

# Current Perspectives on the Impact of Pre-Exposure Prophylaxis Stigma Regarding Men Who Have Sex with Men in the United States

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Patrick D Herron

Department of Family and Social  
Medicine, Albert Einstein College of  
Medicine, Bronx, NY, USA

**Abstract:** Pre-exposure prophylaxis or PrEP is a Food and Drug Administration approved human immunodeficiency virus (HIV) prevention tool that reduces the risk of infection by greater than 90%. While it does not provide protection against other sexually transmissible infections and blood-borne illnesses such as hepatitis C, syphilis, chlamydia, and gonorrhea, it is a highly effective in reducing the risk of transmission of HIV among men who have sex with men. Despite the success of PrEP, there remain barriers to PrEP uptake rooted in stigmatized perspectives shared by health professionals, patients, and community members. The insidious impact of stigma associated with HIV/AIDS has permeated throughout the LGBTQ+ community, healthcare system, society in general and to this day, continues to exacerbate structural and social determinants of health disparities amongst sexual and gender minorities. While the initial resistance to PrEP has abated over time, stigmatized perspectives regarding PrEP continue to impede those at greatest risk from benefiting from effective preventive care.

**Keywords:** PrEP, HIV, AIDS, MSM, stigma

## Origins of PrEP Stigma

2012 marked a watershed moment in the fight to curb the spread of the Human Immunodeficiency Virus (HIV) and Acquired Immunodeficiency Syndrome (AIDS). The Food and Drug Administration (FDA)'s approval of pre-exposure prophylaxis (PrEP) bolstered HIV prevention efforts and has since demonstrated efficacy with HIV transmission reduced by greater than 90% when used as prescribed.<sup>1</sup> Despite the success of PrEP therapy in clinical trials, there were mixed reactions and criticisms regarding the use and promotion of PrEP when first introduced contributing to lower than expected adoption rates. Many of the critics surprisingly were among members of the LGBTQ+ health advocacy community.<sup>2</sup> Concerns about HIV drug-resistance, potential long-term side effects for users, and whether this new innovation would undermine decades of safer sex HIV prevention education led to stigmatization of early adopters of PrEP as engaging in risk compensation or increased HIV risk behavior through condomless sex and complacency towards the possibility of increased exposure to other sexually transmissible infections.<sup>3,4</sup> These concerns and others were also shared at the time by many health professionals and well-known and influential community leaders, including AIDS Healthcare Foundation President Michael Weinstein.<sup>5</sup>

Correspondence: Patrick D Herron  
Email [patrick.herron@einsteinmed.org](mailto:patrick.herron@einsteinmed.org)

A widely disseminated article at the time popularized the phrase, “Truvada Whore,”<sup>6</sup> which would, in turn, be reappropriated soon after by PrEP advocates in their marketing campaigns. While not representative of the all critics, such stigmatizing language and imagery reflected the highly charged atmosphere surrounding the public unveiling of PrEP.<sup>5</sup>

Stigma is born out of existing stereotypes, biases, prejudices, and various forms of oppressive and discriminatory attitudes towards individuals and/or communities of people. The insidious impact of stigma associated with HIV/AIDS has permeated throughout the LGBTQ+ community, healthcare system, society in general and to this day, continues to exacerbate structural and social determinants of health disparities amongst sexual and gender minorities. While the initial resistance to PrEP has abated over time and many of the early critics have come to embrace it as an effective prevention tool,<sup>7</sup> PrEP stigma continues to impede those at greatest risk from preventive care. The Centers for Disease Control (CDC) estimates that the majority of adults considered to be at greatest risk for HIV infection and who would benefit the most from PrEP are not using it.<sup>8</sup> Among the many harms associated with the HIV epidemic was the prevalence of HIV stigma that negatively impacted the emotional well-being and mental health of persons living with HIV/AIDS as well as exacerbating fear, misunderstanding, and discriminatory attitudes and practices. Often times this prejudice extended to those persons assumed to have been exposed to and/or suspected of having HIV/AIDS based not on exhibited clinical signs and symptoms, but on assumptions regarding sexual orientation, race, socioeconomic status, substance use, sexual health behavior, and even geography.<sup>9</sup> Laws enacted to help protect the civil and human rights of persons living with HIV, health education campaigns, and shifts in societal perspectives have significantly diminished, but have not eliminated biases associated with HIV and prevention measures. Some of the deeply embedded tensions between clinical advances and moral judgments were brought to bear following a contentious 2018 op-ed in the New York Times titled, “The End of Safe Gay Sex?”<sup>10</sup>

