Transgender Treatment in High Risk Adolescents

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HEAT
HEALTH & EDUCATION ALTERNATIVES FOR TEENS

- HEAT, founded in 1992, is a program of SUNY Downstate Medical Center and is the only program of its kind in Brooklyn to offer age/developmentally appropriate, and culturally competent comprehensive care for HIV+ and at-risk youth, aged 13-24.
- HEAT utilizes a “one-stop shopping” model, where HIV care is provided by an interdisciplinary team.
- HEAT has focused HIV related clinical programming for perinatally infected youth, young women of color, young MSMs and transgender youth.
- HEAT also serves high risk youth from the above populations categories who are HIV negative, providing HIV C/T, STD screening and treatment, PrEP/PEP services, hormonal therapy (transgender), mental health counseling and an array of prevention services.

Basic Terms and Definitions:

Transsexual

Transvestite

Transgender

Gender Queer

Gender Variant/Gender Non-Conforming

Gender Identity Disorder of Childhood, Adolescence or Adulthood, Not Otherwise Specified (DSM-IV)

Gender Dysphoria (DSM-V)

Intersex/Hermaphrodite

Sources: World Professional Association for Transgender Health (www.wpath.org)

DSM III and DSM IV

Are Gender Identity Disorders Mental Disorders?

- To qualify as a mental disorder, a behavioral pattern must result in a significant adaptive disadvantage to the person or cause personal mental suffering.

- The designation of “gender identity disorder” as psychiatric diagnosis in the DSM-IV was ***highly controversial*** in that it defined a person’s gender identity as an illness and suggests that suggests that pathology is present when that is usually not the case.

- The DSM-V (2013) eliminated the diagnosis of gender identity disorder and replaced it with “gender dysphoria” defined as “a marked incongruence between one’s experienced/expressed gender and assigned gender.”

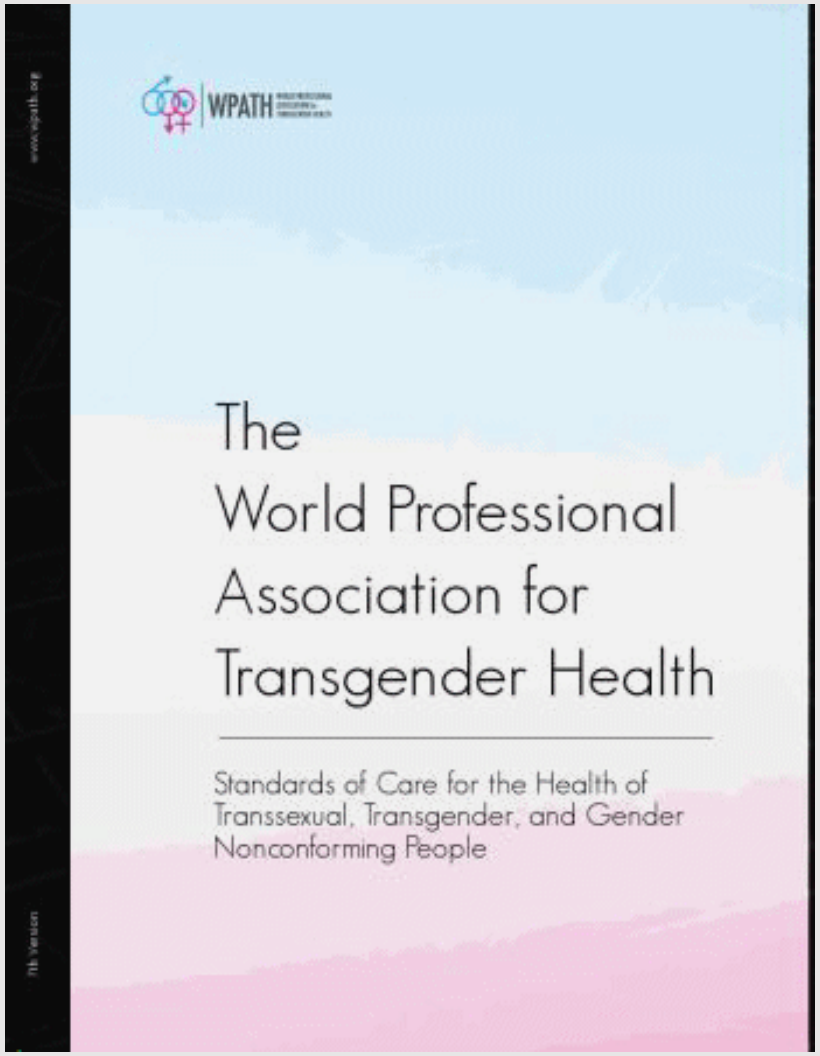
Background of HEAT Transgender Program

- Program roots in HIV care going back to 1992 serving HIV+ and high risk youth, ages 13-24 years
- Began serving HIV+ transgender youth in early 2000's, quickly followed by HIV- youth
- Expanded transgender program in 2008 through LGBT service grant from New York State Department of Health
- General approach of a multidisciplinary team including medical providers, social workers/case managers, psychologist and psychiatrist; weekly interdisciplinary care coordination meetings
- Cultural competency training!!!!

