

**Focus Group and Cognitive Interviews to Assess Questions Developed for the
Transgender HIV Behavioral Survey: A pilot among racial
and ethnic minority male-to-female transgender persons**
A proposed component of the National HIV Behavioral Surveillance (NHBS) System
Results of focus group and cognitive interviews conducted April 24 – May 8, 2008

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1. Introduction

The purpose of this report is to document the results of a focus group discussion and cognitive interview testing for the U.S. Centers for Disease Control and Prevention's (CDC's) Transgender HIV Behavioral Survey (THBS): A pilot among racial and ethnic minority male-to-female transgender persons. Many of the survey questions are similar to those being used in other National HIV Behavioral Surveillance (NHBS) System questionnaires. These questions are designed to measure the prevalence of risk behaviors that might place someone at risk for infection with HIV/AIDS. A new series of questions assessing gender identity, silicone use, and hormone use were created for THBS, and some existing NHBS questions were slightly modified. Because of the length of the instrument and the complexity of the topics, only two types of questions were examined: new THBS questions and questions that both CDC and the RTI researchers thought might be interpreted differently by the special populations targeted for HIV surveillance.

The majority of this report presents a question-by-question analysis of the THBS questions tested. Comments are included for each of the questions, with particular emphasis placed on items that have the potential to generate response error; that is, they might not capture the information they were designed to measure. The discussion of these questions includes descriptions of how respondents interpreted the questions, explanations of why and how questions posed problems for respondents, and, where appropriate, recommendations for question improvement.

The next section briefly describes the methodology for the focus group and cognitive interviewing, encompassing the recruitment method, consent procedure, and data collection methods. The third section of the report presents general findings and recommendations from the focus group discussion, general findings from the cognitive interviews, and then question-by-question analysis and recommendations for modification of the THBS instrument.

This research was made possible through funding by the CDC's National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention (NCHHSTP), and was a collaborative effort between NCHHSTP, RTI International, and the National Center for Health Statistics (NCHS). NCHS

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protocol and methodological standards provided the framework for the project, and RTI carried out the recruitment, data collection, and analysis according to this program.

2. Method

2.1 Recruitment Methods

Because of the sensitive nature of the topic, this project was conducted as an anonymous study. Minimal personal identifiers were collected, which included a first name and a contact telephone number for scheduling and reminder calls. Full name, address, home telephone number, and social security number typically collected for remuneration purposes were not obtained.

RTI initiated recruitment through a transgender community contact who is active in public health and is well known in the transgender community. This unique complement of credentials made the community contact exceptionally well qualified to help us recruit for our project. RTI had worked with this individual on a prior CDC transgender HIV project.

RTI provided our community contact with a letter of introduction about the project and flyers that could be posted to facilitate recruitment. The introduction letter, written for potential research respondents, was given to each person that our community contact identified. The letter gave the potential recruit some basic information about the project and provided contact information for an RTI staff person, the recruitment manager, who was to be called if the individual was interested in participating.

Transwomen (men transitioning to women) who were interested in participating called the recruitment manager; the recruitment manager never called potential recruits without them having first called to express interest in participating. The manager used a screening instrument that had criteria for including and excluding respondents as previously agreed upon by RTI and CDC. The manager typically spent about 10 minutes on the phone with each potential respondent, answering any questions and administering the screening instrument. The screening entailed affirmation of transgender status and collection of demographic information, including age, race, ethnicity, income, and education level. Callers who qualified were scheduled for either the focus group or for an individual interview. They were told the exact time and date of the interview, and the recruitment manager also verified that they knew where the interview or group was held. Approximately 24 hours before the focus group or interview, the recruitment manager or a research assistant called the respondent(s) to remind them of the date and time.

2.2 Eligibility Criteria

To be eligible for the study, respondents had to consider themselves as male-to-female transgender persons, meaning that they had to be male and identify, live, or present themselves as women. Also, the respondents had to be at least 18 years of age. Participation was dependent on the respondents' willingness and consent to be audio taped during the focus group and cognitive interviews. We attempted to recruit persons from a wide range of ages and ethnic and racial backgrounds. Midway through recruitment, at CDC's behest we requested that the community contact assisting in recruitment make additional efforts to recruit young transwomen,

for most of the respondents recruited up to then were aged 30 or older. This change in recruiting yielded several younger transwomen, including at least three under the age of 20.

2.3 Data Collection

Trained RTI interviewers conducted the cognitive interviews and moderated the focus group discussion. All sessions were held in a cognitive lab, a room with a conference table and one-way mirror to permit observation of the data collection by NCHS and note taking by RTI. In addition to taking notes, the RTI note taker verified that the respondents gave voluntary consent and received their honorarium. All data were collected in RTI's Washington, DC office. Prior to data collection, each respondent was asked to read and sign an informed consent form and then asked to complete a respondent data collection sheet. The focus group and interviews were audio-recorded. The tapes were collected at the end of each day by the NCHS representative and brought back to NCHS for storage.

Prior to beginning the interviews or focus group, the interviewer/moderator summarized key elements of the project, and the respondents were given the opportunity to ask questions about their consent and the research. The cognitive interviews were designed to last 1 hour and the focus group 90 minutes. After each data collection event, the respondents were given a \$50 honorarium for their time and effort and a thank you letter from NCHS.

The interviewees had the option of completing the survey on their own or having the interviewer read the questions aloud as they marked their answers. After the survey was completed, the interviewer probed the respondents' interpretation of key terms, the ease with which they chose a response category, and their experiences related to HIV risk behaviors. Through the respondent narrative, interviewers were able to determine how respondents interpreted the intent of each question and could assess to what extent response error had occurred.

3. Results

3.1 Respondent Characteristics

RTI staff members conducted a total of 19 cognitive interviews and moderated 1 focus group of 7 respondents for a total of 26 respondents. Testing the questions on different groups of users allowed us to better determine if there were any age-related or cultural differences in how the questions were understood.

The research respondents (n=26) ranged in age from 18-58 years. The average age of the respondents was 39 years with a median of 41 years. The majority of respondents (69%) had never married; 23% were married or partnered; and an additional 8% were separated. The majority of respondents were non-Hispanic blacks (81%) and the rest were Hispanic. More than half of respondents (58%) had not completed high school, 23% had a high school diploma or its equivalent, 15% had attained some college or an Associate's degree in an occupational/vocational program, and 4% had attained a bachelor's degree as their highest level

of education. † The vast majority of respondents (85%) were unemployed, and 92% had a household income less than \$20,000 per year. The respondent characteristics are presented in Table 1.

Table 1: Respondent Characteristics

	Cognitive Interviews (n=19)	Focus Group (n=7)	Total (n=26)
Age *			
Mean	38	43	39
Median	41	49	41
Min	27	18	18
Max	56	58	58
Marital Status			
Never married	15 (79%)	3 (43%)	18 (69%)
Married/ partnered	3 (16%)	3 (43%)	6 (23%)
Separated	1 (15%)	1 (14%)	2 (8%)
Race/ Ethnicity			
Hispanic	3 (16%)	2 (29%)	5 (19%)
Non-Hispanic Black	16 (84%)	5 (71%)	21 (81%)
Education			
No HS diploma	13 (68%)	2 (29%)	15 (58%)
HS diploma	4 (21%)	2 (29%)	6 (23%)
Some college/ AD	2 (11%)	2 (29%)	4 (15%)
B.A. degree	0 (0%)	1 (14%)	1 (4%)
Employment Status			
Employed	2 (11%)	2 (29%)	4 (15%)
Unemployed	17 (89%)	5 (71%)	22 (85%)
Household Income**			
<\$20K	16 (94%)	6 (86%)	22 (92%)
\$20K-\$30K	1 (6%)	0 (0%)	1 (4%)
>\$30K	0 (0%)	1 (14%)	1 (4%)
* One respondent from the focus group refused to tell age.			
** Two cognitive interview respondents declined to state income.			