In recent years, the number of adult persons living with HIV in the United States has grown to over 1.1 million individuals with estimates of 14% of those persons not knowing their HIV status.<sup>11</sup> Since the height of the epidemic in the mid-1980s, the rate of HIV incidence in the United States has been reduced by greater than two-thirds.

After years of declining new infections, the number of new infections started to plateau in 2013.<sup>11</sup> In 2018, there were 37,832 new HIV diagnoses in the United States and US territories. For the 7 years prior, HIV diagnoses had decreased overall by 11% among adults and adolescents, but increased among some patient populations,<sup>12</sup> which is why the primary goal for national HIV prevention continues to focus on reduction in new infections.<sup>13</sup> Between 2010 and 2016, rates of new HIV infection decreased by 6% with notable drops among heterosexuals, persons who inject drugs, and White men who have sex with men (MSM) but increased rates of infection for Hispanic/Latino MSM and rates of infection among African American MSM remained unchanged.<sup>14</sup> Despite the success of PrEP, the widening gap in HIV prevention affecting Hispanic/Latino and African American MSM warrants a deeper exploration of the stigma and barriers impeding access and uptake of PrEP.

Currently, there are only two FDA-approved medications for PrEP. The first, emtricitabine/tenofovir disoproxil fumarate (FTC-TDF), is sold under the brand name Truvada<sup>®</sup> is recommended for use all adults and adolescents at risk for HIV infection. The second, emtricitabine/tenofovir alafenamide (FTC-TAF), sold under the brand name Descovy<sup>®</sup> was approved by the FDA in 2019 for adults and adolescents, but not recommended for those persons at risk of HIV infection through receptive vaginal sex. PrEP, when taken as prescribed, is very effective in reducing the risk of transmission of HIV. It does not provide protection against other sexually transmissible infections and blood-borne illnesses such as hepatitis C, syphilis, chlamydia, and gonorrhea.

Based on a review of 14 randomized clinical trials, 8 observational studies, and 7 studies of diagnostic accuracy demonstrating that PrEP was associated with decreased risk of infection, the United States Preventative Services Task Force (USPSTF) issued a Grade A recommendation for HIV prevention and HIV screening in adults, adolescents, and pregnant women.<sup>15</sup> The USPSTF guidelines offer an important recognition of PrEP’s efficacy and value as a prevention tool. Further, the USPSTF suggested health professionals should be mindful of the health disparities disproportionately affecting racial/ethnic minorities. From 2014 to 2017, PrEP awareness among MSM in 20 urban communities increased from 60% to 90%, and PrEP usage increased from 6% to 35%. PrEP usage increased in almost all demographic subgroups, but still remained lower among Black and Hispanic MSM.<sup>16</sup>

Studies have shown that White persons meeting criteria for PrEP use were up to 6 times more likely to be prescribed PrEP than Black persons with similar criteria for use.<sup>17</sup> The reason for such discrepancies is multifactorial and not surprising given the historical disenfranchisement of persons of color in the United States. Stigma related to HIV and PrEP affects many persons, but the discrepancies in PrEP usage suggest that there may be different types of stigma and/or exploration of how stigma affects some individuals more substantially than other persons based on race, ethnicity, and cultural perspectives. In regards to PrEP use and promotion of PrEP use among health professionals, there remain knowledge gaps that pose significant deterrents and place a substantial burden on patients wanting to request treatment.<sup>13</sup> These knowledge gaps in conjunction with structural and social determinants of health may help to shed light on the reason for disparities in PrEP usage among MSM and other marginalized patient communities.

