

TRANS HIV TESTING TOOLKIT

MODULE 1: GET THE FACTS ABOUT TRANS PEOPLE AND HIV



“Your gender is not a decision. In most cases it’s not even an observation. It’s like having eyes. If you have eyes, you know you have eyes. You likely can’t pinpoint the specific moment you realized. If asked, you might say you’ve always known you had eyes, but that’d be a lie. You don’t often think about your eyes, but they are always there, making a huge impact on your days. It’s through your eyes that you see the world, and, in many ways, your eyes affect how the world sees you.”¹

I. LANGUAGE – TERMINOLOGY, CONCEPTS, DEFINITIONS

The distinction between sex and gender is often not clear. There is a myriad of terms that trans or gender non-binary individuals use to identify themselves. As providers, health advocates, community health workers, health planners, or HIV test counselors, it is important to be aware of the broad yet imperfect language used to describe people’s gender identities and experiences.

Language used to describe trans people is ever changing and terms may be specific to certain groups within the broader trans community. Terms may vary based on a number of factors such as generational differences, geographic location, native language, and access to conversations on trans-related terminology. Some trans people, however, use binary language (e. g., female or male) because they consider themselves to be binary. Others see themselves as non-binary. These differences may be taken into consideration when working with trans people.

A list of gender identity terminology, concepts and definitions can be found in the Resource Section of this toolkit. The list is neither exhaustive nor does it completely reflect the diverse identities that fall within the transgender “umbrella”. While it is important for providers to be aware of basic terminology, it is even more important for all clients to be given the opportunity to self-identify and provide the information on how they want to be recognized.

“The lack of status awareness among trans women leads to a higher incidence of HIV and negative health outcomes.”

II. HIV AND TRANS COMMUNITY

A. Prevalence and Burden of HIV among Trans People

1. Why Focus HIV testing on Trans Women?

Trans women (people who were assigned ‘male’ at birth and have a female gender identity and/or feminine gender expression) are at high risk of having HIV and of contracting HIV. In a global meta-analysis, the HIV prevalence among trans women in high income countries such as the United States is approximately 22%; however, trans women regardless of country wealth were approximately 49-times more likely to be living with HIV compared to all adults of reproductive ages.¹

Trans women of color, especially African-Americans and Latinas, experience disproportionately high rates of HIV. A 2008 meta-analysis of 29 regional US studies found that race was a significant mediating factor to HIV status among trans women; that is, race influences how much one has of contracting HIV. It is important to emphasize, however, the literature suggests that racism, not just race, influences these women’s risk. Transphobia (specific discrimination experienced by trans people), homophobia, and racism appear to collectively increase risk among trans women of color. Without more nuanced language, it appears as though trans women’s own intrinsic characteristics are placing them at risk for HIV, and as is acknowledged throughout the toolkit that isn’t the case.

For example, HIV prevalence among African American trans women is approximately 56%, whereas the prevalence among Caucasian trans women is approximately 17%.² In other words, African American trans women test positive for HIV more often than Caucasian trans women. Therefore, special considerations for HIV testing should be tailored to communities most in need.

Many trans women are often not aware of their HIV status. A 2008 meta-analysis demonstrated that there was a large discrepancy between lab-confirmed HIV and self-reported HIV infection among trans women (28% and 12%, respectively). Centers for Disease Control and Prevention (CDC) reports that 73% of trans women living with HIV are unaware of their HIV positive status.³ The lack of status awareness among trans women leads to a higher incidence of HIV and negative health outcomes. This finding supports the increased need for HIV testing services and status awareness among trans people.