† According to the U.S. Census Bureau’s 2006 American Community Survey Data Profile Highlights, 84.1% of people aged twenty-five and older have earned their high school diploma and 27% have a Bachelor’s degree or higher. Even if the data for the five respondents under the age of 25 were removed, 52% of the remaining respondents (n=21) did not receive a high school diploma.

3.2 General Findings

Focus Group:

The first phase of data collection began with a focus group. To the extent that people with transgender identities are an understudied group, it was important to incorporate appropriate terminology into the survey questions. Because they are based on group interaction, focus groups are an ideal methodology for exploring acceptable vernacular among socially and culturally distinct subgroups. The dynamics of group interaction allow for a brainstorming of ideas that enumerates terms used by people in the transgender community, terms that may be previously unknown by question designers.

In the focus group, participants were asked to discuss terminology, specifically, their familiarity and comfort with the term *transgender*. All participants were familiar with the term and few alternatives were suggested as more appropriate. However, participants did prefer the phrase *transgender woman* both to describe themselves and to be described by others, though some would describe themselves to non-transgender friends and strangers as simply a woman. Participants were quick to point out that they were only speaking for themselves, and that there is range of terminology used by transwomen in various situations. For example, they indicated that *transsexual* is a commonly accepted term in their communities, but describes a person who has transitioned from male to female through sex reassignment surgery (SRS). None of the focus group participants had undergone SRS, though most knew at least one woman who had.

Participants were not familiar with the phrase *gender variant* and would not use it to describe themselves. One person remarked that it “sounds like a robot or something—not human.”

When asked about their physical sex assigned at birth, participants overall stated that they would check *male*. However, some felt that younger transwomen might check *female* because they have considered themselves female their whole lives and have a different outlook from some of the respondents, who were older. This was an issue that needed to be explored more thoroughly in the cognitive interviews.

Participants were asked to discuss their experience with silicone use. Silicone use was described as a quick and inexpensive way to get a softer, more feminine body shape. All participants were aware of the risks of silicone, whether they had used it or not. They felt that anonymous and confidential survey respondents would be more likely to discuss their experiences with silicone than in an interview or group setting. *Pumping* was a term familiar to all of the African-American participants but was unfamiliar to the Latina participants. Participants who were familiar with pump parties said that at these gatherings, women shared the silicone from a large container but did not share needles: “We have a lot of places where you can get needles and syringes, so I don’t think it’s a problem.”

Participants were asked to examine the survey question (#5) that asked for a number of contacts they could potentially refer to take the survey. They did not find this question confusing, and were comfortable with the idea of asking others to participate in the survey. Note that several of the participants were community leaders and/or active in transgender community activities.

They reported that, in approaching their contacts, they would initially bring up the availability of money or some other type of incentive (grocery cards were mentioned as another possibility). They felt that, without some sort of incentive, participation would be low.

Finally, participants were asked to describe what type of voice they would like to hear reading the questions on the survey (in an Audio-CASI format). Although this information was speculative, and it's not clear if or how it should be incorporated, there was a split between participants who said they would be more comfortable with a transgender woman or woman reading the questions and those who would be comfortable with either a man or a woman's voice. Either way, the tone of voice was deemed important: they felt that the voice should be "personal," "soft," "clear," "professional," and nonjudgmental.

Cognitive Interviews:

Upon completion of the focus group, cognitive interviews were conducted to explore the question response process and the ways in which respondents understood and interpreted the questions. Respondents had few difficulties providing answers, but there was a wide range of interpretations of some questions. Appropriate language was also explored further in the cognitive interviews. A list of analysis highlights is next, followed by a more detailed question-by-question assessment.

Four issues were identified that cut across questions, age groups, and ethnicities.

1. The survey questions are not written in a vernacular typically used by the Hispanic groups with whom we did the cognitive testing. As one respondent put it, the questions seem like they are written by educated, white transgenders and that the survey was "medical." She said that if the survey was written by Hispanics or African Americans, the language would be more colored. She said that her community uses terms like *trans* or *transgirl*. Despite this issue related to wording, the respondents had relatively few problems understanding what the questions were asking. Some words and phrases did generate confusion. Only a few respondents understood what the word *topically* meant, and none of the respondents had heard of the term *gender variant*. Respondents responded with both accurate and inaccurate guesses as to what those terms might mean. However, no one appeared to have provided an incorrect answer to a question based on the inclusion of the term gender variant.
2. Almost all of the respondents had taken hormones and had received silicone injections. Through discussing these behaviors, the risk of HIV infection seemed greater from shared substances than from sharing needles. Several people cited that they did not share needles but did share hormone vials, silicone, or other substances that were injected. The respondents did not distinguish between needles and syringes, nor did we probe for understanding the difference.
3. The timeframe on which the respondents based their responses varied from question to question. The respondents answered some questions in terms of the present and others in terms of the past and present (most typically, the last time they had a job, partner, etc.). As THBS is part of CDC's ongoing HIV surveillance effort, we assume that the questions should address what has occurred recently rather than ever occurred. We therefore suggest

that CDC consider changing questions in which there was confusion to specify the current time period.

4. The cognitive interviews were conducted by two men and two women. In observing the interviews, it appeared that the respondents disclosed more information to the male interviewers. With male interviewers, respondents quickly developed an easy rapport as evidenced by relaxed body language and casual, friendly conversation. Interaction with female interviewers appeared more stilted and respondents were, in general, less gregarious. Although the focus group respondents did not express a preference for a male or female voice in audio-CASI, the observations from the cognitive interviews suggest that a male voice in a nonjudgmental tone would be optimal.

Question-By-Question Analysis

This section is devoted to an individual review of findings for each question tested. Each item contains an analysis of the response process followed by recommendations for question improvement.

Items from the Eligibility Screener

1. **During 2008, did you already complete at least part of the health survey that *YES Woman* is conducting? It could have been here or at another location.**

In general, there were no problems with this question. One respondent did not know if she had and another respondent said that Yes, she had taken the survey, but that it was a couple of years ago. It is likely that the respondents did not hear or skipped over the part that mentioned the year. A trained interviewer assessing eligibility should have no trouble probing to determine if someone has taken the survey previously.

Recommendations:

Training for the interviewers should make them aware that some people may not completely process the question and, in cases where someone says Yes, they should first probe for when the interviewee took the survey and then probe for the organization that conducted it. Further probes to assess eligibility should assess the content of the survey the interviewee said that they took in 2008.

2. **What was your physical sex assigned at birth? [Check only one]**

There were no problems understanding what the question was asking. The respondents, while not always understanding why they were discussing “assignment” while being probed to assess understanding of the question, understood that they were male at birth. In other words, they did not imply or say that someone *decided* they were male, they just *were* male. A few specifically mentioned their sexual anatomy as a reason why they were male or assigned male physical sex at birth. Although, as noted above, some focus group participants said that they felt some younger transwomen might say female, none of the younger respondents in cognitive interviews actually did so.

The heart of the issue is that respondents didn't feel that someone was imposing "male" on them at birth (i.e. the notion that sex is imposed as a classification by someone else rather than self selection or some other form of determination was not voiced in relation to this question as it was for question 3 which relates to gender). Also note, the screening for the focus groups asked for male-to-female transgendered persons and the screening for the cognitive interviews asked for persons who are aged 18 or over who were assigned a male sex at birth, but who identify, live, or present as women and then asked if they were assigned a male physical sex at birth. Although no one screened was excluded from the testing project for saying they were female, anyone who would have done so would have been excluded from the actual survey.

Recommendations:

Training for the interviewers should make them aware that some people confuse sex with gender and masculine/feminine. The interviewers should be trained to ask whether the interviewee's birth certificate originally listed male or female in order to better ensure that no one who is eligible is inappropriately excluded.

