

## Strengthening Prevention and Care for a Priority Population

Transgender people, particularly transgender women, are vulnerable to HIV infection. Available evidence suggests that, in relation to their population size, transgender women are among the most heavily affected populations in the United States. Gaps in knowledge about population size and trends in HIV infections, however, create significant challenges to designing effective prevention programs, directing resources, and tracking progress in this population.

HIV prevention for transgender people is a core priority of the National HIV/AIDS Strategy. As part of its High-Impact Prevention approach, CDC is working with public health partners, other federal agencies, and community leaders to address key gaps in HIV prevention and care for transgender people nationwide.

### What the Available Data Tell Us

Meta-analyses and literature reviews of available studies provide evidence of the effects HIV has taken on the transgender community. In a recent analysis of CDC-funded HIV testing conducted nationwide, transgender women had the highest rates of HIV diagnoses (2.7%), followed by men (0.9%), transgender men (0.5%), and women (0.2%).<sup>1</sup> A 2013 meta-analysis of available research estimated that 22 percent of transgender women were living with HIV in five high-income countries, including the United States.<sup>2</sup> A previous review of published studies conducted in the U.S. estimated that 28 percent of transgender women were living with HIV based on laboratory testing, while only 12 percent self-reported their HIV-positive status. Although these estimates come from different studies within the review, they suggest that many transgender women living with HIV are not aware of their infection.<sup>3</sup>

For transgender men, even fewer data are available. Available evidence indicates that HIV prevalence among transgender men is relatively low (0% to 3%), although a 2011 study suggested that transgender men who have sex with men (MSM) are at substantial risk of becoming infected with HIV.<sup>4</sup>

### Limitations in Data for Transgender Populations

Because there is no reliable system for collecting and sharing sex and gender identity (SGI) information in health records, our nation currently lacks reliable HIV surveillance data for transgender populations.

The primary gaps occur at the level of individual healthcare providers, who either do not collect or do not have a uniform way to report key SGI information. This is due to several factors, including inadequate or inconsistent electronic health record (EHR) formats, physician concerns about violating patient privacy, and providers' discomfort discussing or addressing sex and gender identity with patients. In addition, health departments—which are responsible for compiling and reporting surveillance data to CDC—have not always been equipped to account for SGI information.

Since quality data are critical to High-Impact Prevention, CDC is working closely with partners and advocates to close these gaps. In December 2015, CDC issued updated guidance and a new tool for health departments to compile and analyze transgender-specific surveillance data. CDC recommends a two-step method: asking about sex at birth together with current gender identity. Separately, recent EHR regulations from the U.S. Centers for Medicare & Medicaid Services could lead to improved data in future years by requiring accredited EHR systems to include SGI data fields.

While reliable, truly national surveillance systems take significant time to build, these changes may begin to offer insights in the next few years.

Transgender women of color are known to be especially vulnerable to HIV infection.<sup>5</sup> For example, data from New York City show that between 2010 and 2014, 234 transgender people received a diagnosis of HIV infection. Nearly all (99%) were transgender women, of whom 93 percent were black/African American or Hispanic/Latino, and sexual contact with a male was the predominant transmission category.<sup>6</sup>

## Why Transgender People Are at Particular Risk

While factors associated with HIV infection in transgender populations have not yet been well studied, transgender people often face challenges that have been associated with increased HIV risk or poorer outcomes in other populations.<sup>7</sup> These may include:

- **Social rejection and stigma.** Instances of discrimination, including sometimes outright aggression, manifest themselves in frequent lack of familial and other social support. A lack of legal recognition (e.g., being able to legally change one’s name and sex on state-issued identification and other government forms) can also complicate or discourage access to needed health or social services.<sup>8</sup>

- **Intimate partner violence (IPV) or physical abuse,** which may limit a person’s ability to negotiate condom use or use other prevention methods. Not only are IPV and sexual abuse themselves risk factors for HIV; their other effects—such as depression, increased rates of substance abuse, and reduced willingness to seek medical care and services—can also increase one’s risk of HIV infection.<sup>9</sup>

- **Difficulty accessing education, employment, and housing** due to transphobia and discrimination. As with other populations, these factors may help to explain the elevated rates of drug and alcohol abuse, sex work, incarceration, homelessness, depression, suicide, and unemployment facing the transgender community, all of which are well-established risk factors for HIV infection.<sup>10,11</sup>

- **Lack of access to HIV testing, diagnosis, care, and prevention.** Transgender people may face particular challenges accessing testing and other health services. Available evidence also suggests that transgender people who receive a diagnosis of HIV are considerably less likely than other populations to be linked to or retained in HIV medical care. In addition, fear of potential interactions between HIV medications and the drugs needed for sex reassignment—while not supported by evidence—may lead a transgender person to avoid seeking HIV treatment. Many transgender people are also affected by negative experiences with healthcare providers, as few providers receive adequate training or are sufficiently knowledgeable about transgender-specific health needs. These experiences may discourage them from disclosing their gender identity and keep them from receiving prevention and care services they need.<sup>12</sup>

Key Term	Definition
<b>Gender Expression</b>	How a person represents or expresses their gender identity to others, often through behavior, clothing, hairstyle, or body characteristics.
<b>Gender Identity</b>	An individual’s internal sense of being male, female, or some other designation. Since gender identity is internal, it is not always visible to others.
<b>Transgender</b>	Describes a person whose gender identity or expression does not match the sex they were assigned at birth. For example, a transgender women is a person whose identity is female, but whose sex at birth was male.
<b>Cisgender</b>	Term used to describe people who are not transgender. “Cis-” is a Latin prefix meaning “on the same side as.”