The higher HIV prevalence and lower HIV testing rates among trans women compared to other high risk groups may be due to greater disparities, stigma, and discrimination across many environmental and social contexts. For example, due to lack of job opportunities for trans women, many often engage in sex work for survival. Sex work involves multiple sex partners that are known to be a driver for HIV. Trans women sex workers have a higher HIV prevalence than non-trans female or male sex

“We cannot ignore the disproportionate degree to which trans people experience many cultural, socioeconomic, and health-related cofactors that compound the HIV epidemic and prevention challenges among US trans communities.”

workers.⁴ Prevalence of unprotected receptive anal sex (URAS), the highest sexual risk behavior for transmitting HIV among trans women, can be as high as 55%.⁵ Differences in URAS prevalence occur across ethnic groups; Asian and Pacific Islander trans people, for instance, are 3.6 times more likely than Latina trans women to engage in URAS.⁶ Additional high-risk behaviors include injection drug use and alcohol use, inadequate negotiation skills for safer sex, and low self-efficacy in communicating sexual history with a partner. These risk behaviors are heightened by violence, stigma and discrimination, limited health care access, low to no competence among health care providers, negative health care encounters, and marginalized housing.

High-risk sexual or substance use behaviors alone do not adequately account for the high burden of HIV infection among trans people. We cannot ignore the disproportionate degree to which trans people experience many cultural, socioeconomic, and health-related cofactors that compound the HIV epidemic and prevention challenges among US trans communities. Unemployment rates, for example, are upwards of 23% among trans women;⁷ without the opportunity for equal pay and safe, non-discriminatory working conditions, trans women often turn to sex work as one of the only options for sustainable incomes.⁸ Moreover, without equal access to employment for a living wage or access to medically necessary gender confirmation procedures, trans women do report injection of non-prescribed hormone and “silicone” or soft tissue fillers that have compounded health risk factors beyond that of HIV transmission.

2. What We Know about HIV and Trans Men

There is a lot we do not know about HIV and trans men. While the trans community is diverse and not enough research has been conducted with trans people in general, there is very limited information about trans men in particular. To date, research related to HIV among trans people has almost exclusively focused on trans women. However, there is growing evidence that there is a significant group of trans men who have sex with men (TMSM) and trans men who engage in sex work.

Several areas including Philadelphia, Washington D.C., San Francisco, and Ontario, Canada have conducted needs assessments that focus on or are inclusive of trans men and HIV risk. The few published studies that report HIV rates among samples of trans men have reported 0 – 3% prevalence.^{5,13} These rates are self-reported, however, and are based on small, non-representative samples, so we know that we still do not have sufficient data about the actual HIV prevalence rates among trans men. Despite the methodological flaws in the extant published research, due to the assumption of low rates of HIV among trans men relative to other high-risk groups, there is limited interest in conducting more research on risk behaviors among trans men.



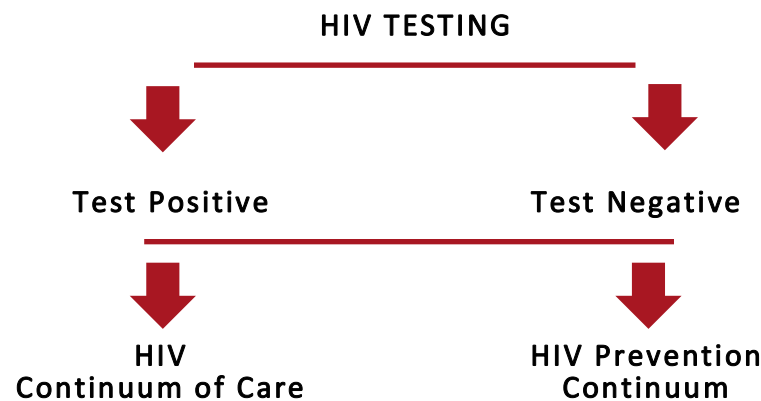
For more specific information on the HIV prevention needs and priorities of trans women and trans men see the HIV Prevention FactSheets in the National Transgender HIV Testing Day (NTHTD) and Toolkit Resources section of this toolkit.

Additionally, specific terms related to HIV prevalence among trans people are available in the NTHTD and Toolkit Resources section at the end of this toolkit.

B. HIV Testing Model for Trans People and the HIV Continuum

We adapted a model to illustrate the two pathways to health after HIV testing. This model emphasizes HIV testing and status awareness as a first and crucial step to HIV prevention. For trans people who test positive, the HIV care continuum provides a framework to engage trans people who are living with HIV in medical care to stay healthy and reduce the risk of transmission to others. For trans people who test negative, the prevention continuum provides a framework to support their engagement in prevention services such as pre-exposure prophylaxis (PrEP), ongoing risk reduction counseling, repeat testing, and other medical, behavioral, and social services as indicated.

