Literature Review on HIV-Related Disparities of the National Quality Center (NQC) and Disparities Learning Exchange

“Of all the forms of inequality, injustice in health care is the most shocking and inhumane”
- Martin Luther King

A) Introduction

Since the emergence of HIV/AIDS in the early 1980s, the global community has witnessed momentous innovations that have significantly changed the landscape of HIV care. In particular, advancements in antiretroviral therapy (ART) over the last twenty years have transformed HIV/AIDS from a rapidly progressing ailment to what most consider a chronic disease. The introduction of ART has dramatically decreased the rates of morbidity and mortality of this population, regardless of sex, race, age and risk factors for transmission of HIV. With timely diagnosis, access to ART and lifelong adherence, people with recently acquired infections can have a life expectancy nearly the same as that of non-HIV-infected individuals. ART also plays a critical role in the prevention of onward HIV transmissions. The landmark HPTN052 clinical trial showed an “immediate and sustained reduction in the risk of HIV transmission after the initiation of ART.” However, reductions in HIV-related morbidity and mortality are uneven across people living with HIV (PLWH) subpopulations due to unequal access to care and variations in the quality of care provided. A gap exists between the quality of care that should be provided based on available professional knowledge, and the care that HIV patients actually receive.


Approximately 70% of the estimated 1.2 million people living with HIV in the United States are not virally suppressed. The statistics of those who make up most of the virally non-suppressed population paint a striking picture of disparities in HIV care since specific populations bear a disproportionate burden of HIV. At 16%, the rate of viral suppression among Black men who have sex with men (MSM) is less than half the rate of viral suppression among White MSM (34%). In 2010, the relative difference in HIV diagnosis rates among Black women was 20-fold compared to White women. While the average suppression rate for all people living with HIV is approximately 30%, less than 6% of youth are actually virally suppressed. And transgender women have significantly lower ART dose adherence and durable viral suppression compared to non-transgender men, even though they have similar rates in terms of receipt of care, treatment, and supportive services. Continuing to improve the health outcomes for both HIV-infected individuals and their communities-at-large over the coming years is unsustainable without targeted efforts to drastically improve the national viral suppression rates.

The Centers for Disease Control defines disparities as “differences in health outcomes or health determinants observed between populations.” The Affordable Care Act offers that a group is a health disparity population when “there is a significant disparity in the overall rate of disease incidence, prevalence, morbidity, mortality, or survival rates in the population as compared to the health status of the general population.”

Due to these persistent HIV-related disparities, the newly updated National HIV/AIDS Strategy (NHAS) emphasizes that “the Nation cannot meet the Strategy goals without reducing disparities.” To address disparities requires focusing on disproportionately affected communities and populations. These subpopulations are identified as gay, bisexual and other

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MSM of all races and ethnicities, Black women and men, Latino men and women, people who inject drugs, youth aged 13 to 24 years, people in the Southern United States, and transgender women. Accordingly, Goal 3 of the NHAS aims to “reducing HIV-related disparities and health inequities.”

In alignment with national HIV public health priorities, the National Quality Center (NQC) in close collaboration with the Health Resources and Services Administration (HRSA) HIV/AIDS Bureau (HAB) proposes to select HIV-related disparities as the key focus of its next national quality improvement initiative. Building upon the success and impact of its in+care Campaign, NQC works toward reducing HIV-related disparities in key communities to ensure that all persons with HIV are virally suppressed and have optimal health outcomes, and to work towards equitable care for all people in the United States.

This new 9-month initiative, called the end+disparities Learning Exchange, actively engages Ryan White HIV/AIDS Program (RWHAP)-funded recipients. NQC provides a series of content-rich webinars and real-world tools to assist local HIV providers in their improvement efforts to increase the viral suppression rates among the following four key subpopulations:

- MSM of Color
- African American and Latina Women
- Youth (aged 13 to 24 years)
- Transgender People

This Literature Review provides an overview and rationale for this important public health goal by describing the individual and population-based benefits congruent with reducing HIV-related disparities and relevant national frameworks.

