

EXPANDING ACCESS TO BIOMEDICAL HIV PREVENTION:

Tailoring Approaches for Effectively Serving Communities of Color



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EXECUTIVE SUMMARY



Scientific advances have made possible the development of clinical interventions that significantly lower the transmission of the HIV virus. These interventions, better known as biomedical HIV prevention, consist of powerful methods that reduce HIV transmission, moving us along a path to ending the HIV epidemic. There are three primary biomedical HIV prevention tools so far: Treatment as Prevention (TasP), Pre-Exposure Prophylaxis (Prep), and Post-Exposure Prophylaxis (Prep). This brief will only focus on TasP and Prep.

This report is the second installment of a two-part report: *Blueprint for HIV Biomedical Prevention.*More than 20 interviews were conducted with a diversity of stakeholders in the summer of 2016 to inform the first part, the *State of the State Report*. For the second

installment those interviews were used as the starting point for distilling a focused list of recommendations for *Expanding Access to Biomedical HIV Prevention* in communities of color.

While the first part presented the state of the state of biomedical HIV prevention in the context of our limited health care systems, the second intends to be more granular, providing recommendations to expand access in communities of color and, more specifically, offer recommendations for individual communities or subgroups.

Despite these scientific advances, all of our gains have not been realized equally. Communities of color have not fully experienced the significant benefits of the new prevention tools. Great educational efforts have occurred to raise awareness and knowledge among the populations that could benefit the most. Clearly, education only is not enough. Transgender women of color and Black and Latino Gay men are still falling behind in the uptake of PrEP compared with White MSM.

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EXECUTIVE SUMMARY

In order to scale up access to biomedical HIV prevention, critical roles and actions by community-based organizations, health care providers, and the broader health system are necessary. This is an essential base upon which to build tailored initiatives to meet specific needs of individual communities or subpopulations. Biomedical HIV prevention creates new opportunities to reduce the alarming HIV health inequities that exist across the country. But simply expanding access to treatment and prevention services without understanding the unique needs, values, and barriers to care of specific groups will cause us to expand rather than shrink these alarming disparities.

In seeing the uptake, evolution, and expansion of biomedical interventions, several trends have emerged and important lessons have been learned. This report features some key cross-cultural findings that can speak to universal truths and address needs of all communities and important background that can help to develop initiatives that are more



INTRODUCTION



Ending AIDS must be more than a slogan; it takes planning, collaboration, and funding to make it real. Over the past five years, significant gains have been made in our efforts to end the HIV epidemic. Powerful new tools have helped us reach these new heights. Despite these successes, all of our gains have not been realized equally. Communities of color have not been able to fully experience the significant gains that are possible with our new tools. In an effort to spur innovation and growth, we prepared this document that features some guided thoughts and principles for working through how to close racial/ethnic inequities in HIV prevention and treatment.

Biomedical HIV prevention consists of powerful tools that can reduce HIV transmission and move us along a path to ending the HIV epidemic. There are three primary biomedical HIV prevention tools:

- Treatment as prevention (TasP) involves providing antiretroviral therapy (ART) to people living with HIV. Extensive research has proven how effective ART is at keeping people living with HIV healthy, and the best outcomes come from diagnosing people as soon as possible after they become infected and then immediately initiating ART. The prevention benefit of ART is that virally suppressed people with HIV do not transmit the virus to others. People who achieve and maintain viral suppression are called "undetectable." The Undetectable=Untransmittable (U=U) campaign is rooted in the concept of treatment as prevention.
- **Pre-exposure prophylaxis (PrEP)** involves HIV negative individuals taking a daily pill containing two antiretrovirals to prevent becoming infected with HIV. First introduced within the last decade, PrEP remains a new intervention that is both safe and highly effective for preventing HIV infection.
- **Post-exposure prophylaxis (PEP)** involves giving people with a very recent exposure or potential exposure to HIV a short course of ART (usually about a month), which can prevent HIV acquisition if treatment is started soon after the exposure.