Figure 1. HIV Testing Pathway



Anthony Fauci, "Ending the HIV/AIDS Pandemic: An Achievable Goal" (presentation, 2015 National HIV Prevention Conference, Atlanta, GA, December 6-9, 2015).

“Trans women have reported that they are often unwilling to engage in medical treatment, including HIV testing, because they are miscategorized as MSM on many clinical forms.”

In detail, both the HIV Continuum of Care and HIV Prevention Continuum presents the sequential steps of to engage trans people in HIV prevention and care with the goals of reduced HIV prevalence and HIV acquisition.

Figure 2. HIV Continuum Model and Intervention Steps



C. Barriers to HIV Testing and Care

Trans women have reported that they are often unwilling to engage in medical treatment, including HIV testing, because they are miscategorized as MSM on many clinical forms.⁹ Needs assessment studies conducted in major cities across the United States since the late 1990s have shown that access to primary health care is highly challenging for many trans people.¹⁰ Trans individuals experience barriers to receiving and remaining engaged in health care.

Such barriers to HIV testing and care can include:

- Concerns about encountering stigma in HIV testing sites and from peers;
- Negative past experiences with health care staff, providers, or agencies overall;
- Prioritizing more urgent needs, such as housing and legal issues, or gender-related care;
- Concerns that HIV treatment might interfere with hormone therapy; and

“A connection with a trusted provider who is also linked into a collaborative network of other providers can open doors to multiple avenues of HIV care and prevention, such as mental health care, case management, legal services, employment services, housing and social support networks.”

- Intersecting mental health issues or other circumstances that make regular testing difficult to prioritize.

Many HIV testing sites are geared toward MSM, and consequently bias is inherent in these testing sites. Below are some steps that address transphobia to ensure that trans people are welcome at HIV testing sites.

D. Addressing Transphobia as a Barrier to Testing among Trans People

Transphobia is a reality that many trans people face. It is important your organization engages with the trans community in a culturally competent way. Make sure to communicate that when trans people do come to your organization, they are welcomed and not faced with discrimination or stigma.

Comprehensive, culturally competent HIV testing and treatment can serve as a portal for clients to address multiple co-occurring burdens. A connection with a trusted provider who is also linked into a collaborative network of other providers can open doors to multiple avenues of HIV care and prevention, such as mental health care, case management, legal services, employment services, housing and social support networks.

Below are some steps that address transphobia to ensure that trans people are welcome to HIV testing sites.

1. Take stock of the first impression that a trans person may have when walking into your organization for HIV testing. If your organization develops or hands out HIV testing brochures, make sure these brochures are relevant and inclusive of the trans population. Display them as appropriate.
2. Acknowledge or post non-discrimination statements or statements that assure equality regardless of race, **gender identity** or sexuality.
3. Consider having a gender-inclusive restroom policy. This will help create a safer and more comfortable environment for trans HIV testing clients and staff.
4. Hire trans people to be on staff. Including trans people as part of your HIV testing staff creates an atmosphere of acceptance and displays the commitment of your organization to equality and non-discrimination policies.
5. Provide sensitivity training to all staff (front desk, receptionist, security, counselors, health educators, etc.) will need sensitivity training when working with trans people. Establish guidelines



with information you find in this toolkit or the NTHTD and Toolkit Resources section and circulate them amongst your staff.

