

Transgender HIV Behavioral Survey (THBS)
PUBLIC COMMENTS

PUBLIC COMMENT #1:

From: lorte004 [<mailto:lorite004@fiu.edu>]
Sent: Friday, December 10, 2010 11:38 AM
To: OMB-Comments (CDC)
Subject: Question on Public Commenting

To whom it may concern:

I am doing a research paper for school on this issue and on the public commenting process. May you please send me the survey that the public is allowed to comment on? Also would you be able to tell me where the funding for this proposed project comes from?

I would like some information on the following survey:

This the numerical information I found for the document.

- Transgender HIV Behavioral Survey (THBS)—(OMB No. 0920-0794, expires December 31, 2010).
- [60-Day-11-0794]

I appreciate your time and help.

Thank you,
Carolina

RESPONSE to COMMENT #1:

Attachments: THBS Questionnaire Dec 2008.pdf;
THBS Eligibility Screener Dec 2008.pdf

Dear Carolina.

Thank you for your inquiry about the Transgender HIV Behavioral Survey for which we are currently seeking public comment.

As you requested, attached is the questionnaire that was used in the Transgender HIV Behavioral Survey Pilot. This questionnaire will be revised based on findings from that pilot and public comments.

Funding for the survey has not yet been identified.

Thank you for your interest in this project.

Sincerely,

Teresa Finlayson

Teresa Jacobs Finlayson, PhD MPH
Epidemiologist
Division of HIV/AIDS Prevention
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PUBLIC COMMENT #2 (TSPN):

From: Salcedo, Bamby [mailto:BSalcedo@chla.usc.edu]
Sent: Saturday, January 01, 2011 10:10 PM
To: OMB-Comments (CDC)
Subject: CDC Data Recommendations

Dear Carol E. Walker:

Please find some recommendations that our Transgender Service Provider Network came up with regarding data collection and trans individuals. Please feel free to contact me if you have any type of questions regarding our recommendations or anything else.

Bamby Salcedo
HIV Prevention Services
Project Coordinator
Childrens Hospital Los Angeles
Ph: (323) 361-5983
bsalcedo@chla.usc.edu

TRANSGENER SERVICE PROVIDER NETWORK

WWW.TSPNLA.ORG

CDC SURVEY DATA RECOMMENDATIONS 12/08/10

Process: The working group met to discuss the process of data collection from the Trans-LA study survey tool. We reviewed the survey tools and recommend the following changes to improve the instrument and process:-

1. Increase Compensation for survey and include transportation assistance.
2. Move -pg D83 to the beginning of the survey so that participants better understand the qualifications of the survey and better understand the various definitions used in the survey.
3. Include HIV/STI testing as an additional incentive offered in conjunction with the survey.
4. Survey is too long. The survey should be condensed to limit the overall burden for participants.
5. ACASSI interview should include training components for participants to ensure comfort and clarity when using the ACASSI system system.
6. Provide materials/questionnaires_instruments in Spanish.
7. Spanish translation should be sensitive to and incorporate regional linguistic differences.
8. If a question on ethnicity is included "tribal affiliation" should be added as a sub-category under Native American.
9. Continue to offer interviews/-surveys on the computer. Completing the survey using an ACASI system is preferable to a paper instrument, or one administered by a worker.
10. Include strengths-based questions related to resiliency.- These questions could be inserted between questions 9-10 on pg D-5.
11. Include questions about how participants receive information and referrals to medical providers and how competent or sensitive to transgender issues they believe their providers to be (internet, office, friend, etc).
12. Change question as it relates to Gender at birth (c-4) – (c-5) Es9-10 (please include specific language related to gender).
- ~~13-~~On page D2, Question 5, include a question or options to specify the current type of employment participants may have.
- ~~14-13.~~ Move silicone section to the health care section.
- ~~15-14.~~ Page 67 should be moved to the health care section. We believe everything related to health should be included in to one section (HCT, TB, etc)

Comment [Josh Rile1]: Might it be useful to include recommendations about what questions could be removed or condensed, etc.

Comment [Josh Rile2]: I'm not sure what this means but I took a stab at it.

Comment [Josh Rile3]: I added this sentence just because I think it's interesting. I agree ☺

Comment [Josh Rile4]: I don't understand this since I haven't seen the instrument, but I think this should be turned into a complete sentence.

Comment [Josh Rile5]: Does this mean currently or ever?

RESPONSE to COMMENT #2 (TSPN):

Dear Bamby Salcedo,

Thank you for your input on the Transgender HIV Behavioral Survey (THBS).