**B) National Frameworks**

1) *National HIV/AIDS Strategy*

In July 2015, the White House Office of National AIDS Policy updated its National HIV/AIDS Strategy (NHAS) with goals to be accomplished by 2020. The vision of the NHAS is for the United States to become a place where “every person, regardless of age, gender, race/ethnicity,
sexual orientation, gender identity, or socio-economic circumstance, will have unfettered access to high quality, life-extending care, free from stigma and discrimination.”

The overall goals for improving national viral suppression rates cannot be achieved without a concerted effort to reduce HIV-related disparities. The NHAS states that “Poor social and environmental conditions, coupled with high rates of HIV among specific populations and in geographic areas, contribute to stubbornly persistent—and in some cases, growing—HIV-related health disparities.” Special consideration needs to be given to the social and environmental determinants of health that often exacerbate the higher burden of HIV-related morbidity and mortality felt by specific populations.

The NHAS suggests several steps (Step 3) that specifically address the goal of reducing HIV-related disparities and health inequities (see Table 1).

Table 1: Selected Steps from the NHAS 2020 Update

<table>
<thead>
<tr>
<th>Step 3.A: Reduce HIV-related disparities in communities at high risk for HIV infection</th>
<th>Step 3.B: Adopt structural approaches to reduce HIV infections and improve health outcomes in high-risk communities</th>
<th>Step 3.C: Reduce stigma and eliminate discrimination associated with HIV status</th>
</tr>
</thead>
<tbody>
<tr>
<td>1) Expand services to reduce HIV-related disparities experienced by gay and bisexual men (especially young Black gay and bisexual men), Black women, and persons living in the Southern United States</td>
<td>1) Scale up effective, evidence-based programs that address social determinants of health</td>
<td>1) Promote evidence-based public health approaches to HIV prevention and care</td>
</tr>
<tr>
<td>2) Support engagement in care for groups with low levels of viral suppression, including youth and persons who inject drugs</td>
<td>2) Support research to better understand the scope of the intersection of HIV and violence against women and girls and develop effective interventions</td>
<td>4) Promote public leadership of people living with HIV</td>
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The upcoming end+disparities Learning Exchange that encourages the promotion and implementation of evidence-based/informed quality improvement interventions, with an emphasis on reaching those most affected by HIV, is directly aligned with the goals outlined in the NHAS Update.

2) HIV Care Continuum
In 2005, the HIV/AIDS Bureau conducted an expert consultation meeting focusing on outreach efforts to engage people living with HIV, which produced an engagement in care continuum model (see Figure 1). Subsequently in 2011, Gardner synthesized the findings of several studies and developed a “spectrum of engagement into HIV care” that is similar to our modern-day HIV Care Continuum.

**Figure 1: Engagement in Care Continuum**

The HIV Care Continuum outlines the sequential stages of HIV medical care that PLWH experience—from receiving an initial diagnosis to maintaining the goal of viral suppression—and shows the proportion of PLWH at each stage. The HIV Care Continuum has the following stages: diagnosis of HIV infection, linkage to care, retention in care, receipt of ARV therapy and achievement of viral suppression. Ideally, HIV-infected persons should progress from HIV diagnosis to immediate linkage with a care provider to full engagement in high quality HIV care. However, the reality is quite different. Research has shown that clients may move between different stages at various points in their lives.

On July 15, 2013, President Obama issued an Executive Order establishing the HIV Care Continuum Initiative to mobilize federal efforts to accelerate improvements in HIV prevention and care through the application of the HIV Care Continuum. The Executive Order stated:

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“data released by the Centers for Disease Control and Prevention show that there are significant gaps along the HIV Care Continuum,” and made the HIV Care Continuum a national public health framework.\textsuperscript{21}

According to the latest CDC data, of the 1.2 million PLWH in the United States in 2012, an estimated 87\% have been diagnosed.\textsuperscript{22} This means that approximately 1 in 8 PLWH (13\%) were unaware of their infection. These individuals were therefore not accessing the care they need to both stay healthy and reduce the likelihood of transmitting the virus. Over the last decade, ART has become more potent, better tolerated and less complex while access to ART has increased. In fact, most PLWH who are on combination ART achieve an undetectable plasma HIV-RNA level.\textsuperscript{23} However, nationally, 40\% of PLWH were engaged in HIV medical care, 37\% were prescribed ART, and 30\% had achieved viral suppression by the end of 2011 (see Figure 2).\textsuperscript{24}


\textsuperscript{24} CDC. Understanding the HIV Care Continuum. 2014 December. Available from \url{http://www.cdc.gov/hiv/pdf/library/factsheets/understanding-hiv-care-continuum.pdf}
Figure 2: U.S. Prevalence-Based HIV Care Continuum, 2011

Note: *Linkage to care measures the % of people diagnosed with HIV in a given calendar year who had one or more documented VL or CD4 test within three months of diagnosis. Because it is calculated differently from other steps in the continuum, it cannot be directly compared to other steps.