Background of HEAT Transgender Program

- Protocol adapted from the WPATH guidelines and influenced by other program models we examined
- Linkages developed with other community based organizations serving transgender youth
- Program approach to care is heavily influenced by the prevalence of high risk issues of the youth referred by the CBOs: homelessness, sex work, untreated mental illness, incarceration history, street hormone and silicone use, HIV
- HEAT utilizes a “syndemic theory” approach to its care model

Framework for a Transgender Treatment Program
WPATH Guidelines: www.wpath.org



Basic Elements of Comprehensive Transgender Care for Youth

- Transgender assessment- self identification by name and gender; history of gender expression; hormone history; access of past medical or mental health services; family issues; explanation of treatment protocol
- Case management- insurance, gender identity on documents, housing, education, employment, etc.
- Mental health screening-intake; establish ongoing counseling; screening for general mental health diagnoses and need for possible psychiatric referral, assessing impact of psych morbidity on gender transitioning; establishing rapport for ongoing supportive counseling or psychotherapy during transitioning

Basic Elements of Comprehensive Transgender Care for Youth

- General Adolescent Health History (eg. HEADSS assessment) including HIV counseling and testing
- Medical Screening- establishing rapport with medical provider, treatment education, harm reduction counseling; blood tests for hormone levels, liver function tests, STD screening, physical exam, hormonal treatment

Case Management Concerns for Transgender Youth

- Health Insurance Coverage!!!!!!
- Homelessness/Housing
- Education
- Employment/job training
- Advocacy-gender on identification cards/other legal documents/health insurance cards; legal name change process
- Support Groups
- ACS-Non-Medicaid Reimburseable Policy

Gender marker on Medicaid card is the biggest obstacle for initiating hormonal therapy

Basic Goals of Mental Health Protocol in Treating Transgender Youth

- Assessing **eligibility** and **readiness** for initiating hormonal treatment (HEAT Protocol is 3 social worker visits and 1 psychologist visit prior to medical visit for initiating hormones)
- Evaluating for psychiatric co-morbidity that may interfere with diagnostic evaluation or treatment
- Psychiatric referral if needed
- Assessing for psychological and social support during treatment
- Demonstrating knowledge and understanding of expected outcomes during treatment (ongoing, and with medical providers)

Potential Benefits for Transgender Youth in Following a Medical Protocol

- Having a doctor, psychiatrist, therapist, etc. who knows your specific issues and with whom you can develop a rapport
- **Informed** consent
- Mental health follow up is essential in monitoring for mood changes and other effects related to hormonal therapy
- Routine health care
- STD screening: Gonorrhea, chlamydia, herpes, HPV, hepatitis A, B and C, HIV

Risks of Hormonal Therapy NOT Under a Doctor's Care

- Young person may not be transsexual and may only be experimenting with gender identity issues
- Risk behaviors involved in being able to buy hormones; often very expensive $$$
- Not sure of quality or exact content of illicitly procured hormones; just because a doctor is willing to write a prescription doesn't mean he or she cares knows about transgender health
- Examples of street hormones often purchased illicitly: "German hormone", "pure hormone", "silicon"

Risks of Hormonal Therapy NOT Under a Doctor's Care

- Needle sharing/"hormone parties"/"pumping parties"- Hep B, Hep C and HIV
- Bacterial infection from non-sterile technique/supplies
- Liver damage; blood clotting problems, deep vein thrombosis
- Interactions with other medications such as HIV and psychiatric medications may have serious side effects
- Untreated mental illness

Potential Benefits for Transgender Youth in Following a Medical Protocol

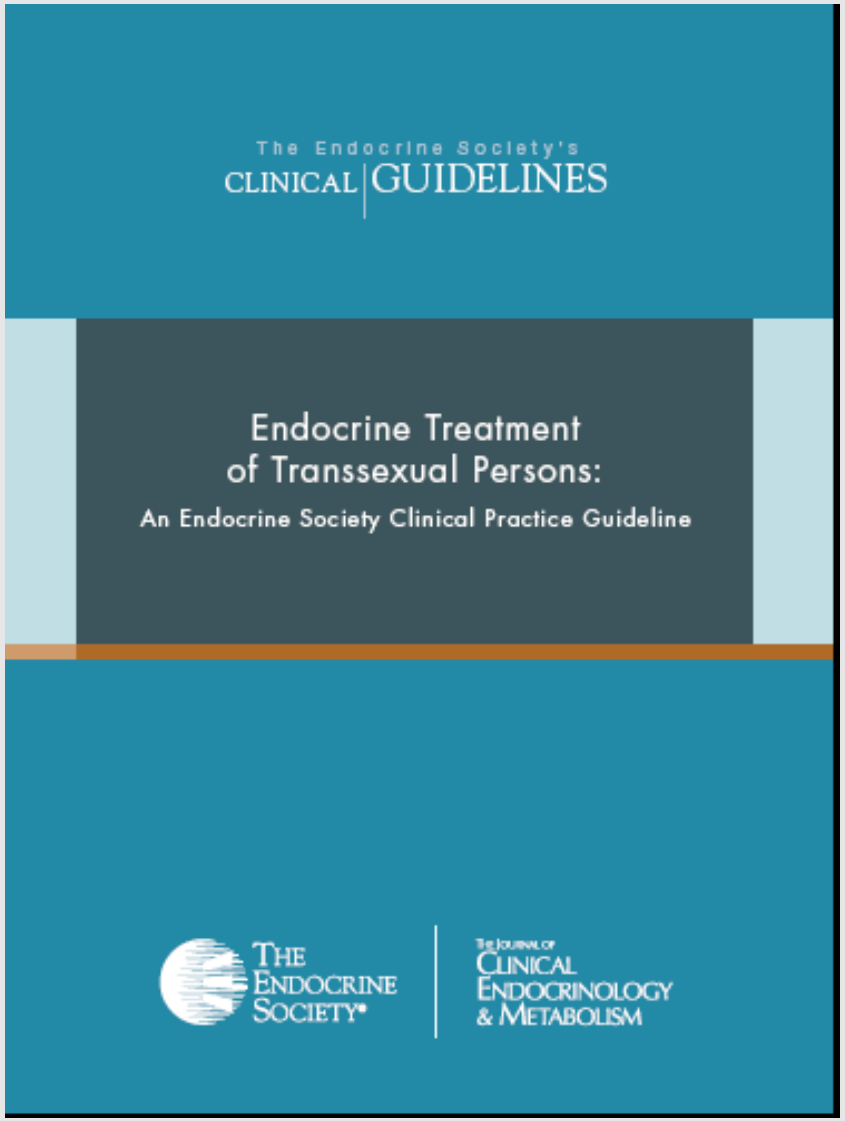
- Medical providers can access hormonal treatment via nominal fees or paid by Medicaid
- Can also jointly treat HIV and/or Hepatitis B/C if present; treatment of these diseases may have multiple drug interactions with hormones and are best done under a physician's supervision
- Access to case management services: housing, education, health insurance
- Referral for legal services: changing legal identity, other legal problems
- Prevention/PrEP AND Harm Reduction Counseling

