EHE plans to ensure that people with HIV are aware of this, to reduce stigma, to ensure that the sexual and reproductive health care needs of people with HIV are met, to promote engagement in care, to support adherence to ART, and to prevent new transmissions.

SOURCES: (1) Prevention Access Campaign. preventionaccess.org. (2) Eisinger RW, et al. HIV viral load and transmissibility of HIV infection: Undetectable equals untransmittable. *JAMA* 2019;321(5):451-452. (3) Calabrese SK and Mayer KH. Providers should discuss U=U with all patients living with HIV. *Lancet HIV* 2019;6(4):e211-e213. (4) HIV Medicine Association. HIV Treatment as Prevention and U=U. <https://www.hivma.org/clinical-practice/hiv-treatment-as-preventions-uu/>.

VIRAL SUPPRESSION IN THE RYAN WHITE HIV/AIDS PROGRAM (2018)



SOURCE: Health Resources and Services Administration. *Ryan White HIV/AIDS Program Annual Client-Level Data Report 2018*. December 2019. <https://hab.hrsa.gov/sites/default/files/hab/data/datareports/RWHAP-annual-client-level-data-report-2018.pdf>.

NOTE: This estimate is based on Ryan White HIV/AIDS Program data showing that approximately 87% of people with an outpatient ambulatory care visit had a suppressed viral load at their most recent test in 2018.

Services Administration (HRSA) is responsible for administering both the Ryan White HIV/AIDS Program and the Health Centers Program. There are nearly 1,400 Health Centers across the country that are community organizations that deliver comprehensive primary care services in underserved communities to persons with and without insurance coverage or the ability to pay for services. Health Centers already conduct HIV tests for more than 2 million people per year, but will expand HIV testing in the EHE priority jurisdictions.

Actions for Impact: As the share of people who know their HIV status rises, it becomes increasingly difficult to find the remaining people who have not been diagnosed. An important focus of current efforts is to integrate HIV and sexually transmitted infection (STI) screenings in sexual health clinics and through viral hepatitis and tuberculosis programs. Additionally, efforts are needed to:

- Leverage both clinical and community-based screening (i.e. screening performed outside of a health care setting, often by community-based organizations) to increase knowledge of HIV status in groups with the lowest rates of diagnosis and with the most cases of late diagnosis.
- Analyze late diagnosis data (i.e. stage 3/AIDS at first HIV diagnosis) to expand testing in non-traditional settings, such as using mobile and pop-up testing in high morbidity areas, and to expand access to home testing.
- Promote U=U as a strategy for lessening HIV stigma that can be a barrier to HIV screening.

2. PEOPLE WITH HIV WHO ARE IN CARE, BUT NOT VIRALLY SUPPRESSED

The specific reasons that individuals in care are not able to achieve and maintain durable HIV viral suppression must be understood and addressed. Strengthening adherence to a treatment regimen is especially important, yet our care systems often make it very hard to be adherent, such as when people do not have access to transportation to medical appointments, when they are unable to be seen for care in a timely manner, or when every pharmacy visit seems to bring ever-changing co-pays or new prior authorization requirements. This is exacerbated by unstable insurance coverage and financial barriers, housing insecurity, inability to carry or take medications due to work schedules, unaddressed stigma and discrimination, and other factors. Moreover, some barriers arise because individuals prioritize other aspects of their lives, whether it is achieving personal goals or managing family responsibilities. Other kinds of supports may be needed to help individuals achieve and maintain adherence to treatment in a manner that is integrated within their lives. These issues have solutions, but the most effective solutions are often structural changes that make existing systems more responsive to individual needs.

