

EXPANDING PREP ACCESS TO HELP END THE HIV EPIDEMIC

In Partnership with National Alliance of State and Territorial AIDS Directors (NASTAD)



HIV remains a major public health crisis in the United States. HIV, which stands for human immunodeficiency virus, is a virus spread through certain bodily fluids that attacks the body's immune system. If left untreated, HIV can make it difficult for the body to fight off infections and diseases and can lead to acquired immunodeficiency syndrome (AIDS). Thanks to modern medical advancements, people living with HIV who are on treatment can live long, healthy lives and pose no risk of sexual transmission to others.

According to the U.S. Centers for Disease Control and Prevention (CDC), there are over 1.1 million Americans currently living with HIV and almost 40,000 new infections every year.¹ While HIV affects Americans from all walks of life, the virus continues to disproportionately impact members of the LGBTQ community. Almost two-thirds of new HIV infections are among gay and bisexual men.² Additionally, according to a 2015 survey of 28,000 transgender adults, transgender women are living with HIV at over

eleven times the rate of the general population.³ HIV also disproportionately affects racial minorities. In 2017, Black gay and bisexual men accounted for the largest number of HIV diagnoses,⁴ and the 2015 survey found that one in five Black transgender women are living with HIV.⁵ These sobering statistics demonstrate the need for a comprehensive strategy to end this epidemic that includes significantly increasing access to highly effective prevention methods like PrEP.

What is PrEP?

PrEP, or pre-exposure prophylaxis, is a safe and effective way to prevent the transmission of HIV. The U.S. Food and Drug Administration approved the use of two medicines, emtricitabine and tenofovir (TDF/FTC, brand name Truvada), to prevent HIV in 2012.⁶ The CDC notes that "PrEP reduces the risk of getting HIV from sex by about 99% when taken daily."⁷ Despite years

of proven efficacy, at-risk individuals continue to face unnecessary barriers to PrEP access, including a lack of education and awareness on the part of individuals who would benefit from PrEP as well as health care providers, a lack of health care coverage, and prohibitive associated costs. According to the CDC, over 1.2 million Americans are at "substantial risk" of contracting

HIV and are eligible for PrEP.⁸ A 2018 study of PrEP use distribution found that no more than 117,000 people—less than 10% of those at substantial risk—were taking PrEP.⁹

¹ Centers for Disease Control and Prevention, *HIV in the United States and Dependent Areas*, <https://www.cdc.gov/hiv/statistics/overview/atagance.html> (last modified Sept. 9, 2019).

² *Id.*

³ Sandy E. James, et al., *The Report of the 2015 U.S. Transgender Survey*, National Center for Transgender Equality, 10 (2016) [hereafter *Transgender Survey*].

⁴ Centers for Disease Control and Prevention, *HIV in the United States and Dependent Areas*, <https://www.cdc.gov/hiv/statistics/overview/atagance.html> (last modified

Sept. 9, 2019).

⁵ *Transgender Survey* at 10.

⁶ U.S. Food and Drug Administration, *Truvada for PrEP Fact Sheet*, <https://www.fda.gov/downloads/drugs/drugsafety/postmarketdrugsafetyinformationforpatientsandproviders/ucm312290.pdf> (accessed Mar. 26, 2019).

⁷ Centers for Disease Control and Prevention, *Pre-Exposure Prophylaxis (PrEP)*, <https://www.cdc.gov/hiv/risk/prep/index.html> (last modified Sept. 9, 2019).

⁸ Dawn Smith, et al., *Vital Signs: Estimated Percentages*

and Numbers of Adults with Indications for Preexposure Prophylaxis to Prevent HIV Acquisition — United States, 2015, Centers for Disease Control and Prevention, <https://www.cdc.gov/mmwr/preview/mmwrhtml/mm6446a4.htm> (last updated Nov. 27, 2015).

⁹ Aaron J. Siegler, et al., *The prevalence of pre-exposure prophylaxis use and the pre-exposure prophylaxis-to-need ratio in the fourth quarter of 2017, United States*, 28 *Annals Epidemiology* 841-849 (2018).

Barriers to PrEP Access and User Persistence

CANDIDATE AND PROVIDER AWARENESS

Key populations impacted by the HIV epidemic are quickly learning about PrEP and are willing to use it. Awareness of PrEP among gay and bisexual men in 20 urban areas across the United States increased significantly—from 61% to 90%—between 2014 and 2017.¹⁰ PrEP use among gay and bisexual men also increased significantly during this period, from 5.7% to 35.1%.¹¹ Despite these welcome increases in PrEP use, inequities persist. For example, while 42% of white gay and bisexual men reported using PrEP in 2017, only 26% and 30% of their Black and Latino peers indicated using it, respectively.¹² Addressing the numerous barriers that create these disparities (discussed below) should be an integral component of local efforts to increase PrEP awareness.