This brief will focus primarily on two of these tools that have the most significant promise thus far: TasP and PrEP. While critically important, the role of PEP is more limited as a prevention strategy. As it relates to PEP, it is essential that: (1) providers know about PEP; (2) providers know how to prescribe it; (3) community members know that PEP exists; (4) community members know that they

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need to start PEP soon after an exposure; and (5) the health system provides multiple community and emergency room access points for PEP, as well as supports the ability to quickly address payment barriers so that persons in need (whether or not they are insured) are not denied timely access to the intervention. For a more detailed discussion of issues around biomedical HIV prevention, see the Blueprint for HIV Biomedical Prevention: State of the State Report.

This report is the second part of a two-part report: *Blueprint for HIV Biomedical Prevention.*¹ We conducted more than twenty interviews with a diversity of stakeholders in the summer of 2016 to inform the first part, the *State of the State Report*, and used those interviews as the starting point for distilling a focused list of recommendations for expanding access to biomedical HIV prevention in communities of color. The recommendations were also informed by discussions that took place at two conferences hosted by NMAC: the National HIV PrEP Summit in December 2016 and the National Biomedical HIV Prevention Summit in December 2017. NMAC staff and a cadre of external reviewers reviewed an initial draft of the report to comment on the priority of the recommendations, propose additional issues for consideration, and provide any other feedback that could benefit the development of the report.



RECOMMENDATIONS FOR COMMUNITIES OF COLOR



As discussed in the State of the State Report, in order to scale up access to biomedical HIV prevention, critical roles and actions by community-based organizations, health care providers, and the broader health system are necessary. We must create a health system for delivering HIV treatment, PrEP, and PEP with the adequate capacity in communities across the country to meet the level of need. This is an essential base upon which to build tailored initiatives to meet specific needs of individual communities or subpopulations. Biomedical HIV prevention creates new opportunities to reduce the alarming HIV health inequities that exist across the country. But, simply expanding access to treatment and prevention services without understanding the unique needs, values, and barriers to care of specific groups will cause us to expand rather than shrink these alarming disparities.

In seeing the uptake, evolution, and expansion of biomedical interventions, several trends have emerged, and important lessons have been learned. Below are some key cross-cultural findings that can speak to universal truths and address needs of all communities:

- Focus on the South and strengthening healthcare infrastructure. Roughly half of new HIV diagnoses in the United States occur in the South, and 54% of Black Americans live in the South. Beyond Medicaid expansion, many parts of the South have a weak healthcare infrastructure, with limited sexually transmitted infection (STI) and HIV treatment and prevention services, and an insufficient number of providers, especially in rural areas.^{2,3} We need to continue to push states in the South and elsewhere to expand Medicaid and support the adoption of telehealth models as well as other investments in geographic regions with high HIV burdens or significant barriers to treatment and prevention access. Despite the importance of expanded medical coverage, the various systems of coverage as well as traditional healthcare service delivery modalities present challenges for many community members.
- Promote biomedical HIV prevention tools through community education and awareness campaigns. Community education campaigns are needed to increase the awareness and uptake of biomedical HIV prevention. These campaigns must speak directly to communities of color and have specific pieces that speak to trans women, trans men, gay and bisexual men and heterosexual men and women about the importance of accessing health care, how to do

RECOMMENDATIONS FOR COMMUNITIES OF COLOR

so, the role of ART in preventing HIV transmission, and the safety and effectiveness of PrEP. To be successful, each campaign must utilize messages and representations informed by and relevant to these targeted communities, their needs, and their priorities. These campaigns will also need to speak to risk perception and include individuals from communities of color to lead prevention efforts.

Strengthen health literacy and increase health system navigation services. Many people of color do not access health care on a regular basis and do not have a relationship with a medical provider. It is essential to promote health literacy by increasing the capacity of these individuals to navigate the health system, including assessing insurance coverage options, enrolling in coverage, identifying a primary care provider, making medical appointments, accessing services, and troubleshooting if problems arise. This may be particularly important in the context of PrEP for HIV-negative individuals who may be unaccustomed to working with the health care system,

Many people of color do not access health care on a regular basis and do not have a relationship with a medical provider.

