

An Open Letter on Sex & Gender

Washington Community Advisory Boards Consensus Statement on Sex and Gender Data Collection in HIV/AIDS Research

To: Community Partners (formerly the Cross-Cab Working Group)

As CAB members, we are keenly aware of our responsibility to represent the concerns of all communities affected by HIV/AIDS. As Washington DC residents, we are acutely aware of the impact of the HIV/AIDS epidemic in the transgender community. In one local survey funded by the District of Columbia, 25% of all transgender participants self reported as HIV positive, while another 22% did not know their status.

At present our DAIDS research networks are extremely inconsistent in how data is collected regarding sex and gender. While some networks collect information about both sex and gender; others collect information only about sex or only about gender. Further, there is a lack of consistency across networks in the use of the words sex and gender.

This makes it difficult to compare data across networks and make observations on differences based on either sex or gender. It also makes it virtually impossible to know how many transgender trial participants are currently in DAIDS trials, and what unique medical challenges they face. Finally, the lack of understanding of this issue continues to be a significant barrier to trial participation for the transgender community.

We recognize the efforts of the Community Partners and all efforts currently underway to more closely coordinate activities across research networks. As local CAB members in the Washington DC area, we also hope to work more closely together. In this spirit, the HIV/AIDS Community Advisory Boards of the Washington DC Area would like to submit the following joint recommendations on data collection of sex and gender information in DAIDS studies.

Therefore, we would like to recommend:

1. **That the DAIDS Research Networks adopt the current definitions of sex and gender as agreed to at the Forum for Collaborative HIV/AIDS Research Summit on Sex and Gender Issues in HIV (November, 2002).** This meeting was sponsored by both the NIH Office of AIDS Research and the Centers for Disease Control and Prevention. The outcome document clearly defines both terms which is consistent with current usage.
2. **That the DAIDS Research Networks adopt a uniform manner of collecting data about *both* biological (birth) sex and gender identity in every research study,** so that differences based on sex and gender can be more clearly observed in DAIDS studies; and so that we can better understand how HIV affects transgender individuals.
3. **That DAIDS Research Network staff receive training on appropriate care for transgender trial participants.**

We ask for your assistance in bringing this matter to the attention of the leaders of DAIDS research networks and look forward to the opportunity to discuss this matter with you further.

Otherwise, we fear these individuals may continue to be overlooked or misidentified in research studies.

A fact sheet is attached.

Sincerely,

Joseph Hall, on behalf of the Washington VA Medical Center CAB (INSIGHT)
Wayne Dicks, on behalf of Georgetown University Medical Center CAB (ACTG)
Colin Gillespie, on behalf of the Capital Area Vaccine Effort (VRC)
Zenovia Wright, on behalf of the Capital Area Vaccine Effort (VRC)
Kofi Akomeah, on behalf of the Capital Area Vaccine Effort (VRC)
Rev. Daniel Hall, on behalf of the Howard University Hospital CAB (IMPAACT)
David Mariner, on behalf of the Howard University Hospital CAB (IMPAACT)

Additional Supporters Include:

Annette Scot, on behalf of Arms of Grace Humanitarian Services
Julie Davids, on behalf of Community HIV/AIDS Mobilization Project (CHAMP)

Mary Ann Horton, Columbus Ohio
Jeffrey Johnston, Washington DC
James Elliott, Seattle Washington
Bryan Cole Smith, Wenonah, NJ

The Transgender Community & HIV/AIDS Research

Written by David Mariner, special thanks to Jessica Xavier and Jordan Blaza

Getting Started: Terms to Know

Many of us have not had to spend a lot of time thinking about our own sex and gender; we were either: born female, raised as a girl, and think of ourselves as a woman; or born male, raised as a boy, and think of ourselves as a man. This is not the case for everyone. In order to talk about transgender issues it's important to understand the differences between birth sex, gender identity, and gender roles.

- Birth Sex refers to the biological characteristics of a person at birth.
- Gender Identity refers to an individual's own sense of themselves as being male or female
- Gender Role refers to the expressions, behaviors and mannerisms that we use to be viewed as masculine or feminine by a particular culture. Understanding 'Transgender'

Transgender is a broad term that includes a variety of people who all have one thing in common; their gender identity, expression, or behavior is not traditionally associated with their birth sex.¹ This term includes those born male who identify as female (male-to-female) and those born female who identify as male (female to male). Transgender includes cross-dressers, individuals who like to wear the clothes of another gender, but while they enjoy exploring this gender role, it is not their gender identity. Transgender also includes those who do not strongly identify with either the male or female gender.

Some transgender individuals are transsexuals; meaning their gender identity is opposite their birth sex, and they live their lives consistent with their gender identity. Transsexual individuals may choose to change their bodies to make them more consistent with their gender identity. This could include taking hormones, or having surgery.

Intersex

You may also hear the term Intersex, which is different from Transgender. An intersex individual is born with an anatomy, or birth sex, that cannot be easily categorized as male or female.

HIV/AIDS in the Transgender Community

There is no national data on the prevalence of HIV in the transgender community, due to a lack of data collection by the Centers for Disease Control and Prevention (CDC) and other federal agencies. Smaller regional studies, however, indicate that the transgender community has been one of the communities hit hardest by this epidemic.

¹ Lawrence, A. A., Shaffer, J. D., Snow, W. R., Chase, C., & Headlam, B. T. (1996). Health care needs of transgendered patients [Letter to the editor]. *JAMA*, 276, 874.

