

Increasing the Involvement of Transgender People in HIV/AIDS Research

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U.S. Transgender Population Estimates

National (NCTE estimate, *Newsweek*, May 2007)
as many as 3 million

San Francisco (SF Department of Public Health, 1994)
2.2% of total population (about 22,000)

Washington, DC (WTNAS, Xavier et al, 2005)
0.7% of total population (about 4,000)

Houston/Harris County (Risser et al, 2005)
as much as 0.5% of total population
(about 16,000)

U.S. Transgender HIV Prevalence Rates

(1992 to 2006, all MTF unless noted)

Virginia: 16%

Minneapolis - St. Paul: 4% San Juan: 14%

Philadelphia: 4% to 19% Chicago: 14% to 19%

Los Angeles: 22% New York City: 22%

Boston: 26% Houston: 27%

Washington: 32% MTF, 3% FTM

San Francisco: 26% to 35% MTF, 2% FTM

Atlanta (sex worker): 68%

What About Treatment? HRSA CADR Analysis

HIV+ & HIV-Affected Clients Served in 2002

Total HIV+ & HIV-affected clients served (all genders*)	Total HIV+ & HIV-affected transgender clients served**	Percent of total HIV-affected transgender clients served**
1,044,172	7,866	0.75%

3,431 (43%) of the total number of transgender clients were served in District of Columbia alone

* all genders = male, female, transgender (no gender vector breakdown)

** numbers not unduplicated (includes multiple visits by same clients)

Lack of Treatment for HIV+ Transgender Women

A study conducted by the National Institute of Mental Health's Healthy Living Project Team found that a sample of 59 male-to-female transgender persons were less likely to take highly active antiretroviral therapy (HAART) compared with a control group of 3755 non-transgender people (59% vs. 82%, $p < .001$).

Control group composition: MSMs (49%) heterosexual women (23%) male IDUs (13%) and heterosexual men (15%). Both groups numerically matched from four cities (San Francisco, Los Angeles, New York and Milwaukee).

- Melendez, R., Exner, T., Ehrhardt, A., Dodge, B., Remien, R., Rotheram-Borus, MJ., Lightfoot, M., Hong, D. (2005). Health and Health Care Among Male-to-Female Transgender Persons Who Are HIV Positive. *American Journal of Public Health*, 95 (10), 5-7.

The Invisible Participants

Transgender People have already participated and are currently participating in DAIDS-sponsored HIV Clinical Research Trials

However, many are not known or recognized by their investigators as transgender

Transgender women are counted as Males, Men who have Sex with Men (MSMs) or women (if post-operative and disclosing)

Transgender men / FTMs are mostly invisible

The Case for Separate Data Collection

High HIV prevalence among transwomen
and HIV among transmen/FTMs

The Critical Importance of Evidence-based
Medicine

Unpublished clinical evidence of hormone
medications (both estrogen and testosterone)

and HIV medication interactions

(Dr. Lori Kohler at UCSF-CAPS –

<http://hivinsite.ucsf.edu/InSite.jsp?doc=2098.4746>)

The Case for Separate Data Collection

Differences between Transgender Women & MSMs

Self-identification by gender identity,
not sex assigned at birth
or current anatomical status

Different health care priorities
(access to transgender care)

Transgender physiology (hormonal therapy)

Greater avoidance of medical providers due to
fears of identity disclosure
and provider hostility/insensitivity

“Sex and Gender Issues in HIV Disease”

(A Report by the Forum for Collaborative HIV Research, November 4 & 5, 2002,
<http://www.hivforum.org/publications/S&G%20Final.pdf>)

“Sex and gender are two concepts that are closely related, yet distinct. While sex is a reflection of reproductive function assigned by the chromosome complement, gender is a person’s self-representation as male or female, how that person is responded to by social institutions on the basis of the individual’s gender presentation or the array of societal beliefs, norms, customs and practices that define “masculine” and “feminine” attributes and behavior. Although usually referred in binary terms, both of these concepts in actuality represent a continuum.”

National Cancer Institute Biometrics Informatics Grid (caBIG) Data Standards, “Representation of Sex and Gender”

July 25, 2005 (accepted September 6, 2005)

(https://cabig.nci.nih.gov/workspaces/VCDE/Data_Standards/)

Definitions of Key Terms:

Sex - the assemblage of physical properties or qualities by which male is distinguished from female; the physical difference between male and female. [NCI Thesaurus - Source: On-line Medical Dictionary]

Gender - the assemblage of properties that distinguish people on the basis of their societal roles [NCI Thesaurus].

Phenotype - the outward appearance of the individual. It is the product of interactions between genes and between the genotype and the environment. [NCI MetaThesaurus]

Genotype - the genetic constitution of the individual; the characterization of the genes. [NCI MetaThesaurus].

Intersex - person (one of unisexual specimens) who is born with genitalia and/or secondary sexual characteristics of indeterminate sex, or which combine features of both sexes.