## Sources of PrEP Stigma

For nearly two decades following the onset of HIV/AIDS gay men and injectable drug users were seen as the “face” of the epidemic with initial reports referencing the mysterious condition as Gay-Related Immune Deficiency (GRID) under headlines such as, “New Homosexual Disorder Worries Health Officials.”<sup>18</sup> Homophobia, which was not only considered socially acceptable but codified into discriminatory laws coupled with sensational reporting in the media reinforced “gay plague” stereotypes that linked the disease with a moral failing of persons infected. Rather than being treated with compassion and care, many persons living with HIV instead were recipients of victim-blaming as though their infection was due in part to a failure to protect themselves and therefore somehow deserving of their declining state of health.

Health professionals were also culpable as the moral authority of medicine has often contributed to health disparities experienced by patients and communities. In the early days of the epidemic, patients were not guaranteed access to health professionals due to fear of the disease and potential exposure.<sup>4</sup> Such attitudes among health professionals are exceptionally rare today, but the lack of health professionals trained in how to prescribe PrEP is still a barrier yet to be resolved. Limited knowledge about PrEP use and/or willingness to engage with patients about their sexual health practices and needs rather than fear are the challenges that must be addressed. What is not clear is

whether these barriers with health professionals are based on stigma or some other health systems deterrent?

Well-intentioned physician advocates for PrEP use may also be sources of harm due to HIV stigma. In a narrative reflecting on his personal experiences as a gay man and medical student in training, Samuel Dubin wrote how he felt fortunate to have a physician who prescribed PrEP but felt “slut-shamed and stigmatized by seeing PrEP as the only option for me because of the intolerable risk of my acquiring HIV.”<sup>19</sup> Focusing on prevention-based approaches is important and necessary to promoting the well-being of patients, but there is a distinction between partnering with a patient to maximize their health promotion and disease prevention options and relegating the patient’s autonomous identity to the sum of their health behaviors.

Internalized shame and negative associations with sexual health behaviors among MSM may impede open dialogue with health professionals.<sup>20</sup> Stigma and shame are closely related to one another as they both seek to socially disqualify individuals and communities from acceptance and equality. Stigma is a social opportunistic disease that attaches to many illnesses and increases morbidity and mortality.<sup>21</sup> This limits the opportunity for engagement on the use of PrEP and other HIV prevention approaches. It may also skew individuals’ perceptions of their eligibility for PrEP despite meeting criteria for those persons most at risk of exposure.<sup>22</sup> Patients initiating conversations with their health provider about PrEP use may be uncomfortable in explaining their interest if there is concern of moral judgment regarding risk compensation or non-adherence to condom usage. Patient interest in utilizing PrEP may be driven in a desire to decrease anxiety and concern about HIV transmission, as well as increasing their sexual pleasure and sensation. These joint motives may be received quite differently by health professionals and social peers. Expression of the latter being difficult for patients given attitudes towards such preferences have historically been framed as reckless, dangerous, and socially irresponsible.<sup>23</sup> Added to these concerns is the reality that among health professionals there remain stigmatized views of sexual and gender minorities that have nothing to do with HIV and/or use of PrEP, but are deeply ingrained biases. A 2014 Kaiser Family Foundation study revealed that 30% of gay men and 45% of bisexual men reported not feeling comfortable discussing sexual behaviors with health professionals.<sup>24</sup> These findings on interpersonal and communication barriers for MSM point to the

difficulty with initiating a conversation with a health professional on the use of PrEP as the same study found that more than half of gay and bisexual men reported that a doctor had never recommended HIV screening.<sup>23,25</sup>

## Mitigating Stigma as Barrier to PrEP

Stigma surrounding the use and promotion of PrEP creates a barrier to treatment and PrEP maintenance. Addressing externalized and internalized stigma regarding PrEP use will require patients and health professionals to reframe our perspective and conversations on its use as an HIV prevention tool. Clinical recommendations can be perceived as moral judgments when inquiring about a patient's sexual behaviors and preferences. Physician assessment of a patient's eligibility for PrEP use, concerns for adherence, and the likelihood of engaging in risk compensation may be influenced by social characteristics such as race contributing to health inequities.<sup>26</sup>

Medical records of Veterans Health Administration (VHA) patients revealed attitudinal barriers in addition to provider knowledge gaps regarding PrEP usage in a study by Skolnick et al.<sup>13</sup> A qualitative analysis of documented conversations with patients showed providers' preferences to focus on behavioral risk reduction strategies. Rather than prescribing, providers discouraged PrEP and would instead suggest limiting or even ceasing sexual activity. Other examples of stigmatizing attitudes included requiring patients to obtain prescriptions from their sexual partner's physician or submission of documentation verifying a partner's serostatus as a pre-requisite to receiving a prescription for PrEP, despite the VHA and CDC not requiring such steps.