Combat stigma associated with HIV and PrEP. Stigma remains a significant barrier to HIV treatment and PrEP. The use of the term "Truvada Whore" (a reference to the drug currently being used for PrEP) and the related issue of "slut shaming" reflect stigma associated with PrEP. It is important to understand the perception and effects of PrEP stigma among gay and bisexual men of color and to recognize that these men often face multiple forms of stigma, including stigma around being HIV positive, being gay or bisexual, being Black or Latino, or being poor or undocumented. Stigma can also have a chilling effect, discouraging individuals and communities from considering whether PrEP might be an option for them and their prevention needs. While stigma has been shown to have a negative impact on PrEP uptake,

adherence, and persistence, there are an increasing

specifically, patient assistance programs.

number of social media campaigns and other interventions designed to combat PrEP stigma. As more cities, counties, and states develop and implement plans to "End the Epidemic" in their jurisdictions, it is important that they take advantage of opportunities to re-conceptualize PrEP in a manner that reduces and discourages stigma across race, gender, sexual orientation, and other identities.

RECOMMENDATIONS FOR COMMUNITIES OF COLOR

across cultures and communities and provide effective HIV treatment and prevention. As efforts are made to expand access to HIV treatment and PrEP among people of color, especially gay and bisexual men and transgender women, we need providers who are: (1) willing and equipped to discuss sexual behavior; (2) willing to treat those with HIV and to prescribe PrEP; and (3) willing to provide respectful and appropriate care, free of stigma and judgment with a contextualized understanding of race. This will require expanding training focused on racial equity and integrating LGBTQ cultural competencies within curricula for future providers, as well as building sustainable systems in clinical and non-clinical settings for supporting biomedical interventions. We must rethink

our assumptions about risk and risk assessment.

Train more providers to be equipped to navigate

Traditional risk assessment describing groups with higher rates of HIV incidence as "high-risk" contributes to stigma and may make people less likely to seek services. To provide effective HIV treatment and prevention, we need providers to eliminate terminology that can be stigmatizing. Moreover, provider biases may cause a clinician to improperly assess someone's risk.

- Expand the scope of sexual health clinics. Increasing uptake of biomedical interventions requires broad provision of medication and restructuring of the current access points of care for sexual health. Public clinics operated by health departments and other facilities offering sexually transmitted infection (STI) screening and treatment must integrate biomedical interventions into their compendium of services both for initiation as well as continuation. Given their role in bridging the gaps of access to care, often in neighborhoods with poor health services, these clinics can achieve a lot by simply integrating biomedical services.
- Adapt service delivery to reach people of color. To take full advantage of biomedical prevention tools, it is not enough to merely offer PrEP in traditional clinical settings. Rather, we need to adapt to meet the needs of priority populations, and we need to deliver PrEP across a variety of settings outside standard business hours and streamline PrEP delivery in clinical practice. This means expanding prevention education and services within primary care facilities, pharmacies, STI and family planning clinics, faith-based settings, and other places where people of color, especially gay and bisexual men and transgender women, are located, such as youth centers, sports clubs, hair salons, and barbershops.
- Actively counter mistrust of providers and the health system. Mistrust of the health care system is a potential barrier to effective HIV treatment and prevention, and people of color in particular may choose not to go to the doctor because they do not trust the health care system. Some mistrust likely stems from previous experiences of stigma and discrimination

in health care settings and exists and persists due to continuing stigma and discrimination. We must counter this mistrust in order to improve access to HIV treatment and PrEP among people of color. Client-centered approaches that empower individuals and communities to be part of the decision-making process related to HIV prevention tools and strategies have the potential to combat mistrust and improve access to biomedical services.

Cultivate a diverse workforce of health researchers and professionals trained in applying multidisciplinary approaches. HIV research and practice must build on and incorporate the knowledge and experience from communities of color. While it is important to leverage peer health navigators who can engage and connect with people of color, it is also important to have members of those communities designing and conducting research studies for their communities as well as working at all levels of community-based organizations, health centers, and health departments. This workforce must be trained to think outside of purely biomedical paradigm and apply social and behavioral approaches. The success of biomedical interventions is dependent on social and behavioral factors affecting medication adherence and treatment acceptability and use. Social and behavioral approaches informed by the needs of communities of color are

important to effectively implement biomedical HIV prevention within these communities. These approaches include, but are not necessarily limited to, studying and addressing factors such as mental health, substance use, housing, and

incarceration.

HIV research and practice must build on and incorporate the knowledge and experience from communities of color.