To improve clinical outcomes, greater attention may be needed to ensure that treating providers prescribe regimens consistent with current guidelines and are monitoring for indications that a regimen change is warranted. It also could mean troubleshooting with patients around issues that impact adherence, such as side-effects, weight gain, dosing schedules (when and how frequently medications must be taken), substance use treatment including medication-assisted treatment (MAT), and other factors. Additionally, other clinical providers can enhance the effectiveness of the primary care provider or the HIV specialist. For example, one study of a patient-centered HIV care model involving collaboration between HIV providers and community pharmacists was shown to have increased viral suppression by 15% from 75% to 86% following the implementation of the program.⁹

Full viral suppression may not be possible for some highly treatment experienced individuals, but this is a relatively small share of people with HIV. The most common ART regimens involve three drugs from two drug classes. A study of the prevalence of transmitted drug-resistant mutations in newly diagnosed individuals from 2013-2016 estimated that only 2.4% of people with HIV are resistant to two drug classes and fewer than one in 200 people with HIV are resistant to three or more classes.¹⁰ An older study of treatment experienced persons found similar results.¹¹

Federal EHE Approach: The National Institutes of Health (NIH) manages the updating and promulgation of the federal HIV treatment guidelines.¹² The HIV/

INNOVATION NEEDED: Improving Health Literacy to Strengthen Engagement in Care

Health literacy is the capacity to obtain, communicate, process, and understand basic health information and services to make appropriate health decisions. More education is needed to better assist some people with HIV in understanding their health care needs and in navigating complex health systems.

A study of adults with HIV in the Deep South found that low health literacy is a significant predictor of missed clinic visits that can signal a person is beginning to disengage from HIV care. Another HIV study found that lower health literacy was associated with weaknesses in the ability of people with HIV to access their electronic medical records, read and understand a message from their provider, and schedule a follow-up appointment.

Health literacy interventions should be seen as critical strategies for improving HIV outcomes. This includes continuing to test and evaluate scalable models for increasing health literacy, as well as improving provider communication skills and practices.

SOURCES: (1) Fazeli PL, et al. Critical, and not functional, health literacy is associated with missed HIV clinic visits in adults and older adults living with HIV in the Deep South [published online ahead of print May 28, 2019]. *AIDS Care*. <http://doi.org/10.1080/09540121.2019.1622641>. (2) Woods SP, et al. Health-related everyday functioning in the internet age: HIV-associated neurocognitive disorders disrupt online pharmacy and health chart navigation skills. *Arch Clin Neuropsychol* 2016;31(2):176-185. (3) Health Literacy Evidence Reviews and Research Summaries. www.cdc.gov/healthliteracy/researchevaluate/evidence-research.html.

AIDS Bureau (HAB) of HRSA publishes a clinical practice guide.¹³ Further, the AIDS Education and Training Center (AETC) Program, a component of the Ryan White HIV/AIDS Program, trains the clinical and non-clinical workforce and helps to ensure medical providers are kept current on ART and other clinical practices. The AETC Program also can train providers on more holistic approaches to assessing and overcoming adherence challenges. CDC supports behavioral, biomedical, and structural interventions, public health strategies, and social marketing campaigns that support engagement in care and increased viral suppression.¹⁴

Actions for Impact: People with HIV have been challenged in achieving or maintaining viral suppression for many reasons. When there are public

messages indicating that everyone can achieve viral suppression, instead of hearing hope, some experience fear and shame. In addition to promoting U=U to reduce HIV stigma, efforts to support people to improve their adherence to their treatment regimens should be built around problem solving that supports individuals and actively resists any messages of failure. More work is needed at the jurisdictional level to:

- Fund models of care that offer more flexible approaches to receiving care (such as through the use of telemedicine).
- Implement programs to deploy people with HIV (whether community health workers, persons working in clinical settings, or peer educators) to operate support groups, conduct one-on-one counseling and education, or develop anti-stigma initiatives that include components focused on health promotion and increased adherence to treatment.

3. PEOPLE WITH HIV WHO HAVE BEEN DIAGNOSED, BUT ARE NOT IN HIV CARE

Nearly one in four people with HIV have been diagnosed, but are not receiving regular HIV care. This critical group is disproportionately responsible for new HIV transmissions and is challenging to identify and serve because efforts to monitor HIV trends are largely focused on people in care.