3. Do you consider yourself to be male, female, or transgender? [Check only one]

Only one (1) person said that he considered himself to be male. Twelve (12, n=63%) people chose transgender. Four (4) people chose female, and two (2) people chose both female and transgender.

The Hispanic respondents said that most Hispanics, especially immigrants, do not know the term transgender. One respondent said transwomen are called "a group of mariposas" (butterflies) within the community, but they are most often called derogatory names by non-LGBT Hispanics. One young Hispanic transwoman said that she usually says that she is a transsexual when talking to other Hispanics/clients. This transwoman knew that transsexual is most often used as someone who has had sexual reassignment surgery, but she said that she prefers the term even though she has not had SRS. She said she had started using the word *transsexual* at 14 years old. She reported that "marimacho" is the Spanish slang used for a butch lesbian.

Several older African American respondents noted that the term *transgender* was not one that they had grown up with and that it has been around for only a few years. Because of this, they said or would have said "female" when they were younger, but now that they were involved in the community they knew they were "supposed to say transgender." These respondents did not appear to be empowered by adoption of the term but instead felt that the use of the term was imposed upon them. Note that this sense of imposition did not appear to generate anger but was indicative that there was not complete comfort with the use of the term as a self-descriptor. Some of these respondents said that they started using the term transgender to be respectful to some people. Others said that they thought that transgender was a good term and that "people are proud to say, 'I'm transgendered.'"

One person said that he was male. He said, "I don't really think there is a thing that is transgender," and "transgender is just another word to keep from using the word gay... a word to pacify someone's feelings." This person, however, also said that on a job form he would either

check transgender or leave it blank. He said that it would be more convenient to choose transgender because he looks like a woman even though he is a man.

Most respondents stated that they would either select female or leave the question blank if male and female were the only answer choices on a job application. Upon seeing a blank answer on the application, employers would often fill in the response on behalf of the applicant, assuming their gender to be female. This way, the transwomen would not be lying on their application, because they did not make the selection, and therefore could not be fired for lying on the application. Some respondents changed their driver's licenses to reflect a female gender. A few respondents, typically those who were older, said that they used male only for forms but used female everywhere else.

Recommendations:

We do not recommend any changes to this question, even though not everyone accepted the part of the question that says, "consider yourself to be." Some respondents noted that they considered themselves to be women but that other people would call them gay men, transgender, or other (often derogatory) names. Other respondents said that they interpreted this question to be asking "what am I labeled?" or "what do people call me?"

4. In the past 12 months, have you ever lived as a woman? By living as a woman, I mean dressing and presenting yourself as a woman.

Not all of the respondents were asked this question because it was originally meant to be asked only of those who did not answer that they were male at birth but consider themselves to be female or transgender (only one person would have been asked this question if we followed this skip pattern – he responded yes). At CDC's urging, the interviewers began asking this question of more respondents in order to understand how the question was interpreted. No one was confused by the question. Common ways of describing how living as a woman was different involved dressing as a woman daily for all purposes (i.e., not just outside of work), wearing cosmetics, etc. When asked, not everyone understood or used the term *presenting*; instead they preferred or better understood the term *living as a woman*.

Recommendations:

No changes are recommended.

5. About how many people do you know personally who were born male but identify, live, act, or consider themselves to be a woman and who are at least 15 years of age, live in [Chicago or Washington DC], and who you've seen in the past 30 days?

See FLASHCARD A

Who you know personally that

- were born male but identify, live, act, or consider themselves to be a woman,

- are at least 15 years of age,
- live in [*project area*], and
- you've seen in the past 30 days.

The respondents provided a wide range of figures. The numbers ranged from 2, in the case of someone who had been incarcerated for a large part of the prior 30 days, to 400, in the case of someone who said that she had gone to a transgender fair. Some other respondents said that they also had gone to a large party or festival--although it was not clear whether this was the same event-- and that they saw 100 or 150 people.

Some of the respondents said that in answering the question, they thought only about people who lived in Washington, DC, proper. Others considered the Washington, DC, suburbs in Maryland and Virginia. One person said that she also included transwomen that she saw that she knows live in Baltimore (approximately 30 to 35 miles away).

Some respondents said that they originally thought of friends and then added more people if the number seemed too small. Others said that they just counted a few friends and then rounded to a number. Although steps can be taken to reduce social desirability bias, we believe a greater threat to validity and reliability lies in lack of common interpretation of the term *know personally*.

At least one respondent was slightly confused by the term *at least 15 years of age* and had to ask for clarification.

Recommendations:

To better limit the research to the appropriate locale, we recommend modifying the question to use the closest official designation possible. In our case, that would be “the city of Washington, DC.” Other specifications might say “the XYZ county” or “PDQ city and ABC county.”

We recommend that CDC consider defining the term *know personally* to better frame the estimates provided (e.g., people you know by name and see at least once a month) or eliminate outliers to better assess the true transwomen network size for the research area.

We recommend that the question be rephrased to change “who are at least 15 years of age” to “who are 15 years of age or older” or “15 or older.”

Items from Core Questionnaire

6. Do you currently have health insurance coverage? This includes Medicaid or Medicare.

The vast majority of respondents were on Medicaid, possibly because of HIV infection. No one misunderstood this question or had any confusion between free emergency services that might be provided by a hospital and care that requires payment by the patient and/or the patient's insurance. Several respondents referred to their Medicaid coverage as DC Alliance, but they knew it was a form of Medicaid coverage.

Recommendations:

No changes are recommended.

6a. Does the insurance cover transgender-related medical care, such as hormone therapy or sexual reassignment surgeries (SRS)?

Most of the respondents had Medicare for insurance. They said that Medicare covered their hormone therapy, but not SRS. When asked what they thought about when thinking of the term *transgender-related health care*, several of the respondents said that they thought of any health care that is provided to a transgendered person (e.g., treatment for a transgendered person's cold). One person said that the first thing that came to mind on hearing the term transgender-related health care was HIV, then injections.

The respondents said that they use the term *reassignment* not *realignment*, and typically they just say "sex change" rather than the more formal term.

Recommendations:

This question is double-barreled in that insurance may cover either hormone therapy or SRS, neither, or both. We suggest that CDC consider asking two or three separate questions related to medical care that a transgendered person might want, but that might not be covered by insurance. Specifically, questions could be asked about hormone therapy, about SRS, and about plastic surgery to make the body appear more feminine.

If the question is retained rather than replaced with specific questions related to medical coverage for transgender issues, we suggest that at least one alteration be made. Although the term transgender-related medical care did not seem to cause any confusion, we suggest using *transgender-specific medical care* as a possible way to avoid any misunderstanding that the question is not asking about general medical care that is provided to a transgendered person. Note that we did not test the term transgender-specific medical care, so it is possible that this term may also be misunderstood.

Some people are very open about their transgender identity. Others prefer to tell only a few people. For the next question, you will see a list of groups you may have told about your transgender identity. For each one, check "YES" if you have told some people in the group or check "NO" if you have not.

7. Which of the following groups have you told about your transgender identity?

- a. Have you told friends who are transgender**
- b. Have you told gay, lesbian, or bisexual friends**
- c. Have you told friends who are not gay, lesbian, or bisexual**

There were no problems with these first three subquestions; however, in regard to all of the subquestions, some respondents were not sure what "Not Applicable" meant. They thought, but were uncertain, that it meant "does not apply."

No one had problems with the term *transgender identity*; however, a few people did say that the two terms, *transgender* and *transgender identity*, were not synonymous. The term was typically interpreted as just another way of saying that someone was transgender.