The following provides important background that can help to develop initiatives that are more effective at meeting the needs of specific communities of color:

Transgender People of Color



Transgender women of color have the highest rates of HIV diagnoses of any subpopulation in the United States.



Half of transgender men diagnosed with HIV are Black/ African American. Effective HIV treatment and prevention may compete with other life priorities, and concern over impact of HIV medications on effectiveness of hormone therapy may impede use of HIV prevention and treatment services among trans people of color.



Surviving every day in a hostile world with high rates of interpersonal violence, lack

of employment options, and discrimination is an overriding challenge for trans people of color, especially trans women of color.







Trans people of color often do not feel seen, respected, or valued by many HIV community stakeholders and the world at large; research shows that these are not merely feelings - they are facts. Racism, sexism, and transphobia exacerbate the challenges faced by trans people of color.

Scaling up access to effective biomedical prevention is a challenge for many groups and on many levels. Transgender people of color have

prevention and care often are not the most pressing issues in the lives of trans people of color. Instead of trying to position HIV care and prevention as urgent priorities for trans people of color, more efforts are needed to address the urgent issues in their lives, and in so doing, find ways to integrate health care and health promotion that includes PrEP, ART, and other services. Moreover, as with cisgender women and other groups heavily impacted by HIV, acknowledging and responding to the trauma experiences of trans people of color is an essential starting point for meeting their needs.

a lot to gain by access to effective treatment and prevention. HIV

Opportunities and Priorities

More HIV community attention has been directed in recent years to learning about and beginning to support the trans community. We need to continue to ensure practices of mutual respect are adhered to when working with all parts of our community, and we need to address the high levels of need for health and other services among trans people, as well as the absence of or inadequacy of trans-led or trans-sensitive services. In addition to having a clear understanding of HIV and other health disparities for both trans women of color and trans men of color, we need a broader understanding of discrimination and violence that trans people of color face in all aspects of their lives. In particular, trans women of color experience disproportionately high rates of murder. Several steps can be taken to create environments more conducive to scaling up access to ART and PrEP for transgender people of color:

disproportionately

- Build the capacity of the HIV clinical and non-clinical care systems to meet the needs of trans people of color. Just as the HIV community has led the way in building LGB-sensitive clinics and agencies and we have built models for cultural sensitivity training among health care agency staff at all levels, we need to greatly expand the trans-competency of our workforce. We must identify and spotlight trans people of color playing various roles within the health system from physicians to peer navigators.
- Hire trans people of color in our agencies. As we collectively work to build our capacity to meet the health and other needs of trans people, we must recruit, hire and nurture trans leadership at all levels of our organizations.
- Generate high quality trans-specific data. Our national, and to varying degrees our state and local, HIV surveillance system struggles with effectively monitoring trans people. This is in part due to their very small share of the overall population and in part due to stigma. Therefore, innovative monitoring strategies are needed, and more investments are needed to monitor the care experiences of trans people. A component of improving monitoring is to continue our advocacy to make questions about sexual orientation and gender identity (SOGI) core elements of clinical care visits that are captured in standardized ways in medical records.

Address safety concerns over HIV medications and hormones. One important barrier to PrEP and ART use is the often-unaddressed safety concerns over the interaction of ART medications and hormones. While there is no present data to suggest that high doses of feminizing or masculinizing hormones would negate the benefit of PrEP, this may result from insufficient research into these drug interactions.⁴ Therefore, the HIV community needs to develop and communicate evidence-based answers to questions over the safety and effectiveness of mixing ART and PrEP with hormones.

Transgender Women of Color

The HIV community can take further steps in service of trans women of color:

• Rethink PrEP marketing for trans women. A defining experience of trans women is they often feel invisible or lost in data-driven discussions that include them with gay and bisexual men or completely exclude them altogether. As we market PrEP, we not only need trans-focused campaigns and programs, but we also need to acknowledge that many trans women perceive PrEP (as its initial marketing suggested) as an intervention primarily for gay and bisexual men. Therefore, we need to fund and advocate for holistic trans health care programs of which PrEP and HIV prevention are just one component. It is imperative that

we include trans women of color as technical experts for the development of PrEP campaigns and programs.

