

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

Attachment 3I: Exploratory HIV Prevention with Positives 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 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 and an interesting fact about yourself.
2. I'd like to hear about your experiences since being diagnosed. What have been some things that have changed as a result of your diagnosis?
3. If you could change one thing about your life after being diagnosed, what would that be? **[Note: positive status cannot be this one thing]**

[If needed] Alternative Questions to generate conversation

- To what degree has your HIV status affected your sexual relationships? [Probe: What kinds of reactions have you gotten when you shared your status with a partner? How did it make you feel when your partner reacted this way?]
 - How do you decide whether or not to reveal your HIV status to a partner?
4. [For those of you who OR if you] have decided to tell people, how have others reacted when you told them? What was that like for you?
 5. We are interested in hearing your opinions on how to minimize new infections through the help of people who are already HIV positive. In your opinion, what are some ways that an HIV positive person can help to limit the spread of HIV? **[Facilitator generates a list on a flipchart; probe on topics mentioned]**
 6. Let's take a look at this list. I want you to tell me which three you think are easier to follow. Then mark down the three things that you think are the most difficult to follow. [Instruct them to then put green stickers next to top reasons, red stickers next to bottom reasons.]
 7. **[Facilitator summarizes green stickers and discusses most popular reasons first. For each, ask:]** What do you think about this idea? What makes this easier to follow? [If it received a red sticker, ask] Some people note that this might be tough to follow. When might this be the case?
 8. **[Summarize least popular reasons—red stickers. For each, ask:]** Why do you think this falls into the “difficult to follow” category? What makes it tough to follow? What would have to happen to make this easier to follow?

Facilitator reads the following

In this next part, we are interested in generating a list of arguments for each of these items on this list, starting with the easiest things to do. To do this, you'll be divided into two groups, each sitting on opposite sides of the table. One group will play the role of "persuaders". This group will get the chance to generate as many ideas as you can think of to try to persuade someone to do a particular behavior. We really want to encourage your creativity. There is not one best idea—so we want to say all those ideas that come to mind.

The other half of the people at the table are the "listeners." Your role is to sit and listen to all the ideas without saying a word. We will be writing the ideas down on these papers as the first group shouts them out. While they are doing this, you should listen to the ideas carefully. When they are done, you as a group will have to look at the list and let us know which will work well and why. For those that are not good arguments, your job will be to tell us how to improve them. If you know of a weakness for an idea that has been expressed, think about how you could change the argument to eliminate that weakness. Some of the best ideas are improvements over existing ones.

I encourage you to go into uncharted territory. Don't hold back any of your ideas if you are in the persuader group. If you are in the listener group, let us know what else might work or how to change things to improve an argument.

Note: facilitator's role is mainly to keep participants on track. Otherwise, facilitator should take a step back and remain in the background. When necessary, facilitator should consider asking the following questions of the "listeners" in particular:

- What else would you add to this list?
- How would you modify or rework this idea?
- Is there anything that should be added from one list to another?

Prior HIV Testing

9. About how many times were you tested for HIV before you tested positive?
10. Where were you tested before? (E.g., private doctor, clinic, HIV/STD clinic, community health center, home test, emergency room, etc.)
11. Where were you tested when you received your HIV positive diagnosis? (E.g., private doctor, clinic, HIV/STD clinic, community health center, home test, emergency room, etc.)
12. What prompted you to get your last HIV test? (E.g., found out partner had HIV, had sex without a condom with person of unknown serostatus, a doctor, media campaign, prevention intervention, etc.)

13. Were you referred to treatment by someone at the test site?
 - How were you referred to treatment for your HIV infection? (E.g., given written information, escorted to treatment, test site called and made an appointment, etc.)
14. Did anyone at the test site talk to you about contacting your sex (or needle-sharing) partners to let them know they were exposed to HIV (this is called partner services)?
15. Did you contact your partners to let them know of their exposure? Or did the health department contact your partners?

HIV Disclosure to Sexual Partners

16. Have you told anyone that you are HIV positive? If yes, how have others reacted when you told them? What was that like?
17. **[If 10=yes]** Have you told your current sexual partner(s) about your HIV status?
 - **[If yes]** Please tell us about your experience. Did you find this hard or easy to do? What made it hard or easy?
18. Do you think that disclosure of your HIV status is an important part of preventing HIV? What makes you say that?

Sexual Activity

19. How has your sex life changed since your HIV diagnosis?
20. What prevention or risk reduction strategies do you practice with your sexual partners? How did you choose those strategies?
21. How important is it for HIV-positive persons to **[insert prevention method/behavior]** when they have sex with other HIV-positive persons? What makes you say that?
22. Have you ever heard of people who are HIV positive purposely choosing to have sex with someone else who is also positive as a prevention or risk reduction strategy? If yes, what do you think of this idea?
23. Have you ever heard of people with HIV purposely choosing to have sex with someone else who is also positive as a prevention or risk reduction strategy? If yes, what do you think of this idea?
24. Have you ever heard of people with HIV taking HIV medicine as prescribed to achieve and maintain an undetectable viral load as a prevention or risk reduction strategy? If yes, what do you think of this idea?

25. Have you ever heard of people with HIV *[insert prevention method/behavior]* as a prevention or risk reduction strategy? If yes, what do you think of this idea?
26. Do you think people you know who are also living with HIV need information about reducing or help to reduce their risk of transmitting HIV?
27. To what extent do you think it's your responsibility to prevent the spread of HIV? Tell me more about that.

