

Form Approved
OMB No: 0920-1901
Exp. Date: 12/31/2018

Attachment 3e: Interview Guide HIV Positive Transgender Women

Public reporting burden of this collection of information is estimated to average 1 hour per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. An agency may not conduct or sponsor, and a person is not required to respond to a collection of information unless it displays a currently valid OMB control number. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden to CDC/ATSDR Reports Clearance Officer; 1600 Clifton Road NE, MS D-74, Atlanta, Georgia 30333; Attn: OMB-PRA (0920-1901)

Interview Guide: Transgender Women Living with HIV

Participant ID: _____ Data Collector ID: _____

Date: _____ Start time: __: __ am/pm End time: __: __ am/pm

INTRODUCTION AND PURPOSE OF INTERVIEW

Hello my name is _____ and I work for [Atlas Research or Abt Associates]. My company was selected by the Centers for Disease Control and Prevention (CDC), Division of HIV/AIDS Prevention (DHAP) to conduct a study to better understand the current barriers and facilitators to HIV prevention, care, and treatment for transgender women.

We are doing this study because we want to learn about how transgender women protect themselves from HIV, and how they take care of themselves if they have HIV. As part of this study, we are asking 20 transgender women living with HIV, 20 HIV-negative transgender women, and 10 providers who see transgender women in their clinic or office, to take part in a one hour interview in three different cities. The conversations we have will help us understand how we can improve HIV prevention and care for transgender women.

This interview is going to include a mix of open-ended and close-ended questions. For any close-ended questions, we will point to a list of responses for you to choose from. Throughout our discussion, if there are any questions you would prefer not to answer, just let me know and we can skip to the next question. Do you have any questions before we begin?

IMPACT OF HIV IN THE TRANSGENDER COMMUNITY

1. How would you describe the impact of **HIV in the transgender community**?
2. How would you describe living with HIV in the transgender community?

INCOME AND HOUSING

3. **During the last 12 months, where did you get your income? (Check all that apply)**

- | | | |
|---|--------------------------|---|
| Working full time job, 35 hours or more a week | <input type="checkbox"/> | 1 |
| Working part-time, less than 35 hours a week | <input type="checkbox"/> | 2 |
| Unemployment benefits | <input type="checkbox"/> | 3 |
| Public assistance (e.g., Welfare, food stamps, AFDC, GA, Cal-works) | <input type="checkbox"/> | 4 |
| VA benefits | <input type="checkbox"/> | 5 |
| Disability, SSA or SSI (Supplementary Security Income) | <input type="checkbox"/> | 6 |
| Main partner or sexual partner supports me | <input type="checkbox"/> | 7 |
| Other family | <input type="checkbox"/> | 8 |

Friends	<input type="checkbox"/>	9
Sex work	<input type="checkbox"/>	10
Selling drugs	<input type="checkbox"/>	11
Hustling (petty theft, shoplifting, panhandling, recycling, scams)	<input type="checkbox"/>	12
Self employed	<input type="checkbox"/>	13
Other <i>Please specify:</i> _____	<input type="checkbox"/>	14
Refused to answer	<input type="checkbox"/>	99

4. How has being a transgender woman affected your ability to **maintain a stable income?**

- a. Have you ever experienced any form of **discrimination due to your gender identity** when trying to maintain a stable income?
- b. Has being able to maintain a stable income **affected your ability to seek HIV care and treatment?** If so, how?

5. **Do you pay for your current housing?**

- Yes 1
- No 0
- Don't Know 77
- Refused to Answer 99
- Not Applicable 14

a. **What best describes your current housing status (Check one)**

- Your own private house or apartment 1
- A home or apartment where you share a mortgage or lease with a roommate 2
- Someone else's apartment or home 3
- A transitional house/halfway house 4
- A shelter 5
- On the streets/homeless 6
- Some other place 7
- Please specify:* _____
- Don't Know 77
- Refused to Answer 99

6. How has being a transgender woman affected your ability to **maintain stable housing?**

- a. Have you ever experienced any form of **discrimination due to your gender identity** when trying to maintain stable housing?

- b. Has being able to maintain stable housing affected your **ability to seek HIV care and treatment?** If so, how?