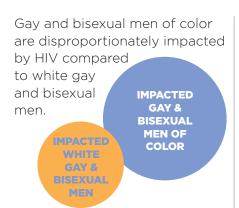


Transgender Men of Color

The HIV community can take further steps in service of trans men of color:

- Conduct research to inform HIV prevention for trans men of color. Trans men's sexual health needs have historically not been studied or included in research. Current data is filled with gaps that inhibit the ability to adequately address their needs. For example, over half of transgender men with diagnosed HIV infection had no identified or reported risk. Additional research is needed to understand HIV risk behavior among trans men, especially those who have sex with other men or trans women. In particular, there need to be strategic efforts to assess the needs of the trans men of color.
- Promote visibility of trans men of color within the LGBT community and beyond. More significant visibility is needed in the gay community for trans masculine individuals, in order to create a more welcoming, inclusive environment where trans men feel more powerful in their relationships with non-trans men. This can in part be accomplished through educating gay and bisexual men about trans masculine individuals in their community. Similar education should also take place within the general population.

Gay and Bisexual Men of Color



Racism, homophobia, and HIV-related stigma are barriers to HIV testing, linkage to care, and treatment adherence and may impede effective HIV

treatment and prevention among gay and bisexual men of color.

Gay and bisexual men of color face additional challenges related to health literacy, medical mistrust, healthcare infrastructure, insurance coverage, poverty, transportation, housing, incarceration, and immigration.



Gay and bisexual men of color must not be left behind in benefiting from ART and PrEP. Effective HIV treatment and prevention are not reaching Black and Latino gay and bisexual men consistent with the disproportionate rates of HIV that these men face and worse HIV outcomes. Black gay and bisexual men account for more new HIV diagnoses than any other subgroup, and Latino gay and bisexual men have experienced a 20% increase in new HIV infections in recent years.⁵ If current rates of HIV diagnoses persist, 1 in 2 Black gay and bisexual men and 1 in 4 Latino gay and bisexual men will be diagnosed with HIV during their lifetimes.⁶ Uptake of PrEP remains slow among gay and bisexual men of color as among communities of color more generally. As of 2015, the majority of people taking Truvada as PrEP are white, while only 10% are Black and 12% are Latino.⁷ Similarly, gay and bisexual men of color, especially young Black and Latino gay and bisexual men, are less likely to receive ongoing HIV care, making it difficult to achieve viral suppression.

Opportunities and Priorities

A concerted effort must be made to reduce disproportionately high rates of HIV diagnoses and disparities in HIV treatment, adherence, and outcomes among gay and bisexual men of color. We must renew our efforts to deploy biomedical HIV tools and meet the HIV treatment and prevention needs of gay and bisexual men of color. Specific steps should be taken in service of gay and bisexual men of color.

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Black Gay and Bisexual Men

The HIV community can take several steps in service of Black gay and bisexual men:

- Follow the science. The HIV Prevention Trials Network (HPTN) 073 Study demonstrated high uptake of PrEP among Black gay and bisexual men when client-centered care coordination was utilized. What is needed now is to implement and bring this evidence-based intervention to scale up in the real world.
- Actively counter mistrust of providers and the health system. Mistrust of the health care system is a potential barrier to effective HIV treatment and prevention, and Black Americans, in particular, may choose not to go to the doctor because they do not trust the health care system. We must counter this mistrust in order to improve access to ART and PrEP among Black gay and bisexual men.
- Cultivate a diverse scientific and clinical workforce trained in applying multidisciplinary approaches. HIV research and clinical practice must build on and incorporate the knowledge and experience of Black gay and bisexual men. Even though progress has been made in this area, there still remains a large gap in the workforce in terms of representation at all levels. While it is important to leverage peer health navigators who can engage and connect with Black gay and bisexual men, it is also important to have Black gay and bisexual men designing and conducting research studies for their communities and serving as providers and leaders of health centers. This workforce must be trained to think outside of purely biomedical paradigm and apply social and behavioral approaches. This may include studying and addressing factors such as mental health, substance use, and incarceration.
- Educate the support systems for Black gay and bisexual men. For example, this includes the women (matriarchal figure) who have influence in the lives of these men and encourage/support them and their care or prevention plans including PrEP. We should also encourage peer support of Black gay and bisexual men.