6. Be aware of the diversity among individuals in the trans community. It is also important that the organization's employees are educated about the social determinants (loss of jobs, social isolation, violence) and high-risk behaviors. Training of HIV testing staff regarding health or sexual risk assessments can improve HIV testing services for the trans community. (See also Sexual Risk Assessment of Trans Client section).
7. Be open to feedback from trans staff and trans clients about your agency's HIV testing programs and services is important when trying to address transphobia in your agency and build trust with the trans community.
8. Keep trans people's information confidential. Many people fear disclosure of their gender identity. Trans people involved in sex work may not only fear disclosure of gender identity but also their HIV status. Testing sites are encouraged to be familiar with their state's requirements on anonymous vs. confidential HIV testing. A frank discussion about the client's concern of the impact HIV disclosure would have, and the agency's duty to report HIV testing information should not deter trans people from testing.
9. Update current intake forms to eliminate gender binary assumptions. Consider using the two-step question to assess for gender identity. (See Section 3 Building Capacity to Increase HIV Testing Efforts for Trans People for the two-step model). Counselors may want to avoid assuming who is, or who is not trans, and use the two-step model to allow all people to self-identify their gender identity.
10. Consider making distinctions between "name on documents or medical records" and "preferred name". This assists medical providers in respecting the trans clients that cannot access legal means of changing their name and ensures continuity in tracking the medical history of the client for continuity of care.

“Understanding the social determinants of health for trans people provides a framework for providers to address the HIV testing needs for trans people.”

III. TRANSGENDER SOCIAL DETERMINANTS OF HEALTH/GENDER AFFIRMING HEALTH CARE

Understanding the context of trans people’s lives is important when designing HIV testing programs to reach the community. Trans people face many social issues that can be barriers to receiving services such as HIV testing. While HIV is a concern to many trans people in their daily lives, HIV prevention and treatment may not be high priorities due to other competing needs. These needs include issues such as:

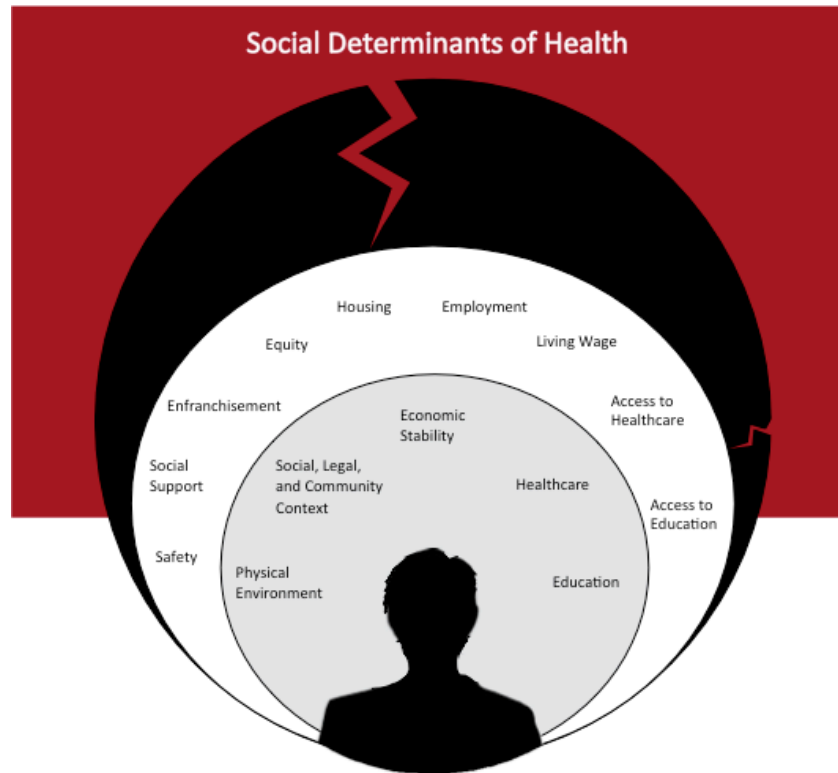
- Transphobia, external and internal
- Family rejection
- Gender identity validation through sex
- High risk sex partners
- Injection risks
- Peer harassment
- Unemployment
- Discrimination in health care
- Housing discrimination
- Violence
- Biases in the criminal justice system

Trans people need to be supported in prioritizing HIV prevention and treatment despite these competing needs.

Understanding the social determinants of health for trans people provides a framework for providers to address the HIV testing needs for trans people. This framework may help public health officials, HIV prevention planners, and community-based organizations support the transgender community in re-prioritizing HIV testing in their health care and daily lives.