We plan to include HIV testing as part of the survey to help us understand and monitor the factors associated with infection in this population.

We will also have a Spanish version available. Data for this survey will be collected the same way data are collected for the National HIV Behavioral Survey which collects similar data for other populations at risk for HIV infection. That is, THBS data will be collected through computer-assisted questionnaires, conducted face-to-face by trained interviewers. Interviewer training will cover how to use appropriate probes, including those used to account for regional linguistic differences in terms, and to clarify confusing questions.

We understand the length of the survey may present a barrier to implementation. We will review the questionnaire with our partners at the health department who conducted the pilot to determine if it can be shortened without diminishing its ability to monitor key HIV-related behaviors and experiences among transgender persons.

The many comments you provided on the questionnaire are also appreciated and will be considered with the other comments received during the public comment period.

Sincerely,

Teresa Finlayson

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PUBLIC COMMENT #3 (NASTAD):

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Executive Director
Julie M. Scofield

January 6, 2011

Carol E. Walker
Acting Reports Clearance Officer
Centers for Disease Control and Prevention
1600 Clifton Road
Atlanta, GA 30333
carol.walker@cdc.hhs.gov

Dear Ms. Walker:

On behalf of the National Alliance of State and Territorial AIDS Directors (NASTAD), the organization which represents the public health officials that administer state and territorial HIV/AIDS and adult viral hepatitis prevention and care programs nationwide, I am writing to provide comments regarding the Centers for Disease Control and Prevention's (CDC) Transgender HIV Behavioral Survey (THBS) that aims to provide a mechanism for describing and monitoring the HIV risk behaviors and HIV prevention experiences of transgender persons. We are pleased that CDC views addressing health disparities and social determinants of health as key to successfully reducing new HIV/STI infections among transgender persons of all races and ethnicities. NASTAD commends CDC for creating new opportunities to examine how public health and communities can assess trends and impacts in risk behaviors for HIV infection, HIV testing behaviors, and HIV prevention services among male-to-female transgender persons in the U.S. and its territories.

NASTAD is pleased to see that CDC's THBS is congruent with the National HIV/AIDS Strategy's (NHAS) focus on reducing new infections by intensifying HIV prevention efforts in communities where HIV is most heavily concentrated. The strategy also calls for state and local health departments as well as federal agencies to monitor progress towards the strategy's goal. The proposed project addresses national goals by providing a mechanism for describing and monitoring the HIV risk behaviors and HIV prevention experiences of transgender persons.

We commend you for identifying health department HIV/AIDS and viral hepatitis programs as a foundation in the nation's public health response to these epidemics in the U.S. As such, our members play an essential role in providing expertise regarding the needs of impacted communities, identifying resource needs to support a public health response to HIV/AIDS and viral hepatitis, and maximizing the use of limited resources targeting

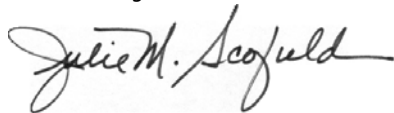
Carol E. Walker, CDC
January 6, 2011
Page Two

transgender communities. We encourage CDC to work with state and local health departments to determine the most impactful ways to enhance the quality, utility, and clarity of the information to be collected and determine how additional information can be thoughtfully analyzed to maximize public health outcomes.

CDC has defined specific goals, objectives and measureable outcomes of the Survey; however, we believe the length of the survey may be a barrier to the proposed implementation plan. NASTAD looks forward to working with CDC on the proposed Transgender Health Behavioral Survey and as you consider the ways in which to minimize the burden of the collection of information on respondents.

Thank you again for the opportunity to provide comments on the draft survey. We appreciate your attention to the comments above. If you have questions related to our comments, please do not hesitate to contact me at (202) 434-8090 or by email at jscofield@NASTAD.org.

Sincerely,



Julie M. Scofield
Executive Director

RESPONSE to COMMENT #3 (NASTAD):

Dear Ms. Julie Scofield.

We appreciate the encouraging support of the National Alliance of State and Territorial AIDS Directors (NASTAD) for the Transgender HIV Behavioral Survey.

We understand the length of the survey may present a barrier to implementation. We will review the questionnaire with our partners at the health department who conducted the pilot to determine if it can be shortened without diminishing its ability to monitor key HIV-related behaviors and experiences among transgender persons.

Thank you for your interest in this project.