## CDC's Support for Transgender-Specific HIV Prevention

CDC and partners have worked to intensify HIV prevention for transgender people in recent years, and they are taking steps to further strengthen these efforts and build the base of evidence needed to design programs and track progress.

### Delivering High-Impact Prevention

Transgender populations are a core priority for nearly all of CDC's major HIV prevention funding programs, including its many grants to health departments and community-based organizations (CBOs). In certain cases, CDC has established programs specifically for transgender communities. For example, CDC has directly funded select CBOs to provide high-impact HIV prevention services to young transgender people of color and their partners. In other cases, transgender people are among a group of clearly defined priority populations, as in CDC's recently announced effort to expand two HIV prevention strategies—pre-exposure prophylaxis, or PrEP, and Data to Care—for transgender women and MSM.

In addition, CDC funds a national network of capacity-building providers to work with health departments and CBOs to build their own capacity to provide culturally relevant programs, services, and interventions for transgender people. These approaches include ensuring that condoms are more freely and readily available, increasing HIV testing activities, increasing prevention agencies' cultural competency with transgender people, and supporting community mobilization around HIV prevention.



### Improving Understanding of HIV among Transgender People

CDC has taken a number of critical steps to improve the collection of national surveillance data on HIV in the transgender community. Specifically, CDC has:

- Revised the data fields used in CDC's National HIV Surveillance System (NHSS) to better account for sex and gender identity
- Issued recommendations and statistical tools for health departments to collect information on current gender identity and report these data to the NHSS
- Worked to raise awareness among healthcare providers of the importance of collecting complete data on sex and gender identity
- Initiated analyses of HIV testing among transgender people through CDC's existing Behavioral Risk Factor Surveillance System

### Advancing HIV Prevention Research

While a number of prevention programs have been adapted for use with transgender populations, none has been tested and proven effective in these populations to date. To address this gap, CDC is working with partners to develop new prevention programs, adapt existing ones, and rigorously assess their impact on HIV risk behaviors and transmission. For example, CDC's Online Safe Space Initiative supports a Minority HIV/AIDS Research Initiative grantee in developing and evaluating the impact of a website for HIV prevention and health promotion tailored to young, black, transgender women and MSM in the U.S. South.

## Raising Awareness, Engaging Communities

Well-designed awareness campaigns can help people better understand their level of risk for HIV and encourage them to take steps to protect themselves, get tested and, if they are living with HIV, seek out care and treatment. Several of CDC's *Act Against AIDS* communications campaigns include campaign materials and activities that are specifically tailored to transgender communities. These include:

- *Doing It*, a new national HIV testing and prevention campaign designed to motivate all adults to get tested for HIV and know their status
- *HIV Treatment Works*, a campaign that encourages people living with HIV to get in care, stay in care, and live well
- *Let's Stop HIV Together*, a national campaign designed to address stigma and complacency, key obstacles to stopping HIV in nearly every community

CDC also conducted formative research in 2015 to inform future communications efforts for transgender communities. This research will help CDC expand the range of culturally and linguistically relevant *Act Against AIDS* materials featuring transgender women of color, particularly black and Latina transgender women.

## Need for Collective Action

Despite significant challenges, our nation has the HIV prevention tools and knowledge to make an enormous difference for transgender people today. Government agencies like CDC must continue to play a central role, but federal action needs to be matched by the efforts of health departments, other state and local agencies, CBOs, and community leaders.

Closing today's data gaps will require significant time and effort, including diligence by healthcare providers and health departments in collecting, compiling, and reporting data on sex and gender identity. Researchers and their institutions must continue to expand the available body of evidence on effective strategies to reduce HIV infections and to improve health outcomes for transgender individuals who are living with HIV. Advocates and members of transgender communities must continue to hold policymakers and public health leaders accountable for action at the federal, state, and local levels.

With new prevention options and increased public awareness of the health needs of transgender people, there is a greater potential to address their HIV prevention and other healthcare needs. CDC will continue working with partners to ensure that transgender people can access the HIV prevention and care they need to remain healthy.

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**"HIV: This is not the end. It's just the start of a new way of life."**  
Jennifer – Asheville, NC  
Living with HIV since 1997.

When I learned I had HIV, the doctors told me I had just 6 weeks to live. As a transgender woman, it was hard to find a doctor who understood my needs, but I kept looking and finally found someone. Now, 17 years later, I take just one pill a day—with very few side effects. I also run my own organization called TransHealth Coordinators that helps health care providers learn how to care for the unique needs of transgender people. Staying healthy leaves me with plenty of energy to pursue my other passions, too, such as painting, gardening, and operating a mountain guest house.

**Get in care. Stay in care. Live well.**