

HIV SURVEY

FINAL (12/20/06)

**TELEPHONE QUESTIONNAIRE PREPARED BY
ROPER PUBLIC AFFAIRS**

INTRODUCTION

Thank you for calling. We appreciate your participation in this survey.

S1. First, what is the code that we given to you by the administrator at the center? __ [ACCEPT ONE LETTER A-Z, SEE EXCEL SPREADSHEET FOR THE CENTER NAMES]

- If they do not have the code direct the person to get the code from the person that talked to them about the survey. Either have the person do it while you wait on the phone or have the person hang up call back after they have it the code.

The goal of the survey is to collect your feedback, and feedback from others, about the needs of HIV-positive women today. The information will help support a larger educational program that will look at the issues positive women face and help develop solutions to help make living with HIV more manageable.

Before we begin, I wanted to let you know that this survey covers topics that may be sensitive and personal, such as questions about emotional well-being, family planning and safer sex. Because these questions may be sensitive and emotional for you to talk about, please let me know if you are uncomfortable with any of them and if you would like to stop the survey now.

If you decide to continue, please know that your responses to all questions will be kept private and confidential. The survey will take about fifteen minutes from start to finish.

Finally, please be aware that during the survey when I use the term "HIV Provider" I mean the person who you see for your HIV medical care, like an HIV doctor or nurse. Feel free to ask me to remind you about what I mean by the term "HIV Provider" at any time during the survey.

[IF PARTICIPATE WANTS TERMINATE SURVEY]

We respect your decision not to answer any more questions for this survey, and thank you for the time that you have given us

SCREENER

S1. Who do you see for your regular HIV care? [READ LIST. IF MORE THAN ONE, SAY:] Which do you consider to be your main HIV Provider? Who prescribes your medicines? [RECORD ONLY ONE RESPONSE.]

Nurse Practitioner or Physicians Asst	1
Family physician (FP or GP)	2
OB-GYN	3
Infectious disease specialist	4
Other (DO NOT READ)	5
Don't know (DO NOT READ)	X
Refused (DO NOT READ)	Y

S2. Is your usual HIV Provider a man or a woman?

Man	1
Woman	2
Don't know	X
Refused	Y

S3. And how long ago were you diagnosed with HIV? You can give me your answer in weeks, months, or years.

# OF WEEKS	[]	
# OF MONTHS	[]	
# OF YEARS	[]	
Don't know	X	[TERMINATE]
Refused	Y	[TERMINATE]

S4. Are you currently taking HIV medications to treat HIV?

Yes	1	
No	2	[TERMINATE]
Don't know	X	[TERMINATE]
Refused	Y	[TERMINATE]

S5. And how long have you been taking HIV medications? You can give me your answer in weeks, months, or years.

# OF WEEKS	[]	
# OF MONTHS	[]	
# OF YEARS	[]	
Don't know	2	[TERMINATE]
Refused	2	[TERMINATE]

[TERMINATE IF FEWER THAN 3 YEARS]

IF TERMINATE READ: Because of the unique topics we are focusing on in this survey, we hope to speak with patients who are currently taking HIV medications and who started on HIV treatment within the past three years. Although we won't continue with the survey, we thank you very much for the time you have given us and appreciate your willingness to share information so that we can understand the some of the concerns faced by HIV-positive women.

S6. Those are all of the questions that I have for you today, in order to receive your \$5 for participation, please give the person who recruited you for this survey following code [INSERT CODE, TERMINATE CODE is 900]

D7. Are you from a Hispanic or Spanish-speaking background, or not?

Yes	1
No	2
Prefer not to answer	3

D8. What is your racial background?

White	1
Black/African American	2
Asian	3
Other	4
Prefer not to answer	5

QUOTAS: 300 AFRICAN AMERICAN, 200 WHITE, 200 HISPANIC - IF TERMINATE DUE TO FILLED QUOTA READ:
Because of the unique topics we are focusing on in this survey, we hope to speak with A diverse group of patients. Although we won't continue with the survey, we thank you very much for the time you have given us and appreciate your willingness to share information so that we can understand the some of the concerns faced by HIV-positive women.

S6. Those are all of the questions that I have for you today, in order to receive your \$5 for participation, please give the person who recruited you for this survey the following code [INSERT CODE, TERMINATE CODE is 900]

MAIN SURVEY

General

1. When did you first learn that you were HIV positive? Was it ... [READ EACH ITEM. ACCEPT MULTIPLE RESPONSES.]

[ROTATE:]

At a gynecological checkup	1
At a physical examination	2
You requested an HIV test	3
During routine medical testing	4
At a substance abuse center or clinic	5
Because you were planning to have a baby	6
After you learned that you were pregnant	7
Because you were incarcerated	8
Other	9
Don't know	X
Refused	Y

2. Since you started treatment for HIV, how many different HIV Providers have you seen?

# of HIV Providers	[]
Don't know	X
Refused	Y

3. [IF MORE THAN 1 HIV PROVIDER IN Q2, ASK:] Please tell me why you changed providers? I will read you a list of reasons and you can select as many as apply. [READ EACH ITEM. ACCEPT MULTIPLE RESPONSES.]