A 2014 CDC report provided information about the 70% of PLWH who were not virally suppressed in 2011. Among these nearly 840,000 PLWH, 20% did not yet know they were infected; 66% had been diagnosed, but were not engaged in regular HIV care; 4% were in HIV care, but were not prescribed ART; and 10% had been prescribed ART, but had not yet achieved viral suppression.26 There are significant disparities in engagement in HIV care across subpopulations of PLWH because of unequal access to care and variations in the quality of services provided.27 For example, African Americans are disproportionately affected by HIV; while comprising 12% of the U.S. population, they represented 44% of new HIV diagnoses in 2014.28 Substantial geographic variation in HIV care outcomes by geographic location has also been observed.29

C) HIV Disparities

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The national viral suppression rate of 30% indicates that much more needs to be done to improve health outcomes for all people living with HIV. The statistics of those who are virally non-suppressed highlight disparities in HIV care (see Figure 3). However, an understanding of the disproportionate burden of HIV felt by vulnerable populations can provide the impetus for systemic and sustainable improvements. Smaller subpopulations with a disproportionately high prevalence of HIV are therefore the most actionable groups for targeted public health interventions that simultaneously reduce overall levels of morbidity, mortality, and onward HIV transmission.

**Figure 3: Diagnoses of HIV Infection by Selected Demographics**

In terms of looking at specific target populations, the National HIV/AIDS Strategy 2020 goals include reducing disparities in the rate of new diagnoses by at least 15 percent among young black gay and bisexual men, and black females as well as increasing the percentage of youth

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with diagnosed HIV infection who are virally suppressed to at least 80 percent.\textsuperscript{31} However, recent reports indicate that these goals have not been met yet in recent years.

\textit{Table 2: National HIV/AIDS Strategy 2020 using surveillance data}\textsuperscript{32}

<table>
<thead>
<tr>
<th>Indicator</th>
<th>2010</th>
<th>2011</th>
<th>2012</th>
<th>2013</th>
<th>2014</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rate of new diagnoses for young black MSM</td>
<td>109.4</td>
<td>112.4</td>
<td>112.9</td>
<td>117.2</td>
<td>116.5</td>
</tr>
<tr>
<td>Rate of new diagnoses for black females</td>
<td>1.7</td>
<td>1.5</td>
<td>1.4</td>
<td>1.3</td>
<td>1.2</td>
</tr>
<tr>
<td>Percentage of youth who are virally suppressed &gt;80%</td>
<td>30.9%</td>
<td>34.3%</td>
<td>38.9%</td>
<td>43.7%</td>
<td>n/a</td>
</tr>
</tbody>
</table>

The Learning Exchange will empower providers across the United States to implement local improvements and can have an impact on the care provided to underserved populations by reducing HIV-related disparities and providing equitable care for all people with HIV across the United States. NQC’s new initiative actively promotes the implementation of interventions to increase the viral suppression rates for the following four subpopulations:

- MSM of Color
- African American and Latina Women
- Youth (aged 13 to 24 years)
- Transgender People

\textit{1) MSM of Color}

Gay, bisexual, and other men who have sex with men (MSM) of all races and ethnicities are disproportionately affected by HIV in the United States.\textsuperscript{33} MSM represent approximately 2% of the U.S. population, yet they accounted for 63% of all new HIV infections in 2010. In 2012, there were an estimated 481,202 MSM living with diagnosed HIV infection; of those, 145,707


\textsuperscript{32} Ibid.

were Black, 207,849 were White, and 99,495 were Latino.\textsuperscript{34} In 2010, the estimated rate of HIV infection among MSM was approximately 46 times that of all other men.\textsuperscript{35}