Sincerely,

Teresa Finlayson

Teresa Jacobs Finlayson, PhD MPH
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PUBLIC COMMENT #4 (NCTE):



January 2, 2010

Transmitted via email

Carol E. Walker
Acting Reports Clearance Officer
Centers for Disease Control and Prevention
1600 Clifton Road, MS-D74
Atlanta, GA 30333

Re: Proposed Data Collections- Transgender HIV Behavior Survey (0920-0794)

Dear Ms. Walker,

The National Center for Transgender Equality (NCTE) is pleased to submit these comments on the Transgender HIV Behavior Survey (THBS). We would like to applaud the Centers for Disease Control and Prevention (CDC) for taking steps to implement the National HIV/AIDS Strategy.

The National Center for Transgender Equality is a national social justice organization devoted to ending discrimination and violence against transgender people through education and advocacy on national issues of importance to transgender people. By empowering transgender people and our allies to educate and influence policymakers and others, NCTE facilitates a strong and clear voice for transgender equality in our nation's capital and around the country.

I. Who Are Transgender People?

When addressing the transgender population and its health needs, it is necessary to understand key terms and concepts. Transgender people are people whose gender identity, expression or behavior is different from those typically associated with their assigned sex at birth. Gender identity is one's internal sense of being male, female, or something else. Since gender identity is internal, one's gender identity is not necessarily visible to others. Additionally, gender expression is how one represents or expresses one's gender identity to others, often through behavior, clothing, hairstyles, voice, or body characteristics.

Some transgender people may decide to transition from one's gender assigned at birth to one's preferred gender. This period may involve accessing medical treatment to physically manifest one's gender identity. There is a well-established medical consensus that: 1) a person's gender identity is a deep-seated, inherent aspect of human identity; 2) efforts to change a person's core gender identity are futile and harmful; 3) some people have a gender identity that differs from

National Center for Transgender Equality

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their assigned or presumed sex at birth; 4) being transgender is, for many individuals, a serious medical condition that requires individualized medical intervention and treatment (often collectively known as sex reassignment), which may, depending upon the person's individual needs, include counseling, hormone therapy, Real-Life Experience, and a wide variety of possible sex reassignment surgeries; and 5) sex reassignment treatments are generally extremely safe and effective in improving both psychological and physical health and well-being.

II. Response To The Proposed THBS

The National HIV/AIDS Strategy calls for intensified efforts to prevent new HIV infections, especially for populations that are disproportionately affected by HIV/AIDS. It highlighted transgender individuals' disproportionate risk for HIV infection and a history of neglect to this population's health needs. The National Center for Transgender Equality and the National Gay and Lesbian Task Force's national survey found that transgender people are four times more likely than non-transgender people to be infected with HIV.¹ Furthermore, the survey found that transgender people of color experience HIV infection at exponential rates compared to that of the general population. For example, African-American transgender respondents reported an HIV infection rate of 24.9% while the general population has an HIV infection rate of 2.64%. These statistics show that transgender individuals are at an elevated risk for HIV infection and prevention efforts must be specifically tailored to this population in order to be effective.

One of the ways to expand effective approaches to HIV prevention is to support and strengthen HIV screening and surveillance activities. The National HIV/AIDS Strategy recognizes that federal agencies must do more to improve existing HIV surveillance to identify populations that are at disproportionate risk for HIV infection and need targeted HIV prevention services. We fully support improving existing HIV surveillance and getting more data on how transgender people are affected by HIV/AIDS. We would like to voice the following concerns about the THBS.

A. The THBS should revise its demographics section to accurately collect data on the transgender population and its risk for HIV infection.

We respectfully request that the target population of THBS should be expanded so that it collects data on **all** transgender individuals. It focuses solely on transgender women at the expense of transgender men and other gender non-conforming individuals. It is true that transgender women have higher rates of HIV infection than transgender men. However, the CDC's decision to focus solely on transgender women means that the agency failed to recognize that a segment of transgender men may be of elevated risk for HIV infection, especially if they have multiple partners, have substance abuse issues, or engage in sex work.² There is also a dearth of data on

¹ Grant, Jaime M. et al. "National Transgender Discrimination Survey Report on Health and Health Care: Findings of a Study by the National Center for Transgender Equality and the National Gay and Lesbian Task Force." Oct. 2010 http://transequality.org/PDFs/NTDSReportonHealth_final.pdf

² Reisner SL et al. "A mixed methods study of the sexual health needs of New England transmen who have sex with nontransgender men." *AIDS Patient Care STDS*. 2010 Aug; 24(8): 501-13.