Latino Gay and Bisexual Men

The HIV community can take several steps in service of Latino gay and bisexual men:

- and linguistically appropriate interventions. Language and culture are important factors that can determine acceptance of ART and PrEP. Therefore, producing materials in Spanish and developing culturally sensitive and responsive messages can be especially important for reaching Latino gay and bisexual men. This should include developing original materials in Spanish, not just translating from existing English resources.
- Tailor HIV treatment and prevention efforts to specific Latino subgroups. It is important not to treat Latinos as if they are a monolithic group. While a large percentage of Latinos in the United States are of Mexican origin, Latinos reflect a range of national origins and cultural backgrounds. We must understand these differences as well as generational differences and differences by immigration status and appropriately vary HIV treatment and prevention interventions for specific Latino subgroups.
- Promote leadership among Latino gay and bisexual men to address issues disproportionately affecting their peers. Effective HIV treatment and prevention often necessitate engaging spokespeople from affected communities. Just as the Young Black Gay Men's Leadership Initiative is committed to building leadership among young Black gay and bisexual men, we need to support more young Latino gay and bisexual men to be leaders on HIV issues within their communities.
- Center the voices of undocumented Latinos. Undocumented people often exist at the margins of society and experience high rates of stigma and discrimination, barriers to employment, limited health insurance options, and the risk of deportation. Fears over immigration status may impede access to effective HIV treatment and prevention among undocumented Latinos living with or at risk for HIV. As we work to better meet the needs of Latino gay and bisexual men, we must make clear that Latinos are welcome in our clinics, organizations, and communities regardless of their immigration status. We must have a firm understanding of the nuances and changes in immigration policy in order to understand the impact on undocumented individuals and keep them informed about their rights, make appropriate referrals to immigration attorneys, and possibly develop new medical-legal partnerships.

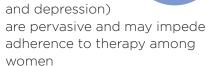
should be taken in service of gay and bisexual

Cisgender Women of Color



Cisgender women of color account for the vast majority of HIV diagnoses among women, and are more women-

centered marketing of PrEP is greatly needed to improve the options for people of color Recent trauma, past trauma, and trauma-related conditions (i.e., substance use and depression)



Attitudes and knowledge of PrEP among providers serving women is often woefully inadequate; providers often do not assess
HIV risks and may fail to offer PrEP to women who would

benefit from it

Women account for roughly 20% of all new HIV diagnoses in the United States, and Black women represent 64% of all new HIV diagnoses among women. Many women of color who would benefit from PrEP remain unaware of it. If they do know about PrEP, they may assume that it is only for gay and bisexual men, the target population of most PrEP awareness campaigns and demonstration projects. Women, especially those who are Black, are often diagnosed late in the course of their HIV infection and have lower rates of viral suppression than men. As with transgender women, cisgender women of color experience various forms of trauma that can impede their ability to access and benefit from HIV treatment and prevention. Strategies for supporting initiation of and adherence to ART and PrEP and promoting trauma-informed primary care are critical for meeting the needs of this subpopulation.

Opportunities and Priorities

Community education and awareness campaigns aimed at engaging Black women around HIV and promoting PrEP have been launched in recent years. More tailored efforts to reach women of color are needed. The HIV community can take several steps in service of women of color:

- Tailor HIV prevention messages to reach women of color. Efforts to support HIV prevention among women of color must engage these women in meaningful conversations about sexual health and risk perception and promote PrEP without characterizing it as being for high-risk people. Many women of color do not perceive themselves as being at high risk for HIV. Community education and awareness campaigns that associate PrEP with being high-risk may reinforce stigma around promiscuity and alienate many women of color who stand to benefit from PrEP. Rather than framing HIV prevention messages solely around risk, we need to emphasize the importance of women of color taking charge of their sexual health and knowing the tools available to keep themselves healthy.
- Offer PrEP in family planning clinics. Many women of color receive health services at family planning health centers, such as Planned Parenthood, which is integral to the health care safety net in every state. As we work to expand access to PrEP among this subpopulation, these health centers offer promising opportunities for delivering on the promise of biomedical HIV prevention.