Federal EHE Approach: CDC's Data to Care Program is an important tool of health departments that involves analyzing HIV surveillance data, including laboratory reports of people with diagnosed HIV, to identify people not in care and re-engage them.¹⁵ Typically, health department programs funded by the Ryan White HIV/AIDS Program use Data to Care information to develop tailored intervention strategies. Nonetheless, initial Data to Care models have had varying levels of success. As part of the EHE Initiative, HRSA expects to invest in jurisdictional programs to heighten the focus on identifying and re-engaging people who have disengaged from care.

Actions for Impact: Differentiated care models can conserve health care resources by recognizing that people with HIV require different levels of services. For some, advances in the clinical management of HIV mean that they need to see their HIV physician just once or twice a year. For others, more regular engagement with clinical staff, as well as social workers and social services providers, is essential to keeping them engaged in care. Jurisdictions need to increase their capacity to actively monitor people both in care and not in care. More attention is needed to:

- Establish or expand data sharing agreements to allow health department prevention and care programs to track client outcomes across programs and evaluate program effectiveness.

INNOVATION NEEDED: Adapting the Clinic for Those with the Greatest Needs

NEW MODELS OF CARE are needed for some of the highest need individuals. This is the idea behind the Max Clinic in Seattle. Psychosocial factors such as mental health problems, substance use disorders, and unstable housing can become overwhelming when dealing with an often inflexible health system that requires advance appointment scheduling and the capacity to negotiate rigid health system rules. To overcome these issues, the Max Clinic offers walk-in access to primary care in a sexually transmitted disease (STD) clinic. The clinic offers food vouchers, cash incentives, no-cost bus passes, and cell phones, as well as intensive case management with cross-agency coordinated care.

This clinic is not available to all people with HIV. It is for persons who have failed to engage in care in more traditional, less intensive services

models. The clients also typically have high rates of substance use and behavioral health problems, as well as significant other barriers to care.

A study of the first 50 clients showed that they were substantially more likely to achieve viral suppression than similar people served in a more conventional Ryan White-funded clinic. They also had significant improvements in sustained viral suppression and engagement in care.

SOURCES: (1) Dombrowski JC, et al. The Max Clinic: Medical care designed to engage the hardest-to-reach persons living with HIV in Seattle and King County, Washington. *AIDS Patient Care STDS* 2018;32(4):149-156. (2) Dombrowski JC, et al. HIV care for patients with complex needs: A controlled evaluation of a walk-in, incentivized care model. *Open Forum Infect Dis* 2019;6(7):ofz294.

INNOVATION NEEDED: Using Data to Support Re-engagement in Care

THE DEMANDS ON PEOPLE WITH HIV to have perfect engagement in care and adherence to treatment over a lifetime are unrealistic.

Public health officials need metrics and tools for spotting individuals who are disengaging from care so that officials can act quickly to overcome barriers. Data to Care is a CDC-supported effort for health departments to integrate surveillance data with other data sources to identify people with HIV not in care and either link or re-link them to care. By identifying the small subset of people not in care, more intensive and effective interventions are more feasible than if clinics or health departments offer the same level of intensive services for all people with HIV. Despite early enthusiasm for this approach, however, some health departments have reported that the payoff has not been as significant as expected. Three factors have been identified as issues: 1) inaccurate surveillance data means that people are being identified who are not truly out-of-care; 2) many people have periods of non-engagement and will re-engage without any intervention needed; and 3) insufficient evidence exists for re-engagement strategies that produce durable outcomes.