Recent CDC data indicate that although Blacks make up 12\% of the U.S. population, they accounted for 41\% of those living with HIV/AIDS in 2012.\textsuperscript{36} A majority (72\%) of Black men with HIV contracted the disease by male to male contact.\textsuperscript{37} Among MSM, Black MSM are the group most affected by HIV (see Figure 4).\textsuperscript{38} In 2010, Black MSM accounted for almost as many new HIV infections as White MSM, despite the differences in population size of Blacks compared to Whites.\textsuperscript{39} There were an estimated 10,600 new HIV infections among Black MSM, in comparison to an estimated 11,200 new HIV infections among White MSM, and 6,700 new HIV infections among Latino MSM.

In 2010, young MSM (aged 13 to 24 years) accounted for 72\% of new HIV infections among all youth, and 30\% of new infections among all MSM.\textsuperscript{40} Young Black MSM are especially affected by HIV. In 2014, they accounted for approximately 4,321 new HIV infections—more than twice as many estimated new infections as either young White MSM (1,291) or young Latino MSM (1,786).\textsuperscript{41} Between 2001 and 2006, the number of HIV infections rose for all MSM, but particularly for young Black MSM (a 93\% increase).\textsuperscript{42} Furthermore, the disparity in HIV prevalence between White MSM and Black MSM increased significantly from 2008 to 2014, particularly among young MSM.\textsuperscript{43}


\textsuperscript{40} CDC. HIV/AIDS: HIV among gay and bisexual men. Updated 2015 Sep 29. Available from \url{http://www.cdc.gov/hiv/group/msm/}

\textsuperscript{41} CDC. HIV/AIDS: HIV among youth. Updated 2016 Apr 27. Available from \url{http://www.cdc.gov/hiv/group/age/youth/}


Though there has been some progress in fighting new HIV infections among Blacks overall, a recent study of MSM in 19 U.S. cities and the District of Columbia revealed a 19% increase in self-reported sex without condoms in HIV-positive Black MSM—from 47% in 2005 to 56% in 2011.\(^45\)

Studies have found that Black MSM are more at risk for HIV even when they have the same or fewer risk behaviors as MSM of other races. The likelihood of having unprotected anal intercourse, engaging in commercial sex work, or having sex with a known HIV-infected partner was not higher among Black MSM than White MSM.\(^46\) There is also evidence that points to Black MSM having fewer partners than White MSM.

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Regardless of these considerations, the HIV-related outcomes for Black MSM are worse than those for White MSM along every step of the HIV Care Continuum (see Figure 5). At 16%, the rate of viral suppression among Black MSM is only about half of the overall national rate (30%). Among those with diagnosed HIV infection, an estimated 47% of White MSM are virally suppressed, as opposed to 28% of Black MSM and 37% of Hispanic MSM.

**Figure 5: Estimated HIV Care Continuum for Black MSM vs. White MSM, 2009-2010**

Even though deaths among persons with HIV have been declining since the availability of effective ART medications, the death rate per 1,000 people living with HIV in 2012 for Blacks (20.5) was higher than the rates for Whites (18.1) and Hispanics/Latinos (13.9).

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Although Hispanics/Latinos make up only 17% of the U.S. population, they accounted for nearly one quarter of all new HIV diagnoses in 2013. Hispanics/Latinos are more likely than Blacks or Whites to be diagnosed with AIDS within three years of their HIV diagnosis. Moreover, Hispanics who only speak Spanish are less likely to be adequately informed about the disease and less likely to know who needs to be tested for HIV. Amongst the Hispanic/Latino population affected by HIV, Hispanic/Latino MSM are disproportionately burdened and account for 7 in 10 new HIV diagnoses among Hispanics/Latinos.

Recent data from the 2016 Conference on Retroviruses and Opportunistic Infections (CROI), highlight the disparity of lifetime risk of HIV transmission between different transmission groups (see Figure 6). The overall lifetime risk of HIV infection among all MSM is 1 in 6. Among White MSM, the lifetime risk is 1 in 11, while the lifetime risk among Latino MSM is 1 in 4. Among Black MSM, the risk reaches a staggeringly high 1 in 2, meaning half of all Black gay men are projected to be diagnosed with HIV in their lifetime. When compared to the overall lifetime risk for HIV diagnosis in the U.S (1 in 99), it is evident that significant disparities still affect vulnerable subpopulations.