- Educate providers about the importance of PrEP for women of color. Many providers fail to discuss PrEP with women and, in some cases, recommend that women do not use PrEP without asking about their sexual or other intimate behaviors. We need providers to be knowledgeable about PrEP and prescriber guidelines and recognize PrEP as an effective tool for reducing disproportionately high rates of HIV diagnoses among women of color. It may also be important to change the criteria for recommending PrEP in prescriber guidelines as a way to support uptake of PrEP among women of color.
- Support the adoption of new models of trauma-informed primary care. There has been significant interest recently in models of trauma-informed primary care. Federal agencies, including the Health Resources and Services Administration (HRSA) and the Substance Abuse and Mental Health Services Administration (SAMHSA), have embraced these approaches. Addressing trauma in clinical settings is critical to effective HIV treatment and prevention for women of color.
- Address unique issues related to juggling family, work, and other responsibilities. Women
 are more likely than men to be single parents and have responsibility for child rearing, which
 may interfere with their ability to manage ART or PrEP by creating competing time demands.
 We need to better understand these unique barriers that women of color face and expand
 access to transportation, childcare, and other programs and services, so that all women can
 benefit from effective HIV treatment and prevention, and we must identify and spotlight
 women of color playing various roles within the health system from physicians to peer
 navigators.

Adolescents and Young Adults of Color

Adherence to medication tends to be lower among adolescents than adults for all types of health conditions, and different kinds of support are needed to support adherence

Financing access to PrEP is an especially large barrier for youth and raises complex confidentiality issues with regard to insurance coverage

Some research suggests the promise of normalizing PrEP early on, following sexual debut so that this prevention intervention is an inherent part of healthy sexual maturation

Adolescents and young adults of color are at exceptionally high risk of acquiring HIV, have the highest percentage of undiagnosed HIV, and experience disparities in access to health care and preventive services, which may further contribute to their disproportionate HIV burden. Even as HIV diagnosis rates declined by 18% among gay and bisexual men between ages 13 and 24 from 2008 to 2014, rates

of new HIV diagnoses among young Black gay and bisexual mostly remained unchanged, and rates have increased among young Latino gay and bisexual men. Only about 25% of young gay and bisexual men achieve viral suppression. Ensuring that adolescents and young adults benefit from effective HIV treatment and prevention is critical for reducing new HIV infections and disparities in communities of color.

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Opportunities and Priorities

State, cities, and health centers have begun to develop policies and protocols for overcoming challenges and barriers that adolescents and young adults face when accessing effective HIV treatment and care. To make further progress, we must continue to tailor efforts to effectively reach young people of color. This must include clarifying and reforming state minor consent laws, safeguarding confidentiality, and establishing funding streams to pay for ART, PrEP and support services for young people interested in HIV care and prevention. The HIV community can take several steps in service of adolescents and young adults of color:

• Work to obtain FDA approval of PrEP for adolescents under age 18. Truvada is the only medication approved by the Food and Drug Administration (FDA) for use as PrEP. Currently, Truvada as PrEP is approved for adult use only. While it may be prescribed off-label to at-risk adolescents, many providers may be unwilling to prescribe in the absence of FDA approval. FDA approval also influences payment options for adolescents to access PrEP. Gilead's assistance programs follow the FDA indication and, as a result, are only available to pay for Truvada as PrEP for people aged 18 and over. Since the FDA approved PrEP in 2012, clinical research studies have begun to examine the safety and effectiveness of PrEP among adolescents under age 18. It is imperative to submit data from these studies for FDA review and approval without unnecessary delay.

• Identify and share best practices for addressing consent, confidentiality, and cost barriers for PrEP. Adolescents face many challenges to obtaining PrEP. One challenge is that in

most states PrEP is not available to adolescents under age 18 without parental consent. This is often a significant barrier to those who are most at risk for HIV diagnosis because they may not have disclosed their sexual orientation or risk behaviors to their parents and may fear the repercussions of disclosure. While minor consent laws exist in all states that allow those under age 18 to consent to health care, including PrEP, under certain circumstances, there is significant confusion over these laws. Even when the laws are clear, providers lack clarity or guidance around prescribing PrEP to adolescents. Additional challenges include concerns about confidentiality among adolescents and young adults on their parents' health insurance and limited payment options. As more jurisdictions and health centers work to find

solutions to these complex issues, identifying and sharing best practices may be the best and most efficient way to move toward large-scale implementation of PrEP among adolescents and young adults of color.

