



## Recommendations for Inclusive Data Collection of Trans People in HIV Prevention, Care & Services



*I'm a female, only my body is a little different and I can penetrate my boyfriends and ejaculate semen.*

### What is the Problem?

Monitoring the continuing spread of the HIV epidemic is essential for determining public health priorities, assessing the impact of interventions, and making estimates of current and future health care needs (Joint United Nations Programme on HIV/AIDS, 2006). Accurate data collection is essential for dissemination of reliable and factual public information and development of meaningful education and prevention programs, and care services. Currently many federal, state, and local agencies inaccurately collect data about individuals' sex and gender. Most often only one question is asked: ***What is your sex?*** or ***What is your gender?***, and only 2 or 4 options are provided requesting only one choice: ***Male*** or ***Female***, or ***Male, Female, Male-to-Female (MTF)***, or ***Female-to-Male (FTM)***. Today, this method is too

simplistic and binary to accurately and effectively collect critical information to assess HIV incidence and prevalence, identify emerging trends, allocate resources, improve health care services, and address service gaps among populations of individuals.

At the end of 2003, an estimated 1,039,000 to 1,185,000 (about 1 in 247) persons in the United States (U.S.) were living with HIV/AIDS, with 24%-27% undiagnosed and unaware of their HIV infection (Centers for Disease Control and Prevention (CDC), 2006; Glynn & Rhodes, 2005; United States Census Bureau, 2008). In 2008, CDC estimated that approximately 56,300 people were newly infected with HIV in 2006 (the most recent year that data are available), and that there has been no significant decline among the yearly incidence of new infections in the last decade (CDC, 2008). One of the fastest growing populations to be infected with HIV are transgender people. In California, publicly-funded counseling and testing sites reported that transgender women have higher rates of HIV diagnosis (6%) than all other risk categories, including MSM (4%) and partners of people living with HIV (5%), and African American transgender women have a substantially higher rate of HIV diagnosis (29%) than all other racial or ethnic groups (California Department of Health Services, 2006).



*I am not FTM or MTF. I'm Genderqueer and have receptive penetrative sex with men.*



*I'm a Femmequeen and have been living with HIV for 3 years.*

A transgender (trans) person is someone who has a different sex, gender identity, and/or gender expression than the one assigned to them at birth, regardless of their sexual orientation (Cabral, 2007; Sausa, Keatley, & Operario, 2007). Due to assumptions and/or discomfort among health professionals to ask questions about gender identity, trans people are either completely missed and not accurately counted in surveillance methods, or miscounted as MSM (often trans women are incorrectly counted as MSM). In addition, many funders, health departments and government agencies do not even allow for the reporting of trans people as clients and patients, as if they don't even exist. A recent meta-analysis of 29 studies specifically focused on trans people underscored the alarming rate of HIV prevalence among trans people in the U.S. (Herbst et al., 2008). Overall, 28% of trans women tested positive for HIV, though when asked about their HIV status only 12% self-reported living with HIV. This highlights the

extraordinary high rate (about 1 in 4) of trans women living with HIV. The high rate of trans women who are undiagnosed or unaware that they are infected is more than twice the national average (57% vs. 27%) (CDC, 2008; Glynn & Rhodes, 2005; Herbst et al., 2008). The same meta-analysis reported a rate of 2-3% (about 1 in 50) among trans men, though few studies accounted for or focused on the growing number of trans men who have sex with gay and bisexual men (Sevelius, 2007). With regards to incidence of new HIV infections, when data is gathered and reported, incidence percentage rates (adjusted for population size and number of persons testing) among trans women are often the highest rate reported among any population group and in many cases twice that of gay and bisexual men (San Francisco Department of Public Health (SFPDH), 2005 & 2008; Herbst et al., 2008).