Recommendations:

We recommend that in question 7, and anywhere else it appears in THBS, the term *Not Applicable* be replaced with *Does Not Apply*. The Does Not Apply column should be immediately next to the Yes/No columns rather than after the “Refused to Answer” and “Don’t Know” columns. We suggest altering the say box preceding the question to specify that someone should check “Does Not Apply” if they do not currently have a relationship with a specific group or type of person.

d. Have you told your family members?

Almost all of the respondents said that they had told all of their family members. In most cases they included their extended family (i.e., not just parents and siblings, but also grandparents, aunts, uncles, cousins, etc.). Hispanic respondents, however, sometimes said that they included only their local family, meaning only the members of the family in the United States--and only those who lived together. In other words, a Hispanic transwoman might say she told her siblings who she lives or used to live with, but not her parents or siblings that might live elsewhere in the United States or outside the United States. This was a sensitive topic of discussion for some of the respondents; a few grew teary eyed as they described difficult relationships with their family.

It is possible that the answers to this question were affected by cultural concepts of family. Although we did not test the questions with Anglo-Americans, Native Americans, or Asian Americans, it is possible that these groups might view *family* as their nuclear family rather than their extended family.

Recommendations:

To avoid confusion about what is meant by family, we suggest that CDC consider replacing the question with several questions that ask about specific family members (e.g., father, mother,).

e. Have you told your medical providers?

f. Have you told your mental health providers?

In regard to the two subquestions about medical and mental health providers, those who had such providers said that they either told their provider directly or that their provider eventually found out when they had to do a medical exam. Those without current medical or medical health providers reported Yes if they had told a past provider; this provider was typically the most immediate past provider.

Respondents who had mental health providers universally said that they told their providers and that they needed to in order to obtain their transgender-specific care. No one indicated that they had a mental health provider whom they had not told.

Only one person saw a difference between “providers” and doctors. She said that “No,” she had not told medical or mental health providers, but had told her doctor. Only two respondents specifically said that they had told their provider because they are still biologically male and that there may be some male health issues that the provider may need to consider.

Recommendations:

We recommend that CDC add the word *current* to these two questions or possibly change the root question (question #7) to specify ever (e.g., for family members) or current (e.g., for providers, employers).

Given that most of the respondents received mental health care specifically because of their transgender identity, as opposed to depression or another form of mental illness, the question about disclosure to a mental health care provider might be unnecessary. We suggest that CDC consider whether there will be enough variation with this question to determine differential HIV risk. If not, then we suggest that the question be deleted.

g. Have you told your employer?

Very few of the respondents were employed in the common sense of the word. Some of them reported that they engaged in sex work or that they had done so in the past. When answering this question, however, they did not refer to sex work clients as employers; instead they referred to retail establishments or other forms of typical employment.

Several of the unemployed respondents said yes because they had told prior employers of their transgender identity—typically, the most recent employer of any duration (i.e., a job they held for longer than a trial period). At least one person chose Yes because her employer knew or had found out, but it was not something that she herself disclosed. At least one other person chose Yes because she thought her co-workers knew, but not the woman she worked for (i.e., not her boss). One person left the question blank because she was not currently employed.

Recommendations:

We recommend that this subquestion be edited to add *current* before employer.

h. Have you told your partner or spouse?

Of all the disclosure questions, this was the one where the respondents most differentiated between current and ever. Although some respondents without current partners or a spouse answered based on their last partner, several respondents stated that they currently didn’t have one. Unfortunately, some of these respondents who did not have a significant other chose No rather than Not Applicable. This selection seemed to be based on a simple yes/no decision rule used to go through the subquestions.

The respondents answered this question in relation to longer-term partners, not sex work clients. Boyfriends were sometimes considered in answering the question, but these boyfriends were longer-term relationships. The main factors in deciding whether someone was a partner was length of time together and the anticipation that the relationship would continue into the future.

Recommendations:

To make answering this question easier, we suggest adding the word *current* before partner or spouse. As suggested earlier, we recommend editing the say box to include wording that calls to mind Does Not Apply as a possible answer.

The next questions are about sexual behavior. Some of the questions are for people who have a penis and some are for people who have a vagina. To ask you the proper questions, we would first like to ask about your physical anatomy.

8. Do you have a surgically constructed vagina?

There were no problems with this question or the say box preceding it. More respondents preferred this wording of the question to the alternative, which was also presented to them. The alternate was a series of questions asking respondents to affirm or deny that they had a surgically constructed vagina, a penis, or were born with a vagina. The respondents said that they thought the current wording of the question was more direct. Some respondents also said that some people would be offended if you asked if they had a penis and some respondents would feel uncomfortable saying they had a penis. This was the case with at least two respondents who said that they prefer to say they have a large clitoris rather than a penis.

Recommendations:

We recommend leaving the question as it is currently worded rather than the alternative phrasing.

Male Sex Partners

9. Have you ever had [*insert “oral or anal” if don’t have vagina; insert “oral, vaginal, or anal” if have vagina*] sex with a man?

There were no difficulties answering this question. Perceptions of *sex* varied by age. Younger persons were less likely than older persons to say that any sexual activity aside from anal intercourse, was sex (e.g., oral sex is not *sex*). When asked what counted as “having sex,” several respondents, especially respondents in their late 20s or early 30s said that mutual masturbation or other forms of noninsertive sexual behavior were considered sex if someone, typically their partner, ejaculated.

For the most part, unless they had a transgendered sexual partner, the respondents did not think of transgendered persons when answering this question. They described the men they have sex with as straight, gay, or bisexual men.

Recommendations:

Because the question already specifies oral or anal sex (or oral, vaginal, or anal), we recommend leaving the question as is.

10. In the past 12 months, has anyone ever forced you to have sex with them?

There was no confusion about this question, but several respondents had a slightly wider definition of sex if force was involved than if the sex was consensual. In essence, for these respondents, if there was forced sexual behavior, regardless of whether penetration occurred, it was considered forced sex. Other respondents, however, said that they thought of “total rape” when asked about forced sex and did not consider other less extreme sexual acts when thinking about the question. More than a few respondents indicated that they were forced or almost forced to have sex at some point in their life, but only one respondent reported that this forced sex had taken place in the last 12 months.

Recommendations:

No changes are recommended.

11. Think about the last time you had sex with a male partner. At that time was this partner aware you were transgender or gender variant?

There was no confusion about what the question was asking. All of the respondents reported whether their last partner knew that they were transgender. In probing, there was no difference in how this question was interpreted—the last male sexual partner could have been someone they had a dating or other non-exchange relationship with, or that person could have been a sex work client. In every case, the respondents reported that they thought that the person knew that they were transgender.

There was confusion about the term *gender variant*. None of the respondents had heard of the term before. Some guessed that it meant someone whose gender varied, others said that they just did not know what the term meant. One person guessed that it meant “versatile.” Another person thought that someone could have more than one gender and said, “You learn something new every day.” Yet another respondent said that gender variant meant, “like it’s different” but then went on to say that gender variant is the same as transgender. Despite this confusion though, no one had difficulty in answering the question because the term was paired with *transgender*.

There appeared to be cultural differences in how transwomen guess or know that someone is aware that they are transgender. The African American transwomen typically said that people who don’t know will ask them if they have kids or will say things like they want to have kids with them. These questions, which are typically asked of biological women, are clues that the person does not know. Hispanic transwomen, however, did not report that people ask them similar questions. They more often said that the way men treated them told them if they knew or not. If someone treated them well, they probably did not know.

Note that the question as tested does not use the phrasing used in the most current version of the THBS. Unlike the one tested, the current version is not time specific in regard to sexual activity; it asks, “Have you ever talked to this partner about your transgender or gender-variant identity?” The cognitive testing did not assess the term *gender variant identity*--only the *term gender-variant*.

Recommendations:

Though there was no confusion from its use, there was no familiarity with the term *gender variant*. We recommend using *transgender* instead throughout the instrument or always pairing *gender variant* with *transgender*.