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Table 1 Data Elements for Specification of Sex and Gender

"Self Reported Person Sex Text Type & Person Sex Phenotype Text Type"

Male-to-Female Transsexual – A person who was assigned to the male gender at birth based on physical characteristics but who identifies psychologically and emotionally as female.

Female-to-Male Transsexual – A person who was assigned to the female gender at birth based on physical characteristics but who identifies psychologically and emotionally as male.

NCI caBIG Data Standards References

- **Cancer Therapy Evaluation Program (CTEP)**
Adverse Event Expedited Reporting System (ADEERS)
<http://ctep.info.nih.gov/reporting/adeers.html>
- **CDC Proposed Health Data Standards**, Common Data Elements Implementation Guide
<http://www.cdc.gov/data/>
- **Clinical Data Interchange Standards Consortium (CDISC)**
Version 1.2 (ODM-1.2.5, Dec 19, 2003)
<http://www.cdisc.org/models/odm/v1.2/ODM1-2-0.htm#MetaDataVersion>
- **Clinical Data Update System (CDUS)**, Version 3.0, Release 2, June 10, 2003
http://ctep.cancer.gov/forms/CDUS_IG_3r2.pdf
- **Health Level Seven** Version 3, Ballot Document 8, August 2004
<http://www.hl7.org/v3ballot/html/foundationdocuments/welcome/index.htm>
- **ISO/IEC 5218:2004 Information Exchange** – Codes for Representation of Human Sexes
<http://www.iso.org/iso/en/CatalogueDetailPage.CatalogueDetail?CSNUMBER=36266&ICS1=35&ICS2=40&ICS3=>
- **The North American Association of Central Cancer Registries (NAACCR)**
http://www.naacr.org/filesystem/pdf/2004NAACCR_Volume_II_10.2_PDF_File.pdf

Recommendation: The Two-Step Method

(Singer, T.B., Cochran, M., & Adamec R. (1997). *Final Report by the Transgender Health Action Coalition (THAC) to the Philadelphia Foundation Legacy Fund* (for the Needs Assessment Survey Project). Philadelphia: Transgender Health Action Coalition)

- First Used in the Delaware Valley Transgender Survey (1996)
- Also used in the Washington DC Transgender Needs Assessment Survey (WTNAS, 1999-2000) and the Virginia Transgender Health Initiative Survey (THIS, 2005-2006)
- CDC Program Evaluation Monitoring System (in process ?)
- CDC HIV Core Surveillance System (? ? ?)

Recommendation: The Two-Step Method

(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,

<http://www.vdh.virginia.gov/epidemiology/DiseasePrevention/documents/pdf/THISFINALREPORTVol1.pdf>)

1. Physical Sex Assigned at Birth (male, female)
2. Gender Identity (man, woman, transgender, androgynous, questioning, gender queer, other)

1 + 2 = Gender Vector

MTF - male to female,

FTM - female to male,

MTnM - male to not male,

FTnM - female to not female

Recruitment Challenges

Different health care priorities
(access to transgender care)

Distance from / avoidance of
medical providers
due to fears of identity disclosure
and provider hostility/insensitivity
discrimination in employment, housing,
education & public accommodations,
survival sex work, substance abuse

Recruitment Strategies

A Holistic Approach:

Incorporate transgender hormonal therapy
in clinical trials setting

Meet the need for technical competency training
in trans hormonal therapy for investigators

Meet the need for cultural competency training
for investigators and clinical trials staff

Hire transgender people to recruit within local
communities

The Hormone Bridge

A retrospective cohort study of HIV+ transgender women seen in a New York City clinic found that combining hormone therapy with HIV care:

**Stopped their self-medication of hormones
Stopped their sharing of needles to inject hormones
Increased their adherence with their HIV meds
Increased their condom use
Decreased their reliance on sex work to pay for hormones**

- Grimaldi J. & Jacobs J. (1998) The HIV hormone bridge: connecting impoverished HIV+ transsexual sex workers to HIV medical care. *AIDSLine*, ICA12/98406957. <http://www.aegis.com/aidsline/1998/dec/m98c1575.html>

A Matter of Social Justice

The traditional focus on health disparities has been in racial and ethnic minorities:

“Widespread access to clinical trials and racial and ethnic proportionality is less a matter of scientific necessity than of social justice.”

- Brawley, O.W. (2004) The Study of Accrual to Clinical Trials: Can We Learn from Studying Who Enters Our Studies? *Journal of Clinical Oncology*, 22 (11), June 2004, 2039-2040.

A Matter of Social Justice

However, the HIV/ AIDS epidemic
has revealed significant health disparities
among gay, lesbian, bisexual and
transgender people

Yet sexual orientation is not routinely
measured in national health statistics,
even with regard to HIV/ AIDS

-Healthy People 2010, U.S. Department of Health and Human Services

A Matter of Social Justice

Health Disparities persist...
due in no small part
to the failure
to measure them,
and act accordingly

A Matter of Social Justice

"Of all the forms of inequality,
injustice in health is the most
shocking and the most inhuman."

- Dr. Martin Luther King, Jr.