Despite these high rates of HIV infection reported among trans women, there is also a concurrent lack of knowledge, comfort, and skills among health and social service providers who work with trans clients and patients (Clements, Wilkinson, Kitano & Marx, 2001; Hussey, 2006; Grossman & D'Augelli, 2006; Nemoto, Sausa, Operario, & Keatley, 2006; Shaffer, 2005). This lack of provider competency has resulted in many trans people avoiding health care services for preventive and urgent/life-threatening conditions (Shaffer, 2005), and trans people having a lower adherence to their HIV medication (Melendez et al., 2005; SFPDH, 2008).

### **What Do We Recommend?**

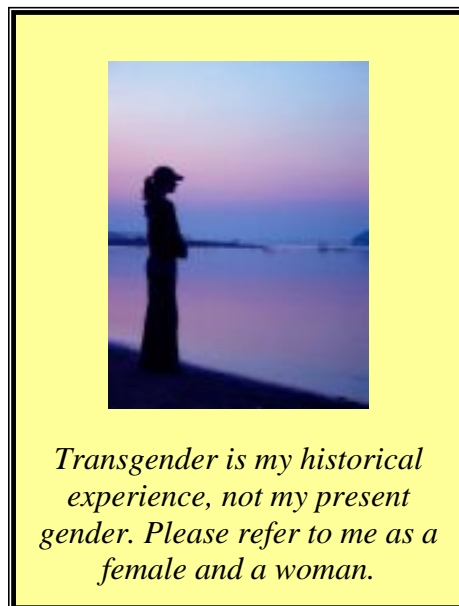
The goal of collecting HIV data is to gather information accurately in order to understand, compare, report, and apply it to enhancing and improving care and services. At present, the way in which sex and gender are asked of clients and patients (if asked at all) is incomplete and results in discrimination against people who do not fall into this assumed binary of being only and always male or female. Today we know that sex and gender is more complex than originally assumed and that many people do not fit conveniently into binary systems (Greenberg, 2006; Sausa, 2006; Wade, 2005). It goes beyond only two socially constructed categories of sex and gender (Male/Man and Female/Woman), and not every male/man is masculine or every female/woman is feminine.

It is imperative to improve and enhance our surveillance and data collection methods to better capture and understand complexities among diverse people. There are demographics and characteristics that over time have been broadened to be more inclusive and better reflect the diversity of the population in

the U.S., such as race and ethnicity. To collapse our many races and ethnicities into 2 or 4 categories would provide an extremely skewed information base (i.e., how would you identify someone who is Puerto Rican if you only had two choices: African-American or White), and what about people who identify as multi-racial or multi-ethnic?

### **The Center of Excellence for Transgender HIV Prevention**

recommends asking 2 questions instead of one to both validate a person's present gender identity and also understand their history. This method is currently being used or discussed in various aspects of CDC research, training, and evaluation projects, and has been used in prior research throughout the last decade yielding increased accuracy in sex and gender information about patients and clients (Adams et al., 2008; Brown, 2002; Kenagy, 2005; Kenagy & Bostwick, 2005; Maine HIV Prevention Community Planning Group, 2003; McGowan, 1999; Xavier, Bobbin, Singer, & Budd, 2005; and Xavier, Honnold, & Bradford, 2007). In addition, the California Department of Public Health, State Office of AIDS' HIV Prevention Research and Evaluation Section is updating its California statewide online system for tracking information about funded HIV education and prevention programs, including counseling and testing services, to include a 2-question system about gender identity. This new information system, called Local Evaluation Online (LEO), provides increased opportunity to evaluate intervention implementation, processes and procedures, and client outcomes. These activities include HIV counseling and testing, outreach, individual interventions, group interventions, HIV prevention case management, prevention education campaigns, and services for testing partners of HIV-positive persons. (California Department of Public Health, Office of AIDS, 2008; C. Krawczyk, personal communication, September 11, 2008).



