

## **Attachment 2 – Transgender HIV Study**

### **Discussion Guide For Focus Groups**

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### **Discussion Guide For Focus Groups**

#### **I. Introduction (NCHS/CDC and our group):**

Welcome. My name is \_\_\_\_\_. Before we start, I want to make sure that you understand who we are and why you're here. RTI International who I work for is collaborating with the National Center for Health Statistics, which is part of the Centers for Disease Control and Prevention (CDC), a federal agency. One of CDC's key missions is to monitor the health of people in the United States. One of the main ways they do that is through information that people provide on surveys and questionnaires.

Before they collect data with questionnaires, they want to make sure that the questions are clear and make sense to people. This is very important to help make sure that the data coming from respondents are of high quality. To accomplish this, questions are tried out on people like yourselves.

#### **Brief overview of the survey:**

Today we are working on testing a set of questions and getting your interpretations and opinions about wording and terms used for CDC's Transgender HIV Behavioral Survey. The survey will be administered to persons who were born male but identify, live or present as women, in several cities through out the United States. In the focus group we will talk in a group about your interpretations and opinions about a set of gender identity questions. These gender questions will be used to determine whether or not a person gets asked follow-up survey questions on behaviors that put people at risk for contracting HIV, the virus that causes AIDS. We'll also discuss silicone use and networking – strategies for finding eligible study participants. The actual survey would ask questions about sexual activities, number of sexual partners, and drug use activities, including the use of silicone and hormones. However, for the discussion today we will only talk about the questions related to gender identity, silicone use, and networking.

#### **Overview and Ground Rules**

Before we continue, I'd like to go over some general information—we'd like to establish some ground rules for our discussion, and tell you about the confidentiality procedures we have in place.

I would like you to know that in the whole discussion today, you don't have to reveal anything that you are not comfortable revealing. We are more interested in how you understand the questions than what you've actually experienced.

For purposes of the group discussion, we'd like you to pick a name that you would like to be called—a first name is fine, it doesn't even have to be your real name. [ASK THEM TO FILL OUT NAME CARDS.]

The consent form you just signed assures you that we will keep your information confidential. We would also like to ask everyone to treat this discussion as confidential. That is, if you learn anything private about another member of the group, we would like to ask you not to discuss that with anyone outside of this room. Although we are required by federal law to keep information private, we cannot guarantee that everyone else will honor your privacy. All we can do is ask that people please agree to that. And again, you should never feel obligated to share any information that you are not comfortable sharing.

We are planning to audio tape this focus group. You have probably noticed the microphones in the room. This is for note-taking purposes, so that I can concentrate on what is said and not worry about taking notes. I will use the tape when writing my notes. The tape will be destroyed after I have verified my notes. We also have a note taker today. [ACKNOWLEDGE NOTE TAKER BY NAME]. [FILL NAME] will serve as the backup to the audio recording and jot down key points.

One of the great things about this discussion is “group dynamic” – ideas that one person raises will remind someone else of a related issue. That’s great, feel free to speak up. But also don’t interrupt each other. We ask that there be only one speaker at a time so that responses can be accurately recorded. You may have more to say about some topics than others, and that’s OK too.

Don’t feel like you have to agree or disagree with anyone in this room. We want to hear about your personal experiences and thoughts and it’s OK to disagree with someone else. But please be respectful of the opinions or experiences of others in the room.

Sometimes groups start talking about subjects that are off the main topic. That’s natural; but please don’t be offended if we steer the conversation back to the material we most need to cover.

Behind me is a one-way mirror. Some of the people who are responsible for developing questions on these topics may observe the discussion so that they can hear your opinions directly from you. [The note taker] will also sit behind this one-way mirror. However, they must agree to keep your identity and anything you say here confidential.

As a courtesy to everyone, please turn off your beepers and cell phones. The discussion will last 90 minutes. We will not have breaks built into it, but should you need to go to the restroom during the discussion, please feel free to leave. However, I would appreciate it if you would go one at a time.