What about providing treatment to minors?

Age of consent for minors can be a tricky issue for medical providers if they are living at home. In general, parental consent is required for minors to access medical treatment.

Under current New York State laws, a minor cannot consent for their own transgender medical treatment but may be able to engage in transgender mental health or case management services .

A minor's ability to consent for their own medical treatment must be considered on an individual basis and medical facility risk management concerns must be taken into consideration. In many cases, more harm than good would come from seeking parental consent. Allowing a minor to consent for their own hormonal treatment should be backed up with a strong justification written into the minor's medical chart and in consultation with the health care facility's risk management department.



First published in the *Journal of Clinical Endocrinology & Metabolism*, September 2009, 94(9): 3132–3154

http://www.endo-society.org/guidelines/final/upload/Endocrine-Treatment-of-Transsexual-Persons.pdf

Treatment Education
Basic Goals of Hormonal Therapy

Male-to-Female:

- Reducing masculinizing effects of endogenous testosterone as early as possible-requires anti-androgens or “testosterone blockers”
- Maximum feminization in the shortest period of time

Female-to-Male:

- Reducing feminizing effects of endogenous estrogen as early as possible
- Maximum masculinization in the shortest period of time

Feminizing Effects of Estrogens

- Breast growth
- Redistribution of body fat to a female pattern
- Decreased upper body strength
- Softening of skin
- Decrease in body and facial hair
- Slowing or stopping the loss of scalp hair
- Decreased fertility and testicular size
- Less frequent, less firm erections
- Most of these changes are reversible, although breast enlargement will not completely reverse after discontinuation of treatment.

Masculinizing Effects of Testosterone

- Skin oiliness; acne
- Facial/body hair growth
- Scalp hair loss
- Increased muscle mass and strength
- Fat redistribution
- Cessation of menses
- Clitoral enlargement
- Vaginal atrophy
- Deepening of voice

HEAT Program Findings

Retrospective chart review of baseline intake data on 57 transgender adolescents/young adults entering care 2007-2011

MTF 93%, FTM 7%

Afr-American/Caribbean 82%; Latino/a 11%; API 3.5%; Biracial/multi-ethnic 3.5%

21% were HIV+

66.7% report history of unprotected receptive anal sex

55% reported consistent condom use

HEAT Program Findings

Risk Factors	N	Percentage
Family Hx Mental Illness	17	38.6
Incarceration	16	34.8
Mental Illness	29	60.4
Physical Abuse	10	20.8
Sexual Abuse	8	16.7
Suicidality	13	27.1
Unstable Housing	31	60.8

HEAT Program Findings

While 27% reported a history of suicidality, a higher % reported a hx of psychiatric diagnosis but not all could be substantiated with a specific diagnosis but did have hx of being on psychotropic medications

42% had hx of “street hormone” use

18% had hx of silicone use

HEAT Program Findings

Findings limited by “snapshot” view at intake; more longitudinal data collection and analysis needed

Comparison between HIV+ and HIV- cohorts would be informative

Further research on outcome measures needed: retention in program; retention and duration on hormonal treatment; retention in psychiatric care; retention in HIV care; other areas yet to be defined

Transgender Youth and HIV: A Delicate Balance between Providing Cross Gender Hormonal Treatment and HIV Care

Medical providers need to be well versed in:

- Issues related to consent for care for hormonal treatment
- Mental health aspects of transgender care
- Specific hormonal regimens (Endocrine Society, Tom Waddell Clinic)
- Prevention counseling specific to this population (needle sharing, silicone use, non-prescribed hormone use)
- Case management issues: gender identity on Medicaid card, legal name changing, housing, education, employment
- Sexual health screening: genital exams, STD screening, Pap smears, etc

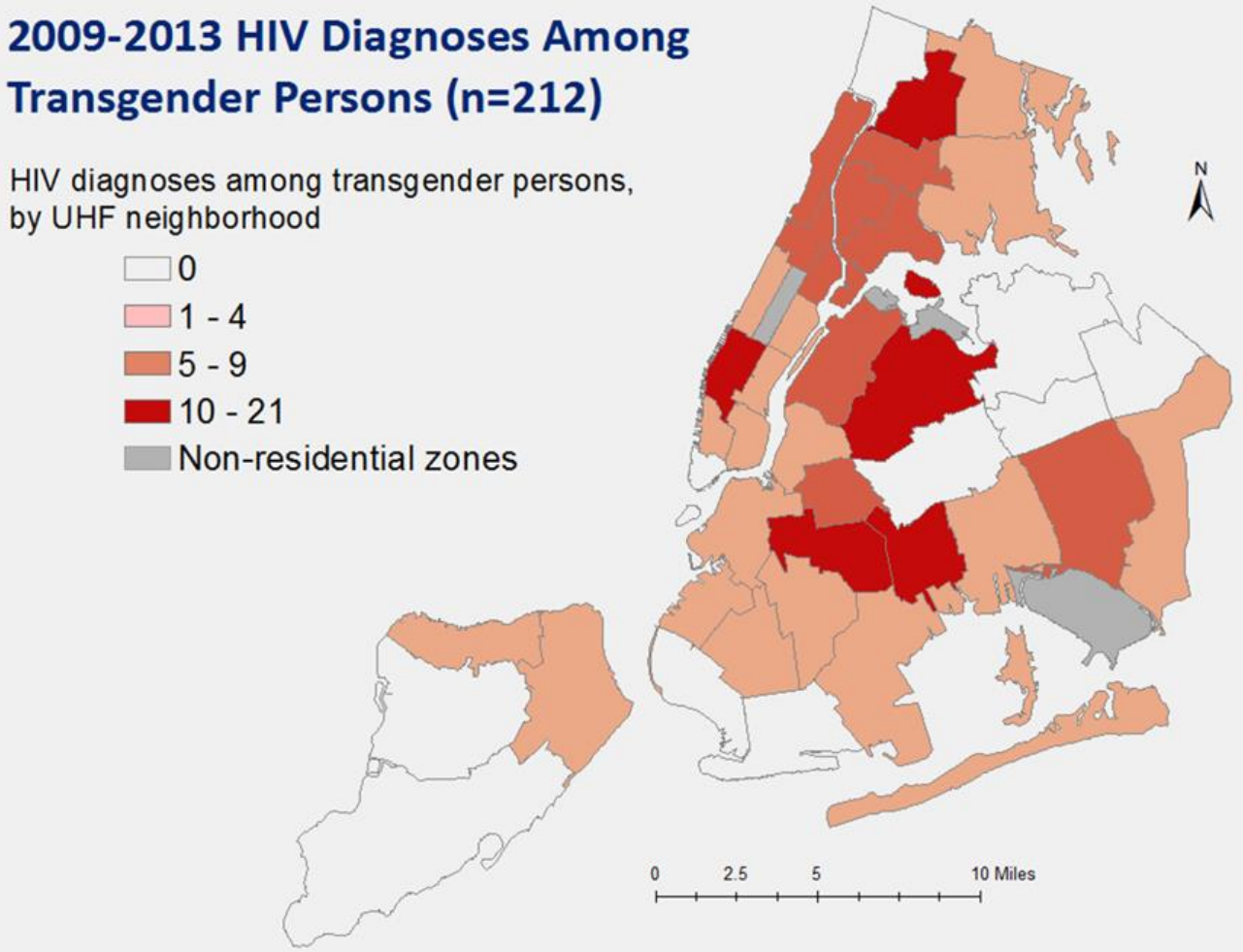
INFINI-T:

PSYCHOSOCIAL INTERVENTIONS TO RETAIN YOUNG TRANSGENDER WOMEN OF COLOR IN HIV CARE

INFINI-T: PSYCHOSOCIAL INTERVENTIONS TO RETAIN YOUNG TRANSGENDER WOMEN OF COLOR IN HIV CARE

- HEAT is the only program of its kind in Brooklyn, NY to offer age/developmentally appropriate, and culturally competent comprehensive care for HIV+ and at-risk youth, aged 13-24; utilizes a “one-stop shopping” model, where HIV care is provided by an interdisciplinary team.
- On INFINI-T, by building up its capacity for TG youth programming, HMI ensures a steady referral base and point of entry for TYWOC.

2009-2013 HIV Diagnoses Among Transgender Persons (n=212)



The highest numbers of newly diagnosed transgender persons lived in West Queens*, Chelsea–Clinton, Bedford Stuyvesant–Crown Heights, Fordham–Bronx Park, and Chelsea–Clinton.