HIV/AIDS for transgender population on the whole. Notably, the National HIV/AIDS Strategy focused on all transgender individuals, and not solely on transgender women, as a population that warrants attention for elevated risk for HIV infection.

Additionally, NCTE commends the CDC for putting two separate questions on the THBS to appropriately inquire about a respondent's sex assigned at birth and gender identity. As the current THBS questionnaire recognizes, distinguishing between these two very different aspects of a person's life can be accomplished by asking two separate questions. However, the question on gender identity should not force a respondent to pick a single answer from among the options "female," "male," and "transgender." A gender identity question formulated in this way does not fully capture many transgender peoples' gender identity. Many transgender people identify as a woman or a man and reject being labeled transgender at all, viewing their transgender history as part of their medical history. For other transgender people, it may be more accurate for them to respond that their gender identity is both female and transgender or both male and transgender, while other gender-nonconforming people may reject being categorized as a woman or a man at all. A proposed pair of questions for sex assigned at birth and gender identity is as follows:

Sex assigned at birth (please check one):

- Male
- Female
- Don't know

Gender identity (please check **all** that apply):

- Male
- Female
- Transgender

Moreover, we recommend that the THBS include additional questions to better understand HIV transmission in the transgender population. A question asking about a respondent's age is essential for several reasons. An age question will help us understand the HIV infection risk of each age group. It will also assist advocacy organizations and clinics effectively tailor HIV prevention services to a variety of ages, not only to the young.

We also recommend that the THBS ask a question on whether a respondent ever engaged in sex work. All individuals, including transgender individuals, who engage in sex work are at elevated risk for HIV infection.³ Accordingly, this type of information is vital to understand a population's risk for HIV infection.

³ Grant, Jaime M. et al. "National Transgender Discrimination Survey Report on Health and Health Care: Findings of a Study by the National Center for Transgender Equality and the National Gay and Lesbian Task Force." Oct. 2010 http://transequality.org/PDFs/NTDSReportonHealth_final.pdf; Harawa, Nina T. and Trista A. Bingham. "Exploring HIV Prevention Utilization Among Female Sex Workers and Male to Female Transgenders." *AIDS Education and Prevention*, 21(4), 356-71, 2009; Xavier, Jessica et al. "Related Needs, And Lifecourse Experiences of Transgender Virginians" Virginia HIV Community Planning Committee and Virginia Dept. of Health. Jan. 2007 <http://www.vdh.state.va.us/epidemiology/DiseasePrevention/documents/pdf/THISFINALREPORTVol1.pdf>

B. The THBS should contain culturally competent questions on transgender population and its risk for HIV infection.

We note that surveys conducted by the CDC and other federal agencies must be conducted in a culturally sensitive manner that recognizes people's gender identity and expression, how people view their bodies, and how people live their lives. Social discrimination is a key factor that explains the health disparities seen in the transgender population. Almost 30% of the respondents in the abovementioned national transgender survey reported delayed accessing medical care due to medical providers' discriminatory practices and ignorance of transgender health issues. A transgender person's experience of being a victim of discrimination can be worsened when one is HIV positive.⁴ The CDC should take steps to ensure that its programs are tailored so they appropriately address transgender health issues. This will encourage transgender individuals to provide honest answers to the THBS's questions and access prevention services, HIV testing, and medical care.

The THBS does not ask about respondents' sexual behavior in a culturally appropriate way.⁵ Additionally, the THBS does not ask about respondents' sexual behavior in a manner that both respects individual identity and that will provide useful information regarding the risks of HIV infection for transgender people versus non-transgender people.⁶ For example, a question like "Have you ever had vaginal or anal sex with a woman?" is double-barreled and makes assumptions about anatomy and sex behavior that may not be accurate. A more accurate way to frame such a question would be as follows:

Have you ever had anal sex with a woman?

Have you ever had vaginal sex with a woman?

Have you ever had oral sex with a woman?