HEALTHCARE

7. Do you currently have health insurance coverage? This includes health exchange/Affordable Care Act (ACA/Obamacare), Medicaid, or Medicare. (*Check one*)

No	<input type="checkbox"/>	0
Yes	<input type="checkbox"/>	1
Don't know	<input type="checkbox"/>	77
Refused	<input type="checkbox"/>	99

IF ANSWERED 'NO', 'DON'T KNOW', OR 'REFUSED TO ANSWER' TO QUESTION 7, SKIP TO QUESTION NUMBER 9

8. What kind of health insurance coverage do you currently have? (*Check all that apply*)

Private health insurance or HMO	<input type="checkbox"/>	1
Medicaid	<input type="checkbox"/>	2
Medicare	<input type="checkbox"/>	3
TRICARE (CHAMPUS)	<input type="checkbox"/>	4
Veterans Administration coverage	<input type="checkbox"/>	5
Some other insurance	<input type="checkbox"/>	6
<i>Please specify:</i> _____		
Don't know	<input type="checkbox"/>	77
Refused to answer	<input type="checkbox"/>	99

9. What types of health care or service providers do you currently see? (*Check all that apply*)

Primary Care or General Provider (e.g., Physician, Nurse Practitioner, or Physician's Assistant)	<input type="checkbox"/>	1
Infectious Disease//HIV Physician or Doctor	<input type="checkbox"/>	2
Specialty Care Physician or Doctor	<input type="checkbox"/>	3
<i>Please list the specialty:</i>		
Mental Health Provider	<input type="checkbox"/>	4
Substance Abuse Counselor	<input type="checkbox"/>	5
Social Worker and/or Case Manger	<input type="checkbox"/>	6
Health Educator in HIV Prevention (e.g., support group counselor at a CBO)	<input type="checkbox"/>	7
Housing Coordinator	<input type="checkbox"/>	8
Other	<input type="checkbox"/>	9
None	<input type="checkbox"/>	10
Don't know	<input type="checkbox"/>	77

IF ANSWERED 'NONE' OR 'REFUSED TO ANSWER' TO QUESTION 9, SKIP TO QUESTION NUMBER 13

10. What do you look for in a healthcare provider?

- a. What services are you seeing these providers for?
- b. What is most important to you when you are receiving care?
- c. How did you find your healthcare provider(s)?

11. Have you shared your gender identity with your healthcare providers?

- a. What are/were your concerns about sharing your gender identity with healthcare providers? (e.g., confidentiality)
- b. What are/were your concerns about sharing your gender identity with others in the healthcare setting? (e.g., case managers, receptionists)
- c. How has sharing your gender identity affected your ability to receive competent health services?
- d. Have you had difficulties with your care due to sharing your gender identity? How so?
- e. Have you ever been denied care due to your gender identity?

12. As part of this study, we are also interviewing healthcare providers in each city. We are currently gathering a list of healthcare providers in each city that provide care to our transgender participants, and from that list we will select 3-4 healthcare providers in each city to invite them to participate in an interview. Are there any healthcare providers that are currently providing or have previously provided you care that you recommend we speak to? Of course, your participation in this interview remains strictly confidential so we will not in any way mention your name or participation in this study.

- a. How long have you been seeing/did you see this provider(s)?
- b. What kinds of healthcare services does this provider provide?

IF PARTICIPANT IS CURRENTLY SEEING A HEALTHCARE PROVIDER, SKIP TO QUESTION NUMBER 14

13. What prevents you from seeking care from a provider?

a. What would be most important to you if you decided to seek care?

GENDER CONFIRMATION SURGERY

14. Have you had **any type of gender confirmation surgery**?

- Yes 1
- No 0
- Refuse to answer 99

a. If yes, **what types of gender confirmation surgery** have you had? (**Check all that apply**)

Lower

- Penectomy (removed penis) 1
- Castration (removed testicles) 2
- Vaginoplasty (constructed a vagina) 3

Upper

- Breast enhancement/augmentation 4
- Facial Feminization Surgery (FFS) 5

Other

Please specify: _____ 6

N/A

- Don't know 77
- Refused to answer 99

15. Does your health insurance cover any of the cost of gender confirmation surgeries?

- Yes 1
- No 2
- N/A 3
- Don't know 77
- Refused 99

a. If yes, what was covered? _____

IF PARTICIPANT HAS NOT HAD LOWER GENDER CONFIRMATION SURGERY OR 'REFUSED TO ANSWER' TO QUESTION 14, SKIP TO QUESTION NUMBER 17

16. You mentioned having **lower gender confirmation surgery**. What, if anything, has your provider told you regarding **safer sex after your surgery**?