“For trans and gender non-binary individuals, constrained access to culturally competent health care and social services, experiences of stigma and discrimination, vulnerability to violence and exploitation, social barriers to maintaining a stable income and safe housing, and intersecting experiences of social marginalization all contribute to negative health outcomes.”

Figure 3. Social Determinants of Health for Trans People¹¹



A. Social Determinants of Health for Trans People

Health does not exist independently of context or causal factors. In addition to the ways in which behavioral, environmental, and genetic factors determine health, so too does one's social and cultural environment. For trans and gender non-binary individuals, constrained access to culturally competent health care and social services, experiences of stigma and discrimination, vulnerability to violence and exploitation, social barriers to maintaining a stable income and safe housing, and intersecting experiences of social marginalization all contribute to negative health outcomes. The National Center for Transgender Equality has recently published a report that states that trans people have experienced disproportionate rates of violence, harassment, mental illness, and discrimination in workplaces, schools, and social service systems.¹²



“By reducing this burden, it is possible that trans people will be better able to avail themselves of options that will improve their health, and the health of their communities.”

Understanding this framework is crucial to successful HIV testing, risk reduction communication and treatment efforts focused on trans people. It is important to understand trans people as individuals and as a community of individuals shoulder a multilayered burden of factors that may prevent them from prioritizing HIV testing and treatment in their health care regimens. By reducing this burden, it is possible that trans people will be better able to avail themselves of options that will improve their health, and the health of their communities. This requires a holistic approach by addressing personal needs and their relationship in the context of a multi-layered environment.

The following sections of this toolkit will review several approaches to building capacity and cultural competency among trans people in HIV testing and prevention, and risk reduction communication.

“In discussing prevention methods, a dialogue that focuses on risk rather than individual body parts provides a safe space for trans people to have conversations around HIV testing and prevention.”

IV. TRANSGENDER HIV PREVENTION STRATEGIES “HIV PREVENTION TOOLBOX”

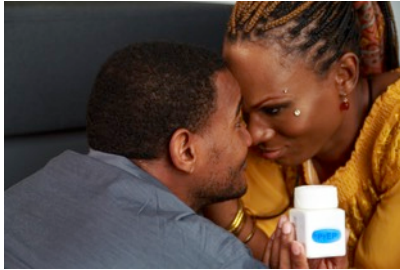
A. Transgender HIV Prevention Toolbox Overview

HIV Prevention methods in this toolkit are an assortment of ideas and approaches to reducing HIV risk. Often, many of the approaches are driven by science, technology and emerging research. Although many HIV prevention tools and interventions mentioned in this toolbox were not specifically tailored for trans people, ongoing discussions, ideas and research are encouraged to identify and include the specific needs and experiences of trans people in HIV prevention, testing and engagement. The tools discussed below are considerations for including in HIV testing conversations with trans people. It should be noted that gender specific descriptors are used with the understanding that they are not culturally trans specific.

Because gendered terms such as “male” or “female” are conceptualized differently among trans people, culturally appropriate HIV prevention conversations regarding trans body parts and their sexual practices are crucial. A familiarity with these HIV prevention methods as it relates to trans people builds trust and enhanced engagement during HIV testing services. In discussing prevention methods, a dialogue that focuses on risk rather than individual body parts provides a safe space for trans people to have conversations around HIV testing and prevention.

Table 1. Transgender HIV Prevention Methods

HIV Prevention Tools	
Male Condoms	A condom is a thin sheath worn over an erect penis to keep seminal fluid (cum) or pre-seminal fluid (pre-cum) from entering a partner’s body during oral, anal, or vaginal sex.
Female Condoms	A female condom is a thin pouch worn inside a vagina or an anus to keep a partner’s seminal fluid (cum) or pre-seminal fluid (pre-cum) from entering their body during intercourse. The female condom has a ring on each end. The inside ring holds the condom in place inside the vagina or anus. The outer ring stays outside the vagina or anus.
Biomedical	
Pre-Exposure Prophylaxis (PrEP)	PrEP is a way for people who don’t have HIV to prevent HIV infection by taking a pill every day. The pill contains two medicines that are also used to treat HIV. If you take PrEP and are exposed to HIV through sex or injection drug use, these medicines can work to keep the virus from taking hold in your body. For more information on PrEP and trans people see PrEP and the Trans Community section below.