## **II. Reactions to Transgender Terms and Gender Assessment**

My primary goal today is not to collect particular information about *you*—instead; I want your opinions on how well certain questions will work for people in your community. For example, I want to make sure the questions are clear and make sense, and aren’t confusing or offensive. I especially want to get your opinion on the terms the researchers use to describe things and people. The researchers who wrote these questions are interested in interviewing people who were assigned a male physical sex at birth but who identify or live as women. The questions are supposed to identify whether or not someone is eligible to take the questionnaire. You should know that I did not write these questions, so don’t worry about hurting my feelings with what you say. Are there any questions?

When you’re answering, feel free to speak about your own experiences and opinions, but also feel free to share experiences and opinions of other transwomen in your community.

1. I have used the term “transwomen”. Are you comfortable with being referred to as a transwoman? Is there a term I should use instead? What do you think most of your friends in this community prefer to be referred to as?
2. In the survey, there are some questions that use the term “transgender.” For example, there is a question that asks if someone’s doctor knows that they are transgender. What do you think of the term “transgender”?

[PROBE: confusing, offensive, what is better? Other example: transgender-sensitive prevention counseling]

3. In the survey, there are some questions that use the phrase “gender variant.” What do you think of that phrase?

[PROBE: confusing, offensive, what is better?]

**NOTE: Moderator will change terminology below to reflect preferences of the group.**

**NOTE: Moderator will hand out gender questions from the screener (see questions at end).**

4. What are some of your general reactions to these questions?

[PROBE: straightforward, easy, hard, long, confusing]

5. Was there anything confusing about the questions? How about anything unclear?

[PROBE: for general words or concepts]

**NOTE: Moderator will walk participants through individual items. For each, ask:**

6. For the question “What was your physical sex assigned at birth?”

Do you think this question is appropriate for you as a transwoman?

How about other transwomen in your community – do you think that they will find this question appropriate? Do you think that they could answer this question easily? [PROBE: Do you think this question is offensive?]

Do you think that other transwomen might choose something other than “male”? Why?

7. For the question “Do you think of yourself as male, female, or transgender?”

Do you think this question is appropriate for you as a transwoman?

How about other transwomen in your community – do you think that they will find this question appropriate? Do you think that they could answer this question easily? [PROBE: Do you think this question is offensive?]

Do you think that other transwomen might choose something other than “female” or “transgender”? Why?

8. Do you think older or younger transwomen would answer these questions differently? If so, how?

9. Do you think that these questions will be enough to let researchers identify people who were assigned a male sex at birth but who identify as women?

Are there any changes you would make to these questions to make them better?

### **III. Silicone Injection Use**

**READ:** I’d like to switch topics now and talk a little bit about “pumping” or injecting silicone and similar substances used to change ones body’s appearance.

10. How comfortable do you think transwomen are answering questions about their experience with injecting silicone?

11. Do you think transwomen inject silicone or any other substance to change their appearance or body shape?

12. Can you walk me through the process of how that works?

[PROBE: what equipment is used in addition to needles?]

NOTE: Moderator should pay special attention to terminology used to described process and paraphernalia and get clarification for unfamiliar terms.

13. Do you think transwomen ever share these injections with others?

[PROBE: how often do people share, how are substances divided]

14. Does anyone have anything else to add or do you know of other ways these substances are injected and shared?

#### **IV. Recruitment Questions**

**READ:** After someone completes the questionnaire, she would be asked to invite three transwomen that she knows to participate. These transwomen will also be paid to participate. When they complete the interview, the person who invited the others will be given an additional bonus payment.

15. Transwomen who know a lot of people may have a greater chance of being asked to participate in the survey. The researchers would like to know the chance someone is asked to participate in the survey. To understand this, the researchers ask participants about how many people they know who meet all the requirements to be in the survey. This is currently asked in one question: “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 [CITY WHERE FOCUS GROUP IS CONDUCTED], and who you’ve seen in the past 30 days?” To assist with answering this question, the interviewer will provide the respondent with a flashcard, containing the information on the flip chart.