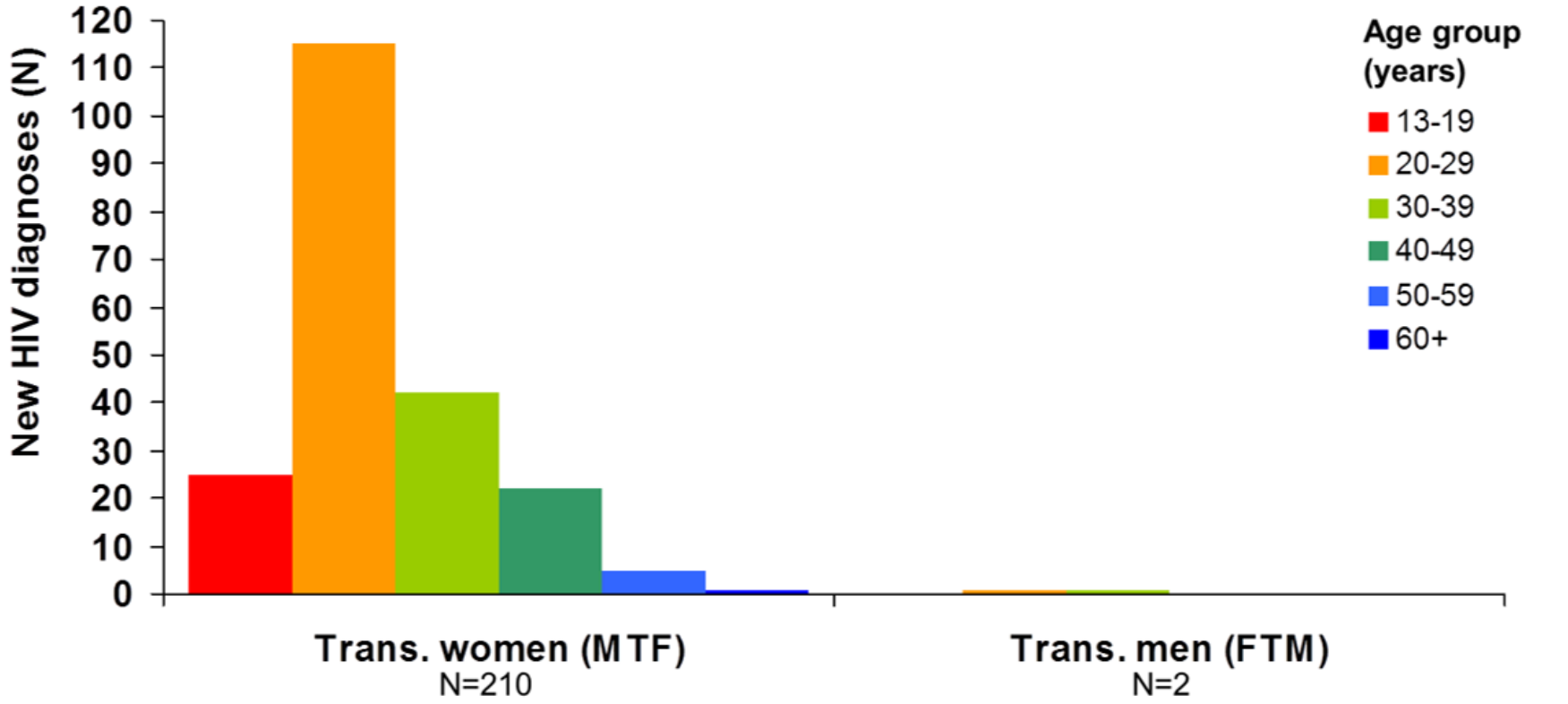
*Rikers Island is classified with the UHF neighborhood of West Queens.
As reported to the New York City Department of Health and Mental Hygiene by June 30, 2014.

Who is Considered Transgender by NYC HIV/AIDS Surveillance?

- **Persons whose current gender identity differs from their sex assigned at birth***
- **Persons classified as transgender can be of any sexual orientation, and may or may not have received hormone therapy or sex reassignment surgery**

* "Sex assigned at birth" refers to male or female sex that was assigned to a person at birth based on their anatomy. The phrase is equivalent in meaning to "sex at birth" and acknowledges that, for instance, some transgender persons assigned male sex at birth and identifying as women may feel that they were always female, in spite of their anatomy.