Biomedical	
Post-Exposure Prophylaxis (PEP)	Post exposure prophylaxis (PEP) is the short-term use of HIV antiretroviral medications after a high-risk event in order to decrease the risk of acquiring HIV. For a consecutive 28 days, two or three antiretroviral drugs are prescribed. PEP is recommended for people who have had a high-risk event within 72 hours. Studies do not show 100% effectiveness of HIV prevention if given PEP. Currently there are no studies involving the effectiveness of PEP and the trans community.
Anti-Retroviral Therapy (ART)	Treatment for HIV includes anti-retroviral therapy (ART), which are medications that people who are living with HIV take to stay healthy. These medications reduce the amount of virus in the body, keep the immune system functioning, and prevent illness. Another benefit of reducing the amount of virus in the body is that it helps prevent transmission to others through sex, needle sharing and during pregnancy and birth.

Social and Behavioral Risk Reduction	
Evidence-Based Interventions (EBIs)	<p>The CDC has identified several evidence-based interventions (EBIs) that are based on research studies showing positive behavioral (e.g., use of condoms; reduction in number of partners, disclosure) and/or health outcomes (e.g., reduction in the number of new STD infections). These studies employed rigorous research designs, with both intervention and control groups, so that the positive outcomes could be attributed to the interventions.</p> <p>Although there are currently no EBIs designed specifically for trans people, there are EBIs that can be adapted to transgender people's HIV testing and prevention needs. This may include:</p> <p>People living with HIV/AIDS Healthy Relationships; WILLOW</p> <p>High Risk HIV Negative People Personalized Cognitive Counseling (PCC); MPowerment; Popular Opinion Leaders (POL)</p> <p>For more information on CDC EBIs go to: (http://www.cdc.gov/hiv/prevention/research/compendium/rr/complete.html)</p>



For more information about EBIs and the trans community see the NTHTD and Toolkit Resources section of this toolkit.

1. Pre-Exposure Prophylaxis (PrEP) and the Trans Community

Proven prevention options are limited in trans populations. With the recent popularity and advancement of PrEP as a biomedical intervention, trans people may want to discuss PrEP as a component of their health care including HIV testing. Although PrEP studies have focused on men who have sex with men (MSM), a recent subgroup analysis of the iPrEx trial, which specifically sought to test the effectiveness of PrEP among trans women, found a protective relationship between PrEP use and HIV transmission. Thus, there is some preliminary evidence to suggest that PrEP is effective in preventing HIV acquisition among trans women when taken as prescribed, but there are a number of adherence barriers, particularly among those with the highest acquisition risk.¹³

Given the lack of studies of PrEP on the trans community, other considerations may be taken into account prior to promoting PrEP as a blanket HIV prevention intervention.

Points to consider in HIV testing conversations with trans clients regarding PrEP:

- An HIV test confirms that a patient is HIV negative prior to initiating PrEP.
- Reminder that PrEP is not a medication that can be taken as needed or once after a high-risk event. PrEP involves daily use of medication with frequent medical visits for lab tests, HIV and other STIs testing.
- What understanding, if any, does the trans client have about PrEP? Educate them that there are few studies that confirm the effectiveness of PrEP among the trans community.
- Does the trans client have a desire to take PrEP on a daily basis with high adherence?
- Does the client practice high-risk behaviors that signal the need for PrEP?
- Assess the financial feasibility of starting PrEP for the trans client. Although some programs and insurance covers PrEP, consideration of co-pay and sustainability of PrEP use for the client is necessary. If cost is a consideration, assess if a client may qualify for the Gilead Patient Assistance Program (PAP) for Truvada or gain assistance from a Patient Assistance Network (PAN).
- Inform the trans client that condoms, lubrication, and decreased URAS rates can be used concurrently with PrEP to help prevent HIV.