- Work to augment resources dedicated to reach young people of color who need ART or PrEP and support them in staying in care and adhering to their medication. Young people typically have poor engagement in health care. They may have trouble taking a pill daily as prescribed and attending medical appointments. We need more resources aimed at helping young people of color to understand the requirements of PrEP, remember their PrEP or ART medications and medical appointments, and maintain adherence.
- Disseminate HIV prevention information through youth serving organizations. It is important to ensure HIV prevention information reaches young people of color in their communities. This may include disseminating information through youth serving organizations, such as Boys and Girls Clubs, Boy Scouts/Girl Scouts, LINKS, Inc., and Jack and Jill. The focus should be placed on organizations that have cultural relevance in their work and work in communities of color.

Build support for comprehensive health

education and the integration of PrEP information into health education curricula.

Comprehensive sexual health education is effective at assisting young people to make healthy decisions about sex, yet many schools lack comprehensive sexual health programs and do not provide relevant sexual health education to LGBT students.

We must continue to work to ensure progression toward the enactment of comprehensive sexual health education legislation at the state and local level, including laws specifically requiring education around PrEP for young people in school.

• Educate communities of color about state laws that affect the sexual health of young people. A number of laws related to school-based healthcare, minor capacity to consent to healthcare serves, the legal age of sexual consent, young people's confidential access to HIV/STI testing, treatment, and prevention, and financing PrEP services affect the sexual health of young people. We need to work with relevant state and local agencies to educate communities about these laws and ensure that they are consistent with supporting effective HIV prevention for these communities.

CONCLUSION



Biomedical HIV prevention is exciting because it presents the tools that we need to curb the impact of HIV on our communities and produce happier, healthier people. We can expand ART and PrEP access to communities of color and seize the opportunity presented by the current moment in HIV treatment and prevention to reduce disparities, prevent HIV transmission, and heal our communities. We have to remember that increasing access to treatment and prevention services without reaching people and communities of color and understanding their needs, values, cultural backgrounds, and barriers to care will cause us to expand rather than shrink these alarming disparities.

We are at a critical moment where we can truly actualize the promise of prevention to bring us closer to achieving equity for people in need and ending the HIV epidemic. There is much we need to do, but we are on our way.

Endnotes

- ¹ This policy brief was prepared for NMAC by Sean E. Bland and Jeffrey S. Crowley of the O'Neill Institute for National and Global Health Law.
- ² Adimora AA, Ramirez C, Schoenbach VJ, Cohen MS. Policies and politics that promote HIV infections in the Southern United States. *AIDS*. 2014;28(10):1393-1397.
- ³ In 2016, there were 271.6 active physicians per 100,000 population in the United States, ranging from a high of 443.5 in Massachusetts to a low of 186.1 in Mississippi, and many states with the lowest number of physicians are in the South. Association of American Medical Colleges. 2017 State Physician Workforce Data Report. November 2017. Available at: https://members.aamc.org/eweb/upload/2017%20State%20Physician%20Workforce%20Data%20Report.pdf.
- ⁴ Mayer KH, Grinsztejn B, El-Sadr WM. Transgender people and HIV prevention: What we know and what we need to know, a call to action. *J Acquir Immune Defic Syndr*. 2016;72(Suppl 3):S207-209.
- ⁵ HIV Incidence: Estimated Annual Infections in the U.S., 2008-2014. Centers for Disease Control and Prevention Fact Sheet. https://www.cdc.gov/nchhstp/newsroom/docs/factsheets/HIV-Incidence-Fact-Sheet_508.pdf. Accessed September 19, 2017.
- ⁶ Hess KL, Hu X, Lansky A, Mermin J, Hildegard I. Lifetime risk of a diagnosis of HIV infection in the United States. *Ann Epidemiol*. 2017;27(4):238-243.
- ⁷ Bush S, Magnuson D, Rawlings M, Hawkins T, McCallister S, Mera Giler R. Racial characteristics of FTC/TDF for pre-exposure prophylaxis users in the US. Paper presented at: ASM Microbe 2016; June 16-20, 2016; Boston, Session 271.