Furthermore, the following question does not accurately reflect transgender people and the wide variety of individual sexual behavior:

"Now I'm going to ask you some questions about having sex with other men. For these questions, 'having sex' means oral or anal sex. Oral sex means he put his mouth on your penis or you put your mouth on his penis. Anal sex means you put

⁴ Lambda Legal. "When Health Care Isn't Caring: Lambda Legal's Survey on Discrimination Against LGBT People and People Living with HIV." 2010 http://data.lambdalegal.org/publications/downloads/whcic-report_when-health-care-isnt-caring.pdf

⁵ Center of Excellence for Transgender HIV Prevention. "Recommendations for Inclusive Data Collection of Trans People in HIV Prevention, Care & Services." <http://transhealth.ucsf.edu/pdf/data-recommendation.pdf>

⁶ Center of Excellence for Transgender HIV Prevention. "Recommendations for Inclusive Data Collection of Trans People in HIV Prevention, Care & Services." <http://transhealth.ucsf.edu/pdf/data-recommendation.pdf>

your penis in his anus (butt) or he put his penis in your anus (butt). Have you ever had oral or anal sex with a man?”

As discussed previously, in order to obtain maximum response rates, questions must be asked in a culturally appropriate manner that will encourage participation. In this case, the reference to “other men” indicates that the interviewer considers the respondent to be a man regardless of the individual’s gender identity. Moreover, the reference to the “penis” as the only genitalia involved indicates an inaccurate presumption about individual anatomy and is likely to induce respondents to not answer the question as expected. Accordingly, the following questions should be asked:

Have you ever had anal sex with a man?

Have you ever had vaginal sex with a man?

Have you ever had oral sex with a man?

Additionally, the THBS has an explanation for what it means by “sex with another man” but does not contain an explanation for “sex with a woman.” The survey should contain an explanation of what it means by “sex with a woman” because it should capture sexual behavior as accurately as possible. Additionally, adding an explanation on this topic will enable THBS to precisely refer to individuals’ anatomy and gauge their HIV infection risk.

C. HIV Prevention and Testing Questions

The THBS is an important data collection tool to study the efficacy of HIV prevention services and frequency of HIV testing. However, it can be improved in several ways for this purpose. For example, the THBS does not address transgender people’s ability to access healthcare. It is well-established that transgender people’s socio-economic status, race/ethnicity and experiences of societal discrimination deters them from accessing necessary medical care. Thus, it is necessary for the THBS to address this issue thoroughly. Since transgender people have difficulties accessing routine medical care, we also suggest that question H6 should be revised so that “your health care provider” be replaced with “a health care provider.”

Additionally, the THBS does not ask respondents to answer questions on what kinds of preventive measures they use to lower their risk of HIV infection besides pre- and post-exposure prophylaxis. The THBS should ask questions on respondents’ condom use, knowledge of a partner’s HIV status, and number of partners. If a respondent engaged in sex work, it is important to explore when and why condoms were not used during sexual activity.

Furthermore, the THBS should have a section on substance abuse and other situations where needle sharing is commonplace. For example, many transgender people cannot access hormones and other medical care that can assist them transition from one gender to another in a

professional medical setting. So, oftentimes, they will access such treatments from the black market and may use needles that are unsanitary.⁷

D. The benefits of including additional questions to the THBS overcome the financial costs and the burden to respondents.

The THBS is a great opportunity for researchers to collect data on HIV transmission and risk for HIV infection amongst the transgender population. The survey can be strengthened by adding additional questions and sections as well as revising existing questions to be culturally sensitive. The THBS must be crafted in a way that maximizes honest answers by the respondents and, thereby, obtain accurate data. This, in turn, will help researchers, medical professionals, and advocacy organizations decrease HIV transmission and find out who are at the highest risk for HIV infection. This benefit outweighs the administrative costs to adding additional questions to the THBS.

We appreciate the opportunity to comment on the THBS and look forward to receiving the results of the survey. Please do not hesitate to contact us if you need assistance.

Sincerely,

s/

Mul Kyul Kim, Esq.
Health Policy Counsel

⁷ Xavier, Jessica et al. "Related Needs, And Lifecourse Experiens of Transgender Virginians" Virginia HIV Community Planning Committee and Virginia Dept. of Health. Jan. 2007
<http://www.vdh.state.va.us/epidemiology/DiseasePrevention/documents/pdf/THISFINALREPORTVol1.pdf>

RESPONSE to COMMENT #4 (NCTE):

Dear Ms. Kim,

We appreciate the input provided from the National Center for Transgender Equality on the Transgender HIV Behavioral Survey (THBS).

THBS was designed for surveying transgender women because this group is at greatest risk for HIV infection. We realize that we are excluding some transgender persons who are also vulnerable to HIV infection and we will explore methods for collecting similar data from them as well.

We would also like to thank you and your colleagues for providing detailed comments on the questionnaire content. Some of the suggested changes have been made; Others will be considered with the other comments received during the public comment period.

Thank you for your interest in this project.

Sincerely,

Teresa Finlayson

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