- a. Has your provider discussed **other types of HIV prevention strategies** with you after your surgery?
- b. In what ways, if any, has **the healthcare you receive changed since your surgery**?

HORMONES AND OTHER SUBSTANCES

17. Have you taken any hormones in the past 12 months? (*Check one*)

- | | | |
|-------------------|--------------------------|----|
| No | <input type="checkbox"/> | 0 |
| Yes | <input type="checkbox"/> | 1 |
| Don't know | <input type="checkbox"/> | 77 |
| Refused to answer | <input type="checkbox"/> | 99 |

18. Can you tell me more about your **experiences using hormones**?

a. What types of hormones have you used? (Check all that apply)

- | | | |
|----------------------------------|--------------------------|----|
| Injectable | <input type="checkbox"/> | 1 |
| Pills | <input type="checkbox"/> | 2 |
| Patch | <input type="checkbox"/> | 3 |
| Other:
<i>Please Specify:</i> | <input type="checkbox"/> | 4 |
| Don't know | <input type="checkbox"/> | 77 |
| Refused to answer | <input type="checkbox"/> | 99 |

b. Where did you get the hormones?

c. Do you think taking **hormones has provided you with opportunities** to receive healthcare? If yes, how so?

d. Can you tell me more about situations where you have used **syringes for hormones outside of medical settings**?

- i. Did you have any **concerns about using syringes for hormones outside of medical settings**? If so, what are they?
- ii. Have you been able to **discuss your concerns with a healthcare provider**?

19. Have you used silicone to change the shape of your body in the past 12 months? (*Check one*)

- | | | |
|-------------------|--------------------------|----|
| No | <input type="checkbox"/> | 0 |
| Yes | <input type="checkbox"/> | 1 |
| Don't know | <input type="checkbox"/> | 77 |
| Refused to answer | <input type="checkbox"/> | 99 |

20. Can you tell me more about your experiences using silicone?

a. Where did you get the silicone?

b. Can you tell me more about situations where you have used **syringes for silicone or other substances** outside of medical settings?

- c. Did you have any concerns about using **syringes for silicone or other substances** outside of medical settings? If so, what are they?
- d. Have you been able to **discuss your concerns with a healthcare provider?**

SEXUAL PARTNERS AND CONDOM USE

21. In the past 12 months, about how many sexual partners have you had?

_____ partners

Don't know

77

Refused to answer

99

22. During the past 12 months, have you had sex with (*Check all that apply*):

Men / Cis (non-trans) men

1

Women / Cis (non-trans) women

2

Transgender men

3

Transgender women

4

Other

5

Please specify: _____

Refused to answer

99

23. In the past 12 months, have you had sex with a (*Check all that apply*):

Steady partner or main partner (e.g., someone with whom you have a relationship)

1

Casual partner

2

Exchange partner (someone who you paid or paid you to have sex with for money, drugs, housing, other items or favors)

3

Refused to answer

99

24. Do you currently have a steady/main partner who has a penis? (This could include partners with whom you have a romantic relationship with, or a steady exchange partner.)

No

0

Yes

1

Refused to answer

99

IF ANSWERED 'NO' OR 'REFUSED TO ANSWER' TO QUESTION 24, SKIP TO QUESTION NUMBER 26

25. What is the HIV status of your main/steady partner? (This could include partners with whom you have a romantic relationship with, or a steady exchange partner.)

HIV negative	<input type="checkbox"/>	0
HIV positive	<input type="checkbox"/>	1
Don't know	<input type="checkbox"/>	77
Refused to answer	<input type="checkbox"/>	99

26. **Have you been the receptive or insertive partner during anal sex?**

Receptive only	<input type="checkbox"/>	1
Insertive only	<input type="checkbox"/>	2
Both	<input type="checkbox"/>	3
Neither	<input type="checkbox"/>	4
Don't know	<input type="checkbox"/>	77
Refused to answer	<input type="checkbox"/>	99

- a. *[If participant has been the receptive partner during anal sex]* How frequently do you use condoms when you have **receptive anal sex**?
- b. *[If participant has been the insertive partner during anal sex]* How frequently do you use condoms when you have **insertive anal sex**?
- c. In what kind of situation would you **use condoms during anal sex**?
- d. Could you tell me about some of the **reasons you would not use condoms** during anal sex?
 - i. If you are not using condoms, what do you do to protect yourself or stay healthy?

