

# Briefing on Pre-Exposure Prophylaxis (PrEP) for Women of Color: An Analysis of Barriers, Facilitators, and Intervention Strategies

# **Executive Summary**

This document synthesizes findings from three distinct research initiatives focused on Pre-Exposure Prophylaxis (PrEP) among women of color in South Florida. The research collectively reveals that despite being disproportionately affected by HIV, these women face a complex, multi-layered web of barriers that significantly hinder the uptake and adherence to this highly effective biomedical prevention tool.

Key takeaways indicate that barriers to PrEP are not merely individual but are deeply embedded in structural, systemic, community, and interpersonal contexts. **Structural barriers** include healthcare system inequities, structural racism, lack of insurance, unaffordable costs, and fears related to immigration status. **Community and interpersonal factors** are profoundly influential, with cultural gender norms (e.g., *machismo*, *marianismo*), religious doctrine, stigma around sexual health, and lack of partner support acting as significant deterrents. Intimate Partner Violence (IPV) emerges as a critical co-occurring factor, where both lifetime and recent experiences of physical and psychological abuse are significantly associated with PrEP knowledge, interest, and perceptions of sexual risk.

At the **individual level**, medical distrust, limited PrEP knowledge, low personal risk perception, and economic dependency on partners create further obstacles. Substance use is another prominent factor, associated with non-adherence and increased sexual risk-taking, although targeted interventions show promise in reducing behaviors like alcohol consumption.

Conversely, significant community strengths and facilitators exist, including historical pride in activism, resilience rooted in family structures, and respect for education. Effective interventions must leverage these assets. The research strongly supports a **multi-tiered approach** that moves beyond simple information dissemination. Core recommendations include: implementing patient-centered, culturally tailored care models; educating healthcare providers to eliminate bias and improve cultural competency; engaging community leaders and influencers to

disseminate accurate information; and developing programs that provide therapeutic support and address social determinants of health like housing, transportation, and economic stability. Ultimately, empowering women of color to take control of their sexual health requires a comprehensive strategy that addresses these intersecting and deeply rooted challenges.

# 1. Context: HIV Disparities and the Promise of PrEP

HIV continues to be a significant health risk for women in the United States, with pronounced disparities affecting women of color, particularly in the South. In South Florida, women of color account for 88% of new HIV cases among all women despite comprising only 67% of the female population. While new HIV cases have declined for other heterosexual subgroups, rates for minority women in the region have remained static since 2014, highlighting a critical gap in prevention efforts.

PrEP, a self-administered biomedical tool, offers an effective, female-controlled method for HIV prevention. However, its utilization among women remains critically low.

- In one New York City HIV clinic, cisgender women had a PrEP use rate of 2.1% compared to 60.1% for cisgender men.
- In Florida in 2017, an estimated 4 per 100,000 women used PrEP, versus 83 per 1,000 men.
- A study of transgender women in Florida found that while PrEP awareness was high (65%), active use was very low (8.2%).

This underutilization is driven by a range of complex and interconnected factors identified across several research initiatives, including the "Empowering Women to Take Control of Their Sexual Health Summit," a pilot intervention study titled "Talking PrEP with Women of Color in Miami," and a quantitative analysis of the impact of Intimate Partner Violence (IPV).

## 2. Multi-Level Barriers to PrEP Utilization

Analysis of data from community focus groups and intervention studies reveals that barriers to PrEP use are not isolated but exist at structural, community, interpersonal, and individual levels.

## 2.1. Structural and Systemic Barriers

Systemic inequities create formidable obstacles for women seeking preventive care.

Healthcare Inequity and Bias: Participants across focus groups reported discrimination
and inequity within healthcare systems, which they perceived as being influenced by
sexist and racist dogma. African American participants noted a lack of representation in
clinical trials and campaigns, fostering a belief that programs are not reliable or safe for
their communities.

- Economic and Insurance Hurdles: Lack of health insurance, the high cost of PrEP, and time constraints for multiple doctor visits were cited as significant challenges for African American and Latina women. The profit-motivated healthcare model in the U.S. was identified as a systemic barrier where patient wellbeing is not always prioritized over profit margins.
- Immigration Status: Fear of deportation is a major deterrent, particularly for Haitian and Latina women. This fear prevents exposure to public health messaging and access to community resources. One participant stated, "undocumented immigrants don't trust doctors or clinics; they are afraid they will end up being deported." Changes to the "public charge" rule in 2018 have reportedly exacerbated these fears.
- Provider Disconnect: African American and Haitian women described a disconnect with and lack of respect from healthcare providers, which they felt stemmed from structural racism and led to chronic social stress and a reduced desire to access healthcare.

#### 2.2. Community and Interpersonal Barriers

Social norms, cultural beliefs, and interpersonal relationships profoundly shape women's ability to engage with PrEP.