Although knowledge of PrEP among primary care providers continues to increase, there is still much room for improvement. Infectious disease specialist practices, local health department specialty clinics, and community health centers with a history of providing HIV care have taken the lead in prescribing PrEP to at-risk individuals. However, to achieve a population-level impact, more primary care providers need to be aware of PrEP and prescribe it to individuals at risk of acquiring HIV. A dearth of PrEP-competent providers continues to be a significant challenge in PrEP candidates accessing the medication, particularly in Southern states and rural areas across the country.¹³ Primary care providers should routinize an evidence-informed protocol to identify which of their patients would benefit from PrEP and offer it as the standard of care.

COSTS AND FUNDING

Costs related to health insurance, PrEP-related doctor visits and lab tests, and restrictions on the use of certain HIV-specific federal funds also impede the goal of making PrEP accessible to everyone who would benefit from it. These expenses also affect user persistence—the length of time that a PrEP user remains adherent to the regimen and therefore remains protected from HIV.

The high price of PrEP medication and related medical expenses make PrEP cost prohibitive for most people who do not have health insurance or access to PrEP assistance programs. Studies have shown that gay and bisexual men who have health care coverage are twice as likely to have used PrEP as their uninsured peers.¹⁴ Having health care coverage also has an impact on PrEP persistence. A study conducted at a public health clinic in Fulton County, Georgia showed that uninsured clients were almost three times as likely

¹⁰ Teresa Finlayson, et al., *Changes in HIV Preexposure Prophylaxis Awareness and Use Among Men Who Have Sex with Men — 20 Urban Areas, 2014 and 2017*, Centers for Disease Control and Prevention, <https://www.cdc.gov/mmwr/volumes/68/wr/mm6827a1.htm> (last rev'd July 11, 2019).

¹¹ *Id.*

¹² *Id.*

¹³ Aaron J. Siegler, et al., *Geographic Access to Preexposure Prophylaxis Clinics Among Men Who Have Sex With Men in the United States*, 109 *Am. J. Pub. Health* 1216-1223 (2019).

¹⁴ Brooke E. Hoots, et al., *Willingness to Take, Use of, and Indications for Pre-exposure Prophylaxis Among Men Who Have Sex With Men—20 US Cities, 2014*, 63 *Clinical Infectious Diseases* 672-677 (2016).

¹⁵ Charlotte-Paige Rolle, et al., *PrEP Implementation and Persistence in a County Health Department in Atlanta, GA* Emory Univ., http://www.croiconference.org/sites/default/files/posters-2018/1430_Holland_1010.pdf (last accessed Sept. 26, 2019).

to have stopped using PrEP within six months after starting to take it.¹⁵

Even for those with health insurance, costs are often still a barrier to getting and staying on PrEP. Although most health insurance plans cover the medication and lab tests for PrEP, patients report challenges in affording related out-of-pocket costs and in overcoming burdensome insurance restrictions like prior authorization requirements. In most cases, assistance programs that are currently available through the drug manufacturer or private foundations can cover all out-of-pocket costs for the medication for patients. However, the complexity of the patchwork of assistance programs that patients in need of financial assistance must navigate may itself become a barrier for both providers and patients. Fortunately, starting in 2021, PrEP should not incur out-of-pocket costs for insured individuals given the recent designation of PrEP as a grade “A” preventive service by the US Preventive Services Task Force. Under the Affordable Care Act, this “A” rating requires Medicaid programs to provide it and private insurers to cover PrEP with no cost to the patient.

Cities and counties also face gaps in public health funding for PrEP medication and related costs. Currently, statutory language and interpretive guidance require funds granted under the Ryan White HIV/AIDS Program (RWHAP) to be used only for the care and treatment of people diagnosed with HIV, precluding the use of RWHAP funds for PrEP medication and PrEP-related medical services like physician visits and laboratory costs. Importantly, RWHAP programs across the country have been able to weave together multiple sources of funding and clinical expertise across HIV prevention and care programs to provide the same level of care for PrEP and RWHAP patients. Cities and counties have also leveraged RWHAP activities such as outreach, risk reduction counseling, targeted testing, and linkage to care to identify PrEP candidates and refer them to a PrEP program. Moreover, the U.S. Department of Health and Human Services recently proposed the *Ending the HIV Epidemic: A Plan for America* initiative that seeks to end the HIV epidemic in the United States within a decade. This plan has a very strong focus on the 48 counties and nine other jurisdictions that account for 50 percent of new HIV infections

nationally.¹⁶ New federal funds have been requested for these cities and counties to expand PrEP access as part of this effort. Furthermore, some states have established PrEP assistance programs that city health departments can leverage as part of a comprehensive local strategy to increase PrEP access for at-risk residents.

