ATTACHMENT 12D: FACILITATOR GUIDE ADOLESCENTS (HIV POSITIVE)

for

Qualitative Evaluation of HIV Counseling, Testing, and Referral Services in Non-Health

Care Settings: Eliciting Consumer Views

New OMB Application

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Facilitator Guide

Adolescents (HIV-positive)

OMB Approved OMB No Exp. date

I. **Welcome and Ground Rules** (5 minutes)

Welcome. My name is _____. Tonight we are here to learn what you think about HIV testing processes, which I will explain more in a moment. We will have about 2 hours for our discussion. I really look forward to hearing your opinions on these services.

Before we begin, I want to review a few ground rules for tonight's group:

- Everything we discuss here today will be kept as private as possible. Your names
 and contact information, which only the study staff knows, will not be given to
 anyone else and no one will contact you after this group is over.
- You have probably noticed the microphones in the room. They are here because we are **audio taping**. I want to give you my full attention and not have to take a lot of notes. At the end of the focus group, I have to write a report and will refer to the tape when writing the report.
- Some of the people working on this project will also be taking notes during our discussion to assure that your opinions are accurately captured.
- Because we are taping, it is important that you try to speak one at a time. I may occasionally interrupt you when two or more people are talking at once to be sure that everyone gets a chance to talk and that responses are accurately recorded. Please only use your first names.
- There may be some sensitive questions asked during this discussion. If at any time you are uncomfortable with my questions, you can choose not to answer. Simply let me know that you prefer not to answer.
- Out of respect for each other, I am asking everyone to keep who is in this group and what is said in this group private. Everyone in this group has the same HIV status. Please do not tell anyone about who was in the group or what was talked about after you leave today.
- As a courtesy to everyone, please turn your cell phone or beeper to vibrate or silent mode. .If you need to go to the restroom during the discussion, please feel free to leave, but please return as soon as possible.

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II. Warm Up / Participant Introductions (10 minutes)

I would like to begin our discussion by talking about us a little. I'd like you to introduce yourself and tell us what your favorite type of music or band is. I'll start...I'm ____ and my favorite group is ____.

[ALLOW GROUP MEMBERS TO INDIVIDUALLY SHARE INFORMATION ABOUT THEMSELVES, KEEPING TIME SO THAT NO MORE THAN 10 MINUTES IS USED FOR THIS PROCESS]

[REMIND GROUP MEMBERS TO USE ONLY THEIR FIRST NAME OR A FALSE NAME. DO NOT START AUDIOTAPE UNTIL INTRODUCTIONS ARE DONE.]

III. Counseling, Testing, and Referral in Non-Health Care Settings

You were asked to participate in this focus group so that we can hear your thoughts and perspectives about the HIV testing process and ways we can make it easier for people to get tested. When I say the HIV testing process, I mean talking to a counselor, getting the test and results, and sometimes receiving referrals for medical care, support, or other prevention services. This is often how the process goes, but it can also happen in different ways.

We are talking to people your age to get an idea of how testing can be improved specifically for them. Before we begin, I want to get a sense of what you, as someone between the ages of 15 and 17, would like to be called (young adults, teenagers, adolescents?).

ASK: Before we begin, does anyone have any questions?

Content-Related Warm-up (5 min)

READ: First, let's talk a little bit about HIV in your community.

1. Is HIV something that people your age think is important?

PROBE: What are some of the specific issues that they are concerned about?

READ: Next, I want to ask about your opinions of HIV testing. Remember, there are no right or wrong answers and everything you say will be kept private. You can base your responses on your opinions, experiences, or what you have heard from others.

2. Now think about people your age who have been tested for HIV. What are some reasons why they decided to get tested for HIV?

3. What are some reasons why teenager at risk for HIV might not get tested?

POSSIBLE PROBES: Listen for internal/psychosocial and external/structural factors

- Finding a location
- Lack of time
- Lack of transportation
- Cost
- Lack of incentives
- Stigma
- Confidentiality or anonymity
- Being discouraged by friends or family
- Fear of what friends or family would think
- Fear of getting blood drawn
- Denial
- Lack of perceived risk
- Fear of getting a positive result
- 4. Where are some of the different places a teenager can go to get HIV tested? [**NOTE**: the moderator will group them into two columns by medical care and non-medical care settings on flip chart.]
- READ: You can see that I've made two columns here. One is what I'll call "medical settings" like a health clinic or a doctor's office. Someone would go there for other medical services, like check ups or other tests. The other column is "non-medical settings" places other than medical settings. [PROBE: if not already included, add examples such as mobile vans, community-based organizations, outreach settings, homeless shelters, needle exchange or substance treatment programs, etc] Does anyone have any questions about what is a medical setting and what is a non-medical setting?
- READ: Now we are going to start talking about your own testing experiences in these settings. We would particularly like to hear about your experiences when you tested positive. Remember that it is important to respect each others privacy, so please don't share anything that you hear today with anyone outside of this group.
- 5. Let's focus for a minute on medical settings like those in this column [medical settings]. For those of you who tested positive in one of these settings, what was the experience like?