11a. Did you tell him that you were transgender or gender variant?

Although most of the respondents said yes, they had told their last male partner they were transgender, at least one person chose Yes because she knew that her partner was aware she was transgender (because of a mutual transwoman friend) and not because she had told her partner. Most of the respondents, especially the older ones, clearly said that they had told their partners first, before any sexual activity took place. Some, however, indicated that they did this only in the case of a romantic interest as opposed to a sex work client. In the latter situation, they said they would not tell the client but that that this person might know anyway, because they suspected that the client was looking specifically for a transwoman.

Recommendations:

No changes are recommended.

Female Sex Partners

12. Have you ever had sex with a woman?

There was no confusion about this question. Most respondents said that they thought of “having sex with a woman” as primarily vaginal sex; they included other activities when probed for further explanation. Because only a few (n=8) respondents had ever had sex with a woman--most saying that it was several years in the past--extensive probing in this area was not conducted. For the most part, the respondents reacted negatively to the idea of having sex with a woman.

Recommendations:

No changes are recommended.

Transgender Sex Partners

13. In the past 12 months, with how many different transgender persons have you had vaginal or anal sex?

Only three of the respondents said that they had had sex with transgendered persons in the past 12 months. Two respondents each reported one (one partner who was typically both transgender and the respondent's lover), but one respondent said that she had sex with five (5) transwomen in the past 12 months. This respondent asked if drag queens counted as transgendered. She said that she has maybe 60 clients a month and that, based on the questions they ask her, they may be transgendered.

One person was confused by the word *different*. Rather than thinking of the word as "separate," she took it to mean "not normal." A few of the respondents were unclear that the question was asking for a number and needed to ask a question to confirm that they were to supply a number. One person said she did not think of zero as an answer and did not know "if you were talking about people like me."

In general, the respondents strongly disliked the idea of having sex with another transgendered woman. A few older respondents noted that the prohibition of "sex between sisters" is not as strong as it was when they were younger, but that they were just not sexually interested in other transwomen.

Recommendations:

We did not specifically probe for interpretation of the word *different* or test the question without that word. As such, no changes in the question are recommended, but we do recommend putting *people* or *transgendered people* next to the blank where a number is to be entered.

Last transgender sex partner

13a. Was the last transgender person you had sex with assigned a male or female sex at birth?

All of the transgendered persons the respondents said they had sex with were men who were transitioning to be women (i.e. transwomen). Two of the participants said that their regular partner is a transwoman. Most of the participants indicated that they would not have sex with a woman even if she were transitioning to become a man or was a transsexual and had the external genitalia of a man. Similarly, most of the participants strongly disliked the idea of having sex with another transwoman, saying it would be like having sex with a sister. At least one participant did not seem to consider the possibility that she could have had sex with a transman until she was asked if the transgendered person she had sex with was assigned a male or female sex at birth.

Recommendations:

No changes are recommended.

Hormone Section

14. Have you ever used hormones to change your body? This would include hormones that are applied topically, taken orally, or injected.

Almost all of the respondents had tried hormones. No one considered naturally occurring hormones in adolescence in providing an affirmative to this question. One of the respondents who had not used any hormones did not appear to understand how they worked. This respondent indicated that she thought people got hormone shots in the areas that they wanted to get bigger (e.g., bigger hips required getting a hormone shot around the hips). This respondent also had not had any silicone injected. Another person said that she was taking hormones because the hormones were “breaking down the male hormones” and that “every little bit of hormone helps.” This person received pills from friends and gave herself hormone injections.

Several respondents did not know what the term *topically* meant. If a respondent knew what it meant, or had it explained by the interviewer, she often described a patch, a cream, or a gel. Topical hormone use was very rare; those that had experience with it referred to it as something they tried, not something they did currently or on an extensive basis.

One Hispanic respondent said that she did not know that topical hormones existed. She also said that the Hispanic transgender community differed from the African American one in that the Latinas do not fight one another and they share more hormones with one another.

One person mistakenly answered No to this question because she was thinking of now rather than ever. In other words, the person used to take hormones but was not currently doing so. This transwoman should have said Yes to question 14 rather than No.

Recommendations:

We recommend changing “topically” to “on the skin.” Given that only one person appeared to have mistakenly answered the question, we do not recommend changing “ever used” to “ever in your life used.” The latter wording was not tested and may be more likely to lead respondents to think of natural hormones that occur in puberty rather than supplemental hormones prescribed to change the appearance of a transgendered person.

15. Have you ever injected or been injected with hormones?

The most common way of taking hormones was by injection. These injections were typically paid for by Medicaid. A few respondents seemed not to have read or heard the entire question because they said Yes but in probing discussed only taking pills. They understood what injections were but somehow misunderstood the question. It is possible that this was due either to haste in completing the questionnaire or to focusing too much on the interviewer and not enough on what the interviewer was saying.

Recommendations:

Although no change appears to be needed, CDC could consider whether adding language about the use of a syringe or needle would reinforce the injection aspect of the question. If CDC does add additional wording to such effect, the question should be assessed with transwomen to ensure that confusion does not arise from respondents’ thoughts about other ways to inject hormones that do not involve a needle or syringe.

16. How often did you get hormone injections in the past 12 months? [Check only one.]

This question was often difficult for the respondents to answer. Most respondents said that they get a shot every two weeks or once a month. These respondents looked for every two weeks or twice a month and had trouble identifying “More than once a month” as the appropriate answer for that frequency.

At least one person answered the question based on what she said she was doing the longest rather than what she was currently doing. This switch in frequency of treatment was made in the month prior to the cognitive interview. No one else said that what they reported was different from what they currently do.

Recommendations:

The current format for the responses may be confusing to respondents because the first category is “Never,” followed by the most frequent response “More than once a day,” and progressively less frequent categories. We suggest reordering the responses so that they flow smoothly in order of frequency. Moreover, we recommend that CDC consider adding the category “Every two weeks” or the category “Twice a month.” It is possible that several of the frequencies listed are very unlikely to be used. As such, CDC should consider deleting the less frequent choices such as “More than once a day” and “Once a day,” thus making “More than once a week” the selection with the highest frequency.

17. How are you getting hormones for your injections? [Check all that apply.]

In general, there was no confusion about this question. The answer options guided the respondents into understanding the question being asked. The respondents answered based on how they were currently getting or most recently got their hormones for injection. They focused specifically on the hormones themselves, not the injection. Thus if they obtained the hormones at a pharmacy using a doctor’s prescription and then went home and injected the hormones themselves, or had someone else inject them, they would say “Through a prescription from a doctor” not “From a friend” or other.

A few respondents noted that it is easier to get a prescription for hormones than it was in the past. One respondent said of doctors, “They’ll prescribe you pills, but not prescribe you injections. Injections are better for your liver and they work better for me.”

Recommendations:

Although the question is worded in the present tense, and respondents seem to answer the same way, we recommend adding the word *currently* before *getting hormones* to further ensure that everyone is using the correct time frame. Several respondents said that although they were currently getting their hormones from a doctor, in the past they got them from friends or on the street.

18. In the past 12 months, with how many people did you use a needle after someone else had injected hormones with it?

Respondents generally interpreted this question as asking whether they had shared needles in the past 12 months. Because this question was asked after one with a similar format, the question about transgendered sexual partners, there was very little confusion that this question was asking for a number. However, instead of providing a “0,” several people wrote in “none.”

In discussing hormone injections, it was clear that although new needles are most often used, transwomen often share the same vial of hormones.

Recommendations:

We do not recommend a change to the question, but we recommend adding “people” next to the blank where a number is to be supplied.

If it is possible in QDS, CDC may wish to require that THBS be programmed such that a number (i.e., numerals rather than alphabetic spelling of numbers) is required for the blank.

