

Development of CDC's Let's Stop HIV Together Social Marketing Campaign for Consumers

Attachment 3i: Exploratory HIV Testing Focus Group Guide

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Welcome

Thank you for coming today. Your participation is very important. I'm _____ and I'm from RTI, a non-profit research organization. The Centers for Disease Control and Prevention (CDC) is sponsoring this research. The purpose of this focus group is to hear your views and opinions on important health topics concerning HIV/AIDS. Your insights are very important to us and your time today is appreciated. We will have about 1 hour for our discussion.

Before we begin, I want to review a few ground rules for our discussion.

- Most importantly, there are no right or wrong answers. We want to know your opinions and what you think about the issues we will be discussing. I do not work for the people who are sponsoring this research, so don't hold back from giving me your honest opinions.
- 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 our discussion, I have to write a report and will refer to the tape when writing the report.
- Behind me is a one-way mirror. Some of the people working on this project are observing this discussion so that they can hear your opinions directly from you and take notes so that your opinions are accurately captured. However, your identity and anything you personally say here will remain secure to the extent allowable by law. Your name, address, and phone number, which only the facility knows, will not be given to anyone and no one will contact you after this focus group is over.
- 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.
- Be sure to only use first names during the discussion. Please do not use your last name. Also, if you bring up a friend or other person you know as an example in our discussions, please do not use their last name either. So, whenever you mention a name, it should only be a first name and never a last name.
- Please turn your cell phone or beeper to vibrate or silent mode. The focus group group will last no more than 1 ½ hours.
- If you need to go to the restroom during the discussion, please feel free to leave, but please return as soon as possible.

Do you have any questions before we begin?

Warm-up

Before we begin our discussion, let's spend a little time getting to know one another.

1. Please tell me your first name, where you are from, and your favorite [X]

Health and Health Care

Let's start out today by talking about our health. We all do some things that are good for our health and some things that aren't as good.

2. How often do you go to the doctor for health screening tests or exams?
3. What are some reasons why you go to visit a doctor or clinic?
 - What type of health screening tests or exams do you get on a regular basis?
 - Do you ask for the tests or exams or does the doctor recommend the tests or exams?
 - **[If requests tests]** What test or exams do you request?
 - **[If doctor recommends tests]** What tests or exams does your doctor recommend?
4. Where do you go to get your health care? E.g., clinic, private practice, ER, other?

HIV Testing and Testing Experiences

Now, let's switch gears and talk about HIV testing and testing experiences.

5. How do you go about finding a place where you can get an HIV test (e.g., ask friend, look on the internet, ask doctor, etc.)?
 - When you think about getting an HIV test, do you usually think about HIV testing alone or do you think about it along with other tests for sexually transmitted diseases (STDs) like gonorrhea, chlamydia, etc.?
6. Why might someone want to get tested for HIV every [X] months?
7. What are some reasons why a person may not want to get tested every [X] months?
 - Can you think of some reasons why a person may not want to know their HIV status, even if they think they might have HIV?
 - **[Probe if necessary]** Fear of...
 - being positive
 - stigma
 - treatment availability
 - needles, doctors, etc.
 - cost of test

8. What do you think might convince someone who has never been tested for HIV because [*insert reason(s) brought up by participant*] to get tested for HIV?
9. Where are some places that you could get an HIV test (e.g., doctor's office, health fair, free clinic)?
10. Have you ever had a health screening at a mobile unit/van? If so, what was the screening for? Where was the mobile unit? What did you think of the experience?
11. To your knowledge, what types of HIV tests are available?
12. Have you heard of an [*insert specific HIV test*]? (E.g. oral fluid test, rapid test)
 - [**Insert explanation of specific HIV test if needed:** E.g., “An oral fluid HIV test is done by taking a swab of your gums. On the other hand, blood tests either prick your finger for a sample of blood or a vial of blood is withdrawn from your arm for testing.”]
13. If the doctor's office or clinic gave you the choice between an [*insert specific HIV test*] or a [*insert specific HIV test*], which would you prefer? What about this method do you prefer?

HIV Self-Testing: Awareness

HIV self-testing (also called “home HIV testing” or “in-home HIV testing”) allows people to take an HIV test in their own home or other private location. There are two types of HIV self-testing:

- A **Rapid Self-Test** is done entirely at home or in a private location and can produce results within 20 minutes. You can buy a rapid self-test kit at a pharmacy or online. The only rapid self-test currently available in the US is the OraQuick In-Home oral fluid test.
- A **Mail-In Self-Test** includes a specimen collection kit that contains supplies to collect dried blood from a fingerstick at home. The sample is then sent to a lab for testing and the results are provided by a health care provider. Mail-in self-tests can be ordered through various online merchant sites. Your health care provider can also order a mail-in self-test for you.