In a study by Quinn et al, cisgender Black MSM between the ages of 16 and 25 were asked to participate in focus groups to discuss experiences with racism and homonegativity and how this impacted PrEP uptake among participants. A key finding of the study was the shared experience among participants of feeling stereotyped by physicians. Disclosures about sexual health behaviors or sexual orientation were immediately met with concern for risk of HIV and other sexually transmitted infections. Some participants shared experiences of "being mistreated, talked down to, or feeling like they were perceived as 'nasty' by White physicians."<sup>27,28</sup> Such examples of interpersonal and communication micro-aggressions can often be attributed to implicit biases, but sometimes reflect explicit biases too. Regardless of the

intention of the health professional, the ability to have meaningful discussions about PrEP becomes problematic.

Discussing sexual health practices and recommendations for PrEP based on preventive health goals cannot be done without recognizing the historical impact of stigma in all its various forms and how it continues to affect personal behaviors and interactions with the healthcare system. Cultural and socioeconomic differences among patients within and across marginalized communities can also affect health outcomes and engagement with healthcare services.<sup>29</sup> In order to create community-based disease prevention strategies, health professionals and public health agencies must be sure to incorporate the perspectives and voice of the community members so that specific needs are prioritized and stigmatized views are counteracted in messaging and outreach efforts.

HIV prevention campaigns typically target those persons or communities considered to be at greatest risk of exposure. This may include the use of advertisements within print media or television programming with overlapping consumer demographics, but has increasingly shifted to the use of social media platforms. While this can be an effective outreach tool in reaching a younger patient population it fails to help address larger community misconceptions. Social marketing to promote PrEP use and benefits intended solely for persons considered to be at risk may increase awareness within those specific subpopulations, but will have limited impact on increasing understanding and support among the larger racial/ethnic communities from which those most vulnerable have intersectional roots. Programs that normalize HIV prevention and treatment among at-risk and HIV-positive and their familial and social communities may further decrease HIV and/or PrEP stigma.<sup>14</sup>

Among the concerns about PrEP stigma is its impact on historically underserved and marginalized communities, who represent some of the subpopulations at greatest risk of exposure and therefore have the greatest need for access and use of PrEP. Latino MSM represents 23% of new HIV infections in the US and the CDC reports that the rate of incidence has increased by 14% or more in recent years.<sup>11</sup> Black MSM represents 44% of new infections. Yet, they represent only 12% and 10%, respectively, of PrEP users.<sup>21</sup> The CDC's National HIV Behavioral Surveillance (NHBS) Study Group collected survey data from 20 urban areas in the United States in 2014 and then again in 2017. One of the goals was to examine the awareness and usage of PrEP. Although PrEP use among

MSM increased by 500% there are differences in uptake for Hispanic and Black MSM and therefore prevention efforts must be tailored to address such disparities.<sup>16</sup>

In response to these trends, the CDC has launched the Targeted Highly-Effective Interventions to Reverse the HIV Epidemic (THRIVE)<sup>30</sup> program to support state and local health department demonstration projects developing community collaboratives that provide comprehensive HIV prevention and care services for Black and Hispanic MSM. Lessons learned from these community-based endeavors can better inform and guide the refinement of health guidelines and strategies that will have optimal outcomes among persons who benefit greatly from PrEP usage.

## Why Focus on Stigma

Stigma was one of the main drivers of the HIV crisis in the 1980s and 1990s and obstacles to enacting effective health promotion and disease prevention. Addressing stigma in all its forms is fundamental to delivering high-quality health care. As we witnessed over the course of the HIV/AIDS epidemic, stigma affected more than just those persons living with the disease. The ripple effect throughout marginalized communities decimated biological families and chosen families. The moral distress experienced by health professionals and community health advocates as they witnessed countless deaths is a painful reminder as to how ignorance, fear, mistrust, and despair were among the most fatal opportunistic infections.

## Disclosure

The author reports no conflicts of interest in this work.

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