[ROTATE:]

	Yes	No	Don't know	Refused
You moved	1	2	Y	Y
Your HIV Provider moved their office	1	2	Y	Y
Didn't connect or work well together	1	2	Y	Y
You weren't receiving the level of medical care you wanted and/or needed	1	2	Y	Y
You weren't receiving the level of emotional care you wanted and/or needed	1	2	Y	Y
The HIV Provider didn't give you care for your needs as a woman	1	2	Y	Y
The HIV Provider didn't communicate well with you	1	2	Y	Y
You were referred to someone else	1	2	Y	Y
Due to insurance or access problems	1	2	Y	Y

4. When thinking about your HIV treatment options, how important are each of the following to you – essential, very important but not essential, somewhat important, not very important or not important at all. First... [READ EACH ITEM.]

	Ess.	Very imp.	Somewhat imp.	Not very imp.	Not at all imp.	Don't know.	Ref.
Long-term success with the medication	5	4	3	2	1	X	Y
Keeps the virus level low or keeps viral load down	5	4	3	2	1	X	Y
Fewer side effects	5	4	3	2	1	X	Y
Type of side effects							
Ability to continue with family planning	5	4	3	2	1	X	Y
Good connection or feeling of partnership with your HIV provider	5	4	3	2	1	X	Y
Ability to live a normal life	5	4	3	2	1	X	Y

Gender differences

5. Do you think that the fact that you are a woman causes HIV to affect you differently than it does a man, or not? If you're not sure, let me know.

Yes	2
No	1
[VOL] It depends	0
Don't know	X
Refused	Y

6. Generally speaking, do you think the challenges of having HIV are greater for women, greater for men, or about the same for both men and women?

Greater for women	1
Greater for men	2
Same	3
[VOL.] It depends/case-by-case basis	4
Don't know	X
Refused	Y

7. Have you and your HIV Provider ever discussed how your HIV medications might affect women differently than they do men?

Yes	1
No	2
Don't know	X
Refused	Y

8. [IF "YES" IN Q7 ASK:] When you talk to your HIV Provider about how HIV medications might affect women differently than men, does he or she... [READ EACH ITEM] or not?

[RANDOMIZE]	Yes	No	Don't know	Ref.
Make you feel comfortable discussing the issue?	1	2	X	Y
Answer your questions to your satisfaction?	1	2	X	Y
Spend enough time with you?	1	2	X	Y
Or, give you referrals to others who could help?	1	2	X	Y

9. How often does your HIV Provider discuss with you:

[RANDOMIZE]	Often	Occasionally	Rarely	Never
How your body might react to treatment	1	2	X	Y
Your emotional needs	1	2	X	Y
The importance of a support system to help care for you or your family	1	2	X	Y
Sexuality or sexual relationships				
Or, additional therapies or care				

10. To what extent, if at all, do you feel that your culture, ethnicity or language impacts the care you receive?

A lot	1
A little	2
Or, not at all	3
Don't know	X
Refused	Y

Emotional well-being

11. Please tell me whether living with HIV has made each of the following much more difficult, somewhat more difficult, or if there has been no change on a daily basis. If an item doesn't apply to you, just let me know.

	Much more difficult	Some-what more difficult	No change	Doesn't apply	Don't know	Ref.
Taking care of your family	3	2	1	0	X	Y
Doing your favorite free-time activities or hobbies	3	2	1	0	X	Y
Getting some kind of exercise						
Doing your work or your employment	3	2	1	0	X	Y
Doing day-to-day chores and activities	3	2	1	0	X	Y

12. Which one of the following statements best describes you at this time? [READ EACH ITEM.]

Living with HIV has caused me to struggle a great deal in managing my daily life	1
Living with HIV has caused me to struggle somewhat in managing my daily life	2
Or, living with HIV has not caused me to struggle in managing my daily life	3
Don't know	X
Refused	Y

13. Please tell me whether or not you have ever felt any of the following since being diagnosed with HIV and, if you have, whether it often, occasionally, rarely, or never interferes with your daily activities [READ EACH ITEM.]