#### Example of the 2 questions and answer choices:

##### **1. What is your sex or gender? (Check ALL that apply)**

- (1)  Male
- (2)  Female
- (3)  Transgender Male/Transman
- (4)  Transgender Female/Transwoman
- (5)  Genderqueer
- (6)  Additional Sex or Gender: Please specify: \_\_\_\_\_
- (7)  Unknown or Question Not Asked
- (8)  Decline to State

##### **2. What sex were you assigned at birth? (Check one)**

- (1)  Male
- (2)  Female
- (3)  Unknown or Question Not Asked
- (4)  Decline to State

### Rationale for the above example:

Asking two questions instead of just one with many choices allows for specific disclosure of a person's history and at the same time validates their present sex and gender identity. Many trans people do not currently identify as trans for a variety of reasons. Some believe it is part of their past and not a present identification, others may not identify with that word trans due to cultural beliefs, social networks, and linguistic norms in geographic locations.

### Question 1:

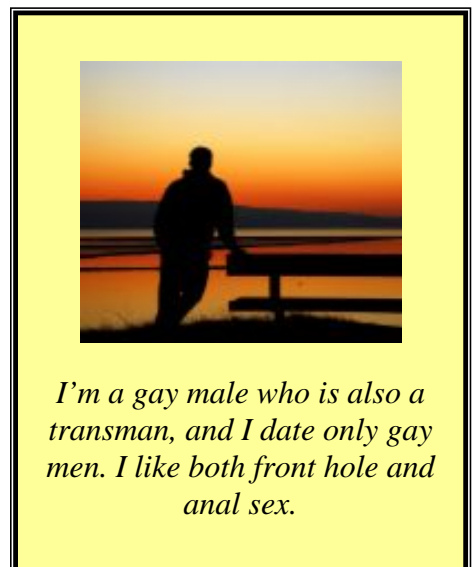
Asking people to check all in the first question allows people to check off more than one category if they view their sex or gender in a multifaceted way. For example, a person may identify as "female" and also "transgender." This may be similar to race or ethnicity in which a person can be more than one race or ethnicity.

The first question requests a person's current sex or gender. Both terms "sex or gender" are asked since there are a variety of definitions today of what is "sex" and what is "gender." In many cases people will mix up or conflate these terms and regardless of one personal definition, for data collection purposes including both versus just one is beneficial for accurate data collection.

With regards to the definition of these terms some believe that "sex" is only "male" or "female" and is strictly biological and can never be changed. Some believe one's sex can only be changed but only through hormone therapy and genital surgeries. Yet, others believe that the definition of sex goes beyond narrow medical definitions of genitalia, chromosomes, hormone levels, and reproductive abilities, which disregards the vast natural differences of biological characteristics that exist among people. They believe the term sex today encompasses also legal, policy, cultural and social issues and a person should not have to undergo surgeries to reassign the sex they were given at birth. This has major implications for document changes (such as birth certificates, passports, driver's licenses, etc.) and U.S. state and national laws (for example, the United Kingdom (2004), Spain (2006), and the state of Iowa (2006) allows trans people to change their legal sex on their birth certificate without undergoing any surgeries). (For further discussion about sex please see Devor, 2002; Sausa, 2006; Vade, 2005).

The definition of the term "gender" or "gender identity" often referring to "man" or "woman" also varies. Some believe that sex is one's biology and gender is socially and culturally constructed (thus you can change your gender but not your sex). Others recognize that one's gender identity includes one's social status, self-identification, legal status, and biology, noting that it is more complex than originally assumed and that new gender theories have moved us beyond an antiquated dichotomous explanation of gender identity to include multi-dimensional and multi-layered concepts. (For further discussion about gender please see Devor, 2002; Sausa, 2006; Vade, 2005).

It's important to provide a space for people to state their specific trans identity or identities and add the "additional category" to clarify which of the many trans identities they may be. There are many more trans identities than MTF or FTM, and some believe



that only having the categories male, female, MTF, and FTM is reductionary and simply recreates a narrow binary thinking about sex and gender. For example today “transgender men” may identify as: transguys, trannyfags, studs, men, males, genderqueers, two-spirit, gender outlaws, gender fluid, bois, FTMs, transsexual men, MSM, TMSM, gay men, etc. Depending on the needs of your data collection, it may be helpful to find out what current terminology is being used by these men to provide more effective health interventions, outreach, counseling and testing, creating educational materials and media campaigns, etc.