![Lifetime Risk of HIV Diagnosis among MSM by Race/Ethnicity](image)

Source: Centers for Disease Control and Prevention

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Figure 6: Lifetime Risk of HIV Diagnosis among MSM by Race/Ethnicity

2) African American and Latina Women

At the end of 2012, approximately one in four people living with HIV in the United States (23%) were women. In 2014, 87% of new infections amongst women (7,242) resulted from heterosexual contact. Women represent 20% (246,372) of the 1,210,835 cumulative AIDS diagnoses in the United States from the beginning of the epidemic through the end of 2014. The CDC reports that of all women living with HIV, only 55% were retained in care and only 30% had achieved viral suppression.

When comparing groups by race/ethnicity, gender, and transmission category, the fourth largest number of all new HIV infections in the United States in 2014 (4,654) occurred among African American women with heterosexual contact (see Figure 7). African American and Latina women continue to be disproportionately affected by HIV, compared with women of other races/ethnicities. Of the total number of estimated new HIV infections among women in 2014, 62% (5,128) were in African American, 18% (1,483) were in Whites, and 16% (1,350) were in Latinas.

Figure 7: Estimates of New HIV Infections in the United States for the Most-Affected Subpopulations, 2014

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In 2010, among women, the relative difference in HIV diagnosis rates for African American women was 20-fold compared with Whites and for Latina women was 3-fold compared with Whites.\(^{61}\)

From 2008 to 2010, the relative differences in HIV diagnosis increased for African American and Latina women compared with White women.\(^{62}\) African American women accounted for 6 in 10 HIV diagnoses among women in 2014.\(^{63}\)

Recent data about lifetime risk also show a significantly higher likelihood of HIV diagnosis for an African American or Hispanic woman than a White woman.\(^{64}\) 1 in 880 White women will be diagnosed with HIV in her lifetime, compared to 1 in 227 Latina women and 1 in 48 African American women. This means that Latina women are 4 times more likely to be diagnosed with HIV than White women and African American women are 18 times more likely to be diagnosed with HIV than White women.

3) **Youth**

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In 2010, Youth (aged 13 to 24) made up 17% of the U.S. population, but accounted for an estimated 26% (12,200) of all new HIV infections. More recently, Youth accounted for an estimated 22% (9,731) of all new HIV infections in 2014. In other words, more than one in five new HIV diagnoses were among persons aged 13 to 24 years. An estimated 1,716 Youth received AIDS diagnoses in 2014, accounting for 8% of all AIDS diagnoses that year.

At the end of 2013, there were an estimated 60,900 youth living with HIV in the U.S.; of these, 31,300 were living with undiagnosed HIV infection. This means that 51.4% of Youth with HIV in the U.S. do not know they are infected, compared to the overall average of 13.0% of HIV-infected individuals across all ages living undiagnosed.

Black and Hispanic/Latino Youth are disproportionately affected by HIV (see Figure 8). Even more strikingly, young Blacks (aged 13 to 19) made up 63% of young people diagnosed with HIV in 2014, yet only represented 14% of the total youth population in the United States.

*Figure 8: Estimated New HIV Diagnoses Among Youth Aged 13-24 by Race/Ethnicity and Sex, United States 2014*

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67 Ibid.

68 Ibid.


Recent CDC data indicate that among HIV-infected persons alive at the end of 2013, 43.7% of Youth had viral loads of <200 copies/mL, as compared to 58.3% of individuals over 55 and the overall average of 54.7% of individuals across all ages. Among HIV-infected persons with one or more viral load tests, 63.5% of Youth were virally suppressed, as compared to 88.7% of individuals over 55 and the overall average of 81.4% of individuals across all ages. These numbers indicate a clear disparity in viral suppression that Youth face.

Young MSM are also disproportionately affected by HIV, particularly young MSM of color. In 2014, young MSM accounted for 8 in 10 new HIV infections among Youth. Moreover, from 2005 to 2014, HIV diagnoses among young MSM increased approximately 87% among Blacks and Hispanics/Latinos and 56% among Whites. Recent data (2010-2014) from young MSM show that this increase in HIV diagnoses has stabilized among Blacks and Whites and slowed to 16% among Hispanics/Latinos.