27. Have you been the **receptive or insertive partner during vaginal sex**? (*NOTE to interviewer, please align questions to participant's response re: gender confirmation surgery in Question 14*)

Receptive only	<input type="checkbox"/>	1
Insertive only	<input type="checkbox"/>	2
Both	<input type="checkbox"/>	3
Neither	<input type="checkbox"/>	4
Don't know	<input type="checkbox"/>	77
Refused to answer	<input type="checkbox"/>	99

- a. *[If participant has been the receptive partner during vaginal sex]* How frequently do you use condoms when you have **receptive vaginal sex**?
- b. *[If participant has been the insertive partner during vaginal sex]* How frequently do you use condoms when you have **insertive vaginal sex**?
- c. In what kind of situation would you use **condoms during vaginal sex**?
- d. Could you tell me about some of the reasons you **would not use condoms** during vaginal sex? (moved from below)

- i. What do you do to **avoid the risk of getting an STD** when you have vaginal sex without a condom? (moved from below)

28. How do you **talk about condom use with your sex partners**?

- a. Do you have **agreements with your current main/steady partner** about anal sex with other partners?
Agreements could be about whether or not you will use condoms during anal within your relationships, whether or not you will have insertive sex with someone other than your partner, whether or not you will use condoms when having insertive sex with someone other than your partner, etc.
- i. Can you please tell me more about that?

INTIMATE PARTNER VIOLENCE

29. In your lifetime, have you ever been physically abused by a romantic or sexual partner? By physical abuse we mean a range of behaviors from slapping, pushing, or shoving to severe acts, such as being beaten, burned, or choked.

- No 0
Yes 1
Refused to answer 99

30. In your lifetime, have you ever been emotionally abused by a romantic or sexual partner? By emotional abuse we mean name-calling, insulting, or humiliating you, or trying to monitor and control or threaten you.

- No 0
Yes 1
Refused to answer 99

IF ANSWERED 'NO' OR 'REFUSED TO ANSWER' TO QUESTION 29 AND QUESTION 30, SKIP TO QUESTION NUMBER 33

31. Do you feel as though the abuse you have experienced is due to being transgender?

- No 0
Yes 1
Refused to answer 99

- a. If so, how?

32. How has your experience with physical, sexual or emotional harm **affected your HIV prevention, care and treatment or strategies**?

- a. Has your experience affected your ability to negotiate condom use with your partner or partners?

HIV DIAGNOSIS AND DISCLOSURE

33. When did you **first learn** of your HIV positive diagnosis?

_____ (month/year)

Don't know

Refused to answer

77

99

34. Tell me about your experience **receiving a positive HIV diagnosis.**

- a. What made you **decide to get tested for HIV?**
- i. **Did you know people** in your social circle (friends, family, and partners) who had been tested for HIV?
 - ii. What are some of the things, if any, that made it **easier for you to get tested for HIV?**
 - iii. What are some of the things, if any, that made it **difficult for you to get tested for HIV?** (e.g., confidentiality, disclosing gender identity, fear, etc.)

35. Have you ever **shared your HIV status with anyone?**

- a. If yes, can you tell me about your experience with **sharing your HIV status** to your friends, family, and current or past partners?
- b. What made you decide **to disclose your HIV status to your current or past sex partners?**
- c. What made you decide to **disclose your HIV status to your friends and family?**
- d. Tell me about a time when you were **concerned about confidentiality** in disclosing your status.
- e. Has disclosing your **HIV status ever put you in danger?** How so?
- f. Have you been in a situation where you felt **your status was exposed** rather than shared or disclosed by choice? If so, can you tell me about that situation?