Silicone Section

19. Have you ever injected, or been injected with, a substance like silicone to change the shape of your body?

Several of the respondents had received silicone injections at some point in their life. Almost all had the silicone administered by nonmedical practitioners. Several also had stories to tell of bad experiences that they heard of related to the injection of the wrong substances. Some respondents said that the wrong substance could cause discoloration as well as illness and that the way to tell if you were getting the right stuff was to look at the color of the silicone.

One person thought that “substance like silicone” included hormones. This person had used hormones and had silicone injected. Although, as mentioned in the comments to question 14, one other person who had not had either silicone or hormones confused the two, this did not appear to be widespread.

A few of the respondents, both in the focus group and in the cognitive interviews, said that they thought some people would not want to admit that they had had silicone injections. They compared the situation to asking a straight woman about plastic surgery and said that the person who had silicone would want people to think that everything was natural. A suggested way of asking the question differently was to ask, “Have you had any work done?”

Of note, several respondents said that one of the most important things to know before getting an injection was HIV status. They said that if you get injected and you are HIV positive, you are going to get sick because the silicone is hard on your immune system. These respondents strongly advocated that anyone who wanted silicone should get tested for HIV first. As one transwoman put it, “It’s important to know your status. If your T-cell count is low something is going to go off.”

Recommendations:

No changes are recommended. The recommended change in wording (“Have you had any work done?”) is not specific enough to likely produce good surveillance data. We believe that because the survey is computer administered, there is less likelihood of a respondent lying about the injection of silicone.

TG Survey: Cognitive Interview Items

Question	Wording in 12/20/07 questionnaire	THBS Question #	Why question is included in survey	Why we are cognitive testing	Probes
<p>1. During 2008, did you already complete at least part of the health survey that <i>[Insert Project Name]</i> is conducting? It could have been here or at another location.</p> <p>No Yes Refused to answer Don't know</p>	Same	ES3	To assess previous participation in the survey	To ensure that the question is not confusing. To ensure that the survey won't be confused with other similar surveys.	<p>Have you ever taken a health-related survey before? Can you tell me about it?</p> <p>Did you know what organization wanted the data? How did you know that?</p>
Notes					
<p>2. What was your physical sex assigned at birth? <i>[Check <u>only one</u>]</i></p> <p>Male Female Intersex/ambiguous Refused to answer Don't know</p>	Same	ES7	To assess if they were male or female at birth. Only persons assigned/born male are eligible to participate.	To make sure there is clear understanding of what is meant by "physical sex" and "assigned at birth."	<p>Can you tell me about a time when you were assigned to a group or class at school?</p> <p>How would you decide a baby's physical sex?</p>
Notes					

Question	Wording in 12/20/07 questionnaire	THBS Question #	Why question is included in survey	Why we are cognitive testing	Probes
<p>3. Do you consider yourself to be male, female, or transgender? [<i>Check only one</i>]</p> <p>Male Female Transgender Other (<i>Specify _____</i>) Refused to answer Don't know</p>	Same	ES8	To make sure the person is eligible (1- persons assigned a male sex at birth, but do not identify as male or 2- men who live or "present" as a woman)	To make sure that the participants believe "transgender" is an appropriate response?	<p>When you think about the words "transgender, male, and female" what comes to mind? How are they different from each other?</p> <p>When discussing gender, how do you describe yourself? Tell me about when & why you first started using that word.</p> <p>How do you answer this type of question on forms or applications that offer only male or female as the option? How do you decide to pick one over the other?</p>
Notes					

Question	Wording in 12/20/07 questionnaire	THBS Question #	Why question is included in survey	Why we are cognitive testing	Probes
<p>4. In the past 12 months, have you ever lived as a woman? By living as a woman, I mean dressing and presenting yourself as a woman.</p> <p>No Yes Refused to answer Don't know</p>	Same	ES9	This question is only asked of persons who are born male and identify as men. We need to make sure that they are considered Transgender according to CDC's operationalization.	To assess what is considered "living as a woman" or "dressing and presenting as a woman"	<p>What happens when someone lives as a woman? What differences do you see between living as a woman vs. a man? [<i>INTWR: get specific examples</i>]</p> <p>IF NO: Can you tell me about someone you know that presents as a woman?</p> <p>IF YES: Do you do anything differently living as a woman than you would living as a man?</p>
Notes					

Question	Wording in 12/20/07 questionnaire	THBS Question #	Why question is included in survey	Why we are cognitive testing	Probes
<p>About how many people do you know personally who were born male but identify, live, act, or consider themselves to be a woman and who are at least 15 years of age, live in <i>[Chicago or Washington DC]</i>, and who you've seen in the past 30 days?</p> <hr/> <p><u>FLASHCARD A</u> (Use with question ES10)</p> <ul style="list-style-type: none"> • Who you know personally that • were born male but identify, live, act, or consider themselves to be a woman, • are at least 15 years of age, • live in <i>[project area]</i>, and • you've seen in the past 30 days. 	<p>About how many people do you know personally that were born male but identify, live, act, or consider themselves to be a woman and who are at least 18 years of age, live in <i>[project area]</i>, and who you've seen in the past 30 days?.</p>	<p>ES10</p>	<p>The question is used to weight data in Respondent Driven Analysis the respondent's network size. The respondent's network size is defined by the number of people the respondent knows who would meet the eligibility criteria for the study and whom the respondent has seen in the past month. The 30-day time period is used to enhance accuracy of recall.</p>	<p>To assess how difficult it is to come up with a response to this question.</p> <p>.....</p> <p>To answer:</p> <p>How did they come up with the number? What is meant by "personally know" How did they determine a persons age? How did they determine if a person lived in the given city? What did they think we meant by "seen"?</p>	<p>Who do you think about when you read this question?</p> <p>Tell me about them & why you thought of them and not someone else. What's your relationship like? How long have you known them? Did you know them before or after they considered themselves a woman? Do they live near you? Where did you see them?</p> <p><i>[INTWR: Count names; if different from the number provided, ask]:</i></p> <ul style="list-style-type: none"> • How did you decide who to count? • How did you come up with that number?
<p>Notes</p>					

Question	Wording in 12/20/07 questionnaire	THBS Question #	Why question is included in survey	Why we are cognitive testing	Probes
<p>5. Do you currently have health insurance coverage? This includes Medicaid or Medicare.</p> <p>No Yes Refused to answer Don't know</p>	Same	7	Health Insurance coverage is a key variable in measuring access to medical care among respondents.	To insure that the participant understands health insurance different from other ways of accessing medical care (e.g., free clinics, ER visits).	<p>Can you tell me a little bit about your insurance coverage?</p> <p>Or</p> <p>Can you tell me about the last time you had health insurance? What was the insurance like?</p>
Notes					
<p>6. Does the insurance cover transgender-related medical care, such as hormone therapy or sexual reassignment surgeries (SRS)?</p> <p>No Yes Refused to answer Don't know</p>	Same	8	To assess access to special treatments/therapies of interest to the transgender community that may be related to HIV risk if performed by an unlicensed practitioner.	<p>To assess what is thought of as “transgender-related healthcare”?</p> <p>To investigate if would be better to use “alignment” than “reassignment”?</p>	<p>Tell me about transgender related health care.</p> <p>How do you usually discuss these kinds of surgery with friends?</p> <p>Do you know any transgender people who have special health care needs? What are they?</p> <p>IF APPLICABLE: Have you ever tried to get these kinds of procedures covered by your insurance? What happened?</p>
Notes					