[RANDOMIZE]	Often	Occ.	Rarely	Never	Don't know	Ref.
Feeling sad	4	3	2	1	X	Y
Major changes in appetite and sleep patterns	4	3	2	1	X	Y
Irritability, anger	4	3	2	1	X	Y
Worry, anxiety	4	3	2	1	X	Y
Gloomy outlook; Don't care about future						
Loss of energy	4	3	2	1	X	Y
Unexplained aches and pains	4	3	2	1	X	Y
Not able to concentrate or make decisions	4	3	2	1	X	Y
Not able to enjoy things once enjoyed	4	3	2	1	X	Y
Recurring thoughts of death or suicide	4	3	2	1	X	Y

[ASK IF ANSWERED RARELY, OCCASIONALLY OR OFTEN TO ONE OR MORE ITEMS IN Q13]

14. How comfortable do you feel or would you feel talking to your HIV Provider about your feelings commonly related to depression? Are you very comfortable, somewhat comfortable, somewhat uncomfortable, or very uncomfortable?

Very comfortable	4
Somewhat comfortable	3
Somewhat uncomfortable	2
Very uncomfortable	1
Don't know	X
Refused	Y

[ASK IF ANSWERED RARELY, OCCASIONALLY OR OFTEN TO ONE OR MORE ITEMS IN Q13]

15. How often do you talk to your HIV provider, if at all, about these feelings?

Often	[]
Occasionally	X
Rarely	Y
Never	

16. [ASK IF "RARELY" OR "NEVER" IN Q14] Why do you say that? [DO NOT READ. ACCEPT MULTIPLE RESPONSES.]

Lack of time in office visit	6
Afraid to bring it up	5
Don't think the provider could help me	4
Think it's a normal reaction to HIV	3
Don't know what to ask or how to ask	2
Afraid of what they would think or say	1
Other	X
Don't know	X
Refused	Y

[ASK IF ANSWERED RARELY, OCCASIONALLY OR OFTEN TO ONE OR MORE ITEMS IN Q13]

17. Have you ever felt the need for additional information or support, other than from your HIV provider, to deal with your feelings and emotions, or not?

Yes	1
No	2
Don't know	X
Refused	Y

18. [IF "YES" IN Q16, ASK:] Where have you looked for this additional support? [DO NOT READ. ACCEPT MULTIPLE RESPONSES.]

Family and friends	1
Case manager or social worker	2
Therapist	3
Support group	4
Nurse or other health care provider	5
Religious clergy	6
AIDS service organization	7
Internet	8
Other	9
Don't know	X
Refused	Y

[ASK EVERYONE]

19. Have you ever discussed issues of safer sex with your HIV Provider, or not?

Yes	1
No	2
Don't know	X
Refused	Y

20. Have you ever discussed issues of contraception with your HIV provider, or not?

Yes	1
No	2
Don't know	X
Refused	Y

21. And are you currently sexually active, or not? If you'd prefer not to answer, just let me know.

Yes	1
No	2
Don't know	X
Refused	Y

22. Are you... [READ EACH ITEM.]

	Yes	No	Don't know	Ref.
Currently pregnant?	1	2	X	Y
[IF NOT CURRENTLY PREGNANT, ASK] Trying to get pregnant?	1	2	X	Y
[IF NOT CURRENTLY TRYING TO GET PREGNANT, ASK] Thinking about getting pregnant some time soon?	1	2	X	Y
[IF NOT CURRENTLY CONSIDERING TRYING TO GET PREGNANT ASK] Or, think you might consider pregnancy in the future?	1	2	X	Y

23. [IF "NO" TO "CURRENTLY PREGNANT" IN Q21, ASK:] Have you become pregnant since you were diagnosed with HIV?

Yes	1
No	2
Don't know	X
Refused	Y

24. [IF "NO" TO ALL IN Q21 AND "NO" TO Q22, ASK:] You mentioned that you have never been pregnant while living with HIV and have no current or future plans to become pregnant. Women have many different reasons for not becoming pregnant – would you mind sharing yours? [DO NOT READ. ACCEPT MULTIPLE RESPONSES.] [SKIP TO GENERAL PREGNANCY UNDERSTANDING SECTION]

Don't want children	2
Don't have a partner	3
Afraid baby would be HIV positive	4
Didn't think it was an option	5
Can't handle children while HIV positive	6
Others would think I'm irresponsible	7
Can't due to medical complications not related to HIV	8
Other	9
Don't know	X
Refused	Y

25. [IF "NO" TO "CURRENTLY PREGNANT" IN Q21, ASK:] Has your HIV provider ever asked if you would want to have a child either now or in the future, or not?

Yes	1
No	2
Don't know	X
Refused	Y

26. Do you or would you feel comfortable talking to your provider about becoming pregnant and your treatment options for pregnancy, or not?