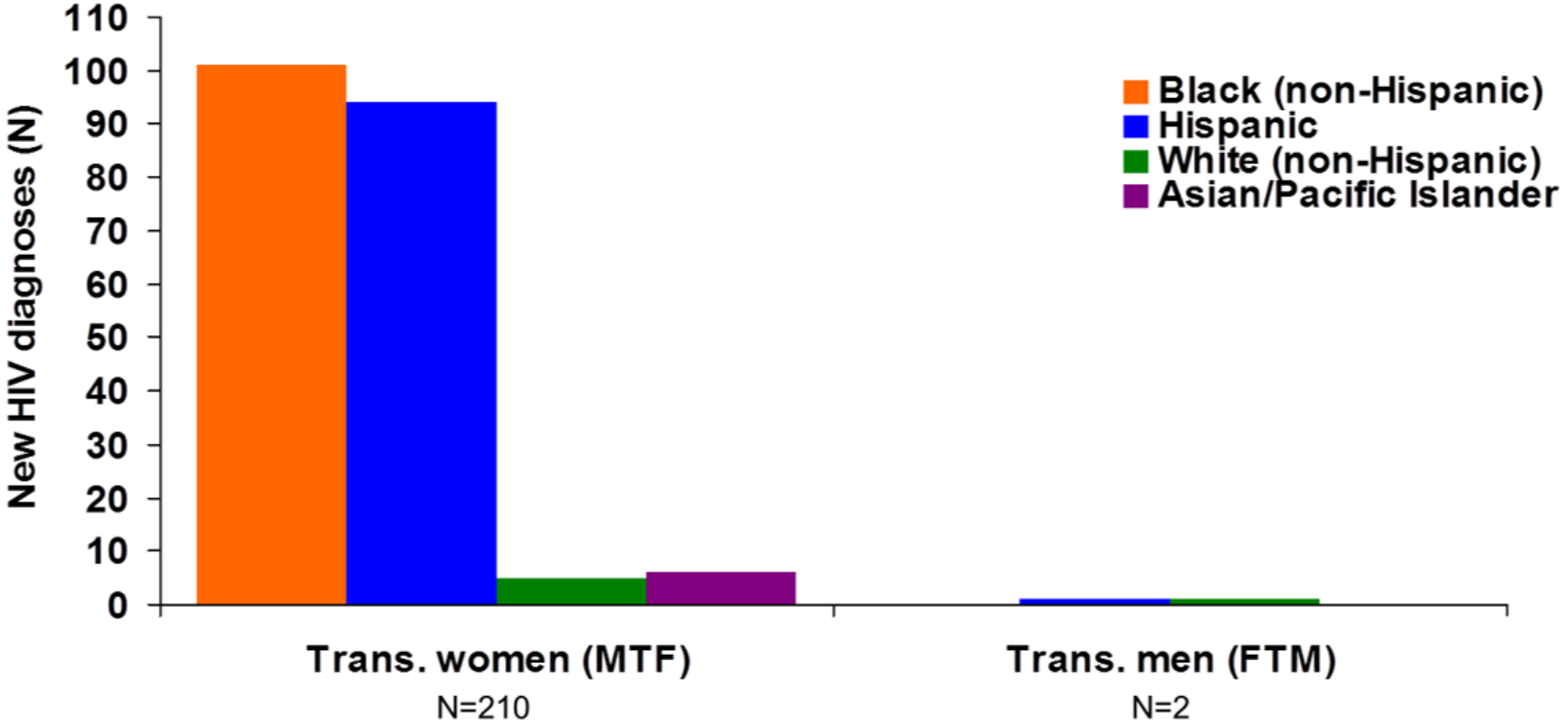
New HIV Diagnoses among Transgender Persons by Gender Identity and Age at Diagnosis in NYC, 2009-2013



Newly diagnosed transgender women (MTF) were predominantly in their 20s. Newly diagnosed transgender men (FTM) were in their 20s and 30s.

As reported to the New York City Department of Health and Mental Hygiene by June 30, 2014.

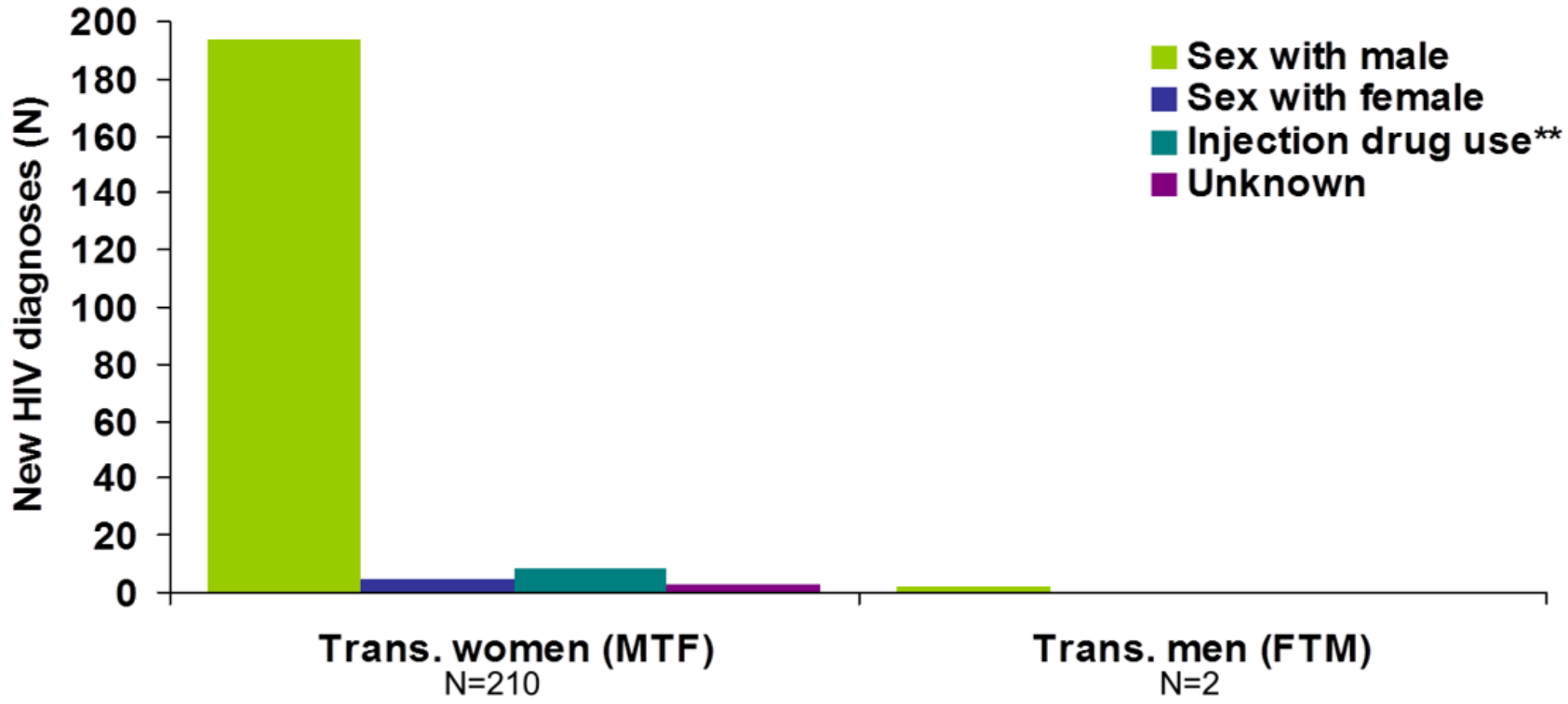
New HIV Diagnoses among Transgender Persons by Gender Identity and Race/Ethnicity in NYC, 2009-2013