In 2014, Zanoni and Mayer found that the HIV Care Continuum for Youth was significantly different from the overall national HIV Care Continuum (see Figure 9). For example, only about 41% of HIV-infected youth ages 13 to 29 are diagnosed, which is less than half the overall rate of HIV diagnosis (87%). Addressing the low percentage of those who are aware of their diagnosis is important because more than 50% of new HIV infections occur as a result of the 21% of people who do not know they are infected. Perhaps even more striking are the data that suggest that less than 6% of HIV-infected youth are virally suppressed, compared to the overall viral suppression rate of 30%. Drop-offs at all points in the Care Continuum contribute


72 Ibid.


to this low rate of viral suppression. Hall and colleagues corroborated these results by finding that the rates for each element on the Care Continuum increase with each older age group (outcomes are worst for those ages 13-24 and best for those ages 55-64) (see Figure 10).  

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4) Transgender People

Transgender communities in the United States are among the groups at highest risk for HIV infection. The term gender identity refers to a person’s internal identification with a gender, and transgender refers to a person whose gender identity does not conform to a binary classification.

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of gender based on biological sex, external genitalia, or their sex assigned at birth. In an analysis of HIV testing events at CDC sites between 2009 and 2011, transgender people were found to have much higher percentages of HIV-positive test results (2.4%), compared to both cisgender males (0.9%) and females (0.2%). Globally, it is estimated that around 19% of transgender women are living with HIV; they are also 49 times more likely to acquire HIV than all adults.

Although transgender people do not make up a large proportion of the HIV-infected population, the prevalence of HIV within the transgender community is disproportionately high. In 2011, the Williams Institute estimated that roughly 0.3% of the total U.S. adult population identifies as transgender (men or women). However, Mizuno and colleagues found that 1.3% of HIV-infected individuals receiving care in the United States self-identified as transgender women, indicating a disproportionate HIV prevalence within this population.

Some studies indicate that the rate of HIV prevalence among transgender women could be as high as 28%, compared to an overall HIV prevalence rate in the United States of approximately 0.4 to 0.9%. Higher percentages of newly identified HIV-positive test results were found among Black transgender women (56%) than among White (17%) or Latina (16%) transgender women.

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Furthermore, compared to cisgender women, transgender women were disproportionately likely to be diagnosed with AIDS within three months of HIV diagnosis. Although MSM and transgender women have similar CD4 counts at diagnosis, transgender women were found to have delayed linkage to care and lower viral suppression rates than MSM.

Williamson found that health care providers and systems are often underequipped in their ability to provide effective care to those who identify as transgender. A provider who is not attuned to the particular needs of this subpopulation is highly prone to inadvertently creating an unreceptive environment for a patient seeking care. This environment may lower the likelihood of a patient staying in care, which ultimately result in poorer health outcomes. Mizuno and colleagues found that transgender women have significantly lower ART dose adherence and durable viral suppression compared to non-transgender men, even though they have similar rates in terms of receipt of care, treatment, and supportive services. Transgender women have higher unmet needs for basic services, like food and housing, which may exacerbate already poor outcomes.

An important consideration is that there have been very few efforts to address HIV-related disparities among transgender men (female-to-male transgender persons). In a systematic literature review conducted by Herbst and colleagues, it was found that, of 29 identified HIV-related studies of transgender peoples, only 5 included data specifically about transgender men.

Due to the low percentage of those who self-identify as transgender in the United States, interventions focused on this population have historically been quite limited. However, due to the high HIV prevalence within this population, reducing this disparity would have a far-reaching impact on HIV-related mortality and morbidity among this underserved community.

D) Conclusion

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The recently updated National HIV/AIDS Strategy places a strong emphasis on the disproportionate burden of HIV on certain subpopulations. Findings from this literature review on disparities in HIV further demonstrate the need and importance on focusing on the following four patient groups: MSM of color, African American and Latina women, Youth (aged 13 to 24 years), and Transgender People.

Based on the success of previous national improvement initiatives, there is momentum for a new national initiative focusing on the reduction of HIV-related disparities by implementing quality improvement interventions that make a tangible difference in health outcomes for vulnerable subpopulations along the HIV Care Continuum.