### Question 2:

The second question requests a person’s sex assigned at birth. Though many people are born with a Disorder of Sex Development (DSD), currently only “male” or “female” is assigned to each newborn and only one of those two categories are placed on a birth certificate in the U.S.

In 2006, a consensus for a new paradigm of care for people diagnosed with "intersex" conditions was developed by 50 international experts and patient advocates. Accompanied by a change in nomenclature referring collectively to these conditions as Disorders of Sex Development, or DSD, a new standard of care was proposed focusing on improved quality of life through a patient-centered model of care with an emphasis on an interdisciplinary team approach to health care delivery ([www.accordalliance.org](http://www.accordalliance.org)).

It is important to note that some people born with DSD may also identify as trans, though most do not. It is important to not conflate the issues of trans people and people with DSD by placing them both within the transgender umbrella. In addition, the inclusion of “Intersex” or “DSD” as a gender or sex category is not recommended for a variety of reasons including the fact that most people with DSD identify as male or female, as highlighted by Emi Koyama from the Intersex Initiative Portland [for further information about this please see Emi Koyama’s article at [www.ipdx.org/articles/letter-outsidein.html](http://www.ipdx.org/articles/letter-outsidein.html)].

### **How to Implement These Changes Effectively?**

- ***STEP 1: Update Your Data Collection Methods***

The first is to update your organization’s data collection forms and databases to include the two question system. If you need consultation or technical assistance on how to do this please contact us (see below for contact information).

- ***STEP 2: Train Your Staff***

The next step is training your staff and health professionals to ask questions about gender identity correctly and consistently. If you need assistance, we provide interactive and educational training to help your staff understand the update and learn how to effectively and accurately ask and record information about gender identity (see below for contact information).

- ***STEP 3: Educate Your Funders and Disseminate the Data***

The third step is educating your funders, health departments and government agencies to update their own systems and record the improved data you are gathering so that together you can better analyze and disseminate information to funders, stakeholders, and consumers to effectively impact the HIV epidemic by improving services and care to all people.

- ***STEP 4: Enhance Your Programs and Services***

The final step is to improve services and programs by utilizing the new information you are gathering to assess HIV incidence and prevalence, identify emerging trends, properly allocate resources, improve health care services, and any address service gaps among trans people.

**Do You Need Any Assistance (consultation and training)?**

Throughout the state of California, the **Center of Excellence for Transgender HIV Prevention** offers:

- ***Professional intermediate and advanced level trainings*** that we create, implement and evaluate tailored to your specific organizational and health provider needs. These trainings may range in length from 2 hours to 2 days and are offered in English and Spanish. Our interactive trainings provide you with cutting edge community-based transgender HIV prevention science, increase your knowledge, and build skills by engaging participants on various learning levels through media, music, activities and exercises, small group work and large group discussions. Training participants can include any medical, health or social service professional (funders, administrators, project directors and managers, clinicians, mental health providers, HIV prevention providers and test counselors, case managers, educators and researchers).
- ***Consultations or technical assistance (TA)*** to enhance programming, capacity building, and conduct effective research and interventions for health professionals serving trans people throughout California. Our consultations may be conducted in person, by phone or e-mail, and are offered in English and in Spanish.

**To request a FREE training or consultation focused on HIV prevention and transgender populations for your organization or local California providers, please contact:**

**JoAnne Keatley, MSW, Director**  
Phone: 415-597-4960  
E-mail: JoAnne.Keatley@ucsf.edu

**[www.transhealth.ucsf.edu](http://www.transhealth.ucsf.edu)**

**Reference Citation for this Document**

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](http://www.transhealth.ucsf.edu)