About 93% of transgender women (MTF) newly diagnosed with HIV between 2009 and 2013 were black or Hispanic. Newly diagnosed transgender men (FTM) were Hispanic and white.

Native American and multi-racial groups are not shown because of small numbers and numbered less than 5 persons each.
As reported to the New York City Department of Health and Mental Hygiene by June 30, 2014.

New HIV Diagnoses among Transgender Persons by Gender Identity and Type of HIV Risk* in NYC, 2009-2013



Sex with a male was the predominant type of HIV risk among newly diagnosed transgender women (MTF) and men (FTM).

*To avoid inappropriately labeling some transgender persons as "men who have sex with men" or "heterosexual," "type of risk" differs from "transmission risk" presented elsewhere. Here, anyone with a history of injecting drugs was assigned this risk. Non-injectors reporting a male sex partner were assigned "sex with male," and non-injectors reporting female sex partners only were assigned "sex with female."

**Injection drug use likely does not include injection of hormones.

As reported to the New York City Department of Health and Mental Hygiene by June 30, 2014.

The INFINI-T Program

- Infini-T is a 5 year demonstration project funded by the Health Resources and Services Administration (HRSA) Special Projects of National Significance (SPNS) under the Ryan White Care Act to address health disparities affecting HIV+ TG women.
- Infini-T is one of 8 projects funded nationally to identify, engage, and retain HIV+ TG young women in HIV care; Infini-T is also recruiting an HIV- comparison group of TG young women
- Infini-T evaluates HEAT's multidisciplinary care model for transgender youth (HIV+/HIV-) as an intervention for engagement and retention in care

INFINI-T Program Goals

- Early identification of newly-diagnosed cases of HIV in TG young women and timely entry into TG/HIV care at HEAT;
- Engagement in mental health, psychosocial, and supportive services for TG young women at HEAT;
- Increase the retention rates of TG young women already receiving TG and/or HIV medical care;

Participants in Infini-T, 2013-15

- HEAT part of consortium of 8 sites across the US providing transgender women of color who are HIV+ through a HRSA/SPNS Initiative to engage and retain transgender women of color into care

- Enrollment through the HEAT Program and its partners – Hetrick Martin Institute, Callen-Lorde Community Health Center, etc.

- Surveys done by participants privately on computer assisted technology

Enrollment and Surveys

- Surveys developed by the 8 sites and UCSF
- We are reporting on several areas of interest
- Sociodemographics – age, ethnicity, insurance, etc.
- Transgender identity/body image
- Transgender violence/transgender phobia/discrimination
- Discrimination
- Mental health
- Provider cultural competence
- HIV care
- Transgender care

Sociodemographics

	Yes	%
• Age (Range 19=34, Md=24)		
• Education, HS or higher	14	60.9
• Race/ethnicity		
• African American/Caribbean	12	52.2
• Afro-Latina	4	17.4
• Latina	6	26.1
• Other	1	4.3
• Insurance		
• Medicaid	18	78.3
• Medicaid & Medicare	4	17.4
• None	1	4.3

Sociodemographics: Income

	Yes	%
In last 6 mo borrowed money to get by financially?	16	69.6
Total income in the past year ($)		
< 600	6	26.1
600-2,999	6	26.1
3,000-5,999	3	13.0
6,000-11,490*	1	4.3
11,491-15,282	0	
15,283-35,999	1	4.2
36,000-59,999	2	8.7
NA	4	17.3

* Federal Poverty Level for single person in 2016 is $11,880

Transgender Identity:
How important is it that….