#### **INTERVIEWER TO USE FLIP CHART WITH BULLETED LIST OF ABOVE**

Do you think this question is easy or hard to answer? Why?

Would it be easier to answer if the question was broken into more than one question? (IF THE GROUP AGREES) How would you divide up the different requirements?

16. Assuming you were OK with the questionnaire, how comfortable would you be asking another transwoman you know to participate in a survey about HIV-related risk behaviors?

17. What kinds of questions do you think the transwomen you know would ask you before they agreed to do the questionnaire?

18. Why would people want to recruit others to take this questionnaire?

19. Finally, I have a question about the voice of the person who will be asking these questions. In the survey, these questions will be recorded. The people answering the survey will hear the questions through headphones. They will record their answers directly in a computer. What kind of voice do you think should be used to record the questions? Should it be the voice of a male, female, “gay-sounding” male, or someone else?

### **Transgender HIV Behavioral Survey (used as reference only)**

#### **Items from the Eligibility Screener**

1. During 2008, did you already complete at least part of the health survey that **[Insert Project Name]** is conducting? It could have been here or at another location.
- No.....  0
- Yes.....  1
- Refused to answer.....  R
- Don't know.....  D

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

Male.....  1

Female.....  2

Intersex/ambiguous.....  3

Refused to answer.....  R

Don't know.....  D

**If the person reports being born female or intersex/ambiguous, then end survey.**

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

Male.....  1

Female.....  2

Transgender.....  3

Other (**Specify** \_\_\_\_\_).....  4

Refused to answer.....  R

Don't know.....  D

**If female or transgender then skip to Q5**

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.

No.....  0

Yes.....  1

Refused to answer.....  R

Don't know.....  D

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 [San Francisco, r Chicago, or Washington DC], and who you've seen in the past 30 days?.

**INTERVIEWER: USE FLASHCARD A**

\_\_\_\_\_ (R=Refused; D=Don't know)

**Items from Core Questionnaire**

6. Do you currently have health insurance coverage? This includes Medicaid or Medicare.
- No.....  0
- Yes.....  **If no, refused or don't know then skip to Q7**
- Refused to answer.....  1
- Don't know.....  R
- D

- 6a. Does the insurance cover transgender-related medical care, such as hormone therapy or sexual reassignment surgeries (SRS)?
- No.....  0
- Yes.....  1
- Refused to answer.....  R
- Don't know.....  D

**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.

7. Which of the following groups have you told about your transgender identity?
- |   | No                         | Yes                        | Refused to answer          | Don't Know                 | Not Applicable             |
|---|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|
| a. Have you told friends who are transgender.....               | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> R | <input type="checkbox"/> D | <input type="checkbox"/> N |
| b. Have you told gay, lesbian, or bisexual friends.....         | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> R | <input type="checkbox"/> D | <input type="checkbox"/> N |
| c. Have you told friends who are not gay, lesbian, or bisexual. | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> R | <input type="checkbox"/> D | <input type="checkbox"/> N |
| d. Have you told your family members.....                       | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> R | <input type="checkbox"/> D | <input type="checkbox"/> N |
| e. Have you told your medical providers.....                    | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> R | <input type="checkbox"/> D | <input type="checkbox"/> N |
| f. Have you told your mental health providers.....              | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> R | <input type="checkbox"/> D | <input type="checkbox"/> N |

**SEXUAL BEHAVIOR**

**SAY:** 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?
- No.....  0
- Yes.....  1
- Refused to answer.....  R
- Don't Know.....  D

**Male Sex Partners**

**If Q8 is no, refused, or don't know SAY:**

Now we would like to ask you some questions about having sex with men. Some of the questions may not apply to you. Please remember your answers will be kept private.

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 (hutt) or he put his penis in your anus (hutt)

**If Q8 is yes, SAY:**

Now we would like to ask you some questions about having sex with men. Some of the questions may not apply to you. Please remember your answers will be kept private.

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).