If any test were to come back positive, you would be able to call a toll-free, 24-hour hotline and get immediate counseling.

14. Before today, have you ever heard of “HIV self-testing” or “home HIV testing”? What have you heard about it?
15. Do you prefer the term “HIV home testing” or “HIV self-testing”? Do you think both terms mean the same thing or something different? Why do you prefer one term over the other?

Define HIV self-testing and the two key methods (oral swab, finger stick):

HIV Self-Testing: Past Use

16. Have you ever taken an HIV self-test?

[If yes]

- What type of self-test did you take (e.g., oral swab, mail-in finger stick)?
- Where did you get the self-test kit?
- What were the reasons you decided to use an HIV self-test? What was the main reason you decided to use an HIV self-test?
- Would you describe the experience of doing the self-test as being hard or easy? Why is that?
- What would have improved the process or made it easier for you?

[If no]

- What are the reasons you haven't used an HIV self-test in the past? What is the main reason you haven't used an HIV self-test in the past?
- What would make HIV self-testing a more appealing option for you?

HIV Self-Testing: Perceptions

17. When you first heard about HIV self-testing, what was the first thing that came to mind?
 - What issues or questions came into your mind?
 - What do you think about the accuracy of the results? Would you trust the results?
18. What steps, if any, do you think would be the most challenging in the HIV self-testing process?
 - How sure are you that you could use the HIV self-test correctly?
 - How sure are you that you could understand the results of the HIV self-test?
19. What advantages might HIV self-testing have over other HIV testing approaches?
20. What disadvantages might HIV self-testing have over other HIV testing approaches?
 - Do you think toll-free hotlines are sufficient for post-test counseling?

HIV Self-Testing: Preferences and Intentions

21. Which type of test would you prefer for your next HIV test? (ask to explain choice)
 - A conventional HIV test (blood draw from a vein) at a community organization, clinic or doctor's office
 - An oral fluid rapid test at a community organization, clinic or doctor's office
 - A rapid finger stick test at a community organization, clinic or doctor's office
 - An oral fluid rapid HIV self-test
 - A mail-in blood sample (finger stick) HIV self-test?
22. Would you trust an HIV test from a community organization, clinic or doctor's office more than, the same as, or less than a self-test? Why?
23. Which type of self-test would you trust more—(oral swab or finger stick) or would you trust them equally? Why?
 - Which do you think would be the easiest for you?
 - Which would you be most likely to recommend to a friend? Why?
 - If you were to take an HIV self-test, would you prefer to take it alone? With a partner?
24. If cost were not an issue, how likely is it that you would use an HIV self-test to test yourself in the future? What about to test a sexual partner?
 - What would make you more willing?
 - Would you be more likely to use an oral swab or finger prick test?
25. To help you decide whether to take an HIV self-test, what information do you need the most?
 - From who/how/where would you want to receive this information?
 - Provide examples (as needed): Price of the test; Accuracy of the test; Confidentiality of the test; How you get results (and how long it takes); Process of performing the test
26. Where do you think HIV self-tests should be sold?
 - What is the maximum amount you would be willing to pay for a rapid HIV test kit?
 - Do you think the self-tests should be offered by community organizations?
27. Would being able to take an HIV self-test increase the likelihood that you would get tested or how often you would get tested for HIV in the future? Why/why not?
28. Do you plan to take an HIV self-test in the future? Why/why not?