	Very/ Extremely	%
• You have a drivers license that says you are female	16	69.5
• Strangers call you she when talking about you	16	69.5
• Family members call you she when talking about you	15	65.2
• Friends call you she when talking about you	16	69.5
• Health care providers refer to you as she	15	65.2
• How comfortable going out in the day	14	60.9
• How comfortable with people knowing you're trans	11	47.8
• How satisfied with your body now	6	26.1
• How satisfied with the way you look	5	21.7
• How satisfied with current level of femininity	9	39.1

*Recoded from 5 point scale of not at all-extremely important

Body Image

	Disagree	Agree*
• I feel good about my body	6	15
• On the whole, I am satisfied with my body	9	12
• Despite flaws, I accept my body for what it is	4	17
• I have a positive attitude toward my body	5	16
• I don’t focus a lot of energy on my body/appearance	11	10
• My feelings towards my body are positive	6	15
• Despite, imperfections I still like my body	5	16

*Recoded from strongly disagree/disagree/neutral vs. agree and strongly agree

Transgender Violence:

How many times have you been…because you were thought to be transgender (answer, once or more)

	N	%
• Verbally insulted (yelled at or criticized)	15	65.2
• Threatened with physical violence	11	47.8
• Had an object thrown at you	9	39.1
• Have been punched, kicked or beaten	8	34.8
• Threatened with a knife, gun, or other weapon	6	26.0
• Been attacked sexually (forced sex act, raped)	7	30.4
• Someone threatened to tell another you're transgender	6	26.0
• Chased or followed you	12	54.5
• Your property been damaged	6	26.0
• Been spat on or spit at	4	17.4
• **Total (any of the above answered yes)**	**18**	**81.8**

Transphobia:
Have you been….because you are transgender?

	Yes	%
• Been made fun of or called names	18	81.8
• Been hit, shoved, or beaten up	5	21.7
• Heard that transgender people are not normal	17	73.9
• Accused of doing wrong (cheat, steal, etc.)	3	12.9
• Forced to take drastic steps b/c of harm to you	1	4.3

Have you experienced discrimination by…

	Yes	%
• Doctor	5	21.7
• Insurance	5	21.7
• Job	9	39.1
• Housing	5	21.7
• Shelter	3	13.0

Mental Health

	Yes	%
• Summary Beck Depression Index (Range 0-19)*	13	56.5
• Summary Beck Anxiety Index (Range 0-21)*	15	65.2
• Experienced intimate partner violence?	9	39.1
• Were sexually abused as a child	12	52.2
• In the past 6 months…..		
Has anyone asked you questions to see if you need MH services?	9	39.1
Has anyone encouraged you to seek MH services?	9	39.1
Have you received MH services?	9	39.1

* Those responding “yes”to at least one symptom questions/Beck Inventories have 21 questions and three categories of response 0-3 from none to more severe

Provider Cultural Competence:
During your last HIV care visit….

	Very/Extremely	%
• Waiting room welcoming for transgender women	13	56.5
• Respectful were front desk staff	13	56.5
• See transgender people working there	3	13.0
• Visible images of transgender women	7	30.4
• Medical provider made you feel comfortable	14	60.8
• Desk staff use correct pronoun	14	60.8
• Medical provider use correct pronoun	13	56.5
• How respected did you feel	13	56.5
• Medical provider judging you	13	56.5
• How confident of provider trans health issues	12	52.1
• Felt provider would keep your medical information private	14	60.8
• If legal ID doesn't match gender ID, staff processing claims	11	47.8
• Overall competence YES	16	69.6

*recoded from Not at all confident/slightly confident vs. Moderately/very/extremely respected

HIV and Health Care Related

	Yes	%
• What was the first year you were treated for HIV? (Range 2005-2015, median =2012 or 3 years ago)		
• In the past 6 mo, has anyone encouraged you to get HIV care?	11	47.8
• Have you ever received primary care for HIV?	17	73.9
• How often in the last 6 mo have you received care in the ER?	6	26.1
• Is your viral load detectable?	4	17.4
• Have you ever been diagnosed with AIDS?	3	13.0
• Does your PCP recommend taking ART?	9	39.1
• Have you ever been prescribed ART?	4	17.4*

Transgender Care: Hormone use

• Ever taken hormones for trans care	18	78.3
• Currently taking hormones	15	65.2
• Taken hormones in past 6 months	16	69.6
• Began hormones		
<3 years	3	13.0
3-5 years	5	21.7
5 + years	6	26.1
NA	9	39.1

Transgender Care: Hormone Use

	Yes	%
• Taken more than prescribed	1	4.3
• Taken less than prescribed	3	13.0
• Longest time w/o hormones, 6 months		
• <1 week	1	4.3
• 1-4 weeks	2	8.7
• 1-3 months	4	17.4
• 3-5+ months	1	4.3
• Entire 6 months	2	8.7
• Who ordered blood test for monitoring/on tx		
My doctor	14	60.9
Another doctor	1	4.3
No blood tests ordered	1	4.3
Ever injected silicone (pumping)		
into any part of your body	3	13.0

Summary of Findings

Approximately 70% living at or below the Federal poverty level

Overwhelming exposure to violence and transphobia with significant exposure to discrimination in areas of basic human need

Significant intimate partner violence, earlier childhood sexual abuse, mental health utilization

Majority feel care is culturally competent

Although findings of those who answered HIV related questions are present, several sections/domains of HIV related questions were not answered at all; suggests stigma or not wanting to think about HIV

Relatively high engagement in transgender care

Thank You!!!!