#### Cultural Gender Roles and Norms:

- In the Latina focus group, cultural values like familismo (prioritizing family needs) and marianismo (placing women in a submissive role) were identified as promoting "sexual silence," inhibiting conversations about sex and condom use.
- Among African American and Haitian women, concepts of misogyny and chauvinism were discussed, where men often hold decision-making power in sexual health matters. Black women noted a dichotomy between a public persona of being "strong" and a lack of power within the home.
- Influence of Religion: Religion was a powerful theme across groups. Latina
  participants noted its determining role in sexual health practices and use of prevention
  tools. Haitian participants described how some churches perpetuate misogynistic
  messages ("women should obey their husbands") and even condone infidelity by
  husbands, while some spiritual leaders have advised people living with HIV against
  treatment.
- Stigma and Lack of Support: Stigma surrounding sexual health, sexuality, and PrEP use is a major barrier. Women feared being judged by providers, family members, or partners. One woman noted a key barrier was "Hiding it from my baby daddy and being looked at as a whore." Lack of partner support was a prominent theme, with some women reporting that their partners actively tried to stop them from taking PrEP.
- Intimate Partner Violence (IPV): IPV is a co-occurring epidemic with HIV. A study of 186 women of color in South Florida found 54% had experienced partner violence. This violence has a direct impact on PrEP-related outcomes and sexual autonomy, making female-controlled prevention methods like PrEP particularly critical. (See Section 3.1 for detailed findings).

#### 2.3. Individual-Level Barriers

Individual circumstances and beliefs present the final layer of challenges.

- Medical Distrust and Health Literacy: Black women expressed significant distrust in the scientific community and providers, fearing judgment and confidentiality breaches.
   This is compounded by low health literacy, which makes women vulnerable to misinformation, "charlatans," and HIV deniers.
- Economic Dependence: Beyond systemic cost barriers, economic dependency on a
  partner disempowers women, negatively impacting their ability to make independent
  decisions about their sexual health or adopt HIV reduction strategies.
- Low Perceived Risk: Studies have consistently shown that an underestimation of personal HIV risk is a common barrier to PrEP uptake and adherence among women.
- Side Effects and Adherence Concerns: Concerns about safety and side effects, such as nausea, headaches, and fainting spells, were reported as barriers. Women also expressed self-efficacy issues, worrying about their ability to remember to take a pill daily.
- Competing Priorities: For transgender women, prioritizing HIV prevention can be difficult when facing extreme discrimination and competing needs such as genderaffirmation procedures, housing, and food security.

# 3. The Impact of Co-Occurring Vulnerabilities

Specific intersecting factors, namely IPV and substance use, create unique and heightened challenges for PrEP implementation.

## 3.1. Intimate Partner Violence (IPV)

A quantitative study on women of color in South Florida revealed specific associations between the type and timing of IPV and PrEP-related factors.

| IPV Experience                | Associated PrEP Outcome                 | Adjusted Odds Ratio (AOR) |
|-------------------------------|---|---------------------------|
| Lifetime<br>Psychological IPV | Increased PrEP Knowledge                | 3.0 (95% CI 1.1–9.4)      |
|                               | Increased PrEP Acceptability / Interest | 2.2 (95% CI 1.1–4.8)      |

|                           | Increased Likelihood of Risky Sexual<br>Behavior if on PrEP | 6.3 (95% CI 1.0–13.6) |
|---------------------------|---|-----------------------|
| Lifetime Physical IPV     | Increased PrEP Knowledge                                    | 5.5 (95% CI 1.2–18.9) |
|                           | Increased Likelihood of Risky Sexual<br>Behavior if on PrEP | 4.3 (95% CI 2.1–11.5) |
| Past-Year Physical<br>IPV | Increased PrEP Acceptability / Interest                     | 1.9 (95% CI 1.7–4.3)  |
|                           | Increased Likelihood of Risky Sexual<br>Behavior if on PrEP | 4.0 (95% CI 1.1–13.9) |

These findings suggest that women with a history of IPV, particularly recent physical violence, may be more interested in PrEP as a protective measure they can control. However, these experiences are also linked to a perception that using PrEP makes safer sex less important.

## 3.2. Traditional Gender Roles and Sexual Autonomy

Adherence to traditional gender roles is significantly associated with PrEP acceptability and sexual risk.

- **Subordination:** A belief in being subordinate to others was significantly associated with **increased interest in using PrEP** (AOR 1.5), possibly because it offers a discreet prevention method in relationships with power imbalances.
- **Self-Silencing:** This trait, which restricts a woman's self-expression to maintain a relationship, was significantly associated with an **increased likelihood of risky sexual behavior if on PrEP** (AOR 1.2).