HIV CARE AND TREATMENT

36. Are you currently receiving HIV care?

- Yes 1
- No 2
- Refused to answer 99

IF ANSWERED 'NO' OR 'REFUSED TO ANSWER' TO QUESTION 36, SKIP TO QUESTION NUMBER 43

37. How long have you been receiving HIV care?

- _____ years _____ months
- Don't know 77
 - Refused to answer 99

38. Have you ever had any **gaps in your HIV care history?** (e.g., stopped taking your medications or stopped seeing your provider)

- Yes 1
- No 2

IF ANSWERED 'NO' TO QUESTION 38, SKIP TO QUESTION NUMBER 40

39. **What were some of the reasons you stopped receiving HIV care?** (You may check more than one)

- The side effects or interactions of HIV medications made taking medications not worth the benefit 1
 - Unable to stay adherent to medications 2
 - Could not pay for doctors' visits and/or medications due to a gap in health insurance or ADAP coverage 3
 - Unable to access provider because appointments were difficult to schedule and/or attend 4
 - Other 5
- Please specify:* _____

40. **Which of the following have been made available to you at your current HIV clinic?** (Check **all that apply**)

- Gender-neutral bathrooms 1
- Gender affirming materials 2
- Transgender-identified staff 3

Practice/clinic staff that are knowledgeable about transgender health 4
 Referrals to organizations that are transgender-competent 5
 Other 6
Please specify _____

41. How did you get **connected to this HIV care clinic**?
- What helped you **get into HIV care**?
 - What keeps you **motivated to attend appointments** at your HIV care clinic?
 - What helps you **stay in HIV care**?
 - What are the things that **make it difficult for you to attend a medical appointment** at an HIV care clinic (e.g., lack of time, money, insurance, transportation)?

42. Have your **family, friends, and/or community ever influenced your intention to seek HIV care**? If so, how? *[Note to interviewer: Please ensure the interviewee identifies if they are talking specifically about family, friends, or communities.]*

- How have they **encouraged you** to get into care or keep you in care?
- How have they **kept you** from getting into care or staying in care?
- What do they/can **they do that is helpful**?
- What do they **do that is not helpful**?

IF INTERVIEWEE IS CURRENTLY IN HIV CARE, SKIP TO QUESTION 44.

43. What has **stopped you from connecting to an HIV care clinic**? *(NOTE to interviewer, if question is not clear, probe with: stigma, discrimination, lack of provider competency)*

- What are the things that **make it difficult for you attend a medical appointment** at an HIV care clinic)? *(NOTE to interviewer, if question is not clear, probe with: lack of time, money, insurance, transportation)*

44. **Have you ever taken medication to treat HIV (antiretroviral therapy/ART)?**

Yes 1
 No 2
 Refused to answer 99

IF ANSWERED 'NO' OR 'REFUSED TO ANSWER' TO QUESTION 442, SKIP TO QUESTION NUMBER 59

45. Are you currently receiving or taking medications to treat HIV (antiretroviral therapy (ART))?

- Yes 1
- No 2
- Refused to answer 99

IF ANSWERED 'NO' OR 'REFUSED TO ANSWER' TO QUESTION 53, SKIP TO QUESTION NUMBER 51

46. How long have you been taking medications to treat HIV (antiretroviral therapy (ART))?

_____ years _____ months

47. Where do you currently obtain medications to treat HIV (antiretroviral therapy (ART))?

- Through a prescription from a doctor 1
- Off the Internet 2
- From someone on the street 3
- From a friend 4
- Other 5
- Please specify:* _____
- Don't know 77
- Refused 99

48. How do you cover the costs of ART? (Check all that apply)

- Insurance 1
- AIDS Drug Assistance Program (ADAP) 2
- Special Benefits Pharmaceutical Assistance 3
- Other drug assistance program 4
- Please specify:* _____
- Don't know 77
- Refused 99

49. When was your last viral load test?

- Within the past 6 months 1
- Within the past 12 months (1 year) 2
- Within 12 months of receiving your HIV diagnosis 3

Don't know
Refused to answer

77
 99

50. What are some of the **things that made you decide to take HIV medications?**
- a. What **helps you take your medication** as prescribed?
 - b. What makes it **difficult for you to take your medication** regularly?
 - c. Do you have any **concerns about taking these medications?**

IF CURRENTLY TAKING HIV MEDICATIONS, SKIP TO QUESTION NUMBER 52

51. Can you tell me what are your **concerns about taking these medications?**

CLOSING

52. Is there **anything else** that you would like to share with us related to your experiences with HIV prevention activities?