The Cooperative Re-Engagement Controlled Trial was a study involving collaboration between health departments and clinics in Connecticut, Massachusetts, and Philadelphia, PA that demonstrated increases in the proportion of persons re-engaged in care and reductions in the time to re-engage in care that may offer a path forward for overcoming these challenges. Additionally, using other data sources such as pharmacy refill data and insurance claims data may be useful for rapidly identifying persons with HIV who are not in care or who are at risk for disengaging from care. Research also spotlights the value of critical metrics that can be used at the clinic level and jurisdictional level to find people not in care, including missed clinic visits as a sentinel indicator.

SOURCES: (1) HIV Data to Care. www.cdc.gov/hiv/effective-interventions/respond/data-to-care/index.html. (2) Bulsara SM, et al. Predictors of adult retention in HIV care: A systematic review. *AIDS Behav* 2018;22(3):752-764. (3) Dombrowski JC, et al. A cluster randomized evaluation of a health department data to care intervention designed to increase engagement in HIV care and antiretroviral use. *Sex Transm Dis* 2018;45(6):361-367. (4) Rana AI and Mugavero MJ. How big data science can improve linkage and retention in care. *Infect Dis Clin North Am* 2019;33(3):807-815. (5) Fanfair RN, et al. Health department randomized trial to re-engage out-of-care HIV infected persons. Conference on Retroviruses and Opportunistic Infections 2019; Seattle. Abstract 1031.

- Develop data dashboards drawn from electronic health records to identify individuals not in care or not virally suppressed on admission to the emergency department or an inpatient hospital.
- Fund differentiated care models that enable the highest need individuals to receive very intensive clinical and support services.
- Monitor missed clinic visits as a sentinel indicator of persons at risk of disengaging from care.

THE TIME IS NOW

Our commitment to ending the HIV epidemic always must be grounded in the goal of supporting all people with HIV to lead long and healthy lives. The EHE Initiative can be successful as long as we keep meeting the needs of people with HIV at the center of our efforts. The Ryan White HIV/AIDS Program and its community and jurisdictional partners can light the path to better HIV health outcomes.

ENDNOTES

- 1 *Ending the HIV Epidemic: A Plan for America*. February 2020. <https://files.hiv.gov/s3fs-public/ending-the-hiv-epidemic-flyer.pdf>.
- 2 Crowley JS, Bland SE. *Big Ideas: Leveraging the Ryan White Program to Make Rapid Start of HIV Therapy Standard Practice*. December 2018. https://oneill.law.georgetown.edu/media/ONL_Gilead_B2_Rapid_P4.pdf.
- 3 *HIV Criminalization in the United States*. Updated March 2019. www.hivlawandpolicy.org/sites/default/files/CHLP%20HIV%20Crim%20Map%20030119.pdf.
- 4 Panagiotoglou D, et al. Building the case for localized approaches to HIV: Structural conditions and health system capacity to address the HIV/AIDS epidemic in six US cities. *AIDS Behav* 2018;22(9):3071-3082.
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- 10 McClung, RP et al. Integrase and other transmitted HIV drug resistance: 23 US jurisdictions. Conference on Retroviruses and Opportunistic Infections 2019; Seattle. Abstract 526.
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- 12 *Guidelines for the Use of Antiretroviral Agents in Adults and Adolescents with HIV*. Updated December 2019. <https://aidsinfo.nih.gov/contentfiles/lvguidelines/adultandadolescentgl.pdf>.
- 13 *Guide for HIV/AIDS Clinical Care*. April 2014. <https://hab.hrsa.gov/sites/default/files/hab/clinical-quality-management/2014guide.pdf>.
- 14 Compendium of Evidence-Based Interventions and Best Practices for HIV Prevention. www.cdc.gov/hiv/research/interventionresearch/compendium/index.html.
- 15 HIV Effective Interventions. www.cdc.gov/hiv/effective-interventions/index.html.

EXPANDING THE USE OF DIFFERENTIATED CARE MODELS CAN RESPOND TO VARYING NEEDS OF PEOPLE WITH HIV AND CONSERVE RESOURCES WHILE IMPROVING OUTCOMES.