STIGMA AND LACK OF CULTURALLY COMPETENT CARE

Finally, some at-risk individuals may avoid taking PrEP due to HIV or PrEP-related stigma and concerns about receiving culturally competent care. To combat negative stereotypes that could prevent at-risk communities from discussing PrEP with their health care provider, cities should seek to counter negative stereotypes through positive education campaigns targeting potential PrEP users and their communities. What’s more, cities should ensure that local health department officials and providers who receive city funding are trained on how to screen for PrEP eligibility and facilitate PrEP persistence in a culturally responsive way that does not further PrEP-related stigma.

¹⁶ U.S. Department of Health and Human Services, *What is ‘Ending the HIV Epidemic: A Plan for America’?*, <https://www.hiv.gov/federal-response/ending-the-hiv-epidemic/overview> (last modified: September 3, 2019).

Municipalities Making A Difference

Municipalities across the country are leading the way on initiatives and policies designed to increase PrEP access and protect at-risk communities.



CHICAGO AND NEW YORK CITY: COMMUNITY ENGAGEMENT APPROACHES TO INFORM PREP IMPLEMENTATION

The Chicago Department of Public Health and the New York City Department of Health and Mental Hygiene have both convened working groups of clinical providers and community representatives to inform what services are needed and how to provide them in a culturally responsive manner. By bringing together a wide array of stakeholders and developing a joint plan, the groups have enabled the health departments to identify gaps in PrEP coverage across each city. Through these PrEP working groups, the health departments have been able to identify and troubleshoot providers' and PrEP users' challenges as they emerge. The group in New York City, for example, prompted providers from across the City to take leadership in collaborating and coordinating city-wide activities.¹⁷



BALTIMORE, CHICAGO, LOS ANGELES, AND NEW YORK CITY: DEVELOPING COMMUNITY-INFORMED SOCIAL MARKETING CAMPAIGNS

More and more cities across the country are developing social marketing and educational campaigns to promote PrEP. Baltimore,¹⁸ Chicago,¹⁹ Los Angeles,²⁰ and New York City²¹ stand out with campaigns that elevate individuals within their communities and counteract stereotypes that stigmatize people impacted by HIV. These four health departments made a concerted effort to understand the underlying myths about PrEP. As part of their processes, each city researched their residents' attitudes, beliefs, and motivating factors related to PrEP use and crafted messages that avoid using fear and guilt while celebrating their city's diversity.

¹⁷ New York City Department of Health, PlaySure Network for HIV Prevention, <https://www1.nyc.gov/site/doh/providers/resources/playsure-network.page> (last accessed Sept. 26, 2019).

¹⁸ Baltimore City Health Department, Baltimore in Conversation, <https://www.baltimoreinconversation.com/> (last accessed Sept. 26, 2019).

¹⁹ AIDS Foundation of Chicago, PrEP4Love, <http://www.prep4love.com/> (last accessed Sept. 26, 2019).

²⁰ LA County Department of Public Health, GETPrEPLA, <http://getprepla.com/> (last accessed Sept. 26, 2019).

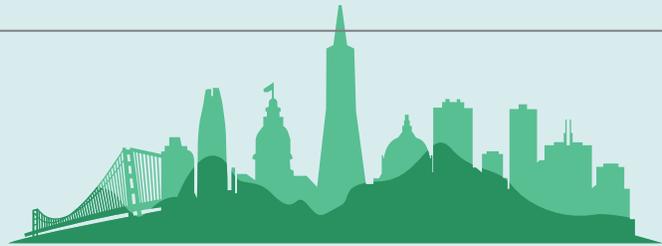
²¹ New York City Department of Health, Health Department Expands Hours and Services at Corona Sexual Health

Clinic, Launches Second "iLISTOS!" Campaign, <https://www1.nyc.gov/site/doh/about/press/pr2018/pr082-18.page> (Oct. 15, 2018).