Question	Wording in 12/20/07 questionnaire	THBS Question #	Why question is included in survey	Why we are cognitive testing	Probes
<p>SAY: Some people are very open about their transgender identity. Others prefer to tell only a few people. For the next question, you will see a list of groups you may have told about your transgender identity. For each one, check “YES” if you have told some people in the group or check “NO” if you have not.</p>	Same	Before Question 10	The SAY box is a transition used to call attention to a new section of the survey.	<p>To assess how the term: “transgender identity” is interpreted.</p> <p>Would including the term “gender variant” improve the question (i.e., transgender or gender variant identity)?</p>	<p>Please tell me about someone who has a transgender identity. What are they like?</p> <p>When would you use the word “gender” when talking with friends?</p>
Notes					
<p>7a. Have you told friends who are transgender?</p> <p>7b. Have you told gay, lesbian, or bisexual friends?</p> <p>No Yes Refused to answer Don't know Not Applicable</p>	Same	10a	<p>It is a measure of how “out” the respondent is about their transgender status.</p> <p>This question will help assess how many closeted transgender persons the recruitment method reaches.</p>	<p>What friends did they consider as transgender and why?</p> <p>If they respond “no”, clarify if they said no because they didn’t know anyone meeting this category.</p> <p>Also, if they said “no” did they already know? If so how did they know??</p>	<p>Please tell me about a time when you told someone you thought about being a woman.</p> <p>Can you tell me a little bit more about this person?</p> <p>What’s your relationship like with them? What made you decide to discuss it with them? Was this an easy or difficult conversation?</p>
Notes					

Question	Wording in 12/20/07 questionnaire	THBS Question #	Why question is included in survey	Why we are cognitive testing	Probes
<p>7c. Have you told friends who are not gay, lesbian, or bisexual?</p> <p>7d. Have you told your family members?</p> <p>No Yes Refused to answer Don't know Not Applicable</p>	<p>Same</p> <p>Same</p>	<p>10c</p> <p>10d</p>	<p>Same</p>	<p>What friends did they consider as transgender and why?</p> <p>If they respond “no”, clarify if they said no because they didn’t know anyone meeting this category.</p> <p>Also, if they said “no” did they already know? If so how did they know??</p>	<p>IF NO: What do you think your family knows about your life? Have you ever thought about telling them? Why or why not?</p> <p>IF YES: What made you decide to discuss it with them? Was this an easy or difficult conversation?</p>
<p>Notes</p>					

Question	Wording in 12/20/07 questionnaire	THBS Question #	Why question is included in survey	Why we are cognitive testing	Probes
7e. Have you told your medical providers?	Same	10e	Same	What friends did they consider as transgender and why?	Please tell me a little bit about your medical providers? Who are they and what do they know?
7f. Have you told your mental health providers? No Yes Refused to answer Don't know Not Applicable	Same	10f		If they respond "no", clarify if they said no because they didn't know anyone meeting this category. Also, if they said "no" did they already know? If so how did they know??	What about mental health providers? IF YES: What made you decide to discuss it with them? IF NO: Have you ever thought about telling any of your doctors or health care providers? Why or why not?
Notes					

Question	Wording in 12/20/07 questionnaire	THBS Question #	Why question is included in survey	Why we are cognitive testing	Probes
<p>(7g). Have you told your employer?</p> <p>(7h). Have you told your partner or spouse</p> <p>No Yes Refused to answer Don't know Not Applicable</p>	<p>Same</p> <p>Same</p>	<p>10g</p> <p>10h</p>	<p>Same</p>	<p>To assess if employer includes exchange sexual partners.</p> <p>To assess if partner includes non-sexual relationships.</p> <p>If they respond “no”, clarify if they said no because they didn’t know anyone meeting this category.</p> <p>Also, if they said “no” did they already know? If so how did they know??</p>	<p>Please tell me about your employer?</p> <p>How do you get money?</p> <p>Can you please tell me about your partner? What makes him or her your partner?</p> <p>Would you ever say you have more than one partner?</p> <p>IF APPLICABLE: Do you think it’s important that your employer know? Tell me why.</p>
<p>Notes</p>					

Question	Wording in 12/20/07 questionnaire	THBS Question #	Why question is included in survey	Why we are cognitive testing	Probes
<p>8. Do you have a surgically constructed vagina?</p> <p>No Yes Refused to answer Don't know</p>	<p>11. Does this apply to you?</p> <p>11a. "I have a vagina that was surgically constructed." 11b. "I was born with a vagina." 11c. "I have a penis." No Yes Refused to answer Don't know</p>	<p>11</p>	<p>Unprotected vaginal sex is an HIV risk behavior. This question was suggested by CDC's expert panel.</p>	<p>Included as cognitive interview item to know which text to use in subsequent sex questions.</p>	<p>Can you tell me about anyone you know with a surgically constructed vagina? What did she have done?</p> <p>Let me ask you about a different way of asking about sexual reassignment surgery. What do you think about asking [INTWR: <i>see 12/20/07 wording</i>]?</p> <p>When you talk about your sexual anatomy, what do you usually say?</p>
<p>Notes</p>					

Question	Wording in 12/20/07 questionnaire	THBS Question #	Why question is included in survey	Why we are cognitive testing	Probes
<p>Say Boxes</p> <p>For these questions, "having sex" means oral or anal sex. Oral sex means your partner put his mouth on your penis or you put your mouth on his penis. Anal sex means you put your penis in his anus (butt) or he put his penis in your anus (butt).</p> <p>OR</p> <p>For these questions, "having sex" means oral, vaginal, or anal sex. Oral sex means your partner put his mouth on your vagina or you put your mouth on his penis. Vaginal sex means your partner put his penis in your vagina. Anal sex means you put your penis in his anus (butt) or he put his penis in your anus (butt).</p>	Same	Before Question 13	The SAY box is included to help insure the respondent knows what CDC means by having sex.	To assess how the participants normally think about the term "having sex."	<p>When you think about the term "having sex" what comes to mind? Does anything have to happen before you say you have "had sex"?</p> <p>In your mind, what <i>doesn't</i> count as 'having sex'?</p>
Notes					

Question	Wording in 12/20/07 questionnaire	THBS Question #	Why question is included in survey	Why we are cognitive testing	Probes
<p>9. Have you ever had <i>[insert “oral or anal” if Q8 in (no, refused, or don’t know; insert “oral, vaginal, or anal” if Q8 = yes]</i> sex with a man?</p> <p>No Yes Refused to answer Don't know</p>	<p>Have you ever had <i>[insert “oral or anal” if Q11 in (0, .R, .D); insert “oral, vaginal, or anal” if Q11=1]</i> sex with a man?</p>	<p>13</p>	<p>HIV behavioral surveillance requires information about risk behavior with various partner types.</p> <p>Gateway question to determine whether or not respondents will be asked a series of questions about sexual behaviors with same sex partners.</p>	<p>To assess what is understood when we use the term “man”?</p> <p>Would they include transgender persons (such as transmen, pre-op or no-op transwomen) in this category?</p>	<p>Tell me a little bit about the men you have had sex with. How would you describe them?</p> <p>When you think about the man or men you have had sex with, do you consider people who were born women, but are now men?</p>
Notes					
<p>10. In the past 12 months, has anyone ever forced you to have sex with them?</p> <p>No Yes Refused to answer Don't know</p>	<p>Same</p>	<p>20</p>	<p>Forced sexual behavior is a risk factor for HIV. This question has been asked in many local HIV surveys with TG persons.</p>	<p>To assess what behaviors/situations are considered forced sexual activity</p>	<p>Do you know anyone who was forced to have sex? Could you tell me about it?</p>
Notes					

Question	Wording in 12/20/07 questionnaire	THBS Question #	Why question is included in survey	Why we are cognitive testing	Probes
<p>11. Think about the last time you had sex with a male partner. At that time was this partner aware you were transgender or gender variant?</p> <p>No Yes Refused to answer Don't know</p>	NA	NA	This question was suggested by CDC's transgender expert panel. Non-disclosure may be related to risk behaviors.	<p>To assess how participants understand "aware you were transgender or gender variant?"</p> <p>Is one term better than the other?</p>	<p>How can someone tell if another person knows they are transgender? (How can you tell if someone knows you are transgender?)</p> <p>How often does your sexual partner or sexual partners know about your gender? Under what circumstances would you tell them about it?"</p> <p>Was there ever a time when it was difficult for you to approach this topic with a potential sexual partner? How did you deal with it? Do you still use that approach (when necessary)?</p>
Notes					