POSSIBLE PROBES:

- Cost
- Incentives
- People who did the testing
- Type of test
- How long it took (for the testing and to get results)

- HIV education
- Risk reduction counseling
- Support and counseling post-test
- Finding and getting to location
- Privacy
- 6. Now let's talk about the other type of testing places those that are in non-medical settings. For those of you who tested positive in one of these settings, what was the experience like? [**NOTE**: Where possible, moderator should try to get specific information about each entry on flip chart list]

POSSIBLE PROBES:

- Cost
- Incentives
- People who did the testing
- Type of test
- How long it took (for the testing and to get results)
- HIV education
- Risk reduction counseling
- Support and counseling post-test
- Finding and getting to location
- Privacy

READ: We've just talked about the reality of getting tested in those kinds of places (that is, non-medical places). Now, I'd like you to think back to when you tested positive and think about what would have improved your testing experience.

General setting

7. Describe what would have been the ideal in terms of location and setting.

Consent/ pre-test information

- 8. What would have been the best way to give permission for HIV testing?
- 9. Do you think it would have been better to give permission by signing a form or by verbally telling the tester? Why?
- 10. What information would you have wanted about the HIV test before agreeing to take the test?

Tests and Results

- 11. Right now, there are three ways to be tested for HIV, getting blood drawn, a finger stick with a drop of blood, or a swab inside your cheek. What are some of the things you would have considered if you were choosing which type of HIV test to get? **PROBES:**
 - Speed of receiving results

- Need to go back for another test
- How you get your results

READ: Now let's consider how you would prefer HIV education and prevention counseling to be done during the testing session.

Counseling

12. Prior to getting your test, you may have spoken with a counselor. What would have improved your counseling experience?

PROBES:

- How long would you have wanted to talk with the counselor?
- Would you have wanted more than one session?
- What kind of information would you have wanted?
- 13. Would you have wanted to discuss your own behaviors that can put you at risk for HIV with the counselor? Why or why not?
- 14. What are some ways the counselor might have put you at ease at the beginning?
- 15. Describe the ideal counselor. What characteristics should he or she have to make it easy to talk about HIV risks and prevention?
- 16. What would you have wanted right after you learned your result?

Referrals

- 17. What types of service referrals would you have wanted?
- 18. What could have been done to make it easy for you to follow through and go to these services?

READ: Now, I would like to switch gears from your opinions about ideal services to general issues related to getting a test in a non-medical setting.

Barriers in Non-medical settings (10 min)

19. What are some things that might prevent teenagers from getting tested for HIV in a non-medical setting?

POSSIBLE PROBES:

- Clinic locations, schedules, staff
- Lack of awareness/knowledge about HIV and availability of testing
- Misperceptions about the test or HIV
- Don't want to know status
- Stigma
- Concerns about privacy
- Prefer to get medical all in one place

- Prefer to get medical from only a doctor or nurse
- Lack of incentives
- Other competing needs and priorities
- Probe based on segmentation (if relevant)

Benefits/Harms of Testing (20 min)

- 20. What do you think are some of the benefits of getting HIV tested? What are some possible negative outcomes of getting an HIV test?
- 21. What are some things that could be done to encourage more young people to be tested in non-medical settings?

POSSIBLE PROBES:

- Listen for both internal/psychosocial and external/structural factors
- Explore issues based on segmentation (if relevant)

IV. Wrap Up

[Moderator to check with observers for any last questions for participants]

Ok, great. We are pretty much out of time. Does anyone have any last thoughts?

I want to thank all of you for coming today. This has been very useful in helping us to better understand what people think of HIV counseling, testing, and referral and ways to improve testing in non-health care settings.

[WRAP UP GROUP, REFER PARTICIPANTS TO FRONT DESK TO GET PAYMENT AND HIV EDUCATIONAL MATERIALS]