Health Care

28. Are you currently being seen by a doctor, nurse, or other health care provider for medical care or treatment for your HIV infection?
29. Do you see a doctor who specializes in the treatment of HIV?
 - What kind of doctor do you see?
 - How often do you see a doctor for your HIV?
 - What kind of facility do you go to (e.g., hospital clinic, private doctor's office, etc.)?
 - When was your last doctor's appointment?
30. Are there things that prevent you from seeing a doctor regularly? (E.g., lack of transportation, concerns about cost, lack of cultural competence related to sexual orientation or racial/ethnic issues, language barriers, etc.)
31. What qualities or characteristics do you find important in medical providers who treat persons living with HIV?
32. What typically happens during visits to your HIV doctor?
 - What kinds of tests are performed?
 - What does the doctor talk to you about?
33. Has your doctor ever talked with you about HIV prevention? If so, what did you talk about? Did you find the conversation helpful?
34. Has your doctor ever talked to you about *[insert specific HIV prevention strategy]*? If so, what did he/she say? Did you find the conversation helpful?
35. Has your doctor ever talked to you about the prevention of other sexually transmitted

diseases or STDs?

- How often does he/she suggest getting tested for STDs?
36. Has your doctor ever given you written material on HIV prevention or HIV treatment issues?
- What kinds of information do you think medical providers should make available to their patients living with HIV?
37. Do think there should be HIV-related information in your doctor's waiting room?
- About what?
 - In what form? (E.g., Magazine, pamphlet, video, etc.)
38. Do you think people trust that they can get the care they need if they have HIV?

Treatment Adherence

39. Are you currently taking medication for your HIV?
- [***If yes***] How soon after your diagnosis did you start taking medications?
40. Does your doctor talk to you about treatment adherence which means taking your HIV medications as prescribed?
- What does she or he tell you?
41. What's your understanding of the relationship between taking your medication as prescribed and your viral load?
- How often do you get your viral load checked?
 - Do you keep track of your viral load?
42. To what extent do you think taking HIV medication as prescribed is important to your health? What makes you say that?
43. To what extent do you think taking HIV medications as prescribed is important to prevent transmitting HIV to a sexual or needle-sharing partner? What makes you say that?

44. Have you had problems taking your medication as prescribed?
- **[If yes]**
 - What kinds of things interfere with taking your medications as prescribed?
 - What kinds of things could help you remember?
 - What you think about receiving messages to remind you to take your HIV meds?
 - **[If no]** What are some approaches you have used to make sure you take your medication as prescribed?
45. Have you ever heard the expression **[Insert expression]**? What does it mean to you?

Viral Suppression

46. Have you heard the expression “viral load?”
- Can you tell me what this expression means in your own words?
47. Have you heard the expression “undetectable viral load?”
- Can you tell me what this expression means in your own words? [Ask the group to take a guess if they say they haven’t heard of the expression]
48. Have you heard the expression “viral suppression” or “suppressed viral load?”
- Can you tell me what this means in your own words? [Ask the group to take a guess if they say they haven’t heard of the expressions]
 - Can you tell me how these expressions (UVL and viral suppression) are the same? Can you tell me how they differ?

Overall Health and Nutrition

49. Do you think that maintaining a healthy lifestyle is important?
50. What kinds of activities do you do as part of a healthy lifestyle? (E.g., exercise, nutrition, limited/eliminated substance use, etc.)
51. Have you ever had any other STDs besides HIV?
52. Have you heard the expression “sexual health?” If yes, what does it mean to you?

- In what ways can sexual health be promoted?

Risk Reduction

53. We know that HIV can be transmitted from an HIV-positive person to an HIV-negative person through sex without a condom. What things prevent people living with HIV from engaging in safer sex? (E.g., substance abuse, self-efficacy re: disclosure of HIV status, attitudes about condoms, etc.)
54. How important do you think the prevention of STDs is to persons living with HIV?
55. Do you know of any alternatives to condom use for preventing HIV? (E.g., serosorting, partner's use of PrEP, PEP, etc.)

Information Seeking

56. Where would you look for information on ways to reduce risky behaviors to prevent the spread of HIV?
57. Have you ever sought out information about HIV since your diagnosis? What type of information were you looking for? Did you find the information you were looking for?
58. Where did you look for the information? Where did you turn first for information?
59. What are the main topics or issues people living with HIV need to be aware of?
60. Is there any kind of HIV-related information for people living with HIV that you would like to see in a brochure or pamphlet?
 - What topics or issues should be included?
 - What level of detail would be appropriate?

Awareness of CDC

61. Are you familiar with the CDC (Centers for Disease Control and Prevention)?
62. How do you know about the CDC?
63. Have you ever used CDC's website? What for?
64. Would you use a CDC website for information on treatment issues, such as adherence to medications? Why or why not?
65. Have you looked for information on HIV on CDC's website?

Mobile Health

66. Do you have a cell phone? If yes, do you send and receive text messages on your cell phone?
- Do you have a text messaging plan on your cell phone?
 - What kind of plan do you have? (E.g., unlimited talk and text, pay as you go, etc.)
67. How would you feel about receiving a text message about HIV on your cell phone? What makes you say that?
68. What do you think about having an HIV-related app for your phone or iPad or tablet?
- Would you download the app on your phone?
 - What information would you like to get from the app?

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.