Question	Wording in 12/20/07 questionnaire	THBS Question #	Why question is included in survey	Why we are cognitive testing	Probes
<p>11a. Did you tell him that you were transgender or gender variant?</p> <p>No Yes Refused to answer Don't know</p>	<p>Have you ever talked to this partner about your transgender or gender variant identity?</p> <p>No Yes Refused to answer Don't know</p>	<p>35</p>	<p>This question was suggested by CDC's transgender expert panel. Non-disclosure may be related to risk behaviors.</p>	<p>To investigate what reasons someone might say "no" ... did they say "no" because they don't identify with "transgender or gender variant"?</p>	<p>Who would you consider to be transgender? What about gender variant? Is there a difference between asking about a "transgender identity"? What about a "gender variant identity"? What term, if any, better describes you?</p> <p>Let me ask you about a different way of asking about whether or not you have talked about being a woman in a man's body. What do you think about asking [12/20/07 wording]?</p>
<p>Notes</p>					

Question	Wording in 12/20/07 questionnaire	THBS Question #	Why question is included in survey	Why we are cognitive testing	Probes
<p>12. Have you ever had sex with a woman?</p> <p>No Yes Refused to answer Don't know</p>	Same	43	<p>HIV behavioral surveillance requires information about risk behavior with various partner types</p> <p>Gateway question to determine whether or not respondents will be asked a series of questions about sexual behaviors with female sex partners.</p>	<p>To assess understanding of “woman”? Would they include transgender persons in this category, like transwomen, or pre-op or no-op transmen?</p> <p>To assess what behaviors are “having sex”?</p> <p>Sexual behaviors are easy to define to the respondent when a penis is involved. – Here there’s no penis so we left it open for the respondent to interpret. Given that we are asking about “ever” respondents may be including women they had sex with before their vagina was constructed.</p>	<p>If you were going to have sex with a woman, what kinds of things do you think you would do?</p> <p><i>(If Yes, When was this? What kinds of things did you do?)</i></p> <p>(When you think about the woman or women you have had sex with, do you consider people who were born men, but are now women?)</p> <p>What <i>wouldn't</i> count as having sex with a woman?</p>
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Question	Wording in 12/20/07 questionnaire	THBS Question #	Why question is included in survey	Why we are cognitive testing	Probes
13. In the past 12 months, with how many different transgender persons have you had vaginal or anal sex?	Same	44	<p>HIV behavioral surveillance requires information about risk behavior with various partner types.</p> <p>Gateway question to determine whether or not respondents will be asked a series of questions about sexual behaviors with transgender partners.</p>	<p>To investigate who the respondents include as sex partners... are transgender persons counted elsewhere as men or women, both? Are both transwomen (MTF) and transmen (FTM) included?</p>	<p>Tell me a little bit about sex with transgender people. When is it sex?</p> <p>When would you say you had sex with a transgender person? What would that person need to be like to be considered transgender?</p>
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Question	Wording in 12/20/07 questionnaire	THBS Question #	Why question is included in survey	Why we are cognitive testing	Probes
13a. Was the last transgender person you had sex with assigned a male or female sex at birth? Male Female Refused to answer Don't know	Same	44e	HIV behavioral surveillance requires information about risk behavior with various partner types	To assess how they know the sex assigned at birth?	How would you know whether or not someone you had sex with was transgender? What if they had surgery on to alter their sexual anatomy?
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Question	Wording in 12/20/07 questionnaire	THBS Question #	Why question is included in survey	Why we are cognitive testing	Probes
<p>14. Have you ever used hormones to change your body? This would include hormones that are applied topically, taken orally, or injected.</p> <p>No Yes Refused to answer Don't know</p>	<p>Have you ever used hormones to change your body? This would include hormones that are applied topically, taken orally, or injected. "Applied topically" means hormones are applied to the skin.</p> <p>No Yes Refused to answer Don't know</p>	<p>46</p>	<p>This question was developed from local surveys and in consultation with external subject matter experts. Injections by unlicensed practitioners are an HIV risk.</p>	<p>Understanding of the phrase "hormones to change your body"? Would they include natural hormonal changes like those during adolescence? Would they include the use of birth control?</p>	<p>Please tell me a little about hormone use? What kinds of things do people do?</p> <p>What do you know about the process? How did you first come to hear about it?</p> <p>Can you tell me about a time when you applied a drug topically? What about taking a drug orally?</p>
<p>Notes</p>					

Question	Wording in 12/20/07 questionnaire	THBS Question #	Why question is included in survey	Why we are cognitive testing	Probes
15. Have you ever injected or been injected with hormones? No Yes Refused to answer Don't know	Same	48	Included as a trigger question to ask subsequent items on hormone injections. Injections by unlicensed practitioners are an HIV risk.	To assess understanding of the types of hormones and injections of interest to CDC	Can you tell me what goes on when someone is injected with hormones? Please walk me through the process.
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Question	Wording in 12/20/07 questionnaire	THBS Question #	Why question is included in survey	Why we are cognitive testing	Probes
<p>16. How often did you get hormone injections in the past 12 months?</p> <ul style="list-style-type: none"> Never More than once a day Once a day More than once a week Once a week More than once a month Once a month Less than once a month Refused to answer Don't know 	Same	50	Included as a trigger for the next questions on hormone injections	To assess how hard it is to answer this question.	<p>How did you decide what your answer was? As far as you know, is there a standard procedure, or is it different person-by-person?</p> <p>Think about someone you know who injects hormones? How often do they do it? How do you know?</p>
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17. How are you getting hormones for your injections? Through a prescription from a doctor From someone on the street From a friend Other (Specify _____) Refused to answer Don't know	Same	51	Hormone injections from unlicensed practitioners are an HIV risk (from contaminated vials and needles).	To assess what is meant by "getting your hormones"?	Tell me how you get your hormones? Please walk me through the process. Has this changed for you over time? Can you tell me about how anyone else you know gets their hormones?
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Question	Wording in 12/20/07 questionnaire	THBS Question #	Why question is included in survey	Why we are cognitive testing	Probes
18. In the past 12 months, with how many people did you use a needle after someone else had injected hormones with it?	Same	56	This question assesses risk to both the individual and their network.	To assess how participants are answering this question. To assess understanding of the question.	<p>Do you usually inject hormones with other people?</p> <p>What do you, meaning all the people present at the time, do when injecting hormones? Can you walk me through the process? Where (for example, your home) do you usually get injections? Can you tell me about the needles?</p> <p>How did you decide who to count? Was there anyone you weren't sure to include? Why?</p> <p><i>[INTWR: Count names if provided. If unclear how # provided corresponds to names, ask]:</i></p> <p>How did you come up with the number of people who injected with the needle?</p>
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Question	Wording in 12/20/07 questionnaire	THBS Question #	Why question is included in survey	Why we are cognitive testing	Probes
<p>19. Have you ever injected, or been injected with, a substance like silicone to change the shape of your body?</p> <p>No Yes Refused to answer Don't know</p>	Same	64	This question is based on local surveys of TG persons. Improper injection of silicone or other substance is both a HIV risk behavior and a risk for other health problems.	<p>To assess understanding of the phrase “substance like silicone to change the shape of your body” and</p> <p>To assess how difficult it was to answer the question</p>	<p>Please tell me about silicone use? What do people do? Why? What do people use besides silicone?</p> <p>Can you tell me about anyone you know who has injected something? Do you think people have a hard time talking about injections to change the shape of their body?</p>
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