HIV Self-Testing: Linkage to care

29. If you tested HIV positive after taking an HIV self-test, what would you do immediately after learning the test result?
- If necessary, provide examples: follow-up with a doctor or clinic for confirmatory test, seek post-test counseling, call toll-free number, etc.
30. Has a health care provider ever talked to you about HIV or STDs? **[If yes]** What did your health care provider say? What do you think about what your health care provider said?
- Who first brought up the topic about HIV or STDs? You or your health care provider?
 - Did they ask you if you wanted to have an HIV test?
 - Did they talk about prevention against HIV or STDs?
31. How often do most people you know get tested?
- Do you have friends who don't get tested as often as you think they should? Why is that?
 - How often do you think people should get tested? Why?
 - Should some people get tested more often? Why?
32. Have you ever been tested for HIV? **[If no, skip to NEVER TESTED SECTION]**
33. Please tell me about the last time you were tested for HIV.
- Did you assume that an HIV test was part of a group of tests done at an exam?
 - Did your doctor offer the test or did you ask for it?
34. How often do you get tested for HIV?
- **[If routine]** Why do you get tested every [X] months?
35. How often do you think you should get tested? Why do you say that?
36. How long has it been since you were last tested?
- **[If at a physical exam or doctor's appointment]** Did your doctor offer the test or did you ask for it?
 - How do you know if you were tested for HIV? (*check to see if participant assumed testing was part of a group of tests*)
37. Why did you decide to get tested? (E.g., Doctor asked, family/friend encouraged me to get tested, partner encouraged me to get tested, made a "mistake"/multiple partners, heard/saw an ad, routine/regular screening)
- Have you ever gotten tested because you had unprotected sex with a partner with unknown HIV status or with an HIV positive partner?

- o **[If yes]** How long after the sex without a condom did you wait to get tested? If answer is <3 months, OK, let's say that your test came back negative, would that assure you that you weren't infected that time you had sex without a condom?
 - o **[If no]** Was it the case that you did not have sex without a condom at all, or did you have sex without a condom and not get tested? What led you to make that decision?
 - Let's say that you had sex without a condom with someone who either didn't know their status or who knew they were positive. If you went in and got tested within two months of having sex without a condom with that person and the test came back negative, would that assure you that you weren't infected? Or, is it possible that you could be positive on a future test – say a few months later?
 - When should you get an HIV test after having sex without a condom?
38. Where were you last tested (e.g., clinic, private doctor's office, etc.)? Have you ever been tested anywhere else? Where?
39. What type of test did you have (e.g., oral, finger prick, blood draw)?
40. What kinds of things would motivate you to get tested again?
- **Probe** for the following:
 - o Better location or more accessible (e.g., closer, accessible by public transport, mobile units, more convenient hours)?
 - o Better facilities (e.g., nicer waiting area, better reading materials and/or music, nicer appearance of facility overall)?
 - o Better service (e.g., professional/courteous staff, privacy/confidentiality, lower cost or free, shorter waiting time)?
41. Did you get the results of your test?
- **[If yes]** How long did you have to wait for your results?
 - o How would you feel if you could get your results more quickly?
 - **[If no]** Why not?
 - o What, if anything, could have encouraged you to get your results?
42. Did anyone go with you when you got tested (e.g., partner, friend, relative)? What about when you got your results?
43. What was the result of your most recent HIV test?
- **[If positive]** When did you first test positive for HIV?

44. Who is (or would be) supportive of you getting tested at least every [X] months?
 - Who does (or would) encourage you to get tested every [X] months?
45. Who is (or would be) opposed to you getting tested every [X] months?
 - Does (or would) anyone discourage you from getting tested every [X] months?
46. If you were to test positive on a future HIV test, would you be afraid that you would be thought of or treated differently? How might you be thought of or treated differently, and by whom?
 - **[If necessary]** How do you think your family would react if you tested positive? How about your friends? How about people you work or go to school with?

NEVER TESTED QUESTIONS

47. How often do you think a person should get an HIV test?
48. In general, are some people more likely than others to get an HIV test?
 - **[If yes]** Who? What makes you say that?
49. What kind of things would convince you to get a test?
50. When do you think a person should get an HIV test?
51. What keeps you from being tested?
 - **Probe** for the following:
 - Fear of being positive?
 - Stigma?
 - Treatment availability?
 - Needles or doctors or other health-care related reason?
 - Cost?
52. What kind of things would convince you to get an HIV test?
53. Where are some places that you could get an HIV test?
 - **Probe** for the following:
 - doctor's office
 - health fair
 - free clinic