- Assess adherence barriers for trans people who are seeking PrEP
- Engage trans people seeking PrEP to include sex partners

For more information about PrEP and the trans community see the NTHTD and Toolkit Resources section of this toolkit.

-
- ¹ Baral, SD, Poteat, T., Stromdahl, S., Wirtz, AI, Guadamuz, TE, Beyrer, C. Worldwide burden of HIV in transgender women: a systematic review and meta-analysis. *Lancet Infect Dis* 2013; 13: 214-222; doi: 10.1016/s1473-3099(12)70315-8
- ² Herbst, JH, Jacobs, ED, Finlayson, TJ, McKleroy, VS, Neumann, MS, Crepaz, N. Estimating HIV prevalence and risk behaviors of transgender persons in the United States: A systematic review. *AIDS Behav.* 2008; 12: 1-17. doi: 10.1007/s10461-007-9299-3
- ³ HIV Among Transgender People. (2015, December 17). Retrieved March 17, 2016, from <http://www.cdc.gov/hiv/group/gender/transgender/>
- ⁴ Operario, D., Soma, T, Underhill, K. Sex work and HIV status among transgender women. *J Acquir Immune Defic Syndr.* 2008; 48(1): 97-103.
- ⁵ Nemoto, T, Bodeker, B., Iwamoto, M, Sakata, M. Practices of receptive and insertive anal sex among transgender women in relation to partner types, sociocultural factors, and background variables. *AIDS Care* 2013; 26 (4): 434-440; doi: 10.1080/09540121.2013.841832
- ⁶ Nemoto, T, Bodeker, B., Iwamoto, M, Sakata, M. Practices of receptive and insertive anal sex among transgender women in relation to partner types, sociocultural factors, and background variables. *AIDS Care* 2013; 26 (4): 434-440; doi: 10.1080/09540121.2013.841832
- ⁷ Herbst, JH, Jacobs, ED, Finlayson, TJ, McKleroy, VS, Neumann, MS, Crepaz, N. Estimating HIV prevalence and risk behaviors of transgender persons in the United States: A systematic review. *AIDS Behav.* 2008; 12: 1-17. doi: 10.1007/s10461-007-9299-3
- ⁸ Sausa, LA, Keatley, J, Operario, D. Perceived risks and benefits of sex work among transgender women of color in San Francisco. *Arch Sex Behav.* 2007; 36: 768-777; doi: 10.1007/s10508-007-9210-3
- ⁹ Sausa, L. A., Sevelius, J., Keatley, J., Iñiguez, J. R., & Reyes, M. (2009). Policy Recommendations for Inclusive Data Collection of Trans People in HIV Prevention, Care & Services. Center of Excellence for Transgender HIV Prevention: University of California, San Francisco. Available online at: www.transhealth.ucsf.edu
- ¹⁰ Bockting, W, and Avery, E. (2005). Transgender Health and HIV Prevention: Needs Assessment Studies from Transgender Communities Across the United States. *International Journal of Transgenderism*, Vol. 8, Nos. 2/3. NY: The Haworth Medical Press.
- ¹¹ Moran, L., Keatley, J., & Goodwin, D. (2016). Transgender HIV/AIDS Health Services Best Practices (Tech.). San Francisco, CA: San Francisco Department of Public Health.
- ¹² Grant, J. M., Mottet, L. A., & Tanis, J. (2011). Injustice at Every Turn, A Report of the National Transgender Discrimination Survey (Rep.). Retrieved February 22, 2016, from National Center for Transgender Equality website: http://www.thetaskforce.org/static_html/downloads/reports/reports/ntds_full.pdf
- ¹³ Deutsch MB et al. HIV pre-exposure prophylaxis in transgender women: a subgroup analysis of the iPrEx trial. *The Lancet* (2015). doi: [http://www.thelancet.com/journals/lanhiv/article/PIIS2352-3018\(15\)00206-4/abstract](http://www.thelancet.com/journals/lanhiv/article/PIIS2352-3018(15)00206-4/abstract). (05 November 2015).