## References

- Adams, A., Lundie, M., Marshall, Z., Pires, R., Scanlon, K., Scheim, A. I. M., & Smith, T. (2008, June). *Getting Primed: Informing HIV Prevention with Gay/Bi/Queer Trans Men in Ontario*. A project of the: Gay/Bisexual/Queer Trans Men's Working Group; Ontario Gay Men's HIV Prevention Strategy; and AIDS Bureau, Ontario Ministry of Health and Long-Term Care. Retrieved October 8, 2008 at: <http://www.queertransmen.org/images/gettingprimed.pdf>
- Brown, N.C. (2002). *Special Concerns Populations: Transgender Needs Assessment*. Chicago: Chicago Department of Public Health Office of Gay and Lesbian Health.
- Cabral, M. (2007). Transgender people and violence against women. In P. Currah, G. G Guevara, & R. M. Juang (Eds.), *Transgender Justice*. New York, NY: The Center for Lesbian and Gay Studies.
- California Department of Health Services (2006). *California HIV counseling and testing annual report: January - December 2003*. Sacramento, CA: Office of AIDS.
- California Department of Public Health, Office of AIDS (2008, June). *HIV Prevention Research and Evaluation (PRE) Section Fact Sheet*. Retrieved October 8, 2008 at: <http://www.cdph.ca.gov/programs/AIDS/Documents/FSPRE2008-06.pdf>
- Centers for Disease Control and Prevention (2006). *HIV/AIDS Surveillance Report, 2005*. Vol. 17. Atlanta: US Department of Health and Human Services, CDC; 2006:1-46.
- Centers for Disease Control and Prevention (2008). *HIV Incidence*. Retrieved August 11, 2008 at <http://www.cdc.gov/hiv/topics/surveillance/incidence.htm>
- Clements, K., Wilkinson, W., Kitano, K., & Marx, R. (2001). HIV prevention and health service needs of the transgender community in San Francisco. In W. Bockting & S. Kirk (Eds.), *Transgender and HIV: Risks, prevention, and care* (pp. 69-89). New York, NY: Haworth Press.
- Devor, H. (2002). Who are "we"? Where sexual orientation meets gender identity. *Journal of Gay and Lesbian Psychotherapy*, 6(2), 5-21.
- Garafalo, R., Deleon, J., Osmer, E., Doll, M., & Harper, G. (2006). Overlooked, misunderstood, and at-risk: Exploring the lives and HIV risk of ethnic minority male-to-female transgender youth. *Journal of Adolescent Health*, 38, 230-236.
- Glynn, M. & Rhodes, P. (2005). Estimated HIV prevalence in the United States at the end of 2003. *National HIV Prevention Conference*; June 2005; Atlanta. Abstract 595.
- Greenberg, J. A. (2006). The roads less traveled: The problem with binary sex categories. In P. Currah, R. M. Juang, & S. P. Minter (Eds.), *Transgender rights* (pp.51-73). Minneapolis, MN: University of Minnesota Press.