54. Have you ever had a health screening at a mobile unit/van?
- **[If yes]** What was the screening for? Where was the mobile unit? What did you think of the experience? What would you think about a mobile van/unit that offered HIV testing?
55. Do you know if any of your close friends have been tested for HIV?
- **[If yes]** Does knowing that they were tested change how you think about them? Why or why not?
 - **[If no]** What would you think if you found out that your friend was tested for HIV? Would you think differently about him or her? Why or why not?
56. Have you ever wanted to get tested because you had [insert sexual or substance-use risk behavior]?
- **[If yes]** How long after the **[insert risk behavior]** would you want to get tested? Did you get tested because you had **[insert risk behavior]**? Why or why not?
 - **[If no]** Why was it that you didn't want to get tested after you had **[insert risk behavior]**? (Assess for perceived risk/vulnerability, lack of knowledge, etc.)
57. How often do most people you know get tested?
- Do you have some friends who don't get tested as often as you think they should? Why is that?
58. Who would encourage you to or be supportive of you getting tested every [X] months?
59. Who would be opposed to you or discourage you from getting tested every [X] months? Why do you think **[insert person]** would be discouraging or non-supportive?
60. If you were to test positive on a future HIV test, would you be afraid that you would be thought of or treated differently? How might you be thought of or treated differently, and by whom?
- **[If necessary]** How do you think your family would react if you tested positive? How about your friends? How about people you work or go to school with?

[BOTH TESTERS AND NON TESTERS CONTINUE HERE]

HIV Testing Perceptions and Preferences

61. What do you think are the advantages to getting an HIV test every [X] months?
62. What do you think are the disadvantages to getting an HIV test every [X] months?

63. If you could sign up to be reminded to get an HIV test every [X] months, would you? Why or why not?
64. What kinds of reminders would work best for you (e.g., text, email)?
65. What should the reminder say?
66. Would you be concerned that others might see the message?

Potential Barriers to HIV Testing

67. What are some reasons why some people don't get tested for HIV?
68. Do you think that people need medical insurance to get an HIV test or a primary care doctor?
69. How do you think the cost of someone's medical insurance would be affected if they had an HIV positive result? Why do you say that?
70. To what extent do you think that people are afraid that getting tested or testing positive might affect their medical insurance? Do you think this fear keeps people from getting tested?
71. To what extent are you worried that getting an HIV test could hinder your ability to [insert factor: E.g. get a job, qualify for insurance]? What if your test result was positive, how would do you think it may impact your ability to [insert factor from above]?
 - **Probe:** Does this fear keep you from getting tested? Do you think it keeps others from getting tested?
72. Can you think of any other reasons why some people don't get tested for HIV? [If yes] what are they?

Theoretical Concepts: Perceptions of Risk, Attitudes, Normative Beliefs, and Behavioral Beliefs

73. How often do you think your partner should get tested? Why do you say that?
74. How would your partner/friends/family react if they knew you got an HIV test?
75. When you think about their possible reactions, does it make you more or less likely to get an HIV test in the future?
76. Would you want your partner to get tested with you?
77. How would your partner/family/friends react if you tested positive?

78. Do you know anyone in your community or have a friend, partner, or family member who is HIV positive?
- What do people think about them?

Relationship Status and Sexual Partners

79. Do you currently have a main sex partner, that is, a partner you would call your spouse, boyfriend/girlfriend, significant other, or life partner?
- How long have you and your main partner been together?
 - Is your main partner male, female or transgender?
 - Is your relationship monogamous or do you also have other partners?

Now, let's talk about your main partner.

80. Has your partner been tested for HIV?
81. What do you think about your partner getting/not getting tested?
- Does knowing that your partner /does doesn't get tested change how you think of him/her?

[Continue if partner tested; else, skip to next section]

82. How often does your partner get tested?
83. Do you know the results of his/her last test?
84. How did you find out your partner's test results?
- He/she told you
 - Saw a copy of his/her test results
 - Went to the doctor/clinic with him/her
85. Does your main partner know your HIV status?
- ***[If no]*** Why haven't you shared your status with your partner?
 - ***[If yes]*** How did your main partner find out your HIV status?
 - I told him/her
 - I showed him/her a copy of my test results
 - He/she went to the doctor/clinic with me

STD Testing

86. Has a doctor or health care provider ever suggested that you be tested for any STD besides HIV?
87. Have you ever been tested for any other STD besides HIV? If yes, which ones?
 - **[If necessary,** name Chlamydia, gonorrhea, syphilis, genital herpes, genital warts, HPV]
88. Do you have any unanswered questions about HIV or HIV testing?
 - **[If yes]** What are the unanswered questions? How do you think you can get the answers you need?
 - **[If no]** Do you feel you know everything you need to know about HIV and HIV testing?
 - **[If yes]** How did you get this information?

Closing

Okay, we are pretty much out of time. Do you have any last thoughts?

Excuse me for one moment while I see if the people observing have any questions that I have not asked. I will be right back.

Thank you for your participation. There is a brochure for you to take with you if you would like. It has information about HIV/AIDS and locations where you can get further information. Have a good day/evening.