HOUSTON: INNOVATING WAYS TO FINANCE CLINICAL SERVICES FOR PrEP AT CITY CLINICS

The Houston Health Department is building a sustainable PrEP program that can cover the cost of providing care for both insured and uninsured PrEP patients. The city's clinic is partnering with a pharmacy to bill health plans for the medication for PrEP. As part of a federal drug pricing program that is available to certain safety-net clinics, the health department can purchase the medication at a discount and bill private health insurance carriers the full cost of the medication. In this way, the clinic can use the savings it obtains from the discounted purchase of the medication to pay for unreimbursed PrEP-related operating costs, including providing PrEP services to uninsured patients.



SAN FRANCISCO: YOUTH-INCLUSIVE APPROACHES

San Francisco began implementing an "Emergency Youth Truvada Fund" in 2017 to help dependents and minors overcome cost barriers. The fund fills financing gaps for minors age 15 and above, who are able to consent to PrEP care without guardian consent in the state. In addition to establishing the fund, San Francisco has emphasized the importance of providing health insurance navigation and navigation to access private assistance programs for PrEP patients across their public health activities.



FORT LAUDERDALE: LEVERAGING LOCAL AND STATE RESOURCES TO INCREASE PrEP USE

The Florida Health Department in Broward County and local health department clinics across Florida are now offering PrEP care to all of their clinic patients. They are partnering with the state health department to procure the medication for their uninsured patients if they're not able to leverage the manufacturer's assistance program. This state-local partnership promises to make PrEP available for everyone in the state who needs it by eliminating cost barriers and ensuring that all public health clinics are able to provide access to it.



SAN FRANCISCO AND NEW YORK CITY: DATA-DRIVEN PROVIDER EDUCATION EFFORTS AND TECHNICAL ASSISTANCE

The San Francisco Department of Public Health and the New York City Department of Health and Mental Hygiene have trained staff who focus on educating providers about PrEP and other preventive services. These public health workers visit and educate providers in areas with the highest incidence of recent HIV diagnoses and few providers prescribing PrEP. They share information about best practices and recommendations and answer questions from clinical staff. Some programs also include education for front desk and clinical support staff to ensure culturally responsive care across the patient's experience at the clinic.



BIRMINGHAM, NEW ORLEANS, BALTIMORE AND FORT LAUDERDALE: SUPPORT FOR PATIENTS NAVIGATING COMPLEX HEALTHCARE SYSTEMS

Health departments across the country now support PrEP navigator positions at clinic and community-based organizations. PrEP navigators serve as patient advocates, helping patients secure health coverage and enroll in PrEP assistance programs. They also provide counseling to support PrEP persistence and connect patients to other support services. PrEP navigators in Baltimore, funded in partnership with the Maryland Department of Public Health, leverage case managers with expertise in health insurance navigation. In Fort Lauderdale, these specialized navigators serve as patient advocates as well as benefits coordinators, not only assisting patients with obtaining health care coverage and financial assistance, but also advocating on their behalf when interacting with new health care systems.

Conclusion

The ability of at-risk individuals to access and remain on PrEP is an integral component of the effort to end the HIV epidemic in the United States. Local leaders have a vital role to play in helping end this epidemic and must prioritize culturally responsive policies, practices, and services that help at-risk communities access safe and effective HIV prevention tools like PrEP. Cities and counties around the country should draw from the aforementioned models in their efforts to further PrEP awareness and education, reduce financial and other barriers to PrEP access and persistence, combat stigma related to people impacted by HIV, and ensure competent, culturally responsive care for PrEP patients.

Additional Resources

General Resources

- HRC HIV & AIDS Online Resource Center
<https://www.hrc.org/explore/topic/hiv-aids>
- What Do I Do? A Handbook to Understanding Health & HIV
<https://www.greaterthan.org/get-prep/>
- Find a PrEP Provider
<https://www.greaterthan.org/get-prep/>

PrEP and HIV Prevention Financing:

- HIV Prevention Billing Coding Guide (NASTAD)
<https://www.greaterthan.org/get-prep/>
- Financing HIV Prevention (NASTAD)
<https://www.nastad.org/financing-hiv-prevention>

- PrEPcost.org (NASTAD)
<http://www.PrEPcost.org>

- Leveraging Financing and Coverage Benefits: Medicaid Strategies to Deliver PrEP Intervention Services (Academy Health)
<https://www.academyhealth.org/publications/2019-01/medicaid-financing-and-coverage-benefits-can-be-leveraged-improve-delivery-hiv-prevention-services>

PrEP Implementation Models

- PrEP and Local Health Departments Educational Series (National Association of County and City State Health Officials)
<https://www.naccho.org/programs/community-health/infectious-disease/hiv-sti/prep-1/prep>