#### 3.3. Substance Use

Alcohol and drug use are prominent factors linked to inconsistent condom use, transactional sex, and non-adherence to PrEP. A pilot intervention study ("Talking PrEP with Women of Color") with 38 PrEP-initiated women found:

- **Significant Reduction in Alcohol Use:** Post-intervention, there was a statistically significant decrease in alcohol use scores (Z = -3.02, p = .003). This suggests that targeted behavioral interventions can effectively reduce this specific risk factor.
- Impact on Sexual Risk: While overall sexual risk scores did not change significantly, women who reported using alcohol or drugs proximal to sex saw a notable (though not statistically significant) 57% decrease in their median sexual risk scores (from 5.25 to 2.25).

## 4. Facilitators and Intervention Benefits

Despite significant barriers, communities possess inherent strengths, and targeted interventions can provide crucial support.

- Community Strengths and Activism: African American and Haitian women identified their communities' history of activism (e.g., the civil rights movement) as a legacy that can be tapped to empower women around sexual health. Community resilience, strong family structures, and the ability to "create power in numbers" were cited as key assets.
- Therapeutic and Educational Benefits: The "Talking PrEP with Women of Color" intervention revealed that participants highly valued its therapeutic benefits. Many women used the one-on-one sessions as a rare opportunity to be heard, relieve stress, and discuss life beyond medication. One participant stated, "Talking to you and relieving stress. I need someone to talk to." The most important aspect of the intervention was "receiving information about PrEP that is geared to a women's needs and interests."
- Individual and Interpersonal Motivators:
  - Personal Connection: Knowing someone who died from HIV/AIDS was a salient motivator for PrEP initiation and adherence. One woman whose parents both died of AIDS stated she was "Initially scared because of not knowing how it worked but took it because of parents."
  - Reminders and Routines: Simple tools like alarm clocks, pill planners, and incorporating PrEP into a routine with other daily medications were effective adherence facilitators.
  - Partner Support: While lack of support is a barrier, positive support can be a
    powerful facilitator. One woman whose fiancé was living with HIV noted he
    "repeatedly remind[ed] me to take it until it became a habit."
  - Personal Testimony: Latina participants suggested using personal testimonies from community members using PrEP as a powerful strategy to normalize its use.

## 5. Strategies and Recommendations

The research converges on the need for a multi-pronged, culturally-attuned strategy to increase PrEP access and use among women of color.

- Educate and Train Healthcare Providers: There is a critical need to improve PrEP knowledge among a broad array of providers, not just specialists. Education should focus on prescribing PrEP equitably and without judgment, and training should include cultural awareness and how to take a consistent, non-coercive sexual history to identify eligible patients.
- 2. Promote Patient-Centered, Culturally Tailored Services: To build trust, providers must employ patient-centered models. This includes addressing a patient's immediate medical concerns and personal priorities (e.g., fertility, gender affirmation) before soliciting sensitive sexual health information. For Latina women, providers must be prepared to explore unfamiliar psychosocial domains, as cultural norms may prevent women from being transparent.
- 3. **Implement Culture-Centered Education and Dissemination:** Public health campaigns must use trusted, community-specific channels.
  - For Haitian and Latino communities: Use local radio stations to reach those who may be illiterate or do not speak English.
  - For Latina audiences: Weave PrEP and HIV prevention storylines into popular Spanish soap operas (*Telenovelas*).
  - Engage Community Influencers: Mobilize political leaders, stakeholders, and spiritual leaders to endorse sexual health education and advocate for women's right to protect themselves.
- 4. Address Fears Among Immigrant Communities: Targeted messaging is needed to counteract fears of deportation and build trust with government and public health entities. Campaigns should clearly communicate that accessing services like PrEP will not jeopardize immigration status.
- 5. **Increase Awareness and Access to Existing Resources:** Promote programs that provide financial assistance and subsidized PrEP, such as Florida's Department of Health PrEP campaign, the Truvada® medication assistance program, and Ryan White health coverage for those with HIV.
- 6. Integrate IPV and Mental Health Support: PrEP navigation models should be trauma-informed. The therapeutic benefits observed in the pilot intervention underscore an unmet need for social support systems where women can express themselves without judgment. A referral system between PrEP providers and IPV service organizations could provide crucial, holistic support.

# 6. Conclusion

Increasing PrEP utilization among women of color in South Florida and beyond requires a sustained, multi-tiered approach that acknowledges and actively dismantles individual, interpersonal, and structural barriers. The challenge is not a lack of tools—as one summit participant noted, "we already have the tools to end the HIV epidemic"—but a failure to address the complex sociocultural factors hindering women's access and empowerment.

Future success depends on moving beyond simplistic awareness campaigns to build systems of care that are culturally congruent, trauma-informed, and patient-centered. This involves training

a diverse medical workforce, engaging communities as equitable partners, and leveraging community strengths like resilience and activism. By providing women with knowledge, social support, and the confidence to negotiate relationships with partners and providers, it becomes possible to empower them to truly take control of their sexual health.