Data from needs assessment and risk behavioral studies have found HIV prevalence in transgender and transsexual women as ranging from

- 14% in San Juan ²
- 19% in Philadelphia ³
- 20% in Chicago ⁴
- 22% in Los Angeles ⁵
- 21-30% in New York ⁶
- 26% in Boston, MA ⁷
- 27% in Houston, TX ⁸

In a Washington DC Survey of the transgender community, 25% of all participants self-reported as HIV positive, including 32% of the male-to-females and 3% of the female-to-males, with another 22% not knowing their HIV status.⁹

Transgender women sex workers are at particularly high risk, since they are often financially induced to engage in barrier-free sex.¹⁰

Barriers for the Transgender Community

Transgender individuals often face stigma and discrimination, which increases their HIV risk while at the same time makes it more difficult for them to access HIV prevention and treatment services. Few transgender sensitive prevention and treatment programs exist.⁴

Many socioeconomic factors in the transgender community negatively impact access to health care, including HIV prevention and treatment services. These factors include a higher unemployment rate, and lack of health insurance.³

² Rodríguez-Madera, S. & Toro-Alfonso, J. (2005). Gender as an Obstacle in HIV/AIDS Prevention: Considerations for the Development of HIV/AIDS Prevention Efforts for Male-to-Female Transgenders. *International Journal of Transgenderism*, 8 (2/3), 113-122

³ Kenagy G. (2002). HIV among transgender people, *AIDS Care*, Vol. 14, No.1, 127-134.

⁴ Kenagy, G., & Bostwick, W. (2005). Health and social service needs of transgendered people in Chicago. *International Journal of Transgenderism*, 8 (2/3), 57-66.

⁵ Simon, P., Reback, C., & Bemis, C. (2000). HIV prevalence and incidence among male-to-female transsexuals receiving HIV prevention services in Los Angeles County. *AIDS*, 14 (18), 2953-2955

⁶ McGowan CK. (1999). Transgender Needs Assessment. The HIV Prevention Planning Unit of The New York City Department of Health, New York, NY.

⁷ Cambridge Cares About AIDS (2006) Transgender Care and Education Needs Diversity (TransCEND) Community Needs Assessment Report (Draft) (2006)

⁸ Risser, J., Shelton, A., McCurdy, S., Atkinson, J., Padgett, P., Useche, B., Thomas, B., & Williams, M. (2005). Sex, Drugs, Violence, and HIV Status Among Male-to-Female Transgender Persons in Houston, Texas. *International Journal of Transgenderism*, 8 (2/3), 67-74.

⁹ 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.

¹⁰ Boles J, and Elifson K. (1994). The social organization of transvestite prostitution and AIDS. *Social Science and Medicine*, 39: 85-93.

Hormone Therapy

Some transgender individuals take hormones like estrogen or testosterone. More research on how HIV/AIDS treatments may interact with hormone therapy is needed. The enrollment of transgender people in clinical trials affords an opportunity to collect this important information regarding their care. While some clinical trials may exclude participants who are taking hormones, many need not unless it is medically necessary. Trials that exclude transgender people who take hormones must clearly explain the medical reasons in the exclusion criteria section of their protocols.

Most HIV/AIDS Research Fails to Accurately Collect Data on Sex and Gender

There is a clear understanding in the HIV/AIDS research community that birth sex and gender identity are two clearly separate concepts.⁵ Still, the majority of HIV/AIDS research fails to accurately collect information on sex and gender. Sadly, most studies still have one box for 'male' and one box for 'female'. DAIDS Research Networks Fail to Accurately Collect Data on Sex and Gender

Among the AIDS research networks supported through the NIH NIAID Division of AIDS, or DAIDS, data collection on sex and gender is sorely lacking. There is inconsistent use of terminology such as the words 'sex' and 'gender' across the research networks. There are inconsistent methods for collecting information on gender and sex across AIDS research networks. In many cases, no information about gender identity is collected.

With incomplete data collection forms, and a general lack of understanding of transgender issues in society at large, it is not uncommon for a transsexual woman to be labeled as 'male' in order to participate in a study, or for a transsexual man to be labeled as a 'woman' in order to participate. Even if it is just a check-mark on a form, not respecting someone's gender identity in this manner is inappropriate, insensitive, and a significant barrier to their trial participation.

Making a Difference

As a concerned community member involved in HIV/AIDS research, you have a tremendous opportunity to be an ally to the Transgender Community. Here are some things you can do:

- Make sure information about birth sex and gender identity is included in each and every research study you review.
- Encourage the research networks you work with to develop consistent guidelines for collecting information about birth sex and gender identity. Ask them to incorporate this into their template documents, so that future studies are consistent with these guidelines.
- Reach out to transgender organizations in your community and encourage their participation in research advocacy.
- Make sure researchers you work with, and your local research site, are sensitive to the needs of transgender trial participants. A training kit "Living Out Loud: How to Serve Transgender Clients Where They Are" is available from Diversity Works (www.dwmm.org, 410 235-1600)

For more information on the Transgender Community

Gender Education & Advocacy

www.gender.org

Gender Education and Advocacy (GEA) is a national organization focused on the needs, issues and concerns of gender variant people in human society.

National Center for Transgender Equality

www.nctequality.org

The National Center for Transgender Equality (NCTE) is a social justice organization dedicated to advancing the equality of transgender people through advocacy, collaboration and empowerment.

National Coalition for LGBT Health

www.lgbthealth.net

The National Coalition for LGBT Health is committed to improving the health and well-being of lesbian, gay, bisexual and transgender individuals and communities through public education, coalition building and advocacy that focuses on research, policy, education and training.

For information on Intersexuality

Intersex Society of North America

www.isna.org

The Intersex Society of North America (ISNA) is devoted to systemic change to end shame, secrecy, and unwanted genital surgeries for people born with an anatomy that someone decided is not standard for male or female.