

PREP EDUCATION FOR YOUTH-SERVING PRIMARY CARE PROVIDERS TOOLKIT

INTRODUCTION

Four decades into the HIV/AIDS epidemic, there is finally a medication that individuals at high risk of HIV acquisition can take to protect themselves. Pre-exposure prophylaxis (PrEP) was approved by the United States Food and Drug Administration (FDA) as the first biomedical HIV prevention tool in 2012. With close to three-quarters of a million HIV-related deaths in the United States by the end of 2013,¹ one would expect that this breakthrough medication would find providers struggling to keep up with the demand from patients clamoring for this effective protection.

Yet nearly four years after FDA approval of Truvada as PrEP, its manufacturer, Gilead Sciences, estimates that just 40,000 U.S. residents—less than 4% of the 1.2 million individuals for whom the Centers for Disease Control and Prevention (CDC) estimates PrEP is indicated—are using it.² The medication has proven highly effective overall. Multiple randomized controlled trials have found that PrEP can reduce transmission in individuals at substantial risk of HIV infection by as much as 92% when used as indicated.³ These findings have been replicated in multiple clinical trial settings. Despite PrEP's clinical success and its potential to change the course of the epidemic, there remains a gap between the efficacy of PrEP and the growing HIV epidemic among youth in the United States.

This toolkit aims to bridge that gap by increasing primary care providers' (PCP) capacity to work more effectively with young people at high-risk of HIV acquisition to provide targeted PrEP education and access and address HIV risk in culturally appropriate ways.

Youth under age 25 are among those most impacted by HIV. In 2014, youth aged 13–24 accounted for more than one in five new HIV infections in the United States. Gay, bisexual, and other men who have sex with men (MSM) accounted for most (80%) new infections among youth. Black/African American and Hispanic/Latino gay and bisexual men are especially affected.⁴

Young women accounted for about 20% of new cases.⁵ Black/African American women in particular as well as Hispanic/Latina women continue to be disproportionately affected by HIV compared with women of other races and ethnicities.⁶

By the end of 2012, an estimated 57,200 youth ages 18–24 were living with HIV. Of these, nearly half (44%) were living with undiagnosed HIV—the highest rate of undiagnosed HIV in any age group.⁷

As with many groups disproportionately affected by HIV, multiple reasons for this health disparity in youth exist. Concerns regarding confidentiality, limited transportation, inconvenient hours, and lack of financial resources or insurance prevent some adolescents from accessing health care. Clinician-related barriers including discomfort serving adolescents, insensitive attitudes, and inadequate communication contribute as well.⁸ While providing PrEP-related care involves having conversations around sexuality, many providers lack knowledge and skills regarding sexual and reproductive health care and are particularly uncomfortable discussing sexual behavior with adolescents.⁹

Lesbian, gay, bisexual, transgender, queer, and questioning (LGBTQ) youth face additional barriers to care. Stigma and discrimination against LGBTQ persons increase stress on LGBTQ youth putting them at higher risk for depression, substance abuse, and sexual behaviors thereby placing them at higher risk of HIV and other sexually transmitted diseases (STDs).¹⁰

Youth who are rejected upon disclosure or discovery of their LGBTQ status, are sometimes thrown out of their homes or face physical, emotional, and/or sexual abuse.¹¹ Homeless youth often engage in survival sex (e.g., sex for food, shelter) thereby increasing their exposure to HIV.¹²

LGBTQ youth may also face discrimination in the health care setting. A 2009 survey by Lambda Legal found that almost 8% of LGB and 27% of transgender persons reported being denied care because of their identity and/or orientation and 11% reported that providers refused to touch them or used excessive precautions.¹³

Poverty, homelessness or marginal housing, low educational attainment, and lack of health insurance or quality health care are experienced at higher rates by some communities of color relative to whites and put youth of color at higher risk of HIV relative to white youth.¹⁴ Studies have found that many low-income urban youth worry about HIV/AIDS but they worry more about food, housing, transportation, and child care.¹⁵ Many of these youth also struggle with the impact of homophobia or transphobia, racism, or both.

Additionally, young women, and particularly young women of color may also face factors which affect their ability to negotiate safer sex,¹⁶ intimate partner violence,¹⁷ and a higher risk of HIV acquisition from heterosexual sex relative to their male partners.¹⁸

Despite its promise, PrEP has not changed the fact that the HIV epidemic has never been solely a medical epidemic. For health care providers, preparing to offer PrEP involves learning not only about the medication but also how to effectively reach and serve those who could benefit most from its use. The barriers to care—including the clinical barriers—described above need to be addressed to deliver care where it is needed. Learning to self-question and critique oneself around biases and interactions with other cultures in order to deliver care that is nonjudgmental and meets the individual patient are essential.¹⁹

According to the CDC, one in three primary care doctors and nurses does not yet know about PrEP. Some who are aware are not offering it.²⁰ The *PrEP Education for Youth-Serving Primary Care Providers Toolkit* offers resources so that all prescribing PCPs—physicians, nurse practitioners, physician assistants, nurse-midwives, nurses, pharmacists, and their staff—can effectively deliver PrEP care to youth at risk of HIV acquisition. The Toolkit seeks to provide solutions to empower providers and promote sexual health.

TOOLKIT OVERVIEW

Section 1: Clinical Tools

- ◆ Offers background information on PrEP, the CDC PrEP guidelines and other tools to help you in [Getting Ready to Offer PrEP](#).
- ◆ The [Clinical Reference Sheet](#) breaks down the clinical components into a simple reference tool. Based on the CDC PrEP Guidelines, it is what you need to know for patient PrEP care in a quick and easy format.
- ◆ [Taking a Sexual History](#) guides clinicians who may not routinely conduct sexual histories in a culturally sensitive approach. Suggested questions are included.

Section 2: Billing for PrEP

- ◆ Provides resources and billing codes to help young people afford PrEP and allow you to capture maximum revenue.

Section 3: HIV, Stigma, and Social Determinants of Health

- ◆ [Check Your Bias](#) tools offer opportunities for self-reflection/education and increasing awareness about potential biases in working with high risk populations, among all staff in your office.

- ◆ [Creating a Welcoming Office](#) provides guidance in making your office welcoming and comfortable for all.
- ◆ Materials in this section provide an overview to familiarize staff with issues facing youth at high risk of HIV and resources to support you in serving in all patients who could benefit from PrEP.

Section 4: Youth and HIV Laws and Policies

- ◆ Provides information and direct source links about minors' consent, confidentiality, and HIV criminalization laws by state in the [State Policy Table](#).

Section 5: Additional Resources

- ◆ While resources are provided throughout the toolkit, [additional resources by topic](#) are included for providers and patients alike.

Many additional resources are provided throughout this toolkit in an easy to access format to equip clinicians and office staff with the tools and knowledge needed to effectively serve young people who could benefit from PrEP. While far from an exhaustive compiling of available resources, these tools and resources are youth-specific though may also be useful in delivering PrEP care to other populations.

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