Yes	1
No	2
Don't know	X
Refused	Y

27. Have you discussed with your HIV Provider whether your treatment options should change if you are going to get pregnant, or not?

Yes	1
No	2
Don't know	X
Refused	Y

28. Has your HIV Provider explained the effects certain HIV treatments may have on you or the baby if you are pregnant, or not?

Yes	1
No	2
Don't know	X
Refused	Y

29. Apart from any discussions with or materials from your HIV Provider, have you ever sought information about HIV and pregnancy from other sources, or not?

Yes	1
No	2
Don't know	X
Refused	Y

Questions for women who are or have been pregnant

30. [IF "YES" TO "CURRENTLY PREGNANT" or IN Q21 AND/OR "YES" TO Q22, ASK:] Did you discuss pregnancy and appropriate HIV treatment options for pregnancy with your HIV Provider prior to becoming pregnant, or not?

Yes	1
No	2
Don't know	X
Refused	Y

31. [IF "YES" TO "CURRENTLY PREGNANT" IN Q21 AND/OR "YES" TO Q22, ASK:] Were you or are you taking anti-HIV treatments while pregnant, or not?

Yes	1
No	2
Don't know	X
Refused	Y

32. [IF "NO" TO Q31, ASK:] Why have you decided not to take HIV treatment while pregnant? [DO NOT READ. ACCEPT MULTIPLE RESPONSES.]

Didn't (or don't) need it	1
Unaware of my options	2
Scared it might harm the baby	3
Afraid of the side effects	4
Couldn't afford it	5
Other	6
Don't know	X
Refused	Y

33. [IF "YES" TO "CURRENTLY PREGNANT" IN Q21 AND/OR "YES" TO Q22, ASK:] When you first found out you were pregnant, how aware were you of the HIV treatment options appropriate for women who are pregnant – very aware, somewhat aware, not very aware, or not at all aware?

Very aware	1
Somewhat aware	1
Not very aware	1
Not at all aware	2
Don't know	X
Refused	Y

General Pregnancy Understanding

34. Where, if anywhere, do you get your information about HIV?

Family and friends	1
Case manager or social worker	2
Therapist	3
Support group	4
Nurse or other health care provider	5
Religious clergy	6
AIDS service organization	7
Internet	8
None	9
Other	0
Don't know	X
Refused	Y

35. Which, if any, of the following statements do you think best describes how you personally view HIV-positive women who would like to have children?

Women have a right to have children no matter their HIV status	1
HIV-positive women can have children provided they receive the appropriate medical information and support	2
HIV-positive women should be strongly urged not to have children	3
Don't know	X
Refused	Y

36. Which, if any, of the following statements do you think best describes how society views HIV-positive women who would like to have children?

Women have a right to have children no matter their HIV status	1
HIV-positive women can have children provided they receive the appropriate medical information and support	2
HIV-positive women should be strongly urged not to have children	3
Don't know	X
Refused	Y

Demography

D1. Are you...?

Married	1
Single	2
Living with a partner	3
Separated	4
Divorced	5
Widowed	6
Don't know	X
Refused	Y

D2. What is the last grade of school you completed?

Less than high school graduate	1
High school graduate	2
Some college	3
Graduated college	4
Graduate school or more	5
Technical school/Other	6
Don't know	X
Refused	Y

D3. In what year were you born?

[ENTER YEAR]	[_____]
Don't know	X
Refused	Y

D4. Right now, how many people including yourself are living in your household, excluding those who are visiting or staying there temporarily?

[ENTER #]	[_____]
Don't know	X
Refused	Y

D5. Do you any have children living at home with you?

Yes	1
No	2
Don't know	X
Refused	Y

D6. Are you a caregiver for any of the following? [READ EACH ITEM. ACCEPT MULTIPLE RESPONSES.]

Child or children	
Parent	1
Brother and/or sister	2
Grandchild	3
Spouse	4
Friend	5
Someone else?	6
Don't know	X
Refused	Y

D9. If you added together the yearly incomes before taxes of all of the members of your household for the last year, what would the total be?

Under \$25,000	1
\$25,000 but less than \$35,000	2
\$35,000 but less than \$50,000	3
\$50,000 but less than \$75,000	4
\$75,000 but less than \$100,000	5
\$100,000 but less than \$125,000	6
\$125,000 but less than \$150,000	7
\$150,000 or more	8
Prefer not to answer	9

D10. Those are all of the questions that I have for you today, in order to receive your \$25 for participation, please give the person who recruited you for this survey following code [INSERT CODE, CODES WILL BE ANYWHERE BETWEEN 1000-1700 BUT EACH RESPONDENT WILL RECEIVE A UNIQUE CODE]

THANK YOU VERY MUCH FOR YOUR TIME AND COOPERATION.