9. Have you ever had *[insert "oral or anal" if Q8 in (no, refused, or don't know; insert "oral, vaginal, or anal" if Q8 = yes]* sex with a man?

- No.....  0
- Yes.....  1
- Refused to answer.....  R
- Don't know.....  D

*If no, refused or don't know skip to the female sex*

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

- No.....  0
- Yes.....  1
- Refused to answer.....  R
- Don't Know.....  D

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?

- No.....  0
- Yes.....  1
- Refused to answer.....  R
- Don't know.....  D

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

- No.....  0
- Yes.....  1
- Refused to answer.....  R
- Don't know.....  D

**Female Sex Partners**

**Note: if Q8 is no, refused, or don't know, then skip to Q13 Transgender Sex Partner Section if Q8 is yes, then continue with this section**

**SAY:** Now we would like to ask you some questions about having sex with women. Some of the questions may not apply to you. Please remember your answers will be kept private.

For these questions, "having sex" means oral, vaginal, or anal sex. Oral sex means your partner put her mouth on your vagina or you put your mouth on her vagina.

12. Have you ever had sex with a woman?

- No.....  0
- Yes.....  1
- Refused to answer.....  R
- Don't know.....  D

**Transgender Sex Partners**

**SAY:** The next questions are about transgender persons with whom you have had sex. By “transgender” we mean persons who were born either male or female but who identify or live as the opposite gender.

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

                             
[Refused = R, Don't know = D]

*If no transgender sex partners, or refused/don't know then skip to the Drug Use History Section*

Last transgender sex partner

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

- Male .....  1
- Female.....  2
- Refused to answer.....  R
- Don't know.....  D

**DRUG USE HISTORY**

**Hormone Section**

**SAY:** The next questions are about hormone use. This means hormones that you have used to change your body to make it more feminine in appearance.

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

- No.....  0
- Yes.....  1
- Refused to answer.....  R
- Don't know.....  D

*If no, refused or don't know then skip to the Silicone*

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

- No.....  0
- Yes.....  1
- Refused to answer.....  R
- Don't Know.....  D

*If no, refused or don't know then skip to the Silicone Section*

16. How often did you get hormone injections in the past 12 months?

- [Check only one.]**
- Never.....  0

- More than once a day.....
- Once a day.....
- More than once a week.....
- Once a week.....  4
- More than once a month.....
- Once a month.....  6
- Less than once a month.....
- Refused to answer.....
- Don't know.....  D

***If never, refused or don't know then skip to the Silicone Section***

- 5
- 7
- R

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

- Through a prescription from a doctor .....  1
- From someone on the street .....  2
- From a friend .....  3
- Other .....  4
- (Specify \_\_\_\_\_)
- Refused to answer.....  R
- Don't know.....  D

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

**[Refused = R, Don't know = D]**    \_ \_ \_

**Silicone Section**

19. Have you ever injected, or been injected with, a substance like silicone to change the shape of your body?
- No.....  0
  - Yes.....  1
  - Refused to answer.....  R
  - Don't Know.....  D

**FLASHCARD A (Use with question 5)**

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.

## **VI. Wrap-Up**

OK. Great. We are pretty much out of time. Does anyone have any last thoughts or questions?

I want to thank all of you for coming today and sharing your opinions. The information you've shared today will be very useful in helping to improve the screener and questionnaire. [MODERATOR OR RTI STAFF PERSON GIVES EACH PARTICIPANT A PACKET CONTAINING A COPY OF THE INFORMED CONSENT FORM, THE THANK-YOU LETTER, AND \$50 CASH INCENTIVE.]

### **MODERATOR NOTE:**

[END AUDIO TAPING. AFTER THE FOCUS GROUP HAS CONCLUDED AND PARTICIPANTS HAVE LEFT THE FOCUS GROUP, THE AUDIOTAPE, ALL CONSENT FORMS AND MODIFIED PARTICIPANT DATA COLLECTION SHEETS WILL BE TURNED OVER TO AN NCHS STAFF PERSON.]