- Grossman, A. H. & D'Augelli, A. R. (2006). Transgender youth: Invisible and vulnerable. *Journal of Homosexuality*, 51(1), 111-128.
- Herbst, J. H., Jacobs, E. D., Finlayson, T., McKleroy, V. S., Neumann, M. S., Crepaz, N. (2008). Transgender HIV prevalence and risk behaviors. *AIDS and Behavior*, 12(1):1-17.
- Hussey, W. (2006). Slivers of the journey: The use of photovoice and storytelling to examine female to male transsexuals' experience of health care access. *Journal of Homosexuality*, 51(1), 129-158.
- Joint United Nations Programme on HIV/AIDS (UNAIDS) (2006). *2006 Report on the global AIDS epidemic*. Geneva: United Nations. Retrieved October 8, 2008 at: [http://www.unaids.org/en/HIV\\_data/2006GlobalReport/default.asp](http://www.unaids.org/en/HIV_data/2006GlobalReport/default.asp).
- Kenagy, G. (2005). Transgender health: findings from two needs assessment studies in Philadelphia. *Health and Social Work*, 30 (1): 19-26.
- Kenagy, G. (2002). HIV among transgender people, *AIDS Care*, 14 (1), 127-134.
- Maine HIV Prevention Community Planning Group (2003) *HIV Risk Among Transgender People in Maine: A Statewide Needs Assessment of Behavioral Risk*. Retrieved October 8, 2008 at: <http://mehivcp.org/Trans%20rprt%20finl.pdf>
- McGowan, C.K. (1999). *Transgender Needs Assessment*. New York: The HIV Prevention Planning Unit of the New York City Department of Health.
- Melendez, R. M., Exner, T. A., Ehrhardt, A. A., Dodge, B., Remien, R. H., Rotheram-Borus, M., Lightfoot, M., Hong, D., and National Institute of Mental Health Healthy Living Project Team (2005). Health and health care among male-to-female transgender persons who are HIV positive. *American Journal Public Health*, 95(10), 5-7.
- Nemoto, T., Sausa, L.A, Operario, D., & Keatley, J. (2006). Need for HIV/AIDS education and intervention for MTF Transgenders: Responding to the challenge. *Journal of Homosexuality*, 51(1), 183-202.
- San Francisco Department of Public Health (2008). *The HIV/AIDS Epidemiology Annual Report 2007*. Retrieved August 11, 2008 at <http://www.sfdph.org/dph/files/reports/RptsHIVAIDS/HIVAIDAnnRpt2007.pdf>
- San Francisco Department of Public Health (2006). *The HIV/AIDS Epidemiology Annual Report 2005*. Retrieved October 8, 2008 at [http://sfhiv.org/files/data\\_reports/hiv\\_aids\\_annual\\_rpt/HIVAIDAnnRpt2005.pdf](http://sfhiv.org/files/data_reports/hiv_aids_annual_rpt/HIVAIDAnnRpt2005.pdf)
- Sausa, L. A. (2005). Translating research into practice: Trans youth recommendations for improving school systems. *Journal of Gay and Lesbian Issues in Education*, 3(1), 15-28.
- Sausa, L. A., Keatley, J. & Operario, D. (2007). Perceived risks and benefits of sex work among transgender women of color in San Francisco. *Archives of Sexual Behavior*, 36(6):768-777.



Sevelius, J. (2007). The transgender men's study: Preliminary findings. In: *US Conference on AIDS*. Palm Springs, CA.

Shaffer, N. (2005). Transgender patients: Implications for emergency department policy and practice. *Journal of Emergency Nursing*, 31, 405-7.

United States Census Bureau (2008). *Table 1: Monthly Population Estimates for the United States: April 1, 2000 to November 1, 2007*. Retrieved August 11, 2008 at <http://www.census.gov/popest/national/NA-EST2006-01.html>

Vade, D. (2005). Expanding gender and expanding the law: Toward a social and legal conceptualization of gender that is more inclusive of transgender people. *Michigan Journal of Gender and Law*, 11, 253-316.

Xavier, J., Bobbin, M., Singer, B. & Budd, E. (2005). A Needs Assessment of Transgendered People of Color Living in Washington, DC *International Journal of Transgenderism*, 8 (2/3), 31-47

Xavier, J., Honnold, J., and Bradford, J. (2007) *The Health, Health-related Needs, and Lifecourse Experiences of Transgender Virginians*. Virginia HIV Community Planning Committee and Virginia Department of Health. Retrieved October 8, 2008 at: [http://www.vdh.virginia.gov/epidemiology/DiseasePrevention/documents/pdf/THISFINALREPORT\\_Vol1.pdf](http://www.vdh.virginia.gov/epidemiology/DiseasePrevention/documents/pdf/THISFINALREPORT_Vol1.pdf)

Supporters of  
“Recommendations for Inclusive Data Collection of Trans People in HIV Prevention, Care & Services”



National Center for Transgender Equality (NCTE)

**until it's over**  
**AIDS ACTION**

AIDS ACTION



HIV Prevention Information, Research, Services,  
and Resources for the City of San Francisco



San Francisco Department of Public Health, AIDS Office - HIV Prevention Section's  
Transgender Advisory Group (TAG)



Transgender Law Center